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A portfolio submitted in the fulfilment
of the requirements for the degree of

PROFESSIONAL DOCTORATE
IN
HEALTH PSYCHOLOGY

By
Kalsoom Akhter

City University London
Department of Psychology

September 2015

THE FOLLOWING PART OF THIS THESIS HAS BEEN REDACTED FOR COPYRIGHT REASONS:

pp 428-429: **Appendix A.** Sleep diary taken from Centre for Clinical Interventions (CCI).

THE FOLLOWING PAPERS HAVE BEEN PREVIOUSLY PUBLISHED

pp 225-243:
Akhter, K., Dockray, S. and Simmons, D. (2012) Exploring factors influencing non-attendance at the diabetes clinic and service improvement strategies from patients' perspectives. In *Practical Diabetes* (29) 3 pp 113-116.

This is the pre-peer reviewed version of the following article: *Exploring factors influencing non-attendance at the diabetes clinic and service improvement strategies from patients' perspectives*, which has been published in final form at DOI: 10.1002/pdi.1670. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

pp 244-281:
Akhter, K., Zeffertt, A., El-Khairi, R., Rafiq, A., Evans, M., Abdullah, N., (2014) Development and evaluation of a 'one-stop workshop' for adolescents with type 1 diabetes. In Clinical Psychology Forum, 254.
http://shop.bps.org.uk/publications/publications-by-subject/clinical/clinical-psychology-forum-no-254-february-2014.html

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SECTION 3 - PROFESSIONAL PRACTICE

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DECLARATION

I grant powers of discretion to the University Librarian to allow this thesis to be copied in whole or in part without further reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgment.

EDITORIAL STYLE

The contents of this doctorate programme will employ the editorial style of the American Psychological Association (APA) as detailed in the Publication Manual of the American Psychological Association (5th edition).

ABBREVIATIONS

BPS	**B**ritish Psychological Society
BMI	**B**ody Mass Index
CPD	**C**ontinuing Professional Development
CBT	**C**ognitive Behavioural Therapy
CLP	**C**hanging Lives Project
DCCT	**D**iabetes Control and Complication Trial
DKA	**D**iabetes Keytocidosis
DHP	**D**ivision of Health Psychology
DNA	**D**id Not Attend
GDM	**G**estational Diabetes Mellitus
HbA1c	**H**aemoglobinA1c
IDDM	**I**nsulin Dependent Diabetes Mellitus
MODY	**M**aturity Onset Diabetes of the Young
NHS	**N**ational Health Service
RCPCH	**R**oyal College of Paediatric and Children Health
REC	**R**esearch Ethic Committee
R&D	**R**esearch and Development
RCT	**R**andomised Controlled Trial
T1D	**T**ype 1 Diabetes
T2D	**T**ype 2 Diabetes
UK	**U**nited Kingdom
USA	**U**nited States of America

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- Akhter, K., Turnbull, T. and Simmons, D. (2015). Influences of social issues on Type 1 Diabetes self-management: Are we doing enough? *Qualitative Research in Psychology*. Submitted in October 2015.

- Akhter, K. and Turnbull, T. (2015). Effectiveness of social support interventions for adolescents with Type 1 Diabetes: A systematic review of interventions based on theoretical framework. *British Journal of Health Psychology*. Submitted in September 2015.

- Akhter, K., Zeffertt, A., El-Khairi, R., Evans, M. and Abdullah, N. (2014). Development and evaluation of a *'One-Stop Workshop'* for adolescents with type 1 diabetes. *Clinical Psychology Forum, 254*, 1-56. ISSN: 1747-5732.

- Akhter, K., Dockray, S. and Simmons, D. (2012). Exploring factors influencing non-attendance at the diabetes clinic and service improvement strategies from patients' perspectives. *Practical Diabetes, 29*(3), 113-116.

Abstracts

Simmons, D., Bunn, C., Akhter, K., Donald, S., Ward, C., Holman, D. and Graffy, J. (2013) Impact of the RAPSID education programme on diabetes knowledge among people with Type 2 diabetes. *Diabetic Medicine, 30*(1), 121-122.

Akhter, K., Zeffertt, A., Evans, M., Abdullah, N. and Pesterfield, C. (2012). Development and evaluation of a "One-Stop Workshop" for adolescents with type 1 diabetes. British Association of General Paediatrics/British Society for Paediatric Endocrinology & Diabetes. *Archives of Disease in Childhood, 97*(1), A123.

Conference Presentations

- Akhter, K. and Turnbull, T. (2015). Effectiveness of social support interventions for adolescents with Type 1 diabetes: a systematic review of interventions based on theoretical framework. *Division of Health Psychology 2015 Annual Conference in London at Radisson Blu Portman.*

- Akhter, K., Turnbull, T. and Simmons, D. (2015). Social support during pregnancy with Gestational Diabetes Mellitus: Exploring post-natal women' perspectives. *Work in Progress - Division of Health Psychology 2015 Annual Conference in London at Radisson Blu Portman.*

- Akhter, K., Dockray, S. and Simmons, D. (2012). Exploring factors influencing non-attendance at the diabetes clinic and service improvement strategies from patients' perspectives. *Health Psychology in Focus – Division of Health Psychology Postgraduate Workshop at Bedford University.*

- Akhter, K., Zeffertt, A., El-Khairi, R., Evans, M., Abdullah, N., Davenport, K., Pesterfield, C., Jenkins Liu, C. and Kaur Pabla, K. (2012). Development and evaluation of a *'One-Stop Workshop'* for adolescents with type 1 diabetes. BMJ & RCPCH: Archives of disease in childhood, 5, (97), supplement1. *Royal College of Peadiatric and Children Health Annual Conference, Glasgow.*

SECTION A - PREFACE

Putting Health Psychology into Practice

This portfolio documents evidence of how the required competences for the professional doctorate in Health Psychology were achieved, highlighting both the knowledge base and skill levels required to become a qualified Health Psychologist. Specifically, the portfolio consists of practical examples of how health psychology theory and knowledge have been put into practice within the National Health Service (NHS) settings, in the form of five case studies, generic professional competence, one systematic review and a doctoral thesis (with two additional 10,000 words worth publishable articles), conducted over a period of three and half years. A common thread runs through all the competences in that the focus is on the psychosocial and behavioural aspects related to Type 1 diabetes, Type 2 diabetes and Gestational diabetes.

It is widely known that psychosocial and behavioural factors are crucial to successfully cope with the recommended treatment strategies and maintain a good quality of life regarding diabetes. This topic was chosen for my training because despite the strong emphasis on psychosocial care for people with diabetes, the provision of psychosocial assessment and management is seemed far from optimal level. The focal point is mostly on managing medical aspects of diabetes rather than considering the influences of psychosocial and behavioural factors on diabetes management from patients and Health Care Professionals' (HCPs) perspectives. The Health Psychology research related to exploring such factors is sparse. I identified the importance and the role of Health Psychology in the design and evaluation of psychosocial and behavioural interventions and service evaluation projects. I also recognised its potential role in facilitating the individuals' behaviour and in making valuable contributions towards increasing psychological knowledge in this area.

The main consultancy case study related to patients' non-attendance. I carried out a quantitative piece of work to assist the service in better understanding the reasons of non-attendance and strategies to improve current services. The evaluation and outcomes of this project brought a change into the service level and send text message reminders before patients' appointments. The findings of this project were disseminated into a peer-review journal called '*Journal of Practical Diabetes'* to inform professional practice in this area. My experience in consultancy influenced me to explore adherence related factors in diabetes through a qualitative piece of research work in the future. This has further improved my experience in undertaking different types of consultancy work.

The first optional case study entitled '*Communicate the processes and outcomes of interventions and consultancies'* was related to the development and evaluation of one-stop workshop/intervention for young adult patients with Type 1 diabetes. The aim of this workshop was to evaluate its feasibility to increase patients' awareness of their healthcare needs (e.g. medical, psychological and social) by enhancing confidence, knowledge and skills related to diabetes self-care, as well as engage with them in collaborative discussions in a community and group based setting and to model problem solving through discussion. This intervention improved my confidence and knowledge to work with the multidisciplinary teams (of adult and paediatric diabetes clinics) by playing a variety of roles ranging from designing, planning, conducting, managing, monitoring/evaluating, writing and disseminating.

This subsequently led to the first teaching and training competence called *'Improving communication skills of young adult patients with Type 1 diabetes'*. The aim of the training was to improve patients' knowledge about different types of communication (verbal, non-verbal & para-verbal, passive, assertive and aggressive), improve effective communication skills to apply in real life and understand a link between communication, relationship and health. Having attended the teaching and training workshop and having had the opportunity to deliver my first teaching and training to young adult patients, I felt more confident in my ability to plan, deliver and evaluate such training. This process led to me having a better understanding of different learning models as well as understanding of how to apply them practically to meet the individual needs of participants.

The second teaching and training competence was entitled *'Increasing awareness and enhancing knowledge about some psychological and social aspects of managing Type 2 diabetes mellitus to HCPs'*. The aims were to enhance knowledge and understanding about some potential psychosocial factors in managing Type 2 diabetes, increase systematic understanding and awareness of psychosocial knowledge and increase understanding of the appropriate application of such knowledge from a Health Psychology perspective. I was very pleased with the training as a first experience of interacting face-to-face with a group of HCPs and felt the content and structure was appropriate and thus achieved the learning outcomes.

The second optional competency unit was entitled *'Disseminating psychological knowledge to address current issues in society'*. This was related to exploring influences of social issues on diabetes self-management through qualitative methodology (including focus groups and semi-structured interviews). Throughout this overall project, I believe that I had developed a greater understanding and practice-based knowledge about social issues and their influence on diabetes management and mental health. This project also improved my confidence to design, develop and manage focus group in the future. The findings highlighted the role that social determinants play in sustaining ill health among diabetes patients, which was submitted as a manuscript into a peer-review journal as part of the doctorate.

The chosen topic for the systematic review and the doctoral thesis was social support, though the target groups were different. The area of social support during pregnancy with Gestational diabetes was identified for the thesis first by some clinic observations followed by some current literature search. However, the topic for the systematic review entitled *'Effectiveness of social support interventions for adolescents with Type 1diabetes: a systematic review of interventions based on theoretical framework'*. This involved conducting a literature search for the *'One-stop workshop/intervention'* (mentioned above). A review of the evidence in this area highlighted very informative findings. These included parents have a small to large effect-size on a variety of diabetes management and psychosocial outcomes; home based interventions could be more viable and accessible alternative for intervening with many of the families in comparison to office or hospital based intervention. This approach may not only increase access, but also may have a high likelihood of being accepted by adolescents and their families. This whole process of conducting systematic reviews improved my writing and analysing skills.

During my clinic observations and literature search for the thesis much of the focus has been upon treatment and screening routines of Gestational Diabetes Mellitus rather than acknowledging the importance of social support, which influences health and well-being during pregnancy. Therefore, the aims were to explore and understand the importance, meaning and experiences of social support and identify the sources and categories of such support from post-natal women' perspectives. The findings demonstrated the content of each type of support and unhelpful experiences revealed mental health and diabetes care related issues that can inform clinic-based social support interventions or peer discussion forum in the presence of a HCP.

The health psychology-training programme has provided me with the opportunity to apply health psychology theory and knowledge in practice. For example, the development and evaluation of various service evaluation projects and behaviour change interventions. In doing so my research skills have been greatly enhanced by designing, conducting, evaluating and interpreting findings, which are skills required by a health psychologist. My thesis demonstrates that I also have the ability to conduct research in health psychology independently.

The competences gained through the training program have collectively equipped me with the skills to practice as a health psychologist. I have also continued my professional development in a variety of ways, including attending conferences, training and through the dissemination of psychological knowledge with publications. For example, the consultancy work was published in the *'Journal of Practical Diabetes'* and first optional case study in the *'Clinical psychology Forum'*. Various abstracts related to competences were submitted to well-known conferences and some articles are still in the process of publication. In addition, I have gained a wealth of experience in providing psychological advice and guidance to others, within both a consultancy capacity and within my role in the NHS. Having acquired the competences to practice as qualified health psychologist, I now endeavour to seek opportunities for employment in a health psychologist role with more of a clinical focus, where I am involved in both the design and direct provision of psychosocial interventions for patients.

To conclude, this portfolio has demonstrated how I have consolidated my learning on the doctoral health psychology-training programme to achieve the standards required to become a qualified health psychologist in the areas of research, consultancy, teaching and training and behaviour change interventions. This has involved analysing the evidence base and applying health psychology theory and knowledge in innovative and creative ways to address key challenges in diabetes mellitus. Please see a Figure 1 below depicting an overview of the DPsych work.

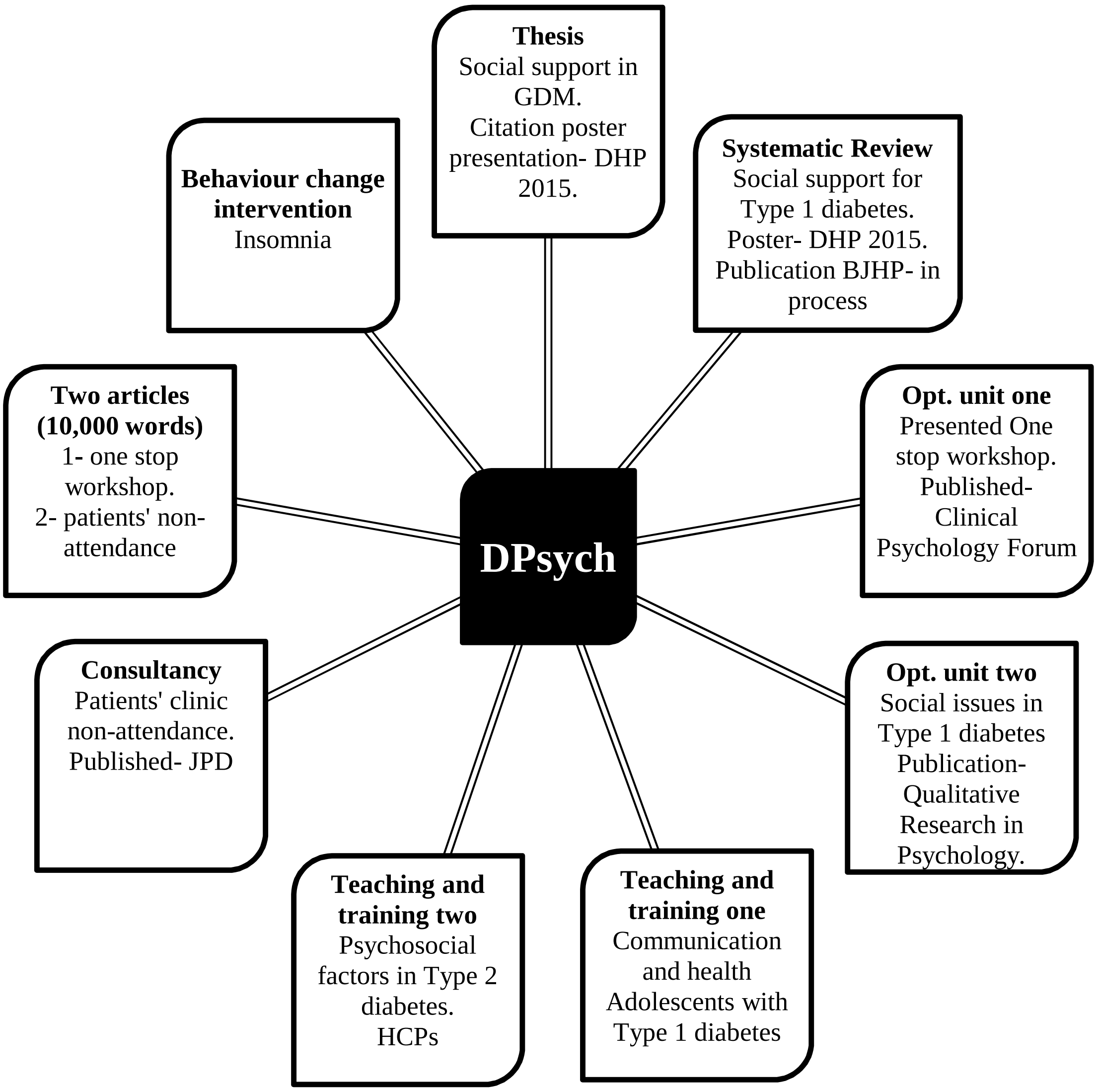

Figure 1: An overview of DPsych work

Section 2A - RESEARCH

Social support during pregnancy with Gestational Diabetes Mellitus: Exploring post-natal women' experiences.

ABSTRACT

Aims/objectives: The majority of the literature has focused upon treatments and screening routines for Gestational Diabetes Mellitus (GDM). However, knowledge about the importance and experiences of social support during pregnancy period is sparse. Social support not only affects health and well-being, but also influences pregnancy outcomes. The aims of this thesis were to 1) explore and understand importance, meaning and experiences of social support from post-natal women' perspectives and 2) identify the sources and types of social support received/perceived during pregnancy with GDM.

Method: Twelve semi-structured interviews were conducted to gain an in-depth understanding about social support during pregnancy. Data were analysed using Interpretative phenomenological analysis (IPA).

Results: The findings demonstrated that women perceived the receipt of three distinct types of support. The most frequently mentioned types included: emotional support and the receipt of information/advice. Sources varied by type of support and most frequently included: HCPs and husbands/partners. This study also highlighted some of the unhelpful/disappointing experiences and recommendation to improve current services. Participants' accounts of their experiences indicated that social support seemed to work as a protector/buffer to cope with their stressful life events, therefore improving/maintaining well-being, which represent the *'Stress Buffering Model'* of the social support theory.

Conclusion: Examples depicting the content of each type of support and unhelpful experiences revealed mental health and diabetes care related issues that can inform clinic-based social support interventions or peer discussion forum in the presence of a HCP. Recognising the importance of social support could potentially be very important to health-care during pregnancy as it is a time when health promotion and prevention are of critical importance.

Supervision Plan

Research thesis: Social support during pregnancy with Gestational Diabetes Mellitus: Exploring post-natal women' experiences.

Units in this area of competence	Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)	Supporting evidence to be complied for this unit of competence
2.2 Design psychological research	**Setting:** Gestational diabetes clinic **Client/Target Group:** Patients who developed Gestational diabetes during their pregnancy **Description of work:** Designed a proposal based on a novel areas of psychological research.	- Proposal for the research.
2.3 Conduct psychological research	Conducted literature search and found no evidence of exploring experiences of social support during pregnancy with Gestational Diabetes Mellitus (GDM) from post-natal women' perspectives. This research particularly focused upon exploring various types of support and sources received/perceived during pregnancy.	- Approval letters from the City University London research ethic committee, NHS research ethics committee, NHS R&D - Information sheet - Consent form - An invitation letter for the patients
2.4 Analyse and evaluate psychological research data	A semi-structured interview style was applied to collect the data, which was analysed using IPA method. The findings revealed some interesting findings related to patients' experiences as well some recommendations to improve current services. Participants' accounts of their experiences indicated that social support seemed to work like a protector/buffer to cope better with their stressful life events, therefore improving/maintaining well-being. This framework represents the 'Stress Buffering Model' of social support theory. The content of each type of support and unhelpful experiences revealed mental health and diabetes care related issues that can inform clinic-based social support interventions or peer discussion forum.	
2.5 Initiate and develop psychological research		

Target for completion: … October, 2013 … Workplace contact? Yes … If yes please give name: [redacted]

Chapter- 1 Introduction

This chapter presents the theoretical background and the framework of the thesis. It focuses on the experiences of social support during pregnancy with GDM and different types of support received/perceived from formal and informal sources during that period. Furthermore, a theoretical framework is presented that will later be used when discussing the findings.

1.1- Historical perspective of GDM

During the last century, it has been recognised that women with Diabetes Mellitus (DM) had poor outcomes for their pregnancies. In the 1940s, women who later developed DM (years after childbirth) demonstrated abnormally high prevalence of adverse foetal outcomes and neonatal mortality (Miller, 1946). In the 1950s, the first definition of GDM identified the condition as a transient maternal condition that affected the foetal outcomes negatively and that abated after delivery (Carrington, Shuman & Reardon, 1957). In the 1960s, it was recognised that the degree of glucose intolerance during pregnancy was related to the risk of the woman developing DM within a few years after the pregnancy. Criteria for the interpretation of the Oral Glucose Tolerance Test (OGTT) were suggested (O'Sullivan & Mahan, 1964) and During the 1980s; the cut-off values of the OGTT were adapted to modern methods for measuring blood glucose (American Diabetes Association, 2003). During the ‘Fourth International Workshop-Conference on Gestational Diabetes’ in 1998, GDM was recognised as *'any degree of glucose intolerance or hyperglycaemia (high blood glucose level) with onset or first recognition during pregnancy'* (Metzger & Coustan, 1998).

1.1.1- Definition of GDM

In order to discuss the role/importance of social support from health psychology perspectives in pregnancy particularly with GDM, it is crucial to understand this illness, its treatment and some risk factors on a woman and her baby’s health.

1.1.2- Non-technical language explaining GDM

Insulin is a hormone produced in the pancreas that enables cells to absorb glucose in order to turn it into energy. During pregnancy, maternal resistance to the action of insulin develops so that glucose can be more easily transported across the placenta to the growing foetus. Resistance to insulin becomes apparent in the second trimester and declines progressively. Insulin resistance returns to normal after pregnancy, usually within six weeks of giving birth. For about seven in every 100 pregnant women, resistance to insulin is excessive and the woman's blood sugar becomes too high. This is known as Gestational diabetes. If Gestational diabetes develops and the resistance to maternal insulin becomes too pronounced, fatal hyperinsulinaemia can cause accelerated growth with fatal adiposity, increased birth weight and prenatal complications. The woman and her baby can be harmed by the high blood sugar levels if untreated, and there may be adverse effects after pregnancy. Evidence is increasing that the offspring are at increased risk of obesity and high blood pressure in later life. Lowering blood sugar levels can reduce the harmful effects, but women will only receive treatment if they are correctly diagnosed early enough in pregnancy. Several tests are used to find out if a woman has Gestational diabetes. Most involve giving the woman a very sugary drink or food, and taking a series of blood sugar tests over one to three hours; this is known as the OGTT. Limitations of the OGTT are that it requires women to fast from the night before, drink a glucose solution and wait for two or three hours before having the final blood test. Therefore, other tests that do not require this level of involvement by the pregnant women or healthcare staff have also been proposed. These include taking just one blood test after an overnight fast or taking just one test with no fasting (Farrar, Duley & Lawlor, 2011).

1.1.3- Introduction (from a medical perspectives)

Gestational diabetes mellitus (GDM) is a frequent medical condition during pregnancy and is currently, GDM is defined as *'carbohydrate intolerance resulting in hyperglycaemia of variable severity with onset or first recognition during pregnancy'* (World Health Organisation, WHO, 2013; Malcolm, 2012). GDM defined in this way includes women with undiagnosed pre-existing diabetes, as well as those for whom the first onset is during pregnancy. GDM has in the past been categorised by severity of glucose impairment, less severe being referred to as impaired glucose tolerance, and more severe as GDM. Hyperglycaemia is now viewed as a continuum with higher levels along the complete distribution of glycaemia in pregnant women being associated with adverse effects (Hyperglycemia and Adverse Pregnancy Outcome (HAPO) Study Cooperative Research Group, 2008).

GDM appears to result from the same broad spectrum of physiological and genetic abnormalities that characterize diabetes outside of pregnancy (Buchanan & Xiang, 2005). In 2013, more than 21 million live births globally were affected by diabetes during pregnancy, with more than 79,000 children developing Type 1 diabetes (König, Junginger, Reusch, Louwen, & Badenhoop, 2014). Globally the number of women diagnosed with GDM is rising. Factors associated with this rise include increasing rates of obesity, reduced levels of exercise and Type 2 Diabetes Mellitus (T2DM) (Catalano & Hauguel-De Mouzon, 2011; NICE, 2008a; Simmons, 2011; Mulla et al., 2010).

To significantly reduce the prevalence of diabetes requires the global community to pay particular attention to the medical care of reproductive-age women, especially the daughters of diabetic mothers. There is a vicious cycle; the daughter of GDM mother becomes obese, gets pregnant, develops GDM, has a daughter, who becomes obese. Recent findings support this recommendation in that a profound increase in family history of gestational diabetes was reported in mothers with GDM (König, Junginger, Reusch, Louwen, & Badenhoop, 2014). For example, in Mexico, 50.8% of the inhabitants are women with 24% of those women being of reproductive age ranging from 15-44 years, the probability of pregnant women having some type of diabetes is greater than 13% (Ramírez-Torres, 2013).

1.2- Pathophysiology of GDM

GDM usually occurs midway through pregnancy (Scollan-Koliopoulos, Guadagno & Walker, 2006) and usually goes away after pregnancy. Because of the effects of the pregnancy hormones, there is a decrease in the ability of cells to produce insulin, which is known as increased insulin resistance (Templeton & Pieris-Caldwell, 2008). Women who have GDM are unable to produce extra insulin to overcome this resistance and as a result, the level of glucose in the blood becomes higher than usual. These chronically high levels of blood glucose mean that women are unable to absorb the glucose into their cells and within a short time of eating are considered to be glucose intolerant (Templeton & Pieris-Caldwell, 2008).

In pregnancy, insulin resistance increases with advancing gestation (Clapp, 2006). There are several possible processes that conspire to cause severe insulin resistance in muscle, liver and adipose tissue, such as the presence of subclinical inflammation, the increase of placental hormones, reduced adiponectin secretion and excess lipolysis (Barbour, McCurdy, Hernandez, Kirwan, Catalano & Friedman, 2007). In addition, hormones secreted from the placenta, including tumour necrosis factor-alpha, placental lactogen, cortisol and progesterone are thought to be the likely triggers of these physiological changes (Clapp, 2006; Devlieger, Casteels, & Van Assche, 2008). Increasing insulin resistance in pregnancy, especially during the third trimester, helps to meet the increased nutrient requirement for fetal development and promotes fetal growth by increasing maternal glucose supply (Devlieger et al., 2008).

During pregnancy, two major processes regulate the glucose. Firstly, as the pregnancy proceeds, a progressive insulin resistance develops, mainly during the third trimester. This insulin resistance seems to be caused by an increasing maternal weight gain combined with the desensitizing effects the placental hormones exert on insulin. Secondly, the β cells in the pancreas normally increase their production of insulin in order to compensate for the insulin resistance, so for most pregnant women the circulating glucose levels remain normal and stable despite the changes in the glucose regulation (Buchanan & Xiang, 2005).

1.2.1. Diagnosis and screening

The incidence of GDM is increasing worldwide. While GDM has a genetic link (Fernández-Morera, Rodriguez-Rodero, Menéndez-Torre & Fraga, 2010), the increasing incidence has been also been attributed to obesity (Abayomi, et al., 2013), and increasing age at the time of birth (Wu, Nohir, Bech, Vestergaard & Olsen, 2012; Webb, 2013). Excessive maternal weight gain during the first trimester (>2 kg) has been found to be a significant predictor of GDM, independent of BMI prior to conception (Morisset, et al., 2011). Unfortunately, obesity is such a worldwide epidemic that it should be considered a threat to global health (Sullivan, 2014).

The diagnostic criteria for classification of GDM are extremely varied throughout the world. GDM is identified by diagnostic oral glucose tolerance test, indicated by positive screening for oral glucose challenge test as *'high risk'* based on the risk factors such as those stated above or presence of symptoms such as polydipsia and polyuria (Kjos & Buchanan, 1999).

Screening protocols for GDM also vary. Some adopt universal serum screening (Griffin, Coffey, Johnson, Scanlon, Foley & Stronge, 2000), while others suggest risk factor based serum screening (Scott, Loveman, McIntyre & Waugh, 2002). It may be less cost-effective to screen all women at low risk of GDM who are aged less than 25 years, normal body weight, no family history of diabetes mellitus, not part of ethnic groups at increased risk of Type 2 diabetes (Metzger & Coustan, 1998). Serum screening is advised between 24 to 28 weeks' gestation or earlier and repeated in those at high risk (Setji, Brown & Feinglos, 2005). Ultrasonographic monitoring of foetal growth has been suggested as an adequate method of screening for macrosomia in those at low risk (Schaffer-Graff, Coyne & Lazarus, 2004). GDM is often asymptomatic and 50% of cases have no classic risk factors (McIntyre, Cheung, Oats & Simmons, 2005), emphasising the importance of adequate diagnosis (Tieu, Crowther & Middleton, 2008). The World Health Organization (WHO, 2013) provides the following guidelines for the diagnosis of gestational diabetes. One or more of following criteria met:

- fasting plasma glucose 5.1-6.9 mmol/l
(92-125 mg/dl)
- 1-hour plasma glucose $\geq$ 10.0 mmol/l
(180 mg/dl) following a 75 g oral glucose load*
- 2-hour plasma glucose 8.5-11.0 mmol/l
(153-199 mg/dl) following a 75 g oral glucose load (Mays, 2014).

1.2.2. Risk factors for GDM

Research has discovered various factors, which potentially increase the risk of developing GDM (Morisset, St-Yves, Veillette, Weisnagel, Tchernof & Robitaille, 2010). For instance, advancing maternal age (Ben-Haroush, Yogev & Hod, 2004; Kieffer, Sinco & Kim, 2006) and maternal overweight (Body Mass Index (BMI) equal to or greater than 25 kg/m^2) or obesity (BMI equal to or greater than 30 kg/m^2, Cnattingius & Lambe, 2002) are the two most common ones (Morisset et al., 2010). It is important to notice that the prevalence of these two risk factors is increasing worldwide, which is associated with increasing prevalence of GDM (Petry, 2010). High parity, non-white race/ethnicity, family history of diabetes mellitus (Cypryk, Szymczak, Czupryniak, Sobczak & Lewinski, 2008), maternal high or low birth weight and polycystic ovarian syndrome are known as non-modifiable risk factors for GDM (Cypryk et al., 2008; Petry, 2010). The modifiable risk factors include history of having a macrosomic (birth weight 4000 g or more) infant and history of GDM (Petry, 2010). Other modifiable risk factors are lifestyle related, which include physical inactivity (Chasan-Taber, Schmidt, Pekow, Sternfield, Manson et al., 2008), having low fibre and high glycaemic load diet (Zhang, Solomen, Mason & Hu, 2006), excessive weight gain during pregnancy, especially for those who are overweight or obese (Hedderson, Gunderson & Ferrara, 2010), smoking and on certain drugs (Dornhorst & Rossi, 1998).

1.3 Health risks

Women who develop GDM during their pregnancy have more risks of developing Type 2 diabetes later on in their life in comparison to those who did not develop it. GDM also brings serious health implications for the mother and babies during pregnancy and labour period. Uncontrolled hyperglycemia during pregnancy leads to an increased risk for preeclampsia, preterm labor, respiratory distress syndrome, feeding difficulties, unstable hypoglycemia, hyperbilirubinemia, and an operative birth (Coustan, Lowe, Metzger, & Dyer, 2010; Landon, 2010). Poor GDM management can further lead to fetal macrosomia, shoulder dystocia, and birth trauma (Landon, 2010). Women with GDM have a high risk of GDM in future pregnancies (Getahun, Nath, Ananth, Chavez, & Smulian, 2008) and a 35% to 65% risk of Type 2 diabetes mellitus (T2DM) within 10 to 20 years (CDC, 2011). Risks faced during pregnancy and postpartum periods have been demonstrated below.

1.3.1. Type 2 Diabetes Mellitus - postpartum

Controversy exists among recommended guidelines for postpartum glucose (PPG) testing in women with GDM (Abraham & Wilk, 2014). The American Diabetes Associaltion (ADA) recommends that women with GDM be reevaluated every 3 years when results are normal and annually if IGT is identified (ADA, 2014). The American Colllege of Obtestricians and Gynacologists (ACOG) recommends that women with GDM receive PPG testing at 6 to 12 weeks postpartum (ACOG, 2013), whereas WHO recommends PPG testing at 6 weeks, yet does not support long-term screening (Karagiannis, Bekiari, Manolopoulos, Paletas, & Tsapas, 2010).

For most women with GDM, their blood glucose levels return to normal after delivery, but they are at an increased risk of Type 2 diabetes in the future (Templeton & Pieris-Caldwell, 2008). In a recent review and meta-synthesis study, the relative risk of developing Type 2 diabetes mellitus after a pregnancy with GDM was more than a 7-folded compared to women with a normoglycemic pregnancy (Bellamy, Casas, Hingorani & Williams, 2009). According to Getahun et al. (2010), when GDM is diagnosed during a first pregnancy, the patient has a 41% risk of developing GDM again during a subsequent pregnancy.

In United States of America (USA), the American Diabetes Association (ADA) recommends measurements of fasting glucose in the immediate post-partum period in order to identify women with persisting hyperglycaemia after childbirth (Kitzmiller, Dang-Kilduff & Taslimi, 2007). When normal blood glucose levels in the immediate postpartum period are observed, an OGTT is recommended some time during the first two to six months postpartum. If the second measurement postpartum is normal, the ADA recommends annual testing for DM (Kitzmiller et al., 2007). However, an American study found that only a third of the women underwent the ADA recommended screening (Almario, Ecker, Moroz, Bucovetsky, Berghella & Baxter, 2008).

1.3.2. Health risks for mothers and babies during pregnancy

Specific risks of uncontrolled diabetes include fetal anomalies, preeclampsia, macrosomia, intrauterine fetal demise, neonatal hypoglycemia, and neonatal hyperbilirubinemia, among others. In addition, diabetes in pregnancy increases the risk of obesity and Type 2 diabetes in offspring later in life (Holmes, Young & Patterson, 2011). Other adverse outcomes include increased rates of maternal hypertension, preterm labour, low birth weight and stillbirth (Langer, Yogev, Most & Xenakis, 2005; Fan,Yang, Gao, Lintu & Sun, 2006).

Negative impacts of GDM on the health of women and their babies have been consistently reported (Landon, Spong, Thom, Carpenter, Ramin & Casey, 2009; HAPO Study Cooperative Research Group, 2008; Reece, Leguizamón & Wiznitzer, 2009). Short-term risks for women with GDM include increased need for induction of labour (Anderberg, Källén & Berntorp, 2010; Ju, Rumbold, Willson & Crowther, 2008; Landon et al., 2009), a risk of caesarean section primarily due to the large size of the fetus and medical complications such as hypertension (Dodd et al., 2007; Landon et al., 2009; HAPO Study Cooperative Research Group, 2008). The incidence of cephalopelvic disproportion, uterine rupture, shoulder dystocia and perineal lacerations is increased in women with GDM due to the increased likelihood of having a Large-for-Gestational Age (LGA) or macrosomic (birth weight 4000 g or more) baby (Jastrow, Roberge, Gauthier, Laroche, Duperron & Brassard, 2010).

One of the most significant health risks for babies born to mothers with GDM is being LGA or macrosomic (Landon et al., 2009; HAPO Study Cooperative Research Group, 2008; Reece et al., 2009). Being a LGA foetus or macrosomic infant is a surrogate for many of the complications associated with GDM (Esakoff, Cheng, Sparks & Caughey, 2009). LGA or macrosomic infants are at increased risk of birth injury, such as shoulder dystocia, perinatal asphyxia, bone fractures and nerve palsies (Henriksen, 2008; HAPO Study Cooperative Research Group, 2008). Babies LGA at birth are more likely to be heavier at every age (adjusted for height) and to develop early overweight or obesity and T2DM (Whincup, Kaye, Owen, Huxley, Cook & Anazawa, 2008). In addition, babies born LGA are at increased risk of developing metabolic syndrome (a cluster of risk factors defined by the occurrence of three of the following: obesity, hypertension and low HDL cholesterol concentration) in childhood, adolescence or adulthood (Guerrero-Romero, Aradillas-García, Simental- Mendia, Monreal-Escalante, De la Cruz Mendoza & Rodríguez-Moran, 2010; Harder, Roepke, Diller, Stechling, Dudenhausen & Plagemann, 2009). Development of the metabolic syndrome during childhood predicts adult T2DM at 25 to 30 years of age (Morrison, Friedman, Wang & Glueck, 2008). These health problems repeat across generations (Mulla et al., 2010).

Besides the risks relating to LGA or macrosomia, other perinatal risk factors for babies born to women with GDM include respiratory distress syndrome, hypoglycaemia, hyperbilirubinaemia (increased levels of bilirubin in the blood), cardiomyopathy (the deterioration of the function of the heart muscle layer), hypocalcaemia, hypomagnesaemia, polycythaemia, hyperviscosity and admission to neonatal nursery (HAPO Study Cooperative Research Group, 2008; Reece et al., 2009). Other longer-term risks for those babies include developing type 1 diabetes mellitus (Harder et al., 2009) and having impaired neuro behavioral development (Rizzo, Metzger, Dooley & Cho, 1997).

Maternal obesity without GDM is also associated with LGA infants (Ehrenberg, Mercer, & Catalano, 2004), and childhood obesity may be a consequence of LGA independent of GDM (Wang & Dietz, 2002). However, GDM remains an independent risk factor for LGA (Ehrenberg et al., 2004) and childhood obesity (Vohr et al., 1999). The potential negative health consequences for children born of GDM pregnancies continue into adolescence (Gillman, Rifas-Shiman, Berkey & Field Colditz., 2003) as demonstrated by higher rates of glucose intolerance and obesity for GDM offspring compared to those of normal pregnancies and highest risk is among racial and ethnic minority groups (Sinha, Brydon & Taylor, 2003).

This is of concern particularly as over the last two decades; GDM incidences has been steadily increasing in developed countries, such as the United Kingdom (UK), USA, Australia and New Zealand (Carolan, Steele & Margetts, 2010). Thus, there is an important need for excellent treatment and preferably prevention strategies for GDM in women (Symons-Downs & Ulbrecht, 2006).

1.4- Management/treatment of GDM

The treatment for GDM includes recommendations of diet, physical exercise and frequent monitoring of blood glucose levels (American Diabetes Association, 2004). The primary aims of treatment for GDM are to optimise glycaemic control and improve pregnancy outcomes (Alwan, Tuffnell & West, 2009; Kim, 2010). Providing dietary and lifestyle advice is usually recommended as the primary therapeutic strategy for women with GDM to achieve primary aims (NICE, 2008b). If diet and lifestyle management alone are not enough to achieve good maternal glycaemic control, insulin therapy or oral hypoglycaemics, such as metformin may be indicated (NICE, 2008a; Silva, Pacheco, Bizato, De Souza, Ribeiro & Bertini, 2010).

1.4.1- Self-monitoring of glucose levels

Monitoring of glucose levels is recommended several times daily with self-administered chemical testing of a drop of blood from the finger (Cohen, 1992). Ideally, women with GDM are recommended performing blood glucose measurements on a daily basis: before breakfast, midday, evening meals and the evening snack (Cohen, 1992). A review regarding the efficacy of self-monitoring of blood glucose (SMBG) in the management of GDM reveals that the efficacy regarding diet controlled GDM is indecisive. The SMBG might be best used as a teaching tool to validate physical activity and dietary regime. However, SMBG might improve neonatal outcomes in a cost-effective manner without causing excessive stress (Homko, Sivan & Reece, 1998). A 10% improvement in self-efficacy from the baseline was found among women performing SMBG (Homko, Sivan & Reece, 2002). Another review by Jovanovic (2008) states that meal-based SMBG is a valuable tool to improve outcomes of pregnancy and that available clinical evidence supports testing at four times a day in diet-treated GDM (i.e. before breakfast and one hour after each meal during the day).

1.4.2- Diet

Following a diagnosis of GDM, women are advised to make lifestyle changes mainly to diet. The recent update of the ADA recommend that the focus of the dietary recommendations in GDM addresses the food choices for appropriate weight gain during pregnancy, normalised blood glucose level and absence of ketones (Bantle, Wylie-Rosett, Albright et al., 2008). These recommendations provide an initial carbohydrate-controlled meal plan that is subsequently modified based on the individual results of self-monitoring of blood glucose and assessment of the situation (Bantle et al., 2008). Carbohydrates, not less than 175 g/day, should be allocated over the daily intake. Three small-to-moderate-sized meals are recommended and an additional two to four snacks. Carbohydrates for breakfast might be less well tolerated than at other meals and an evening snack might be necessary to prevent ketones developing overnight (Bantle et al., 2008). A Cochrane review concludes that the effects of dietary advice in preventing GDM are inconclusive. However, some results indicate that a low glycaemic index diet may be beneficial for some outcomes of mother and child (Tieu, Crowther & Middleton, 2008). Women with GDM assigned to a low-glycaemic index diet are found to be significantly less likely to meet the criteria of insulin treatment. In the group of women with GDM assigned to a conventional high fibre and higher glycaemic index diet, almost half of the women who met the criteria for insulin therapy avoided the therapy after changing to the low-glycemic index diet (Moses, Barker, Winter, Petocz & Brand-Miller, 2009).

Gestational weight gain is a risk factor for GDM and limiting energy intake should result in limited Gestational weight gain (Bantle et al., 2008). Weight loss should not be aimed for, since there are concerns about weight loss in pregnancy and the potential for the associated ketonaemia to be associated with reduced intellectual function in the offspring (Rizzo, Metzger, Burns & Burns, 1991). Other options include, lowering dietary fat intake up to 30% of total energy intake (Knowler, Barrett-Connor & Fowler, 2002); using a low glycaemic diet, which has shown to be associated with a reduction in the development of Type 2 diabetes (Barclay, Petocz & McMillan-Price, 2008), reducing 0.43% in HbA1c (Opperman, Venter & Oosthuizen , 2004) and increasing consumption of both dietary fibre and 3 portions of wholegrain cereal (Kaline, Bornstein, Bergmann, Hauner & Schwarz, 2007; Tieu, Crowther & Middleton, 2008).

Toiba (2013) reported that researchers recommended calculating energy intake based on 30 kcal/kg of present pregnancy weight for normal-weight women, 24 kcal/kg for overweight women, and 12 kcal/kg for morbidly obese women. Normally, weight loss diets are not recommended during pregnancy; however, for women with GDM who are considerably overweight, the IDF (2009) reported that reducing energy intake by no more than 30% of habitual intake is not associated with ketosis and does not cause harm.

1.4.3- Physical activity

Changes to physical activity are also recommended but the guidelines for GDM for physical activity are general (Hoffman, Kronfeld, Cooper & Harris, 2003). Even though exercise has long been accepted as an adjunctive therapy in the management of diabetes in the non-pregnant population, exercise in the past has not been a serious part of the management of GDM (Dempsey, Butler & Williams, 2005). One of the reasons for this is the dearth of research to clearly support recommendations for or against different types, duration and intensity of physical activity during pregnancy (Ceysens, Rouiller & Boulvain, 2006; Kramer & McDonald, 2006).

In the absence of either medical or obstetric complications, the American College of Obstetricians and Gynaecologists (ACOG, 2002) recommended 30 minutes or more of moderate physical activity on most, if not all, days of the week for pregnant women. In a Finnish trial (Aittasalo, Pasanen, Fogelholm, Kinnunen & Ojala, 2008), a counselling intervention was successful in increasing the amount of leisure time physical activity during pregnancy among primiparas (first time mothers) recruited from maternity clinics.

Physical exercise is one of the best ways to control weight and stay healthy (Lee, Djoussé, Sesso, Wang &Buring, 2010). Currently, experts and obstetricians increasingly emphasize the role of exercise in preventing and managing GDM. A recent meta-analysis showed that high levels of activity before pregnancy (OR = 0.45, 95 % CI, 0.28–0.75) or in early pregnancy (OR = 0.76, 95 %, CI 0.70–0.83) were both significantly associated with a lower risk of GDM (Tobias, Zhang & van Dam, 2011). Previous observational studies also showed that women with GDM who undergo exercise intervention had superior blood glucose control and required a lower dose of insulin (De Barros, Lopes, Francisco, Sapienza & Zugaib , 2010; Halse, Wallman, Newnham & Guelfi, 2014).

Furthermore, Symons-Downs and Ulbrecht (2006) conducted a quantitative study to examine the exercise beliefs and behaviours of postpartum women who had GDM during a recent pregnancy. They found that the strongest perceived advantage of exercise during pregnancy was controlling blood glucose and postpartum in controlling weight. The findings of this study also suggested that the most common barrier to exercise during pregnancy was fatigue and postpartum is due to a lack of time. Women reported that their husbands/partners most strongly influenced their exercise during pregnancy and postpartum, but they exercised more during the postpartum period than before or during pregnancy.

Interventions aimed at increased physical activity combined with dietary regime have revealed decreased incidence of Type 2 diabetes Mellitus in high-risk groups with metabolic syndrome (Orozco, Buchleitner, Gimenez-Perez, Roque, Richter et al., 2008). Furthermore, evidence from post-hoc subgroup analyses from the Diabetes Prevention Program (DPP, 2002) demonstrated that an intensive behavioural lifestyle intervention (including diet and weight control) to prevent Type 2 diabetes was equally effective among women with and without self-reported prior history of GDM (Ratner, Christophi, Metzger, Dabelea, Bennett et al., 2008). However, despite worries of developing diabetes after a pregnancy, more women gain weight (than lose weight) after their pregnancy complicated by GDM and their exercise level does not change after pregnancy (Stage, Ronneby & Damm, 2004). In addition, women with a history of GDM, 90% knew that GDM was a risk factor, but only 16% perceived themselves to be at high risk for Type 2 diabetes (Kim, McEwen, Piette, Goewey, Ferrara & Walker, 2007). Women with three to five servings of fruits and vegetables each day reported lower chances of moderate/high risk reception than women who consumed less than three servings a day (Kim et al., 2007). Women who perceived themselves to be at moderate/high risk more often planned to modify their future lifestyle behaviours (Kim et al., 2007).

In addition, several studies demonstrate that women with a history of GDM are no more likely to adopt healthy lifestyle behaviours like diet and exercise than women with no history of GDM (Fehler, Kennedy, McCargar, Bell & Ryan, 2007; Stage et al., 2004). Women with a history of GDM who would like to modify their risk for Type 2 diabetes describe multiple barriers to lifestyle change (via surveys), including lack of time and energy due to competing work and family demands, and difficulties obtaining child care (Kieffer et al., 2006; Swan, Kilmartin & Liaw, 2007). Furthermore, glucose intolerance resolves with delivery in about

90% of women with GDM (Kjos, Peters, Xiang, Henry, Montoro et al., 1995), so women may not perceive lifestyle modification as necessary.

Overall lifestyle modification that promotes weight loss is a key to preventing or delaying Type 2 diabetes in women with histories of GDM (Stage et al., 2004; Linne, Barkeling & Rossner, 2002). Sustained change is however difficult to achieve. In one study, 121 Danish women with GDM were surveyed 11 to 42 months after their pregnancies (Stage et al., 2004). Despite having been told they needed to change their lifestyle, only 18% of the women with a BMI greater than 25 kg/m2 had lost weight and more than 33% had gained weight. Furthermore, 16% were diagnosed with diabetes and 18% with Impaired Glucose Tolerance (IGT) at follow-up (Stage et al., 2004).

Overall, the goal of behavioural intervention is to influence psychosocial mediators of health behaviours in order to enact the desired behavioural changes. Several behavioural theories, particularly the theory of reasoned action and planned behaviour and social cognitive theory (Bauman, Sallis, Dzewaltowski & Owen, 2002) posit that confidence to perform a task (otherwise known as self-efficacy) and the available social support for that task can be key mediators and moderators of lifestyle behaviours. For example, in the Diabetes Prevention Program (DPP), self-efficacy for physical activity was associated with greater performance of physical activity (Delhanty, Conroy & Nathan, 2006) and self-efficacy for not overeating was associated with lower baseline BMI (Delhanty, Meigs, Hayden, Williamson & Nathan, 2002). In another randomized study, overweight women enrolled in a behavioural weight-loss intervention program reported greater use of behavioural strategies to elicit social support for weight loss and physical activity; these women had greater than 10% weight loss and increased physical activity more frequently than controls (Gallagher, Jakicic Napolitano & Marcus, 2006).

A recent systematic review examined types of physical activity and found the most successful exercise programs in postpartum women were those with objectively set goals usually incorporating devices such as pedometers (Nascimento, Pudwell, Surita, Adamo & Smith, 2013). Previous studies that specifically used pedometers in the postpartum population report an increase in physical activity (Clarke, Freeland-Graves, Klohe-Lehman, Milani, Nuss & Laffrey, 2007; Maturi, Afshary & Abedi, 2011).

Both studies relied on self-reporting of step counts from the pedometer, with no indication as to whether the women would have preferredweb-based storage of the step data.Kim et al. suggested the combination of internet based support with a more traditional approach may be more successful than the internet support alone (Kim, Draska, Hess, Wilson & Richardson, 2012).

1.5. Women's perceptions and experiences during and after a pregnancy complicated by GDM

It is not sufficient to only know about the treatment of the GDM, but it is also very important to understand women's perceptions and experiences after diagnosis of the GDM to understand the impact of the diagnosis and importance and efficacy of the treatment. Evans & O'Brien (2005) conducted interviews with women diagnosed with GDM, which showed that being diagnosed with GDM during pregnancy is merged with the perception of the woman and her child as being at risk. Four themes were identified in a qualitative study, describing the women's experiences of their pregnancy: *'living a controlled pregnancy', 'balancing', 'being a responsible mother' and 'being transformed'* (Evans & O'Brien, 2005). The findings challenged HCPs to discuss openly and reassess their present models of care for pregnant women and their families (Evans & O'Brien, 2005).

In another study, women with prior experiences of GDM were compared with matched controls with no experience of GDM. The findings of this study demonstrated that women with prior GDM reported significantly less well-being, vigour and psychic health during their pregnancy (Sjogren, Robeus & Hansson, 1994). Furthermore, a less positive experience of the pregnancy, recollecting more worries about health during pregnancy was demonstrated. The women with prior GDM reported significantly more physical health problems and worries about health after delivery than women included in the control group. Additionally, women with prior GDM were more committed to maintain the GDM diet regime after the delivery (Sjogren et al., 1994).

1.5.1- Role of social support in pregnancy

The role of social support has been demonstrated quite influential during pregnancy. (Barona-Vilar, Escriba-Aguir, & Ferrero-Gandia, 2009; Eichorn, 2008). It is a well-known determinant of psychological and physical health (Cohen & Syme, 1985; Sarason, Sarason & Pierce, 1990; Thoits, 1995). It is linked to a number of health related behaviours during pregnancy such as drinking, smoking, and substance abuse (Dunn, Pirie & Hellerstedt, 2003; Hutchins & DiPietro, 1997; Lindenberg, Strickland, Solorzano, Galvis, Dreher & Darrow, 1999). In addition, it is also related to maternal and infant outcomes such as labour complications and birth weight (Orr, 2004; Feldman, Dunkel-Schetter, Sandman & Wadhwa, 2000).

Although pregnancy and the birth of a child are often joyful, they are also typically stressful experiences characterized by substantial psychological and physical change (Lederman, 1984). Supportive relationships may enhance feelings of well-being, personal control, and positive effect, thereby helping women to perceive pregnancy-related changes as less stressful (Tietjen & Bradley, 1985). This may result in lowered rates of stress-induced biochemical responses and fewer stress-related health behaviours such as smoking and alcohol use (Pagel, Smilkstein, Regen, & Montano, 1990).

Postpartum support from formal medical sources and personal ties has been found important for low income women in improving health and perceived efficacy in parenting skills (Shaw, Levitt, Wong, & Kaczorowski, 2006). Also, strong perceived support from significant others and parents have predicted lower levels of maternal depression (Kroelinger & Oths, 2000) and anxiety both during and following pregnancy (Rini, Dunkel-Schetter, Hobel, Glynn, & Sandman, 2006) as well as improved mother-infant interaction (Clemmons, 2001). Low levels of support have been linked to depression in pregnant women in the perinatal and postpartum periods (Xie, He, Koszycki, Walker, & Wen, 2009) and to substance abuse, poor nutrition, and lack of exercise (Hutchins & DiPietro, 1997; Rodriguez, Bohlin, & Lindmark, 2000).

Disruption of social networks during pregnancy substantially alters neonatal outcomes, impacting stress responses, and subsequently, birth weight, cognitive development and even infant mortality (Vrekoussis et al., 2010). Disruption of social support during this time can include segregation from others or negative social interactions. For many pregnant women, a primary means of social support is the father of the baby. Pregnant women reporting significant stressful life events, such as job loss, physical discomfort, difficulty performing physical work, and increased economic needs, had increased depressive symptoms if their partners were unsupportive or unconnected, but did not report such symptoms if they had high levels of support from their partners (Chapman et al., 1997).

Greater partner support, in the form of aid and attachment, has been linked to lower anxiety levels and stronger attachment to the infant (Zachariah, 2009), and to lower emotional distress postpartum and less distressed infants to novel stimuli or situations (Stapelton et al., 2012). Overall, the effects of social support on maternal and infant health may be more pronounced among women who experience high levels of environmental stress (Collins, Dunkel-Schetter, Lobel & Scrimshaw, 1993). Interactions between support and stress are generally interpreted as evidence for a stress-buffering effect of social support (Cohen & Wills, 1985).

1.5.2- Importance of social support in participating and maintaining lifestyle changes

Diabetes-specific studies have demonstrated that social relationships, and particularly marriage, may mediate lifestyle and medical surveillance behaviours, glycaemic control and other health outcomes (Burke, Giangiulio, Gillam, Beilin & Houghton, 2003). For example, some studies have found increased marriage quality leads to enhanced diabetes-related quality of life but not to better glycemic control (Trief, Wade & Britton, 2002; Trief, Ploutz-Snyder, Britton, 2004). Other studies have found that spousal support was more strongly related to adherence to lifestyle changes than to medical surveillance such as medication use and foot care (Trief et al., 2004) and that joint decision making about behaviour changes was facilitated by longer term relationships between spouses or partners (Beverly & Wray, 2010).

The importance of social factors have been identified as influencing women's capacity to maintain a healthy lifestyle, which suggests the need to further explore the influence of social context on postpartum women's health behaviours (Evans, Patrick & Wellington, 2010). Previous quantitative research has suggested that social support and self-efficacy are related to physical activity levels and diet in women with a history of Gestational diabetes (Kim, McEwen & Kieffer, 2008; Smith et al., 2005; Zehle, Smith & Chey, 2008). Similar to the findings of Evans et al (2010), lack of time, child care obligations, motivation and fatigue have been previously identified as barriers to sustaining behavioural change postpartum (Keiffer et al., 2006). Similarly, in a qualitative study exploring women's experience of Type 2 diabetes following Gestational diabetes, women revealed that maintaining lifestyle change was more difficult over time and given people's busy lives (Patrick, 2006). Although the women in this study expressed awareness of their risk for developing diabetes, they did not engage in major lifestyle changes to prevent the development of Type 2 diabetes. Fehler and coleagues (2007) found that although women with Gestational diabetes made positive changes in diet and exercise during pregnancy, these changes were no longer evident by 6 months postpartum, reinforcing the importance of ongoing follow-up (Fehler et al., 2007). These findings indicate that social determinants of health, such as gender role and support, influence women's capacity to engage in healthy behaviours postpartum (Evans et al., 2010).

The phenomena or meanings of social support during pregnancy with GDM have not been explored previously, particularly from post-natal women' perspectives, who developed GDM first time during their pregnancy. Gaining some understanding about it could be beneficial for developing community-based programmes (involving families, if possible) to increase awareness about various types of support (e.g. emotional, informational & practical). This may in turn prevent women from developing potential complications during pregnancy and may strengthen the relationships with their healthcare professional, families and friends.

1.6- Social Support Theory

The last two decades of research in Social and Health Psychology have established that availability of cohesive social support networks is integral to promoting both physical (Cohen & Wills, 1985; Kiecolt-Glaser & Glaser, 1989; O'Donovan & Hughes, 2008; Uchino, Cacioppo & Kiecolt-Glaser, 1996) and mental health well-being (Brewin, Andrews & Valentine, 2000; Kafetsios & Sideridis, 2006; Lakey & Cronin, 2008; Lakey & Orehek, 2011). Theoretical models of social support specify the following two important dimensions: (1) a structural dimension, which includes network size and frequency of social interactions, and (2) a functional dimension with emotional (such as receiving love and empathy) and instrumental (practical help such as gifts of money or assistance with child care) components (Charney, 2004). Most research has found that quality of relationships (functional dimension) is a better predictor of good health than quantity of relationships (structural dimension), although both are important (Southwick, Vythilingam & Charney, 2005).

In the literature, Cohen's (1988) research on developing concepts related to social support, stress, and health provide an insight to understand the concept and elements of social support. He views social support as a broad term incorporating various aspects of an individual's network of social resources. His underlying theory is based on the idea that social support, along with other factors (i.e. socioeconomic status, mental health, stress and personality) has a significant impact on health (Cohen & Wills, 1985; Cohen, Underwood, & Gottlieb, 2000). Cohen et al. (2000) referred to three main categories of social support (i.e., emotional, informational and tangible or instrumental support) (Schaefer, Coyne & Lazarus, 1981; Taylor & Seeman, 1999; Cohen et al., 2000; Israel, Farquhar, Schultz, James & Parker, 2002).

Emotional support (e.g. feeling loved, appreciated, and valued) – the term implies a warm or caring relationship, but emotional support may be as simple as presence or companionship and willingness to listen (McCourt, 2009). Emotional support is that which gives a person a feeling of being loved and cared for, thereby enhancing feelings of self-worth (Schaefer et al., 1981; Cohen, 1988).

Informational support (e.g. advice or guidance) **–** providing good information and advice is widely perceived as being supportive. It underlies the ability to make positive choices, increases confidence and sense of security. It may also help to increase personal sense of control (McCourt, 2009). Informational support provides feedback and assistance in problem solving by offering written or verbal information (Schaefer et al., 1981; Cohen, 1988).

Practical or tangible support (assistance in tasks) – the type of practical or instrumental support may vary widely. It may include financial support for a pregnant woman or physical comfort measures (McCourt, 2009).Tangible or instrumental support is direct assistance provided to a person (Schaefer et al., 1981; Cohen, 1988).

The distinction summarised above is useful since the effects of social support are likely to depend heavily on personal perception. Different people will view different things as supportive, influenced by personal circumstances and preferences as well as cultural and social factors that guide norms and expectations (McCourt, 2009). According to Cohen et al. (2000), social support is defined as the *"social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships"* (p. 4). There is evidence in the literature (Cohen & Wills, 1985) that perceived social support is found to be more significant in relation to health behaviours than actual social support. Cohen and Wills (1985) rationale for this concept is that if the resources of support are not perceived by an individual, they cannot be utilized. It is the perceived adequacy and appropriateness of support that has been found in some studies, relate positively to mental or physical health (Barrera, 1986, Hirsch & Rapkin 1986).

Cohen's theory is supported by a number of studies that found perceived social support was more influential than actual social support in health and well-being (Giblin, Polan, & Ager, 1990; Schaffer & Lia-Hoagberg, 1997; Feldman et al., 2000; Rudnicki, Graham, Habboushe & Ross, 2001). Cohen and Wills (1985) conducted a theoretical meta-analysis of 40 correlational studies to gain evidence to support their hypotheses regarding social support and its effect on health and well-being. Two theories emerged from this and other studies. The first of these theories is the *'main effect model'*. This theory is based on the idea that social support has a beneficial effect on health regardless of whether or not an individual is experiencing stress. Conversely, the second theory, the *'stress buffering model'* suggests that social support acts as a buffer to allow people to cope better with stressful life events, thereby improving or maintaining well-being (Cohen et al., 2000, see Figure 1 below). In summary, both theories focus on the relationship between social support and pregnancy-related events (e.g., health behaviours, emotional well-being and outcomes).

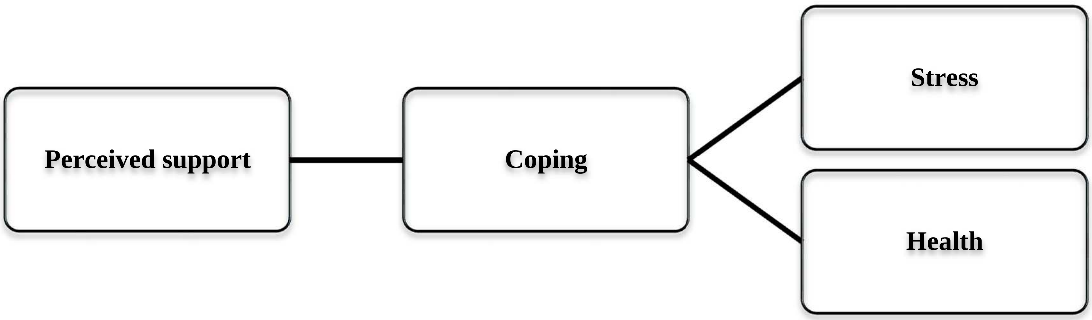

Figure 1: Adopted stress buffering model

1.6.1- Sources of social support

Sources of social support can be divided into two main categories: formal (e.g. professionals and paid helpers) and informal (e.g. family, friends, neighbours and community groups). It is important to remember that professionals are not the main source of social support, except for very isolated people. Abrams, in his seminal study (Bulmer & Bulmer, 1986) of neighbourhood care argued that kin, friendships and neighbourhood relationships are of overwhelming importance in social support, and public services should seek to facilitate such support networks where possible and should consider focusing specific interventions on those who lack good support networks (McCourt, 2009).

1.7- Social support and psychological perspectives/theories of social support

It is important to understand the nature of social support and how it effects or may operate. There are several key frameworks for understanding potential mechanisms of its effectiveness. Although they offer different, potentially competing perspectives, it is possible that in explaining such complex phenomena, they are complementary. Since health is multi-faceted and influenced by a wide range of physiological, environmental, psychological and social factors. Although the approach of biomedicine has been rooted in a paradigm that tends to view such issues as separate, research into social support and health adds weight to the alternative view that such factors are closely inter-related (Arney 1982, Scheper-Hughes & Lock 1987).

Psychological perspectives

Psychological perspectives tend to be individually oriented, focusing on the impact of various influences on the perceptions, feelings and behaviours of individuals. Key psychological frameworks include the stress buffering, coping and effect on health behaviour hypotheses that:

- Social support acts as a buffer against stress (Cobb, 1976).
- It assists the development of coping strategies that support health (Wheatley, 1998).
- It influences behaviours that affect health (Culpepper & Jack 1993).

Social support, therefore, is widely viewed as protective against the negative effects of psychosocial risk factors on health and is often mediated through responses to stress. The ‘buffering’ hypothesis suggests that psychosocial support can help counter, or decrease the negative impact of risk factors (Wheatley, 1998).

Stress is part of everyday life, and is increased in periods of considerable change, such as pregnancy, changing home or job, or bereavement (Murray-Parkes, 1971, Marris, 1974) even where the change is viewed positively. Such psychological risk factors appear to play a role in reducing the person’s ability to cope with stress, or encourage responses to stress that may not benefit health. For example, in a study of what influences women’s health behaviour during pregnancy, Aaronson (1989) found that both perceived and received support had independent positive effects on women’s ability to modify behaviours such as drinking alcohol or smoking. Similarly, Cannella (2006) found that social support was independently related to positive health practices in pregnant women. Another important theoretical strand comes from cognitive psychology: the view that beneficial effects of support are cognitively mediated. This theory proposes that perceptions of support may influence a person's interpretation of stressors, their knowledge of coping strategies and self-concept (Cohen & McKay 1983).

A number of studies have proposed that social support helps to protect women from the negative effects of stress and difficult life events (Robertson, Grace & Wallington, 2004). For instance in a study (Giurgescu, Penckofer & Maurer, 2006) of the relationships between social support, uncertainty and prenatal coping concluded that social support had a significant direct effect on preparation for motherhood. Strong associations have been found between levels of support, stress and incidence of problems, such as anti-natal and postnatal depression, particularly in women with other risk factors and in adolescent mothers. Similar results were reported by Jesse, Walcott-McQuigg & Mariella (2005), who found higher levels of stress and lower levels of social support and self-esteem were associated with higher levels of depressive symptoms.

Sociological perspectives

Sociological perspectives provide greater focus on the influence of social and cultural environment on health and on the individual's capacity to cope with stressors and maintain healthy behaviours. Different sociological frameworks suggest that social support:

- Has a protective effect on health by making the experience of stress less likely in the first place.
- Can facilitate recovery from illness.
- Protects against the negative effects of psychosocial risk factors on health (McCourt, 2009).

Broadhead, Kaplan and James (1983) argued that social support is both an outcome of healthy social competence and a contributing cause of good health: those with good health or social resources are more likely to obtain social support, encouraging a cycle of positive health benefits. Conversely, those who lack such social resources are less likely to be able to obtain the support they need. This is endorsed by research into maternity care that suggests socially disadvantaged women tend to receive poorer quality of support from service providers (McCourt & Pearce, 2000, Lewis & Drife, 2004; Lewis, 2007). Similarly, Oakley's trial of social support for pregnant women suggested that women offered additional support were more likely to gain additional support from their partners (Oakley, Hickey & Rajan, 1996).

In sum, the above-mentioned social and psychological perspectives demonstrate positive influences of social support on mental and physical health. In this study, the interest is to find out which social resources and categories the participants themselves highlight as important when describing their experiences and perspectives.

1.8- Scope of the study

There has been a long tradition of performing quantitative research based on testing of a hypothesis in obstetrics and gynaecology. However, recently the use of qualitative research has increased. Qualitative research generally starts with a broad question and without pre-identified concepts, uses an exploratory approach and is hypothesis generating rather than hypothesis testing (Corbin & Strauss, 2008). A review addressing qualitative research in obstetrics and gynaecology reports that qualitative studies are usually text-based, represent different theoretical approaches, explore the research question to investigate from the point of view of those studied and often focuses the process by which things happen (Pope & Campbell, 2001). Qualitative research may have the power to influence positively the clinical practise; for example, the knowledge obtained from a qualitative study not only reveals experiences and perceptions of individuals, but understanding of the phenomena studied, stimulates debate and inspires to further research (Pope & Campbell, 2001).

Some recent qualitative research though has been undertaken related to the following areas:

- ‘Meaning of an at risk pregnancy with GDM (Evans & O'Brien, 2005).
- Pregnant women’s experiences of acquiring and living with GDM during pregnancy in Sweden (Persson, Winkvist & Mogren, 2009)
- Barriers and facilitators of postpartum follow-up care at the clinics in women with recent GDM (Bennett, Ennen, Carresese, Hill-Briggs & Levine 2011)
- Barriers and facilitators to healthy lifestyle changes during postpartum, with the aim of developing an intervention program (Nicklas, Zera, Seely, Abdul-Rahim, Rudloff & Levkoff, 2011)

- Health behaviours of postnatal women with a history of GDM (Evans, Patrick & Wellington, 2010)
- Living with gestational diabetes in rural communities (Abraham & Wilk, 2014)
- Diabetes self-management in a low-income population: impacts of social support and relationships with the health care system (Vest, Kahn, Danzo, Tumiel-Berhalter, Schuster, ´e Karl,Taylor, Glaser, Danakas & Fox, 2013)

1.8.1- Aims of the thesis

There is a paucity of research exploring different sources of support (e.g. from partners, Persson et al., 2009, family members and other sources) and forms/types of support perceived and received (during pregnancy with GDM) from post-natal women' perspectives exclusively, which can potentially enable us to understand how different types and sources of support are likely to influence health outcomes. No UK based study was found related to the chosen field. A much more thorough investigation into the concept of social support during pregnancy with GDM is needed, especially at the subjective level. Understanding post-natal women' experiences related to social support could facilitate the development of interventions or community/clinic-based programmes to potentially enhance their health during pregnancy. In addition, maternal health promotion programs that focus on identifying and meeting the long term health needs of women who have experienced GDM could include peer support groups for women. Some of the many questions remaining to be addressed, which this research is attempting to explore. Focusing upon the social support theory, specifically the aims of the thesis are to:

1. Understand the meanings of social support from post-natal women' perspectives who developed GDM during their pregnancy.
2. Identify the sources (e.g. partners, family, HCPs & so forth) and categories (e.g. emotional, informational, practical etc) of social support received/perceived during pregnancy.

Chapter 2 - Methodology, Methodological Considerations and Procedures

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2.1. The status of knowledge

An issue to consider when doing research in general, and qualitative investigations in particular is to reflect on how knowledge is constructed. That is, the meaning the utterance is meant to communicate is produced in a dialogue between the interviewer and the interviewee. Every meaning the participant wishes to share with the researcher will have to be coded in language, and the interviewer will have to decode it again to grasp the intended meaning (Rommetveit, 1972). The utterance may therefore be seen as dialogically construed (Rommetveit, 2008). Language is not seen as a neutral container in which the meaning content lies ready for the researcher to collect, both the sender and the receiver is seen as working together to produce the meaning (Rommetveit, 2008).

2.2. Argumentation for a qualitative method

The aim of this study is to get an in-depth understanding of how gestational diabetes related women perceive and receive various kinds of support from different sources around them during pregnancy. Put differently, a central objective is to gain what Geertz has called 'thick descriptions' (1973), which is rich and detailed descriptions that acknowledge the depth of the participants' subjective experiences. This in-depth understanding calls for the use of qualitative methods. Qualitative methodology provides specific, meaningful and rich information about experiences and focuses on analysing responses and attempting to extract meanings (Patton, 2002; Silverman, 2006; Vance, 2005; Richardson & Mallon, 2005; Myers & Pringle, 2005; Inkson & Myers, 2003; Fischlmayr, 2002).

More specifically, semi-structured interviews were judged to be the most appropriate method for data collection. Even though other qualitative methods might have given rich and detailed information about the participants' actions , what they say and do, they would not reveal what Kvale (1996) calls the participant's *'everyday world'*. With its openness and flexibility, the semi-structured interview serves this purpose well (Fog, 2004). Moreover, as most studies on managing GDM have employed quantitative methods, exploring the topic with qualitative methods might contribute to other understandings than those found in earlier studies.

When recognizing the subjective experiences of the participants, the social contexts the phenomena are situated in are made explicit (Valsiner, 1984). This has often been considered a core difference between qualitative and quantitative methods, namely the way they treat variability (Valsiner, 1984). Some theorists claim that quantitative methods have a tendency of seeing variation as *"noise"* (Valsiner, 1984, p. 454) and contexts as *"fog"* (Elster, 2007, p.455), and contrast these to qualitative methods that they describe as more interested in incorporating subjectivity in their analysis. Following such arguments, a qualitative approach fits the purpose of this study well as the analytical focus is what types and sources of social support are perceived supportive and to look at the variation in the phenomenon.

Although there has been a long tradition of performing quantitative research based on testing of a hypothesis in obstetrics and gynaecology, recently the use of qualitative research has increased. Qualitative research generally starts with a broad question and without pre-identified concepts, uses an exploratory approach and is hypothesis generating rather than hypothesis testing (Corbin & Strauss, 2008). A review addressing qualitative research in obstetrics and gynaecology reports that qualitative studies are usually text-based, represent different theoretical approaches, explore the research question to investigate from the point of view of those studied and often focuses the process by which things happen (Pope & Campbell, 2001). Qualitative research may have the power to influence positively the clinical practise. For example, the knowledge obtained from a qualitative study not only reveals experiences and perceptions of individuals, but understanding of the phenomena studied, stimulates debate and inspires to further research (Pope & Campbell, 2001).

Although it is clear in the literature that the condition of GDM may affect the future health status of the woman and her child, no studies have addressed the qualitative research field exploring the experiences of social support during pregnancy (with GDM) from post-natal women's perspectives. Qualitative methodology is considered more sensitive than questionnaires in measuring qualitative changes and experiential accounts (Willig, 2001). Thus, the qualitative approach based on the research question can enable a deeper exploration of the experiences from post-natal woman' perspectives.

2.3. Target group and setting

The participants in this study were those women who developed Gestational diabetes during their pregnancy and were registered at the Cambridge University Hospital's diabetes clinic.

An opportunistic sample of 12 post-natal women (diagnosed with Gestational diabetes during pregnancy) was utilised to recruit participants according to this study's criteria. The HCPs were contacted in the Gestational diabetes clinics for the recruitment of this study. The inclusion criteria were that participants must: (a) be registered with the clinic (b) be diagnosed with GDM in the current pregnancy and (c) have a follow-up appointment in the clinic for blood glucose tolerance test (6-8 weeks at postnatal). Exclusion criteria were: (a) below the age of 18; (b) illiteracy or inability to read or understand English language due to medical conditions such as cognitive and visual impairment, (c) Type 1 diabetes, Type 2 diabetes or Maturity Onset Diabetes of the Young (MODY) during pregnancy, (d) inability to sign the consent form and (e) caesarean birth or loss of baby.

All potential and interested participants (who developed Gestational diabetes during their current pregnancy) were identified from the clinic databases. They were contacted by the HCPs from the clinic initially. The researcher informed the HCPs to inform the potential patients about the study at their last visit (before the delivery date) in the clinic. Participants were invited via a telephone call by the researcher two weeks before the participants' oral glucose tolerance test date. The interested participants were posted an invitation letter (from the lead Consultant Diabetologist, please see Appendix A) and the information sheet (please see Appendix B) related to the study. The researcher interviewed those women, who were interested in taking part in this research irrespective of their treatments (e.g. diet, tablet or insulin during their pregnancy).

Patients were invited to take part in the study, which was also booked for their oral blood glucose tolerance test after their pregnancy at the clinic, so this way they were reminded about their clinic appointments as well. The lead consultant diabetologist and other HCPs had access to patients' records. Patients' participation in this study was entirely voluntary. The researcher contacted the participants via the telephone a week before their blood glucose tests. If they were interested in taking part in the study participants were assured that they can leave the study at any time, if they wanted. However, the initial approach to potential participants was made by the health care professionals & principal investigator (who was used to meet those participants on regular basis as part of their treatment), by asking participants, if they would like to take part in this study. The invitation posted to patients' homes included a general introduction to the research topic as well as the aims of the study and reasons for conducting it. Those invited were presented with information about what their involvement would entail such as anticipated length of the interview and where it would be conducted.

The group finally interviewed consisted of 12 women (post-natal) diagnosed with Gestational diabetes. Three participants (respondents) came from Eastern Europe and the remaining participants were British from the UK. The age and the ethnicity were not the essential criteria for the target group. Two women developed GDM in their second pregnancy, but the remaining participants developed it in their first pregnancy.

In the end, the issue of selecting interviewees was resolved by picking those who met the study's criteria and accepted the invitation. This turned out to be sufficient. After twelve interviews, I had achieved what is often referred to as *"saturation"* (Flick, 2002, p 64-65), which meant that new interviews did not bring any new information with them.

2.4. Data collection – Qualitative interviews

Prior to conducting semi-structured interviews separately with each of the participants, the topics to be discussed were decided upon in advance, but the ordering of them varied between the different interviews (Kvale, 1996; Fog, 2004). Each interview started with an introduction to the general questions followed by some specific questions related to the aims of the study and the information given in the invitation letter and the information sheet was repeated. After this, participants were asked to sign a consent form (see Appendix C).

2.5. Interview guide

The interview guide was developed using the guidelines offered by Smith, Jarman and Osborn (1999). They were designed to be neutral rather than one-sided in order to tap on the participants' experience, while staying as close as possible to the research agenda. The questions were not designed to lead the participants, rather to elicit their own process of meaning making. They were also informally tested in advance on a number of GDM patients, to receive feedback on their clarity, meaningfulness, neutrality and focus on the topic. The interview guide attempted to focus on the participants' own personal experiences rather than their perceptions of others' experiences (their friends for example). The interview guide consisted of three main parts (please see Table 1 in Appendix D).

In the first part, general questions related to GDM and treatments were also asked for. The second part aimed to focus on gaining some in-depth information from participants' point of views related to the sources and types of social support during pregnancy period. Finally, the third part was about exploring the influence of support (during pregnancy) at the postnatal period and some suggestions to improve the services from their perspectives. At the end of the interview, the participants were asked if there was anything else they would like to share with the researcher. This was to assure that aspects they thought important were not left out. All the interviews were tape-recorded. A preventive action taken to avoid direct misunderstandings was that I often summarized what they said during the interview and asked whether or not my interpretation was correct.

The interviews were conducted in the hospital's clinic, where participants had their appointments. The length of the interviews was up to an hour as some participants had further appointments for an oral glucose tests at the hospital. The National Health Service (NHS) Research Ethic Service (RES, please see Appendix E) and Reasearch and Development (R&D) department (please see Appendix F) approved this study.

The purpose of the topic guide was to guide the interview process and to ensure that the identified issues/topics were discussed. The specific questions in the interview were aimed to elicit material which corresponds and stays close to the phenomenon explored, yet allowed the participants to feel comfortable sharing their experience in their own way. At the outset of each interview (Part 1), patients were asked to provide some general information about their first reaction or thought, when they were diagnosed with GDM, what kind of treatment was recommended and who supported them to follow the treatment. This gave patients the opportunity to *'tell their story'*, to ease them into the interview process and to assist with the understanding of the context of their experiences/perspectives.

2.6. The researcher

As the principal researcher, I completed all aspects of the study including recruitment of participants, gathering consents from participants, data collection (interviews with patients), analysis of the data and gaining approvals from the City University London, the Research Ethic Committee, NHS R&D and NHS site specific. Having a background in psychology and health psychology, but not being a registered health professional working within the NHS, there was concern that I would be considered as an 'outsider' to the populations of interest. It is regarded that having such a position may influence the way in which the research study is approached, analysed and evaluated (Hockey, 1993). On one hand it can be an advantage having someone from the outside who can retain an objective outlook, impartial to any conflicting evidence (Schutz, 1976) which may be regarded as more valued (Robson, 1993).

In qualitative research the researcher is regarded as the primary data collection tool and direct, personal contact with participants is a vital part of the process. Hammersley & Atkinson (2007, p16) acknowledged that within this encounter as researchers there is "*no way in which we can escape the world in order to study it*", as such it is assumed that the researcher has the potential to introduce bias and subjectivity to the data collected. Although the influence that researcher's preconceptions, beliefs and experience can have upon the interpretation of data is accepted it is regarded as necessary that such influences are critically evaluated and recognised (Altheide & Johnson, 1994). In analysing data collected the researcher, informed by their theoretical position, interprets what participants have said rather than simply reproducing their meanings. In order to ensure that the data collected and explored is a true reflection of the participants' views or opinions. Researchers should make every effort to set aside their own preconceptions or assumptions by reflecting upon how such factors may influence the process.

2.7. Ethical considerations

The ethical implications of this research study were carefully considered at the initial stage of the development of the project. Ethical guidelines proposed by the NHS Research Ethic Committee as well as those proposed by City University London were adhered to. The proposal for this research project was granted full ethical approval by the Department of Psychology at City University (see Appendix G). Three issues were particularly important to consider – informed consent, confidentiality and debriefing.

Informed consent was achieved using a consent form which was signed by the participants before starting the interview procedure. A clear account of what the study explored, what to expect within the interview and their rights (e.g. confidentiality, right to withdraw and contact details of researcher and supervisor) was outlined at the start, both verbally and in writing, and the participants were given ample time to consider the task and whether they were interested in participating, and to ask any questions.

Confidentiality was strictly followed throughout the study. The recorded interviews were kept in the hospital's locked coded cabinet. In addition, all names and identifying details were changed while transcribing. The consent forms which had the participant's real names, as well as the list which relates pseudonym to real name were kept separately from the data. All computer files with identifying details (such as digital recordings of the interviews) were kept under password protection. Participants were also reassured verbally and via information sheet that all the provided information will be kept securely on the NHS password protected computer and the NHS safe encrypted USB and only the Chief & principal investigators of this study will be able to access to it.

I did not foresee any risk of physical or mental harm to the participants in the process of data collection for this study. Nevertheless, to manage any emotional issues arising during the interview, debriefing was conducted in a number of ways. At the end of the interview, a discussion was initiated as to how the participant felt. This was to gauge whether the interview had any negative effects on the participants.

Participants were assured that all the information (provided as part of the interview based study) would be kept confidential and will not effect on any of their rights of using the current services. Participants were also informed before starting the interview that this interview requires disclosing personal information and they can withdraw from the study any time, if they don't feel comfortable carrying on. They were also reassured at the initial stage of the interview that this interview can be stopped at any stage, if the baby require feeding, or need to take him/her outside or when he/she gets upset. All efforts were made to provide a suitable room to the participants and their young babies.

2.8. Transcriptions

The material to be analysed consisted of the transcriptions from the interviews. To ensure that the transcripts represented the written text, the interviews were transcribed verbatim (word-for-word). The transcript included any vocal utterances (such as uhm), broken words or sentences, and non-verbal communications. This was in order to create a text which was as close a representation as possible. After the first reading, I checked the transcriptions against the digital device material, and made changes if this was necessary. Furthermore, all interviews were transcribed as soon as they were completed, so that it was easier to remember the context in which the statements were made, such as irony and particular body language.

These preventive measures were taken due to the controversies surrounding the issue of transcriptions. Many scholars argue that the transformation from oral to written text represents a (re-) construction rather than a direct copy (e.g. Kvale, 1996; Fog, 2004). Transcribing word-for-word and as soon as possible after the interviews was therefore done in an effort to heighten the representativeness of the transcripts to the oral speech. Importantly, precautions have been taken during transcription and final presentation to prevent that the participants cannot be recognized. All information that could be used to identify a specific person was left out of the transcripts and the presentation.

2.9. Procedure

Participants' interviews were conducted in a quiet room at the hospital. The eligible participants were identified by the HCPs working at the clinic. The HCPs were informed about the study and were also requested to initiate the first information with the women (at their last week in the clinic before their delivery) and provide an information sheet. An invitation letter was sent from the principal investigator with an information sheet two weeks before their OBGTT after their deliveries. This letter also contained information related to patients' Oral Blood Glucose Tolerance Test (OBGTT) appointment date and time in the clinic as part of their treatment procedure. The researcher contacted the participants via telephone, if no response was received after a week of being sent the invitation letter and information sheet.

Before starting the interview, participants were asked if they would like to share their experiences through an interview, which would be recorded on the NHS digital voice recorder for the purpose of a DPsych Health Psychology thesis by ensuring that their names in the transcript would remain anonymous. They were also made aware of their rights to withdraw at any time during the interview. Participants were assured of confidentiality and protection of their identities before and after the interviews. The researcher provided the information (see Appendix B) about the study to the participants and obtained their written consents (see Appendix C) to take part in the study. At the start of the interview, some general questions were asked, followed by some in-depth questions, including some probes. Each interview lasted up to one hour.

During the process of transcribing interviews, participants' names were kept confidential by giving each participant a study number. All the audio recorded information were kept on an encrypted tape recorder and all the written information (e.g. consent forms) and were kept in a locked coded room at the clinic. All the data was anonymised for analysis and publication. All interviews were started by thanking participants for their time and contributions to the study. The participants were debriefed to ensure that they left the room in the same state as before the interview.

Chapter 3 - Choice of Methodology and Philosophical Considerations

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3.1. Research design

This study uses a qualitative research design. The data was gathered from a small sample by means of a semi structured interview guide. The data was then analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009).

3.2. Participants

IPA methodology typically involves small, homogenous samples, because they share the experience of a particular situation, event or condition (Willig, 2008).

3.3. Overview of IPA

IPA was developed in the mid-nineties by Jonathan Smith as a method which aimed to explore how individuals make sense of their experiences within their life (Smith, 1996). Continuing the tradition in psychology established by William James at the beginning of the 20th Century, which focused on subjective and personal accounts, the researcher in psychology can focus on the exploration of human experience, looking at experiential material in its own terms, rather than trying to conceptualise and minimise the experience as predefined theoretical and abstract concepts (Eatough & Smith, 2008). In a way, this approach aims to focus attention on the experiential rather than the experimental (Smith et al., 2009).

IPA is a qualitative method, which draws on three main philosophies – Phenomenology, Hermeneutics and Idiography. IPA is phenomenological in that it is primarily concerned with a deep exploration of an individual’s life-world and lived experience. Influenced by phenomenological philosophers such as Husserl (1927) and Heidegger (1927/1962), IPA aims to conduct a systematic exploration of the content of our consciousness, our personal and social experiences and our own process of understanding and reflecting on them (Smith et al., 2009). IPA takes on board Husserl’s proposition that experience involves first order activity as well as second order reactions to that activity in the form of mental and emotional processes (Husserl, 1927).

IPA acknowledges that direct access to pure experience is not possible, and therefore our attempts to explore experience are mediated through the process of making sense of that experience, by the participant and then by the researcher. As stated by Smith, Flowers and Larkin (2009): *"IPA is concerned with human lived experience, and posits that experience can be understood via an examination of the meanings which people impress upon it"* (2009, p.34). This implies that the phenomenology adopted by IPA is not purely descriptive as some other approaches within phenomenological psychology aspire to (Giorgi, 1992). Rather, in accordance with Heidegger's approach to phenomenology, IPA also draws on Hermeneutics, proposing that it is through the lens of our interpretation (in Heidegger's language: how things appear to us) that we can investigate and understand lived experience (Smith et al., 2009). This hermeneutic position, following Gadamer (1990/1960), involves a cyclical process. The researcher intentionally brackets her/his own experience in order to pay careful attention and engage fully with the participant's account. This is followed by a process of analysis of that account from the perspective of the researcher, acknowledging their particular standpoint. Subsequently, the researcher will return to the participants' material to reflect on how they made sense of this material and whether this endeavour closely relates to the participants' narratives (Smith et al., 2009).

IPA attempts to *'know'* the participants' life/world to the extent that is possible. Thus, during the process "a double-hermeneutic is involved. The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003, p. 51). Within this double hermeneutic, the researcher is both empathic - trying to adopt an insider's perspective, and questioning – trying to illuminate the experience using psychological knowledge and theory (Smith et al., 2009).

IPA is also idiographic. This means that it is concerned with understanding the particular rather than attempting to make claims about a large group or population. This implies that the focus of research is on the detailed accounts and specific occurrence of lived-experience. At the same time, ideography means that the process of analysis draws on particular experiences and unique processes, which can then tentatively inform us about wider experiences (Smith et al., 2009). As stated by Smith, Flowers and Larkin (2009): *"Only through painstakingly detailed cases of this sort can we produce psychological research which matches and does justice to the complexity of human psychology itself"* (2009, p.38).

As mentioned earlier, IPA is claimed to be particularly suited for the investigation of novel topics which concern the subjective experience of individuals, are multi-dimensional, and involves an exploration of the process of sense-making of issues which are significant to the individual. Limitations of IPA, with particular focus on those relevant to this research project, will be discussed in the discussion chapter.

3.4. Rationale for choice of methodology

Qualitative methodology seems most appropriate for this particular research, since it attempts to catch a glimpse of the sense the participants are making of the experiences of receiving/perceiving different types and sources of social support and what it means to them. This methodology also helped the participants express how they managed GDM with some support in daily life. IPA was also chosen because of its focus on meaning making processes, both for the participant and researcher, which are crucial to this research.

It could be suggested that Grounded Theory might have been a useful method for this project, particularly if the aim of the project would have been the development or construction of a theory which strives to explain social support (Charmaz, 2006). However, rather than developing a theory about social support, thus assuming it is a defined and clear construct, this research aimed to take a more exploratory approach, looking at the perception of various sources and types of social support as an undefined novel experience which will be attempted to be revealed and understood as an experience of this particular group of participants. Instead of a theory, IPA enables the development of a tentative model which can illuminate the participants' experiences, presented as relationships between themes (Smith et al., 2009). In addition, the freedom of IPA allows openness to multiple levels of interpretation, as well as to various theoretical underpinnings and methodological procedures (Larkin, Watts & Clifton, 2006). This allows the research process to be flexibly guided by the ongoing interaction between the researcher and the data.

3.5. Rationale for Interpretative Phenomenological Analysis methodology

IPA is a relatively new qualitative methodology developed specifically within Psychology. It is derived from phenomenology which is both a philosophy and a research method. IPA has a number of important facets which are in keeping with the aims of the present study. Phenomenologists believe that knowledge and understanding are embedded in our everyday world and the aim of the researcher is to describe as accurately as possible psychological phenomena (Groenewald, 2004).

Phenomenologists do not ask whether participants' accounts of what happened to them may be *'true'* or *'false'*, the search for meaning in accounts surpasses any objective truth or reality (Reid, Flowers & Larkin, 2005). IPA explicitly acknowledges that direct access to the personal meaning offered by the participants is not possible due to the researcher's central role in research and analysis. The *'double hermeneutic'* recognises that researchers interpret through their own conceptual and perceptual lens the interpretations made by those being studied (Scott, 1996). IPA researchers are encouraged to reflect upon the values, experiences, interests, preconceptions and assumptions they bring to the research process in recognition of the impossibility of remaining *'outside'* of one's subject matter (Willig, 2008). Such reflexivity helps to ensure the accessibility and clarity of IPA (Brocki & Wearden, 2006).

3.6. Epistemological standpoint

IPA permits a relatively wide range of epistemological standpoints to be taken while conducting a research study. This was termed by Larkin and colleagues (2006, p.114) as *"epistemological openness"*. I would like to describe here the epistemological standpoint which I took within this research study. The focus of this study is on experience, and the ways in which the participants make meaning of their experiences of various types and sources of social support. This means that no direct proposition is made about whether what they are reporting is 'true' in the *'outside world'*. This means that this study assumes a relativist ontological position (Willig, 2001).

While it is obviously a struggle to identify where description ends and interpretation begins, various IPA researchers have tended to be more or less interpretative in their approach to the participants' accounts (Bramley & Eatough, 2005; Shinebourne & Smith, 2009). In accordance with Larkin and colleagues (2006) who advocate the interpretative possibilities within IPA, I believe IPA goes beyond description because it aims not only to describe what it is like to be experiencing a certain phenomenon ('the insider's perspective'), but also what it means for the participants to experience it. This interpretative position has been termed by Paul Ricoeur *'hermeneutics of meaning-recollection'* (1981), since it draws out or discloses the meaning of the experience for the participant and for the researcher. Within this research I aim to align myself with this interpretative position while at the same time staying as close as possible to the participants' accounts.

3.7. Reflexivity

In order to establish integrity and trustworthiness in qualitative inquiry, the process of research should coincide with a process of self-awareness on the part of the researcher. This entails a constant examination of personal and professional influences on the research process – both in terms of collection of data and analysis (Finlay, 2002). IPA acknowledges that research is a dynamic process, and the participants' experiences are seen through the interpreting eyes of the researcher (Smith & Osborn, 2003). Using Willig's (2001) distinction between two types of reflexivity (personal and epistemological); I will address epistemological reflexivity within this section.

3.8. Epistemological reflexivity

I would like to continue to address in this section the issue of description vs. interpretation within phenomenological research. The debate on description versus interpretation has been a long standing one in the history of phenomenological philosophy, and its application in research. It moves from the Husserlian perspective of seeing things *'as they are'*, in a pure descriptive sense, to the Heidegger's interpretative perspective of representation. This could be also seen as an ongoing tension between understanding and explaining, between attempting to display the parts of a phenomenon and making sense of it.

Some researchers see these two positions as different alternatives, in which the researcher should choose either a purely descriptive position, aiming (as much as it is possible) to reach the experience of the participant without adding any interpretations of the researcher (*Giorgi, 1992*), or to acknowledge and explore the function of an interpreter and 'translator' of the reported material. Other researchers claim that these two positions can be seen as two points on a continuum, in which there are many levels of interpretation going further and further away from the participants' pure experiences (Larkin et al., 2006).

When reflecting on the process of this research project, I realised that there has been a creative tension between these two approaches. My position shifted a number of times in the process of trying to make sense of the raw data and establish my standpoint in relation to IPA. I aimed for a more experience-focused perspective, trying to present my participant's voice and stay as close as possible to their reported experience. This was partly because I aimed to give voice and acknowledge their experiences.

3.9. Validity

In order to assess the validity, cross reading of the transcripts was used to evaluate the quality of the findings (Henwood & Pidgeon, 1992). Two other researchers read the analysis and examined trustworthiness, coherence and vividness – I asked them to evaluate whether the analysis made sense to them, fitted together and felt authentic. This was carried out at a number of stages within the analysis: I asked one colleague to go through my theme list and see if the theme title does indeed reflect what is described in the quotes. I then also asked two other colleagues to go through one transcript and the final written analysis, to examine whether the analysis could be seen as a trustworthy and valid representation of that transcript. Overall, the researchers agreed with my interpretation. In some places where comments were suggested, these were incorporated and the text was changed accordingly. Please see Appendix H for their comments.

3.10. Analytic strategy

Initially, the interviews were listened to a number of times (including during transcription), and any observations were noted down. Then, once transcribed, the transcript was read and re-read carefully, in order to fully immerse myself in the data. The interviews were also listened to at the same time as reading the transcripts so as to have an image of the person talking while reading the text. At this stage, tentative ideas, thoughts and reflections were written on the left hand margin of the transcript. This stage could be described as relatively fluid, since comments were made on anything, which seemed significant – important words, reflections on manner of speech, repetition, hesitancy, emotional reactions and so forth.

Subsequently, in the first stage of the analysis, themes, concepts and higher-order ideas were written on the right hand side of the transcript (Smith & Osborn, 2003). The process of delineating emergent themes was conducted at the first stage of higher-order interpretation, involving insight into and focuses on the psychological content of the participant’s material. These themes were then listed separately, connections sought between themes and clusters of themes were formed, constantly referring back to the text to check that the meaning stays as close as possible to the original (Langdridge, 2004). A table was constructed for all themes, subthemes and their corresponding quotes. An example could be found in Appendix I.

The above stages were conducted for each individual transcript separately. Following this, the themes from the different transcripts were grouped together, connections between them drawn up, and commonalities and differences between participants were sought. This stage was aimed at finding patterns across cases, and the product of this process was a tentative model or larger picture, which linked the participants in their relationship with social support related experiences. At this stage, a sifting, thinning and refining took place, both on the level of themes and sub-themes, as well as on the level of quotes. Some of the slightly less relevant themes and quotes were put aside to maintain coherence and brevity (for example explaining process of injecting insulin). In addition, certain general viewpoints were excluded (as they were not related to supportive or unsupportive experiences) in order to present what was unique to this population.

Within the write-up stage, which followed, a re-evaluation of theme labels was conducted, and the final choice reflected the immersion in the data and reflection on relationships between the themes, quotes and overall transcripts. The writing up also involved a refinement of the quotes by cutting out what could be dispensed with, for example hesitancies, without jeopardising the meaning and intention of the quote. At this stage, the analysis started to take shape, and final decisions, based on an extensive process of distillation, were made as to what would be included in the final draft of the analysis.

Chapter 4 - Analysis and Results

4.1. Introduction

This analysis follows a number of themes, which together attempt to present a glimpse into the patients' experiences related to social support from formal and informal sources during pregnancy with GDM. The material is clustered into two major themes, which are then divided into sub-themes. The major themes are organised around the process of meaning making, namely the participants' attempts to understand what was unhelpful, what does social support mean to them and how that influenced on their diabetes management. A description of patients' provided suggestions to improve current services will be illustrated at the end of the analysis.

Data in the form of direct quotes from the interviews are used. In order to preserve anonymity, the participants' names and any identifying details were changed. Each quote can be located through a pseudonyms, page number and line number respectively (e.g. Kelly, p. 2, 1-10). Identifying details are indicated by: [?]. Pauses and silences are indicated by: […] and non verbal reactions are placed in parentheses [ ]. The text of the transcripts was left completely un-edited, and presented in the participants' language and expression, including grammatical errors, in order to stay as close as possible to their perspectives.

4.2- Results

A discussion of the themes and sub-themes generated from the data will now be presented using the framework mentioned in Table 3 (please see Appendix J).

4.2.1- Theme 1: Pillars of social support

In this theme, various types of support received/perceived from different formal and informal sources and its affect on participants' wellbeing will be highlighted. This section will look first at participants' reported different types of support (depicted as practical (help me in doing stuff), emotional (listen and understand me when feeling low) and informational support (provide guidance and advice) and then move to an exploration of intra-psychological processes and some psychological management techniques.

4.2.1.1- Help me in doing stuff (Practical support)

HCPs

In general, there were high expectations from women for the HCPs with diabetes during pregnancy, which were reported as often fulfilled in practice. This was identified as particularly important during pregnancy because the women who developed Gestational diabetes were expected to attend antenatal clinic approximately every two weeks. It was clear that each woman perceived a particular type of practical support helpful/useful when received from different health care professionals or clinic staff in specific situations.

'Prompt response'

Sandra mentioned an example of a practically prompt and supportive attitude from the receptionist during waiting time and being in pain. She narrates her story/experience of one of her clinic visits when she was 36 weeks pregnant and sitting in the waiting area for her regular clinic appointment. During waiting time, she started feeling contractions, but there was a long waiting time to be seen by a HCP. Therefore, she mentioned it to a receptionist, who responded promptly by calling staff members, who took her to an appropriate room where it was discovered that she was almost in labour. The sense of such a prompt response by taking her condition seriously seemed to be very valuable experience for her in that painful situation.

"When I came to hospital because I had an appointment anyway with one of the diabetes [team member] I mentioned it that I had really bad contractions like for four to five hours and at that time when I was talking to someone the contractions like has gone. There was a long waiting time but when I mentioned that on the reception desk, I don't know I thought maybe I should not be worrying about it but I was actually bit concerned and the pain during the day was really bad, quite regular, so I was like worried that it might be that time and I was only 36 weeks pregnant so ahh yeah so they took me I didn't have to wait like there were many people and a really long queue. They took me straight away for the test and then they moved me to for a scan and I was that 3 cm diluted already so I was almost in labour but it stopped and then they kept me in the Hospital for 2 days and that was it". Sandra, p. 4, 140-153.

Receiving such a prompt, serious and supportive response in a delicate situation (at the right time) seemed to meet her expectations from the clinic staff. She seemed very pleased with the efforts put in to provide support as quickly as they could.

"I was hoping that people would act quickly and they did not ignore it. I just mentioned it and I was really really glad with how quickly they reacted and how helpful everyone was". Sandra, p. 5, 157-159

Furthermore, another patient perceived a sense of taking her request very seriously by a midwife to provide some practical support despite of being very busy at her work routine. One of the experiences was when the patient contacted the clinic midwife feeling very guilty and nervous to request for some medical equipments, which she broke down and the other one ran out. However, the midwife responded very quickly and assured her not to worry about that, which brought smile on the patient's face while describing it. The patient seemed to be very considerate about the NHS staff's busy schedule and felt quite guilty for causing any inconvenience by calling and asking for particular equipments, which she decided to pick it up herself as she was used to work quite close to that clinic. The patient also reflected on lack of her organisational skills and appreciated the midwife's prompt and supportive response in that occasion when the patient felt that she should have made the arrangements for ordering the repeat prescription for the medical equipments. She seemed to be very pleased with the overall experience with the HCPs, which she found very productive and according to her expectations.

"There was a lady called [?] and she was really helpful, when I rang because she would either uhm there was a couple of occasions I ran out of strips that go in my machine, I broke my machine uhh and really did think oh no I have really done something wrong uhm and she would always as soon as I rung she would call back straight away. She would say don't worry its fine [ ]. I must be the worst patient in the world. I am causing so much. The people in the NHS you know are so busy as it is. They don't need me ringing up going, I am sorry, I broke my machine you know just causing them another headache, but she was so lovely and I was at work at the time. I only work ten minutes away from the clinic so I said its ok. I am only ten minutes away and she would say come on down and pick up the new machine or pick up the strips and stuff because I was very disorganised at ordering or going to my GP surgery. And getting my repeat prescription of my test strips in time. I would say leave it far

too late so uhm she was very helpful. Uhm, everybody who I have appointment with here was as you would expect very nice". Nicola, P.5, 139-157.

A similar experience has also been illustrated by another patient, where a prompt and supportive response received from the same midwife was very much appreciated. As she seemed to find time for the patients despite of being very busy in the clinic to provide any support she could to solve any of their possible issues or provide some medical equipment straight away if she could.

"There was one of the midwives, she was really helpful. I think her name is [-] and she is one of the main diabetes midwifes. She was extremely supportive and always makes time for you. Even if it is a very busy clinic she will take time out and advise you on any little thing or any issues you may have. One example is one day I told her that I needed a new sharps bin and she found one for me straight away and things like that she really good yeah". Karen, p.8, 266-273.

Intra-psychic processes:

Sense of going an extra mile

Nicola described a very helpful experience, where an urgent practical support was needed. With the diagnosis of GDM, it is suggested to keep monitoring blood sugar levels using the given equipment quite consistently every day. However, unfortunately at a weekend, Nicola's machine got broke down and she felt anxious by thinking the possible outcomes of not being able to monitor her readings. Ultimately, she contacted at the hospital's reception desk (as the outpatients clinic was closed) to get some help. A person on the other side of the telephone was perceived to be exceptionally supportive in terms of contacting the relevant person regarding her issue, getting back to her in time with a solution to pick up the machine later on. This type of urgent support in need seemed to be quite helpful for the patients' mental health in terms of protecting them from going into panic or anxious state, which might make their condition more complicated.

"I did find that one weekend I broke my machine and I had to ring up and I wasn't sure I'd would have to go a whole weekend without taking any readings. Was that going to be ok? Was that not going to be ok was I going to be in trouble for not having or taking my readings? So I rang the hospital and one of the obviously the clinic is closed on the weekend

and I couldn't get through to anybody and I just kept going round and round in this telephone loop. Then I rang the reception main hospital reception I spoke to a chap there and he was extremely helpful. He realised the diabetes clinic was closed and did not know what to do. So he took my phone number and found out for me what he could do. Then he rang me back and said that I could phone a certain person on this number he will be able to get a spare machine for you if you can get to the unit and pick it up. Uhm he was very very helpful". (Nicola, p.13, 416-430.

Partner/Husband

'Being there for me'

A variety of experiences described, involved getting some practical help with routine activities related to managing GDM and time resources in relation to regularly performed household duties. In the following case, Lisa's partner seemed to be quite helpful in terms of helping her doing some practical jobs at home generally. However, during pregnancy he became extra supportive in terms of doing some home shopping accurately and many other things, which were acknowledged and appreciated much more than his support even before the pregnancy.

"It is completely based on my partner really he's very strong, he's uhm also generally a good person and keeps everything ticking along, so when I was diagnosed with Gestational diabetes , he was very supportive and he went out shopping and got the right stuff and ways I have to measure and do all those things". Lisa, p.1, 34-38.

Similarly, Karen mentioned getting some practical support in almost everything, e.g. shopping, home chores and diabetes management regime. She seemed to be feeling a sense of having an excellent companion, who does everything without saying or any reminder.

"He generally does everything; the shopping anyway, the chores as well and he does the laundry and yeah and he will bring me the equipment you know if he's in the kitchen he will bring it out to that sort of thing". Karen, p. 5, 138-142.

During pregnancy with GDM, some husbands seem to provide more practical support in home chores than pre-pregnancy period. The following patient Sandra found quite difficult to do various home tasks, therefore her husband decided to fulfil those responsibilities, which he continued after her delivery as well. Developing some understanding to ease off some responsibilities as a husband here was perceived very helpful.

"Like I found a lot of support from my husband because when I was pregnant I couldn't do a lot of things like at home. So he did a lot for me and I feel even now he is still trying and he has got into that habit. So now it is very helpful that he can vacuum or help me with other stuff which I used to do normally and now he understands I think little bit more". Sandra, p. 6, 187-192.

Perception of receiving a variety of practical support (in need) was demonstrated by Lisa, whose husband helped her to follow the diet regime, which could work to manage her GDM as well as providing a sense of companionship or moral support. For instance making a particular breakfast to suit her GDM medicine while she might be busy injecting the medicine, which gave her a sense of companionship.

"It was just a question of a sort of being with me, reminding me e.g., we found that porridge works quite well. So he would get up and make the porridge while I was doing the insulin and giving me the feeling that we are doing it together". Lisa, p.5, 167-170.

Being available as a husband to provide companionship and doing things, which could make a real difference, were perceived very effective. For instance doing some physical activity, e.g. walking after meals is recommended quite useful for women with GDM; therefore, Kristy's husband was used to support her in that regular routine despite of any weather conditions without any fail or complain. Having a companion during that process seems to make it little easy for the patient, which was found very valuable.

"Having Gestational diabetes we got into the habit of going for walks after meals so even when the weather turned bad I'd be and it would be dark outside my husband, I would drag him out for a walk just for 10-15 minute, something like that we need to go for a walk and I know I didn't want to go for a walk and I know he certainly didn't want to go for a walk. Because it was getting cold and wet but he would always without complaining and without fail and it was you know it was really nice". Kristy, p.9, 282-290.

Another helpful practice adopted by her husband was to make a particular breakfast, which she did not want to cook and neither she liked it, but it was very important to make up for her protein intake. Thus, her husband used to cook it by adding her favourite ingredient, which seemed to make it most desirable breakfast for her. From her perceptive, it seems that sometimes, small things can make big difference for the person in such a condition.

"Also this may sound quite sad but I don't like eggs and I don't cook eggs, I've never cooked eggs because I don't like eggs but uhm I couldn't eat my breakfast anymore so I couldn't have muesli and one thing they recommended was like scrambled eggs on toast stuff because of the protein offset. So every morning while I was pregnant my husband got up and made me my breakfast because I don't really do eggs and I've not cooked eggs and he has made them and I don't like them but I love cheese he would put cheese and I know it sounds really sad but its little things like that he did which was just really fab". Kristy, p.9, 290-.300.

Husband's support in terms of looking after a newborn baby especially at night time was perceived very helpful. During early weeks after delivery, fulfilling some responsibilities as a father to give some time to mum to take some rest was very much appreciated. Working as a team and understanding a partner's needs, (e.g. sleep) during that period was found extremely supportive.

In the night he will get up with me, we don't, we take it in turns in terms of I will get up and kind of feed him and then go back down again and then next time he gets up he will do the kind of bum changes and stuff and in the early weeks when he wouldn't go down at night and I was really tired I'd go to bed and he would stay up with him and then he would like tag team. It so yeah, he's been really really helpful. Kristy, p.13, 420-427.

Family members

'We could not have done it without our loved ones'

Receiving some practical support from a close by family network system seemed to be quite influential during pregnancy or after delivery. Lorraine and Kirsty described experiences of receiving some support to look after their children/babies from their local family network system or mothers, which they appreciated very much. Here patients seemed to demonstrate meaning of supportive network in the form of giving a responsibility to close family members without any hesitancy or letting them play their roles with confidence. Having availability of such support can be useful for mothers to pay attention to their health, especially with GDM as well as complete any pending home chores.

"Mother-in-law probably and my sisters because we have huge family so yeah and then they all have young children so they know what I am going through sort of things. Yeah as far support my support network is good because we all live close within a mile with each other, so we can look after each other's children so that's good. Probably sisters, mother in law and mother probably and my my partner he has given me some support as well [ ]". Lorraine, p. 287-294.

"My mum. She has been really good, because she is a childminder obviously it's built in anyway but she's made a point that she has Thursday free and she comes over every Thursday to kind of helps me or we go shopping. We have also moved house when he was three weeks old. So if it had not been for my mum there is no way we could have done it so she was fantastic so yeah". Kirsty, p.12, 398-404.

4.2.1.2- Listen and understand me when feeling low (Emotional support)

HCPs

Intra-psychic processes

'Thank you: how did you know I needed that'

The process of delivering a baby seemed to be quite emotional, where HCPs' support in the form of encouragement and reassurance is very much appreciated. Nadia perceived such support from midwives during delivery time and post-delivery in the form of receiving something to eat with some very encouraging and kind/caring words. In her views, midwives seemed to understand her needs without asking, which was appreciated very much and found extremely helpful.

"Some midwives who delivered him were saying that you are doing well [?] and offered me a couple of bits of toast and I said yes please. So they got me toast and a cup of tea. They said you are doing really great and to take some rest. They were really great when I was on the delivery unit". Nadia, p.18, 606-610.

During pregnancy with GDM, patients seemed to get attached with (or appreciate) those HCPs who provide support using effective communication skills with kind and caring behaviour at the initial visit. The following patient Kirsty seemed to be very grateful and appreciated the effective support received in the form of having reassurance to contact the dietician anytime for an advice or query. Patients like Kirsty seemed to expect such caring service from HCPs, which was understood appropriately. Delivering such a simple information but with kind and caring behaviour can affect patients' psychological wellbeing positively.

"The first time I came to the clinic here was really nice because the people that I dealt with here were really really lovely and they were really really helpful and they were kind of like if you need us, I always remember the girl uhm, she was the dietician I think and she sort of wrote her name down on a card and said you know if you need any advice or anything then call me on this number and this my name and that was really nice and it was just kind of like ahh that you know that's great I feel like I could ring them if I have got any kind of concerns or queries and that you know that would be great". Kirsty, p.9, 271-281.

'Thank you for monitoring routine'

GDM patients are encouraged to be seen by the HCPs almost every two weeks to monitor their sugar levels. Ann perceived such a regular routine was very useful, in terms of getting reassurance and advices through regular meetings about some occasional high blood sugar levels to manage them appropriately with the medicine.

"Every two weeks with the diabetes team, which was nice to have again those regular checkups because every now and again I would get high readings and uhm I am sort of panic a little bit. Uhm and I would then come and see them and they would kind of reassure me you know tell me how to manage it better or to increase the insulin. Uhm so it was quite nice having the regular meetings". Ann, p.4, 133-139.

'So nice, they said I managed really well'

Perception of some positive feedback from HCPs regarding diabetes management (after putting a lot of efforts) seemed to boost patients' confidence level. Mandy seemed to have lack of self-belief on managing Gestational diabetes, but an optimistic response from the HCPs improved her confidence level to believe on herself, which she signifies as gaining *‘sense of achievement’*. The sense of such feeling/perception potentially brings optimal results on mental and physical health.

“They said it sort of gave a nice overview of the whole the whole time of managing my sugars and in both cases they said oh you have really well uhm you’ve managed them really well over so they sort of gave me are review of how I had done over the whole of the period and basically told me I had done everything I should have done and that I had managed well and hopefully that would I think that made me feel confident that I had her. It gave me that sort of sense of achievement”. Mandy, p.9, 287-294.

Most women with GDM at the last clinic visit (before the delivery of their babies) seemed to get quite nervous or anxious by thinking about their deliveries. Karen also had similar feelings of getting nervous by thinking about the delivery of her baby at the last visit, but the HCPs calmed her down through some positive, encouraging, empathic and reassuring words related to her performance in diabetes management (including medical and behavioural aspects). Particularly in the last semester, she lost some weight in comparison to first two semesters, which is believed quite important for managing sugar levels during pregnancy with GDM. She seemed quite pleased after receiving such optimistic comments from the HCPs related to her diabetes management, which seemed to boost her confidence level and bring positive effect on her mood as well.

“Uhm I think one of the experiences of my last visit uhm I expressed that I had a bit of an anxiety about the birth uhm and I was a little bit anxious about what was to come but they were very sympathetic and they said you’ve done really well on this diet, your readings are very good and your weight has not increased too much. This is because I had put on quite a bit of weight in the first two semesters of my illness but it’s down there in that last bit. So they said I’d done really well with my readings and things. So that was quite nice and positive yeah”. Karen, p. 8, 251-260.

Husbands/partners

‘Doing it together’

Having a husband’s accompany during clinic visits can be a huge source of emotional support particularly in certain situations. For instance, Sandra seemed to perceive quite exposed by waiting for an appointment in the clinic’s waiting area as a person with GDM, especially when she felt quite unwell after the scan during pregnancy. At that time having her husband's accompany seemed to make her feel comfortable and less anxious by thinking that other people might be looking at me (or observing my condition).

"I came alone for the scan but then I got very sick and um then he [husband] came with me which made a big difference more than psychological difference to me because you feel quite exposed when you are out there, it makes you feel quite bad. Especially if you have diabetes". Sandra, p.2. 42-47.

Furthermore, a sense of companionship or togetherness was perceived by Lisa too, when her husband was used to come along for the appointments and then suggest what she needs to eat or do to manage the sugar levels. He seemed to be involved in supporting her diabetes management regime just to provide a sense of assurance that she is not alone on this path.

"He (husband) came to the appointments with me so that was nice because they been giving him morning time off work and I think it is also this feeling that we are doing it together and he was sort of you just keeping me together and sometimes you would measure it and it would turn up to be too high and he was just kind of involved and he was kind of following it all and sort of saying um what I could have and what I could not have, sort of suggesting alternatives and things". Lisa, p.9, 310-316.

During pregnancy with GDM, adopting a healthy eating lifestyle is considered quite important to manage it. However, it can be quite difficult for the pregnant patients living with a family to do it on their own. Therefore, having husbands' accompany can be quite helpful to keep the momentum of healthy eating consistently on track. As most of the following patients described that their husbands changed their eating habits or ate same things to support their partner/wives, which gave them feelings that they are not alone in this procedure.

"Maybe my husband he was trying not to eat sweets [ ] may be to help me you know with the diet. So we had to change everything like our lifestyle to adapt to what was required". Sandra, p.3,79-8.

“He was trying to change his diet in yeah more or less, so at least we both ate similar things”. Sandra, p.3, 92-93.

“My partner always was always supporting me uhm when I was eating he was eating and he would eat the same as I would. He wouldn’t you know like you know he wouldn’t order a pizza or eat it in front of me. He would you know we would eat together, he hates fish so he would have meat instead of fish when I had fish because he knows I love fish. Uhm but yeah we would, we would (repeated) do it together”. Nadia, p.10, 336-342.

“If we went out for a meal we would not go to a fast food place, we would go and get a sandwich instead so we could read the packet. So it was nice to have his support”. Nadia, p.11, 368-370.

“He changed his diet slightly to support me in what I was eating”. Ann, p.3, 86-87.

“It was probably my husband most of really kind of really helpful in kind of changing my diet and he would eat what I would eat. So we would not have Carbs with the meals or would have very few Carbs”. Kirsty, p.4, 120-124.

Spending some quality time with husband was perceived very pleasant and relaxing. Going for a walk together as part of the diabetes regime during pregnancy seemed to work really well to take some relaxation break from day to day busy schedule and giving a sense of doing it together.

“It was our special time as well. It was kind of we are going for walk every night. It was kind of yeah it was time where we could take time out for ourselves as well. It was really nice, so yeah [ ]”. Kirsty, p.10, 315-318.

Self-monitoring of blood sugar levels is quite consistent regime during pregnancy with GDM, which can be forgotten easily as a first time experience with GDM. Therefore, husband’s support in terms of reminding about blood tests was found quite effective. It can develop a sense of good companionship. Having a reminder about those tests can help the patient to eat or inject insulin accordingly and reduce the chances of any complications.

So like I can give you the example that I could forget about checking the blood because it supposed to be normally after one hour I ate something. So my husband will normally remind me that he will always remind that its one hour gone already so you need to check your blood test. Sandra, p.4, 114-118.

'De-stress love'

Having pregnancy with GDM can be quite stressful for some working mothers. As in the case of following patient Mandy, who seemed to fulfil her work related duties with full devotion without paying much attention to her health sometimes. Such working situation seemed to make her quite lethargic and stressed. Having husband's emotional support in such situation in the form of encouragement and providing rationality of things seemed to relieve her stress levels or heal any psychological pain.

"I think I got a lot of support from my husband actually uhm at times when I was perhaps under more stress, related to may be work or fatigue. So I think I got a lot of extra support in that area with them, helping me to de-stress or bring things into perspective". Mandy, p.4, 109-113.

Other family members

Sense of being cared/concerned and understood

Pregnancy with the diagnosis of GDM can be quite a tricky process in terms of trying to manage blood sugar levels, following a certain regime and developing hormonal changes. Lisa seemed to get quite anxious by thinking about the impact of sudden changes due to the Gestational diabetes on the health of her baby. Therefore, speaking to her mother at that time seemed to be quite soothing, reassuring and calming for her, especially hearing very warm and caring words, which seemed to boost her confidence level.

"She (mum) was very caring, she just seemed very warm and especially when she was ringing up when I was very nervous about it". Lisa, p.8, 280- 281.

Similarly, Sandra received emotional support from her family members in those occasions when she was very concerned about the affects of diabetes on her baby's health. Family seemed to provide support in the form of encouragement and reassurance by illustrating various examples of similar cases to increase her positive thinking.

"It was mainly a kind of mental support because I was like I had in my head I was really worried especially about the baby because you never know how it can affect the baby. So my husband, my family they were like trying to convince me that you will be fine and that they know someone else who had it and it was all right, so I should not be worried so things like that". Sandra, p.2, 70-75.

Attempts at psychological management

The participants employ a variety of strategies for alleviating the psychological distress caused by the sometimes overwhelming thoughts and feelings associated with diabetes management and work pressures. To some extent, these management techniques could be seen as 'ways out', attempts to break the vicious circles that sustain the psychological pain. However, these attempts often only reduce the discomfort for a short period.

'Finding conversations as cathartic'

Talking to family members about work related stressors seemed to relieve Mandy's constant worries, which she perceived very helpful at that time. Having certain types of pressures, as part of her job seemed to overwhelm her mental health, but coming home and sharing it with someone at home seemed to unburden herself from continuous tension.

"There was quite a lot of stress attached with that job as well so I found uhm I would have lots of conversations when I got home". Mandy, p.4, 126-127.

Furthermore, she explained that despite knowing/understanding the reasonable explanation to her problems, sharing them comprehensively with a family member seemed to make her feel quite therapeutic/energising. In addition, it seemed to satisfy her self-rationality.

"I also think that a lot of other time and this is with all the people I talked about it a long way, a lot of, the vast majority of time you actually know a lot you know the answers to your own problems you know why you feel the way you do uhm you know I can rationalise things quite well but often just like go through the process of talking about it that someone is very cathartic definitely". Mandy, p.6, 179-185.

'Reminding to "Say No" to work'

Family support seemed to be very valuable to manage stress by making the person to understand the value of word 'No' sometimes related to work commitments. As Mandy illustrates, although she could manage diet regimen, to manage stress, she required some support from family in the form of reminding her to work less to relax during pregnancy with GDM. Here family members seemed to play the role of a counsellor to de-stress her from work related commitments.

"My supportive people [family] definitely help me manage my stress levels uhm because I think I know what to do with the diet control and everything else but there were definitely times where I would let the stress of having a busy week because there are too many things planned in so yeah, just reminding me that I needed to stop working and that was enough marking [for school work] and uhm you know I could say no to that and all that kind of stuff". Mandy, p.7, 220-227.

'My mum: always there to listen'

Fluctuations in blood sugar levels during pregnancy with GDM seemed to be quite common issue with some patients. This put them in a complicated situation particularly in terms of choosing what to eat or not to eat. Therefore, gaining some emotional support (in the form of some advice, encouragement and kind, caring and empathic word) from mothers after disclosing the situation via telephone contact seemed to be quite cathartic for the patients at that time. Here patients seemed to demonstrate a perception of such relationship, who they believed can understand their situations or concerns and will put their best efforts to support them in any way possible.

"If I got a high reading and I was starving and I I would call my mum. Yeah I think it was just probably my mum if I had to ring someone". Lorraine, p.3, 91-93.

"Well when I say support is it if I could not eat anything I would phone her up and say I can't eat anything [ ] and yeah she would probably say few more weeks sort of things yeah". Lorraine, p.4, 108-111.

"I would speak to my mum but she would say sort of say few things you know. Make sure you test few times after that probably why just in case you know you got it so so yeah it would be my mum anyway because she sort of understands anyway so". Lorraine, p.9, 280-284.

"If I have any worries or concerns she is always there and I am like mum mum mum this so yeah she is really helpful". Kirsty, p.13, 433-435.

A very close mother and daughter relationship has been demonstrated by the patients. Especially, during pregnancy, daughters seemed to get quite close to their mothers in terms of gaining some emotional support and advice in difficult situations. Kelly was contacted by a HCP for an initial conversation about the diagnosis of GDM to provide some general information about her health as well as some information about some potential risks or complication during birth. She became very disturbed and distressed after receiving such alarming information about her baby. At that time, she could only think of her mother who could understand her situation. She provided some emotional support in the form of reassurance, encouragement and a practical solution to such situation by finding out information in detail rather than getting worried unnecessarily by jumping on a conclusion.

"I called up my mum after the initial conversation when the lady had mentioned about the still birth and I was very upset. I said oh the lady said that the baby would have normalities [meant abnormalities] and stuff like that. My mum said, don't worry about it. Try to get a bit more information and there is no point getting too upset about it". Kelly, p.8, 242-248.

'She was always there reassuring and encouraging'

Perception of a sister's support in terms of providing information, reassurance and being there when needed the most was also described very valuable. Here Kirsty seems to demonstrate an unconditional support from her sister at every step, who seems to be ready to provide any support and in any way she can using her professional skills or expertise to explain rationality behind diabetes regime and psychosocial skills to provide encouragement when the patient was feeling very low by thinking about baby's health. Be empathetic and provide reassurance using word 'we' seems to make the patient feel that her sister is alongside her in this journey or concerning situation, which increased/boosted her confidence level.

"My sister who is here with me today with [?], she has always supported me. She is fab, she'll kind of do whatever I need (paused). She always is I mean she's a Radiographer so she is kind of semi-scientific with me so she always kind of sympathetic but also keeps me in check in terms of you know she keeps on the same head of you need to do this and there is a reason why you are doing it and your not just doing it.. for sort of thing so she was really helpful and if I was having particular bad moments or if I was upset or worried about how big the baby was going to because all these things cross your mind when you find out these sort of thing. She was always there and reassuring and saying it's not gonna be you know it's not gonna be a problem you're gonna manage it, it gonna be fine and everything you know we'll be fine". Kirsty, p.5, 150-163.

Friends

Intra-psychic processes:

'Sense of being understood'

Various patients seem to perceive a very supportive behaviour from friends in cooking special meals, which were suitable for the health of women with GDM. Such a kind, caring and supportive behaviour was very much appreciated by the patients. Arranging some social events during pregnancy with friends to cook and share meal ideas suitable for managing diabetes seem to be quite interesting and supportive activity for some patients. A very kind, understanding and caring attitude and behaviour was perceived when visiting them at their homes by cooking and eating the special meals suitable for diabetes management. This kind of support in food choices was appreciated very much.

"I think people tried, we went to one of our friends' house and she cooked a special diabetic meal". Lisa, p.8, 258-259.

"I have got two quite close friends here and uhm they were quite supportive, I didn't see much of them as usual but one of them always comes round for dinner and she is vegetarian so the vegetarian diabetic which was quite a specific kind of meal uhm that was nice and we cooked together and my other friend was quite supportive we talked about it quite a bit and she sort of baked me nice things. I did feel that people around me were being supportive and caring". Lisa, p.9, 293-300.

"If I went to someone's house they would you know what ever I could eat they would cook and everyone would have the same and obviously everyone was being very supportive so". Nicola, p.7, 231-233.

Colleagues

Sense of being valued/concerned

During interviews, some patients also shared their experiences about receiving emotional support from their work colleagues. During pregnancy with GDM, it is suggested to patients to continue monitor blood sugar levels after every meal. Such regimen can be forgotten easily at work place due to being busy or so on. However, Sandra seemed to have very supportive colleagues who knew about her condition and were very helpful in reminding her about the testing regimen, which she perceived very supportive and concerning attitude.

"Even at work it was the same uhm like when I had my lunch break and then after I ate, I had to come back to work. I sometime kept forgetting that I suppose to check the blood [sugar levels] but they [colleagues] were reminding me". Sandra, p.4, 121-124.

One of the explicit experiences of receiving some amazing support was demonstrated by Nicola, who was used to work quite long hours (from early morning until late afternoon) in the IT department. As part of her diabetes regime, the patient required going out for a walk after every meal with the permission and support of her colleague when leaving her alone to do her job as well. The patient's work requirements or job role seem to be very busy and constantly attending some telephone calls, where it could be quite difficult to manage all the work load/duties by one person. However, her colleague seemed to be extremely supportive, kind, caring and empathetic person to let her go happily for walks, understand her health requirements and support her in diabetes management. Nicola was used to work in the same hospital where she had her clinic appointments related to GDM, so she had the permission of her colleague and manager (boss) to go to attend her appointments without feeling any guilt. She seemed to be reassured by her colleague and manager that everything will be taken care of in her absence at work, so she felt comfortable and less stress or overwhelmed by following diabetes related regime at work as well as attending her appointments. Therefore, such a kind and caring practical and emotional support from a work colleague with an empathic attitude was perceived very valuable.

"Every day at work, I start work at seven thirty and I finish at four o'clock so I would generally eat my breakfast at work and my lunch. I work in the same office as my friend and we do the same job. Uhm we are on an IT a helpdesk and sometimes it can get really busy. So I would have my breakfast at you know at about eight or eight thirty and then within an hour I would have to go for a ten, fifteen minute walk and the same with my lunch. I would have my lunch at twelve and then again after an hour I would have to go, leave the office. So every day for about six weeks that I was at work I would have leave the office and leave her on her own to deal with all the phone calls. It didn't matter if all hell had broken loose and the service was crashing here there and everywhere because you're on a computer helpdesk. Even if the phones were going off the hook she would always say to me, just go I don't mind. I could go and not feel guilty that I was leaving her alone to do a job that basically I'm getting paid to do work for". Nicola, p.8, 265-281.

"Very, very empathetic very, very supportive friend and uhm, uhm because you do feel a bit guilty because you think oh God I'm skiving you know I'm gonna get in trouble for taking a ten, fifteen minute walk but uhm she was absolutely brilliant. Whenever I needed to go and for hospital appointments as well because if you're at the clinic you never know how long you're gonna be. You could be three hours and it's like oh God I'm leaving here alone again you know. She was great because I didn't have to worry about work because sometimes you can worry about work but she just made it so that's something I didn't have to worry about. She would always cover me and my boss is very supportive and sympathetic as well that she just took care of the situation at work and was like just go, ha ha, just go, yeah". Nicola, p.9, 292-305.

One of the components/elements of support, in terms of demonstrating interest in knowing/understanding GDM by colleagues was highlighted quite useful by Mandy. Talking about GDM related regime and answering any questions from colleagues about it made her feel quite skilled person in this area. She perceived such support quite effective in a way that it boosted her confidence and developed a sense of being valued and concerned by her colleagues.

"People are quite interested in the idea of having Gestational diabetes now you manage it uhm especially my female colleagues who have got children or small children particularly they would talk about it quite a lot with me which was quite nice. So you feel like you are

becoming an expert on it and they are you know asking things or how it is going or how your appointments have been. So that's quite supportive as well in a way". Mandy, p.6, 169-176.

Close network

'I managed it because I had the support around me'

Generally, supportive advice from those people, who really care about the person with GDM, seems to be very influential for the patients. As in the case of Mandy, receiving some supportive advice (in terms of keep reminding her constantly to prioritise her health) from a number of kind and caring people was perceived very important for her self-care. Mandy seemed to pay less attention to her health care sometimes due to being engrossed in her work load or "*letting the stress of the job to take priority over everything else*" at some point during her pregnancy. Therefore, having a reminder at that stage, not to ignore her health seemed to be very important to help her to break the tunnel vision/restricted vision towards her work and draw her attention to prioritise her own health. Having continuous reminders, advices and encouragement by very close people, seemed to save her from falling apart during pregnancy. All this support seemed to provide a sense of union, thus, perceived very important and valuable for her health.

"I think that one of the key things I suppose supportive advice I got from everyone including my husband my mum and my work colleagues was to consciously remind me that I needed to prioritise my own health. I was under pressures of work and the stress of work because there were definitely times where I was working too hard and not looking after myself. So not eating enough or uh not sleeping or resting enough so I think that definitely uhm sort of.. there were points where I was not listening to my own body and how I was feeling and I was getting .. and I had to just keep working and I was just letting the stress of the job to take priority over everything else". Mandy, p.7, 207-218.

"I think yeah that having people reminding you that actually that's all well and good but this is more important. It seems silly things to have to be reminded that this is more important but I think sometime you almost get tunnel vision at work". Mandy, p.8, 240-245.

"I was definitely good rated uhm several times through both pregnancies by people and I think that was quite important because I think otherwise I would have had like mini mini breakdowns kind of you know". Mandy, p.8, 248-251.

An essence of this thesis has been summarised by Ann in terms of describing her feelings or meaning of support. From her perspectives, having supportive network around her made certainly easy to manage diabetes during pregnancy.

"I felt like I managed what I was doing but I had the support around me. So yeah. It definitely made it a lot easier to deal with having Diabetes, having a support around". Ann, p.4, 118-120.

Various people providing support in the form of cooking food suitable for the person with GDM and avoiding sweet desserts, was perceived as a sense of unity by Karen. It was also perceived as a nice gesture by those people to support her in any way they could.

"Helping with the cooking in the correct sort of things not, uhm a lot of partners and friends and people don't order pudding when you are at a restaurant. It shows solidarity with you, it's just nice as well but it's not necessary (smiling). They don't sort of flaunt their sort of chocolates or sweets in front of you if you see what I mean". Karen, p. 7, 215-220.

4.2.1.3- Provide guidance and advice when needed the most (Informational support)

HCPs

HCPs mostly provide information regarding diabetes management, but how patients perceive them; this will be discussed in this section.

'Thanks for understanding me and my condition'

An effective way of providing information was perceived by Nadia, which meant explaining medical information in a way that the patient could understand them accurately and apply them practically.

"She was very understanding and she explained things very well to me and she also told me she taught me a little bit about like body parts, so you know what was happening to the pancreas so when I was eating what was happening. So that made me understand much much better ah". Nadia, p.4, 134-138.

During pregnancy with GDM, having informational support from a midwife is considered extremely important to tackle some dubious issues. Nadia described one of the positive experiences, where a midwife provided an immediate support by understanding her condition, when needed the most. After following what was suggested over the telephone, the patient felt improvement in her health (i.e. blood sugar levels).

"The midwives were really good when they were on call as well yeah. If I ever had any questions because there was a couple of a time my blood sugars dropped quite low like to 4.0 or 4.1 very low and I called them and said if I eat is that gonna shoot up. She said that I should eat something but just a small amount like a mouthful of cereal and then after an hour to check and then call her back once I had done the test. So I did what she said and after one hour it had gone up to 5.3". Nadia, p.16, 518-525.

Having reassurance through face-to-face conversation from a HCP seemed to be perceived much better than receiving written up information about GDM in certain situation. A similar experience was demonstrated by Sandra. Who received written information about her diagnosis, which made her quite upset because she found such information quite disheartening. However, after meeting with a HCP, she received some reassuring verbal information in an effective and comprehensive way, which gave her peace of mind, self-confidence and a sense of understanding her.

"Some people they have not got an idea about it and they will still write things, so when I came to [the clinic] and I spoken with a lady. It helped me and I felt a little bit more like ok that is normal. I have got it now, so she explained how to deal with it, how to do the blood test checking and that it wasn't actually done bad". Sandra, p.1, 27-31.

Patients with GDM seem to have their personalised approach to perceive a certain type of informational support effective related to their understanding and needs. For instance, Kelly perceived receiving information in pictorial form more effective than in any other way (according to her needs) to gain some knowledge about food to avoid and eat and portion sizes. Dieticians seem to have a standardised book to provide guidance to diabetes patients about food and portion sizes, which some patients really appreciate. The following patient Kelly was provided some advice about certain things to avoid and eat and to take as a snack. She seemed to have some misconceptions about eating sweet things with GDM, which were cleared out by gaining information about some certain sweet things can be taken during pregnancy with GDM. Acquiring fact-based information in a visual way increased her confidence level to try a variety of food rather than having dubious thought about eating/trying certain food choices. Here the HCP seemed to apply a visual strategy to provide the information, which Kelly could understand.

"I came to the diabetes clinic and the lady was very helpful. Uhm She showed me a booklet, which guided me through the portion sizes and things and gave me some advice about things to avoid uhm and sort information sheets of what were good things to eat and what I shouldn't have. Then she also advised me about certain snacks that I could eat that were sweet but were ok. This was nice because I thought I couldn't eat anything sweet. Uhm so I went home after that feeling like I could eat a bit better normal food because I sort of initially didn't want to eat anything because I didn't know what was right or wrong". Kelly, p.2, 43-53.

Furthermore, she explained that gaining information from the Dieticians' standardised book more effective than just receiving written information about food guidelines. Through that book, she could visually see various kinds of food to eat and specification of portion sizes quite clearly. Providing information in such an effective way seems to develop a sense of understanding patients' needs.

"They did give me some written information which sort of summarised the sort of things you could eat but obviously the book was really helpful because it had the visual. It looks like it said specifically that how many grams and stuff". Kelly, p.14, 455-458.

Furthermore, having lack of information or incorrect information seems to make patients anxious about certain medical aspects as in the case of following patient. Diane seemed to be quite scared about her baby's heartbeat during her stay in the hospital. However, after receiving comprehensive and satisfactory information verbally from a male nurse related to her queries, she felt much supported. She perceived such approach very supportive, effective and understanding to provide information. She also appreciated and praised his knowledge and skills to provide information in an effective, calming and non-frightening way, which seemed to give her reassurance and improve her confidence level.

"On the DAFNE ward, I had, it was the one nurse the man. He was brilliant because when I knew you know it was almost afraid about something about the CTG , he was almost I was giving him the questions and he was explaining to me for 10 minutes. How everything is, should I be afraid or no and which kind of.... they have got a procedure also and he was like the angel there. I really wish you know that all the staff can be like him but people there are very different. But if you got the knowledge I think he had a lot of knowledge and a lot of experience. He can explain and it is really really helpful, somebody gonna have to explain to you what is it and don't be afraid, you gonna have to be calmed by yourself. He was just like the psycho". Diane, p.12, 378-392.

Mothers

'Mum's advice made pregnancy less stressful'

Working continuously till the last month of pregnancy seemed to be quite difficult for some women with GDM, especially due to long working hours and following diabetes regime. At that time, having some informational support or advice related to general health from family members can be quite useful particularly when a mother is unable to think of resolving any issue due to various types of stressors. As Mandy seemed to work quite long hours (almost 12 hours), which were affecting her blood sugar levels due to may be stress or fatigue. She shared this experience with her mother. She advised her to discuss it with the manager regarding her health condition and a possibility to decrease some hours at the last month of pregnancy. After gaining such guidance from her mother, she seemed to have increased her confidence level and managed to speak to her manager, who accepted her request. So overall, mother's advice/suggestion and a sense of understanding her needs was perceived to be very useful in terms of making the last stage of pregnancy slightly easy for her to manage it.

"Mum gave me advice to go and talk to my employer to see if I could change my timetable slightly maybe I had some challenging classes straight after lunchtime and I was worried that was interfering with my blood sugar uhm levels so which I did do actually and I did go to talk to my finance the manager in charge of the timetable and at the last stage of the pregnancy I did reduce my time table slightly. Uhm so that was good advice because I then had slightly better timetable and a slightly less stressful end for my pregnancy while I was at work". Mandy, p.5, 140-149.

‘Another set of ears to hear information’

During pregnancy with GDM, women are provided various types of information, especially for those who develop it first time. Therefore, it can be quite overwhelming for some patients to remember everything during short duration of their appointments. One of the ways perceived very useful in terms of remembering the information (provided at the diabetes clinics) at home was by bringing their mothers or mother in laws during the clinic appointments. The family members seemed to be coming along with the patients to attend the appointments by understanding their conditions and needs.

“Mother-in-law supported me quite a lot. She came with me quite a lot to the appointments here so she could be another set of ear to hear what they were sort of saying and help me follow up at home”. Ann, p.3, 91-94.

“My mum came with me as well couple of times to help me to remember what they were saying and applying it at home”. Ann, p.3, 96-98.

‘Being there for me always’

Ann described a similar perception of supportive network. She perceived it very useful in terms of having a sense of someone from family alongside whenever was needed. Family’s supportive behaviour of coming along to the clinic appointment and making notes of information provided by the HCPs to help her at home was perceived very valuable in terms of implementing the information appropriately. Having a sense of reassurance from an excellent supportive network at home to be there for her, seemed to boost her confidence to manage the Gestational diabetes.

“Just really letting me to take the reins but been there support if I need them. Yeah and uhm when uhm I have support here from the in laws and my mum. They would write down the notes of what they were saying and then I would take them home and remember what they have written. So I could try to do everything properly. So that was really quite helpful and then uhm husband came along to the extra scan I had as well to check that the baby was growing ok. Uhm so I just I felt like I had a good network of support uhm even it was just to be there for me”. Ann, p.4, 107-116.

Friends/peers

'Lucky to know someone who had it'

Receiving some information related to diabetes management from peers seems to be quite useful for some patients, particularly those who developed GDM during pregnancy. Patients seem to feel a sense of reassurance after gaining some advice or information from friends as well as a sense of not being alone on this pathway of GDM. Consultations based on sharing and discussing similar experiences with peers was perceived very useful in terms of understanding a real picture of diabetes management and eating regimen. In addition, patients seemed to find very reassuring to know those peers, who did not have diabetes after their deliveries.

"I had consulted a couple of friends who I'd known who had Gestational diabetes and they gave me some advice as well, so I found that quite helpful. I was quite lucky that I knew someone who'd had it really I think". Kelly, p.4, 118-127.

"I've got other mother friends who have children about the same age as my daughter and they are all kind of new friends. I would not bring them to hospital with me for this, this particular sort of thing uhm but I did tell them that I had it and someone else had had it and she told me a lot about what to expect uhm and also what she had eaten when she wanted snacks". Karen, p. 6, 168-174.

Improving confidence level and perceiving a sense of reassurance was also perceived by receiving some information from a peer related to the medication. Diane was quite concerned and not very happy about taking the prescribed medication, but after discussing with a friend/peer and gaining some reassuring information boosted her confidence level and encouraged peace of mind.

"When I found out that I got diabetes and to go tablets and I met with ladies in my work and they actually the one of them she explained to me that I shouldn't be afraid to take the metformine because metformin isn't going to put you on hypos. It is more safe tablet like the insulin and I should be alright and she explained to me little bit how this is everything happened. And after once she explained to me I was settled and calmed. And I was just following you know to take the medicines". Diane, p.6, 194-2002.

4.2.2. Theme 2- Upsetting incidents

During interviews, patients shared some of their experiences, when they felt they were ignored, frustrated with the HCPs' behaviour/attitude, received unsupportive examination process and were disappointed with the treatment process.

4.2.2.1- Dissatisfaction with communication

"No-one told me that I would be feeling this way"

One of the patients Lisa appeared to be quite frustrated and disappointed with the HCPs' overall behaviour at one of the clinic visits. One of the visits was related to diabetes glucose test when she was not informed initially what could be the potential immediate effect of this test on her health. She was left alone to face the unexpected health condition. There seemed to be a lack of professionalism and empathy during the clinic encounter with the patients.

"I was uhm sitting there shivering and shaking and nobody reacted, no-one told me that I would be feeling this way. They didn't say oh you may feel sick or anything". Lisa, p.2, 49-52.

'Lack of acceptance to hear different'

Sense of not acknowledging patients' perspectives regarding different types of treatments, was also perceived by the patient Lisa. She seemed to feel hesitant to share her views regarding different types of treatment as well as asking the HCPs for a different kind of treatment other than what she was prescribed. She believed that they might think negative about her or have unpleasant attitude towards her, in response to sharing or asking for a different treatment. She also had some concerns that this kind of discussion might affect on her current treatment as well.

"I always feel that it is not appreciated if you ask for different treatment actually I think; you feel that they will think badly of you in some way". Lisa, p.2, 56-58.

'Harsh way of delivering truth'

Providing fact-based information to manage GDM in an empathetic way seems to be quite important from the following experience. During one of the clinic visits, Nicola felt quite offensive, disappointed and disheartened after receiving some abrasive feedback from a HCP (diabetes consultant) related to her diabetes management especially her diet related regime. She seemed to believe that she was putting all the efforts to manage GDM and was expecting some encouragement after putting some efforts. However, she received some critical comments, which made her feel quite sad and discouraged/disappointed. One of the nurses, who was present in the room, realised the whole situation and reassured her (on behalf of the consultant) later on by explaining her rationality behind this conversation or a harsh way of providing the information for her wellbeing and better outcomes.

"So uhm that was a little bit upsetting to begin with because I was thinking I was doing really well. I was really trying but it just felt like it wasn't good enough for her. So I came away feeling a little bit deflated uhm but straight away after I had come out of that appointment uhm there was a diabetic nurse who I would see before she was sitting in the appointment with me and I think she realised how harsh this women had been and she came running out after me and she said to me not to worry and also told me that I was doing really well. She said that it's just that she was being honest with you and when you think about it, she is just saying what she has to say. You have to be honest, you have to say look you have diabetes. Sort your diet out; otherwise it will only get worse for you. If you do get pregnant again you will get it later on in life. So she was giving me you know the hard truth. It was just the delivery of it, it was a little harsh". Nicola, p.6, 179-194.

<u>'Unwilling to believe me'</u>

On the other hand, when Lisa was diagnosed with GDM, one of the HCP seemed to be dubious about her diagnosis and was not willing to believe, she has insulin resistance problem. She was quite disappointed with the HCP's attitude of not believing on her diagnosis.

"So actually she disagrees with my consultant who is meant to be a specialist in diabetes and gave me wrong information and then she didn't seem to be willing to believe my history even though it is fairly kind of I don't know it's not the sort of thing people would make up that they have insulin resistance, most people don't really know what insulin resistance is". Lisa, p.7, 240-245.

A sense of being overlooked and apprehensive by the HCPs was also described by a patient Lisa. She seemed to be quite disappointed when discussing her clinic experiences, particularly when disbelieved by the HCPs about her previous history of a diagnosis of Polycystic Ovary Syndrome (PCOS). Her point seemed authentic that HCPs need to trust the patient as ‘this is the only person who has got the whole picture’. In addition, to understand the patient’s situation, HCPs need to put themselves into their position. In other words, HCPs need to use empathetic approach or patient centred approach. This means that they need to provide enough time to listen and understand the whole picture/story from patients’ perspectives by putting themselves into their situation. Lisa seemed to be extremely unsatisfied with the services received overall.

“I suppose I felt if you have a pre history and if you know about your situation it makes you feel disregarded if the treatment people don’t believe you because in a way I think in a way sometimes the only person who has got the whole picture is me and myself because the NHS don’t do that very well. They don’t seem to look at everything and don’t have enough time but if they work like that then it is important to have some kind of ear to the patient”. Lisa, p.13, 465-472.

“I think overall it was not done very well as a whole but I suppose it’s always a compromise between the facilities they have available”. Lisa, p. 14, 508-509.

‘Sense of being rushed’

A disappointing and distressing experience was described by Diane with the HCPs relying on giving leaflets rather than explaining information comprehensively just to save some time. She seemed to find easy to understand all the provided information verbally and comprehensively rather than in written form, as reading written information sometimes develops various curiosities or questions to ask to the HCPs. Therefore, providing leaflets to read does not seem to satisfy certain patients’ needs/concerns and they do not seem to find it helpful due to not having satisfactory and enough information. Sometimes, they seem to lose peace of mind due to insufficient information after returning to homes.

“I was also a bit upset with the time because the staff doesn’t have much time to spend with you they are meant to explain to you but rather than they are giving you just leaflets. For me this was a little bit annoying”. Diane, p.16, 535-538.

"The leaflets, just read it for yourself and you know. They are giving you leaflet as I was going home. I'm going to read this leaflet but oh I have a question where am I going to go. I don't know if it can happen to for example you know ok you are going to have to be induced. The lady Doctor asked if I understand what is mean. I said maybe little bit because my midwife she didn't tell me. She just told me you know they are simple level of the information that she give me to read, to the leaflet to read". Diane, p.17, 540-548.

"I didn't have a lot of you know enough information for me to have it and just go home and to calm down". Diane, p.17, 550-551.

<u>'Conflicting, confusing messages: don't know what to do first'</u>

Last stages of pregnancy with GDM seem to be quite frustrating for the patients in terms of not being assured about the delivery process (e.g. normal, c-section or induction) and continuously keep thinking about the size of the baby. The following patient Kirsty faced a similar situation when she came in the clinic for a scan, where HCPs discussed an option of inducing her early due to considering her baby's size, which she seemed to accept it mentally after a while. However, later on she was informed and assured by another HCP, that there is no need to go through induction by considering her current situation. She seemed to be quite confused and frustrated by receiving conflicting messages from different HCPs. Even though she gave them empowerment to make a decision for her delivery on the basis of their expertise, they seemed to have individual preferences related to her condition and potentially lacking competence to make a firm decision based on evidence. So, after all the confusing and in between process/situation, it was decided to induce her few days early from her full term. Overall, this whole experience developed a sense of incompetency of HCPs' skills and was perceived quite frustrating, unhelpful and overwhelming at the last stage of her pregnancy.

"We had one lot of people saying that oh you are fine, don't worry, you are controlling it by diet. We will have the scan and see how big the baby is. I had the scan and the baby was looking a bit bigger than what he should be at that point. Uhm and then the people we spoke to said oh we want to bring you to be induced. It is better to be induced blah blah blah. So I was like ok. So at that time, I brought myself a week early to say ok right I have accepted that I am going to be induced now, discussed that sort of things. Then we saw someone else and he said don't worry about being induced, you will be fine to go to 40 weeks. So we had kind

of conflicting messages and it was really confusing because we didn't know what to do first. They didn't think like anybody else could tell what to do the best. So it was kind of like what we do it. It seemed like it was personal preference of the consultants and what their feelings were about what we should do not. There was any kind of founded evidence if you know what I mean. Its quite, you kind of want to be led by the expert and they didn't seem to be happy to make a decision either way [ ]. Uhm so being here was good because I did feel kind of more happy about it, but I was a bit kind of. I would rather said someone to me that you are going to be induced or not going to be induced rather than kind of in between. So in the end, we agreed that consultant that said to go fulltime. We agreed to kind of come in three days early to be induced. So that we were kind of, we were almost half way there really, because the first lot of people said come at 38 weeks, 39 weeks to be induced and the other guy said go to 40 weeks [ ]. I was like oh what to do". Kirsty, p.11, 344-371.

Kelly described a similar experience, where she seemed to be very confused and dissatisfied about HCPs' views of inducing her two weeks early than her due date. Such behaviour and thinking could be due to having lack of confidence and trust on HCPs' decisions/skills based on her experiences and observations during clinic visits. Patients like Kelly seemed to develop trust and confidence when HCPs provide care with empathy, by understanding and believing the patients and by paying attention on individual needs. All these factors seem to make the patients feel that their and baby's health is taken seriously by the HCPs.

"I think because they were doing everything on the statistics, saying oh we got to induce you at 38 weeks and to me again that felt like that wasn't proper and got to be very careful about these things because of the shoulders' desiccations and stuff like that but again they knew that some of it at 38 weeks was completely average, but yeah they still have to induce you. I didn't really understand why they had to do that. I never understood that". Kelly, p.12, 394-400.

4.2.2.2- Dissatisfaction with treatment/procedure

'Annoyed with late diagnosis'

Talking about the diagnosis of diabetes, Lisa described one of her clinic experiences, which made her quite angry. This experience was related to the diagnosis of diabetes quite late, which made her quite anxious. She had a sense of getting diabetes during pregnancy due to her previous diagnosis (PCOS). However, it was not picked up until quite late rather than in an early diabetes related test, which made her quite upset with the HCPs, who knew about her previous illness. Lisa was used to live in Germany, and according to her knowledge, Health care professionals in Germany conduct diabetes related tests quite early, if a patient had PCOS. She seemed to prefer the approach of testing diabetes very early due to PCOs, as she believed that any further delay could affect her and her baby's health. Perceiving a serious impact of late diagnosis made her quite anxious and stressed when she came to know through different resources (e.g. internet and different people from her country) about the impact of late diabetes diagnosis with PCOS.

"I generally to be honest when I got the diagnosis ahh [ ] was quite annoyed because I actually got them to test me for diabetes a lot earlier because I had, there were reasons for me to believe that I would probably get it that I develop it not necessarily but it was more likely with most women when PCO Syndrome I was more likely to have a Gestational Diabetes and in Germany that means they test you a lot earlier and here they don't. Uhm that made me quite nervous when I hadn't had the test here yet". Lisa, p.2, 65-72.

<u>'People don't take Gestational diabetes seriously'</u>

Lisa was not very happy with the treatment process overall, as she described a number of unsupportive experiences with the HCPs, which made her think that her diagnosis was not taken very seriously. Her journey of diagnosis with GDM seemed to be quite frustrating due to may be HCPs' lack of empathy or understanding patients' perspectives.

"I didn't really feel that the treatment here was very good and all together especially from the department apart from one or two people and then I also think in a way that if you have people don't take you Gestational diabetes seriously if it then stays then people get very close to the idea". Lisa, p.12, 407-411.

A sense of not being taken sincerely by the HCPs was perceived by the patient when seen by different HCPs at every clinic visits as a next patient on the system. It could be more beneficial or supportive if she was seen by the same HCP regularly, who would remember her treatment regime and her as a person previously. Lisa also acknowledged the fact that it might be possible to apply the rule of seeing same HCP on regular basis, but the infrastructural system (basic organisational system) does not allow this rule to take place in the NHS.

As one of the HCP during one of the clinic visits (with diabetes and obstetric team), assumed the incorrect treatment regime (due to not reading the medical notes appropriately) and started giving an advice to follow on in the future. It could potentially be harmful for the patient if Lisa had not realised that this was the case (i.e. the advice was based on assumption rather than looking at notes). Overall, this whole experience made her believe that she was not taken seriously as a patient, which demonstrates lack of efficiency in care and lack of communication between teams of HCPs looking after same patients.

"I did not feel as I was being taken seriously as a person I felt I was very much on a sort of a finishing line of people who were just coming through the system uhm so I didn't see the same people at different visits. I think if it is possible but I know the NHS doesn't necessarily work that way if there had been a bit more consistency that you actually do see someone again who remembers you from the last time". Lisa, p.13, 445-451.

"I always had to sit in the sort of corner so even when I was seeing the diabetes and obstetric teams together they hadn't sort of looked at my notes – one of them actually thought I was only diet controlled so she was advising me for that situation which wasn't the case I was all ready on insulin and if I hadn't realised that's what she was assuming so indirectly she would have given me the wrong advice". Lisa, p.13, 451-457.

"So this thing about reading the notes properly and communicating with each other, if you got two teams, the diabetes and the obstetric teams, they do actually need to talk to each other that they are having problems". Lisa, p.13, 459-462.

'Long wait: you are tired in your final stage and want to be at home'

An experience of going through a long and distressing waiting time was perceived very difficult especially at the last stage of pregnancy. Sandra found one of her multi clinic visits (midwife and diabetes clinic) quite unexpectedly long, just by waiting to be seen by the HCPs. She found such experience quite overwhelming due to being at last stage of her pregnancy and sitting continuously for quite long time. She seemed to be unable to go out for a walk in case she was called out. She seemed to be referring to other patients' complains as well as her about the long waiting time. In addition, she seemed to be trying to increase awareness about the pain or physical discomfort and tiredness felt by the patients due to consistently long waiting.

"I think the waiting time, first like I say that I had an appointment once at 2 o'clock which was a problem because my midwife she could see me on Tuesday which was a huge problem because that was the day I had diabetes appointment as well. So I had an appointment here with the diabetes clinic at 2 o'clock and an appointment with the midwife at 4 0'clock or half pass four. So I thought I should be fine because normally the appointment itself does not take that long but the waiting time it takes ages. It's like once I came here at 2 o'clock and was still here until 5 or 6 o'clock and everyone kept complaining because like you are pregnant, I felt alright for me it did not bother me that much that I had to sit, because you have to wait you cannot go for a walk because you have to wait, anytime somebody can call you [for an appointment], so that was the part of experience and I heard everyone complained about it because you know you are tired and if you are like in your final stage, you want to be at home". Sandra, p.6, 208-223.

'Lack of continuity in care'

Disappointment in the continuity of care was perceived as one of the issues in terms of explaining everything about the diagnosis and treatment to a new HCP every time to make him/her understand about her condition's situation. She seemed to find it quite annoying/frustrating experience and prefer to have one person looking after or providing care throughout the pregnancy.

"Once I had very nice person and he tried to explain to me like quite well, but I was already in my final stage, so it too late and the problem was that I see someone else. Once someone knows you I know they got papers and if you see someone else you have to repeat it like every single time from the beginning because to understand your position". Sandra, p.8, 258-263.

'Lack of efficient behaviour'

Perception of an unhelpful experience from a HCP was illustrated by Nadia, which made her quite anxious and panic. Patients are eligible to provide information about themselves in their medical notes, which needs to be respected and taken into consideration during their clinic visits professionally. With the following patient Nadia, the situation became quite frustrating. As despite of her written request ('not to be seen by a male HCP alone in any stage of her pregnancy'), she was left alone with a male HCP without reading or paying any attention to her medical notes. She seemed not only uncomfortable in his presence, but felt very anxious, nervous and panic at the last stage of her pregnancy. Due to feeling highly anxious, she was unable to pay attention to what he suggested related to her diabetes management. Such carelessness from HCPs of not reading medical notes could be quite dangerous for her health or her baby, which was perceived quite an alarming experience from her perspectives.

"The only time I felt was not helpful when they did not read my notes properly and they put me in a room er it was another diabetes Doctor but it was a man and they put me in a room with a man and I told them in my notes it quite clearly stated that when giving birth uhm and any appointments up to then I didn't want any other man in the same room as I'm in. Men make me very nervous if I'm on my own and they literally sort of said oh can you wait here for a moment and then someone will come and see you. Obviously when someone says Doctor it could be a man or women and then obviously I'm heavily pregnant and now I'm sitting in a room with a man and he is explaining stuff to me and I froze [-] and he said something like now do you understand and I said sorry I didn't hear anything that you said. I just started fidgeting and twitching and I felt anxiety coming on. I felt very panicky and that was the only time because they didn't read my notes". Nadia, p.13, 431-446.

Patients are provided contact details with reassurance that somebody will be available on the telephone to receive their messages. However, a sense of lack of efficiency from the HCPs was perceived by Diane, when she contacted the HCPs after feeling quite awful due to some disturbance in her blood sugar levels at work, but received no reply even after trying repeatedly. She seemed to be quite distress at that time and was hoping/expecting some urgent support to manage such an alarming condition in her perspective, but felt very disappointed after finding no one available on the telephone.

"I was at work at this time and I felt really really horrible because I was checking my blood sugar every half an hour because I felt so bad and it was going up and I decided to call to the nurses here on the number which I had it in my book. And it was really difficult because the call says leave the message [repeated three times]. It wasn't like you know that somebody will pick up the telephone straight away and tell me what to do". Diane, p.7, 221-228.

On another occasion, Diane had very disappointing and distressing feeling after receiving no reply despite of leaving a message with a HCP. She seemed to find difficulty getting hold of someone on the telephone to ask some urgent questions related to her diabetes. Eventually, when she found a nurse to get some advice, it was suggested her to wait for her call regarding her query, but unfortunately, no reply was received at all. This unprofessional and negligible behaviour made her quite angry and distressed. Diane seemed to acknowledge the HCPs' busy schedule, but expected some support what was assured over the phone.

"She thought she took my details and she said to me I am gonna have to call you back. Until when I came to the hospital to give the birth, nobody called me back. This was really stressful and really. I was to be honest I was very angry because you know its [-] on my side if you are the nurse if somebody is leaving you to do it you know this kind of message and you got risk and also because of your age. If you got knowledge you just realise just ok you don't have time you know may be for few hours because they are busy in the hospital but just. She said to me I am gonna have to take advice from my colleagues and I am gonna have to call you back. If somebody is saying you something like this, you know you are just waiting for the support". Diane, p.8, 241-255.

4.2.2.3- Dissatisfaction with the medicalisation of pregnancy

'I am medicalised'

A sense of disconnection from midwife led care was perceived by Mandy due to being treated medically for the GDM. She felt the focal point was much more on diabetes related issues (e.g. blood sugar levels) rather than on patients' personal/psychological needs (e.g. receiving some information solely from the midwife) particularly during pregnancy. These needs were noticed particularly when Mandy heard from her friends (with no GDM) receiving special midwife care and this made her realise what kind of care she is missing may be due to the diagnosis of GDM.

"Being hospital led was the sense of detachment from the midwife-led experience that lots of my friends had because I am medicalised, sometimes it's so medicalised that the focus is on the diabetes, on your sugar levels, on your eating and I think you will almost feel like you are you know... if you are talking about your pregnancy health in those terms that's fine but I think I definitely felt like I lacked more.. sort of how you are doing conversational stuff that you get from midwife led the more personal". Mandy, p.12, 401-410.

A difference was described between a midwife led care and a medicalised care and its affect on how a patient experiences/perceives the journey of pregnancy. Perception of having a midwife-led care seemed to be related to more pleasurable experience of pregnancy than just having medical care. Considering personal care related issues during pregnancy from Mandy's perspective, having midwife led care could be very beneficial to get some peace of mind than just discussing medical side of pregnancy with GDM. Here focal point seems to be on GDM related issues, which makes the patient left out of personal care and emotional side of pregnancy. From a patient's perspectives, receiving some personal care means receiving answers related to personal health care questions during pregnancy could make this experience quite smooth and enjoyable (by resolving various doubts), which she believed that she missed that side of care.

"I think having midwife part of what you see enjoying you know your pregnancy and enjoying the experience and I think when it is medicalised you don't have that midwife led care and there is little bit of you especially towards the end I suppose you go sort of you are overloading with data on how you are doing but then you sort of feel like you haven't perhaps had more personal side and perhaps you haven't enjoyed it which you might have done". Mandy, p.14, 462-469.

Similarly, Kelly seemed quite upset and dissatisfied with the lack of patient centred care. She expected to be treated and understood by the HCPs as a person managing various diagnoses with the pregnancy. During clinic visits, she seemed to observe that HCPs focused more likely on the blood sugar level values and guidelines of managing them than paying attention to a patient's previous diagnosis or individual needs. She perceived such support ineffective and dissatisfactory.

"It's all the statistics and kind of treating basic statistics rather than based on your history. I suppose they have to do it based on the statistics and everything but I didn't feel very much like individual. I felt bit like that's what they do with everyone, so that's what they would do with me as well". Kelly, p.13, 411-415.

4.3- Recommendations to improve current services

During interviews, patients provided a variety of suggestions to improve GDM related services based on their learning. Although, this area does not relate with the thesis' aims and neither with the IPA, it seemed to be very important to enhance current services. Thus, patients' provided suggestions will be illustrated descriptively.

Conduct tests in advance

Lisa had developed PCO syndrome before her pregnancy, therefore she expected from the HCPs to conduct some tests to examine the symptoms of GDM during pregnancy. She believed that her tests were conducted quite late and having late diagnosis affected her diabetes management. Thus, she suggested organising such tests in early stages of pregnancy for those people who already have developed a condition before pregnancy by exploring their background history, which might help them to manage the GDM in early stages of pregnancy.

Provide a non-crowded sitting room

Furthermore, Lisa suggested providing a separate room to the patients to sit after the OGTT, which can be quite comfortable for them. This suggestion was based on her experience, when she felt quite unwell after giving some blood as part of the OGTT. She seemed to feel quite embarrass/uncomfortable by sitting in the waiting area in front of other people, while getting hold of herself.

Provide safe food recipes/meal plans

One of the treatments of managing the Gestational diabetes is eating the food, which is suitable to keep the blood sugar level stable. The following patient Sandra seemed to stick to always eating certain type of same food by assuming/imagining any negative effect of eating different food on her or baby's health. Therefore, she believed that having a food recipe (provided by the HCPs) combining different types of food choices suitable to manage GDM would be very useful for the patients like her.

Similarly, another patient Lorraine suggested providing a personalised meal plan & list of carbohydrate free things. Here patient Lorraine seemed to have developed a lot of knowledge about nutritional food choices, particularly, carbohydrates. For instance, consumption of carbohydrates more than body requirements can make diabetes management quite difficult. Some patients may lack such knowledge; therefore, she suggested providing them a meal plan, which suits their needs.

Provide education about food choices and diet plan

It was also suggested to provide information about different food choices for three meals a day to try at home. As some patients may have lack of knowledge in terms of what to eat or not to eat to manage GDM. It can be quite frustrating for some patients during pregnancy to see/feel the changes in their blood sugar levels despite of eating healthy food, as in the case of Kirsty. So it was suggested providing a sample meal plan to try for some time can be helpful for patients like her.

Home visits at post-natal by a midwife

One of the important suggestions provided by Nadia related to the post-natal period was to have home visits by the diabetes midwives. During pregnancy, women are looked after by the clinic HCPs, but after delivery, it was suggested to be looked after by a diabetes midwife at home within first few weeks. Generally, women are seen by the HCPs at the diabetes clinic after 6-8 weeks of their deliveries to conduct the OGTT, but having a mid-wife led support at home before that test was suggested very important in terms of exploring a mother’s lifestyle and management routine and providing encouragement and information to boost her confidence level.

Similarly, Mandy highlighted the importance of midwife led support during pregnancy. She believed that having diagnosed with GDM, the focus/emphasis is much more on medical care rather than personalised care (provided by a midwife), which she preferred. However, unfortunately she could not receive such midwife led support as much as she expected like other women who do not have GDM. Therefore, she suggested that having such personalised support in the clinic would be quite useful for mothers/women like her to feel reassured and cared for.

Patients are provided various types of information after the diagnosis to manage the GDM. Patients seemed to have preferences in terms of receiving information. For instance, Ann preferred receiving written information more helpful in comparison to just receiving verbal information, because it saves you from writing down all the verbal information provided during the clinic appointment and have something to take home to read about the condition. Therefore, it was suggested to provide written information to all the GDM patients.

Similarly, Karen found receiving information very useful during clinic visits in print form to remember things later on at home. She seemed to have gained some knowledge and learnt about unhealthy food choices from the written information, which was perceived very valuable. However, she suggested providing such information by designing an attention grabbing or eye-catching leaflet could be followed up (in terms of understanding it) easily by the patients.

During GDM, some patients are recommend diet treatment only and some diet plus (e.g. with medicine) after consistent monitoring of blood sugar levels. Patients are advised by the diabetes specialist dieticians to eat healthy diet in small portion sizes. They use a standardised book, which demonstrates the portions sizes (in pictorial form) of a variety of food people mostly eat in day-to-day life. Here the patient meant gaining information about the quantity (or portion sizes) of food, she should/should not follow to eat. She seemed to find useful gaining information by looking at the pictures of certain food with its portion sizes (in grams) and nutritional values (e.g. carbohydrates).

However, Diane preferred to have verbal information by the HCPs about diabetes management or explaining the information written on the leaflet in their own words before giving it to the patients. Here patient seemed to be suggesting of providing comprehensive information verbally, as the leaflet may not provide sufficient or satisfactory information.

One of the patients Karen highlighted the use of waiting time for something quite productive as a suggestion to improve current services. She believed that pregnant women with GDM can be helped by providing discussion groups with those people who have developed this condition (peers). However, for this purpose, community based setting would not be feasible to attend those peer group forums due to some pregnant women’ work commitments/schedule. Therefore, arranging a peer discussion forum (to join voluntarily) in the clinic during waiting time of their appointments could be a way to make such time quite productive for the patients.

Having peers in the discussion group/forum to share their experiences in a kind, caring and empathic way could be useful to satisfy those patients’ needs who may achieve some confidence and reassurance after discussing any issues/difficulties with their peers. In addition, they may feel less lonely and stress/frustrated going through on this pathway.

One of the other advantages of such discussion group could be feeling quite relieved and emotionally supported after sharing experiences with each other in a non-professional and light environment. This suggestion requires designating some staff members/HCPs to devote their time for this forum.

Chapter 5 - Discussion

5.1. Overview of the Analysis

This study contributes useful information to extend knowledge and understanding of social support in managing GDM during pregnancy. The data of this study generated two different main themes. The first theme that emerged from the women's stories reveals the efficacy of social support during pregnancy and its influences on their mental and physical health. In addition, it highlighted various categories of support received during pregnancy from formal and informal sources, grounded in a specific context of family, work and clinic life. However, the second theme highlighted some unhelpful experiences from patients' perspectives. Based on such experiences, patients also provided some useful suggestions to improve current services.

The data from the first section indicate that women perceive the receipt of three distinct types of support (informational, emotional and practical) and have seven supportive relations (e.g. husband/partner, HCPs, mothers, sisters, colleagues, friends, mother in law) in their networks. Although the sources varied at some occasions by type of support provided, the role of husbands/partners and HCPs was prominent in most of the narratives. The types of emotional and informational support were discussed most frequently in terms of their importance and consistent influence on Gestational diabetes management related practices. Participants also seemed to be making some intra-psychic process or psychological meaning making processes throughout both sections as well as using some coping strategies mainly in the first section.

Emotional help related to diabetes management regime was the most acknowledged type of support among the participants and appears to be more forthcoming from HCPs, mothers and partners/husbands. Women reported perception of support from HCPs in the form of encouraging (e.g. 'you are doing well, you have manage them really well), reassuring, kind, caring and concerning words, positive feedback or empathetic communication related to diabetes management, which seem to increase their confidence level and gave them a sense of achievement, being valued and appreciated. Managing Gestational diabetes (e.g. blood sugar levels) with a variety of hormonal development and work related stressors and fatigue at this stage does not seem an easy task. Thus, receiving some positive feedback and acknowledgement related to their efforts (to manage it) from HCPs, seemed to be very valuable for them in terms of improving their confidence/self-esteem. However, husbands seem to provide emotional support by accompanying to the clinic appointments, adopting same eating lifestyle as wife, not eating sweet things, helping to de-stress their wives by talking to bring things into perspectives (when feeling stressed/fatigued due to work pressures) and going for walks to spend some quality time. The perceived role of a husband/partner during the interviews was portrayed by the women as a very close friend, who they could share anything without hesitancy and he will listen, understand and resolve the complexity of the situation or an issue very calmly. In addition, there seemed to be strong empathic feelings from husbands/partners towards their wives/partners to support them in eating regime by sacrificing their favourite food and also make them feel that they are '*doing it together'* and not letting them feel alone on this journey. Such an emotional support can be very influential and effective to follow the recommended diet regime and ultimately can have positive influence on mental health as well as diabetes management.

In other family members, mothers, sisters and mother in law were included. However, most often it was the mother as a main source of contact, who provided support over the telephone or face to face in the form of warm and caring words. Particularly, when women were used to feel nervous after being unable to manage the sugar levels. At that time, supportive words were mentioned regarding worries about the babies, listening worries/distress about the jobs, reminding to stop working for some time and providing reassurance related to worries or concerns linked to diabetes management. Women seemed to find some peace of mind by discussing their issues/concerns, dubious thoughts or difficulties with their mothers, as they seemed to believe that only mothers can understand their situation and can provide honest solution and console regarding those issues.

On the other hand, friends seem to provide emotional support by cooking and eating food suitable for diabetes management regime. The sample who was interviewed, only few were able to visit their friends during pregnancy, but they seemed to very much appreciate their friends' support in terms of paying attention to their diet related requirements (e.g. cooking healthy meals) as part of Gestational diabetes management regime.

Work was also an important area of life during pregnancy, as most of the women used to spend a number of hours to fulfil their work responsibilities. Managing diabetes related tasks quite frequently can be quite difficult especially in busy work routine. Therefore, some very kind and caring work colleagues provided support in the form of reminding them about monitoring sugar levels, happily let them go for walks after meals (a suggested routine to adopt in their lifestyle) as well as handle their job responsibilities, show interests in knowing and understanding the GDM and have conversations about it in concerning manners. Overall, colleagues seemed to try to provide a variety of genuine emotional support as much as they could to make it comfortable and uncomplicated for the patients to follow the diabetes regime during their working hours.

By looking at the umbrella of emotional support perceived from people around them, the documentation of empathic support and assurance revealed the unexpected role husbands play in supporting their wives. Typically, women are thought to provide substantially more emotional support than men due to their increased empathy (Wellman & Gulia, 1999; Wellman & Wortley, 1990). Therefore, it was quite surprising that not only mothers and HCPs (mostly women), but husbands/partners were also the top sources mentioned by the women. Our findings suggest that women perceive, their husbands do provide some degree of emotional support and assurance during pregnancy. A study by Singh and Ram (2009) also showed that a substantial proportion of men provided a notable level of support to their wives during pregnancy. Overall, emotional support seemed to act as a buffer (or coping mechanism) against stressors and be protective against current distress. In addition, supportive social relationships are important in the reduction of high psychological distress levels, although in different forms.

Furthermore, perception of receiving information/advice from HCPs and mothers was also very frequently reported type of support by the patients. HCPs seemed to provide information in an effective way from patients' perspectives in terms of explaining medical terms in a simple language. This strategy seemed to help patients to understand the provided information and imply in their routine appropriately. The role of a midwife to provide some advice was considered extremely essential/vital to tackle some dubious conditions during pregnancy. The patients seemed to feel improvements in their health after speaking to their midwives, which they very much appreciated.

The patients described a further classification of the informational support, as they seemed to have their personalised approach in terms of perceiving such support effective or ineffective. Receiving comprehensive and satisfactory information verbally was perceived more effective than the written ones. Such approach was perceived much supportive, effective, understanding, calming and non-frightening, which seemed to provide reassurance and improve their level of confidence. Some patients described feeling quite upset and disheartening after receiving written information about the GDM. Such experiences seem to demonstrate the risks and sensitivity of the illness perceived as a shock for the patients after reading the written information about the diagnosis. Therefore, speaking to a HCP about the diagnosis and its procedures comprehensively was perceived very reassuring and effective in terms of getting some peace of mind and confidence. Some patients preferred receiving information in pictorial/visual form (by looking at the standardised book of dieticians) more effective than in any other way in terms of improving their level of understanding about the specification of portion sizes. Acquiring visual based information from dieticians not only help patients to clear out any misunderstandings about eating/avoiding food choices, but also increase patients' level of confidence to try a variety of food.

One of the other frequently reported sources of support was the mothers. Patients seemed to perceive informational support from their mothers in the form of guidance, advices or suggestions during pregnancy. This type of source of support was mainly perceived by the patients as a buffer to de-stress themselves and to boost their level of confidence to resolve various issues. This type of support ultimately seemed to make the last stage of pregnancy with GDM less complicated to manage for the patients. In addition, mothers or mother in laws' accompany during the clinic appointments to make some notes from the HCPs' provided information and remind them at home was perceived very valuable. Some patients believed, they were unable to remember everything explained in a short period. So having a family member during the appointment time seemed to reassure them that they would not miss any of the valuable information to apply at home. This type of support also seemed to develop some positive and pleasant feelings about family members' caring and supportive attitude and behaviour.

Furthermore, informational support from friends/peers was also perceived very reassuring to discuss and gain some experience-based information. Patient seemed to believe more likely on those peers' provided information who had gone through such condition during their pregnancy. Such support not only provided encouragement to not to feel alone by facing any difficulties of diabetes management, but also boosted their confidence. In addition, it seemed to provide them some peace of mind and motivated to continue following the recommended diabetes regimen.

The role of HCPs and staff providing practical/tangible support to patients was also reported quite frequently. HCPs and staff members' support in the form of taking prompt actions in the instances of labour pain and providing medical equipments promptly when needed the most in urgency was perceived very valuable. As this type of urgent support not only reduced anxiety but also developed some pleasant feelings, which ultimately affected their conditions positively (rather than getting complicated).

In most instances, husbands/partners' practical support with routine activities in relation to performing household tasks and support in diabetes management practices was perceived very helpful as it eased off a burden of some tasks. Husbands also seemed to provide support in following diet regimen by cooking particular food and eating same/similar food as their wives ate. Such support not only influenced wives to eat healthy/recommended food but also provided a sense of companionship or moral support, which seemed to develop some pleasant feelings about their husbands/partners. Providing company to do physical activity (e.g. walking as recommended after meal times) in any weather conditions was also perceived very valuable.

Additionally, husbands' support in terms of reminding the patients about monitoring their sugar levels was also perceived very effective. As remembering to monitor blood sugar levels frequently for a person who developed GDM first time can be a challenging task. Having a reminder not only can help the patients to eat or take medicine according to the blood sugar levels but can also protect their health from developing any complication. Husbands seemed to continue their tangible support after the delivery in terms of looking after the newborn babies at night-time to provide some time to mothers to take some rest. Patients who had children already found very supportive of having some family members close by to look after their children while they could pay more attention to their health as well do some residual home tasks.

Similar findings regarding family support were reported in Mayberry and Osborn's study (2012). This study was conducted using focus groups to explore the relationship between family support and adherence to medication regimens for adults with diabetes. Their results revealed that instrumental/practical support (or observable actions that help patients manage their illness) was the most common type of social support (Mayberry & Osborn, 2012). Patient-reported examples of instrumental support included tasks such as spouses maintaining medical appointments and doing the grocery shopping. Furthermore, the empirical literature on social support and the management of diabetes among adolescents and their families has revealed significant and positive effects on patient adherence to treatment. In a randomized controlled trial, adolescents with type 1 diabetes and their families participated in ten sessions of behavioural family systems therapy. Behavioural family systems therapy is a family-focused multifaceted intervention that targets communication between family members, problem-solving skills, family beliefs that affect communication, and potential barriers to problem-solving tasks (Wysocki, Harris, Greco, Bubb & Elder, 2000). The results of this study yielded significant improvements in parent-adolescent relationships and family communication as reported by parents and adolescents (Wysocki et al., 2000).

Overall, the current study's finding demonstrates that women likely value practical help with routine activities (e.g. home chores, childcare etc). Providing such support by understanding patients' needs can bring a substantial and positive effect on mind, help in managing diabetes with confidence and reduce stress in such a condition. Themes regarding social support from various sources seem to highlight two main areas of health frequently reported by the patients: diabetes management related regimen and stress. Social support seemed to provide reassurance, guidance, and strength. It also appeared to improve patients' confidence and develop motivation and encouragement to continue following the suggested pathway without feeling lonely. Similar finding were demonstrated in Gallant's (2003) study, which found that a modest positive relationship exists between social support and chronic-illness management, especially for diabetes. This relationship was also apparent in Berg's (2005) qualitative study, which demonstrated that women with Type 1 DM during pregnancy are in an extremely exposed situation during pregnancy and need a lot of support. Responsibility for the child, who acts as a demanding subject through the measured blood-glucose levels (Berg & Honkasalo, 2000), becomes a yoke and thus, contributes to feelings of enslavement (Berg, 2005).

In general, social support is thought to affect mental and physical health through its influence on emotions, cognition and behaviours (Cohen, 1988). In the case of mental health, social support is thought to maintain regulation of these response systems and to prevent extreme responses associated with dysfunction. This regulation occurs through communication and through the provision of coping assistance (Caplan, 1974; Cassel, 1976). Literature on social support and coping mechanisms indicate that social support can function as coping assistance (e.g. O'Brien & DeLongis, 1997; Thoits,1986; Baqutayan, 2011) in the sense that active participation of significant others can influence breast cancer patients' efforts to manage their physical as well as emotional conditions (Kim, Yeobhan, Shaw, Mctavish & Gustafson, 2010). As suggested by Thoits (1986), significant others can suggest ways of managing physical or emotional distress caused by breast cancer, or even can participate directly in breast cancer patients' efforts. As a result, social support can help bolster self-esteem of individuals as well as the sense of control over their situations (Brown & Harris, 1978). A strong sense of control and confidence would strengthen breast cancer patients' own coping efforts by leading them to rely on active coping strategies (e.g. positive reframing) rather than passive/avoidance coping strategies (e.g. self-blame) (Kim et al., 2010).

Social support is also thought to play a role in the risk for, progression of and recovery from physical illness. In this case, the hypothesis is that social relationships influence behaviours with implications for health, such as diet, exercise, smoking, alcohol intake, sleep and adherence to medical regimen. Moreover, the failure to regulate emotional responses also contributes to physiological problems and can trigger health relevant changes in the responses of the neuro-endocrine, immune, and cardiovascular systems (Cohen, 1988; Cohen, Kaplan & Manuck, 1994; Uchaino, Cacioppo & Kiecolt-Glaser, 1996).

The role of perceiving distinct types of support effective in the current study seemed to work as a buffer to cope better with anxiety or strain (developed by their condition or circumstances/situations at work, home or in the clinic) as well as following/managing diabetes related tasks/routine. Such phenomenon links with social support theory (mentioned in the introduction section). Therefore, patients' reported tools of social support have been put together under one framework of social support theory (please see Figure 2).

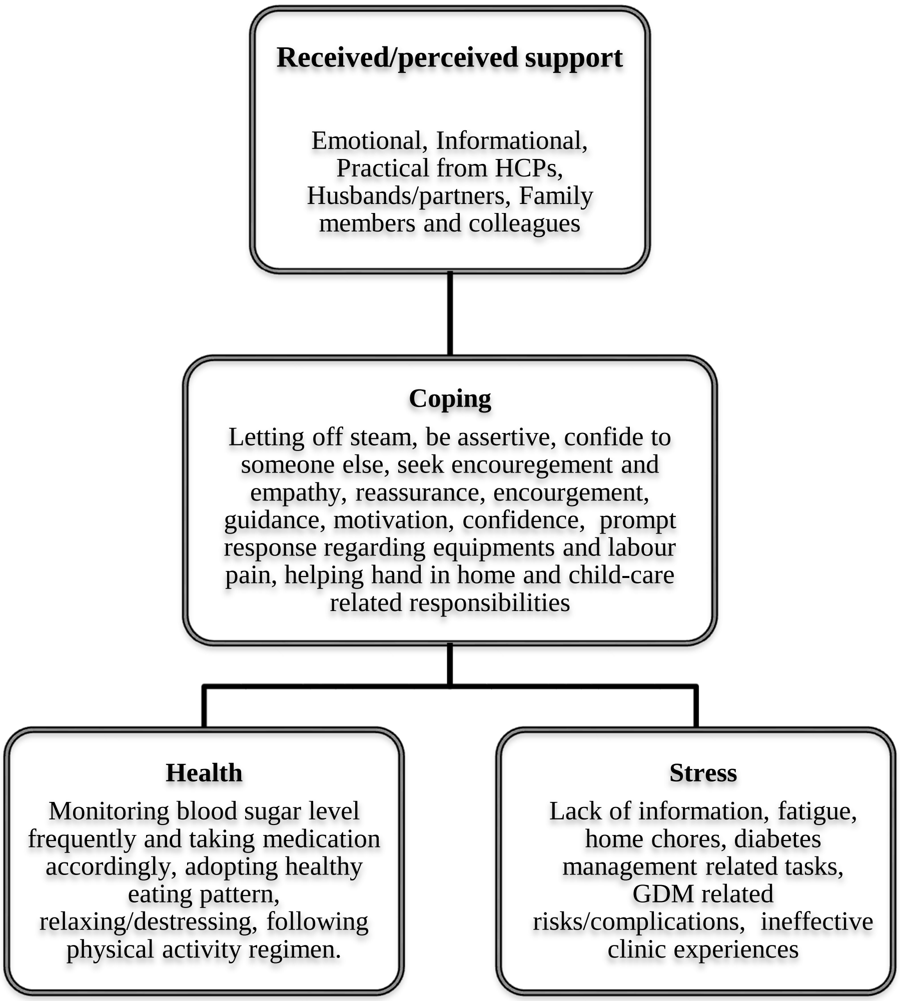


Figure 2: Patients' reported experiences and influences of social support according to the framework of social support theory

Ineffective support has the potential to add to a person's stress burden during a life transition, e.g. pregnancy period (Rini, Dunkel Schetter, Hobel, Glynn & Sandman, 2006). The social support theory emphasizes the role of cognitive appraisal and coping in shaping the course and outcome of stressful encounters during the course of living (Coyne & Lazarus, 1980; Lazarus, 1981). Social support has been suggested to provide protection/buffer in a number of ways from stressful events by playing a role in the causal chain linking stress to health (Cohen, Gottieb & Underwood, 2000):

- First, support may intervene between the stressful events and stress reaction by preventing a stress appraisal. More specifically, the perception that others can and will provide resources may redefine the harm potential of a situation and boost one's perceived ability to cope with imposed demands, therefore less likely perceive the event as stressful (Thoits, 1986).

- Second, support beliefs may reduce the affective reaction to a stressful event, dampen physiological responses to the event, or prevent/alter maladaptive behavioural responses. The availability of persons to talk to about problem is also been found to reduce the intrusive thoughts that act to maintain chronic maladaptive responses to stressful events (Lepore, Silver, Wortman & Wayment, 1996).
- Finally, support may alleviate the impact of stress by providing a solution to the problem by reducing the perceived importance of the problem, or by providing a distraction from the problem. It may also sedate the neuro-endocrine system, so that people are less stress reactive, or facilitate health-promoting behaviours such as exercise, proper nutrition and rest (Cohen & Wills, 1985; House, 1981).

Further to the role of social support, patients also shared some of their unhelpful clinic-based experiences followed by some recommendations to improve the clinic services. Pregnancy with GDM could be quite an emotional, distressing, shocking and anxious time for women due to various concerns and risks regarding their babies' health. Some patients seemed to felt unsupported, frustrated and disappointed during their pregnancy period by the HCPs. The patients described a number of reasons, which includes:

- Lack of communication and midwife-led care
- Late diagnosis
- Being sceptical
- Disappointment with the treatment process and not reading the medical notes
- Disbelieving/distrusting the patients
- Treating as a medicalised patient rather than a pregnant lady
- Long waiting time
- Unsatisfactory information through leaflets
- Unprofessional/careless behaviour
- Conflicting messages
- Insensitive way of providing information.

Drawing upon the overall sense of unhelpful experiences, patients seemed to perceive less patient-centred care. For instance, lack of attention towards acknowledging or understanding patients' needs and insufficient personalised/collaborative/empathetic approach seemed to be reported quite frequently. Please see Figure 3 (Appendix K) for themes depicting patients' perceived supportive and unsupportive experiences.

In regards to some unhelpful experiences and general concerns, patients provided various types of recommendations to improve current services. The most frequently mentioned suggestions were:

- Conducting blood sugar tests in advance
- Providing education about food choices/diet plans
- Organising mid-wife led support during and after pregnancy
- Applying a variety of methods to provide information according to patients' needs
- Setting up/designing/constructing a peer discussion forum during waiting time in the clinic.

One of the issues regarding the late diagnosis during pregnancy was frequently mentioned during interviews. Therefore, they suggested monitoring patients' sugar levels (particularly who have history of diabetes) at the initial stages of pregnancy and provide information to manage it. Women who receive diagnosis at the last stages of pregnancy seem to start developing concerns or worries for their baby or themselves or start blaming themselves that '*I have done something wrong to myself therefore I got GDM and now my baby's health is at risk due to me'*.

Some patients received diagnosis of GDM over the phone, which was not perceived very empathetic. Thus, it was suggested when declaring the diagnosis, HCPs need to focus on listening to women' concerns/queries regarding the diagnosis. Patients also need to be provided some reassurance and information regarding *'what are the most common things they can start doing until their first appointment in the clinic'*, which could reassure them until they see any HCP. Overall the above mentioned suggestions not only can be beneficial to improve the current clinic services but also for the wider NHS stakeholders, who are keen to bring effective changes at their services to make them more beneficial for the patients with GDM.

5.2- Issues to Consider

Quality markers

When evaluating validity and reliability, some attention should be given to the ways in which these concepts are understood differently in qualitative research. Madill, Jordan and Shirley (2000) claim that reliability in qualitative research should be understood in the context of the epistemological standpoint taken within particular research projects. The epistemological standpoint here (see Method chapter) implies that there is no attempt to achieve reliability in the positivist sense, but rather that *'diverse perspectives can provide a fuller understanding of social psychological phenomena'* (Madill et al., 2000, p.17). Madill and colleagues (2000) also claim it is important that the epistemological position is clear and the research is conducted in a way which is consistent with that epistemology. I tried to convey my epistemological standpoint in the Method chapter, and I hope I was able to demonstrate transparency about the relationship to the material, as well as grounding the analysis in participants' accounts, thus aiming to achieve quality and rigour.

Using many quotes throughout the analysis is intended to ground my analysis in concrete examples. This is also to allow the reader to judge the appropriateness and trustworthiness of my interpretations of the data, and to allow alternative understandings and interpretations. Credibility checks, in the form of cross reading, have been discussed in the Method chapter.

5.3- Limitations/Challenges

In this section some issues will be presented, which need to be taken into account while evaluating this research project. Insofar as this research is a process rather than an *'end result'* and does not seek to confirm or refute a-priori theory, these issues can be seen as challenges, rather than purely as *'limitations'* which obstruct empirical proof of prior hypotheses.

Methodological challenges

A concern raised about IPA is that it tends to be over-focused on cognition (Willig, 2001). It is claimed that the focus on meaning, thought processes and how the participants understand their experience gives less room for the embodiment of the experience, the ways in which it is implicitly felt in a direct, pre-reflective way (Willig, 2008). However, IPA researchers acknowledge that direct access to these levels is practically impossible, as we cannot fully access an individual's experience without the filter of his/her cognition and expression. Smith and colleagues (2009) claim that the degree of phenomenological enquiry within IPA includes many different levels of reflexivity, including the ‘pre-reflective reflexivity’ (p.189), thus implying that every experience includes some basic level of awareness or reflexivity. However, careful attention should indeed be paid to the pre-reflective experiences within interviews, not just to the ‘deliberate, controlled reflection’ (Smith et al., 2009). This is attempted here by giving voice and importance to any expression of embodiment, feeling and by paying close attention to non-verbal expressions, which are taken into account and analysed alongside the verbal material.

An additional limitation concerns the data gathering. The interview schedule and questionnaire were developed early on in the research process and, upon reflection, could have been designed in a more open and participant-led way. As with all research involving self-reported interview responses, there is the potential for recall bias. The current research relies solely on self-reported interview data. It would be useful to validate our findings with studies that include observed interpersonal interactions. The interview developed here may be too detailed for some research purposes although we did interview a small sample of women. The participants were recruited opportunistically and the sample size was small. The findings of this study are still meaningful to understand this group of women.

Several strengths of this study should also be noted. One was that it highlighted a perception of informational, emotional and practical support perceived from HCPs, mothers and partners not only from a single source. Because pregnant women also receive support from various individuals during their pregnancies, and studying the interplay between the supports provided by the partners, HCPs and by other individuals (e.g., mothers, sisters, friends, and colleagues) was very valuable.

Generalization

The issue of generalization is certainly controversial in qualitative methodology (Fog, 204; Kvale, 1996). Beyond doubt, generalizing is associated with quantitative studies seeking to apply the results from a sample to a population (Kvale, 1996). As the assumption of representativeness is not fulfilled in qualitative studies, this type of generalization is not possible. Moreover, they are not always wanted. In a conceptual U-turn, avoiding the concepts developed within more positivistic research traditions. Thagaard (2003) has proposed that we rather talk about transferability than generalization. Transferability resemble that of analytic generalization and relates to questions concerning whether the findings in a specific study may be used to say something other people in a similar situation. In this study it is argued that the findings are transferable and interesting for others than the women with GDM. Even though the accounts of the interviewees might not represent the general, it says something about what sources and categories of social support are perceived very effective during pregnancy with GDM. Particularly, the concepts developed in the present study could be useful for further investigations.

5.4- Implications

Some women recounted that although medical information to manage diabetes were available to them, support related to the psychological aspects of pregnancy-induced diabetes was scarce. A holistic approach to care that does not minimize the significance of the physical dimensions of GDM but includes the psychological and social dimensions is recommended. Health professionals need to acknowledge the particulars of women's experience with diabetes and be cognizant of the emotional impact, time commitment, and the burden of work and household responsibilities, it has for women and their families.

Unconditional respect for the lived realities of these women is needed from all the main sources/people mentioned in this study as they try to cope with diabetes and pregnancy. Working in partnership with pregnant women, health professionals can assist in the development of a diabetic regimen that is congruent with the woman's values/needs and priorities and fits with the context of her life. Health professionals need to be prepared to listen; show presence/attentiveness and the women need to feel that they are being heard to foster their well-being. Peer support can facilitate the normalization of experiencing pregnancy with diabetes through peer-support forum during waiting time at the clinic under the supervision of HCPs. As such forum can save pregnant women's time and energy to go to another place, speciality for those who continue working during pregnancy. In addition, peer support forum can play a major role after pregnancy (during their 6-week post-natal visit or in community) to share experiences related to managing pregnancy and gain information to maintain a healthy lifestyle to prevent themselves from getting Type 2 diabetes in the future. Primary prevention strategies through health promotion programme at the school/college level to minimize modifiable risk factors in all women of childbearing age are essential. Additionally, broad-based, family-oriented or clinic based interventions may have farreaching appeal and mental and physical health benefits. In some cases, interventions can be integrated with existing health services.

The findings of this study also highlighted that partners and family members were sources of support throughout the women's pregnancy. Family members, particularly the partners, need to be included in assessment and care of pregnant women and their input valued. To remain focused solely on the pregnant woman as separate from her family limits the HCPs' ability to help facilitate family cohesion and mutual support during an anxiety-provoking event. By caring for a woman with GDM in the context of her family, the HCP is prepared to facilitate and support the coping and adaptation of the woman, the family members, and the family as a whole. HCPs overall seemed to emphasise on or prioritise medical aspects of GDM.

However, patients preferred emotional and empathetic side of receiving care and support, which seemed to be believed very important to develop a caring relationship rather than perceived a '*medicalised person*'. To sustain a medicalised view of pregnancy, can distort the women's lived experience of her pregnancy and jeopardize her sense of personhood/being a person and normalcy. The findings of this study also draw attention towards focusing upon psychological aspects of GDM rather than just clinical outcomes, as psychosocial aspects can complement/influence/ clinical outcomes. The overall goal should be to support the pregnant woman's desire to live a life best suited for both the child's health and her own well-being. This includes an open, caring relationship where the individual woman is understood and supported, and encouraged to be reconciled with her disease. It also includes informing her partner and other significant persons about her need for support (Berg, 2005). Further research is needed involving HCPs to explore what are their beliefs and what hinders providing such support during pregnancy with GDM.

Women seemed to be more satisfied/comfortable after discussing their feeling/thoughts with their mothers and husbands and gained more confidence or developed motivation to follow the diabetes regimen. More research is needed to explore what factors facilitate women dealing with diabetes in pregnancy when they don't have mothers and husbands during the pregnancy period. Pregnancy is a family event, and the findings from this study suggest further research be conducted that focuses on family members, particularly their partners. Further investigation of the benefits associated with galvanizing spousal support during pregnancy is recommended. Further research that directly links with what was discussed in this study and other underlying factors affecting the presence, or absence of social support would contribute to understanding how social support can be strengthened in ways that promote women's health during pregnancy with GDM.

Further research into the experiences of women with GDM from a phenomenological perspective is needed to provide awareness into the unique ways in which women perceive the influence of various types and sources of social support during pregnancy on their mental and physical health. Current study's findings certainly point to emotional and informational support as separate support functions having potentially substantial implications for health and well-being. Combination of effective and ineffectives social support related experiences provides insight to the reader to evaluate their influences on health. This research initiated this line of inquiry to some extent, but further exploration can develop and enhance our understanding of the subjective meanings of this experience for women.

This research has the potential to guide psychosocial interventions that attempt to provide or enhance social support (Lu, Lu, & Dunkel-Schetter, 2005). It is important to note that, in our view, social support is not pregnancy specific, but rather implicates a general set of characteristics believed to underlie appraisals of effective support. These findings have implications for research on partner support during pregnancy and may inform efforts to improve maternal foetal health. More generally, the results reported here highlight the potential for the efficacy of certain types of support on mental and physical health to provide a useful addition to existing conceptualizations of social support.

5.5- Conclusion

Specific data from this study provide possible insights to researchers studying social support and HCPs developing interventions in this population. It is likely that, in pregnancy, only certain types or sources of support may be helpful, such as emotional support by members of a women's naturally-occurring family network and HCPs. Formative qualitative research that details the nature of such support networks in distinct settings is an important first step in establishing effective social support interventions for pregnant women.

Examples depicting the content of each type of support and unhelpful experiences revealed mental health and diabetes care related issues that can inform clinic-based social support interventions or peer discussion forum in the presence of a HCP. Recognizing importance of social support could potentially be very important to health-care during pregnancy (a specific period of time when health promotion and prevention are of critical importance).

References

Abayomi, J., Wood, L., Spelman, S., Morrison, G. and Purewal, T. (2013). The multidisciplinary management of type 2 and gestational diabetes in pregnancy. *British Journal of Midwifery*, 21(4), 236-242

Abraham, K. and Wilk, N. (2014). Living With Gestational Diabetes in a Rural Community. *MCN, American Journal of Maternal/Child Nursing*, 39(4), 239–245

American Diabetes Association. (2014). Diagnosis and classifi cation of diabetes mellitus (Position Statement). *Diabetes Care*, 37(Suppl. 1), S81-S89. http://dx.doi.org/10.2337/dc14-SO81

American College of Obstetricians and Gynecologists. (2013). *Gestational diabetes mellitus* (Practice Bulletin No. 137). Washington, DC: Author. doi:10.1097/01.AOG.0000433006.09219.f1

American College of Obstetricians and Gynecologists. (2002). ACOG Committee Opinion No. 267. Exercise during pregnancy and the postpartum period. *Obstetric Gynecology*, 99,171-173

American Diabetes Association. (2003). Gestational diabetes mellitus. *Diabetes Care*, *26*(1), S103-5.

American Diabetes Association. (2004). Gestational diabetes mellitus. *Diabetes Care*, 27(1), 88-90.

Altheide, D.L. and Johnson, J.M. (1994). Criteria for assessing interpretive validity in qualitative research. In Denzin, N. K. & Lincoln, Y. S. (Eds.), *Handbook of Qualitative Research* (pp. 485-499). Thousand Oaks, CA: Sage.

Aaronson, L.S. (1989). Perceived and received support: Effects on health behaviour during pregnancy. *Nursing Research*, *38*(1), 4-9.

Anderberg, E., Källén, K. and Berntorp, K. (2010).The impact of Gestational diabetes mellitus on pregnancy outcome comparing different cut-off criteria for abnormal glucose tolerance. *Acta Obstetricia et Gynecologica Scandinavica*, 89(12), 1532–7.

Alwan, N., Tuffnell, D. J. and West, J. (2009). Treatments for Gestational diabetes. *Cochrane Database of Systematic Reviews Issue, (*3). Art. No.: CD003395. DOI: 10.1002/14651858.CD003395.pub2.

Arney, W. (1982). *Power and the Profession of Obstetrics*. Chicago: University of Chicago Press.

Aittasalo, M., Pasanen, M., Fogelholm, M., Kinnunen, T. I. and Ojala, K. (2008). Physical activity counselling in maternity and child health care - a controlled trial. *British Medical Council of Women's Health, 8,* 14.

Almario, C.V., Ecker, T., Moroz, L. A., Bucovetsky, L., Berghella, V. and Baxter, J. K. (2008). Obstetricians seldom provide postpartum diabetes screening for women with Gestational diabetes. *American Journal of Obstetric Gynecology, 198,* 528.e1-5.

Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology, 14*(4), 413–45.

Bauman, A.E., Sallis, J. F., Dzewaltowski, D.A. and Owen, N. (2002). Toward a better understanding of the influences on physical activity: the role of determinants, correlates, causal variables, mediators, moderators, and confounders. *American Journal of Preventative Medicine, 23*(2), 5-14.

Baqutayan, S. (2011). Stress and social support. *Indian Journal of Psychological Medicine, 33*(1), 29-34.

Ben-Haroush, A., Yogev, Y. and Hod, M. (2004). Epidemiology of Gestational diabetes mellitus and its association with Type 2 diabetes. *Diabetic Medicine, 21*(2), 103-13.

Bennett, W.L., Ennen, C.S., Carrese, J.A., Hill-Briggs, F., Levine, D.M., Nicholson, W.K. and Clark, J.M. (2011). Barriers to and Facilitators of Postpartum Follow-Up Care in Women with Recent Gestational Diabetes Mellitus: A Qualitative Study. *Journal of Women's Health, 20*(2), 239-245.

Beverly, E.A. and Wray, L.A. (2010). The role of collective efficacy in exercise adherence: a qualitative study of spousal support and Type 2 diabetes management. *Health Education Resource*, *25*(2), 211–223.

Broadhead, W.T., Kaplan, B.H. and James, S.A. (1983). The epidemiological evidence for a relationship between social support and health. *American Journal of Epidemiology, 117*(5), 521–37.

Brewin, C.R., Andrews, B. and Valentine, J.D. (2000). Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology*, *68*, 748–766.

Buchanan, T. A. and Xiang, A.H. (2005). Gestational diabetes mellitus. *Journal of Clinical Investment*, *115*(3), 485-91.

Bulmer, M and Abrams, P. (1986). *Neighbours: the work of Philip Abrams*. Cambridge: Cambridge University Press.

Burke, V., Giangiulio, N., Gillam, H.F., Beilin, L J. and Houghton, S. (2003). Physical activity and nutrition programs for couples: A randomized controlled trial. *Journal of Clinical Epidemiology, 56*, 421-432.

Barbour, L.A., McCurdy, C.E., Hernandez, T.L., Kirwan, J.P., Catalano, P.M. and Friedman, J.E. (2007). Cellular mechanisms for insulin resistance in normal pregnancy and Gestational diabetes, *Diabetes Care*, *30*(2), S112–S119.

Bung, P., Artal, R., Khodiguian, N., and Kjos, S. (1991). Exercise in Gestational diabetes: an optional therapeutic approach? *Diabetes*, *40*, 182–185.

Barclay, A.W., Petocz, P. and McMillan-Price, J. (2008). Glycaemic index, glycaemic load, and chronic disease riskda meta-analysis of observational studies. *American Journal of Clinical Nutrition, 87,* 627–637.

Brand-Miller, J., Hayne, S., Petocz, P. and Colagiuri, S. (2003). Low glycaemic index diets in the management of diabetes: A meta-analysis of randomized controlled trials. *Diabetes Care, 26*, 2261–2267.

Brocki, J. & Wearden, A. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in Health Psychology. *Psychology and Health, 21*(1), 87-108.

Bantle, J.P., Wylie-Rosett, J., Albright, A.L., Apovian, C.M., Clark, N.G., Franz, M.J., Hoogwerf, B.J., Lichtenstein, A.H., Mayer-Davis, E. and Mooradian, A.D. (2008). Nutrition recommendations and interventions for diabetes: a position statement of the American Diabetes Association. *Diabetes Care, 31,* S61-S78.

Bramley, N., and Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology and Health*, 20, 223–235.

Brown, G.W. and Harris, T. (1978). *The Social Origins of Depression*. New York: Free Press.

Bellamy, L., Casas, J.P., Hingorani, A.D. and Williams, D. (2009). Type 2 diabetes mellitus after Gestational diabetes: a systematic review and meta-analysis. *Lancet, 373,* 1773–1779.

Berg, M. & Honkaslo, M.L. (2000). Pregnancy and diabetes: a hermeneutic phenomenological study of women's experiences. *Journal of Psychometric Obstetric Gynaecology, 27*(1), 39–47.

Berg, M. (2005). Pregnancy and diabetes: how women handle the challenges. *Journal of Perinatal Education, 14,* 23–32.

Caplan, G. (1974). *Support Systems and Community Mental Health: Lectures on Concept Development.* New York: Behavioural Publications.

Barona-Vilar, C., Escriba-Aguir, V. and Ferrero-Gandia, R. (2009). A qualitative approach to social support and breastfeeding decisions. *Midwifery*, 25, 187–194

Coustan, D. R., Lowe, L. P., Metzger, B. E. and Dyer, A. R. (2010). The Hyperglycemia and Adverse Pregnancy Outcome (HAPO) study: Paving the way for new diagnostic criteria for gestational diabetes mellitus. *American Journal of Obstetrics and Gynecology*, 202(6), 654.e1-654.e6. doi.org/10.1016/j.ajog.

Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. (2011). *National diabetes fact sheet*. Retrieved from www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf

Clemmens, D. (2001).The relationship between social support and adolescent mothers' interactions with their infants: a meta analysis. *Journal of Obstetric and Gynacology Neonatal Nursing*, 30, 410–20.

Chapman, H. A, Hobfoll, S. E. and Ritter, C. Partners' stress underestimations lead to women's distress: A study of pregnant inner-city women. *Journal of Personality and Social Psychology*, 73, 418-425.

Clarke, K. K., Freeland-Graves, J., Klohe-Lehman, D. M., Milani, T. J., Nuss, H. J. and Laffrey, S. (2007). "Promotion of physical activity in low-income mothers using pedometers," *Journal of the American Dietetic Association*, 107 (6), 962–967.

Cassel, J. (1976).The contribution of the social environment to host resistance. *American Journal of Epidemiology, 104*, 107-123.

Coyne, J.C. and Lazarus, R.S. (1980). Cognitive style, stress perception, and coping. In Kutash, I. L. & Schlesinger, L. B. (Eds.), *Handbook on Stress and Anxiety: Contemporary Knowledge, Theory, and Treatment*. San Francisco: Jossey-Bass.

Clapp, J.F. (2006). Effects of diet and exercise on insulin resistance during pregnancy. *Metabolic Syndrome and Related Disorders, 4*(2), 84–90.

Cnattingius, S. and Lambe, M. (2002). Trends in smoking and overweight during pregnancy: prevalence, risks of pregnancy complications, and adverse pregnancy outcomes. *Seminars in Perinatology, 26*(4), 286-95.

Cypryk, K., Szymczak, W., Czupryniak, L., Sobczak, M. and Lewinski, A. (2008). Gestational diabetes mellitus - an analysis of risk factors. *Endokrynologia Polska* (Warszawa), *59*(5), 393–97.

Carolan, M., Steele, C. and Margetts, H. (2010). Attitudes towards Gestational diabetes among a multiethnic cohort in Australia. *Journal of Clinical Nursing*, *19*(17-18), 2446-53.

Collins, N., Dunkel-Schetter, C., Lobel, M. and Scrimshaw, S.C. (1993). Social support in pregnancy: psychosocial correlates of birth outcomes and postpartum depression. *Journal of Personality and Social Psychology, 65*, 1243-58.

Cohen, S., Kaplan, J. R., and Manuck, S. B. (1994). Social support and coronary heart disease: Underlying psychologic and biologic mechanisms. In Shumaker, S. A. & Czajkowski, S. M. (Eds.), *Social Support and Cardiovascular Disease*. New York: Plenum.

Cohen, S. and Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310-357.

Cohen, S. (1988). Psychosocial models of the role of social support in the aetiology of physical disease. *Health Psychology, 7*(3), 269-297.

Cohen, M.P. (1992). Pregnancy in women with diabetes. *Journal of Women's Health*, *1*, 81-7.

Cohen, S. and McKay, G. (1983). Social support, stress and the buffering hypothesis: a theoretical analysis. In: Baum, A., Singer, J.E. & Taylor, S. editors. *Handbook of Psychology and Health*. Hillsdale, NJ: Erlbaum.

Cohen, S. and Syme, S. (1985). Issues in the study and application of social support. In: Cohen, S.& Syme, S. *Social Support and Health*. San Francisco: Academic Press, 3-22.

Cohen, S., Underwood, L.G. and Gottlieb, B.H. (2000). *Social Support Measurement and Intervention: A guide for Health and Social Scientists*. New York: Oxford University Press.

Cypryk, K., Szymczak, W., Czupryniak, L., Sobczak, M. and Lewinski, A. (2008). Gestational diabetes mellitus - an analysis of risk factors. *Endokrynologia Polska*, *59*(5), 393-7.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychometric Medicine, 38*(5), 300–14.

Cannella, B. (2006). Mediators of the relationship between social support and positive health practices in pregnant women. *Nursing Resource, 55*(6), 437–45.

Catalano, P.M. and Hauguel-De Mouzon, S. (2011). Is it time to revisit the Pedersen hypothesis in the face of the obesity epidemic? *American Journal of Obstetrics and Gynaecology*, *204*, 479–487

Culpepper, L. and Jack, B. (1993). Psychosocial issues in pregnancy. *Primary Care*, *20*(3), 599–619.

Charney, D.S. (2004). Psychobiological mechanism of resilience and vulnerability: Implications for successful adaptation to extreme stress. *American Journal of Psychiatry, 161*, 195–216.

Corbin, J. M. and Strauss, A. (2008). *Basics in Qualitative Research: Techniques and Procedures for Developing Grounded Theory.* Thousand Oaks: Sage Publications.

Carrington, E.R., Shuman, C.R. and Reardon, H.S. (1957). Evaluation of the prediabetes state during pregnancy. *Obstetric Gynaecology, 9*(6), 664-9.

Ceysens, G., Rouiller, D. and Boulvain, M. (2006). Exercise for diabetic pregnant women. *Cochrane Database Systematic Re*view, *3,* CD004225.

Charmaz, C. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* London: Sage.

Dornhorst, A. and Rossi, M. (1998). Risk and prevention of type 2 diabetes in women with Gestational diabetes. *Diabetes Care, 21*(2), B43-B49.

Devlieger, R., Casteels, K. and Van Assche, F.A. (2008). Reduced adaptation of the pancreatic B cells during pregnancy is the major causal factor for Gestational diabetes: current knowledge and metabolic effects on the offspring. *Acta Obstetricia et Gynecologica Scandinavica, 87*(12), 1266–70.

Dodd, J.M., Crowther, C.A., Antoniou, G., Baghurst, P. and Robinson, J.S. (2007). Screening for Gestational diabetes: the effect of varying blood glucose definitions in the prediction of adverse maternal and infant health outcomes. *Australian and New Zealand Journal of Obstetrics and Gynaecology, 47*(4), 307–12.

Dabelea, D., Snell-Bergeon, J.K., Hartsfield, C.L., Bischoff, K.J., Hamman, R.F. and McDuffie, R.S. (2005). Kaiser Permanente of Colorado GDM Screening Program: Increasing prevalence of Gestational diabetes mellitus (GDM) over time and by birth cohort: Kaiser Permanente of Colorado GDM Screening Program. *Diabetes Care*, *28*(3), 579-84.

Delhanty, L., Conroy, M. and Nathan, D. (2006). The DPP Research Group. Psychological predictors of physical activity in the Diabetes Prevention Program. *Journal of American Diet Association*, *106*, 698–705.

Delhanty, L., Meigs, J., Hayden, D., Williamson, D. and Nathan, D. (2002).The Diabetic Prevention Program Research Group. Psychological and behavioural correlates of baseline BMI in the Diabetes Prevention Program. *Diabetes Care, 25*, 1992–1998.

Dunkel-Schetter, C., Sagrestano, L.M., Feldman, P. and Killingsworth, C. (1986). Social support and pregnancy: A comprehensive review focusing on ethnicity and culture. In: Pierce, G. R., Sarason, B. R., Sarason, I. G., editors. *Handbook of Social Support and the Family*. New York: Plenum, 375–412.

Dunn, C. L. Pirie, P.L. and Hellerstedt, W. L. (2003). The advice-giving role of female friends and relatives during pregnancy. *Health Education Research*, *18*(3), 352–62.

Dempsey, J.C., Butler, C.L. and Williams, M.A. (2005). No need for a pregnant pause: physical activity may reduce the occurrence of Gestational diabetes mellitus and preeclampsia. *Exercise Sport Science Review, 33*(3), 141-9.

Diabetes Prevention Program Research Group. (2002). Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *New England Journal of Medicine, 346,* 393–403.

De Barros, M. C., Lopes, M. A., Francisco, R. P., Sapienza, A. D. and Zugaib, M. (2010). Resistance exercise and glycemic control in women with gestational diabetes mellitus. *American Journal of Obstetric Gynecology*, 203(6),556, e1-6.

Eichorn, K. (2008). Soliciting and providing social support over the internet: an investigation of online eating disorder support groups. *Journal of Computer-Mediated Communication*, 14, 67–78.

Evans, M. K. and O'Brien, B. (2005). Gestational diabetes: the meaning of an at-risk pregnancy. *Qualitative Health Research*, *15*(1), 66-81.

Evans, M. K., Patrick, L. J. and Wellington, C. M. (2010). Health behaviours of postpartum women with a history of Gestational diabetes. *Canadian Journal of Diabetes, 34*(3), 227-232.

Esakoff, T. F., Cheng, Y.W., Sparks, T. N. and Caughey, A. B. (2009). The association between birth weight 4000g or greater and perinatal outcomes in patients with and without Gestational diabetes mellitus. *American Journal of Obstetrics and Gynaecology*, *200*(6), 672.e1–672.e4.

Elster, J. (2007). *Explaining social behaviour. More Nuts and Bolts for the Social Sciences.* Cambridge: Cambridge University Press.

Ehrenberg, H. M., Mercer, B. M. and Catalano, P. M. (2004). The influence of obesity and diabetes on the prevalence of macrosomia. *American Journal of Obstetric Gynaecology, 191*, 964–968.

Eatough, V. and Smith, J. A. (2008). Interpretative phenomenological analysis. In Willig, C. & Stainton-Rogers, W. (Eds). *The Sage Handbook of Qualitative Research in Psychology*. London: Sage.

Fehler, K. L., Kennedy, L.E., McCargar, L. J., Bell, R. C. and Ryan, E. A. (2007). Postpartum dietary changes in women with previous Gestational diabetes mellitus. *Canadian Journal of Diabetes, 31*(1), 54-61.

Feldman, P. J., Dunkel-Schetter, C., Sandman, C. A. and Wadhwa, P. D. (2000). Maternal social support predicts birth weight and fetal growth in pregnancy. *Psychosomatic Medicine, 62*, 715-725

Fischlmayr, I.C. (2002). Female self-perception as barrier to international careers? *International Journal of Human Resource Management*, *13*(5), 773-783.

Fan, Z., Yang, H., Gao, H., Lintu, H. and Sun, W. (2006). Pregnancy outcome in Gestational diabetes. *International Journal of Gynaecology & Obstetrics, 94*(1), 12-16.

Farrar, D., Duley, L. and Lawlor, D.A. (2011). Different strategies for diagnosing Gestational diabetes to improve maternal and infant health. *Cochrane Database of Systematic Reviews*, 10. Art. No.: CD007122. DOI: 10.1002/14651858.CD007122.pub2.

Fog, J. (2004). *Med samtalen som udgangspunkt: det kvalitative for sknings interview*. København, Akademisk Forlag.

Finlay, L. (2002). ‘Outing’ the Researcher: The Provenance, Principles and Practice of Reflexivity. *Qualitative Health Research, 12*(4), 531–45.

Flick, U. (2002). *An Introduction to Qualitative Research*. London: Sage.

Fernández-Morera, J. L., Rodriguez-Rodero, S., Menéndez-Torre, E. and Fraga, M. F. (2010). The possible role of epigenetics in gestational diabetes: Cause, consequence, or both. *Obstetrics and Gynecology International*, (605163), 1-7. doi: 10.1155/2010/605163

Getahun, D., Nath, C., Ananth, C. V., Chavez, M. R. and Smulian, J. C. (2008). Gestational diabetes in the United States: Temporal trends 1989 through 2004. *American Journal of Obstetrics and Gynecology*, 198(5), 525.e1-525.e5.

Getahun, D., Fassett, M. J. and Jacobsen S.J. (2010). Gestational diabetes: risk of recurrence in subsequent pregnancies. *American Journal of Obstetrics and Gynecology,* 203, 467. e1–467.e6.

Gallant, M.P. (2003). The influence of social support on chronic illness self-management: A review and directions for research. *Health Education and Behaviour*, *30*, 170–195.

Guerrero-Romero, F., Aradillas-García, C., Simental- Mendia, L.E., Monreal-Escalante, E., De la Cruz Mendoza, E. and Rodríguez-Moran, M. (2010). Birth weight, family history of diabetes, and metabolic syndrome in children and adolescents. *Journal of Paediatrics, 156*(5), 719–23.

Gallagher, K. I., Jakicic, J. M., Napolitano, M. A. and Marcus, B. H. (2006). Psychosocial Factors Related to Physical Activity and Weight Loss in Overweight Women. *Medical Science of Sports and Exercise*, *38*(5), 971-80.

Giblin, P.T., Polan, M. L. and Ager, J.W. (1990). Effects of social supports on attitudes, health behaviours and obtaining prenatal care. *Journal of Community Health*, *15*(6), 357-369.

Giurgescu, C., Penckofer, S. and Maurer, M.C. (2006). Impact of uncertainty, social support and prenatal coping on the psychological well-being of high-risk pregnant women. *Nursing Res*ource, *55*(5), 356–65.

Giorgi, A. (1992). Description versus interpretation: Competing alternative strategies for qualitative research. *Journal of Phenomenological Psychology*, *23*(2), 119-135.

Geertz, C. (1973). Thick description: toward an interpretive theory of culture. In Geertz, C. (Ed.). *The Interpretation of Cultures.* New York: Basic Books.

Griffin, M.E., Coffey, M., Johnson, H., Scanlon, P., Foley, M. and Stronge, J. (2000). Universal vs. risk factor-based screening for Gestational diabetes mellitus: detection rates, gestation at diagnosis and outcome. *Diabetic Medicine, 17,* 26–32.
Gillman, M., Rifas-Shiman, S., Berkey, C., Field, A.E. and Colditz, G.A. (2003). Maternal Gestational diabetes, birth weight, and adolescent obesity. *Paediatrics, 111*:e221–e7.

Gavard, J.A. and Artal, R. (2008). Effect of exercise on pregnancy outcome. *Clinical Obstetric Gynaecology, 51*, 467–480.

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods, 3*(1), 1-26.

Gadamer, H. (1990/1960). Truth & Method (2nd Ed). New York: Crossroad. Cited by Smith, J., Flowers, P. & Larkin, M. (2009). I*nterpretative Phenomenological Analysis: Theory, Method and Research.* London: Sage.

HAPO Study Cooperative Research Group, Metzger, B.E., Lowe, L.P., Dyer, A.R., Trimble, E.R., Chaovarindr, U., Coustan, D.R., Hadden, D.R., McCance, D.R., Hod, M., McIntyre, H.D., Oats, J.J., Persson, B., Rogers, M.S. and Sacks, D.A. (2008). Hyperglycaemia and adverse pregnancy outcomes. *New England Journal of Medicine, 358,* 1991–2002.

House, J. S. (1981). *Work Stress and Social Support*. Reading, Mass: Addison-Wesley.

Hockey, J. (1993). Research Methods: Researching peers and familiar settings. *Research Papers in Education, 8*/2,199-225.

Hedderson, M.M., Gunderson, E.P. and Ferrara, A. (2010). Gestational weight gain and risk of Gestational diabetes mellitus. *Obstetrics & Gynaecology, 115*(3), 597–604.

Hirsch, B.J. and Rapkin, B.D. (1986) Social networks and adult identities: profiles and correlates of support and rejection. *American Journal of Community Psychology, 14*(4), 395–412.

Henriksen, T. (2008). The macrocosmic foetus: a challenge in current obstetrics. *Acta Obstetricia et Gynecologica Scandinavica, 87*(2), 134–45.

Harder, T., Roepke, K., Diller, N., Stechling, Y., Dudenhausen, J.W. and Plagemann, A. (2009). Birth weight, early weight gain, and subsequent risk of type 1 diabetes: systematic review and meta-analysis. *American Journal of Epidemiology*, *169*(12), 1428–36.

Hutchins, E. and DiPietro, J. (1997). Psychosocial risk factors associated with cocaine use during pregnancy: A case control study. *Obstetric Gynaeco*logy, *90*(1), 142–7.

Henwood, K.L. and Pidgeon, N.F. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology, 83*, 97-111.

Husserl, E. (1927). "*Phenomenology". Edmund Husserl's article for the Encyclopaedia Britannica* (R.E. Palmer, Trans.). Retrieved 20 July 2009 from: http://www.hfu.edu.tw/~huangkm/phenom/husserl-britanica.htm#_ftn1

Heidegger, M. (1962/1927). *Being and Time*. Oxford: Blackwell.

Hoffman, R.M., Kronfeld, D.S., Cooper, W.L. and Harris, P.A. (2003). Glucose clearance in grazing mares is affected by diet, pregnancy, and lactation. *Journal of Animal Science, 81*, 1764-1771.

Homko, C.J., Sivan, E. and Reece, E.A. (1998). Is self-monitoring of blood glucose necessary in the management of Gestational diabetes mellitus? *Diabetes Care, 21*(2), B118-22.

Homko, C.J., Sivan, E. and Reece, E.A. (2002).The impact of self-monitoring of blood glucose on self-efficacy and pregnancy outcomes in women with diet controlled Gestational diabetes. *Diabetes Education, 28*(3), 435-43.

Hammersley, M. and Atkinson, P. (2007). *Ethnography: Principles in Practice* (3rd ed.). London: Routledge.

Halse, R. E., Wallman, K. E., Newnham, J. P. and Guelfi, K. J. (2014). Home-based exercise training Improves Capillary glucose profile in GDM women. *Medicine and science in sports and exercise,* 46(9),1702–9.

Holmes, V. A., Young, I. S. and Patterson, C. C. (2011). Diabetes and Pre-eclampsia Intervention Trial Study Group. Optimal glycemic control, preeclampsia, and gestational hypertension in women with type 1 diabetes in the diabetes and pre-eclampsia intervention trial. *Diabetes Care*, 34,1683–1688

Hutchins, E. and DiPietro, J. (1997). Psychosocial risk factors associated with cocaine use during pregnancy: a case-control study. *Obstetric Gynacology*, 90, 142–7.

International Diabetes Federation Clinical Guidelines Task Force. (2009). *Global guideline on pregnancy and diabetes.* Brussels: International Diabetes Federation.

Inkson, K., and Myers, B. (2003). The big OE: Self-directed travel and career development. *Career Development International*, *8*(4), 170-181.

Israel, B. A., Farquhar, S. A., Schultz, A. J., James, S. A. and Parker, E. A. (2002). The relationship between social support, stress, and health among women on Detroit’s east side. *Health Education and Behaviour, 29*(3), 342-360.

Ju, H., Rumbold, A.R., Willson, K.J. and Crowther, C.A. (2008). Borderline Gestational diabetes mellitus and pregnancy outcomes. *BioMedCentral Pregnancy and Childbirth, 8,* 31.

Jastrow, N., Roberge, S., Gauthier, R.J., Laroche, L., Duperron, L. and Brassard, N. (2010). Effect of birth weight on adverse obstetric outcomes in vaginal birth after caesarean delivery. *Obstetrics & Gynaecology*, 115(2 Pt 1), 338–43.

Jesse, D.E., Walcott-McQuigg, J. and Mariella, A. (2005) Risk and protective factors associated with symptoms of depression in low-income African American and Caucasian women during pregnancy. *Journal of Midwifery Women Heal*th, *50*(5), 405–10.

Jovanovic, L.G. (2008). Using meal-based self-monitoring of blood glucose as a tool to improve outcomes in pregnancy complicated by diabetes. *Endocrine Practice, 14*(2), 239-247.

Kim, C., McEwen, L. N., Piette, J.D., Goewey, J., Ferrara, A. and Walker, E. A. (2007). Risk perception for diabetes among women with histories of Gestational diabetes mellitus. *Diabetes Care, 30*, 2281–2286.

Kim, C., McEwen, L. N. and Kieffer, E.C. (2008). Self-efficacy, social support, and associations with physical activity and body mass index among women with histories of Gestational diabetes mellitus. *Diabetes Education, 34*, 719-728.

Kim, C. (2010). Managing women with Gestational diabetes mellitus in the postnatal period. *Diabetes, Obesity and Metabolism, 12*, 20–25.

Kim, J., Yeob Han, J., Shaw, B., Mctavish, F. and Gustafson, D (2010). The Roles of Social Support and Coping Strategies in Predicting Breast Cancer Patients' Emotional Well-being: Testing Mediation and Moderation Models. *Journal of Health Psychology, 15*(4), 543–552.

Kieffer, E.C., Sinco, B. and Kim, C. (2006). Health behaviours among women of reproductive age with and without a history of Gestational diabetes mellitus. *Diabetes Care, 29*(8), 1788-93.

Kafetsios, K. and Sideridis, G.D. (2006). Attachment, social support, and well-being in young and older adults. *Journal of Health Psychology, 11*(6), 863–876.

Kiecolt-Glaser, J.K. and Glaser, R. (1989). Interpersonal relationships and immune function. In: Carstensen, L. & Neale, J. (eds) *Mechanisms of Psychological Influence on Physical Health*. New York: Plenum Press.

Knowler, W.C., Barrett-Connor, E. and Fowler, S.E. (2002). Diabetes Prevention Program Research Group. Reduction in the incidence of type 2 diabetes with lifestyle changes or metformin. *New England Journal of Medicine, 346*, 393-403.

Kramer, M. S. and McDonald, S.W. (2006). Aerobic exercise for women during pregnancy. *Cochrane Database Systematic Review, 3*, CD000180.

Kvale, S. (1996). *Interviews: an Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: Sage.

Kjos, S. L. and Buchanan, T.A. (1999). Gestational diabetes mellitus. *New England Journal of Medicine, 341*, 1749–1756.

Kjos, S. L., Peters, R.K., Xiang, A., Henry, O.A., Montoro, M. and Buchanan, T.A. (1995). Predicting future diabetes in Latino women with Gestational diabetes. *Diabetes, 44*,586 –591.

Kitzmiller, J.L., Dang-Kilduff, L. and Taslimi, M. M. (2007). Gestational diabetes after delivery. *Diabetes Care, 30*(2), S225–S235.

Kaline, K., Bornstein, S.R., Bergmann, A., Hauner, H. and Schwarz, P.E. (2007).The importance and effect of dietary fiber in diabetes prevention with particular consideration of whole grain products. *Hormonal Metabolism Research, 39*, 687–93.

Kroelinger, C. D. and Oths, K.S. (2000). Partner support and pregnancy wantedness. *Birth*, 27, 112–9.

Karagiannis, T., Bekiari, E., Manolopoulos, K., Paletas, K. and Tsapas, A. (2010). Gestational diabetes mellitus: Why screen and how to diagnose. *Hippokratia Quarterly Medical Journal*, 14(3), 151-154.

König, A. B., Junginger, S., Reusch, J., Louwen, F. and Badenhoop, K. (2014). Gestational diabetes outcome in a single center study: Higher BMI in children after six months. *Hormone & Metabolic Research*, 46, 11, 804-809.

Kim, C., Draska, M., Hess, M. L., Wilson, E. J. and Richardson, C. R. (2012). “A web-based pedometer programme in women with a recent history of gestationaldiabetes”. *Diabetic Medicine*, 29 (2), 278–283.

Landon, M. B. (2010). The NICHD maternal and fetal medicine unit (MFMU) network gestational diabetes mellitus trial: Can we use the results as the basis for changing current screening approaches? *The Journal of Maternal-Fetal and Neonatal Medicine*, 23(3), 210-213. doi:10.3109/14767050903550683

Lee, I. M., Djoussé, L., Sesso, H. D., Wang, L. and Buring, J. E. (2010). Physical activity and weight gain prevention. *The Journal of the American Medical Association*, 303(12), 1173–9.

Landon, M.B., Spong, C.Y., Thom, E., Carpenter, M.W., Ramin, S. M. and Casey, B. (2009). A multicenter, randomised trial of treatment for mild Gestational diabetes. *New England Journal of Medicine*, *361*(14), 1339–48.

Langer, O., Yogev, Y., Most, O. and Xenakis, E.M. (2005). Gestational diabetes: the consequences of not treating. *American Journal of Obstetrics and Gynaecology, 192*(4), 989–97.

Linne, Y., Barkeling, B. and Rossner, S. (2002). Natural course of Gestational diabetes mellitus: long-term follow up of women in the SPAWN study. *British Journal of Gynaecology*, *109*, 1227-1231.

Lakey, B. and Cronin, A. (2008). Low social support and major depression: Research, theory and methodological issues. In: Dobson, K.S. & Dozois, D. (eds). *Risk Factors for Depression*. San Diego, CA: Academic Press.

Lakey, B. and Orehek, E. (2011). Relational regulation theory: A new approach to explain the link between perceived social support and mental health. *Psychological Review*, *118*, 482–495.

Lewis, G. and Drife, J. (2004). *Why Mothers Die: 2000–2002. The Sixth Report on Confidential dental Enquiries into Maternal Deaths in the United Kingdom.* CEMACH. London: RCOG Press.

Lewis, G. (2007). *The Confidential Enquiry into Maternal and Child Health (CEMACH). Saving Mothers' Lives: reviewing maternal deaths to make motherhood safer – 2003–2005, The Seventh Report of Confidential Enquiries into Maternal Deaths in the United Kingdom.* London: CEMACH.

Larkin, M., Watts, S. and Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3,* 102-120.

Langdridge, D. (2004). *Introduction to Research Methods and Data Analysis in Psychology*. Harlow: Pearson Education.

Lindenberg, C.S., Strickland, O., Solorzano, R., Galvis, C., Dreher, M. and Darrow, V.C. (1999). Correlates of alcohol and drug use among low-income Hispanic immigrant childbearing women living in the USA. *International Journal of Nursing Studies, 36*(1), 3–11.

Lain, K.Y. and Catalano, P.M. (2007). Metabolic changes in pregnancy. *Clinical Obstetric Gynaeco*logy, *50*(4), 938-48.

Lederman, R.P. (1984). *Psychosocial Adaptation in Pregnancy: Assessment of Seven Dimensions of Maternal Development.* Englewood Cliffs, NJ: Prentice Hall.

Lazarus, R.S. (1981). The stress and coping paradigm. In Eisdorfer, C., Cohen, D., Kleinman, A. and Maxim, P. (Eds.), *Models for Clinical Psychopathology*. New York: Spectrum.

Lepore, S.J., Silver, R.C., Wortman, C.B. and Wayment, H.A. (1996). Social constraints, intrusive thoughts and depressive symptoms among bereaved mothers. *Journal of Personality and Social Psychology, 70,* 271-282.

Lu, Q., Lu, M.C. and Dunkel-Schetter, C. (2005). Learning from success and failure in psychosocial intervention: An evaluation of low birth weight prevention trials. *Journal of Health Psychology, 10*(2), 185-195.

Metzger, B.E. and Coustan, D.R. (1998). Summary and recommendations of fourth international workshop-conference on Gestational Interventions for pregnant women with hyperglycaemia not meeting Gestational diabetes and type 2 diabetes diagnostic criteria (Review) 18 diabetes mellitus. *Diabetes Care*, *21*(2), B161–B167.

Miller, H.C. (1946). The effect of diabetic and prediabetes pregnancies on the foetus and new born infant. *Journal of Paediatric*, *26,* 455-61.

Mulla, W.R., Henry, T.Q. and Homko, C.J. (2010). Gestational diabetes screening after HAPO: has anything changed? *Current Diabetes Reports*, *10*(3), 224–8.

Morrison, J.A., Friedman, L.A., Wang, P. and Glueck, C.J. (2008). Metabolic syndrome in childhood predicts adult metabolic syndrome and type 2 diabetes mellitus 25 to 30 years later. *Journal of Paediatrics*, *152*(2), 201–6.

Morisset, A.S., St-Yves, A., Veillette, J., Weisnagel, S.J., Tchernof, A. and Robitaille, J. (2010). Prevention of Gestational diabetes mellitus: a review of studies on weight management. *Diabetes/ Metabolism Research and Reviews*, *26*(1), 17–25.

Moses, R.G., Barker, M., Winter, M., Petocz, P. and Brand-Miller, J.C. (2009). Can a low glycaemic index diet reduce the need for insulin in Gestational diabetes mellitus? A randomized trial. *Diabetes Care*, *32*(6), 996-1000.

McCourt, C. and Pearce, A. (2000). Does continuity of care matter to women from minority ethnic groups? *Midwifery*, *16,* 145–54.

McCourt, C. (2009). Social Support. In Squire, C. (Ed.). *The Social Context of Birth*. Oxford: Radcliffe Medical Press, 187–210.

Myers, B. and Pringle, J. K. (2005). Self-initiated Foreign Experience as Accelerated Development: Influences of Gender. *Journal of World Business*, *40*, 421-431.

Murray-Parkes, C. (1971). Psychosocial transitions: a field for study. *Social Science Med*icine, *5*, 101–15.

Marris, P. (1974). *Loss and Change*. London: Routledge and Kegan Paul.

McIntyre, H.D., Cheung, N.W., Oats, J.J.N. and Simmons, D. (2005). Gestational diabetes mellitus: from consensus to action on screening and treatment. *Medical Journal of Australia, 183*(6), 288–9.

Mayberry, L.S. and Osborn, C.Y. (2012). Family support, medication adherence, and glycaemic control among adults with type 2 diabetes. *Diabetes Care*, *35*, 1239–1245

Madill, A., Jordan A. and Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualise and radical constructionist epistemologies. *British Journal of Psychology*, *91*(1), 1-20.

Maturi, M. S., Afshary, P. and Abedi, P. (2011). “Effect of physical activity intervention based on a pedometer on physical activity level and anthropometric measures after childbirth: a randomized controlled trial.” *BMC Pregnancy and Childbirth,* (11), 103.

Morisset, A. S,, Tchernof, A., Dubé, M. C., Veillette, J., Weisnagel, S. J. and Robitaille, J. (2011). Weight gain measures in women with gestational diabetes mellitus. *Journal of Womens Health* (Larchmt), 20(3), 375–80.

Mays, L. (2014). Gestational Diabetes and Postpartum Metabolic Syndrome. *International Journal of Childbirth Education,* 29 (4), 101-105.

Malcolm, J. (2012). “Through the looking glass: Gestational diabetes as a predictor of maternal and offspring long-term health.” *Diabetes/Metabolism Research and Reviews,* 28 (4), 307–311.

Nascimento, S. L., Pudwell, J., Surita, F. G., Adamo, K.B. and Smith, G. N. (2013). “The effect of physical exercise strategies on weight loss in postpartum women: a systematic review and meta-analysis,” *International Journal of Obesity,* 38(5), 626-35

NICE. (2008a). *Antenatal care: routine care for the healthy pregnant woman. NICE Clinical Guideline 62. Antenatal care: routine care for the healthy pregnant woman*. London: NICE.

NICE. (2008b*). NICE clinical guideline 63. Diabetes in pregnancy: management of diabetes and its complications from preconception to the postnatal period*. London: NICE.

Nicklas, J.M., Zera, C.A., Seely, E.W., Abdul-Rahim, Z.S. Rudloff, N.D. and Levkoff, S.E. (2011). Identifying postpartum intervention approaches to prevent type 2 diabetes in women with a history of Gestational diabetes. *British Medical Council Pregnancy Childbirth, 11*, 23.

Oakley, A., Hickey, D. and Rajan, L. (1996). Social support in pregnancy, does it have long-term effects? *Journal of Reproductive Infant Psychol*ogy, *14*, 7–22.

O'Sullivan, J. B. and Mahan, C. M. (1964). Criteria for the Oral Glucose Tolerance Test in Pregnancy. *Diabetes*, *13*, 278-85.

O'Donovan, A. and Hughes, B.M. (2008). Access to social support in life and in the laboratory: Combined impact on cardiovascular reactivity to stress and state anxiety. *Journal of Health Psychology, 13*(8), 1147–1156.

O'Brien, T. B. and DeLongis, A. (1997). Coping with chronic stress: An interpersonal perspective. In: Gottlieb, B. H. (1997). *Coping with Chronic Stress.* New York: Plenum Publishing Corporation.

Opperman, A.M., Venter, C.S., and Oosthuizen, S. (2004). Meta-analysis of the health effects of using the glycaemic index in meal-planning. *British Journal of Nutrition, 92*, 367-81.

Orozco, L.J., Buchleitner, A.M., Gimenez-Perez, G., Roque, I.F.M., Richter, B. and Mauricio, D. (2008). Exercise or exercise and diet for preventing Type 2 diabetes mellitus. *Cochrane Database Systematic Review, 3,* CD003054.

Orr, S.T. (2004). Social support and pregnancy outcome: A review of the literature. *Clinical Obstetric Gynaecology, 47*(4), 842–55.

Petry, C.J. (2010). Gestational diabetes: risk factors and recent advances in its genetics and treatment. *British Journal of Nutrition*, *104*(6), 775–87.

Patton, M.Q. (2002). *Qualitative Evaluation and Research Methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Patrick, L. (2006). *The Meaning of Type 2 Diabetes for Women with Previous Gestational Diabetes*. Hamilton, ON: McMaster University.

Pope, C. and Campbell, R. (2001). Qualitative research in obstetrics and gynaecology. *British Journal of Obstetrics and Gynaecology, 108*(3), 233-7.

Persson, M., Winkvist, A. and Mogren, I. (2009). ‘From stun to gradual balance’ – women's experiences of living with Gestational diabetes. *Scandinavian Journal of Caring Sciences*, *24*(3), 454–462.

Pagel, M.D., Smilkstein, G., Regen, H. and Montano, D. (1990). Psychosocial influences on newborn outcomes: A controlled prospective study. *Social Science and Medicine*, *30*, 597–604.

Reece, E.A., Leguizamón, G. and Wiznitzer, A. (2009). Gestational diabetes: the need for a common ground. *Lancet*, *373*(9677), 1789–97.

Rizzo, T.A., Metzger, B.E., Dooley, S.L. and Cho, N.H. (1997). Early malnutrition and child neurobehavioral development: insights from the study of children of diabetic mothers. *Child Development*, *68*(1), 26–38.

Rudnicki, S.R., Graham, J.L., Habboushe, D. F. and Ross, R.D. (2001). Social support and avoidant coping: Correlates of depressed mood during pregnancy in minority women. *Women & Health, 34*(4), 19-34.

Richardson, J. and Mallon, M. (2005). Career interrupted? The case of the self-directed expatriate. *Journal of World Business*, *40*, 409-420.

Robertson, E., Grace, S. and Wallington, T. (2004). Antenatal risk factors for postpartum depression: a synthesis of recent literature. *General Hospital of Psychiatry*, *26*, 289–95.

Ratner, R. E., Christophi, C. A., Metzger, B. E., Dabelea, D., Bennett, P. H., Pi-Sunyer, X., Fowler, S. and Kahn, S. E. (2008). Diabetes Prevention Program Research Group: Prevention of diabetes in women with a history of Gestational diabetes: effects of metformin and lifestyle interventions. *Journal of Clinical Endocrinology and Metabolism*, *93*(12), 4774-4779.

Ricoeur, P. (1981). *Hermeneutics and the Human Sciences*. Cambridge: Cambridge University Press.

Rizzo, T., Metzger, B.E., Burns, W.J. and Burns, K. (1991). Correlations between ante-partum maternal metabolism and child intelligence. *New England Journal of Medicine*, *325,* 911–916.

Rommetveit, R. (2008). *Språk, individuell psyke, og kulturelt kollektiv.* Oslo: Gyldendal akademisk.

Rommetveit, R. (1972). *Språk, tanke og kommunikasjon : ei innføring i språkpsykologi og psykolingvistikk*. Oslo : Universitetsforlaget.

Reid, K., Flowers, P. and Larkin, M. (2005). Interpretative phenomenological analysis: An overview and methodological review. *The Psychologist*, *18*, 20–23.

Robson, C. (1993). *Real World Research*. Oxford: Blackwell

Rini, C., Dunkel Schetter, C., Hobel, C.J., Glynn, L.M. and Sandman, C.A. (2006). Effective social support: Antecedents and consequences of partner support during pregnancy. *Personal Relationships*, 13, 207.10.1111/j.1475-6811.2006.00114.x

Ramírez-Torres, M. A. (2013). The importance of gestational diabetes beyond pregnancy. *Nutrition Reviews*, 71, (Suppl. 1), 537-541.

Rini, C., Dunkel-Schetter, C., Hobel, C. J., Glynn, L. M. and Sandman, C. (2006). Effective social support: antecedents and consequences of partner support during pregnancy. *Personal Relation*, 13, 207–29.

Rodriguez, L., Bohlin, G. and Lindmark, G. (2000). Psychosocial predictors of smoking during pregnancy. *Journal of Reproductive and Infant Psychology*, 18, 203–223.

Sullivan, D. H. (2014). Obesity prevention starts prenatally. *International Journal of Childbirth Education*, 29(6), 12-15.

Shaw, E., Levitt, C., Wong, S. and Kaczorowski, J. (2006). Systematic review of the literature on postpartum support to improve maternal parenting, mental health, quality of life, and physical health. *Birth*, 33, 210–20.

Singh, A. and Ram, F. (2009). Men’s involvement during pregnancy and childbirth: evidence from rural Ahmadnagar, India. *Popular Review*, *48*, 83-102. 35.

Stage, E., Ronneby, H. and Damm, P. (2004). Lifestyle change after Gestational diabetes. *Diabetes Research and Clinical Practice*, *63*(1), 67-72.

Swan, W., Kilmartin, G. and Liaw, S.T. (2007). Assessment of readiness to prevent type 2 diabetes in a population of rural women with a history of Gestational diabetes. *Rural Remote Health*, *7*(4), 802.

Sjogren, B., Robeus, N. and Hansson, U. (1994). Gestational diabetes: a case-control study of women’s experience of pregnancy, health and the child. *Journal of psychometric Research, 38*,815-822.

Schaefer, C., Coyne, J. C. and Lazarus, R. S. (1981). The health-related functions of social support. *Journal of Behavioural Medicine*, *4*(4), 381-406.

Schumaker, S. A. and Brownell, A. (1984).Toward a Theory of Social Support: Closing Conceptual Gaps. *Journal of Social Issues*, *40*(4), 11–36.

Simmons, D. (2011). Diabetes and obesity in pregnancy. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *25*, 25–36.

Silva, J.C., Pacheco, C., Bizato, J., De Souza, B.V., Ribeiro, T.E. and Bertini, A.M. (2010). Metformin compared with glyburide for the management of Gestational diabetes. *International Journal of Gynaecology & Obstetrics, 111*(1), 37–40.

Symons-Downs, D. and Ulbrecht, J. S. (2006). Understanding exercise beliefs and behaviours in women with Gestational diabetes mellitus. *Diabetes Care*, *29*, 236–240.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, *11*, 261–271

Smith, J.A., Jarman, M. and Osborn, M. (1999). *Doing interpretative phenomenological analysis. In Qualitative Health Psychology: Theories and Methods*. London: Sage Publications.

Smith, J.A., Flowers, P. and Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research.* London: Sage.

Smith, J.A. and Osborn, M. (2003). Interpretative phenomenological analysis. In Smith, J. A. (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage.

Smith, B.J., Cheung, N.W., Bauman, A.E., Zehle, K. and McLean, M. (2005). Postpartum Physical Activity and Related Psychosocial Factors among Women with Recent Gestational Diabetes Mellitus. *Diabetes Care*, 28, 2650-2654.

Silverman, D. 2006. *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction.* London: Sage Publications.

Schaefer, C, Coyne, J. C. and Lazarus, R. S. (1981).The health-related functions of social support. *Journal of Behavioural Medicine*, *4*, 381-406.

Southwick, S.M., Vythilingam, M. and Charney, D.S. (2005). The psychobiology of depression and resilience to stress: Implications for prevention and treatment. *Annual Review of Clinical Psychol*ogy, *1*, 255–91.

Sinha, B., Brydon, P. and Taylor, R. (2003). Maternal ante-natal parameters as predictors of persistent postnatal glucose intolerance: A comparative study between Afro-Caribbean's, Asians and Caucasians. *Diabetic Medicine*, *205*, 382-386.

Sarason, B.R., Sarason, R. G. and Pierce, G. R. (1990).Traditional views of social support and their impact on assessment. In: Sarason, B., Sarason, I. and Pierce, G., editors, *Social Support: An Interactional View*. New York: Wiley.

Skjervheim, H. (2000). *Objektivismen – og studiet av mennesket*. Oslo: Gyldendal Akademisk.

Shinebourne, P. and Smith, J.A. (2009). Alcohol and the self: An interpretative phenomenological analysis of the experience of addiction and its impact on the sense of self and identity. *Addiction Research and Theory*, *17*(2), 152-167.

Scott, D.A., Loveman, R., McIntyre, L. and Waugh, N. (2002). Screening for Gestational diabetes: a systematic review and economic evaluation. *Health Technology Assessment*, *6*(11), 1–172.

Scollan-Koliopoulos, M., Guadagno, S. and Walker, E. (2006). Gestational diabetes management: Guidelines to a healthy pregnancy. *Diabetes Care*, *31*(6), 14-25.

Scott, D. (1996) Methods and data in educational research. In Scott, D. and Usher, R. (eds.) *Understanding Educational Research*. London: Routledge.

Setji, T., Brown, A. and Feinglos, M. (2005). Gestational Diabetes Mellitus. *Clinical Diabetes*, *23*, 17-24.

Schaffer-Graff, U.M., Kjos, S.L., Fauzan, O.H., Buhling, K.J., Siebert, G. and Buhrer, C. (2004). A randomized trial evaluating a predominantly fetal growth-based strategy to guide management of Gestational diabetes in Caucasian women. *Diabetes Care*, *27*(2), 297–302/

Schaffer, M. A. and Lia-Hoagberg, B. (1997). Effects of social support on prenatal care and health behaviours of low-income women. *Journal of Obstetrics, Gynaecological, and Neonatal Nursing*, *26*(4), 433-440.

Schutz, A. (1976). The Stranger. In Bowker, G. & Carrier, J. (Ed.). *'Race and Ethnic Relations*.' London: Hutchison.

Scheper-Hughes, N. and Lock, M.M. (1987). The mindful body: a prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly*, *1*(1), 6–41.

Tobias, D. K., Zhang, C. and van Dam, R. M. (2011). Physical activity before and during pregnancy and risk of gestational diabetes mellitus: a meta-analysis. *Diabetes Care*, 34(1), 223–9.

Toiba, R. (2013). Gestational diabetes. *Today's Dietitian*, 48-54.

Templeton, M. and Pieris-Caldwell, I. (2008). Gestational diabetes mellitus in Australia, 2005–06, Diabetes series no. 10. Cat. no. CVD 44. Canberra: Australian Institute of Health and Wealfare.

Thoits, P.A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, *54*, 416-423.

Thagaard, T. (2003). *Systematikk og innlevelse: en innføring i kvalitativ metode*. Bergen: Fagbokforl.

Trief, P.M., Wade, M.J. and Britton, K.D. (2002). A prospective analysis of marital relationship factors and quality of life in diabetes. *Diabetes Care*, *25*, 1154–8.

Trief, P.M., Ploutz-Snyder, R. and Britton, K.D. (2004). The relationship between marital quality and adherence to the diabetes care regimen. *Annual Behavioural Medicine*, *27*, 148–54.

Taylor, S. E. and Seeman, T. E. (1999). Psychosocial resources and the SES-health relationship. *Annals New York Academy of Sciences*, *896*, 210-225.

Tieu, J., Crowther, C.A. and Middleton, P. (2008). Dietary advice in pregnancy for preventing Gestational diabetes mellitus. *Cochrane Database Systematic Review*, (2). Art. No.: CD006674. DOI: 10.1002/14651858.CD006674.pub2.

Thoits, P.A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behaviour*, 53–79.

Tietjen, A.M. and Bradley, C.F. (1985). Social support and maternal psychosocial adjustment during the transition to parenthood. *Canadian Journal of Behavioural Science*, *17*, 109-121.

Tuomilehto, J., Lindstrom, J. and Eriksson, J.G. (2001). Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance. *New England Journal of Medicine*, *344*, 1343–50.

Uchino, B.N., Cacioppo, J.T. and Kiecolt-Glaser, J.K. (1996). The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. *Psychological Bulletin*, *119*, 488–531.

Vrekoussis, T., Kalantaridou, S. N., Mastorakos, G., Aoumakis, E., Makrigiannakis, A., Syrrou, M., Lavasidis, L. G., Relakis, K. and Chrousos, G.P. (2010).The role of stress in femal reproduction and pregnancy: an update. *Annals of the New York Academy of Sciences*, 1205L, 69–75.

Vest, B. M., Kahn, L. S., Danzo, A.,Tumiel-Berhalter, L., Schuster, R. C., Karl, R.,Taylor, R., Glaser, K., Danakas, A. and Fox, C. H. (2013). Diabetes self-management in a low-income population: impacts of social support and relationships with the health care system. *Chronic Illness*, 9(2), 145–155.

Vance, C.M. (2005). The personal quest for building global competence: A taxonomy of self-initiating career path strategies for gaining business experience abroad. *Journal of World Business*, *40*, 374-385.

Vohr, B. R.. McGarvey, S.T. and Tucker, R. (1999). Effects of maternal Gestational diabetes on offspring adiposity at 4-7 years of age. *Diabetes Care*, *22*(8), 1284–91.

Valsiner, J. (1984). Two alternative epistemological frameworks in psychology: The typological and variational modes of thinking. *Journal of Mind and Behaviour*, *5*(4), 449-470.

Wu, C. S., Nohr, E. A., Bech, B. H., Vestergaard, M. and Olsen, J. (2012). Long-term health outcomes in children born to mothers with diabetes: A population-based cohort study. *PLoS One*, 7(5), 1-7. doi: 10.1371/journal/pone.0036727

Webb, J. (2013). Diagnosis and treatment of gestational diabetes. *Nurse Prescribing*, 11(1), 14- 20.

World Health Organization. (2013). *Diagnostic criteria and classification of hyperglycaemia first detected in pregnancy*. Retrieved from http://apps.who. int/iris/bitstream/10665/85975/1/WHO_NMH_MND_13.2_eng.pdf?ua=1

World Health Organisation (WHO). (2013). Diagnostic criteria and classification of hyperglycaemia first detected in pregnancy. Available from http://apps.who.int/iris/bitstream/10665/85975/1/WHO_ NMH_MND_13.2_eng.pdf

Whincup, P.H., Kaye, S.J., Owen, C.G., Huxley, R., Cook, D.G. and Anazawa, S. (2008). Birth weight and risk of type 2 diabetes: a systematic review. *Journal of American Medical Associiation*, *300*(24), 2886–97.

Willig, C. (2001). I*ntroducing Qualitative Research in Psychology: Adventures in Theory and Method.* Maidenhead: Open University Press.

Willig, C. (2008). *Introducing Qualitative Methods in Psychology* (2nd Ed). Buckingham: Open University Press.

Wang, G. and Dietz, W.H. (2002). Economic burden of obesity in youths aged 6–17 years: 1979–1999. *Paediatrics, 109*(5), E81–7.

Wellman, B. and Gulia, M. (1999). The network basis of social support: a network is more than the sum of its ties. In: Wellman, B. (editor). *Networks in the Global Village: Life in Contemporary Communities*. Boulder: Westview Press.

Wellman, B. & Wortley, S. (1990). Different strokes from different folks: community ties and social support. *American Journal of Sociology, 96,* 558-88.

Wysocki, T., Harris, M.A., Greco, P., Bubb, J. and Elder, C.L. (2000). Randomized controlled trial of behavior therapy for families of adolescents with insulin-dependent diabetes mellitus. *Journal of Paediatric Psychology, 25*, 23–33.

Xie, R. H., He, G., Koszycki, D., Walker, M. and Wen, S. W. (2009). Prenatal social support, postnatal social support, and postpartum depression. *Annals of Epidemeology,* 9, 637–43.

Zachariah, R. (2009). Social support, life stress, and anxiety as predictors of pregnancy complications in low-income women. *Research Nursing Health,* 32, 391–404.

Zehle, K., Smith, B. J. and Chey, T. (2008). Psychological factors related to diet among women with recent Gestational diabetes: opportunities for intervention. *Diabetes Educator, 34*, 807-814.

Zhang, C., Solomon, C.G., Manson, J.E. and Hu, F.B. (2006). A prospective study of pre-gravid physical activity and sedentary behaviours in relation to the risk for Gestational diabetes mellitus. *Archives of Internal Medicine, 166*(5), 543–8.

Appendices

IMS Institute of Metabolic Science

Appendix A

Invitation letter

Date

Dear

Hospital No:

I would like to invite you to take part in a research study, which is part of a trainee Health Psychologist's (Kalsoom Akhter) academic thesis. This study is related to exploring experiences regarding social support received/perceived during pregnancy with Gestational Diabetes Mellitus (GDM). Any information received from you will be helpful for our health care professionals to gain more understanding about some potential needs of women during pregnancy with GDM, as well as for researchers to develop some interventions to support women with GDM during pregnancy in the future.

This study requires interviewing participants (at least for an hour, which will be recorded) to gain more understanding about the social support system. Please read enclosed the information sheet related to this study. If you are happy, please phone (( ) or e-mail [redacted]) to let the researcher know about your interest to take part in this study on your Oral Glucose Tolerance Test day in the clinic during your waiting time in the clinic.

The information you provide will be kept confidential and your participation in this study is completely voluntary. You can withdraw at any time by e-mailing or phoning the investigator of this study: (Kalsoom Akhter: (or [redacted]

We would be very grateful to you for all your support.

With best wishes

Dr.

Appendix B

Information sheet

Project Title: Gestational Diabetes Mellitus: Exploring the Experiences and meanings of Social Support (GDM-EESS)

We would like to invite you to take part in a research study related to social support system during pregnancy with GDM. This research is being conducted as part of an educational project (DPsych Health Psychology thesis) and also to help health care providers to gain more understanding about some potential needs to women during pregnancy with GDM. Before you decide you need to understand, why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study aims to gain understanding about your experiences of any support received or perceived from family members, friends, partners and health care professionals during pregnancy with GDM. The purpose of this study is to explore your experiences through an interview methodology to recognise your feelings and views related to social support.

Who is organising this study?

This study is being conducted by Kalsoom Akhter, a trainee Health Psychologist and is being supervised by Dr Catherine Sykes at the City University London and D

Why I have been invited?

You have been invited to take part in this study due to developing GDM during your current pregnancy first time.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw/drop out of the study at any time without giving a reason. This would not affect the standard of care you receive.

What I have to do, if I take part in this study?

The study requires providing information related to your experiences as part of an interview, which could last at least an hour and it will be audio recorded for research purposes. No potential risks are envisaged. You will be requested to provide as much information as you can related to your experiences of receiving/perceiving social support during your pregnancy.

Will my taking part in this study be kept confidential?

Yes. We will follow ethical and legal practice and all information, which is collected through this research, will be stored securely and kept strictly confidential for this study’s purposes. Only the investigator and the supervisors will have access to it. No identifying information is included in any part of the write-up or reporting process. Any information about you, which leaves the hospital, will have your personal information removed, so that you cannot be recognised from it.

Where is the information kept?

The information obtained will be kept on a secure password protected NHS computer, NHS encrypted tape recorder, and on the NHS safe USB. All the provided information (saved on computer and in paper form) will be kept secure for at least 3 years and after that will be disposed off securely.

What are the possible benefits of taking part?

By taking part in this study, you will be providing information related to social support, you received/perceived during pregnancy from potentially various sources, which could be useful for the future studies/interventions to support Gestational diabetes women during pregnancy. You will also be offered a £10 mother care gift card to say thank you for taking the time to take part in the study.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the investigator who will do her best to answer your questions [01223 59645 [redacted] ain unhappy and wish to complain formally, you can do this through the NHS complaints procedures. Details can be obtained from the hospital. Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you do not feel comfortable in speaking with the investigator, you may contact PALS, the Patients Advisory and Liaison Services [].

Who is organising and funding the research?

This research is organised and funded by the City University London.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable ethical opinion by the NHS Research Ethics Committee. This study has also been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number: PSYETH 11/12 030).

What will happen to the results of the study?

Once the study is complete, we aim to present the results at conferences for health professionals and to write them up for publication in scientific journals. However, no one will be able to link any data back to individuals, as we will only use anonymised results, which means that all the given information will be coded when the data will be analysed.

Can I change my mind and have information removed?

Yes, you can do this at any time. If you decide at a later date, that you no longer wish that your provided information to be used in this study, then all you need to do is to contact the investigator via e-mail or phone to inform about your decision and you will be assured that your provided information will not be used in this study.

What actions do I need to take?

If you are happy with the above information, please sign the consent form (that you agree for your information being used in the current study) and we can start the interview process. This is not a formal contract and you are free to withdraw or have any information collected from you be removed if you wish.

Who can I contact for further information?

If you have any questions or concerns regarding this intervention, please do not hesitate to contact:

Kalsoom Akhter
Tel:
E-mail:

Dr.
Tel:
E-mail:

Participants will be given a copy of information sheet and consent form to keep.

Appendix C

Consent form

Participant study number ☐☐☐☐

Research Ethics application reference: **PSYETH 11/12 030 (City University London)**

Project Title: Gestational Diabetes Mellitus: Exploring the Experiences and meanings of Social Support during pregnancy from post-natal women' perspectives (GDM-EESS)

Researcher: **Kalsoom Akhter**

	Please initial box
1. I confirm that I have read and understand the information sheet dated 25/07/12 (version No. 1.2) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary that I am free to withdraw my consent at any time without necessarily giving a reason and without my medical treatment or legal rights being affected.	☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the City University London or from the where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
4. Please initial the box if you would like to receive the information related to the results of this study and provide your current e-mail address to receive a link/information related to the results of this study. **e-mail:**	☐
5. I understand that all information I give will be treated confidentially and will not be used or released in such a way that I could be identified. Therefore, I give permission to use my results for publication.	☐
6. I agree to take part in the above study, which involves audio recording of my interview.	☐

Name of Patient Date Signature

Name of person taking consent Date Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix D

Interview Guide

Aim: Understand the experiences and meanings of social support from post-natal women' perspectives who developed GDM first time during their current pregnancy.

The following questions relate to this aim: Q4, Q5, Q6

Aim: Identify the sources of social support received/perceived during pregnancy.

The following question relate to this aim: Q2 probe, Q4

Aim: Identify the categories of social support received/perceived during pregnancy

The following question relate to this aim:Q3

Part 1:

Q1: What was your first reaction or thought, when you were diagnosed with GDM?

Q2: Tell me what kind of treatment was recommended to manage your GDM?

Probe: In that situation, who supported you to follow the treatment?

Part 2:

Q3: What kind of support did you receive from your family/ friends/HCPs/partner regarding treatment?

Q4: Tell me more about your partner/family/friend's role in terms of supporting you during pregnancy.

Q5: Tell me about your experience of one of your visits in the clinic to get some support related to managing Gestational diabetes.

Q6: Tell me what else did you think was supportive for you during pregnancy?

Part 3:

Q7: Tell me how you perceive any influence of social support on your well being after pregnancy now?

Q8: Can you think of any changes that can be made in the current services, which can be beneficial for or supportive to Gestational diabetes patients in the future?

Thank you for answering all the questions. Is there anything you would like to ask me in relation to this interview?

Table 1: An interview guide/schedule

Appendix E

Approval from the NHS RES

NHS
Health Research Authority

21 August 2012

Mrs Kalsoom Akhter
NHS

Dear Mrs Akhter

Study title:	**Gestational Diabetes Mellitus: Exploring the experiences and meanings of social support during pregnancy from post-natal women' perspectives.**
REC reference:	**12/EE/0334**
Protocol number:	**PSYETH 11/12 030**

Thank you for your letter of 13 August 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

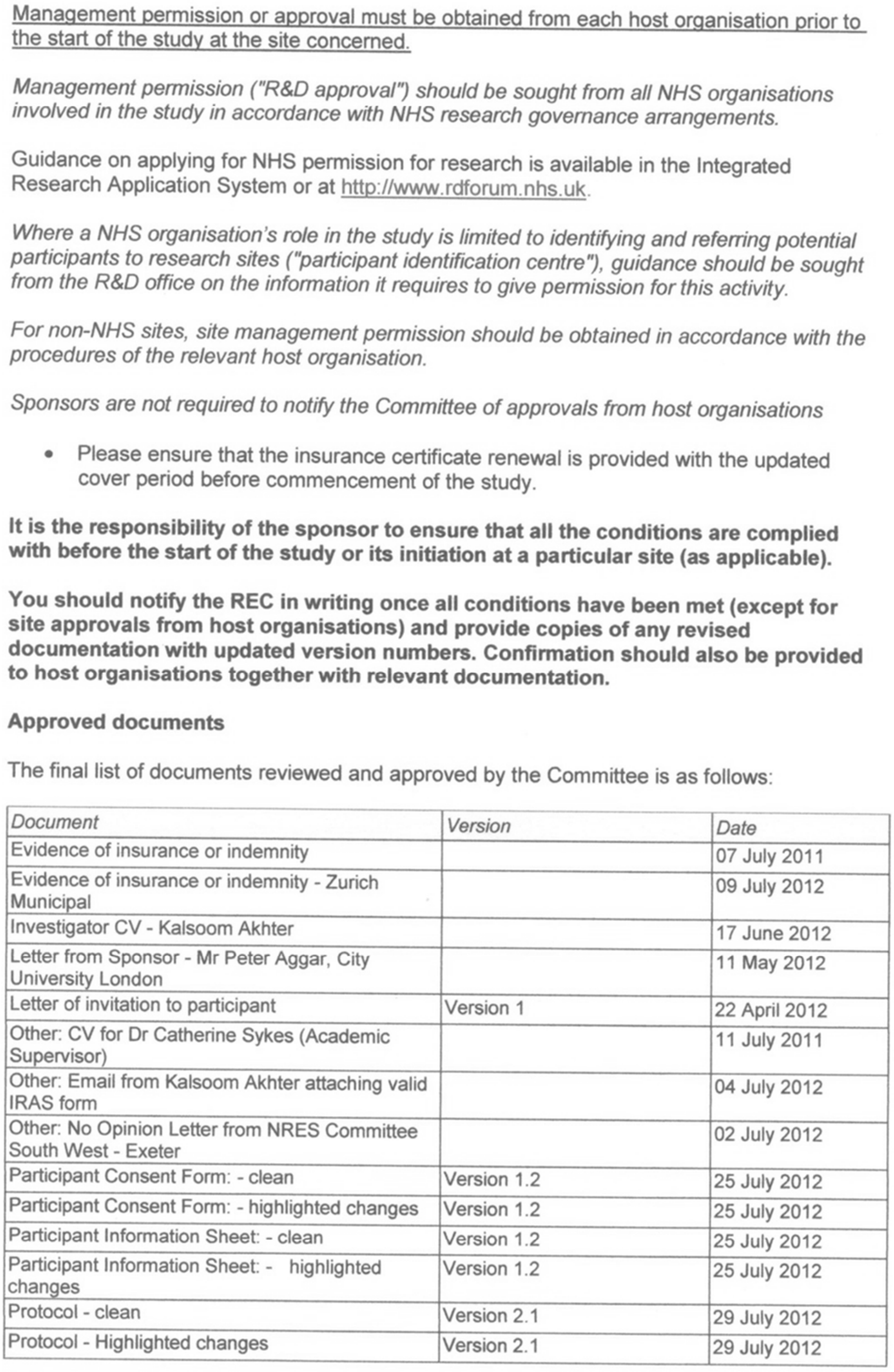
NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.



Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

- Please ensure that the insurance certificate renewal is provided with the updated cover period before commencement of the study.

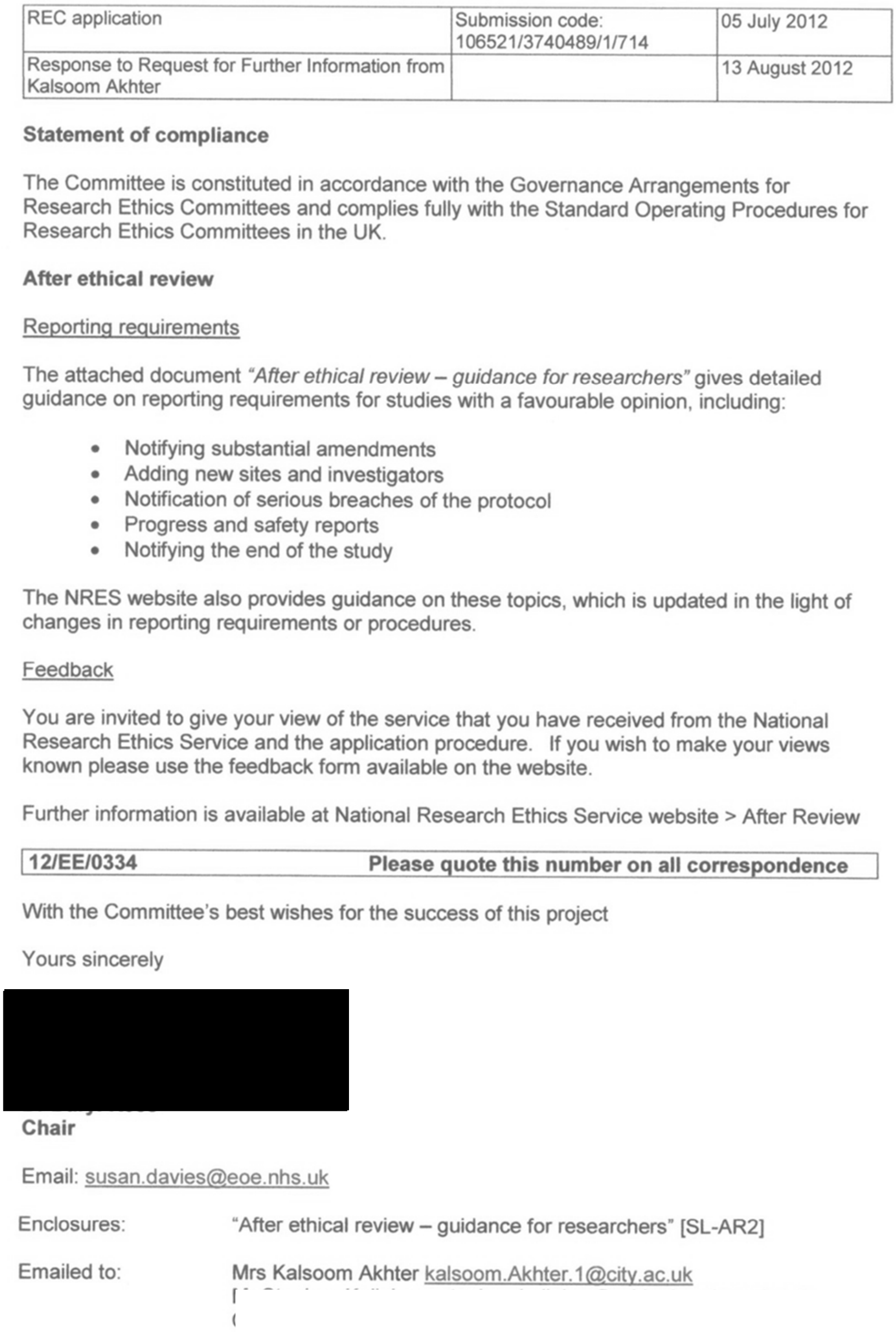
It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of insurance or indemnity		07 July 2011
Evidence of insurance or indemnity - Zurich Municipal		09 July 2012
Investigator CV - Kalsoom Akhter		17 June 2012
Letter from Sponsor - Mr Peter Aggar, City University London		11 May 2012
Letter of invitation to participant	Version 1	22 April 2012
Other: CV for Dr Catherine Sykes (Academic Supervisor)		11 July 2011
Other: Email from Kalsoom Akhter attaching valid IRAS form		04 July 2012
Other: No Opinion Letter from NRES Committee South West - Exeter		02 July 2012
Participant Consent Form: - clean	Version 1.2	25 July 2012
Participant Consent Form: - highlighted changes	Version 1.2	25 July 2012
Participant Information Sheet: - clean	Version 1.2	25 July 2012
Participant Information Sheet: - highlighted changes	Version 1.2	25 July 2012
Protocol - clean	Version 2.1	29 July 2012
Protocol - Highlighted changes	Version 2.1	29 July 2012



REC application	Submission code: 106521/3740489/1/714	05 July 2012
Response to Request for Further Information from Kalsoom Akhter		13 August 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/EE/0334	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

[redacted]

Chair

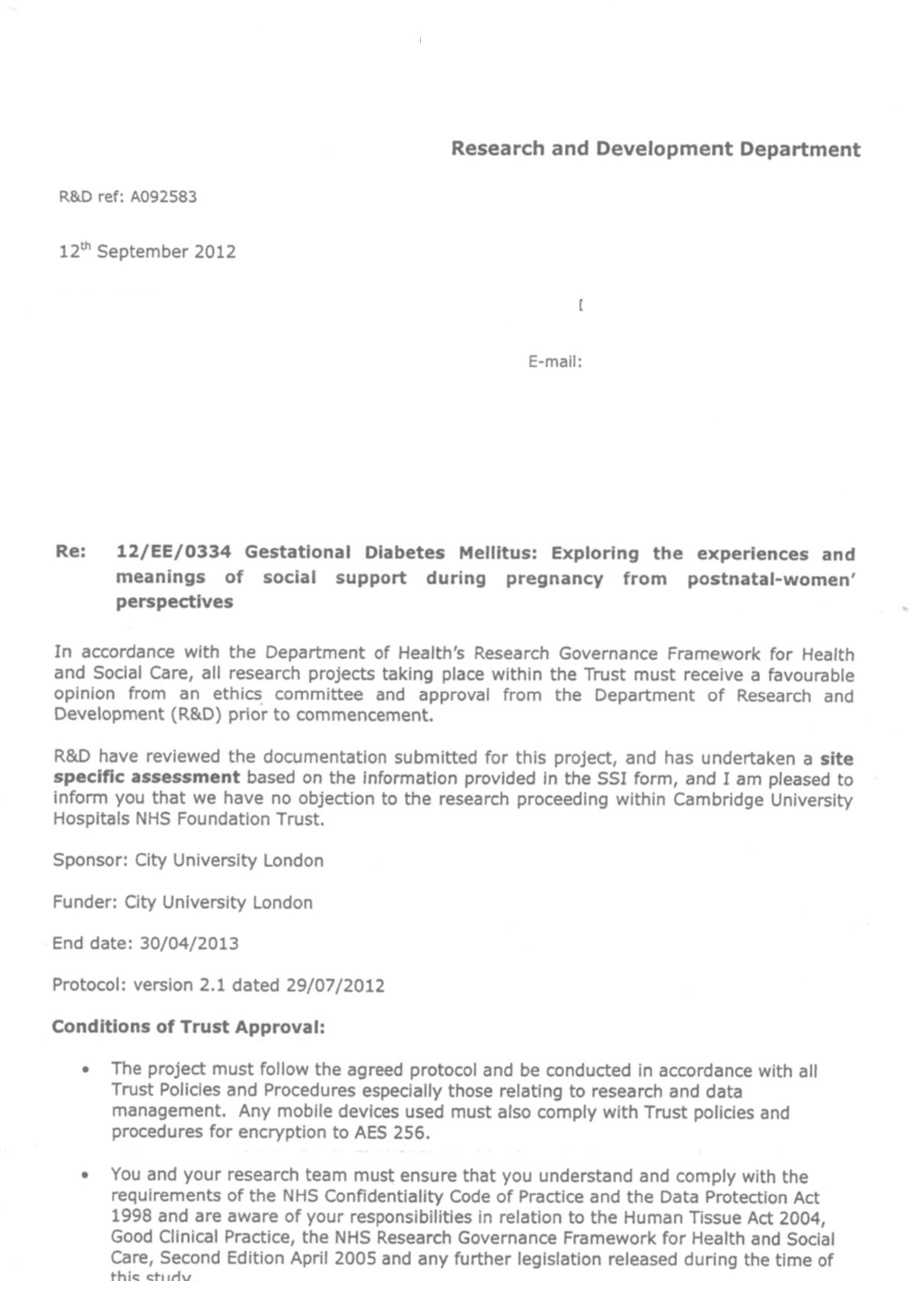
Email: susan.davies@eoe.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Emailed to: Mrs Kalsoom Akhter kalsoom.Akhter.1@city.ac.uk

Appendix F

Approval from the NHS R&D



Research and Development Department

R&D ref: A092583

12th September 2012

[

E-mail:

Re: 12/EE/0334 Gestational Diabetes Mellitus: Exploring the experiences and meanings of social support during pregnancy from postnatal-women' perspectives

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

R&D have reviewed the documentation submitted for this project, and has undertaken a **site specific assessment** based on the information provided in the SSI form, and I am pleased to inform you that we have no objection to the research proceeding within Cambridge University Hospitals NHS Foundation Trust.

Sponsor: City University London

Funder: City University London

End date: 30/04/2013

Protocol: version 2.1 dated 29/07/2012

Conditions of Trust Approval:

- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management. Any mobile devices used must also comply with Trust policies and procedures for encryption to AES 256.
- You and your research team must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998 and are aware of your responsibilities in relation to the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study

- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

- You and your research team must provide to R&D, as soon as available, the date of first patient first visit.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:

- the EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Regulations 2004;

- the EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Amendment Regulations 2006;

Amendments

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

Annual Report

It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please refer to our website ______________________ for all information relating to R&D including honorary contract forms, policies and procedures and data protection.

Should you require any further information please do not hesitate to contact us.

Yours sincerely

[redacted]

Research Governance Manager

Appendix G

Approval from the City University London

CITY UNIVERSITY
LONDON

School of Social Sciences

Northampton Square
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11 May 2012

Dear Sir/Madam,

Project Title: Gestational Diabetes Mellitus: Exploring the experiences and meanings of social support during pregnancy from post-natal women' perspectives

Research Ethics application reference: PSYETH 11/12 030

We confirm that we fully support the above research to be carried out by Kalsoom Akhter as part of her DPsych in Health Psychology at City University. We believe Kalsoom Akhter to be a committed researcher with the ability to carry out this piece of work. City University will sponsor the research and has the appropriate indemnity insurance to cover the research.

Yours faithfully,

[redacted]

Professor Dermot Bowler
Chair, Psychology Department Research and Ethics Committee

[redacted]

Mr Peter Aggar

Quality and Researcher Administrator

The University for business and the professions

Appendix H

Reviewers' comments

At two stages of the research write-up process, a cross reading was conducted in order to understand whether my process of analysis stays as close as possible to the transcripts and reads true to others. For this purpose, I chose two reviewers; and who were very much familiar with qualitative methodologies, especially IPA. Initially, when developing a first initial table of themes, I asked them to look atit (in the table each theme and sub-theme was presented with quotes beside it), and let me know whether they thought the theme title fitted the quotes. The first reviewer; Professor commented on making the themes and sub-themes' names more interesting and adding line numbers and pseudonyms. I used their comments to enhance the quality of the analysis. I am adding here their responses (in the form of emails):

Reviewer 1

Regarding the themes, I found it at times hard to see the difference between social and emotional support - that is why I think other theme names might have been more to the point and interesting - also then you could have more focused sub-themes. On another note - I would encourage you to use pseudonyms rather than numbers for the participants (more in line with the phenomenological epistemology), and to put the line-numbers of the extracts in her table, so that you can easily transfer these to the text.

The second reviewer also commented on the names of the themes and interpretation process.

Reviewer 2

I do not feel that you have actually completed the analysis and interpretation process. For example, in the second theme *"participants disappointing/unhelpful experiences"*, I could quite clearly see three main sub-themes emerge that could describe the individual categorisations you have written. In the first theme *"sources and categorisations of social support"* you again need to interpret and synthesise this into a more simplistic structure - at the moment it is too much of a practical description/categorisation and there are elements which could be integrated in to other categories. It would also be useful at that stage to also have any additional elements of her IPA analysis e.g. analysis of individual differences in participant's perspective: where the core emphasis lies with each individual, repetition of words/word usage dominance etc.

All the suggested changes were made. Reviewers were sent the revised table of theme and sub-themes' names with the analysis section to view the interpretation process. A further response was received regarding the sub-themes:

Reviewer 1

Indeed - a great improvement!! Well done!

For me - theme names could be even more creative in this phenomenological epistemology by using patients' perspectives and words rather than words from psychology.

I would delete 'sense of' in most of them, as it gets very repetitive.

I am not saying that you literally has to change the theme names, but I would encourage you to personalise these rather than being general/theoretical/formal.

Your descriptions of the themes and interpretations of the extracts are excellent and should, in my opinion, remain the same.

All the suggested amendments were made in terms of making the sub-themes more personalise to patients' experiences/perspectives. The reviewers were happy with the revised version of the theme table.

Appendix I

Extraction of themes and subthemes with quotes

Quotes followed by: Pseudonyms, page numbers, line numbers

Identifying details [-]

Pauses and silences [......]

Non-verbal reactions [ ]

Main Theme	Sub-themes		Quotes
Pillars of social support	**Help me in doing stuff**	HCPs *'Prompt response'*	*When I came to hospital because I had an appointment anyway with one of the diabetes [team member] I mentioned it that I had really bad contractions like for four to five hours and at that time when I was talking to someone the contractions like has gone. There was a long waiting time but when I mentioned that on the reception desk, I don't know I thought maybe I should not be worrying about it but I was actually bit concerned and the pain during the day was really bad, quite regular, so I was like worried that it might be that time and I was only 36 weeks pregnant so ahh yeah so they took me I didn't have to wait like there were many people and a really long queue. They took me straight away for the test and then they moved me to for a scan and I was that 3 cm diluted already so I was almost in labour but it stopped and then they kept me in the Hospital for 2 days and that was it. Sandra, p. 4, 140-153.* *I was hoping that people would act quickly and they did not ignore it. I just mentioned it and I was really really glad with how quickly they reacted and how helpful everyone was. Sandra, p. 5, 157-159* *There was a lady called [?] and she was really helpful, when I rang because she would either uhm there was a couple of occasions I ran out of strips that go in my machine, I broke my machine uhh and really did think oh no I have really done something wrong uhm and she would always as soon as I rung she would call back straight away. She would say don't worry its fine [ ]. I must be the worst patient in the world. I am causing so much. The people in the NHS you know are so busy as it is. They don't need me ringing up going, I am sorry, I broke my machine you know just causing them another headache, but she was so lovely and I was at work at the time. I only work ten minutes away from the clinic so I said its ok. I am only ten minutes away and she would say come on down and pick up the new machine or pick up the strips and stuff because I was very disorganised at ordering or going to my GP surgery. And getting my repeat prescription of my*

			test strips in time. I would say leave it far too late so uhm she was very helpful. Uhm, everybody who I have appointment with here was as you would expect very nice. Nicola, P.5, 139-157. *There was one of the midwives, she was really helpful. I think her name is [?] and she is one of the main diabetes midwives. She was extremely supportive and always makes time for you. Even if it is a very busy clinic she will take time out and advise you on any little thing or any issues you may have. One example is one day I told her that I needed a new sharps bin and she found one for me straight away and things like that she really good yeah. Karen, p.8, 266-273.*
		Intra-psychic processes: *Sense of going an extra mile*	*I did find that one weekend I broke my machine and I had to ring up and I wasn't sure I'd would have to go a whole weekend without taking any readings. Was that going to be ok? Was that not going to be ok? Was I going to be in trouble for not having or taking my readings? So I rang the hospital and one of the obviously the clinic is closed on the weekend and I couldn't get through to anybody and I just kept going round and round in this telephone loop. Then I rang the reception main hospital reception I spoke to a chap there and he was extremely helpful. He realised the diabetes clinic was closed and did not know what to do. So he took my phone number and found out for me what he could do. Then he rang me back and said that I could phone a certain person on this number he will be able to get a spare machine for you if you can get to the unit and pick it up. Uhm he was very very helpful. Nicola, p.13, 416-430.*
		Partner/Husband *'Being there for me'*	*It is completely based on my partner really he's very strong, he's uhm also generally a good person and keeps everything ticking along, so when I was diagnosed with Gestational diabetes , he was very supportive and he went out shopping and got the right stuff and ways I have to measure and do all those things. Lisa, p.1, 34-38.* *He generally does everything; the shopping anyway, the chores as well and he does the laundry and yeah and he will bring me the equipment you know if he's in the kitchen he will bring it out to that sort of thing. Karen, p. 5, 138-142.* *Like I found a lot of support from my husband because when I was pregnant I couldn't do a lot of things like at home. So he did a lot for me and I feel even now he is still trying and he has got into that habit. So now it is very helpful that he can vacuum or help me with other stuff which I used to do normally and now he understands I think little bit more. Sandra, p. 6, 187-192* *It was just a question of a sort of being with me, reminding me e.g. we found that porridge works quite well. So he would get up and make the porridge while I was doing the insulin and giving me the feeling that we are doing it together. Lisa, p.5, 167-170.*

			Having Gestational diabetes we got into the habit of going for walks after meals so even when the weather turned bad I'd be and it would be dark outside my husband, I would drag him out for a walk just for 10-15 minute, something like that we need to go for a walk and I know I didn't want to go for a walk and I know he certainly didn't want to go for a walk. Because it was getting cold and wet but he would always without complaining and without fail and it was you know it was really nice. Kirsty, p.9, 282-290. *Also this may sound quite sad but I don't like eggs and I don't cook eggs, I've never cooked eggs because I don't like eggs but uhm I couldn't eat my breakfast anymore so I couldn't have muesli and one thing they recommended was like scrambled eggs on toast stuff because of the protein offset. So every morning while I was pregnant my husband got up and made me my breakfast because I don't really do eggs and I've not cooked eggs and he has made them and I don't like them but I love cheese he would put cheese and I know it sounds really sad but its little things like that he did which was just really fab. Kristy, p.9, 290-.300.* *In the night he will get up with me, we don't, we take it in turns in terms of I will get up and kind of feed him and then go back down again and then next time he gets up he will do the kind of bum changes and stuff and in the early weeks when he wouldn't go down at night and I was really tired I'd go to bed and he would stay up with him and then he would like tag team. It so yeah, he's been really really helpful. Kristy, p.13, 420-427.*
		<u>Family members</u> *'We could not have done it without our loved ones'*	*Mother-in-law probably and my sisters because we have huge family so yeah and then they all have young children so they know what I am going through sort of things. Yeah as far support my support network is good because we all live close within a mile with each other, so we can look after each other's children so that's good. Probably sisters, mother in law and mother probably and my my partner he has given me some support as well []. Lorraine, p. 287-294.* *My mum. She has been really good, because she is a childminder obviously it's built in anyway but she's made a point that she has Thursday free and she comes over every Thursday to kind of helps me or we go shopping. We have also moved house when he was three weeks old. So if it had not been for my mum there is no way we could have done it so she was fantastic so yeah. Kirsty, p.12, 398-404.*
	Listen and understand me when feeling low	<u>*HCPs*</u> ***Intra-psychic processes:***	*Some midwives who delivered him were saying that you are doing well [?] and offered me a couple of bits of toast and I said yes please. So they got me toast and a cup of tea. They said you are doing really great and to take some rest. They were really great when I was on the delivery unit. Nadia, p.18, 606-610.*

		'Thank you: how did you know I needed that'	*The first time I came to the clinic here was really nice because the people that I dealt with here were really really lovely and they were really really helpful and they were kind of like if you need us, I always remember the girl uhm, she was the dietician I think and she sort of wrote her name down on a card and said you know if you need any advice or anything then call me on this number and this my name and that was really nice and it was just kind of like ahh that you know that's great I feel like I could ring them if I have got any kind of concerns or queries and that you know that would be great. Kirsty, p.9, 271-281.*
		'Thank you for monitoring routine'	*Every two weeks with the diabetes team, which was nice to have again those regular checkups because every now and again I would get high readings and uhm I am sort of panic a little bit. Uhm and I would then come and see them and they would kind of reassure me you know tell me how to manage it better or to increase the insulin. Uhm so it was quite nice having the regular meetings. Ann, p.4, 133-139.*
		'So nice, they said I managed really well'	*They said it sort of gave a nice overview of the whole the whole time of managing my sugars and in both cases they said oh you have really well uhm you've managed them really well over so they sort of gave me are review of how I had done over the whole of the period and basically told me I had done everything I should have done and that I had managed well and hopefully that would I think that made me feel confident that I had her. It gave me that sort of sense of achievement. Mandy, p.9, 287-294.* *Uhm I think one of the experiences of my last visit uhm I expressed that I had a bit of an anxiety about the birth uhm and I was a little bit anxious about what was to come but they were very sympathetic and they said you've done really well on this diet, your readings are very good and your weight has not increased too much. This is because I had put on quite a bit of weight in the first two semesters of my illness but it's down there in that last bit. So they said I'd done really well with my readings and things. So that was quite nice and positive yeah. Karen, p. 8, 251-260.*
		<u>Husbands/partners</u> *'Doing it together'*	*I came alone for the scan but then I got very sick and um then, he [husband] came with me, which made a big difference more than psychological difference to me because you feel quite exposed when you are out there, it makes you feel quite bad. Especially if you have diabetes. Sandra, p.2. 42-47.* *He (husband) came to the appointments with me so that was nice because they been giving him morning time off work and I think it is also this feeling that we are doing it together and he was sort of you just keeping me together and sometimes you would measure it and it would turn up to be too high and he was just kind of involved and he was kind of following it all and sort of saying um*

			what I could have and what I could not have, sort of suggesting alternatives and things. Lisa, p.9, 310-316. *Maybe my husband he was trying not to eat sweets [ ] may be to help me you know with the diet. So we had to change everything like our lifestyle to adapt to what was required. Sandra, p.3,79-81* *He was trying to change his diet in yeah more or less, so at least we both ate similar things. Sandra, p.3, 92-93* *My partner always was always supporting me uhm when I was eating he was eating and he would eat the same as I would. He would not you know like you know he would not order a pizza or eat it in front of me. He would you know we would eat together, he hates fish so he would have meat instead of fish when I had fish because he knows I love fish. Uhm but yeah we would, we would (repeated) do it together. Nadia, p.10, 336-342.* *If we went out for a meal we would not go to a fast food place, we would go and get a sandwich instead so we could read the packet. So it was nice to have his support. Nadia, p.11, 368-370.* *He changed his diet slightly to support me in what I was eating. Ann, p.3, 86-87. It was probably my husband most of really kind of really helpful in kind of changing my diet and he would eat what I would eat. So we would not have Carbs with the meals or would have very few Carbs. Kirsty, p.4, 120-124.* *It was our special time as well. It was kind of we are going for walk every night. It was kind of yeah it was time where we could take time out for ourselves as well. It was really nice, so yeah [ ]. Kirsty, p.10, 315-318.* *So like I can give you the example that I could forget about checking the blood because it supposed to be normally after one hour I ate something. So my husband will normally remind me that he will always remind that its one hour gone already so you need to check your blood test. Sandra, p.4, 114-118.*
		'De-stress love'	*I think I got a lot of support from my husband actually uhm at times when I was perhaps under more stress, related to may be work or fatigue. So I think I got a lot of extra support in that area with them, helping me to de-stress or bring things into perspective. Mandy, p.4, 109-113.*
		Other family members	*She (mum) was very caring, she just seemed very warm and especially when she was ringing up when I was very nervous about it. Lisa, p.8, 280- 281.*

		Sense of being cared/concerned and understood	*It was mainly a kind of mental support because I was like I had in my head I was really worried especially about the baby because you never know how it can affect the baby. So my husband, my family they were like trying to convince me that you will be fine and that they know someone else who had it and it was all right, so I should not be worried so things like that. Sandra, p.2, 70-75*
		Attempts at Psychological management: *'Finding conversations as cathartic'*	*There was quite a lot of stress attached with that job as well so I found uhm I would have lots of conversations when I got home. Mandy, p.4, 126-127.* *I also think that a lot of other time and this is with all the people I talked about it a long way, a lot of, the vast majority of time you actually know a lot you know the answers to your own problems you know why you feel the way you do uhm you know I can rationalise things quite well but often just like go through the process of talking about it that someone is very cathartic definitely. Mandy, p.6, 179-185.*
		'Reminding to "Say No" to work'	*My supportive people [family] definitely help me manage my stress levels uhm because I think I know what to do with the diet control and everything else but there were definitely times where I would let the stress of having a busy week because there are too many things planned in so yeah, just reminding me that I needed to stop working and that was enough marking [for school work] and uhm you know I could say no to that and all that kind of stuff. Mandy, p.7, 220-227.*
		'My mum: always there to listen'	*If I got a high reading and I was starving and I I would call my mum. Yeah I think it was just probably my mum if I had to ring someone. Lorraine, p.3, 91-93* *Well when I say support is it if I could not eat anything I would phone her up and say I can't eat anything [ ] and yeah she would probably say few more weeks sort of things yeah. Lorraine, p.4, 108-111.* *I would speak to my mum but she would say sort of say few things you know. Make sure you test few times after that probably why just in case you know you got it so so yeah it would be my mum anyway because she sort of understands anyway so. Lorraine, p.9, 280-284.* *If I have any worries or concerns she is always there and I am like mum mum mum this so yeah she is really helpful. Kirsty, p.13, 433-435.* *I called up my mum after the initial conversation when the lady had mentioned about the still birth and I was very upset. I said oh the lady said that the baby would have normalities [meant abnormalities] and stuff like that. My mum said, don't worry about it. Try to get a bit more information and there is no point getting too upset about it. Kelly, p.8, 242-248.*

		'She was always there reassuring and encouraging'	*My sister who is here with me today with [?], she has always supported me. She is fab, she'll kind of do whatever I need [......]. She always is I mean she's a Radiographer so she is kind of semi-scientific with me so she always kind of sympathetic but also keeps me in check in terms of you know she keeps on the same head of you need to do this and there is a reason why you are doing it and your not just doing it.. for sort of thing so she was really helpful and if I was having particular bad moments or if I was upset or worried about how big the baby was going to because all these things cross your mind when you find out these sort of thing. She was always there and reassuring and saying it's not gonna be you know it's not gonna be a problem you're gonna manage it, it gonna be fine and everything you know we'll be fine. Kirsty, p.5, 150-163.*
		<u>Friends</u> **Intra-psychic processes:** *'Sense of being understood'*	*I think people tried, we went to one of our friends' house and she cooked a special diabetic meal. Lisa, p.8, 258-259.* *I have got two quite close friends here and uhm they were quite supportive, I didn't see much of them as usual but one of them always comes round for dinner and she is vegetarian so the vegetarian diabetic which was quite a specific kind of meal uhm that was nice and we cooked together and my other friend was quite supportive we talked about it quite a bit and she sort of baked me nice things. I did feel that people around me were being supportive and caring. Lisa, p.9, 293-300.* *If I went to someone's house they would you know what ever I could eat they would cook and everyone would have the same and obviously everyone was being very supportive so. Nicola, p.7, 231-233.*
		<u>Colleagues</u> *'Sense of being valued/concerned'*	*Even at work it was the same uhm like when I had my lunch break and then after I ate, I had to come back to work. I sometime kept forgetting that I suppose to check the blood [sugar levels] but they [colleagues] were reminding me. Sandra, p.4, 121-124.* *Every day at work, I start work at seven thirty and I finish at four o'clock so I would generally eat my breakfast at work and my lunch. I work in the same office as my friend and we do the same job. Uhm we are on an IT a helpdesk and sometimes it can get really busy. So I would have my breakfast at you know at about eight or eight thirty and then within an hour I would have to go for a ten, fifteen minute walk and the same with my lunch. I would have my lunch at twelve and then again after an hour I would have to go, leave the office. So every day for about six weeks that I was at work I would have leave the office and leave her on her own to deal with all the phone calls. It didn't matter if all hell had broken loose and the service was crashing here there and everywhere because you're on*

			a computer helpdesk. Even if the phones were going off the hook she would always say to me, just go I don’t mind. I could go and not feel guilty that I was leaving her alone to do a job that basically I’m getting paid to do work for. Nicola, p.8, 265-281. *Very, very empathetic very, very supportive friend and uhm, uhm because you do feel a bit guilty because you think oh God I’m skiving you know I’m gonna get in trouble for taking a ten, fifteen minute walk but uhm she was absolutely brilliant. Whenever I needed to go and for hospital appointments as well because if you’re at the clinic you never know how long you’re gonna be. You could be three hours and it’s like oh God I’m leaving here alone again you know. She was great because I didn’t have to worry about work because sometimes you can worry about work but she just made it so that’s something I didn’t have to worry about. She would always cover me and my boss is very supportive and sympathetic as well that she just took care of the situation at work and was like just go, ha ha, just go, yeah. Nicola, p.9, 292-305.* *People are quite interested in the idea of having Gestational diabetes now you manage it uhm especially my female colleagues who have got children or small children particularly they would talk about it quite a lot with me which was quite nice. So you feel like you are becoming an expert on it and they are you know asking things or how it is going or how your appointments have been. So that’s quite supportive as well in a way. Mandy, p.6, 169-176.*
		Close network *‘I managed it because I had the support around me’*	*I think that one of the key things I suppose supportive advice I got from everyone including my husband my mum and my work colleagues was to consciously remind me that I needed to prioritise my own health. I was under pressures of work and the stress of work because there were definitely times where I was working too hard and not looking after myself. So not eating enough or uh not sleeping or resting enough so I think that definitely uhm sort of.. there were points where I was not listening to my own body and how I was feeling and I was getting .. and I had to just keep working and I was just letting the stress of the job to take priority over everything else. Mandy, p.7, 207-218.* *I think yeah that having people reminding you that actually that’s all well and good but this is more important. It seems silly things to have to be reminded that this is more important but I think sometime you almost get tunnel vision at work. Mandy, p.8, 240-245.* *I was definitely good rated uhm several times through both pregnancies by people and I think that was quite important because I think otherwise I would have had like mini mini breakdowns kind of you know. Mandy, p.8, 248-251.*

			I felt like I managed what I was doing but I had the support around me. So yeah. It definitely made it a lot easier to deal with having Diabetes, having a support around. Ann, p.4, 118-120. *Helping with the cooking in the correct sort of things not, uhm a lot of partners and friends and people don't order pudding when you are at a restaurant. It shows solidarity with you, it's just nice as well but it's not necessary (smiling). They don't sort of flaunt their sort of chocolates or sweets in front of you if you see what I mean. Karen, p. 7, 215-220.*
	Provide guidance and advice when needed the most	HCPs *'Thanks for understanding me and my condition'*	*She was very understanding and she explained things very well to me and she also told me she taught me a little bit about like body parts, so you know what was happening to the pancreas so when I was eating what was happening. So that made me understand much much better ah. Nadia, p.4, 134-138.* *The midwives were really good when they were on call as well yeah. If I ever had any questions because there was a couple of a time my blood sugars dropped quite low like to 4.0 or 4.1 very low and I called them and said if I eat is that gonna shoot up. She said that I should eat something but just a small amount like a mouthful of cereal and then after an hour to check and then call her back once I had done the test. So I did what she said and after one hour it had gone up to 5.3. Nadia, p.16, 518-525.* *Some people they have not got an idea about it and they will still write things, so when I came to [the clinic] and I spoken with a lady. It helped me and I felt a little bit more like ok that is normal. I have got it now, so she explained how to deal with it, how to do the blood test checking and that it wasn't actually done bad. Sandra, p.1, 27-31.* *I came to the diabetes clinic and the lady was very helpful. Uhm She showed me a booklet which guided me through the portion sizes and things and gave me some advice about things to avoid uhm and sort information sheets of what were good things to eat and what I shouldn't have. Then she also advised me about certain snacks that I could eat that were sweet but were ok. This was nice because I thought I couldn't eat anything sweet. Uhm so I went home after that feeling like I could eat a bit better normal food because I sort of initially didn't want to eat anything because I didn't know what was right or wrong. Kelly, p.2, 43-53.* *They did give me some written information which sort of summarised the sort of things you could eat but obviously the book was really helpful because it had the visual. It looks like it said specifically that how many grams and stuff. Kelly, p.14, 455-458.*

			On the DAFNE ward, I had, it was the one nurse the man. He was brilliant because when I knew you know it was almost afraid about something about the CTG[1]*, he was almost I was giving him the questions and he was explaining to me for 10 minutes. How everything is, should I be afraid or no and which kind of.... they have got a procedure also and he was like the angel there. I really wish you know that all the staff can be like him but people there are very different. But if you got the knowledge I think he had a lot of knowledge and a lot of experience. He can explain and it is really really helpful, somebody gonna have to explain to you what is it and don't be afraid, you gonna have to be calmed by yourself. He was just like the psycho. Diane, p.12, 378-392.*
		<u>Mothers</u> *'Mum's advice made pregnancy less stressful'*	*Mum gave me advice to go and talk to my employer to see if I could change my timetable slightly maybe I had some challenging classes straight after lunchtime and I was worried that was interfering with my blood sugar uhm levels so which I did do actually and I did go to talk to my finance the manager in charge of the timetable and at the last stage of the pregnancy I did reduce my time table slightly. Uhm so that was good advice because I then had slightly better timetable and a slightly less stressful end for my pregnancy while I was at work. Mandy, p.5, 140-149.*
		'Another set of ears to hear information'	*Mother-in-law supported me quite a lot. She came with me quite a lot to the appointments here so she could be another set of ear to hear what they were sort of saying and help me follow up at home. Ann, p.3, 91-94.* *My mum came with me as well couple of times to help me to remember what they were saying and applying it at home. Ann, p.3, 96-98.*
		'Being there for me always'	*Just really letting me to take the reins but been there support if I need them. Yeah and uhm when uhm I have support here from the in laws and my mum. They would write down the notes of what they were saying and then I would take them home and remember what they have written. So I could try to do everything properly. So that was really quite helpful and then uhm husband came along to the extra scan I had as well to check that the baby was growing ok. Uhm so I just I felt like I had a good network of support uhm even it was just to be there for me. Ann, p.4, 107-116.*

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[1] Continuous Cardiotocographic machine (or CTG) can be used to monitor baby's heart rate during labour. This records the baby's heart rate continuously on a piece of paper.

		<u>*Friends/peers*</u> *'Lucky to know someone who had it'*	*I had consulted a couple of friends who I'd known who had Gestational diabetes and they gave me some advice as well, so I found that quite helpful. I was quite lucky that I knew someone who'd had it really I think. Kelly, p.4, 118-127.* *I've got other mother friends who have children about the same age as my daughter and they are all kind of new friends. I would not bring them to hospital with me for this, this particular sort of thing uhm but I did tell them that I had it and someone else had had it and she told me a lot about what to expect uhm and also what she had eaten when she wanted snacks. Karen, p. 6, 168-174* *"When I found out that I got diabetes and to go tablets and I met with ladies in my work and they actually the one of them she explained to me that I shouldn't be afraid to take the metformine because metformin isn't going to put you on hypos. It is more safe tablet like the insulin and I should be alright and she explained to me little bit how this is everything happened. And after once she explained to me I was settled and calmed. And I was just following you know to take the medicines". Diane, p.6, 194-2002.*
Upsetting incidents/ Unhelpful experiences	**Dissatisfaction with communication**	*"No-one told me that I would be feeling this way"*	*I was uhm sitting there shivering and shaking and nobody reacted, no-one told me that I would be feeling this way. They didn't say oh you may feel sick or anything. Lisa, p.2, 49-52*
		'Lack of acceptance to hear different'	*I always feel that it is not appreciated if you ask for different treatment actually I think; you feel that they will think badly of you in some way. Lisa, p.2, 56-58.*
		'Harsh way of delivering truth'	*So uhm that was a little bit upsetting to begin with because I was thinking I was doing really well. I was really trying but it just felt like it wasn't good enough for her. So I came away feeling a little bit deflated uhm but straight away after I had come out of that appointment uhm there was a diabetic nurse who I would see before she was sitting in the appointment with me and I think she realised how harsh this women had been and she came running out after me and she said to me not to worry and also told me that I was doing really well. She said that it's just that she was being honest with you and when you think about it, she is just saying what she has to say. You have to be honest, you have to say look you have diabetes. Sort your diet out; otherwise it will only get worse for you. If you do get pregnant again you will get it later on in life. So she was giving me you know the hard truth. It was just the delivery of it, it was a little harsh. Nicola, p.6, 179-194.*

		'Unwilling to believe me'	*So actually she disagrees with my consultant who is meant to be a specialist in diabetes and gave me wrong information and then she didn't seem to be willing to believe my history even though it is fairly kind of I don't know it's not the sort of thing people would make up that they have insulin resistance, most people don't really know what insulin resistance is. Lisa, p.7, 240-245.* *I suppose I felt if you have a pre history and if you know about your situation it makes you feel disregarded if the treatment people don't believe you because in a way I think in a way sometimes the only person who has got the whole picture is me and myself because the NHS don't do that very well. They don't seem to look at everything and don't have enough time but if they work like that then it is important to have some kind of ear to the patient. Lisa, p.13, 465-472.* *I think overall it was not done very well as a whole but I suppose it's always a compromise between the facilities they have available. Lisa, p. 14, 508-509.*
		'Sense of being rushed'	*"I was also a bit upset with the time because the staff doesn't have much time to spend with you they are meant to explain to you but rather than they are giving you just leaflets. For me this was a little bit annoying. Diane, p.16, 535-538.* *The leaflets, just read it for yourself and you know. They are giving you leaflet as I was going home. I'm going to read this leaflet but oh I have a question where am I going to go. I don't know if it can happen to for example you know ok you are going to have to be induced. The lady Doctor asked if I understand what is mean. I said maybe little bit because my midwife she didn't tell me. She just told me you know they are simple level of the information that she give me to read, to the leaflet to read. Diane, p.17, 540-548.* *I didn't have a lot of you know enough information for me to have it and just go home and to calm down. Diane, p.17, 550-551.*
		'Conflicting, confusing messages: don't know what to do first'	*We had one lot of people saying that oh you are fine, don't worry, you are controlling it by diet. We will have the scan and see how big the baby is. I had the scan and the baby was looking a bit bigger than what he should be at that point. Uhm and then the people we spoke to said oh we want to bring you to be induced. It is better to be induced blah blah blah. So I was like ok. So at that time, I brought myself a week early to say ok right I have accepted that I am going to be induced now, discussed that sort of things. Then we saw someone else and he said don't worry about being induced, you will be fine to go to 40 weeks. So we had kind of conflicting messages and it was really confusing because we didn't know what to do first. They didn't think like anybody else could tell what to do the best. So it was kind of like what we do it. It seemed like it was personal preference of the consultants and what their feelings were about what we should do not. There*

			was any kind of founded evidence if you know what I mean. Its quite, you kind of want to be led by the expert and they didn't seem to be happy to make a decision either way [ ]. Uhm so being here was good because I did feel kind of more happy about it, but I was a bit kind of. I would rather said someone to me that you are going to be induced or not going to be induced rather than kind of in between. So in the end, we agreed that consultant that said to go fulltime. We agreed to kind of come in three days early to be induced. So that we were kind of, we were almost half way there really, because the first lot of people said come at 38 weeks, 39 weeks to be induced and the other guy said go to 40 weeks [ ]. I was like oh what to do. Kirsty, p.11, 344-371. *I think because they were doing everything on the statistics, saying oh we got to induce you at 38 weeks and to me again that felt like that wasn't proper and got to be very careful about these things because of the shoulders' desiccations and stuff like that but again they knew that some of it at 38 weeks was completely average, but yeah they still have to induce you. I didn't really understand why they had to do that. I never understood that. Kelly, p.12, 394-400.*
	Dissatisfaction with treatment/ procedure	*'Annoyed with late diagnosis'*	*I generally to be honest when I got the diagnosis ahh [ ] was quite annoyed because I actually got them to test me for diabetes a lot earlier because I had, there were reasons for me to believe that I would probably get it that I develop it not necessarily but it was more likely with most women when PCO Syndrome I was more likely to have a Gestational Diabetes and in Germany that means they test you a lot earlier and here they don't. Uhm that made me quite nervous when I hadn't had the test here yet. Lisa, p.2, 65-72.*

		'People don't take Gestational diabetes seriously'	*I didn't really feel that the treatment here was very good and all together especially from the department apart from one or two people and then I also think in a way that if you have people don't take you Gestational diabetes seriously if it then stays then people get very close to the idea. Lisa, p.12, 407-411.* *I did not feel as I was being taken seriously as a person I felt I was very much on a sort of a finishing line of people who were just coming through the system uhm so I didn't see the same people at different visits. I think if it is possible but I know the NHS doesn't necessarily work that way if there had been a bit more consistency that you actually do see someone again who remembers you from the last time. Lisa, p.13, 445-451.* *I always had to sit in the sort of corner so even when I was seeing the diabetes and obstetric teams together they hadn't sort of looked at my notes – one of them actually thought I was only diet controlled so she was advising me for that situation which wasn't the case I was all ready on insulin and if I hadn't realised that's what she was assuming so indirectly she would have given me the wrong advice. Lisa, p.13, 451-457.* *So this thing about reading the notes properly and communicating with each other, if you got two teams, the diabetes and the obstetric teams, they do actually need to talk to each other that they are having problems. Lisa, p.13, 459-462.*
		'Long wait: you are tired in your final stage and want to be at home'	*I think the waiting time, first like I say that I had an appointment once at 2 o'clock which was a problem because my midwife she could see me on Tuesday which was a huge problem because that was the day I had diabetes appointment as well. So I had an appointment here with the diabetes clinic at 2 o'clock and an appointment with the midwife at 4 0'clock or half pass four. So I thought I should be fine because normally the appointment itself does not take that long but the waiting time it takes ages. It's like once I came here at 2 o'clock and was still here until 5 or 6 o'clock and everyone kept complaining because like you are pregnant, I felt alright for me it did not bother me that much that I had to sit, because you have to wait you cannot go for a walk because you have to wait, anytime somebody can call you [for an appointment], so that was the part of experience and I heard everyone complained about it because you know you are tired and if you are like in your final stage, you want to be at home. Sandra, p.6, 208-223.*
		'Lack of continuity in care'	*Once I had very nice person and he tried to explain to me like quite well, but I was already in my final stage, so it too late and the problem was that I see someone else. Once someone knows you I know they got papers and if you see someone else you have to repeat it like every single time from the beginning because to understand your position. Sandra, p.8, 258-263.*

		'Lack of efficient behaviour'	*The only time I felt was not helpful when they did not read my notes properly and they put me in a room er it was another diabetes Doctor but it was a man and they put me in a room with a man and I told them in my notes it quite clearly stated that when giving birth uhm and any appointments up to then I didn't want any other man in the same room as I'm in. Men make me very nervous if I'm on my own and they literally sort of said oh can you wait here for a moment and then someone will come and see you. Obviously when someone says Doctor it could be a man or women and then obviously I'm heavily pregnant and now I'm sitting in a room with a man and he is explaining stuff to me and I froze [-] and he said something like now do you understand and I said sorry I didn't hear anything that you said. I just started fidgeting and twitching and I felt anxiety coming on. I felt very panicky and that was the only time because they didn't read my notes. Nadia, p.13, 431-446.* *I was at work at this time and I felt really really horrible because I was checking my blood sugar every half an hour because I felt so bad and it was going up and I decided to call to the nurses here on the number which I had it in my book. And it was really difficult because the call says leave the message [repeated three times]. It wasn't like you know that somebody will pick up the telephone straight away and tell me what to do. Diane, p.7, 221-228.* *She thought she took my details and she said to me I am gonna have to call you back. Until when I came to the hospital to give the birth, nobody called me back. This was really stressful and really. I was to be honest I was very angry because you know its [-] on my side if you are the nurse if somebody is leaving you to do it you know this kind of message and you got risk and also because of your age. If you got knowledge you just realise just ok you don't have time you know may be for few hours because they are busy in the hospital but just. She said to me I am gonna have to take advice from my colleagues and I am gonna have to call you back. If somebody is saying you something like this, you know you are just waiting for the support. Diane, p.8, 241-255.*
	Dissatisfaction with the medicalisation of pregnancy	*'I am medicalised'*	*Being hospital led was the sense of detachment from the midwife led experience that lots of my friends had because I am medicalised, sometimes it's so medicalised that the focus is on the diabetes, on your sugar levels, on your eating and I think you will almost feel like you are you know... if you are talking about your pregnancy health in those terms that's fine but I think I definitely felt like I lacked more.. sort of how you are doing conversational stuff that you get from midwife led the more personal. Mandy, p.12, 401-410.*

			I think having midwife part of what you see enjoying you know your pregnancy and enjoying the experience and I think when it is medicalised you don't have that midwife led care and there is little bit of you especially towards the end I suppose you go sort of you are overloading with data on how you are doing but then you sort of feel like you haven't perhaps had more personal side and perhaps you haven't enjoyed it which you might have done. Mandy, p.14, 462-469. *It's all the statistics and kind of treating basic statistics rather than based on your history. I suppose they have to do it based on the statistics and everything but I didn't feel very much like individual. I felt bit like that's what they do with everyone, so that's what they would do with me as well. Kelly, p.13, 411-415.*

Table 2: Extraction of themes and subthemes with quotes.

Appendix J

Themes and sub-themes

Main Theme	Sub-themes	
Pillars of social support	**Help me in doing stuff**	*HCPs* **Intra-psychic processes:** *'Prompt response'*
		Sense of going an extra mile
		Partner/Husband *'Being there for me'*
		Family members *'We could not have done it without our loved ones'*
	Listen and understand me when feeling low	*HCPs* ***Intra-psychic processes:*** *'Thank you: how did you know I needed that'*
		'Thank you for the monitoring routine'
		'So nice, they said I managed really well'
		Husbands/partners *'Doing it together'*
		'De-stress love'
		Other family members *Sense of being cared/concerned and understood*
		Attempts at Psychological management: *'Finding conversations as cathartic'*
		'Reminding to "Say No" to work'
		'My mum: always there to listen'
		'She was always there reassuring and encouraging'
		Friends ***Intra-psychic processes:*** *'Sense of being understood'*
		Colleagues *Sense of being valued/concerned*
		Close network *'I managed it because I had the support around me'*
	Provide guidance and advice when needed the most	*HCPs* *'Thanks for understanding me and my condition'*
		Mothers *'Mum's advice made pregnancy less stressful'*
		'Another set of ears to hear information'
		'Being there for me always'
		Friends/peers *'Lucky to know someone who had it'*
Unhelpful experiences	**Dissatisfaction with communication**	*"No-one told me that I would be feeling this way"*
		''Lack of acceptance to hear different'
		'Harsh way of delivering truth'
		'Unwilling to believe me'
		'Sense of being rushed'
		'Conflicting, confusing messages: don't know what to do first'
	Dissatisfaction with treatment/procedure	*'Annoyed with late diagnosis'*
		'People don't take Gestational diabetes seriously'
		'Long wait: you are tired in your final stage and want to be at home'
		'Lack of continuity in care'
		'Lack of efficient behaviour'

	Dissatisfaction with the medicalisation of pregnancy	*'I am medicalised'*

Table 3: An overview of themes and sub- themes.

Appendix K

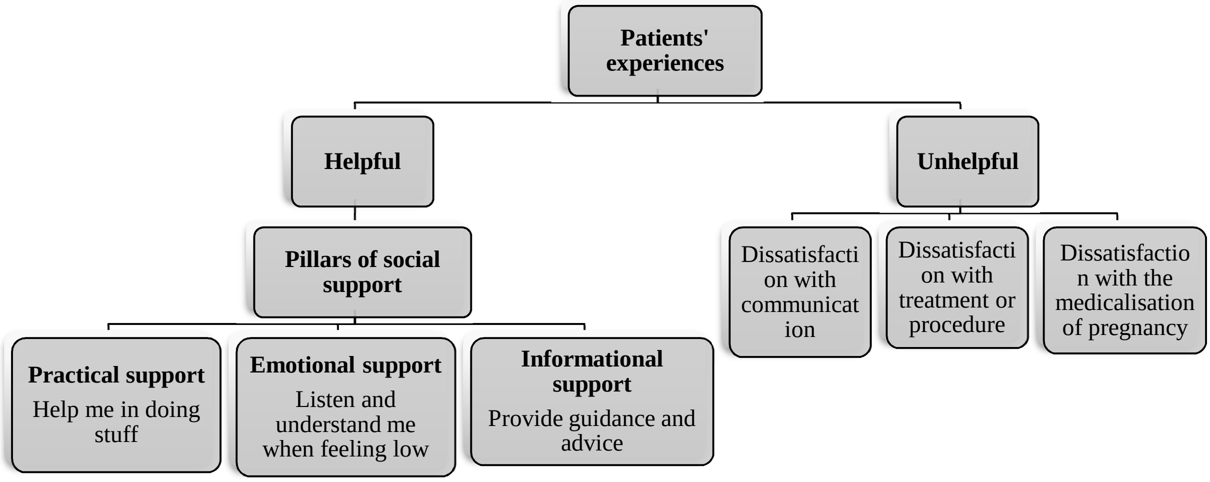


Figure 3: Graphic model/Summary of reported experiences

Section 2B - SYSTEMATIC REVIEW

Effectiveness of social support interventions for adolescents with Type 1 Diabetes: a systematic review of interventions based on theoretical framework

Supervision Plan

Systematic Review: Effectiveness of social support interventions for adolescents with Type 1 Diabetes: a systematic review of interventions based on theoretical framework

Units in this area of competence	**Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)**	**Supporting evidence to be complied for this unit of competence**
2.1 Conduct systematic reviews	**Target group**: Adolescents with Type 1 diabetes. **Type of interventions:** Theory based social support related interventions. **Description of work:** The literature search highlighted various interventions, focusing upon the positive impact of social support on diabetes self-care and metabolic control, but the nature of effective and theory based interventions was very sparse. Thus the aims of this review were to identify peer and family support interventions for adolescents with Type 1 diabetes and examine the effectiveness of theory based interventions on adolescents' diabetes and psychosocial functioning. The Cochrane library, database of systematic reviews, database of abstracts of reviews of effectiveness and Health Technology Assessment database were searched for any previously conducted systematic review. Randomised controlled trials/interventions were included, which aimed to improve adolescents' metabolic control and psychosocial/behavioural aspects. 14 studies were eligible for this review. Interventions that focused on monitoring HbA1c, psychosocial and behavioural aspects of diabetes management suggest that multi-component interventions may be more successful for adolescents than ones that just focus on one aspect. Effectiveness of various theoretical/therapeutic frameworks: social learning and self-efficacy, home-based family system and multi-systemic therapy were identified. Interventions including parents demonstrated a small to large effect-size on a variety of diabetes management and psychosocial outcomes. Home-based interventions could be more viable/accessible alternative for intervening with families in comparison to office/hospital-based interventions. This approach may not only increase access, but also may have a high likelihood of being accepted by adolescents and their families. A paper will be submitted to a peer review journals.	Proposal Data Extraction Quality Assessment Supporting evidence-search diary Abstract submitted to the DHP 2015 conference. Cope of the paper.

Target for completion: … June, 2013 … Workplace contact? Yes … If yes please give name:[redacted]

[redacted]

Background

The management of Type 1 Diabetes

Type 1 Diabetes (T1D) requires managing an intensive and challenging regimen. This includes integration of daily medical tasks (insulin injections, frequent blood glucose tests) and lifestyle modifications (close monitoring of food intake and regular exercise) in everyday life (Glasgow, Fisher, Anderson, LaGreca, Marrero et al., 1999; Pendley, Kasmen, Miller, Donze, Swenson & Reeves, 2002). Although near-normal blood glucose control may decrease the risk of several long-term diabetic complications in individuals with T1D (Diabetes Control and Complications Trial, DCCT Research Group, 1993, 1994), adolescents often have difficulty juggling all of the aspects of a demanding treatment regimen. Developing adequate treatment-related behaviours may be particularly important in adolescence, as it is considered a critical time for the development of disease management behaviours that may persist through adulthood (Pendley et al., 2002).

Parents and family members' support

Social support from parents and other family members is especially important for adolescents with T1D (Delamater, 2009) in terms of encouraging and providing support for treatment-related behaviours (Pendley et al., 2002). Research has suggested that parental involvement in blood glucose monitoring has been shown to support more frequent monitoring, which is associated with better metabolic control (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). In addition, high level of support from family members leads adolescents to better adhere to their diabetes regimen (La-Greca, Auslander, Greco, Spetter, Fisher et al., 1995; Forsander, Persson, Sundelin, Berglund, Snellman et al., 1998). In several randomized trials family-based interventions improved family relations, communication, problem-solving skills, treatment adherence and metabolic control. For example, Anderson and colleagues (1999) showed that a low-intensity office-based, family intervention increased parental involvement, while decreasing diabetes-related family conflict (Anderson, Brackett, Ho, & Laffel, 1999; Laffel, Vangsness, Connell, Goebel-Fabbri, Butler et al., 2003). A variety of other interventions indicate that family-based, behavioural procedures such as goal-setting, self-monitoring, positive reinforcement, behavioural contracts, supportive parental communications, and appropriately shared responsibility for diabetes management have improved regimen adherence, parent-adolescent relationship and glycemic control (Murphy, Rayman, & Skinner, 2006; Anderson, Brackett, Joyce & Laffel, 1999). However, low levels of family support and increased family conflict have been consistently associated with poor diabetes self-management, metabolic control, psychosocial adaptation, and Quality Of Life (QOL) in adolescents with T1D (Pendley et al., 2002; Whittemore, Kanner & Grey, 2004; Wysocki, 1993).

Research has highlighted an important area that during adolescence, young adults strive for autonomy and parents' attempts to monitor/control their child's treatment may be viewed as intrusive or nagging. Such attempts may result in adolescents becoming resistant, defiant, and noncompliant (Berg, Wiebe, Beveridge, Palmer, Korbel et al., 2007; Cameron, Skinner, De Beaufort, Hoey, Swift et al., 2008). Therefore, research supports the need for adolescents and parents to work cooperatively with open communication and flexible problem-solving skills in order to negotiate shared responsibility for treatment management (Schilling, Knafl, & Grey, 2006; Wysocki, 1993; Wysocki, Taylor, Hough, Linscheid, Yeates, et al., 1996). Parental guidance, warm and caring behaviours, open communication and expression of feelings have demonstrated protective effects on metabolic control and psychosocial adjustment (Davis, Delmater, Shaw, La Greca, Eidson et al. et al., 2001; Faulkner & Chang, 2007). Interventions based on family-focused teamwork increased family involvement without causing family conflict and helped to prevent deterioration in glycemic control (Laffel, et al., 2003; Delamater, 2009).

Other researchers have targeted families at high risk for problems. Wysocki, Harris, Buckloh, Mertlich, Lochrie et al., (2008) demonstrated that intensive behaviour family systems therapy improved outcomes in families with high levels of conflict. Ellis, Yopp, Templin, Naar-King, Frey et al. (2007) demonstrated that a comprehensive home and community-based intervention improved outcomes in families with low socioeconomic status. The majority of these family-based interventions focused primarily on problem solving and communication. However, variables such as coping and self-efficacy also have been associated with improved adherence, family functioning, psychosocial adjustment, and metabolic control (Graue, Wentzel-Larsen, Bru, Hanestad, & Sovik, 2004; Griva, Myers, & Newman, 2000).

Role of family and peers

Although familial support is a necessary aspect of diabetes management, research has shown that it is not sufficient to ensure adequate disease management. Particularly by considering adolescents' age and its requirements, supports needs to be occurred across different settings, such as at home and in school. Consequently, family members and peers can both optimally facilitate diabetes management (Pendley et al., 2001). To understand the role of family and peer support, it is important to examine social support in the context of development. In early adolescence, social networks expand as adolescents spend increasing amounts of time outside of the family. At this stage, they develop social relationships with peers, both in and out of school (Pendley et al., 2001). They become affiliated with peer groups, spend more unsupervised time (Simmons & Blyth, 1987), and derive significant support from friends (Furman & Buhrmester, 1992; Levitt, Guacci-Franco, & Levitt, 1993). Adolescents receive instrumental and self-esteem support from friends (Berndt & Perry, 1986).

As peer influence steadily peaks during early adolescence (Fuligni, Eccles, Barber, & Clements, 2001), support received from parents is viewed as less positive (Furman & Buhrmester, 1992; Paikoff & Brooks-Gunn, 1991). In addition, both parents and adolescents report less cohesive relationships with one another (Collins & Russell, 1991). Although these changes in social support may be normal and may facilitate the development of autonomy, they may also place the adolescent at risk for psychological difficulties (Berndt & Hestenes, 1996).

Peer group interventions

Given the increasing importance placed on peer relationships in adolescence, peer group interventions have also been evaluated and indicate that peer group support and problem solving can improve short-term glycemic control (Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989; Kaplan, Chadwick & Schimmel, 1985). Group coping skill training improved glycemic control and QOL for adolescents involved in intensive insulin regimens (Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999**;** Grey, Boland, Davison, Yu, & Tamborlane, 1999). Stress management, problem-solving and coping skill training, delivered in small groups, has reduced diabetes-related stress (Hains, Davies, Parton, Totka, & Amoroso-Camarata, 2000), improved social interaction (Mendez & Belendez, 1997), increased glucose monitoring and improved glycemic control (Cook, Herold, Edidin, & Briars, 2002).

Social support from peers has been rated as important by adolescents with T1D (Greco et al., 1991); peers are more likely than family members to provide companionship and emotional support in relation to diabetes care (La Greca et al., 1995). By focusing upon the peers' influence, Greco and colleagues (2001) implemented a structured group intervention, aimed at increasing knowledge and social support of diabetes care. Following the intervention, adolescents and their friends demonstrated higher levels of knowledge about diabetes and support, as well as a higher ratio of peer to family support.

Nonetheless, there is not an absolute shift from parental to peer support, as adolescents continue to seek guidance and advice from their parents (Fuligni et al, 2001). Therefore, maintaining close and supportive relationships simultaneously with parents and friends might be a way towards an effective support for adolescents with T1D. This approach might open up a door for intervention to assemble supports from the multiple systems (e.g. family and peers) (Pendley et al., 2002).

A systematic review (Hampson et al., 2001) focusing upon educational and psychosocial interventions indicated small to medium beneficial effects on diabetes management outcomes. It was also suggested that behavioural intervention that were theoretically based were significantly more effective than those that were not (Hampson, Skinner, Hart, Storey, Gage et al., 2000). No systematic review was found in the literature related to the efficacy/effectiveness of theory based social support (e.g. peer and family) interventions on adolescents' metabolic control, psychosocial factors.

Review questions

The aim of this review is not only to systematically analyse interventions targeting diabetes outcomes in adolescents, but also clearly define the intervention approach and its theoretical framework. The questions of this systematic review are:

1. What kinds of peer and family support interventions based on a theoretical framework have been tested for effectiveness in adolescents with T1D?
2. What types of approaches have beneficial effects (efficacy/effectiveness) on diabetes functioning and psychosocial functioning?

Methods

Search strategy

A systematic computerised search was performed in CINAHL, E-journals, Econlit library, Information Science and Technology abstract, Psycharticles, Socindex, Medline, PsychInfo, Embase, Psychological and Behavioural Sciences Collection, Psychinfo, Socindex and Cochrane Central Register of Controlled Trials (CCRCT). In addition, hand searches were conducted in the following journals*: The Diabetes Educator* (from 1980-2013) and *Diabetes Care* (from 1978-2012), considered to have highest topic relevance. The Cochrane library, database of systematic reviews, Database of abstracts of reviews of effectiveness and Health Technology Assessment database were searched for any previously conducted systematic review.

The National Research Register database was searched for unpublished literature. The reference list of review articles and all studies included within the review were searched in order to find other potentially eligible studies and leading authors were contacted for their additional published or unpublished work.

The following search terms were used to find studies: (1) Adolescence OR adolescent OR youth OR young people OR young person, OR teen OR juvenile OR puberty (2) Diabetes (3) Program OR intervention OR randomised controlled trial OR RCT (4) Peer OR family OR parent OR friend and (5) Outcome OR efficacy OR control OR communicat OR social OR knowledge OR diet OR skill OR exercise. The reference lists of the retrieved studies and other key reviews (e.g. Hampson et al., 2000, Hampson et al., 2001) were checked in order to capture other relevant publications, which were not found in the computerised database searches.

Selection criteria

All interventions/Randomised Controlled Trials (RCTs) eligible for inclusions were trials of a theory based interventions delivered at a variety of setting, e.g. clinics, community centres, homes or offices. Interventions that involved improving education alone were excluded from the review. Adolescents with T1D (age <18 years), their peers or friends and parents or families were included in this review. Interventions that involved children only and no family member, parents or peers/friends were excluded from the review. Two domains of outcome measures were extracted: diabetes functioning and psychosocial functioning. Studies had to report outcome measures both at the baseline and post intervention.

Data screening

First the search results from the separate databases were combined. Next the duplicates were removed from the list. The first author applied the described inclusion criteria in a standardised manner. First studies were screened for relevance using the title, then abstract and then full text articles.

To ensure that all potential studies were included within the review, when it could not be determined from the abstract that they met the inclusion criteria, the full article was obtained for further review. The selected full papers were screened to ensure that they met all of the eligibility checks. A data screening form was developed to assess the studies' characteristics (published between 1985-2015 years, please see Appendix A).

Critical Appraisal

The Effective Public Health Practice Project (EPHPP) has developed and tested a tool for assessing the methodological quality of primary studies in public health (Thomas, Ciliska, Dobbins & Micucci, 2004). The tool is based on previously established guidelines (Mulrow, Cook & Davidoff, 1997; Jadad, Moore, Carroll, Jenkinson, Reynolds, Gavaghan & McQuay, 1996), has been examined by experts in the field, and has received excellent ratings (Deeks, Dinnes, D'Amico, Sowden, Sakarovitch, Song, Petticrew & Altman, 2003). This tool and accompanying dictionary are available at http://www.ephpp.ca. This tool consists of six criteria: selection bias, study design, confounders, blinding, data collection methods and withdrawals and dropouts.

Each study was appraised according to the six criteria and rated as "strong", "moderate" or "weak" according to characteristics of each criterion reported in the study. The researcher independently scored all relevant articles for quality. The intent of the critical appraisal was to extract data from the methodologically strong and moderate studies. Ten out of seventeen studies seemed to be quite strong in terms of their quality. Please see Table 3 for the results of quality assessment of included moderate to strong studies.

Author/Date	**Selection Bias**	**Study Design**	**Confounders**	**Blinding**	**Data Collection Methods**	**Withdrawals/ Dropouts**	**Global Rating**
Ellis, Naar-King, Frey, Templin, Rowland and Greger, (2004)	Strong	Strong	Moderate	Strong	Strong	Moderate	Strong
Ellis, Frey, Naar-King, Templin, Cunningham and Cakan, (2005)	Moderate	Strong	Moderate	Moderate	Strong	Strong	Strong
Ellis, Yopp, Templin, Naar-King, Frey and Cunningham, (2007)	Strong	Strong	Moderate	Weak	Strong	Strong	Moderate
Harris, Freeman and Beers, (2009)	Moderate	Strong	Weak	Moderate	Strong	Strong	Moderate
Satin, La Greca, Zigo and Skyler, (1989)	Strong	Strong	Strong	Strong	Strong	Strong	Strong
Nansel, Iannotti and Liu, (2012)	Moderate	Strong	Strong	Strong	Strong	Strong	Strong
Kaplan, Chadwick and Schimmel, (1985	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong
Viklund, Ortqvist and Wikblad, (2007	Moderate	Strong	Moderate	Moderate	Strong	Strong	Moderate
Wysocki, Harris, Greco, Harvey, McDonell and Elder, (1997)	Strong	Strong	Weak	Moderate	Strong	Moderate	Moderate
Wysocki, Harris, Greco, Bubb, Elder-Danda and Harvey, (2000)	Strong	Strong	Strong	Moderate	Strong	Weak	Moderate
Wysocki, Greco, Harris, Bubb and White, (2001)	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong
Wysocki, Harris, Buckloh, Mertlich, Sobel Lochrie, Taylor, Sadler, Nelly Mauras and White, (2006)	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong
Wysocki, Harris, Buckloh, Mertlich, Lochrie, Mauras and White, (2007)	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong
Wysocki, Harris, Buckloh, Mertlich, Lochrie and Taylor, (2008)	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong
Newton, K. T. and Ashley, A. (2013)	Strong	Strong	Weak	Moderate	Strong	Strong	Moderate
Jaser, S. S.. Patel, N., Rothman, R. L., Choi, L. and Whittemore, R. (2014)	Strong	Strong	Weak	Moderate	Strong	Strong	Moderate
Kichler, J. C., Kaugars, A. S., Marik, P., Nbors, L. and Alemzadeh, R. (2013)	Moderate	Strong	Moderate	Moderate	Strong	Moderate	Strong

Table 3: Quality Assessment Results for Methodologically Relevant Studies (n = 17)

Study synthesis

The included studies relied on different study design based on different theories/therapies. In addition, the studies differed with regards to the theories/therapies used to evaluate the efficacy of intervention on diabetes and psychosocial outcomes. The different theoretical approaches and psychosocial outcomes led to heterogeneity in the operationalisation of social support among adolescents with T1D. Due to this heterogeneity, it was not possible to perform a meta-analysis.

Study quality was assessed (by two reviewers) under two broad headings, namely methodological quality (confidence that the study design, conduct and analysis have avoided or minimised biases in its treatment comparison) and reporting quality (the provided information about the design, conduct and analysis of the study). The two reviewers assessed the quality of the selected studies independently and compared ratings (0-2, available as supporting information). If there was more than a 1 point difference in ratings the reviewers met to resolve these discrepancies and agreed on a further rating. One study fulfilled all the study criteria and was given a maximum score of 28 points. Sixteen remaining studies were defined as being of high quality, with scores ranging from 24 to 27 points (please see Appendix C).

Results

Study selection process

The search strategy identified 1024 abstracts (69 in the CCRCT, 28 in other searches, e.g. hand search, reference sections, personal correspondences and 927 in rest of the other databases (mentioned above) for perusal. Having reviewed these abstracts, 63 (14 in the CCRCT, 28 in other searches and 22 in the rest of the other databases) were retrieved for further perusal. Of these, 25 articles were located which were possibly relevant. No further studies were found through hand searching and reference lists. A total of 14 out of 25 studies met the inclusion criteria and 11 were excluded from the review.

However, some further search was conducted (due to being late in publication process) using the same terms (mentioned above) from 2012 and 2015 years. This new search revealed 2050 articles on the above mentioned databases, but only nine articles seemed relevant by reading the titles. After reviewing the abstracts, only three met the inclusion criteria and six were excluded. So overall, 17 (14+3) studies were included in the review (see Figure 1). A total of 17 (11+6) studies were excluded from the review for a number of reasons; non-RCT studies, no theoretical framework and included children, Type 1 and Type 2 diabetes and articles that provided a summary of studies already included in the review.

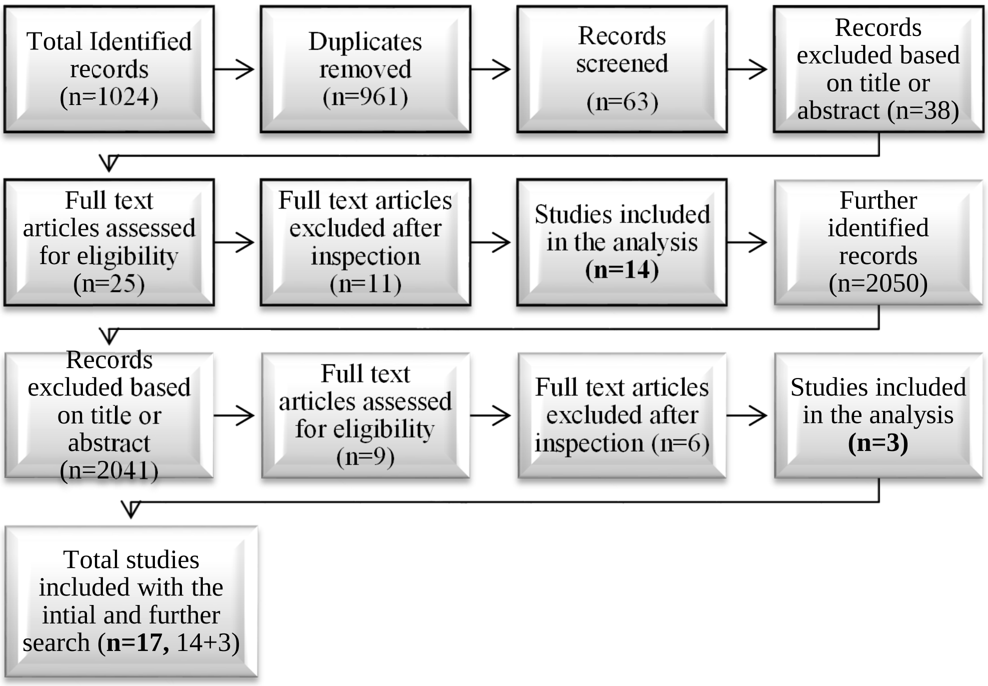


Figure 1: Study selection process

Study characteristics

The selected studies varied considerably with regards to their study characteristics (see table 1). Studies were conducted between 1985 and 2015, but most were published after 2000 than in the 1980s. The length of the studies (including the follow-up period) ranged from 4 months to 2 years (one preliminary study was 7 week long, a web-based study). Six studies exceeded 6 months in duration.

The majority of studies (n=16) were conducted in the United States of America (USA) (94.2%), and only one study was conducted in Sweden (5.8%). Reports were frequently explicit about where the interventions had been conducted. Hospital outpatient clinics (n=13) (76.5%) were the most likely setting for interventions, followed by home and community based setting (17.6%) and a school based setting (5.9%). The most typical setting was the diabetes outpatient clinics.

Although all studies within this review were RCTs, only 14 reported the method of randomisation and the remaining three did not specify it clearly (Ellis, Naar-King, Frey, Templin, Rowland et al., 2004; Harris, Freeman & Beers, 2009; Satin, La Greca, Zigo & Skyler, 1989). Nine studies reported baseline differences between groups but no significant differences were noted. Of the remaining studies, one reported significant and non-significant differences at the baseline (Kichler et al., 2013), two reported significant differences between groups at the baseline (Wysocki, Harris, La Greca, Bubb, Elder-Danda et al., 2000; Wysocki, La Greca, Harris, Bubb & White, 2001) and five did not report baseline differences between groups specifically (Harris et al., 2009; Viklund, Ortqvist, & Wikblad, 2007; Ellis, Frey, Naar-King, Templin, Cunningham et al., 2005; Newton and Ashley, 2013; Jaser et al., 2014). Most studies reported the ethnicity of the participants with the exception of two studies (Viklund et al., 2007; Satin et al., 1989).

The sample size varied greatly from 11 to 127 (in each group). Details of sample size justification were provided for five studies based on power analysis calculations (Nansel, Iannotti & Lui, 2012; Ellis et al., 2007; Viklund et al., 2007; Newton and Ashley, 2013; Kichler et al., 2013). Studies included RCTs in the review typically had one intervention group with a control group (76.5%). A small number had two intervention groups with one control/comparison group (23.5%). The total number of adolescents in 17 studies was 1623 (mean value, n=95.4). More than half of the studies involved fewer than 130 participants. Given that most of the studies involved an intervention group and a control group, subject numbers per condition tended to be sufficient. The mean age of adolescents across all the studies was 14.29 years and the mean duration of diabetes was 5.6 years.

Only thirteen studies reported the attrition rates between 4% to 37%. Ten studies followed participants up at 6 months post-intervention. Some studies reported lngth duration from 6 months (Ellis et al., 2004) to 6-10 week long (Harris et al., 2009) and 7 week long (Newton and Ashley, 2013). One study followed up participants at 4 months only (Kaplan et al., 1985). Three studies only reported 3 months’ post treatment outcomes (Wysocki et al., 1997, Wysocki et al., 2000; Jaser et al., 2014). All studies provided a full description of the intervention and used HbA1c (except the Newton and Ashley, 2013) as the primary outcome measure, which was measured at baseline and at each follow-up. Validated measures were used to assess secondary outcomes in eleven studies, which varied between studies. The most interventions were delivered by a range of highly qualified professionals. However, in some studies it was difficult to identify who delivered which part of the intervention.

The majority of the interventions used some form of social, psychological, cognitive and behavioural skills training (82.4%), followed by group therapy, independent problem solving (11.7%) and lecture/discussion based session (5.9%). There was an enormous variety in the aspects of diabetes management addressed by the interventions. This review will highlight some guiding theoretical principles mentioned in the interventions followed by the effect sizes related to medical and non-medical outcomes (see Table 4 for the abbreviations used).

Abbreviations	Full term	Abbreviations	Full term
IDDM	Insulin Dependent Diabetes Mellitus	DSMP	Diabetes Self Management Profile
CPMC	Chronically Poor Metabolic Control	IBC	Interaction Behaviour Code
PARQ	Parent-Adolescent Relationship Questionnaire	DFBC	Diabetes Family Behaviour Checklist
CT	Current Therapy	FRI	Family Relationship Index
SC	Standard Care	BGT	Blood Glucose Test
ES	Educational Support	MEPS	Mean Ends Problem Solving
MST	MultiSystemic Therapy	DMS	Diabetes Management Scale
BFST	Behavioural Family Systems Therapy	IBC	Interaction Behaviour Code
BFST-D	BFST for Diabetes	ER	Emergency Room visits
CBQ	The Conflict Behaviour Questionnaire	DMS- A	Diabetes Management Scale- Adolescents
DRC	Diabetes Responsibility and Conflict	DMS-P	Diabetes Management Scale-Parents
TEQ	Treatment Evaluation Questionnaire	EATADH	Eating Adherence
PARQ	The Parent Adolescents Relationship Questionnaire	INSADH	Insulin Adherence
IC	Issues Checklist	SCI	Self-Care Inventory
ICL	Issues CheckList	TADS	Teen Adjustment to Diabetes scale

Table 4: Abbreviations used for intervention questionnaires and different groups

Theoretical framework

Social learning and self-efficacy theory

One study (Kaplan et al., 1985) evaluated the value of social learning intervention for helping IDDM teenagers to improve social skills and to avoid peer influence. The development of the intervention was guided by the principles of social learning and self-efficacy theory (Bandura, 1977). Results regarding metabolic control at the 4 month follow-up demonstrated that those in the experimental group had significantly low HbA1c than the control group. Both groups' HbA1c reduced from baseline to four months follow-up. There was positive (but non-significant) correlations between social support satisfaction and HbA1c as well as knowledge and HbA1c. Similarly, there was a positive but significant correlation between the MEPS and HbA1c ($p<0.01$). These correlations suggest that those who were most satisfied with their networks of social support actually had the poorest control. This study has not explicitly specified the outcomes of the secondary measures for the control group.

Overall, the results indicate that social learning group demonstrated a decline in their metabolic control in comparison to the control group. The results of this study also highlight the importance of behaviour in the control of T1D rather than just focusing upon knowledge. In addition, teenagers in poor metabolic control may actually be very content with their social support network, which could be a particular problem for teenagers who are close to their peer network and are strongly influenced by them.

Similarly, Newton and Ashley (2013) conducted a pilot web-based intervention utilising self-efficacy theory to improve compliance to treatment protocols and sychosocial functioning in adolescents with type-1 diabetes. Self-Efficacy was significantly correlated with positive putcome expectations and diabetes self-management and diabetes quality of life for youths. In an exit survey, 90% of participants indicated that they were more willing to comply with their treatment protocol after participating in the intervention. Overall an online website seemed to be a promising tool to bring adolescents with a chronic disease together, providing problem solving activities and social support.

Empowerment approach

Viklund and colleagues (2007) used a randomized pre-test/post-test design. They randomly assigned participants to either a 6-week intervention group or a 6-month wait-listed control group after attending a meeting with their parents regarding the empowerment education programme. The aims of this study were to determine the effects of an empowerment programme on glycemic control and empowerment and to study the role of parental involvement. Overall, this empowerment programme for teenagers showed no beneficial glycemic or empowerment effects after 6 and 12 months after the intervention.

Social cognitive theory, self-regulation model and system theory

Nansel et al., (2012) designed a multicenter, parallel group study with equal randomization, grounded in theories (mentioned above). The intervention was designed to help families (of youth with T1D) improve diabetes management by facilitating problem-solving skills, communication skills, and appropriate responsibility sharing. The intervention had a significant effect on HbA1c change from baseline at the 24 months interval. Change from baseline in blood glucose monitoring frequency showed a significant adverse effect at the 24-month interval. No significant group differences were found in change across the study duration for any measure of adherence. Overall, positive effects were achieved on the HbA1c levels but not on adherence at the follow up. Such findings could be due to various variables e.g. multi-sites, two different age groups, delivering it to parent-child together etc.

Positive psychology

Jaser et al (2014) focused upon the effects of positive affect (PA) on health, and a review of the literature found that PA or feelings that reflect pleasurable engagement with the environment is related to favourable health outcomes (Pressman & Cohen , 2005). Following the protocol that has been successful in adults with chronic illness (Charlson, Boutin-Foster, Mancuso, et al, 2007), the PA intervention was designed to increase PA through gratitude, self-affirmation, small gifts, and parental affirmations. The aim was to pilot-test the feasibility and acceptability of a positive psychology intervention to improve adherence. No main effects for treatment were observed at the 6-month follow-up. However, there was a significant association between adolescents' levels of positive affect and measures of adherence, including self-report and meter downloads of glucose monitoring. Overall, the high levels of participation and retention indicate that adolescents and their parents were receptive to a positive psychology approach (Schilling, Knafl &Grey, 2006), which places an emphasis on positive emotions and strengths, rather than problems (Jaser et al., 2014).

Intervention based on home based behavioural family system therapy

Seven studies (Harris et al., 2009; Wysocki, Harris, La Gerego, Harvey, McDonell et al., 1997; Wysocki et al., 2000; Wysocki et al., 2001; Wysocki et al., 2006; Wysocki, Harris, Buckloh, Mertlich, Sobel et al., 2007; Wysocki et al., 2008) evaluated the application of

BFST for families of adolescents with diabetes. BFST is based on psychosocial principles of targeting family communication and problem solving factors (Robin & Foster, 1989).

Harris and colleagues (2009) examined whether home-based BFST produced clinically significant change in family conflict with a sample of adolescents with poorly controlled diabetes and their families. Post-treatment DRC and CBQ scores for adolescents, mothers and fathers in the treatment group were all lower than at pre-treatment and the comparison group respectively. Findings suggested that BFST resulted in improvements in mother and adolescents reported diabetes-specific conflict as well as parent-reported general parent-adolescent conflict.

Wysocki et al (1997) compared the social validity of the BFST and ES group interventions as treatments for communication, problem-solving and conflict-resolution skills. The results of this comparison indicated that adolescents and their mothers who had experienced BFST rated it as significantly more acceptable, applicable and effective in terms of improving family communication, problem solving and conflict-resolution skills than did those who experienced the ES intervention.

Furthermore, Wysocki and his associates (2007) demonstrated that 10 sessions of BFST improved family communication and problem-solving based on parent and adolescent report (Wysocki et al., 2000) and direct observation of family interactions (Wysocki, Miller, La Greco, Harris, Harvey et al., 1999). These benefits persisted for 12 months (Wysocki et al., 2001). Wysocki and associates (Wysocki et al., 2006, 2007) conducted another randomized trial implementing a modified version of BFST that focused more specifically on diabetes-related issues (BFST-D), demonstrating significant improvements in glycemic control, treatment adherence, and diabetes related family conflict immediately post-treatment, with greater improvements in diabetes-related family conflict and glycemic control for adolescents in very poor glycemic control at baseline. These effects were largely maintained over a 12-month follow-up (Wysocki et al., 2008).

Intervention based on Multi-SystemicTherapy (MST)

MST is an intensive, home- based treatment model, is designed to target the multiple systems, within which youth with serious problems and their families are embedded in. It targets adherence related problems within the family system, schools, peer network, health care system and the broader community systems (Ellis et al., 2004). Three studies were conducted comparing the effectiveness of MST to standard multidisciplinary care for adolescents with poorly controlled T1D (Ellis et al., 2004; 2005; 2007).

Ellis and colleagues (2004) demonstrated that adolescents receiving MST had significant improvements in metabolic control (from study entry to the 6-month post-test). In addition, adolescents had increased adherence on the DMS, frequency of blood sugar testing, insulin compliance and improved insulin adherence (measured by 24 Hour Recall). There were no significant differences from baseline to 6-month post-test on any outcome measure for adolescents in the standard care condition.

In general, parents in the treatment condition reported high levels of satisfaction with the MST intervention. Adolescent who received MST had a significantly decreased number of hospital inpatient admissions during the 6-month study period. Overall, adolescents who received MST had significantly improved adherence to blood glucose testing and metabolic control (in comparison to control group) from study entry to the six months post-test. Following the findings of this study, Ellis and colleagues conducted two further studies (in 2005 and 2007), which demonstrated the effectiveness of the MST in comparison to standard care.

Following the review of the MST and BFST, Kichler et al (2013) developed the Kicking In Diabetes Support (KIDS) project, which aimed to provide both peer group and family-based interventions to adolescents with T1DM and their parents. At 4 months posttreatment, parents and youth reported increased parent responsibility, and parents reported improved youth diabetes-specific quality of life. Although there were no statistically significant changes in hemoglobin A1c values and health care utilization frequency from 6 months prior to and 6 months posttreatment, other psychosocial changes (i.e., increases in parent responsibility and diabetes-specific quality of life) were documented. Therefore, this treatment was found to be a promising intervention for use in an outpatient clinical setting to aid in improving the psychosocial functioning of youth with Type 1 diabetes

Multifamily group intervention plus parent simulation

One study (Satin et al., 1989) evaluated the impact of a 6-week Multi-Family (MF) group intervention and parent Simulation (S) on adolescents' metabolic control and psychosocial and family functioning. Results demonstrated significant improvements/decrements in metabolic control in the multi-family and parents simulation group in comparison to the control group in the first, second and third cycle of the study. In terms of perception/attitude, improvement was noted in adolescents' attitudes toward a teenager with diabetes, for those in the MF and MF + S groups relative to the controls (C).

In regards to parents' estimates of their youngsters' self-care, mothers tended to report that their adolescents were more careful about their diabetes care at post treatment, relative to pre-treatment levels, regardless of group membership. However, for those who participated in the second and third study cycles, only mothers in the MF and MF + S groups reported increased perceptions of their youngsters' overall self-care, whereas mothers in the C group reported a decrement in their youngsters' self-care.

Effect sizes

A review of the 17 RCTs identified yielded eleven interventions for which just sufficient detail was provided to enable effect sizes to be calculated. Effect sizes were computed from observed means and Standard Deviations (SDs) of the intervention and control groups using Cohen's d (Cohen, 1988). Effect sizes could be computed for HbA1c in six of the 17 interventions (please see Table 2 in Appendix B). For the remaining interventions, insufficient data (e.g. no means or SDs) were available to calculate the effect size.

There was considerable diversity in the other outcomes studied. For eight of the interventions (Wysocki et al., 2000; Wysocki et al., 2006; Wysocki et al., 2007; Wysocki et al., 2008; Harris et al., 2009; Ellis et al., 2007; Kichler et al., 2013; Newton and Ashley, 2013), effect sizes could be computed on outcomes coded as psychosocial (i.e. PARQ, DRC, TADS, SCI, DSMP, IBC for positive & negative communication, CBQ, DFBC, FRI, diabetes quality of life, self-efficacy of diabetes management, children' depression inventory, diabetes family conflict, brief symptom inventory, behavioural assessment scale for children, diabetes family relationship questionnaire, paediatric quality of life inventory, readiness to change the balance of responsibility scale, diabetes family responsibility questionnaire).

However, four interventions' effect sizes could be computed (Wysocki et al., 2000; Ellis et al., 2004; Ellis et al., 2005; Ellis et al., 2007) coded as diabetes management and adherence related factors (i.e. ICL, recall interview conflict scores, recall interview adherence factors, DMS for adolescents & parents, blood glucose meter, insulin adherence, eating adherence, BGTS, ER, hospital admissions & BGT frequency). Ellis et al's (2005) study though did provide medium to large effect sizes for some of the measures and the remaining reported as non-significant, no standard deviations were reported (please see Appendix A).

HbA1C

Negative effect sizes regarding HbA1c were indicated in Wysocki et al (2007) at a long term follow-up periods. However, it is noted that HbA1c for the BFST-D group was significantly lower than that of the SC group at months 6, 9, 12, 15 and 18 and significantly lower than that of the ES group at months 9, 15 and 18. Additionally, two more studies demonstrated negative effect sizes regarding HbA1c (Ellis et al., 2004; Ellis et al., 2007). However in Ellis et al's (2004) study, adolescents receiving MST had significant improvements in metabolic control from study entry to the 6-month post-test. Similarly, in Ellis et al's (2007) study, a significant change occurred (i.e. HbA1c decreased .92%) in youth in single-parent families assigned to MST.

At 3 month follow up, a MF group intervention plus parent simulation based study (Satin et al., 1989, 3 groups) was found to have a large effect size on metabolic control measured by the HbA1c. Further follow up effect size was also quite large in this study when MF +S was compared with C at 6 months. The findings of the 2nd and 3rd study cycles of this study also demonstrated a large effect size at 3 months and at 6 months.

Findings of a 3 months long study (Wysocki et al., 2000), demonstrated a small effect size on HbA1c (0.28 when BFST compared with ES rather than CT, 0.18). At 7 months, the MST based intervention (Ellis et al., 2005) was compared with the SC using two approaches: intent-to treat analysis and per protocol analysis, where a medium effect size on HbA1c (0.64) was found only in the per protocol analysis.

Psychosocial measures

Negative effect sizes regarding psychosocial measures were indicated in Wysocki et al.'s (2000) at the 3-months period. However, BFST improved significantly more on the overt conflict and deficit scale and on extreme belief scale than the CT. A significant main effect for groups on change in the DRC family composite scores was found, favouring the BFST group, but no significant main effects for the SCI & TADS. At 6 months, BFST based intervention (Wysocki et al., 2006) was found to have a moderate effect size on one of the subscales called family structure (0.48).

The following study (Wysocki et al, 2007), at 6-months follow up, indicated a medium effect size on the diabetes self management profile (0.56). These results are indicated to be sustained at one year (0.6) and at 18 months (0.36). This study had negative effect sizes related to DRC scale at 6, 12 and at 18 months.

Furthermore, negative effect sizes were indicated in the following study (Wysocki et al., 2008) related to IBC for negative communication for all participants at 6, 12 & 18 months. However, it is noted that adolescents and mothers in the BFST-D group had significantly lower scores than SC group (at all follow-ups) and ES at the 6-month follow-up only. For positive communication, high medium effect sizes were indicated in this study for:

- Adolescents (at 6-months, 0.6, 12-months, 0.30 and 18-months, 0.54)
- Mothers (at 6-months, 0.60, 12-months, 0.53 and 18-months, 0.61)
- Fathers (at 6-months, 0.37, 12-months, 0.66 and 18-months, 0.44).

A 5-8 week long home based BFST (Harris et al., 2009) indicated negative effect sizes on DRC & CBQ outcome measures for all participants. However, post treatment BFST group (including all participants) scored much lower on the DRC and CBQ measures than the control group. At 7-months, MST based intervention (Ellis et al., 2007) was found to have very small and large effect sizes on family functioning as measured by the FRI (0.02), DFBC (primary caregivers, 0.13) and DFBC (secondary caregivers, 0.94).

A web-based 7 weeks long intervention (Newton and Ashley, 2013) demonstrated small effect sizes for diabetes quality of life (0.19) and self-efficacy of diabetes management (0.21). However, Kichler and colleagues's (2013) kicking in diabetes support intervention demonstrated small to medium effect sizes at 6 months posttest on readiness to change the balance of responsibility scale (0.23), diabetes family relationship questionnaire (0.28), paediatric quality of life inventory diabetes (0.43) and diabetes family relationship questionnaire (0.47).

Diabetes management and adherence measures

In terms of diabetes management and adherence related factors, negative effect sizes were indicated in the Wysocki and colleagues (2000) study on all IC, intensity, duration and diet amount scores at 3-months. This study also indicated small effect-sizes on frequency (0.06), insulin (0.20) and exercise (0.17), and a moderate effect size on diet composition (0.5) and a large effect size on testing/eating frequency (0.71). Moreover, another study (Ellis et al., 2004) indicated negative effect sizes at 6-month follow up related to DMS- A, DMS-P, EATADH & hospital admissions. However, there was a significant difference between the intervention and the control groups at 6-months on the hospital admissions. This study also indicated a small effect size on BGTS (0.15) and moderate effect sizes on meter (0.36) and INSADH (0.48). Furthermore, at 7-months, an MST based intervention (Ellis et al., 2005) was found to have moderate effect sizes on admissions (0.63 and 0.65) and large effect sizes on meter (1.09 and 1.01) and BGTS (0.83 and 1.05). A moderate effect-size was indicated in Ellis and associates' (2007) study on BGT frequency (0.67) at 7-months post-test.

Overall, a variety of studies used diverse outcome measures. Some studies provided insufficient data to estimate accurate effect sizes. However, three outcome measures were consistently used across studies: 1) the HbA1c (across 6 studies), 2) PARQ (across 2 studies) and 3) DRC (across 3 studies). These studies had inconsistencies in the follow up periods and had the small sample sizes (please see table 2 for the division of sample size for each group and follow up).

It is noted by looking at the individual effect sizes of the studies that two interventions (Wysocki et al., 2007; Wysocki et al., 2008) were much longer in duration (e.g. 18-months) than the remaining seven interventions. However, much larger effect-sizes (at 3-month, 2.08 & 6-month, 1.25) were found in Satin et al (1989), related to HbA1c in comparison to all the remaining studies. Thus it has been singled out for description in order to suggest the features of the relatively more effective interventions for adolescents.

Satin and colleagues

This study evaluated a MF group intervention in 32 adolescents with or without parental simulation of diabetes and compared this to Control Group (CG). The groups were composed of three to five families that met with professional group leaders who used principles of group therapy once a week for 6-weeks. The first 2 weeks focused on feelings about diabetes and how it affected family members, and subsequent weeks focused more on diabetes management. In the parental simulation group, adolescents taught their parents how to manage their ‘diabetes’. The simulation lasted 1 week and parents discussed their experience at subsequent meetings.

At 3-month follow-up, HbA1c had decreased for the parental simulation group but increased for the other two groups, particularly for the CG. Overall, the largest effect-size for HbA1c in this study was produced by the parental simulation condition. No other intervention in any study included in the present review used parental simulation, yet it appeared to be dramatically effective in producing beneficial changes in HbA1c among adolescents.

Discussion

Fourteen studies were included in this review, which aimed to evaluate the effectiveness of a range of family and peer support interventions based on a theoretical framework for adolescents with T1D. As few studies included the same comparisons and outcomes, a meta-analysis was not conducted for this review.

Due to different approaches and theoretical models underpinning the studies, a direct comparison is difficult. However, some marked differences in results are apparent. Wysocki and colleagues’ (2000; 2001) studies reported that BFST (compared with CT & ES) yielded more improvements in parent-adolescent relationships, which is not consistent with the finding of Wysocki et al (2006, all subscales of the PARQ= ns). Wysocki et al (2000) also indicated that their intervention (BFST) had no effect on treatment adherence (SCI) at post-treatment. This is contrary to the results reported by Wysocki et al (2001) that BFST group showed significant improved treatment adherence (SCI) at 6 and 12 months follow up. It may be that these disparities can be accounted for by differences in the nature of the intervention. Alternatively, this may be the product of the different length of time to follow-up. Wysocki et al (2000) included 3 month follow up, but unlike other studies did not measure outcomes at 6 and 12 months. It may be that short term social support based behavioural interventions promote improvements in parent-adolescent relationships. However, the treatment adherence can be improved and maintained by prolonged change in family interaction patterns.

It is noted that despite Viklund et al (2007) tailoring their intervention to support adolescents through the empowerment programme to improve their glycemic control, the intervention group did not significantly differ from the control group. One interpretation of these effects was suggested that the programme actually started an empowerment process which temporarily resulted in a negative effect on HbA1c in the older teenagers (Viklund et al., 2007). The HbA1c did not increase in the younger individuals in this study. Another interpretation could be that perhaps the teenagers were too young to incorporate the described components of empowerment (Fennell et al, 1991).

There was a suggestion that in those teenagers who invited their parents, HbA1c did not increase, which is in accordance with the literature (Graue, Wentzel-Larson, Hanestad & Sovik, 2005; Barlow & Ellard, 2004; Anderson et al., 1999). Empowerment programmes without parental involvement are therefore probably not suitable for teenagers with diabetes (Viklund et al., 2007). Satin and colleagues (1989) conducted a study involving teenagers (mean age 14.6 years) and their parents into three groups: 1) MF, 2) MF plus parent simulation and 3) a control group. Both intervention groups showed improvement in glycaemic control.

Furthermore, the issue of parental involvement has been addressed in a variety of studies, identified in a previous systematic review (Hampson et al., 2001) and the evidence supports the widely held clinical view that developmentally appropriate, negotiated responsibility has beneficial outcomes. In this review, a variety of interventions (with significant HbA1c values: Wysocki et al., 2006, Wysocki et al., 2007, Ellis et al., 2004 & Ellis et al., 2005) involved parents and had beneficial effects on diabetes management. However, the parental simulation approach used by Satin and colleagues resulted in a large beneficial effect on HbA1c.

Findings from the included RCTs

None of the RCTs identified in this review were conducted in the United Kingdom (UK), thus the generalisability of any of the findings to the UK setting remains unknown. However, the work conducted in the USA provides valuable information about likely effective components of interventions and is therefore, a good starting point for designing a UK intervention. The importance of integrating medical, behavioural and psychosocial components into the interventions was underscored by at least five of the RCTs (Ellis et al., 2004; Wysocki et al., 2006; Wysocki et al., 2007; Wysocki et al., 2008; Satin et al., 1989;

Jaser et al., 2014; Kichler et al., 2013). The results from integrating medical and non-medical aspects of diabetes management suggest that multi-component interventions may be more successful for adolescents than ones that just focus on one aspect (e.g. psychological in Newton and Ashley, 2013).

Participants were paid some money for completing the BFST based interventions and highly trained therapists delivered those complex interventions. Thus these kinds of interventions could be quite expensive and may not be available in clinic settings (Wysocki et al., 2008). However, it has been suggested to focus on optimising feasibility and cost-effectiveness through reducing the number of sessions, evaluating delivery to multiple families or supplementation of BFST-D sessions via Internet (Wysocki et al., 2008). Despite paying money to participants in the BFST interventions, sample sizes were quite low, which could be due to the nature/model of these interventions (Harris et al., 2009).

In addition, MST based interventions to treat adolescents with poorly controlled diabetes were relatively costly, intensive (compared to other services such as outpatient psychotherapy, Ellis et al., 2005) and lacked long-term follow ups. Thus additional studies are needed to continue to identify effective and cost-efficient treatments to improve diabetes management and health outcomes among such high risk adolescents (Ellis et al., 2005).

Although clinic-integrated interventions including families designed to be integrated into the health care setting, they require staff time to consult with families at each visit (Nansel et al., 2012; Jaser et al., 2014; Kichler et al., 2013). Translation of such interventions to the health care setting given current staffing is known to be challenging (Pagoto, 2011). However, conducting web-based interventions could be a potential alternative, as Newton and Ashley (2013) did but incorporating medical and behavioural aspects of diabetes amangement.

Home-based interventions appear to be a viable and accessible alternative for intervening with many of the families (Ellis et al., 2004). Such interventions provide an ecologically valid, family-centred means of engaging adolescents and their parents in treatment (Harris & Mertlich, 2003). In addition, they may also allow the Health Care Professionals (HCPs) to better understand the *‘real-world’* barriers to regimen adherence. It is also important to note that Ellis et al’s (2005) home-based intervention demonstrated high rates of recruitment (70%) as well as high retention rates (75%) in a treatment that lasted >5 months on average.

This suggests that when such interventions are provided in a way that increases access, they have a high likelihood of being accepted by such adolescents and their families (Ellis et al., 2005).

Studies included in the review were RCTs, which prevented evaluation of the intervention with potential biasness. Most studies reviewed had an explicit theoretical basis underlying the intervention. A theoretical basis determines not only the contents of the intervention but the most appropriate outcomes to measure and when to measure them (Hampson et al., 2001). The follow up period in most of the reviewed studies was 6 months or more than that (i.e. 7, 12, 15, 18, 24). The length of appropriate follow-up should be based on the theoretical model underlying the assumed intervention effects on different outcomes. Long-term effects are unlikely for interventions that do not address long-term maintenance issues (Hampson et al., 2001).

Limitations

It is acknowledged that this review includes a relatively small number of studies describing randomised controlled trials with rather small sample sizes, which makes it difficult to draw conclusions from the results. Furthermore, insufficient data was available to calculate effect sizes for all the outcomes reported in those studies. Thus the effect sizes used in the review may have been unrepresentative. Sample sizes were not based on power calculations in all the studies and the power of the studies was rarely discussed. Most studies have been conducted in the USA, and the generalisablity of these findings to the UK setting is undetermined. Interventions developed in the USA require modification and re-evaluation for application in the UK (Clark & Hampson, 2001).

This review exposed a variety of interventions, mostly including parents and rarely including peers that have been developed for adolescents with T1D. These interventions have taken place in a variety of settings and been evaluated by assessing widely differing outcomes or aspects of diabetes management. A further limitation was that the length of follow-up of participants was often quite short (3-7-months in most studies) to assess the effectiveness in the long-term. Not all the selected studies were included in this review due to:

1. Having no explicit theoretical background (Løding, Wold & Skavhaug, 2008; Anderson et al., 1989; Hansson, Ryden & Johnsson, 1994; Anderson et al., 1999; Laffel et al., 2003)
2. Not RCTs (Hansson et al., 1994; Løding, Wold, Skavhaug & Graue, 2007; Salamon, Hains, Fleischman, Davis & Kichler, 2010; Greco, Pendley, McDonell & Reeves, 2001; Harris et al, 2005; Ellis et al 2008),
3. Including children only (Forsander et al 2000; Nansel et al 2009) or adults (Philis-Tsimikas, 2011)
4. Not involving parents or peers.

Conclusion

Based on the process of analysis and discussion of the research identified by this review, it can be concluded that interventions including parents (using multifamily behavioural principles) have small to large-sized beneficial effects on a variety of diabetes management outcomes. Studies identified here addressing the issue of parental involvement support the evidence that developmentally appropriate and negotiated responsibility has beneficial outcomes.

There is a need for well-designed clinical trials of these interventions in the UK. The evidence-base, arising primarily from studies in the USA, provides a starting point to design interventions in the UK. Quantitative and narrative analysis of the evidence-base suggests that interventions are more likely to be effective if they demonstrate the inter-relatedness of the various aspects of diabetes management. The evaluation of interventions needs to be by well-designed theory based RCTs, which report results in such a way that effect sizes can be calculated. Home based interventions could be more viable and accessible alternative for intervening with many of the families in comparison to office or hospital based intervention. This approach may not only increase access, but also may have a high likelihood of being accepted by adolescents and their families.

Recommendations for future research

In order to strengthen the evidence base for the future, more studies need to be conducted in the UK, as research findings from other countries may not always be transferable to the UK context. In addition, studies with larger sample sizes are needed. Longitudinal studies are needed to measure the impact of interventions over the longer-term. Few studies in this area have evaluated the cost effectiveness of interventions. Future studies should estimate the costs associated with delivering such interventions involving families to support adolescents to manage T1D. Future studies needs to clarify more explicitly about the theoretically guided design of the intervention and the selection of the outcomes. Outcomes need to be assessed using reliable and valid measures, preferably ones that are widely used so that evidence across studies can be combined. The lack of UK-based studies involving parents highlights a gap in the evidence, which can be filled by conducting some research to develop interventions for adolescents. The development process should involve stakeholders (i.e. adolescents, their families and all types of HCPs) to design an outline of potentially cost-effective and feasible interventions in the context of NHS diabetes services. They also needs to be understood and accepted by doctors and nurses as key and integral parts of diabetes care.

References

Anderson, B.J., Wolf, F.M., Burkhart, M.T., Cornell, R.G. and Bacon, G.E. (1989). Effects of a peer group intervention on metabolic control of adolescents with IDDM: Randomized outpatient study. *Diabetes Care*, *12*, 184–188.

Anderson, B., Ho, J., Brackett, J., Finkelstein, D. and Laffel, L. (1997). Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Paediatric*, *130*(2), 257–265

Anderson, B.J., Brackett, B.A., Joyce, H.O. and Laffel, L.M.B. (1999). An office-based intervention to maintain parent–adolescent teamwork in diabetes management. *Diabetes Care*, *22*, 713–721.

Berndt, T. and Perry, B. (1986). Children’s perceptions of friendships as supportive relationships. *Developmental Psychology*, *22*, 640–648.

Berndt, T.J. and Hestenes, S.L. (1996). The developmental course of social support: Family and peers. In Smolak, L., Levine, M. P. and Striegel-Moore, R. (Eds.). *The Developmental Psychopathology of Eating Disorders* (pp. 77–106). Mahwah, NJ: Lawrence Erlbaum.

Berg, C.A., Wiebe, D.J., Beveridge, R.M., Palmer, D.L., Korbel, C.D. and Upchurch, R. (2007). Mother child appraisal involvement in coping with diabetes stressors and emotional adjustment. *Journal of Paediatric Psychology*, *32*, 995–1005.

Boland, E.A., Grey, M., Oesterle, A.L., Fredrickson, L. and Tamborlane, W.V. (1999). Continuous subcutaneous insulin infusion: A new way to lower risk of severe hypoglycemia, improve metabolic control, and enhance coping in adolescents with Type 1 diabetes. *Diabetes Care*, *22*, 1779–1784.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behaviour change. *Psychological Review*, *84*,191-215.

Barlow, J.H. and Ellard, D.R. (2004). Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child Care Health Development, 30*, 637–645.

Cameron, F., Skinner, T., De Beaufort, C., Hoey, H., Swift, P. andAanstoot, H. (2008). Hvidoere Study Group on Childhood Diabetes. Are family factors universally related to metabolic outcomes in adolescents with T1D? *Diabetic Medicine, 25,* 463–468.

Collins, W.A. and Russell. G. (1991). Mother–child and father–child relationships in middle childhood and adolescence: A developmental analysis. *Developmental Review, 11,* 99-136.

Cook, S., Herold, K., Edidin, D.V. and Briars, R. (2002). Increasing problem solving in adolescents with Type 1diabetes: The Choices Diabetes Program. *The Diabetes Educator, 28,* 115–124.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Earlbaum Associates.

Clark, M. and Hampson, S.E. (2001). Implementing a psychological intervention to improve lifestyle self-management in type 2 diabetes. *Patient Education and Counselling, 42*, 247–56

Charlson, M., Boutin-Foster, C. and Mancuso, C. A. (2007). Randomized controlled trials of positive affect and self-affirmation to facilitate healthy behaviors in patients with cardiopulmonary diseases: rationale, trial design, and methods. *Contemporary Clinical Trials,* 28, 748-762.

Deeks, J. J., Dinnes, J., D'Amico, R., Sowden, A. J., Sakarovitch, C., Song, F., Petticrew, M. and Altman, D. G. (2003). Evaluating non-randomised intervention studies. *Health Technology Assessment*, 7(27):iii-x, 1-173.

Diabetes Control and Complications Trial. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin dependent diabetes mellitus. *New England Journal of Medicine, 329*, 977-86.

Diabetes Control and Complications Trial. (1994). Effect of intensive diabetes treatment on the development of long-term complications in adolescents with insulin-dependent diabetes mellitus. *Journal of Paediatric*, *125*, 177-88.

Davis, C.L., Delamater, A.M., Shaw, K.H., Greca, A.M., Eidson, M.S., Perez-Rodriguez, J.E. (2001). Parenting styles, regimen adherence, and glycemic control in 4- to 10-year-old children with diabetes. *Journal of Paediatric Psychology, 26*, 123–129.

Delamater, A.M. (2009). Psychological care of children and adolescents with diabetes. *Paediatric Diabetes*, *10*(12), 175-184.

Ellis, D. A., Naar-King, S., Frey, M., Templin, T., Rowland, M. and Greger, N. (2004). Use of multi-systemic therapy to improve regimen adherence among adolescents with T1D in poor metabolic control: a pilot investigation. *Journal of Clinical Psychology in Medical Settings, 11*, 315–324.

Ellis, D. A., Frey, M., Naar-King, S., Templin, T., Cunningham, P. and Cakan, N. (2005). Use of multisystemic therapy to improve regimen adherence among adolescents with Type 1 diabetes in chronic poor metabolic control: A randomized controlled trial. *Diabetes Care*, *28*, 1604–1610.

Ellis, D. A., Yopp, J., Templin, T., Naar-King, S., Frey, M.A. and Cunningham, P.B. (2007). Family mediators and moderators of treatment outcomes among youths with poorly controlled Type 1 diabets: Results from a randomized controlled trial. *Journal of Paediatric Psychology, 32*,194–205.

Ellis, D.A., Naar-King, S., Templin, T., Frey, M.A., Cunningham, P., Sheidow, A., Cakan, N. and Idalski, A. (2008). Multisystemic therapy for adolescents with poorly controlled T1D: Reduced diabetic ketoacidosis admissions and related costs over 24 months. *Diabetes Care, 31*, 1746-1747.

Faulkner, M.S. and Chang, L.I. (2007). Family influence on self-care, quality of life, and metabolic control in schoolage children and adolescents with Type 1 diabetes. *Journal of Paediatric Nursing, 22,* 59–68.

Furman, W. and Buhrmester, D. (1992). Age and sex differences in perceptions of networks of personal relationships. *Child Development, 63*, 103–115.

Fuligni, A. J., Eccles, J. S., Barber, B. L. and Clements, P. (2001). Early adolescent peer orientation and adjustment during high school. *Developmental Psychology, 37*(1), 28-36.

Forsander, G. A., Persson, B., Sundelin, J., Berglund, E., Snellman, K. and Hellstrom, R. (1998). Metabolic control in children with insulin-dependent diabetes mellitus 5 years after diagnosis: Early detection of patients at risk for poor metabolic control. *Acta Paediatric, 87,* 857–864.

Forsander, G.A., Sundelin, J. and Persson, B. (2000). Influence of the initial management regimen and family social situation on glycemic control and medical care in children with T1D mellitus. *Acta Paediatric*, *89*, 1462–1468.

Glasgow, R. E. Fisher, E. B. Anderson, B. J. Greca, A. Marrero, D. Johnson, S. B. Rubin, R. R. and Cox, D. J. (1999). Behavioural science in diabetes: contributions and opportunities. *Diabetes Care, 22*(5), 832–843.

Greco, P., Greca, A. M., Auslander, W., Spetter, D., Skyler, J. S., Fisher, E. and Santiago, J.V. (1991). Family and peer support of diabetes care among adolescents. *Diabetes*, *40*(1), 537A.

Greco, P., Pendley, J.S., McDonell, K. and Reeves, G. (2001). A peer group intervention for adolescents with T1D and their best friends. *Journal of Paediatric Psychology,* 26, 485-490.

Graue, M., Wentzel-Larsen, T., Bru, E., Hanestad, B.R. and Sovik, O. (2004). The coping styles of adolescents with T1D are associated with degree of metabolic control. *Diabetes Care*, *27*, 1313–1317.

Graue, M., Wentzel-Larsen, T., Hanestad, B.R. and Sovik, O. (2005). Health-related quality of life and metabolic control in adolescents with diabetes: the role of parental care, control, and involvement. *Journal of Paediatric Nursing, 20,* 373–382.

Grey, M., Boland, E.A., Davidson, M., Yu, C. and Tamborlane, W.V. (1999). Coping skills training for youths with diabetes on intensive therapy. *Applied Nursing Research*, 12*,* 3–12.

Griva, K., Myers, L.B. and Newman, S. (2000). Illness perceptions and self-efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology & Health, 15,* 733–750.

Harris, M.A. and Mertlich, D. (2003). Piloting home-based behavioural family systems therapy for adolescents with poorly controlled diabetes. *Children's Health Care*, *32*, 65–79.

Harris, M.A., Freeman, K.A. and Beers, M. (2009). Family therapy for adolescents with poorly controlled diabetes: initial test of clinical significance. *Journal of Paediatric Psychology*, 34(10), 1097-107.

Hampson, S.E., Skinner, T.C., Hart, J., Storey, L., Gage, H. and Foxcroft, D. (2001). Effects of educational and psychological interventions for adolescents with diabetes mellitus: a systematic review. *Health Technology Assessment*, *5*, 1–77.

Hansson, K., Ryden, and O' Johnsson, P. (1994). Parent-related family climate: a concomitant to metabolic control in juvenile IDDM. *Family Systems Medicine, 12*, 405–13.

Hains, A.A., Davies, W.H., Parton, E., Totka, J. and Amoroso-Camarata, J. (2000). A stress management intervention for adolescents with T1D. *The Diabetes Educator, 26*, 417–424.

Jadad, A. R., Moore, R. A., Carroll, D., Jenkinson, C., Reynolds, D.J., Gavaghan, D. J. and McQuay, H. J. (1996). Assessing the quality of reports of randomized clinical trials: is blinding necessary? *Control Clinical Trials*, 17(1),1-12.

Kaplan, R.M., Chadwick, M.W. and Schimmel, L.E. (1985). Social learning intervention to promote metabolic control in type I diabetes mellitus: pilot experiment results. *Diabetes Care, 8*(2), 152–155.

Laffel, L.M., Vangsness, L., Connell, A., Goebel-Fabbri, A., Butler, D. and Anderson, B.J. (2003). Impact of ambulatory, family-focused teamwork intervention on glycemic control in youth with T1D. *Journal of Paediatric*, *142*(4), 409–416.

La Greca, A.M., Auslander, W.F., Greco, P., Spetter, D., Fisher, E.B. and Santiago, J.V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Paediatric Psychology*, *20*, 449–476.

Levitt, M.J., Guacci-Franco, N. and Levitt, J.L. (1993). Convoys of social support in childhood and early adolescence: Structure and function. *Developmental Psychology*, *29*, 811-818.

Løding, R.N., Wold, J.E., Skavhaug, Å. and Graue, M. (2007). Evaluation of peer-group support and problem-solving training in the treatment of adolescents with T1D. *European Diabetes Nursing*, *4*, 28–33.

Løding, R. N., Wold, J. E. and Skavhaug, Å. (2008). Experiences with a group intervention ... with T1D and their parents. *European Diabetes Nursing*, *5*(1), 9-14.

Mulrow, C. D., Cook, D. J. and Davidoff, F. (1997). Systematic reviews: critical links in the great chain of evidence. *Annals of International Medicine*, 126(5),389-391.

Murphy, H., Rayman, G., & Skinner, T.C. (2006). Psycho-educational interventions for children and young people with T1D. *Diabetic Medicine*, 23, 935–943.

Mendez., F. and Belendez, M. (1997). Effects of a behavioural intervention on treatment adherence and stress management in adolescents with IDDM. *Diabetes Care*, *20*, 1370–1375.

Nansel, T.R., Iannotti, R.J. and Liu, A. (2012). Clinic-Integrated Behavioral Intervention for Families of Youth With T1D: Randomized Clinical Trial. *Paediatrics, 129*(4), e866-e873.

Pressman, S. D. and Cohen, S. (2005). Does positive affect influence health? *Psychological Bulletin*, 131, 925-971.

Pendley, J.S., Kasmen, L.J., Miller, D.L., Donze, J., Swenson, C. and Reeves, G. (2002). Peer and family support in children and adolescents with T1D. *Journal of Paediatric Psychology, 27*, 429–438.

Paikoff, R. L. and Brooks-Gunn, J. (1991). Do parent-child relationships change during puberty? *Psychological Bulletin*, *110*(1), 47-66.

Pagoto, S. (2011). The current state of lifestyle intervention implementation research: where do we go next? *Translational Behavioural Medicine, 1*(3), 401–405.

Philis-Tsimikas, A., Fortmann, A., Lleva-Ocana, L., Walker, C. and Gallo, L.C. (2011). Peer-led diabetes education programs in high-risk Mexican Americans improve glycemic control compared with standard approaches: a Project Dulce promotora randomized trial. *Diabetes Care, 34*(9), 1926-31.

Salamon, K.S., Hains, A.A., Fleischman, K.M., Davies, W.H. & Kichler, J. (2010). Improving adherence in social situations for adolescents with T1D mellitus (T1DM): a pilot study. *Primary Care Diabetes*, *4*(1), 47-55.

Satin, W., La Greca, A.M., Zigo, M.A. and Skyler, J.S. (1989). Diabetes in adolescence. Effects of multifamily group intervention and parent simulation of diabetes. *Journal of Paediatric Psychology, 14*, 259–275.

Schilling, L.S., Knafl, K.A. and Grey, M. (2006). Changing patterns of self-management in youth with type I diabetes. *Journal of Paediatric Nursing*, *21*, 412–424.

Simmons, R.G. and Blyth, D.A. (1987). *Moving into adolescence: The impact of pubertal change and school context*. New York: Aldine De Gruyter.

Schilling, L. S., Knafl, K. A. and Grey, M. (2006). Changing patterns of selfmanagement in youth with type 1 diabetes. *Journal of Pediatric Nursing*, 21, 412-424.

Thomas, B. H., Ciliska, D., Dobbins, M. and Micucci, S. (2004). A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews Evidence Based Nursing*, 1(3),176-184.

Viklund, G., Ortqvist, E. and Wikblad, K. (2007). Assessment of an empowerment education programme. A randomized study in teenagers with diabetes, *Diabetic Medicine, 24*(5), 550–556.

Whittemore, R., Kanner, S. and Grey, M. (2004). The influence of family on physiological and psychosocial health in youth with T1D: A systematic review. In: Melnyk, B., Fineout-Overholt, E., (editors). *Evidence-based practice in nursing and healthcare: A guide to best practice*. Philadelphia: Lippincott Williams & Wilkins. p. CD 22-73-CD 22-87.

Wysocki, T. (1993). Associations among teen-parent relationships, metabolic control, and adjustment to diabetes in adolescents. *Journal of Paediatric Psychol*ogy, *18*(4), 441–452.

Wysocki, T., Taylor, A., Hough, B.S., Linscheid, T.R., Yeates, K.O. and Naglieri, J.A. (1996). Deviation from developmentally appropriate self-care autonomy: association with diabetes outcomes. *Diabetes Care*, 19(2), 119–125.

Wysocki, T., Harris, M., Greco, P., Harvey, L., McDonell, K. and Elder, C. (1997). Social validity of support group and behaviour therapy interventions for families of adolescents with insulin-dependent diabetes mellitus. *Journal of Paediatric Psychology*, *22*, 635–649.

Wysocki, T., Miller, K., Greco, P., Harris, M.A., Harvey, L.M. and Taylor, A. (1999). Behaviour therapy of families of adolescents with diabetes: Effects on directly observed family interactions. *Behaviour Therapy*, *30*, 507–525.

Wysocki, T., Harris, M. A., Greco, P., Bubb, J., Elder-Danda, C. andHarvey, L.M. (2000). Randomized controlled trial of behavior therapy for families of adolescents with insulin-dependent diabetes mellitus. *Journal of Paediatric Psychology*, *25*, 23–33.

Wysocki, T., Greco, P., Harris, M.A., Bubb, J. and White, N.H. (2001). Behavior therapy for families of adolescents with diabetes: Maintenance of treatment effects. *Diabetes Care*, *24*, 441–446.

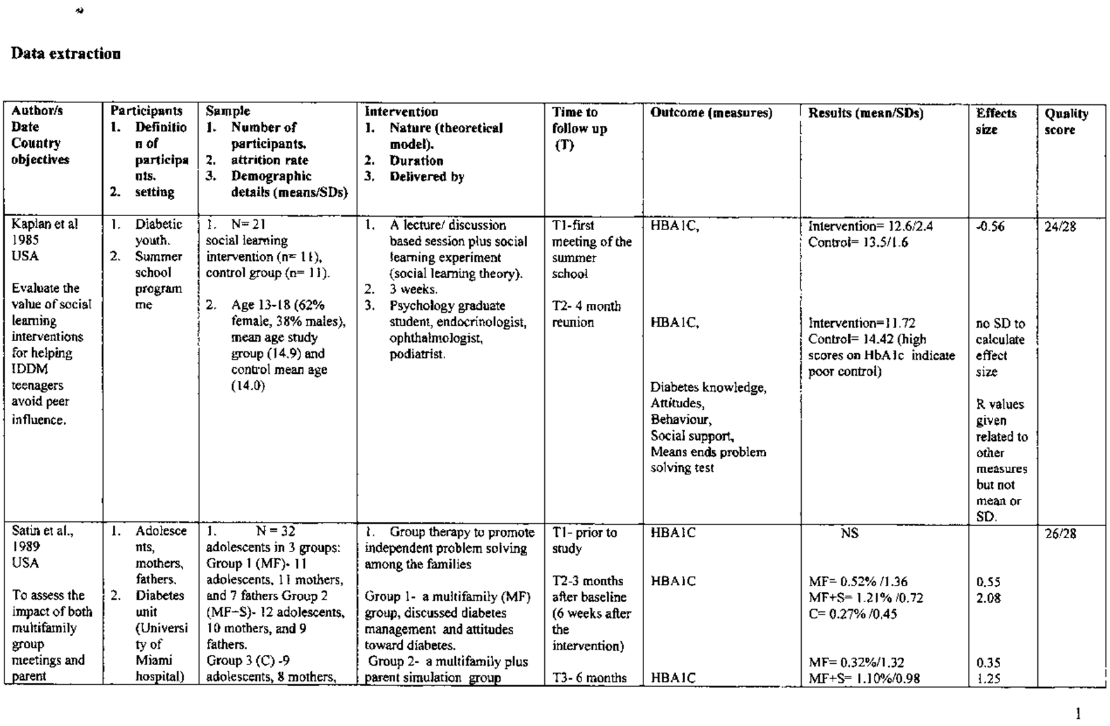
*Wysocki, T., Harris, M.A., Buckloh, L.M., Mertlich, D., Sobel Lochrie, A., Taylor, A., Sadler, M. Nelly Mauras, N. & White, N.H. (2006). Effects of behavioural family systems therapy for diabetes on adolescents' family relationships, treatment adherence, and metabolic control. *Journal of Paediatric Psychology*, *31*(9), 928–938.

Wysocki, T., Harris, M. A., Buckloh, L. M., Mertlich, D., Lochrie, A. S., Mauras, N. and White, N. H. (2007). Randomized trial of behavioral family systems therapy for diabetes: Maintenance of effects on diabetes outcomes in adolescents. *Diabetes Care, 30,* 555–560.

Wysocki, T., Harris, M. A., Buckloh, L. M., Mertlich, D., Lochrie, A. S. and Taylor, A. (2008). Randomized controlled trial of behavioral family systems therapy for diabetes: Maintenance and generalization of effects on parent-adolescent communication. *Behaviour Therapy*, *39*, 33–46.

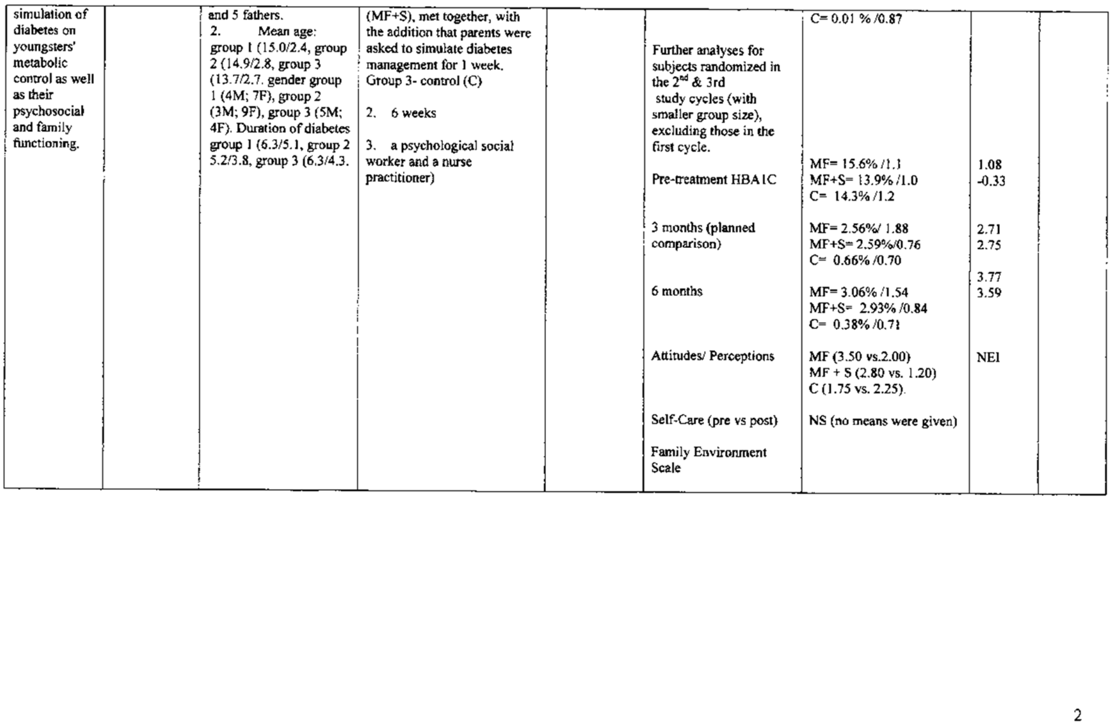
Appendix A

Data Screening



Data extraction

Author/s **Date** **Country** **objectives**	**Participants** **1. Definition of participants.** **2. setting**	**Sample** **1. Number of participants.** **2. attrition rate** **3. Demographic details (means/SDs)**	**Intervention** **1. Nature (theoretical model).** **2. Duration** **3. Delivered by**	**Time to follow up (T)**	**Outcome (measures)**	**Results (mean/SDs)**	**Effects size**	**Quality score**
Kaplan et al 1985 USA Evaluate the value of social learning interventions for helping IDDM teenagers avoid peer influence.	1. Diabetic youth. 2. Summer school programme	1. N= 21 social learning intervention (n= 11), control group (n= 11). 2. Age 13-18 (62% female, 38% males), mean age study group (14.9) and control mean age (14.0)	1. A lecture/ discussion based session plus social learning experiment (social learning theory). 2. 3 weeks. 3. Psychology graduate student, endocrinologist, ophthalmologist, podiatrist.	T1-first meeting of the summer school T2- 4 month reunion	HBA1C, HBA1C, Diabetes knowledge, Attitudes, Behaviour, Social support, Means ends problem solving test	Intervention= 12.6/2.4 Control= 13.5/1.6 Intervention=11.72 Control= 14.42 (high scores on HbA1c indicate poor control)	-0.56 no SD to calculate effect size R values given related to other measures but not mean or SD.	24/28
Satin et al., 1989 USA To assess the impact of both multifamily group meetings and parent simulation of diabetes on youngsters' metabolic control as well as their psychosocial and family functioning.	1. Adolescents, mothers, fathers. 2. Diabetes unit (University of Miami hospital)	1. N = 32 adolescents in 3 groups: Group 1 (MF)- 11 adolescents, 11 mothers, and 7 fathers Group 2 (MF–S)- 12 adolescents, 10 mothers, and 9 fathers. Group 3 (C) -9 adolescents, 8 mothers, and 5 fathers. 2. Mean age: group 1 (15.0/2.4, group 2 (14.9/2.8, group 3 (13.7/2.7. gender group 1 (4M; 7F), group 2 (3M; 9F), group 3 (5M; 4F). Duration of diabetes group 1 (6.3/5.1, group 2 5.2/3.8, group 3 (6.3/4.3.	1. Group therapy to promote independent problem solving among the families Group 1- a multifamily (MF) group, discussed diabetes management and attitudes toward diabetes. Group 2- a multifamily plus parent simulation group (MF+S), met together, with the addition that parents were asked to simulate diabetes management for 1 week. Group 3- control (C) 2. 6 weeks 3. a psychological social worker and a nurse practitioner)	T1- prior to study T2-3 months after baseline (6 weeks after the intervention) T3- 6 months	HBA1C HBA1C HBA1C Further analyses for subjects randomized in the 2^{nd} & 3rd study cycles (with smaller group size), excluding those in the first cycle. Pre-treatment HBA1C 3 months (planned comparison) 6 months Attitudes/ Perceptions Self-Care (pre vs post) Family Environment Scale	NS MF= 0.52% /1.36 MF+S= 1.21% /0.72 C= 0.27% /0.45 MF= 0.32%/1.32 MF+S= 1.10%/0.98 C= 0.01 % /0.87 MF= 15.6% /1.1 MF+S= 13.9% /1.0 C= 14.3% /1.2 MF= 2.56%/ 1.88 MF+S= 2.59%/0.76 C= 0.66% /0.70 MF= 3.06% /1.54 MF+S= 2.93% /0.84 C= 0.38% /0.71 MF (3.50 vs.2.00) MF + S (2.80 vs. 1.20) C (1.75 vs. 2.25). NS (no means were given)	0.55 2.08 0.35 1.25 1.08 -0.33 2.71 2.75 3.77 3.59 NEI	26/28



Wysockie et al., 1997 USA 1. To determine if family ratings of the acceptability, applicability, and effectiveness of BFST as a treatment for parent-adolescent conflict and communication problems would be significantly more favorable than family ratings of ES along the same dimensions. 2. To evaluate whether favourable ratings of the acceptability, applicability, and effectiveness of BFST and ES by recipients of those treatments are associated with pre-treatment characteristics of patients and families. 3. To assess whether objectively measured treatment gains through BFST are associated with more favorable family ratings of the acceptability, applicability, and effectiveness of that intervention in order to validate the clinical significance of observed treatment benefits.	1. Families and adolescents (paid incentives $50 to adolescents, $50 to families) 2. St. Louis, Missouri, or Jacksonville (across 2 sites)	1. N = 119 2. Mean age (14.5 – BFST and 14.1- ES), duration of IDDM (5.4- BFST, 4.5- ES), gender (M/F: 15/19- BFST, 20/20- ES)	1. 10 sessions of Behavioural-Family Systems Therapy (BFST) based on 4 components: (a) problem-solving training (b) Communication skills training (c) Cognitive restructuring methods (d) Functional and structural family therapy followed by behavioural homework . 10 sessions in the education and support (ES) group. A 45-minute educational presentation by a diabetes professional on 1 of the 10 topics followed by 45 minutes of family interaction about that topic (BFST) 2. 3 months (post treatment) 3. BFST= two licensed, Ph.D. psychologists ES = a master's level social worker and a master's level health educator	Baseline 3 months (current paper) 6 months (none) 12 months (none)	Parent Adolescent Relationship Questionnaire (PARQ) Teen Adjustment to Diabetes Scale (TADs) Diabetes Responsibility and Conflict Scale (DRC) Treatment evaluation questionnaire (TEQ)	No mean/SDs	(NEI to calculate effect size) NEI to calculate the ES	26/28
Wysockie et al, 2000 Florida. USA To compare short term outcomes of three treatments: Current therapy BFST Educational support	Families & adolescents (paid incentives $50 to adolescents, $50 to families) St. Louis, Missouri, or Jacksonville (across 2 sites)	N =119 baseline-CT (41), ES (40), BFST (38) posttreatment-3 months-CT (41), ES (39), BFST (35). Mean age (14.3 – CT, 14.5 –BFST and 14.1-ES), duration of IDDM (5.2- CT, 5.4- BFST, 4.5-ES). Gender (M/F: 20/21- CT, M/F: 15/23- BFST, 15/25- ES).	*CT*- examination by a physician and GHb assay three or more times annually ES- 10 sessions in 12 weeks. Each 45-min long educational presentation on one of the 10 topics, followed by 45 minutes of family interaction about that topic led by the facilitator. BFST- 10 sessions based on 4 components: (a) problem-solving training (b) Communication skills training (c) Cognitive restructuring	Baseline & 3 months	**Parent-Adolescent Relationship Questionnaire (PARQ)**: ▪ Overt conflict/skill deficits • Extreme beliefs	(M/SD) Baseline= CT (51.2/3.9), ES (52.8/5.4), BFST (53.3/5.7). Post-treatment= CT (51.0/5.4), ES (51.4/5.6), BFST (50.2/6.7). Baseline= CT (49.6/3.4), ES (51.2/5.1), BFST (51.1/4.4). Post- treatment = CT (49.4/3.9), ES (50.1/6.3),	-0.14 -0.21 -0.64	28/28

		HBA1C (11.8- CT, 11.9-BFST, 11.8-ES)	methods (d) Functional and structural family therapy followed by behavioural homework. Group BFST (involving adolescents and families). 3 months long CT- physicians. ES-A master's level social worker master's level health educator BFST- two licensed psychologists			BFST (46.9/5.3).	-0.50	
					• Family structure	Baseline= CT (51.7/6.6), ES (52.3/6.4), BFST (51.7/5.6). Post- treatment = CT (50.8/6.4), ES (51.3/7.0), BFST (49.8/6.4).	-0.15 -0.21	
					The Issues Checklist: • Number of items endorsed	Baseline= CT (15.4/4.5), ES (16.9/6.0), BFST (17.4/6.8). Post- treatment = CT (13.9/5.1), ES (14.0/5.0), BFST (12.9/5.8).	-0.19 -0.22	
					• Total frequency of conflict	Baseline= CT (58.7/42.3), ES (70.8/47.7), BFST (94.0/133.1). Post- treatment = CT (53.2/42.9), ES (54.9/45.5), BFST (42.2/38.3).	-0.25 -0.27	
					• Total intensity of conflict	Baseline= CT (31.0/13.1), ES (36.5/13.9), BFST (40.8/20.2). Post- treatment = CT (29.0/16.9), ES (31.9/16.3), BFST (26.7/16.2).	-0.13 -0.31	
					Recall interview conflict scores: Frequency	Baseline= CT (2.1/1.9), ES (2.1/1.3), BFST (2.3/1.3). Post- treatment = CT (1.7/5.9), ES (1.9/4.4), BFST (2.1/4.1).	0.06 0.04	
					intensity	Baseline= CT (1.7/1.3), ES (1.7/0.7), BFST (1.9/1.2). Post- treatment = CT (1.8/3.2), ES (1.3/3.1), BFST (1.2/2.3).	-0.18 -0.03	

					duration	Baseline= CT (8.5/9.1), ES (11.0/19.3), BFST (10.7/15.5). Post- treatment = CT (7.3/12.8), ES (7.1/22.3), BFST (4.6/12.2).	-0.21 -0.11	
					Diabetes Responsibility and Conflict Scale(DRC)	Baseline= CT (28.6/8.3), ES (29.5/8.1), BFST (32.5/9.4). Post- treatment = CT (25.5/6.5), ES (26.2/7.0), BFST (24.8/7.6).	-0.10 -0.2	
					Teen Adjustment to Diabetes Scale (TADS)	Baseline= CT (72.8/10.5), ES (77.0/10.2), BFST (78.2/9.7). Post- treatment = CT (77.3/9.6), ES (77.0/10.7), BFST (73.6/11.3).	-0.38 -0.31	
					Recall interview adherence factors: Insulin	Baseline= CT (-.11/.39), ES (.09/.51), BFST (.02/.49). Post- treatment = CT (-.07/.77), ES (-.01/.89), BFST (.09/.79).	0.20 0.11	
					testing/eating frequency	Baseline= CT (-.17/.78), ES (-.31/.58), BFST (.52/.75). Post- treatment = CT (-.01/.96), ES (-.27/.83), BFST (.32/.93).	0.34 0.71	
					diet composition	Baseline= CT (-.14/.37), ES (.10/.89), BFST (.04/.46). Post- treatment = CT (-.12/.76), ES (-.11/.76), BFST (.26/.81).	0.5 0.48	

					diet amount	Baseline= CT (-.22/.91), ES (-0.9/.97), BFST (.32/.87). Post- treatment = CT (.23/.94), ES (-.03/.74), BFST (-.21/.58).	-0.46 -0.24	
					exercise	Baseline= CT (.15/.83), ES (.12/.78), BFST (-.29/.58). Post- treatment = CT (-.05/.45), ES (.02/.51), BFST (.03/.82).	0.17 0.01	
					Self-Care Inventory (SCI)	Baseline= CT (51.1/6.6), ES (49.4/7.7), BFST (46.7/9.3). Post- treatment = CT (49.7/6.8), ES (49.5/7.6, BFST (47.5/8.7).	-0.32 -0.26	
					HBA1C	Baseline= CT (11.8/3.1), ES (11.8/2.9), BFST (11.9/3.3). Post- treatment = CT (11.7/3.2), ES (11.6/2.5), BFST (12.3/2.9).	0.18 0.28	
				6 months 12 months	None None			
Wysockie et al., 2001 USA To reports the effects of BFST at 6 and 12 months of follow-up on measures of parent-adolescent relationships	Families and adolescents (12-17) (paid incentives $50 to adolescents, $50 to families) St. Louis, Missouri, or Jacksonville (across 2	N = 119 Baseline (CT=41, ES=40, BFST=38) 3 months (CT=40, ES=38, BFST=37) 6 months (CT=40, ES=37, BFST=36) 12 months (CT=38, ES=36, BFST=34). M/SD age 14.3/1.3 years, duration of diabetes 5.2 /3.7years, Hollingshead	*CT*- examination by a physician and GHb assay three or more times annually ES- 10 sessions in 12 weeks. Each 45-min long educational presentation on one of the 10 topics, followed by 45 minutes of family interaction about that topic led by the facilitator. BFST- 10 sessions based on 4 components: (a) problem-solving training (b) Communication skills training (c) Cognitive restructuring	Baseline 3 months (post treatment, conducted post hoc, reduced & increased pts from 2000 study) 6 months 12 months	**PARQ** Overt conflict/skill deficits	(M/SD). some did not have SDs Baseline= CT (51.2/3.9), ES (52.8/5.4), BFST (53.3/5.7). 3 months= CT (-0.2), ES (-1.4), BFST (-3.1). 6 months= CT (-0.8), ES (-1.4), BFST (-2.4). 12 months = CT (-2.5), ES (-2.8), BFST (-3.0).	NEI	26/28
					PARQ Extreme beliefs	Baseline= CT (49.6/3.4),		

and adolescents' psychological adjustment to diabetes, adherence to the diabetes regimen, and diabetic control	sites)	Four Factor Index of Social Status raw score 43.1/12.0, and total GHb 11.9/3.1%. gender 51 males and 68 females. Racial composition (at the two centers) 79% Caucasian, 20% African-American, and 1% Hispanic. Analysis of Tanner stage = 2.5% stage I, 51.3% stages II-IV, and 46.2% stage V. Family composition 54.6% living with both biological parents, 32% with one biological parent, 11.8% with one biological and one stepparent, and 1.6% with other.	methods (d) Functional and structural family therapy followed by behavioural homework. Group BFST (involving adolescents and families). 3 months long CT- physicians. ES-A master's level social worker master's level health educator BFST- two licensed psychologists			ES (51.2/5.1), BFST (51.1/4.4). 3 months = CT (-0.3), ES (-0.9), BFST (-4.1). 6 months= CT (-1.2), ES (-0.8), BFST (-3.9). 12 months = CT (-0.9), ES (-1.9), BFST (-4.2).		
					PARQ Family structure	Baseline= CT (51.7/6.6), ES (52.3/6.4), BFST (51.7/5.6). 3 months = CT (-0.7), ES (-1.1), BFST (-2.0). 6 months= CT (-1.1), ES (-2.1), BFST (-2.6). 12 months = CT (-2.8), ES (-3.2), BFST (-2.4).		
					DRC	Baseline= CT (28.6/8.3), ES (29.5/8.1), BFST (32.5/9.4). 3 months =CT (-2.9), ES (-3.1), BFST (-6.8). 6 months= CT (-2.6), ES (-4.6), BFST (-7.0). 12 months = CT (-3.8), ES (-4.9), BFST (-6.1).		
					SCI	Baseline= CT (51.1/6.6), ES (49.4/7.7), BFST (46.7/9.3). 3 months =CT (-1.4), ES (0.1), BFST (0.8). 6 months= CT (-2.6), ES (-0.3), BFST (1.8). 12 months = CT (-5.4), ES (-1.2), BFST (3.3).		
					TADS	Baseline= CT (78.2/10.5), ES (77.0/10.2), BFST (72.8/9.7) 3 months =CT (-0.8), ES		

						(0.0), BFST (0.7). 6 months= CT (-2.3), ES (-1.9), BFST (-2.9). 12 months = CT (-4.6), ES (-2.2), BFST (-1.9).		
					GHb (%)	Baseline= CT (11.8/3.1), ES (11.8/2.9), BFST (11.9/3.3). 3 months =CT (-0.1), ES (-0.2), BFST (0.4). 6 months= CT (0.6), ES (0.5), BFST (0.2). 12 months = CT (1.1), ES (0.3), BFST (0.9).		
Wysockie et al, 2006 USA To determine whether a revised intervention with diabetes-specific behavioural components, BFST for Diabetes (BFST-D), would have more robust effects on treatment adherence and diabetic control.	Adolescents (aged 11-16) and their families (incentives were given). two paediatric centres in the South-eastern and Midwestern United States	N = 104 Standard care (SC)=32 Educational support (ES)=36 Behavioural Family Systems Therapy for Diabetes (BFST-D)=36. M/SD Age (SC=14.2/1.9, ES=14.4/1.9, BFST-D=13.9/1.9) Diabetes duration (SC=5.9/4.0, ES= 5.5/3.2 , BFST-D= 5.1/3.0). HbA1c (%) (SC= 9.5/1.5, ES= 9.7/1.6 , BFST-D= 9.6/1.6). Hollingshead SES index (SC= 40.3/14.2 , ES= 40.1/11.6 , BFST-D=40.4/13.7). Gender Male (SC= 16 (50%) , ES= 20 (56%) , BFST-D= 21 (58%).	SC= physicians'' treatment. ES=diabetes education and social support. 12 sessions including adolescent s and parents. a 45-min lecture on 1 of the 12 topics, followed by 45 min of family interaction about that topic led by the facilitator . BFST-D=12 sessions based on 4 components: (a) problem-solving training (b) Communication skills training (c) Cognitive restructuring methods (d) Functional and structural family therapy followed by behavioural homework. Delivering some didactic information and teaching families to acquire and apply the targeted skills at home. Theory/therapy: Group BFST	Baseline ONLY	Brief Symptom Inventory Millon Adolescent Clinical Inventory the Family Assessment Device.	Analysis not reported (will be reported in the future paper).		26/28
				Baseline & 6 months (post-treatment)	**Parent–Adolescent Relationship Questionnaire(PARQ):** Overt conflict/Skill deficits.	Baseline= SC (50.7 /5.9), ES (50.8/6.4), BFST-D (50.8/7.3) 6 months= SC (49.9/6.3), ES (49.6/6.1), BFST-D (50.0/6.7).	0.01 0.06	
					Extreme Beliefs	Baseline= SC (50.4/7.3), ES (49.7/8.1), BFST-D (51.7/7.0) 6 months= SC (48.7/8.8), ES (48.8/7.5), BFST-D (48.7/8.4).	0.0 -0.01	
					Family structure	Baseline= SC (49.7/6.6), ES (49.2/7.6), BFST-D (51.3/7.3) 6 months= SC (48.2/7.6),	0.48	

		Female (SC= 16 (50%) , ES=16 (44%) , BFST-D= 15 (42%). Race/ethnicity Caucasian (SC= 17 (53%) , ES= 27 (75%) , BFST-D= 22 (61%). African-American (SC= 11 (34%) , ES= 9 (25%) , BFST-D= 12 (33%). Hispanic (SC= 2 (6%) , ES= 0 , BFST-D= 1 (3%). Other (SC= 2 (6%) , ES= 0 , BFST-D= 1 (3%). Family composition Intact (SC= 13 (41%) , ES= 15 (42%), BFST-D= 16 (43%). Blended (SC= 4 (13%) , ES= 5 (14%) , BFST-D= 7 (19%). Single parent (SC= 11 (34%) , ES= 12 (33%) , BFST-D= 11 (32%). Other (SC= 4 (13%) , ES= 4 (11%) , BFST-D= 2 (5%). Insulin modality Injections (SC= 25 (78%) , ES= 27 (75%) , BFST-D= 27 (75%). Insulin pump (SC=7 (22%) , ES=9 (25%) , BFST-D=9 (25%).	6 months Facilitators: SC=paediatric endocrinologist or other qualified clinician and a certified diabetes educator ES=Experienced diabetes nurses BFST-D= a psychologist, or a licensed clinical social worker			ES (48.0/8.3), BFST-D (51.9/7.2).	0.46	
					The Diabetes Responsibility and Conflict Scale (DRC).	Baseline= SC (25.9), ES (29.4), BFST-D (27.5) 6 months= SC (29.4), ES (32.1), BFST-D (26.9).	NEI	
					The Diabetes Self-Management Profile (DSMP).	Baseline= SC (53.0), ES (55.2), BFST-D (54.7) 6 months= SC (51.4), ES (54.6), BFST-D (57.4).	NEI	
					Glycosylated Hemoglobin (HbA1c).	Baseline= SC (9.5), ES (9.7), BFST-D (9.6) 6 months= SC (9.2%), ES (8.9%), BFST-D (8.8%).	NEI	
Wysockie et al,, 2007 USA	Adolescents and families. (paid	N = 104 (92 completed 6 months evaluation,	SC= physicians'' treatment. ES=diabetes education	Baseline	DSMP (total scores)	SC (53.0/10.8), ES (55.1/9.5), BFST-D (55.4/10.8).		27/28

To evaluate the maintenance of these improvements over an additional 12 months' follow-up of these families.	incentives $50 to adolescents, $50 to families) Two paediatric diabetes referral centres	88, 12 months, 85, 18 months). SC=32 ES=36 BFST-D= 36 M/SD Age (SC=14.2/1.9, ES=14.4/1.9, BFST-D= 13.9/1.9) Diabetes duration (SC=5.9/4.0, ES= 5.5/3.2 , BFST-D= 5.1/3.0). HbA1c (%) (SC= 9.5/1.5, ES= 9.7/1.6 , BFST-D= 9.6/1.6). Hollingshead SES index (SC= 40.3/14.2 , ES= 40.1/11.6 , BFST-D=40.4/13.7). Gender Male (SC= 16 (50%) , ES= 20 (56%) , BFST-D= 21 (58%). Female (SC= 16 (50%) , ES=16 (44%) , BFST-D= 15 (42%). Race/ethnicity Caucasian (SC= 17 (53%) , ES= 27 (75%) , BFST-D= 22 (61%). African-American (SC= 11 (34%) , ES= 9 (25%) , BFST-D= 12 (33%). Hispanic (SC= 2 (6%) , ES= 0 , BFST-D= 1 (3%). Other (SC= 2 (6%) , ES= 0 , BFST-D= 1 (3%).	and social support. 12 sessions including adolescent s and parents. a 45-min lecture on 1 of the 12 topics, followed by 45 min of family interaction about that topic led by the facilitator . BFST-D=12 sessions based on 4 components: (a) problem-solving training (b) Communication skills training (c) Cognitive restructuring methods (d) Functional and structural family therapy followed by behavioural homework. Delivering some didactic information and teaching families to acquire and apply the targeted skills at home. Theory/therapy: Group BFST 6 months Facilitators: SC=paediatric endocrinologist or other qualified clinician and a certified diabetes educator ES=Experienced diabetes nurses BFST-D= a psychologist, or a licensed clinical social worker		DRC (family composite score) A1C (%)	SC (25.7/6.8), ES (29.1/6.8), BFST-D (27.2/7.6). SC (9.6/1.5), ES (9.7/1.6), BFST-D (9.6/1.6).		
				3 months	DSMP (total scores) DRC (family composite score) A1C (%)	SC (-), ES (-), BFST-D (-). SC (-), ES (-), BFST-D (-). SC (9.2/1.7), ES (8.8/1.5), BFST-D (8.9/1.6).	NEI -0.17 0.06	
				6 months	DSMP (total scores) DRC (family composite score) A1C (%)	SC (52.1/8.8), ES (54.7/ 10.3), BFST-D (57.1/7.6). SC (29.2/10.2), ES (31.7/11.4), BFST-D (26.3/8.8). SC (9.1/1.8), ES (8.9/1.2), BFST-D (8.8/1.5).	0.56 0.23 -0.28 -0.47 -0.16 -0.08	
				9 months	DSMP (total scores) DRC (family composite score) A1C (%)	SC (-), ES (-), BFST-D (-). SC (-), ES (-), BFST-D (-). SC (9.5/1.7), ES (9.5/1.3), BFST-D (8.7/1.3).	NEI -0.47 -0.61	
				12 months	DSMP (total scores) DRC (family composite score) A1C (%)	SC (51.6/11.0), ES (55.6 /11.7), BFST-D (58.2/9.1). SC (25.0/11.1), ES (27.7/8.9), BFST-D (25.7/11.0). SC (9.6/1.6), ES (9.3/1.4), BFST-D (8.9/1.4).	0.6 0.22 0.06 -0.22 -0.43 -0.28	
				15 months	DSMP (total scores) DRC (family composite	SC (-), ES (-), BFST-D (-). SC (-), ES (-), BFST-D (-). SC (9.6/1.6), ES (9.6/1.4),	-0.62 -0.71	

		Family composition Intact (SC= 13 (41%) , ES= 15 (42%), BFST-D= 16 (43%). Blended (SC= 4 (13%) , ES= 5 (14%) , BFST-D= 7 (19%). Single parent (SC= 11 (34%) , ES= 12 (33%) , BFST-D= 11 (32%). Other (SC= 4 (13%) , ES= 4 (11%) , BFST-D= 2 (5%). Insulin modality Injections (SC= 25 (78%) , ES= 27 (75%) , BFST-D= 27 (75%). Insulin pump (SC=7 (22%) , ES=9 (25%) , BFST-D=9 (25%).			score) A1C (%)	BFST-D (8.6/1.3).		
				18 months	DSMP (total scores) DRC (family composite score) A1C (%)	SC (53.3/10.9), ES (55.3 /11.2), BFST-D (57.3/10.4). SC (23.6/10.1), ES (28.8/9.8), BFST-D (25.4/10.4). SC (9.6/1.7), ES (9.5/1.5), BFST-D (8.8/1.5).	0.36 0.09 0.17 -0.34 -0.47 -0.46	
Wysockie et al, 2008 USA To analyse whether effects of the revised BFST-D intervention on family communication and problem solving were lasting and associated with improved diabetes outcomes.	Adolescents (11-16) and families. (paid incentives $50 to adolescents, $50 to families) two paediatric centres in the Southeast and Midwest U.S.	N = 104 (adolescents) N= 102 (mothers) N = 87 (fathers) SC=32 ES=36 BFST-D= 36 M/SD Age (SC=14.2/1.9, ES=14.4/1.9, BFST-D= 13.9/1.9) Diabetes duration (SC=5.9/4.0, ES= 5.5/3.2 , BFST-D= 5.1/3.0). HbA1c (%) (SC= 9.5/1.5, ES= 9.7/1.6 ,	SC= physicians'' treatment. ES=diabetes education and social support. 12 multifamily sessions including adolescent s and parents. a 45-min lecture on 1 of the 12 topics, followed by 45 min of family interaction about that topic led by the facilitator . BFST-D=12 sessions based on 4 components: (a) problem-solving training (b) Communication skills training (c) Cognitive restructuring methods (d) Functional and	Baseline	Interaction Behaviour Code (IBC) for negative communication.	Adolescents= SC (4.0/2.7), ES (3.3/2.3), BFST-D (3.5/1.9). Mothers = SC (3.8/2.4), ES (3.5/2.6), BFST-D (3.8/2.8). Fathers= SC (2.1/1.8), ES (2.2/1.9), BFST-D (1.9/.16).		27/28
				6 months	IBC for negative communication	Adolescents= SC (4.0/2.5), ES (3.5/1.9), BFST-D (2.1/1.7). Mothers = SC (3.5/2.2), ES (4.1/2.8), BFST-D (2.5/2.0). Fathers= SC (1.9/1.5), ES	-0.76 -0.73 -0.45 -0.57 0.13	

		BFST-D= 9.6/1.6). Hollingshead SES index (SC= 40.3/14.2 , ES= 40.1/11.6 , BFST-D=40.4/13.7). Gender Male (SC= 16 (50%) , ES= 20 (56%) , BFST-D= 21 (58%). Female (SC= 16 (50%) , ES=16 (44%) , BFST-D= 15 (42%). Race/ethnicity Caucasian (SC= 17 (53%) , ES= 27 (75%) , BFST-D= 22 (61%). African-American (SC= 11 (34%) , ES= 9 (25%) , BFST-D= 12 (33%). Hispanic (SC= 2 (6%) , ES= 0 , BFST-D= 1 (3%). Other (SC= 2 (6%) , ES= 0 , BFST-D= 1 (3%). Family composition Intact (SC= 13 (41%) , ES= 15 (42%), BFST-D= 16 (43%). Blended (SC= 4 (13%) , ES= 5 (14%) , BFST-D= 7 (19%). Single parent (SC= 11 (34%) , ES= 12 (33%) , BFST-D= 11 (32%). Other (SC= 4 (13%) , ES= 4 (11%) , BFST-D= 2 (5%). Insulin modality	structural family therapy followed by behavioural homework. Delivering some didactic information and teaching families to acquire and apply the targeted skills at home. Theory/therapy: Group BFST 6 months Facilitators: SC=paediatric endocrinologist or other qualified clinician and a certified diabetes educator ES=Experienced diabetes nurses BFST-D= a psychologist, or a licensed clinical social worker	12 months 18 months Baseline 6 months 12 months 18 months	IBC for negative communication IBC for negative communication IBC for positive communication IBC for positive communication IBC for positive communication IBC for positive communication	(2.3/1.7), BFST-D (2.1/1.5). Adolescents= SC (4.5/2.6), ES (2.9/2.6), BFST-D (2.6/1.9). Mothers = SC (4.1/2.5), ES (3.2/2.3), BFST-D (2.9/2.7). Fathers= SC (2.3/1.9), ES (2.0/1.8), BFST-D (1.9/1.5). Adolescents= SC (4.2/1.8), ES (3.0/2.2), BFST-D (2.8/2.1). Mothers = SC (4.5/2.4), ES (3.4/2.6), BFST-D (3.1/2.4). Fathers= SC (2.0/1.6), ES (1.9/1.7), BFST-D (1.9/1.6). Adolescents= SC (1.8/1.0), ES (1.9/.9), BFST-D (1.8/.9). Mothers = SC (3.5/1.4), ES (3.4/1.3), BFST-D (3.2/1.3). Fathers= SC (2.0/1.1), ES (2.0/.8), BFST-D (2.2/.8). Adolescents= SC (1.6/1.1), ES (1.5/1.0), BFST-D (2.1/.9). Mothers = SC (2.7/1.3), ES (2.9/1.4), BFST-D (3.6/1.3). Fathers= SC (1.6/.7), ES (1.5/.8), BFST-D (1.8/.7). Adolescents= SC (1.7/1.1), ES (1.6/1.3), BFST-D	-0.11 -0.73 -0.11 -0.48 -0.13 -0.21 -0.05 -0.77 -0.09 -0.58 -0.11 -0.06 0.0 0. -0.11 -0.21 -0.15 0.18 0.25 0.45 0.6 0.60 0.5 0.28 0.37 0.27 0.30	

		Injections (SC= 25 (78%) , ES= 27 (75%) , BFST-D= 27 (75%). Insulin pump (SC=7 (22%) , ES=9 (25%) , BFST-D=9 (25%).			HBA1C DRC DSMP	(2.0/.9). Mothers = SC (2.8/1.3), ES (2.7/1.5), BFST-D (3.5/1.2). Fathers= SC (1.3/.9), ES (1.4/.8), BFST-D (1.9/.9). Adolescents= SC (1.4/1.1), ES (1.7/1.1), BFST-D (2.0/1.3). Mothers = SC (2.7/1.3), ES (3.2/1.4), BFST-D (3.5/1.2). Fathers= SC (1.3/1.0), ES (1.3/.9), BFST-D (1.7/.8). Only reported pearson correlation of IBC (+ve & -ve for adolescents, mothers, fathers) No means or SDs.	0.53 0.53 0.66 0.62 0.54 0.27 0.61 0.21 0.4 0.44	
Viklund et al 2007 Sweden To determine the effects of an empowerment programme on glycaemic control and empowerment, and to study the role of parental involvement.	Adolescents (aged 12-17) and parents. Out-patient clinic	N= 55 Intervention group (18) Control group (14). 38 started and 32 completed the study/programme. Intervention group (girls/boys)- 11/7 Age-14.3/1.6 Duration of diabetes- 6.4/4.6 HBA1C- 7.4/1.2 Control group girls/boys- 8/6 Age – 14.1/0.8 Duration of diabetes – 7.3/3.7 HBA1C – 8.1/1.8	2 hours group education based on the concepts of empowerment e.g. goal setting, problem solving, coping with stress, social support, motivation followed by discussion. (empowerment theory) Intervention= 6 weeks long a diabetes nurse specialist	6 months 12 & 24 months together 12 months	HBA1C Swedish version of the diabetes empowerment scale (Swe-DES-23) HbA1c (parental involvement group) HbA1c (no parental involvement group)	Intervention group= increased from 7.4 to 8.2% (difference 0.8%, NS. Control= from 8.1 to 8.4% (difference 0.3%, NS). NS (no separate mean values were reported).	No SDs were given Combined values were reported related to both groups for all follow ups.	26/28

Nansel et al 2012 USA (multicenter, parallelgroup study with equal randomization) To test the effect on diabetes management outcomes of a low-intensity, clinic-integrated behavioural intervention for families of youth with type 1 diabetes	children/Adolescents (aged 9-12, 12-15) and parents Geographically disperse pediatric endocrinology clinics in the United States (Boston, MA; Chicago, IL; Jacksonville, FL; and Houston, TX).	N = 70% completed the study Intervention= 89% Usual care group= 93% Age (inter- 12.5 , control - 12.4). Gender-F/M (inter- 102/99 , control -96/ 93) Race/ethnicity : inter- white (145), Hispanic (21), black (15), other (11) control - white (131), Hispanic (16), black (19), other (10). Number of adults in home 1 (26 inter, 25 control) 2 (147 inter, 138 control >3 (19 interven,16 control) Family income <$50,000 (control, 37, inter, 50) <$50,000-$99,999 (74 control, 64 inter). 100,000+ (57 control, 69 inter). Duration of diabetes Regimen (4.9 control, 4.8 inter) Pump (62 control, 69 inter) Injection (127 control, 132 inter) HBA1C (8.3 control, 8.4 inter)	In person facilitating problem-solving skills, communication skills, and appropriate responsibility sharing in 30 minute long sessions (with some flexibility) followed by telephone calls to assess progress. (social cognitive theory, self-regulation Models and systems theory) 24 months health advisors	Baseline	HBA1C	Estimated values from diagram not given in a table form & no SDs). Intervention= 8.4 Control= 8.3	No SDs Not enough information to calculate ES	26/28
				6 moths	HBA1C	Intervention= 8.8 Control= 8.8		
				12 months	HBA1C	Intervention= 9.0 Control=9.1		
				18 months	HBA1C	Intervention= 8.9 Control= 9.1		
				24 months	HBA1C &	Intervention= 8.8 Control= 9.1		
					Adherence in parents and older youth 11+ (Diabetes Self-Management Profile)	Intervention (child-reported adherence)= 1.28 Control (child-reported)= -0.03 Intervention (parent-reported Adherence)= -1.0 Control (parent-reported Adherence)= -2.0		
					HBA1C (age 9-11)	NS		
				Baseline	HBA1C (age 12-14 only)	Intervention =8.5 Control =8.6		
				6 months	HBA1C (age 12-14 only)	Intervention =8.9 Control =9.0		
				12 months	HBA1C (age 12-14 only)	Intervention =9.1 Control =9.2		
				18 months	HBA1C (age 12-14 only)	Intervention =9.0 Control =9.3		
				24 months	HBA1C (age 12-14 only)	Intervention =8.8		

						Control =9.4		
Harris et al 2009 USA To determine whether home-based BFST (Harris & Mertlich, 2003) produced clinically significant change in family conflict with a sample of adolescents with poorly controlled diabetes and their families.	Adolescents (13-18) and primary caregivers. Hospital	N = 58 Behavioural family system therapy (BFST)= 18 Comparison group = 40 M/SD Mean age (BFST- 16.0 /0.9, Comparison-15.2 /1.5 Duration of diabetes (BFST- 6.2 /3.8, Comparison-4.8 /3.2 HbA1c Baseline (BFST- 11.4/1.4, Comparison- 11.1 /1.6. Posttreatment (BFST- 11.1/1.4. Race (%) African American (BFST- 33, Comparison- 47). Caucasian (BFST- 67, Comparison- 53). Gender (%) Female (BFST- 33, Com- 55) Male (BFST- 67, Compar- 45) Family composition (%) Single parent (BFST- 33, Comp- 44). Hollingshead IndexDistribution (in frequency): Major professional (BFST- 1, Comp- 5). Minor professional (BFST- 8, Como- 14). Clerk or Sales (BFST- 6,	10 1.5-hr sessions of home-based version of BFST BFST consists of four therapy components that are used in accord with each family's needs as identified by their responses to the questionnaires completed at baseline: problem-solving training, communication skills training, cognitive restructuring, and functional/structural family therapy (BFST-D model) 8 weeks a master's level social worker or a doctoral level psychologist in-training with extensive training from the principal investigator (PI) in diabetes management and BFST	Baseline Post-treatment (6-10 weeks)	Diabetes Responsibility and Conflict Scale (DRC)	**Adolescents** Pre-treatment - (BFST, 30.7/15.0, Control----	.57	27/28
						Post-treatment- (BFST, 25.4/12.8, Control,37.7/12.3.	-1.00	
						Mothers Pre-treatment - (BFST,29.7/15.0, Control,-	-0.58	
						Post-treatment- (BFST, 23.9/6.9, Control, 37.6/13.5	-1.01	
						Fathers Pre-treatment - (BFST, 27.1/8.1, Control,----	-.82	
						Post-treatment- (BFST, 26.6/7.6,Control, 36.3/11.2	-.87	
						Adolescents Pre-treatment - (BFST, 6.1/5.7,Control,---	-.09	
					Conflict Behavior Questionnaire (CBQ)	Post-treatment- (BFST, 4.5/4.5, Control, 6.6/5.5	-0.38	
						Mothers Pre-treatment - (BFST, 9.5/4.7,Control,----	.36	
						Post-treatment- (BFST, 5.1/5.0, Control, 7.3/6.1	-.36	
						Fathers Pre-treatment - (BFST, 9.9/6.1,Control,---	.41	
						Post-treatment- (BFST,	-.07	

		Comp- 7). Semi-skilled (BFST- 3, Comp- 14).			HbA1c	6.8/7.2,Control, 7.3/6.3, ES, -.07). NS correlations		
Ellis et al 2004 Michigan To determine whether poorly controlled adolescents and their families could be recruited and retained in MST treatment and to determine if MST would improve treatment adherence and metabolic control.	Adolescents (only mean age was given) and families. children's hospital.	N= 25 (adolescents) Intervention (MST)= 13 Standard care (Control)= 12 61% African American, 30% were Caucasian 9% other ethnic or racial background. 56% male 70% lived in families with two caregivers (either with two biological parents, or a parent and a Stepparent/partner/grand parent) 30% lived with single parents. Mean age of adolescents= 13.6 years (*SD* =1.6). Mean age of the adolescent's primary caregiver (in all cases a female)= 39.1 years (*SD* = 7.6). Mean family income = $31,000 (*SD* = $17,350).	MST based on 9 treatment principles. a multisystemic assessment of the strengths and weaknesses of the family, then based upon this assessment tailor treatment goals and interventions to each family to best treat the adherence problem. No set number of sessions. MST combined: Family interventions Community level interventions Peer interventions Interventions within the health care system (MST= cognitive–behavioural therapy, parent training, and behavioural family systems therapy). 6 months therapists	Baseline	GHb	MST= 17.03/2.62 SC= 18.13/3.96	-0.27	27/28
					DMS-A = Diabetes Management Scale–Adolescent	MST= 64.55/12.98 SC=66.94/12.93	-0.18	
					DMS-P = Diabetes Management Scale–Parent	MST= 66.84/13.84 SC=67.27/11.2	-0.03	
					Meter = frequency of blood glucose testing from meter	MST= 1.74/0.87 SC= 2.03/1.17	-0.24	
					INSADH = 24 Hour Recall Insulin Adherence	MST= 0.98/0.22 SC= 1.02/0.17	-0.23 -0.37	
					EATADH = 24 Hour Recall Dietary Adherence	MST= 23.48/2.26 SC=24.29/2.16	-1.75	
					BGTS = 24 Hour Recall Blood Glucose Testing Adherence	MST= 1.17/1.19 SC= 2.08/0.52	-0.45	
					ER = emergency room visits	MST= 0.06/0.25 SC=0.27/0.46	0.07	
					Admissions= inpatient hospital admissions	MST= 0.56/0.25 SC= 0.47/1.13		
					Satisfaction With Treatment	MST= SC=	(No mean or SDs)	

				6 months	GHb	MST= 14.47/2.98 SC= 16.65/3.26	-0.66	
					DMS-A = Diabetes Management Scale–Adolescent	MST= 66.27/14.11 SC= 68.69/13.60	-0.17	
					DMS-P = Diabetes Management Scale–Parent	MST= 69.07/13.44 SC= 69.93/11.92	-0.07	
					Meter = frequency of blood glucose testing from meter	MST= 2.30/1.51 SC= 1.91/1.07	0.36	
					INSADH = 24 Hour Recall Insulin Adherence	MST= 1.10/0.22 SC=0.92/0.37	0.48	
					EATADH = 24 Hour Recall Dietary Adherence	MST= 22.79/3.61 SC= 24.63/2.20	-0.83	
					BGTS = 24 Hour Recall Blood Glucose Testing Adherence	MST= 2.00/0.85 SC= 1.83/1.12	0.15	
					ER = emergency room visits	MST= 0.13/0.34 SC= 0.13/0.35	0	
					Admissions= inpatient hospital admissions	MST= 0.00/0.00 SC= 0.60/1.24	-0.48	
					Satisfaction With Treatment	MST= SC=	(No mean or SDs)	

Ellis et al 2005 Michigan To test the efficacy of MST in improving adherence to medical regimen and metabolic control and in reducing unnecessary hospital use among adolescents with CPMC.	Adolescents (aged 10-17) with CPMC and their families An endocrinology clinic within a tertiary care children's hospital	N = 127 (adolescents) MST= 64 Standard care (SC) =63 M/SD Child age (MST- 13.4/ 1.9, SC- 13.1 /2.0) Parent age (MST- 39.7 /7.7, SC- 37.9 /5.9). Annual family income ($) MST- 28,437 /18,617 27,SC- 468 /17,285 Child sex Male (MST-38, SC- 24) Female (MST- 26, SC- 39) Number of parents in home Two(MST- * 36, SC-33) One (MST- 27, SC- 27) Other/missing (MST- 1 , SC-3) Child ethnicity African American (MST- 44, SC- 36) White (MST- 13, SC- 20) Other (MST- 7, SC- 7) Duration of diabetes (MST- 5.3/3.9, SC- 5.2 /4.8 A1C (%) (MST- 11.4 /2.2, SC- 11.3 /2.3). Insulin regimen 2–3 injections/day (MST- 56, SC- 58) _4 injections/day (MST- 2, SC- 1) Insulin pump (MST- 6, SC- 4)	home-based psychotherapy plus standard medical care. family-centered, community based treatment based on nine treatment principles. a multisystemic assessment of the strengths and weaknesses of the family, then based upon this assessment tailor treatment goals and interventions to each family to best treat the adherence problem. No set number of sessions. MST combined: Family interventions Community level interventions Peer interventions Interventions within the health care system (MST= cognitive-behavioural therapy, parent training, and behavioural family systems therapy). 6 months therapists	Baseline 7 months	A1C Meter Insulin adherence Dietary adherence Blood glucose testing adherence Emergency department visits Admissions A1C	**INTENT TO TREAT** Baseline- MST= 11.4 , SC= 11.3 7 months- MST= 10.8 SC= 11.2 Baseline- MST= 1.8 SC=2.2 7 months- MST= 2.5 SC= 2.0 Baseline- MST= 1.1 SC=1.1 7 months- MST= 1.2 SC= 1.1 Baseline- MST= 23.6 SC= 23.8 7 months- MST= 23.5 SC= 23.8 Baseline- MST= 1.8 SC= 2.2 7 months- MST= 2.2 SC= 2.1 Baseline- MST= 0.09 SC= 0.16 7 months- MST= 0.17 SC= 0.10 Baseline- MST= 0.44 SC= 0.43 7 months- MST= 0.13 SC= 0.54 **PER PROTOCOL** Baseline- MST=11.6, SC=11.3 7 months- MST=10.8, SC= 11.3	NS 1.09 NS NS 0.83 NS 0.63 0.64 1.01	27/28

				12 months 18 months 24 months	Meter Insulin adherence Dietary adherence Blood glucose testing adherence Emergency department visits Admissions	Baseline- MST= 1.8 SC=2.2 7 months- MST= 2.6 SC= 2.1 Baseline- MST= 1.0 SC=1.1 7 months- MST= 1.2 SC= 1.1 Baseline- MST= 23.4 SC= 23.8 7 months- MST= 24.0 SC= 23.8 Baseline- MST= 1.8 SC= 2.2 7 months- MST= 2.4 SC= 2.1 Baseline- MST= 0.10 SC= 0.16 7 months- MST= 0.18 SC= 0.10 Baseline- MST= 0.46 SC= 0.43 7 months- MST= 0.13 SC= 0.54 NONE NONE NONE	NS NS 1.05 NS 0.65	
Ellis et al 2007 USA To investigate whether family demographic characteristics such as the		N=127 MST= 64 SC=63 Single parent= 65 Two parent= 61		Baseline	DFBC primary caregiver DFBC secondary caregiver	MST= 27.52/7.05 SC=28.44/5.86 Single parent=28.07/6.96 Two parent=28.02/6.00 MST= 22.63/7.80 SC=25.83/9.22 Single parent= ------- Two parent=--------		26/28

number of parents in the home would moderate the effects of MST on treatment outcomes.					FRI	MST= 8.87/3.27 SC=8.69/3.31 Single parent=9.01/3.39 Two parent=8.60/3.20		
					HbA1c	MST= 11.40/2.25 SC=11.29/2.34 Single parent=11.69/2.27 Two parent=11.03/2.28		
				Post-treatment 7m	BGT frequency	MST= 1.82/1.15 SC= 2.17/1.33 Single parent= 1.94/1.28 Two parent= 2.05/1.24		
					DFBC primary caregiver	MST= .47/4.02 SC= -.18/4.73	0.13	
					DFBC secondary caregiver	MST= 3.32/7.93 SC= -1.63/5.25	0.94	
				12months 18months 24months	FRI	MST= .16/2.79 SC= .09/2.89	0.02	
					HbA1c	MST= -.68/1.68 SC= .09/1.66	-0.46	
					BGT frequency	MST= .71/1.08 SC= -.16/1.28	0.67	
Newton and Ashley (2013) USA To evaluate the feasibility and effectiveness of a web-based intervention. Hypothesis	Adolescents with Type 1 diabetes An online website Paediatric diabetes centre	N= 50 15% Experimental (n=25) Control (n=25) Age: 13-18 Caucasians 23 25 Non-caucsns 2 0	Web based Self-efficacy theory Facilitate activities and discussions on weekly basis Facilitators not mentioned 30s to 1 hour	7 weeks	Diabetes quality of life	Post-treatment Exp-192/28 Con-188/21	0.19	
					Self-efficacy of diabetes management	Exp-36.7/6.8 Con-35.3/6.4	0.21	
					Positive outcome expectations of diabetes management	Exp-44.5/6.9 Con-48.8/6.3	-0.68	

that intervention participants would report a higher combined effect of diabetes-related self-efficacy, outcome expectations and quality of life than the control.					Negative outcome	Exp-26.6/6.2 Con-27.6/7.5	-0.13	
Jaser et al (2014) USA To pilot-test the feasibility and acceptability of a positive psychology intervention to improve adherence to diabetes management. The preliminary efficacy of the intervention on family conflict, quality of life, and glycemic control. The association between changes in positive affect	Adolescents with Type 1 diabetes. Paediatric diabetes clinic	N = 39 15% Intervention (n= 20) Control= (n=19) Age (13-17) **Inter** **con** Males (40%) (58%) White (65) (94) Non-white (35) (6.0)	Positive psychology 8 week long Facilitators not mentioned	3 months 6 months	Positive and negative affect scale Children' depression inventory Self-care inventory Diabetes family conflict scale Quality of life inventory Mean frequency of blood glucose monitoring HbA1c	------ no mean/sd values given for measures.	None	NEI

and adherence.								
Kichler et al. (2013) USA To implement the Kicking in Diabetes Support (KIDS) project intervention to determine the impact of this treatment on improving psychosocial adjustment and diabetes management among adolescents with T1DM and their parents using a wait list control design methodology	Adolescents with Type 1 diabetes Outpatient clinical mental health	N = 30 33% Inspired by Multisystemic Therapy and Behavioural Family Systems Therapy Applied the Kicking in Diabetes Support (family therapy) Age (15.17 years mean) T1DM duration of 5.64 years. 53% girls 76.7% Caucasian 83.3% married parents	KIDS provides both peer group and family-based interventions to adolescents with T1DM and their parents. 6 months A licensed psychologists	6 months	**Primary care giver**	Pre and post between group comparison		
					Brief symptom inventory		0.03	
					Behavioural assessment scale for children		0.00	
					Diabetes family relationship questionnaire		0.47	
					Paediatric quality of life inventory generic		0.06	
					Paediatric quality of life family impact module		0.05	
					Readiness to change the balance of responsibility scale		0.23	
					Self care inventory		0.11	
					Diabetes family responsibility questionnaire		0.47	
					Paediatric quality of life inventory diabetes		0.43	
					Youth Brief symptom inventory		0.00	
					Diabetes family relationship questionnaire		0.28	
					Readiness to change the balance of responsibility scale		0.09	
					Paediatric quality of life inventory generic		0.11	
					Paediatric quality of life inventory diabetes		0.00	
					Self care inventory		0.14	
					Hb A1c (baseline)	10.04/2.33	NEI	
					Hb A1c (6 months)	9.74/2.05		

Note:
Not Enough Info (NEI)
No effect size was calculated for Pre treatment or baseline
Effect Size= ES
ES calculated for 3 Groups by comparing intervention group with the control group 1 and control group 2
Dash (-) represent no values given in the paper.

Appendix B

Effect sizes of studies

Study **No of pts in each condition**	**GHb/HbA1c**	**Psychosocial**	**ES**	**Other measures related to diabetes management & adherence related factors**	**ES**
**Satin et al., 1989 Mf=11 Mf+s=12 C=9	3 months 0.55 (mf vs c) 2.08 (mf +s vs c) 6 months 0.35(mf vs c) 1.25 (mf +s vs c) 2nd & 3rd study cycles (with smaller group size), excluding those in the first cycle. 3 months (planned comparison) 2.71(mf vs c) 2.75(mf +s vs c) 6 months 3.77(mf vs c) 3.59(mf +s vs c)				
**Wysocki et al, 2000 Bfst=35 Ct=41 Es=39	3 months 0.18 (bfst vs ct) 0.28 (bfst vs es)	PARQ: Overt conflict/skill deficits	-0.14 (bfst vs ct) , -0.21(bfst vs es)	The Issues Checklist: No. of items endorsed	-0.19(bfst vs ct) , -0.22 (bfst vs es)
		Extreme beliefs	-0.64 (bfst vs ct), -0.50 (bfst vs es)	Total frequency of conflict	-0.25(bfst vs ct) , -0.27 (bfst vs es)
		Family structure	-0.15 (bfst vs ct) , -0.21(bfst vs es)	Total intensity of conflict	-0.13(bfst vs ct), -0.31(bfst vs es)
		DRC	-0.10 (bfst vs ct), -0.2(bfst vs es)	Recall interview conflict scores: Frequency	0.06(bfst vs ct) , 0.04 (bfst vs es)
		TADS	-0.38(bfst vs ct) , -0.31(bfst vs es)	intensity	-0.18(bfst vs ct) , -0.03(bfst vs es)
		SCI	-0.32(bfst vs ct), -0.26 (bfst vs es)	duration	-0.21(bfst vs ct) , -0.11(bfst vs es)
				Recall interview adherence factors: Insulin	0.20(bfst vs ct) , 0.11(bfst vs es)
				testing/eating frequency	0.34 (bfst vs ct), 0.71(bfst vs es)
				diet composition	0.5 (bfst vs ct), 0.48 (bfst vs es)
				diet amount	-0.46(bfst vs ct) , -0.24(bfst vs es)
				exercise	0.17(bfst vs ct) , 0.01(bfst vs es)

**Wysocki et al, 2006 Bfst-d=36 Sc=32 Es=36	6 months	PARQ: Overt conflict/Skill deficits. Extreme Beliefs Family structure	0.01(bfst-d vs sc), 0.06 (bfst-d vs es) (bfst-d vs sc), -0.01 (bfst-d vs es) 0.0 0.48(bfst-d vs sc) , 0.46(bfst-d vs es)		
**Wysocki et al,, 2007 Bfst-d=36 Sc=32 Es=36	3 months -0.17 (bfst-d vs sc) , 0.06 (bfst-d vs es) 6 months -0.16(bfst-d vs sc), -0.08 (bfst-d vs es) 9 months -0.47(bfst-d vs sc), -0.61 (bfst-d vs es) 12 months -0.43(bfst-d vs sc), -0.28 (bfst-d vs es) 15 month -0.62 (bfst-d vs sc), -0.71 (bfst-d vs es) 18 months -0.47(bfst-d vs sc) , -0.46 (bfst-d vs es)	3 months DRC (family composite score) 6 months DSMP DRC (family composite score) 9 month DRC (family composite score) 12 months DSMP (total scores) DRC (family composite score) 15 months DRC (family composite score) 18 months DSMP (total scores) DRC (family composite score)	NEI 0.56 (bfst-d vs sc), 0.23 (bfst-d vs es) -0.28(bfst-d vs sc), -0.47 (bfst-d vs es) NEI 0.6 (bfst-d vs sc) , 0.22 (bfst-d vs es) 0.06(bfst-d vs sc) , -0.22 (bfst-d vs es) NEI 0.36(bfst-d vs sc), 0.09 (bfst-d vs es) 0.17(bfst-d vs sc), -0.34 (bfst-d vs es)		
**Wysocki et al, 2008 Bfst-d=36 Sc=32 Es=36 Only adolescents		6 months IBC for -tive communi Adolescents Mothers Fathers 12 months IBC for -tive communi Adolescents Mothers Fathers 18 months Adolescents Mothers Fathers	-0.76(bfst-d vs sc) , -0.73(bfst-d vs es) -0.45(bfst-d vs sc) , -0.57 (bfst-d vs es) 0.13(bfst-d vs sc) , -0.11(bfst-d vs es) -0.73(bfst-d vs sc) , -0.11 (bfst-d vs es) -0.48 (bfst-d vs sc), -0.13 (bfst-d vs es) -0.21(bfst-d vs sc) , -0.05 (bfst-d vs es) -0.77(bfst-d vs sc) , -0.09(bfst-d vs es) -0.58(bfst-d vs sc) , -0.11(bfst-d vs es) -0.06(bfst-d vs sc) , 0.0 (bfst-d vs es)		

		6 months IBC for +tive communi Adolescents	0.45(bfst-d vs sc) , 0.6 (bfst-d vs es)		
		Mothers	0.60(bfst-d vs sc) , 0.5 (bfst-d vs es)		
		Fathers	0.28(bfst-d vs sc) , 0.37 (bfst-d vs es)		
		12 months IBC for +tive communi Adolescents	0.27 (bfst-d vs sc), 0.30 (bfst-d vs es)		
		Mothers	0.53(bfst-d vs sc) , 0.53 (bfst-d vs es)		
		Fathers	0.66(bfst-d vs sc), 0.62(bfst-d vs es)		
		18 months IBC for +tive communi Adolescents	0.54(bfst-d vs sc), 0.27(bfst-d vs es)		
		Mothers	0.61 (bfst-d vs sc), 0.21(bfst-d vs es)		
		Fathers	0.4(bfst-d vs sc), 0.44 (bfst-d vs es)		
*Harris et al 2009 Bfst=18 Comparison= 40		Post treatment	BFSTvs control:		
		DRC			
		Adolescents	-1.00		
		Mothers	-1.01		
		Fathers	-.87		
		CBQ			
		Adolescents	-0.38		
		Mothers	-.36		
		Fathers	-.07		
*Ellis et al 2004 Mst=13 C=12	-0.66 (mst vs sc at 6 m)			DMS-A	-0.17
				DMS-P	-0.07
				Meter	0.36
				INSADH	0.48
				EATADH	-0.83
				BGTS	0.15
				ER	0
				Admissions	-0.48
*Ellis et al 2005 Mst=64 Sc=63	Intent to treat 7 months Mst vs cs: ns Per protocol (4 pts excluded) 0.64 (sig)			**Intent to treat**	Mst vs sc:
				Meter	1.09
				INSADH	Ns
				EATADH	ns
				BGTS	0.83
				ER	ns
				Admissions	0.63
				Per protocol	
				Meter	1.01
				INSADH	ns
				EATADH	ns
				BGTS	1.05
				ER	ns
				Admissions	0.65

*Ellis et al. 2007 Mst=64 Sc=63 only adolescents	-0.46 (mst vs sc)	DFBC primary caregiver DFBC secondary caregiver FRI	0.13 0.94 0.02	BGT frequency	0.67
*Newton and Ashley (2013) Experimental=25 Control =25 Adolescents	None (web-based)	7 weeks Diabetes quality of life Self-efficacy of diabetes management Positive outcome expectations of diabetes management Negative outcome	0.19 0.21 -0.68 -0.13		
*Jaser et al (2014) Intervention = 20 Control= 19 Adolescents	No mean/sd values given	Positive and negative affect scale Children' depression inventory Self-care inventory Diabetes family conflict scale Quality of life inventory	No mean/sd values given for 3 and 6 months	Mean frequency of blood glucose monitoring	No mean/sd values given
*Kichler et al. (2013) N = 30 Adolescents	Baseline 10.04%, SD 2.33% 6-month 9.74%, SD 2.05%) NEI to calculate ES	**Primary care giver** 6 months (pre and post groups comp.) Brief symptom inventory Behavioural assessment scale for children Diabetes family relationship questionnaire Paediatric quality of life inventory generic Paediatric quality of life family impact module Readiness to change the balance of responsibility scale Self care inventory Diabetes family responsibility questionnaire	0.03 0.00 0.47 0.06 0.05 0.23 0.11 0.47 0.43		

		Paediatric quality of life inventory diabetes	0.00		
		Youth			
		Brief symptom inventory	0.28		
		Diabetes family relationship questionnaire	0.09		
		Readiness to change the balance of responsibility scale	0.11		
		Paediatric quality of life inventory generic	0.00		
		Paediatric quality of life inventory diabetes	0.14		
		Self care inventory			

Table 2: The effect sizes for GHb/HbA1c, psychosocial & other outcome variables for each intervention.

Note: Two ESs for an individual variable represent comparison of two intervention groups individually with a control group.

**** :** two intervention groups and one control group study

***:** one intervention group and one control group study

Appendix C

Quality Assessment of Studies

Study (author/s & year)	Intervention questions/ aims clearly stated	Approach appropriate for the questions	Intervention context clearly described	Role of the facilitator clearly described	Use of appropriate measures relevant to aims	Mode of delivery clearly described	Sampling method clearly described	Sampling strategy (e.g. selection of individual by age etc) appropriate	Method of data collection clearly described	Data collection method appropriate	Method of analysis clearly described	Analysis appropriate for the research question	Use of a theory	Conclusion supported by sufficient evidence	total scores
Kaplan et al 1985	1, 1	2, 2	2, 2	1, 1	2, 2	2, 2	2, 2	1, 1	2,2	2,2	1, 1	2, 2	2, 2	2, 2	24/28
Satin et al 1989	2, 2	2, 2	2, 2	2, 2	2, 2	2, 2	2, 2	1, 1	2, 2	2, 2	2, 2	2, 2	1, 1	2, 2	26/28
Wysoki et al 2006	2, 2	2, 2	2, 2	2, 2	2, 2	2, 2	2, 2	1, 1	2,2	2,2	1, 1	2,2	2,2	2,2	26/28
Viklund et al2007	2,2	2,2	2,2	1,1	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	26/28
Wysoki et al 2008	2,2	2,2	2,2	2,2	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	27/28
Wysoki et al 2000	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	28/28
Ellis et al 2005	2,2	2,2	2,2	2,2	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	27/28
Wysoki et al 2007	2,2	2,2	2,2	2,2	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	27/28
Wysoki et al 1997	2,2	2,2	2,2	1,1	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	26/28
Wysoki et al 2001	2,2	2,2	2,2	1,1	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	26/28
Ellis et al 2004	2,2	2,2	2,2	2,2	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	27/28
Ellis et al 2007	2,2	2,2	2,2	2,2	2,2	1,1	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	26/28
Harris et al 2009	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	27/28
Nansel et al 2012	2,2	2,2	2,2	1,1	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	26/28
Newton and Ashley (2013)	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	1,1	2,2	2,2	2,2	26/28
Jaser et al (2014)	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	1,1	2,2	2,2	2,2	26/28
Kichler et al. (2013)	2,2	2,2	2,2	1,1	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	2,2	27/28

Extra Table (supporting evidence)

Search Diary

Database name and provider	Date range	Search completed	Search strategy	Total number of references retrieved
Medline, e-journals, CINAHL, psychinfo, socindex, library information science and technology abstracts, psycharticles, econlit, psychology and behavioural science collection)	1958-2012	14/8/12	((Adolescence) OR (adolescent) OR (youth) OR (young people) OR (young person), OR (teen) OR (juvenile) OR (puberty)) AND Diabetes AND ((Program) OR (intervention) OR (randomised controlled trial) OR (RCT)) AND ((Peer) OR (family) OR (parent) OR (friend)) AND ((Outcome) OR (efficacy) OR (control) OR (communicat) OR (social) OR (knowledge) OR (diet) OR(skill) OR (exercise)).	927
EBM Reviews (Cochrane central register of controlled trials	1890-2012	15/8/12	Adolescence OR adolescent OR youth OR young people OR young person, OR teen OR juvenile OR puberty AND Diabetes AND Program OR intervention OR randomised controlled trial OR RCT AND Peer OR family OR parent OR friend AND Outcome OR efficacy OR control OR communication OR communicating OR social OR knowledge OR diet OR skill OR exercise	69
Medline, e-journals, CINAHL, psychinfo, socindex, library information science and technology abstracts, psycharticles, econlit, psychology and behavioural science collection)	2012-2015	27/12/15	Adolescence OR adolescent OR youth OR young people OR young person, OR teen OR juvenile OR puberty AND Diabetes AND Program OR intervention OR randomised controlled trial OR RCT AND Peer OR family OR parent OR friend AND Outcome OR efficacy OR control OR communication OR communicating OR social OR knowledge OR diet OR skill OR exercise	2050

Extra table: Search diary

SECTION 2C - TWO ARTICLES

Article one

Exploring factors influencing non-attendance at the diabetes clinic and service improvement strategies from patients' perspectives

Note: ***This article has been published in a peer review journal, 'Journal of Practical Diabetes. Therefore amendments were made according to the journal's requirements/guidelines. The articles written below is the original version of write up.***

Abstract

A significant number of people with Type 1 diabetes do not attend their clinic appointments. This study investigated the reasons underlying this decision and explored possible service improvement strategies. This was a cross-sectional telephone survey among all patients with Type 1 diabetes missing at least one appointment at a diabetes clinic between 1 October 2009 and 30 September 2010. Patients were asked two questions: why they did not attend the appointment and how attendance could be improved. The initial 'Did Not Attend' (DNA) rate for all appointments was 17.6% (808/4595 appointments). Of these, the largest number were missed by patients (n=252) with Type 1 diabetes. After excluding 79 patients no longer under the service, 126/173 (72.8%) were able to be contacted and answered the questions. Forgetting the appointment was the most frequent response (34.9%). Many patients advised not to send appointment reminder letters too far ahead of appointments (12.7%, 16) and to send a text message reminder (26.2%, 33) two weeks before the appointment. The findings suggest that there is a role for improving the administrative approach to patients' appointments, reminding patients in advance and improving communication between hospital staff and patients.

Key words: Type 1 diabetes; DNA; phone survey; forgetting; text message.

Introduction

Diabetes is the fourth leading cause of non-violent death globally (World Health Organisation, WHO, 2007). According to current estimated numbers by the WHO (2011), more than 220 million people worldwide have diabetes. In 2004, an estimated 3.4 million people died from consequences of high blood sugar (WHO, 2011). Without urgent action being taken, diabetes-related deaths are set to increase by more than 50% over the next 10 years (WHO, 2007). Unless preventative measures are taken, 380 million people worldwide will have diabetes by 2025, with the largest increase occurring in the developing countries (World Diabetes Foundation, 2007). In the UK, prevalence of diabetes is much higher in England (5.4%, n= 2,338,813) in comparison to Northern Ireland (3.7%, n= 68,980), Scotland (4.1%, n= 223,943) and Wales (4.9%, n= 153,175) (Diabetes UK, 2010). Most health experts agree that the UK is facing a huge increase in the number of people with diabetes. Since 1996 the number of people diagnosed with diabetes has increased from 1.4 million to 2.8 million. By 2025 it is estimated that over four million people will have diabetes. The figures are alarming and confirm that diabetes is one of the biggest health challenges facing the UK today (Diabetes UK, 2010).

Diabetes is a chronic disease, requiring a high degree of lifelong self-management with regular health professional support and supervision (Griffin, 2004; Stone, Palmer, Saxby & Devaraj, 1999). Maintaining a near normal blood glucose level reduces the incidence of diabetic complications such as eye disease, kidney disease and neuropathy (Diabetes Control and Complication Trial, 1993), which can lead, and contribute, to significant morbidity related to foot ulcer amputations; renal failure, coronary heart disease and stroke (Ngwenya, van Zyl & Webb, 2009).

Diabetes requires regular and structured follow up and surveillance by health professionals (Williams, 1994). Patients' attendance at diabetes clinic is associated with improved medical outcomes, but significant numbers of people with Type 1 diabetes choose not to attend (Lawson, Lyne, Harvery & Bundy, 2005). Non-attendance of appointments is one of the major contributors to poor control in diabetic patients (Mollentze & Koning, 2007). Patients who miss appointments also miss opportunities for detecting complications and treatment adjustments. As a result, these patients may experience poorer outcomes (Ngwenya, van Zyl & Webb, 2009), and are more likely to return at a later stage frequently with advanced diabetic complications and risk factors than those attending regularly (Stone et al., 1999; Simmons & Clover, 2007; Griffin, 2004). Furthermore, non- attendance at a diabetes clinic has been associated with poorer glycemic control (Jacobson, Adler, Derby, Anderson & Wolfsdorf, 1991).

People receiving specialist care from hospital diabetes clinics have a better prognosis in terms of glycaemic control, survival and low risk of hospital admission (Goyder, Spiers, McNally, Drucquer & Botha, 1999). People who do not attend the diabetes clinic often do not receive optimum management and are likely to return at a later stage, frequently with advanced diabetes related complications. Jacobson and colleagues (1991) found that 34% of patients with Type 1 diabetes who did not attend care had poor glycaemic control, compared to those who kept their appointments.

Patients who miss appointments also miss opportunities for detecting complications and treatment adjustments and, as a result, may experience poorer patient outcomes (Ngwenya, Van Zyl & Webb, 2009). Therefore, while non-attendance at diabetes clinics may be less prevalent than in other health care settings, the outcome may be worse in terms of morbidity and mortality (Griffin, 1998). Not attending outpatient clinics is a significant problem nationally and high costs are incurred when many patients fail to attend their clinic appointments.

The effects of non-attendance are poor management of clinics, with vacant appointments leading to idle time and poor utilisation of medical and clerical staff time (Dockrey, Rajkumar, Chapman, Bulpit & Nicholl, 2001). Waiting-list times are extended because of the need for repeat appointments. Patients who need immediate care may also be required to wait longer to be seen because of a high (unanticipated) turnout of unscheduled patients (Ngwenya, van Zyl &Webb, 2009). Non-adherence with regularly scheduled clinic appointments can also obstruct efforts to shorten waiting lists, affect continuity of care, contribute to long waiting times, engender negative patient-provider relationships (Paterson, Charlton & Richard, 2010; Husain-Gambles, Neal, Dempsey, Lawlor & Hodgson, 2004; Weinger, McMurrich, Yi, Lin & Rodriguez, 2005), reduce clinic efficiency, lower productivity (Hamilton, Luthra, Smith & Evans, 2002; Hardy, O'Brien & Furlong, 2001) and can impact successful diabetes management (Griffin, 1998).

Non-attendance represents one of the most costly problems in outpatient care, both in terms of economical and human resources spent (Moore, Wilson-Witherspoon & Probst, 2001). The efficiency of the health system is thus hindered (Benoit, Ji, Fleming, Philis-Tsimikas, 2004). A study evaluating the financial significance of failed appointments revealed that non-attendance results in allocated resources not being utilised. For example, staffs get paid, even when patients do not attend (Moore et al., 2001). The financial cost of missed appointments in the National Health Service (NHS) has been estimated at £360 million per year (Stone et al., 1999) most of this is accounted for by non-attendance in primary care and hospital outpatient clinics (Mitchell & Selmes, 2007). The national 'did not attend' (DNA) rate for all specialties for 1996–97 was 12% (Government Statistical Service, 1995).

Reasons for decisions not to seek specialist help are not well understood. There has been little research amongst those who decide not to attend long-term. In this study, we will use a social cognition model, the Self-regulatory Model (SRM) (Leventhal & Cameron, 1987) to address this clinical problem. The model has been predictive of a range of health behaviours and adaptive outcome across illness groups (Petrie & Weinman, 1997) including medical help-seeking (Cameron, Leventhal, & Leventhal, 1993) and the employment of diabetes self-care activities (Glasgow, Strycker, Hampson, & Ruggiero, 1997; Griva, Myers, & Newman, 2000; Hampson, Glasgow, & Foster, 1995; Hampson, Glasgow, & Toobert, 1990; Skinner & Hampson, 1998). The SRM consists of three stages that regulate behaviour:

(1) Perception of the health threat (illness perceptions or personal models, these terms are used interchangeably);
(2) The action plan or coping stage representing the individual's response to their personal model;
(3) The appraisal stage in which the individual evaluates the success or failure of coping actions.

Personal models are structured around five main dimensions (Leventhal, Diefenbach, & Leventhal, 1992):

(1) **Identity** which consists of symptoms and the label given to the illness;

(2) **Cause** of illness (e.g., genetic or environmental factors, own behaviour);
(3) **Time line** or Course of Illness;
(4) **Controllability/Curability** and
(5) **Consequences** (perceived physical, psychological or economic consequences).

An important feature of the model is that of parallel processing where perceptions of health threat take place both on a cognitive level and on an emotional level, one for regulation of danger (danger control) and the other for the regulation of fear (fear control). Each of the two parallel processing systems has a feedback loop allowing information from the appraisal stage to feedback into the prior stages. Thus, if a particular coping strategy is perceived to be ineffective, an alternative coping response may be adopted which may result in a change in the representation of the illness. These evaluations could lead to a re-appraisal of various coping responses such as personal skills or those of health professionals (Lawson, Lyne, Bundy & Harvey, 2007).

Recent data from our clinic population based diabetes register (from 1 October 2009 to 30 September 2010) indicated that 808/4595 (17.6%) of patient attendances were defaulted. This proportion was quite high compared to other centres (Griffin, 1998; Dyer, Lloyd, Lancashire, Bain & Barnett, 1998) as well as in comparison to the national average figure and was affecting the management of the clinics. It was decided to investigate the reasons for non-attendance and possible service improvement strategies from patients' points of view.

Patients and method

The records of patients who missed one or more appointments in the previous 12 months (i.e. 1 October 2009 to 30 September 2010) were reviewed on the hospitals' databases. The initial DNA rate for all appointments was 17.6% (808/4595 appointments). Of these, the largest number were missed by patients (n=252) with Type 1 diabetes. Of the 252 defaulting patients, 79 were excluded: 42 patients were excluded from the evaluation because they did not have any follow-up appointments in the clinic in the future, two patients were discharged, one patient was deceased and 32 patients were under 25 years of age (considered a group with special features and served by other clinics) and two had moved away.

The remaining patients were telephoned (at least a month before their next appointment) from the hospital to ask briefly two simple and open-ended questions (see Box 1) without giving a series of options for answers, just to gain an understanding of their perspectives. The telephone conversation lasted 5–8 minutes (including the introduction [see Box 1 in Appendix C), depending on the patient's communication style. Patients were given the option of giving more than one reason for not attending and more than one suggestion for improving the services. Patients' responses were recorded on the Microsoft Excel sheet, which included columns related to the following areas:

1. Patients' names.
2. Telephone numbers.
3. DNA date.
4. Reasons for non-attendance.
5. Service improvement strategies.
6. Reminder strategies.

Patients' responses were included as themes into the Microsoft word document, which were analysed quantitatively. Patients' telephone numbers, next appointment dates and demographic information (i.e. gender, age) were obtained from the Hospital Information Support System (HISS). General practices were contacted to obtain those defaulting patients' telephone numbers whose phone numbers were not listed on HISS. The hospital database was used to identify clinical characteristics (e.g. BMI, HbA1c, and cholesterol) of non-attenders. The records of a comparable number of age and gender matched 'attenders' (i.e. patients attending the clinic during this period) were randomly selected from the database. The trainee Health Psychologist (KA) conducted the telephone survey (approved by the patient safety department of the hospital) in February–March 2011 asking why patients did not attend the appointment and how attendance could be improved. Patients were called three times between 8am and 4pm (weekdays) and on Saturdays (9:30am to 3:30pm). Contact was made with 126 (72.8%) patients. This work was approved as a service evaluation.

Results

The mean age was 43.9±12.7 years and 45.7% were women. The mean BMI (27.1±4.1 vs 26.9±4.4kg/m2) and systolic blood pressure (133±24 vs 132±17mmHg) of non-attenders and attenders were similar. Nonattenders' HbA1c (8.8±1.7 vs 8.2±1.4%, $p<0.001$), total cholesterol (4.9±1.1 vs 4.7±0.9mmol/L, $p=0.04$) and diastolic blood pressure (79±11 vs 77±9mmHg, $p=0.04$) were significantly higher among non-attenders.

Table 1 includes reported reasons for non-attendance of patients (please see Appendix A) and Table 2 recommendations for improving attendance (please see Appendix B). Although patients were given open options to give more than one reason for nonattendance and service improvement strategy, all interviewed patients mentioned only one reason for non-attendance, one service improvement strategy and one reminder strategy. All data were recorded on paper to be entered onto the Microsoft Excel sheet to analyse them quantitatively. The main cause of non-attendance was forgetfulness (34.9%). Many patients (81, 64.3%) suggested that receiving a reminder would help them to remember their appointments, with 26.2% (33) preferring to receive a text message, 19.8% (25) an email or text message, 8.7% (11) a letter, 7.1% (9) an email and 2.4% (3) a telephone call only. Some patients (22.2%, 28) did not want a reminder and 13.5% (17) did not know.

Discussion

These data clearly support previous findings that patients with Type 1 diabetes who do not attend their specialist clinic appointments have poorer blood glucose control in comparison to those who regularly attend their appointments. Due to the benefits from tighter glucose control, and ability to access new therapies (e.g. continuous subcutaneous insulin infusion), attendance at diabetes specialist clinics remains important. In view of the rapidly changing lifestyle and demands in a modern world and the differences between different countries, we felt it was important to take a contemporary snapshot of the reasons for default from diabetes clinics by people with Type 1 diabetes.

Forgetting the appointment remains the most common reason for not attending appointments, followed by being too ill, work related issues or being out of the country, and administrative errors. The findings are consistent with other studies, which also mention forgetting as the major reason for missing clinic appointments (Jacobson et al., 1991; Griffin, 1998; Pieper & DiNardo, 1998; Downer, Meara & Da Costa, 2006; NHS Executive North West, 1997; National Audit Office, 1995). On the other hand, our findings do reflect a major move towards modern media for contacting patients to remind them, with 53% advising a preference for either a text or an email reminder. The majority of patients had already given their mobile numbers to the clinic, making this a feasible option. A relatively recent study (Downer et al., 2006) examined the effectiveness of sending appointment reminders to patients' cell phones via text messaging and found that only 9.8% of 20 488 patients who received a text message failed to attend their appointments, in comparison to 19.5% of patients in a historical control group (who had a cell phone, but received no reminder message).

A Cochrane review of randomised, controlled trials of text messaging to remind patients of appointments is under way (Car, Gurol-Urganci, de Jongh, Vodopivec-Jamsek & Atun, 2008); however, none of the studies listed focused on diabetes. We believe our findings support the need for a randomised controlled trial of text messaging among patients attending/defaulting diabetes clinics. Our findings also highlight other reasons for default, particularly relating to administrative processes. A major suggestion for improving the service from patients' perspectives was not to send appointment letters too far ahead of the clinic appointments (e.g. sending appointment letters one month prior to annual review visits rather than six or more months in advance). It was also felt that improvements could be made in communication with staff, and in the use of technologies for patients (e.g. providing a specific telephone number and an email address) to cancel, change or rearrange their appointments. Such conveniences are already available in many general practices. Anticipation of long waiting times between arrival at the clinic and being seen remains an issue that reduces attendance among these more vulnerable patients with Type 1 diabetes.

Of course, not all of the reasons for default are the result of the need to remind busy people of a forthcoming appointment or administrative issues. A range of psychosocial and behavioural reasons underlie default among some patients, which includes: health beliefs (Mirotznik, Ellen Ginzler, Zagon & Baptiste, 1998); resistance to consultation (Wogelius & Poulsen, 2005); perceived social support (Ramm, Robinson & Sharpe, 2001); living in a deprived area (Neal, Lawlor, Allgar, Colledge, Ali, Hassey, et al., 2001); work commitment or unable to get time off from work (Sharp & Hamilton, 2001); past negative experiences with medical teams (Sharp DJ, Hamilton, 2001); childcare problems (Freed, Ellen, Irwin & Millstein, 1998); long waiting times and lack of transportation (Lacy, Paulman, Reuter & Lovejoy, 2004) and personal or family illness and fear of the medical encounter (Van Baar, Joosten, Car, Freeman, Partridge et al., 2006). In view of this, other options are to provide counselling and education to non-attendant patients to review their reasons of non-attendance, to consider using positive reinforcement or giving incentives for attendance.

Care providers need to be aware of their communication skills, which may also affect clinic attendance (Pieper & DiNardo, 1998), as a few patients during the phone survey for this audit did mention the need to improve staff's communication with patients. Issues with the relationship between patients and health professionals are a well recognised barrier to self-care (Simmons, Weblemoe, Voyle, Prichard, Leakehe & Gatland, 1998).

One of the limitations of the survey could be that patients may have been worried that, if they gave negative feedback about the service or reasons other than forgetting the appointment, this may affect their future care, though patients were reassured that the information they provided would be kept confidential and would not affect the care they receive from the clinic. It is also important to note that the findings of this study cannot be generalised, as the cohort surveyed on the telephone was not representative of the non-attenders as a whole. A significant proportion of non-attenders could not be contacted (27.2%) and their responses might have included other viewpoints which could have affected the results.

Although qualitative methodology could potentially be more beneficial in terms of gaining richer data in comparison to quantitative methodology, it was not feasible to apply it in the current project because of some practical barriers. In addition, this project was conducted for service evaluation purposes rather than for research reasons. Thus, it is recommended that a qualitative study be conducted in the future, based on the issue of non-attendance and patients' expectations from the services in order to gain an in-depth understanding of barriers or facilitators to clinic appointments.

In conclusion, reasons for nonattendance identified among patients with Type 1 diabetes are similar to those reported by the national audit office and several other regions and trusts, with a large proportion of non-attenders saying that they forgot their appointments. This suggests that there is a role for reminding patients in advance, and that potential improvements in patients' attendance rates can be achieved by applying this strategy.

A text message strategy has not been reported previously for an adult diabetes clinic and a randomised controlled trial of sending text message reminders (as suggested by many patients) is warranted.

References

Benoit, S.R., Ji, M., Fleming, R. and Philis-Tsimikas, A. (2004). Predictors of dropouts from a San Diego diabetes program: a case control study. *Preventing Chronic Disease*, *1*, 1–8.

Cameron, L.D., Leventhal, E.A. and Leventhal, H. (1993). Symptoms representations and affect as determinants of care seeking in a community dwelling adult sample population. *Health Psychology*, *12*, 171–179.

Car, J., Gurol-Urganci, I., de Jongh, T., Vodopivec-Jamsek, V. and Atun, R. (2008). Mobile phone messaging reminders for attendance at scheduled healthcare appointments. *Cochrane Database of Systematic Reviews,* (4). [DOI: 10.1002/14651858.CD007458]

Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine, 329*, 977–981.

Diabetes UK. (2010). *Diabetes in the UK: Key statistics on diabetes*. https://www.diabetes.org.uk/documents/reports/diabetes_in_the_uk_2010.pdf

Dockrey, F., Rajkumar, C., Chapman, C., Bulpit, C. and Nicholl, C. (2001).The effects of reminder calls in reducing non-attendance rates at care of the elderly clinics. *Postgraduate Medical Journal*, *77*, 37-39.

Downer, S. R., Meara, J. G., Da Costa, A.C. and Sethuraman, K. (2006). SMS text messaging improves outpatient attendance. *Australian Health Review*, 30 (3), 389-96.

Dyer, P.H., Lloyd, C.E., Lancashire, R.J., Bain, S. C. and Barnett, A.H. (1998). Factors associated with clinic non-attendance in adults with Type 1 diabetes mellitus. *Diabetic Medicine*, *15*, 1135–1141.

Freed, L.H., Ellen, J.M., Irwin, C.E. and Millstein, S.G. (1998). Determinants of adolescents' satisfaction with health care providers and intentions to keep follow-up appointments. *Journal of Adolescents Health, 22*(4), 5–9.

Government Statistical Service. (1995). *Outpatients and ward attenders, England 1996-97.* London: Department of Health.

Goyder, E.C., Spiers, N., McNally, P. G., Drucquer, M. and Botha, J.L. (1999). Do diabetes clinic attendees stay out of hospital? A matched case-control study. *Diabetic Medicine*, *16*, 687–691.

Griva, K., Myers, L. B. and Newman, S. (2000). Illness perceptions and selfefficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology & Health*, *15*, 733–750.

Griffin, S.J. (1998). Lost to follow-up: the problem of defaulters from diabetes clinics. *Diabetic Medicine*, *15*(3), S14–S24.

Glasgow, R.E., Strycker, L.A., Hampson, S.E. and Ruggiero, L. (1997). Personal-model beliefs and social environmental barriers related to diabetes self-management. *Diabetes Care, 20*, 556-561

Hamilton, W., Luthra, M., Smith, T. and Evans, P. (2002) 'Non-attendance in general practice: A questionnaire survey'. *Primary Health Care Research and Development*, *3*, 226-230.

Hampson, S. E., Glasgow, R.E. and Foster, L. S. (1995). Personal models of diabetes among older adults: relationship to self-management and other variables. *Diabetes Educator*, 21, 300–307.

Hampson, S.E., Glasgow, R.E. and Toobert, D.J. (1990). Personal models of diabetes and their relations to self-care activities. *Health Psychology, 9*, 632–646.

Hardy, K.J., O'Brien, S.V. and Furlong, N.J. (2001). Information given to patients before appointments and its effect on non-attendance rate. *British Medical Journal*, 323, 1298–300.

Hussain-Gambles, M., Neal, R., Dempsey, O., Lawlor, D. and Hodgson, J. (2004). Missed appointments in primary care: questionnaire and focus group study of health professionals. *British Journal of General Practice, 54,* 108–113.

Jacobson, A.M., Adler, A.G., Derby, L., Anderson, B.J. and Wolfsdorf, J.I. (1991). Clinic attendance and glycemic control. *Diabetes Care*, *14*, 599–601.

Lacy, N. L., Paulman, A., Reuter, M. D. And Lovejoy, B. (2004). Why we don't come: Patient perceptions on no-shows. *Annals of Family Medicine, 2*(6), 541-545.

Lawson, V.L., Lyne, P.A., Bundy, C. and Harvey, J.N. (2007). The role of personal models, coping and evaluation in care-seeking among people with type 1 diabetes. *Psychology & Health*, *22*(2), 175-191.

Lawson, V.L., Lyne, P.A., Harvey, J.N. and Bundy, C.E. (2005). Understanding Why People with Type 1 Diabetes Do Not Attend for Specialist Advice: A Qualitative Analysis of the Views of People with Insulin-dependent Diabetes Who Do Not Attend Diabetes Clinic. *Journal of Health Psychology*, 10 (3), 409-423.

Leventhal, H. and Cameron, L. (1987), Behavioural theories and the problem of compliance. *Patient Education and Counselling*, *10*, 117-38.

Leventhal, H., Diefenbach, M. and Leventhal, E. (1992). Illness cognition: Using common-sense to understand treatment adherence. *Cognitive Research and Therapy*, *16*,143-163.

Mirotznik, J., Ellen Ginzler, E., Zagon, G. and Baptiste, A. (1998). Using the Health Belief Model to Explain Clinic Appointment-Keeping for the Management of a Chronic Disease Condition. *Journal of Community Health, 23*(3), 195-210.

Mitchell, A. J. and Selmes, T. (2007).Why don't patients attend their appointments? Maintaining engagement with psychiatric services. *Advances in Psychiatric Treatment, 13,* 423-434.

Moore, C.G., Wilson-Witherspoon, P. and Probst, J.C. (2001). Time and money: effects of no-shows at a family practice residency clinic. *Family Medicine*, *33,* 522–7.
Mollentze, W.F. and Koning, J.M.M. (2007). Where have all the diabetics gone? *South African Medical J*ournal, *97,* 6.

National Audit Office. (1995). *National Health Service outpatient services in England and Wales. Report by the controller and auditor general*. London: National Audit Office.

National Health Service Executive North West. (1997). *Non-attendance in Outpatient Clinics: Guidance for Best Practice*. London: Department of Health.

Neal, R.D., Lawlor, D.A., Allgar, V., Colledge, M., Ali, S. and Hassey, A. (2001). Missed appointments in general practice: retrospective data analysis from four practices. *British Journal of General Practice, 51*(471), 830–2.

Ngwenya, B.T., Van Zyl, D.G. and Webb, E.M. (2009). Factors influencing non-attendance of clinic appointments in diabetic patients at a Gauteng hospital in 2007/2008. *Journal of Evolution, Medicine and Dental Sciences, 14*(2), 106-109.

Paterson, B.L., Charlton, P. and Richard, S. (2010). Non-attendance in chronic disease clinics: a matter of non-compliance? *Journal of Nursing Healthcare and Chronic Illness, 2,* 63–74.

Petrie, K.J. and Weinman, J.A. (Eds.). (1997). *Perceptions of Health and Illness: Current Research and Applications*. Singapore: Harwood.

Pieper, B. and DiNardo, E. (1998). Pearls for practice: reasons for missing appointments in an outpatient clinic for indigent adults. *Journal of American Association of Nursing Practice, 10,* 359–364.

Ramm, C., Robinson, S. and Sharpe, N. (2001). Factors determining nonattendance at a cardiac rehabilitation programme following myocardial infarction. *New Zealand Medical Journal, 114*(1132), 227–9.

Sharp, D. J. and Hamilton, W. (2001). Non-attendance at general practices and outpatient clinics. *British Medical Journal, 323*(7321), 1081–2.
Simmons, D. and Clover, G. (2007). A case control study of diabetic patients who default from primary care in urban New Zealand. *Diabetes and Metabolism*, *33*(2),109-113.

Simmons, D., Weblemoe, T., Voyle, J., Prichard, A., Leakehe, L. and Gatland, B. (1998). Personal barriers to diabetes care: lessons from a multiethnic community in New Zealand. *Diabetic Medicine, 15,* 958-964.

Skinner, T. C. and Hampson, S. E. (1998). Social support and personal models of diabetes in relation to self-care and well-being in adolescents with type 1 diabetes mellitus. *Journal of Adolescence, 21*, 703-715.

Stone, C. A., Palmer, J. H., Saxby, P. J. and Devaraj, V.S. (1999). Reducing non-attendance at outpatient clinics. *Journal of the Royal Society of Medicine, 92*, 114-118.

Van Baar, J.D., Joosten, H., Car, J., Freeman, G.K., Partridge, M.R., van Weel, C. and Sheikh, A. (2006). Understanding reasons of asthma outpatient (non)-attendance and exploring the role of telephone and e-consulting in facilitating access to care: exploratory qualitative study. *Quality and Safety in Health Care*, *15*(3), 191–195.

Weinger, K., McMurrich, S., Yi, J., Lin, S. and Rodriguez, M. (2005). Psychological characteristics of frequent short-notice cancellers of diabetes medical and education appointments. *Diabetes Care, 28,* 1791–1793.

Williams, R. (1994). Diabetes mellitus. In Stevens, A., Raftery, J., eds. *Health care needs assessment reviews.* Oxford: Radcliffe Medical Press.

Wogelius, P. and Poulsen, S. (2005). Associations between dental anxiety, dental treatment due to toothache, and missed dental appointments among six to eight-year-old Danish children: a cross-sectional study. *Acta Odontologica Scandinavica, 63*(3), 179–82.

World Diabetes Foundation. (2007). *Diabetes and non-communicable diseases – now considered as big a threat to Africa as HIV/AIDS.* Available from www.worlddiabetesfoundation.org/media(3781,1033)/WDFpressreleaseEN.pdf.pdf. (Accessed 08/08/2007).

World Health Organisation. (2007). *Diabetes*. Available from http://www.who.int/mediacentre/factsheets/fs312/en/index.html. (Accessed 08/08/2007).

World Health Organization (2011). *Diabetes fact sheets*. http://www.who.int/mediacentre/factsheets/fs312/en/index.html.

Appendix A

Reasons for DNA	No. of responses (n =126)
Forgot	44 (34.9%)
Too ill	20 (15.8%)
Work related problems	15 (11.9%)
Administrative errors	8 (6.3%)
Holidays/out of country	9 (7.1%)
Bad weather conditions	4 (3.2%)
Personal reasons	8 (6.4%)
Had other appointments on that day	7(5.6%)
Did not necessary to attend my appointment	3 (2.4%)
Never missed	3 (2.4%)
Lost the letter	2 (1.6%)
Transport	1 (0.8%)*
Appointment changes by the clinic	1 (0.8%)
Neglecting diabetes	1 (0.8%)

Table 1: Reported reasons for non-attendance.

*The unexpected non-attender; DNA (did not attend).

Appendix B

Suggestions	No. of responses (n = 126)
No suggestions was given	49 (38.8%)
Generally happy with the clinic	17 (13.5%)
Avoid sending letters too far ahead of appointments	16 (12.7%)
Reduce waiting time	7 (5.5%)
Make parking easier	4 (3.2%)
Provide options to attend the clinic on different days and times	4 (3.2%)
Start sending blood test reminders before annual reviews	3 (2.4%)
Make childcare arrangements close by the clinic	1 (0.8%)
Avoid changing already booked appointments	2 (1.6%)
Make it possible to see same doctor always	1 (0.8%)
Improve the administrative system	1 (0.8%)
Have a facility to be able to make future appointments within the clinic in person.	1 (0.8%)
Improve communication between staff & patients	16 (12.7%)
Improve use of technologies, e.g. arrange an appointment cancellation website	4 (3.2%)

Table 2: Reported suggestions to improve the service.

Appendix C

Box 1: Introduction

Before asking the questions to patients, a reason of the telephone call was mentioned briefly with an introduction:

My name is ……… and I am ringing on behalf of the diabetes clinic at the ……………….Hospital to try to find out why some people do not attend their appointments. We are hoping to improve the way the clinic runs from the feedback we receive. I only have 2 questions, so they shouldn't take long. Could you spare the time to help us, we would very much appreciate it. All your provided information will be kept confidential and will not affect your future care in the diabetes clinic

(1) What were reasons of your non-attendance on the dates (dd/mm/yy)?

(2) How do you think we could make it easier for you to attend the clinic, do you have any suggestions?

Figure 1: Introduction before conducting the telephone survey and the questions asked to patients.

Section 2C - Article 2

Development and Evaluation of One-Stop Workshop for adolescents with type 1 Diabetes

Note: This article has been published in the Clinical psychology Forum. Therefore amendments were made according to the requirements/guidelines of this forum. The articles written below is the orgional final version of the write-up.

Abstract

Aims: Workshops using a group format are potentially beneficial in adolescence in terms of their capacity not only to provide knowledge and skills to manage diabetes but also to address the participants' psychosocial needs such as attaining peer approval and fostering a sense of belonging. Despite the anticipated advantages, group programmes have been underutilized for adolescents with Type 1 diabetes and the literature is limited in identifying and describing caveats and logistics for using group approaches with this population. The aims of the development and piloting of our current community- based workshop for adolescents with Type 1 diabetes were to 1) to evaluate the feasibility of the workshop as a mode of delivery of health care information from service evaluation perspectives and 2) for participants, we aimed not only to increase awareness of healthcare needs, but also to engage them in discussions in a community and group based setting. **Method**: We approached 174 patients identified from our clinical database, aged 15-20, using an assessment form (AF) to determine interest in attending a workshop and asking about specific topics of interest which were then incorporated into the designed programme. 44 AF were received back and invitation letters and a timetable then sent to 17 participants interested in attending, with 7 attending the workshop (aged 15-18). Importantly, an integrative approach was utilised by involving the broad multidisciplinary adult and paediatric clinical teams in this programme, which dealt with medical, psychological and social aspects of diabetes management and was delivered using a variety of interactive tools. **Results:** The outcome evaluation suggested that the workshop improved communication with health care professional, promoted more frequent Blood Glucose (BG) testing and improved skills of carbohydrate counting and physical activity. Specifically, most participants reported enjoying the workshop (86%), learning about diabetes management (58%) and the ability to prioritise health care needs (72%). Most also reported improved confidence to communicate with peers (72%) and health care staff (72%). 57% said that they will now monitor BG more frequently. **Conclusion:** This workshop demonstrated a potentially feasible, effective and optimal method to deliver group based education in a community setting for young adults with Type 1 diabetes focusing upon patient-centred approach. Participants appreciated the idea of attending the workshop with their peers and found it beneficial to learn about diabetes in a group setting.

Key words: Type 1 diabetes, adoelscents, workshop, community-based, medical, psychological and social aspects.

Introduction

Diabetes mellitus is a relatively common chronic disease for which there is, as yet, no known cure. There are two main forms of diabetes: insulin-dependent diabetes mellitus or Type 1 diabetes and non-insulin-dependent or Type 2 diabetes. Type 1 diabetes usually develops in childhood and adolescence, whereas Type 2 diabetes is not usually diagnosed before the age of 40 years (Hampson, Glasgow & Foster, 2001; Gage, Hampson, Skinner, Hart, Storey et al., 2004). Type 1 diabetes is the result of destruction of the beta cells of the pancreatic islets of Langerhans by the autoimmune system. These cells are progressively destroyed, resulting in a loss of insulin production. Insulin is a hormone that enables glucose that is circulating in the blood to be utilised by muscle and adipose tissue, and is involved in the mobilisation of the glucose stored in the liver (Hampson et al., 2001).

Acute complications of diabetes

Lack of insulin prevents glucose uptake, which results in high levels of blood glucose (hyperglycaemia). Symptoms of hyperglycaemia include excessive urination (polyuria), thirst (polydipsia), weight loss and a feeling of lassitude. Insulin deficiency also leads to the excessive breakdown of fats and the production of ketones, which are excreted in urine. This breakdown of adipose tissue also results in weight loss. If hyperglycaemia continues, high ketone levels cause ketoacidosis, manifested by vomiting, dehydration, Kussmaul breathing and finally coma, which can be fatal (Hampson et al., 2001). It is a particular problem for adolescents and is treated by hospital admission to prevent complications (Gage et al., 2004).

An isolated admission for Diabetes KetoAcidoses (DKA) can usually be attributed to either a concurrent acute illness, or, in teenage males, to excessive alcohol consumption (Thompson & Greene, 1997). However, the single most common cause of ketoacidosis is now widely accepted to be intermittent or non-existent insulin administration (Morris, Boyle, McMahon, Greene, MacDonald et al., 1997; Thompson, Cummings, Chalmers & Newton, 1995). Despite this, there is little evidence related to the reasoning behind young people's repeated and dangerous insulin manipulation behaviour.

Another acute complication of diabetes is the hypoglycaemia, which is relatively common but treatable. In hypoglycaemia, blood glucose levels drop to dangerously low levels and individuals may experience sweating, shaking and palpitations. However, if it is left untreated, glucose levels may continue to fall, leading to neuroglycopaenia (confusion, lack of coordination, odd behaviour) with cognitive dysfunction, and, in severe hypoglycaemia, unconsciousness and death can result if blood sugars are not elevated. Although, the true prevalence of hypoglycaemia is not known because minor episodes are not usually reported (Gage et al. 2004), studies looking at the prevalence of severe hypoglycaemia in children and adolescents quote ranges of 4–86 episodes per 100 patient years (Goldstein, England, Hess, Rawlings & Walker, 1981; Diabetes Control and Complications Research Group, 1994).

Epidemiology

Type 1 diabetes is the third most common chronic condition in young people after asthma and cerebral palsy (Betts, Buckley, Davies, McEvilly & Swift, 1996), affecting 18 to 20 per 100, 000 children a year in the United Kingdom (Onkamo, Vaananen, Karvonen & Tuomilehto, 1999). In Great Britain, rates range from a low of 6 in southern England to 19.8 (per 100,000 per year) in Scotland, and other studies report a higher incidence in urban compared to rural populations, particularly where there is a low incidence generally (Lamb, 1997).

The management of Type 1 diabetes

The aim of diabetes management is to maintain blood glucose levels as near as possible to the normal range (6.5-7.0). Glycated haemoglobinA_{1c} (HbA_{1c}) is now used as the set standard for estimating average blood glucose control in about 12-weeks period. Regular assessments are recommended and results are used to guide modifications to insulin prescriptions and other management advice (Hampson et al., 2001). However, it is crucial to understand how a chronic illness interfaces with biological, psychological and social developmental processes among adolescents (Williams, Holmbeck & Greenley, 2002).

Diabetes in adolescence

Adolescence is a particularly critical time for young people with diabetes. Whether diagnosed in childhood or adolescence, during this transitional period young people learn to take responsibility for and manage their own diabetes (Allen, Tennen, McGrade, Affleck &

Ratzan, 1983; Anderson, Auslander, Jung, Miller, Santiago et al., 1990; Wysocki, Clarke, Meinhold, Bellando, Abrams et al, 1992). As they integrate self-management of diabetes into their emerging lifestyles, adolescents experience directly the relationship between their actions and their blood glucose levels, which influences their beliefs about diabetes and its treatment. Therefore, these will be formative years in the development of such beliefs. Once fully integrated and accepted, these beliefs will be difficult to change, and are important predictors of self-care and well-being (Glasgow, Strycker, Hampson & Ruggiero, 1997; Hampson, Glasgow & Foster, 1995; Skinner & Hampson , 1998; Skinner, John & Hampson, 2000).

On the other hand, high rates of treatment non-adherence to the demanding Type 1 diabetes treatment regimen and less than optimal glycemic control have been consistently reported (Morris, Boyle, McMahon, Greene, MacDonald et al., 1997; Wysocki, Greco & Buckloh, 2003; Helgeson, Siminerio, Escobar & Becker, 2007). Maintaining adequate treatment adherence and glycemic control in Type 1 diabetes requires the young person to organize several critical daily management tasks including exercise, dietary intake, blood glucose monitoring, and insulin administration, especially related to carbohydrate intake. Effective completion of these complex tasks requires a range of cognitive skills including organization, planning, problem solving, working memory, and behavioural self-regulation (Bagner, Williams, Geffken, Silverstein & Storch , 2007) that encompass the broad cognitive domain of executive functioning (Gioia, Isquith, Guy & Kenworthy , 2000).

A young person’s overall level of competence in executive functioning (e.g., ability to set goals and organize tasks and flexibility to adapt to treatment regimens) may be an important influence on adherence to treatment in Type 1 diabetes and potentially on glycemic control (McNally, Rohan, Pendley, Delamater, Drotar et al., 2010). This issue has been addressed in Bagner et al’s (2007) study, which demonstrated an association between executive functioning, as measured by the Behavior Rating Inventory of Executive Functioning (BRIEF) (Gioia, Isquith, Guy & Kenworthy, 2000), and treatment adherence in a sample of youth with Type 1 diabetes. However, this study did not test alternative models of the relationship between executive functioning and treatment adherence, and did not include a measure of glycemic control. Age-related differences in executive functioning were not controlled.

Moreover, the fact that only one model of association between level of executive functioning and treatment adherence was tested limited the validity of inferences that could be drawn. For example, Bagner et al. (2007) suggested that their findings supported the hypothesis that greater executive functioning facilitates adherence. On the other hand, it is also possible that adherence, especially problematic adherence, may lead to poor glycemic control, which, in turn, may have a negative impact on memory and executive functioning (Gaudieri, Chen, Greer & Holmes, 2000). Because these alternative pathways of influence have very different implications for targeting interventions, it is important to compare them. Finally, Bagner et al. (2007) did not describe the relationship of executive functioning and adherence to glycemic control. For this reason, the clinical relevance of their findings was limited.

To address the above methodological problems, McNally et al (2010) conducted a study to investigate the relationship among executive functioning, diabetes treatment adherence, and glycemic control. The results indicated that executive functioning skills (e.g., planning, problem-solving, organization, and working memory) were related to adherence, which was related to diabetes control. These findings suggest that not only emergence of a new lifestyle, impacts upon adolescents' diabetes self-care and treatment adherence but also the potency of executive functioning.

Metabolic control during adolescence

Research consistently demonstrates that there is a marked worsening of metabolic control during adolescence (Allen, Zaccaro, Palta, Klein, Duck, et al., 1992), associated with the onset and progression of complications in this age group (Diabetes Control and Complications Research Group, 1994; Flack, Kaar, Laatikainen, 1996; Kovacs, Charron-Prochownik, Obrosky, 1995). Although this decline is partly attributable to the physiological changes occurring at this time, the decline in self-care behaviour is of at least equal importance (Anderson et al., 1990; Allen et al., 1992; La Greca, Follansbee, Skyler, 1990). This deterioration is particularly marked and of concern in the area of insulin administration. Self-report data have suggested that missed insulin injections are common and the pharmacy record data from the DARTS database demonstrated that about 28% of adolescents and young adults do not even obtain sufficient insulin to fulfil their prescribed regimen (Morris et al., 1997). This decline in self-care is also characterised by young people dropping out of the healthcare system and not attending diabetes services (Skinner, Hampson, 1998; Olsen & Sutton, 1998).

Chronic complications of diabetes

Poor glycaemic control is of concern during adolescence because of its effects on height, weight and puberty. The excess morbidity and mortality in patients with diabetes result from the long-term microvascular and macrovascular (e.g. retinopathy, renal failure, neuropathy, atherosclerosis, peripheral artery disease, coronary heart disease and cerebrovascular disease) complications of diabetes. These are of less immediate relevance to adolescents, but it is likely that better diabetes control (strict metabolic control) from an early age will postpone or even prevent some of these complications (Diabetes Control and Complications Research Group., 1994, 2000). Thus interventions designed to help people manage their diabetes more effectively are essential (Norris, Engelgau & Narayan, 2001). This article describes an evaluation of an innovative, educational workshop developed to help people with diabetes and engage in collaborative discussion to take control of their disease.

Background

Psychosocial and educational interventions

In the past, psychosocial and educational interventions have been used to improve adolescents’ knowledge, skills and management of all aspects of their diabetes. Educational interventions primarily teach diabetes related knowledge and skills such as testing blood glucose levels and injecting insulin correctly (Gage et al., 2004). Psychosocial interventions are diverse and provide training and support in such areas as social skills, diabetes-related problem-solving and coping skills, communication skills, and individual and family based counselling. It is widely recommended that such interventions should be an integral part of diabetes care (St Vincent Joint Task Force for Diabetes, 1999; Betts et al., 1996).

Teaching approaches

In the past, educational interventions for diabetes self-management have focused on passive, didactic formats where patients do not interact with the instructor and generally used a lecture or print format (Day, 2000; Elasy, Ellis, Brown, & Pichert, 2001; Norris et al., 2001; Whittemore, 2000). However, interventions are now moving toward a collaborative format where patients actively participate in the learning process through small group discussions, role-playing, and other interactive techniques (Day, 2000; Elasy et al., 2001; Glasgow & Anderson, 1999; Norris et al., 2001; Whittemore, 2000). A systematic review (Norris et al.,

2001) of randomized control trials of diabetes self-management training concluded that collaborative interventions were more successful than didactic ones. Therefore, a brief pilot and group based collaborative workshop was developed in a community centre after reviewing the literature and following the needs assessment (see the one-stop workshop section for detail).

Method

Selection of the target group

All young adult patients (n = 224) aged 15 to 20 were selected for the workshop from the hospital's databases, which were currently registered in the paediatric and adult diabetes clinics. Total number of current young adult patients was 174 according to the required age range (see Figure 1).

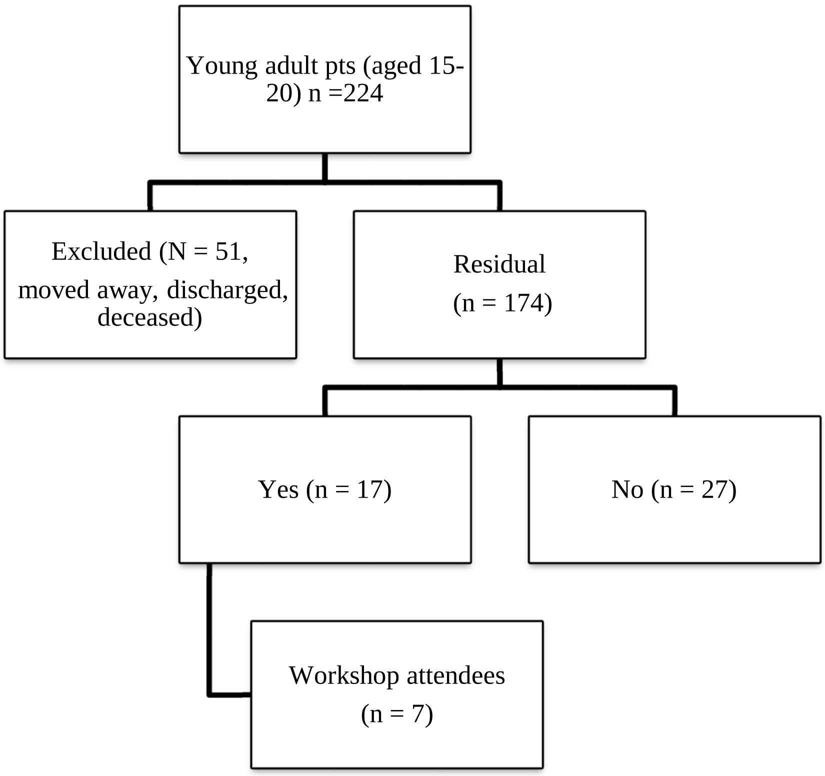


Figure 1: Process of selecting target group

How young people were approached and recruited

Selected young adult people were posted some information sheets (see Appendix A) related to conducting a workshop in a community centre and a response form (see Appendix B, with a pre-stamped & addressed envelopes) to find out their interests of attending the workshop on a voluntary basis and what they would like to know more about diabetes on that day (their preferred topics). A reminder telephone call was made after 2 weeks of posting the information related to the workshop and 25% (44/174) responses were received, in which 9% (17/174) sent their replies as ‘YES’ to attend the workshop in comparison to 15% (27/174), who replied ‘NO’. A number of reasons were given for not being able to attend the workshop from young adults’ perspectives and one of the major reasons was ‘not needed, I am satisfied with my diabetes management’. The least common reason was other problems, which young people reported as ‘I am in the middle of exam’ ‘I previously done DAFNE’, ‘I am at the university’ (see figure 2).

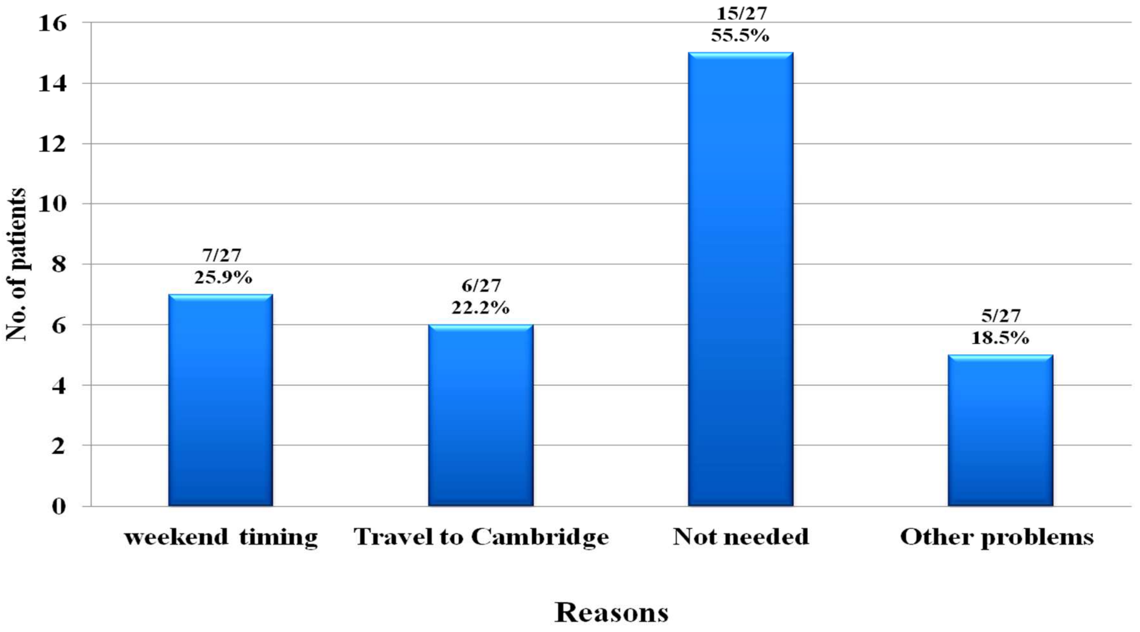


Figure 2: Number of patients with different types of reasons

A large number of people also suggested some topics (e.g. carbohydrate counting, diet and exercise, blood glucose, insulin, diabetes complications, alcohol, depression), about which they wanted to gain more knowledge on the workshop day and one of the popular areas related to diabetes they wanted to learn more about was carbohydrate counting, which has been ranked by order of their preferences after receiving their responses rather than providing them options to select:

1. Diet & carbohydrate counting
2. blood glucose, insulin, exercise, treatments, and diabetes complications
3. alcohol
4. depression

All potential young adults who agreed to attend the workshop (n = 17) were sent invitation letters (please see appendix C) from diabetes consultants and timetables with the venue details and parental consents forms (for those who were under 18, please see appendix D). Selected young adults were also contacted by telephone 2 weeks before the workshop just to confirm whether they have received all the information related to the workshop and also to confirm their attendance on the workshop day. After this procedure, 10 people informed that they will not be able to attend the workshop on that day because of work commitments and exam revision. Thus, to increase the number of young adults, some cards (please see appendix E) were prepared and placed in diabetes clinics of the hospital and also some leaflets were delivered to 5 different local surgeries in Cambridge to advertise the workshop. However, no response was received after the advertisement, which could potentially be due to exam revising term in schools and colleges, as some adolescents did mention this issue on the telephone, when they were contacted to send the feedback forms back to us. On the workshop day, seven young adult patients arrived, age ranged 15-18, in which 5 were females and 2 were males.

All the written material was prepared for young adult people using appropriate language that reflected their age group. In addition a parental consent form was reviewed by the patients' health and safety department before it was sent to the patients' homes, as the workshop was established as a part of the service evaluation. Both parents and young adults were given the opportunity to discuss the workshop on the phone, via e-mails or face to face with the consultants or workshop developers/coordinators by providing contact details on the invitation letter.

The 'One-Stop workshop'

In summer 2011, a scoping exercise was conducted to develop a pilot *'One-Stop Workshop'* for young adult patients[2] aged 15-20 with type 1 diabetes, which was endorsed by the diabetes clinics' Health Care Professionals (HCPs).

Need for the workshop

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[2] We will use term 'young adult' (as some patients under 16 or 18 attend paediatric diabetes clinic and others over 16 or 18 attend adult diabetes clinic) instead of adolescents (as it has been described in the literature, Hampson et al., 2001; Gage et al., 2004)

The selected target group was identified as potentially ‘hard to reach’ with the older teenagers in the paediatric setting sometimes finding difficulty transitioning to the young adult’s clinic setting within the adult department. There was also an evidence of low clinic attendance (e.g. 1, 2 or 3+ DNA) and even drop out (noticed in the clinic databases) from the services in this age group and this action can interfere with adolescents’ future physical and psychological well-being. According to HCPs, this group required gaining more knowledge about the importance of managing their diabetes, bringing optimal changes into their lifestyle and developing some understanding about those factors which may impact on their diabetes management and discussing any barriers which hinder this management pathway now. There is a need to promote a shared understanding in the NHS of the benefits of undertaking the trial in the community by involving multi-disciplinary team.

Aims

The aims of the development and piloting of the current workshop were to

- To evaluate the feasibility of the One-Stop Workshop in relation to delivering it at a community level on group basis and involving MDTs from both clinics in the delivery of a collaborative programme.
- To increase participants’ awareness of their healthcare needs (e.g. medical, psychological and social) by enhancing confidence, knowledge and skills related to diabetes self-care.
- To engage participants in collaborative discussions in a community and group based setting and to model problem solving through discussion.

Although the traditional view of diabetes education is the delivery of information by knowledgeable HCPs to those patients who have lack of information, with the assumption that improved knowledge will lead to an effective change in self-management behaviours, in the current workshop, a patient–centred model was adopted (see figure 3) rather than just the traditional didactic approach. This approach allows patients’ needs and views to be acknowledged and allows patients to develop the capacity to observe themselves, make sensible judgements, feel confident, and recognise desirable outcomes (Clark & Gong, 2000; Coles, 1996). Studies using only didactic methods have not shown any positive results (McIntosh, Withers & Hutchinson, 2000; Muhlhauser et al, 1995). Educational efforts which have employed a pragmatic approach by teaching self-care skills have shown to improve metabolic control by improving self-care behaviour (McIntosh et al,, 2000; Muhlhauser, Bott, Overmann, Wagener, Bender et al., 1995; Rickheim, Weaver, Flader & Kendall, 2002). This could for example include interactive instruction on blood glucose monitoring training, blood glucose pattern recognition and control, or problem solving for high or low blood glucose and meal planning (Diabetes UK, Care Recommendations, 2003).

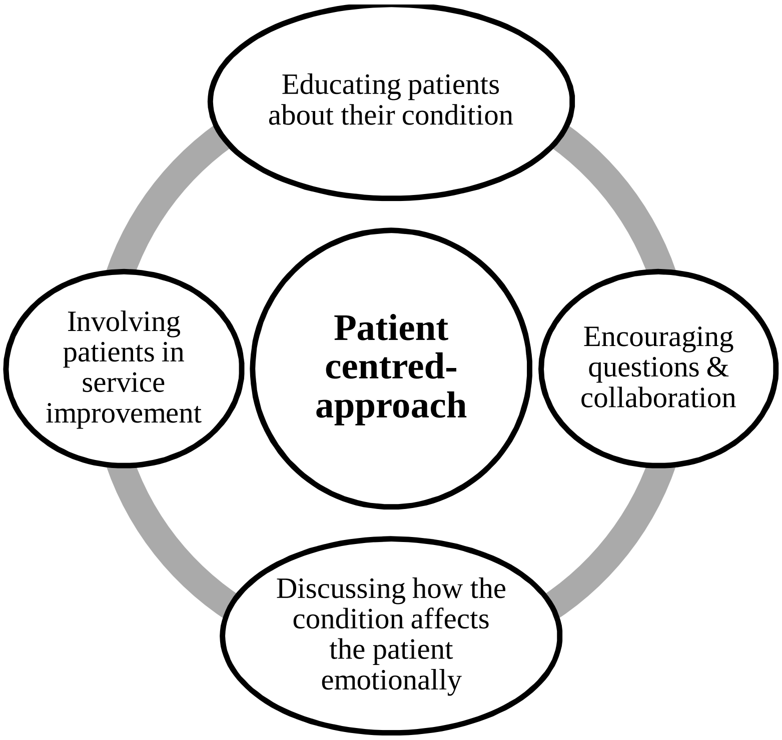

Figure 3: Patient-centred model

One-stop workshop as a platform was set up to give young people an opportunity to share their stories with other peer group members. As peers constitute an essential component of psychosocial experiences for adolescents. Adolescents often look to their peers for standard of normality (Gibson, 2000) and strive to obtain peer approval by conforming to peer-defined attitudes, values and behaviours. Peer networks are of particular importance for adolescents with chronic health conditions as they deal with both developmental tasks and disease-related challenges (Kyngas, Hentinen, & Barlow, 1998; Logan, Zelikovsky, Labay, & Spergel, 2003; Weissberg-Benchell & Antisdel, 2000). Peer support enhances adolescents' ability to overcome health challenges (Kyngas & Rissanen, 2001) and helps reduce the stigma and anxiety of carrying out self-managing behaviours such as taking medications (Berg, Tichacek, & Theodorakis, 2004). Adolescents with chronic conditions are twice as likely to adhere to medical treatment when they perceive support from friends (Kyngas & Rissanen, 2001). As such, optimal management of chronic illness in adolescents can be facilitated by positive peer relationships (Butler & Cooper, 2004).

Evidence suggests that interventions using a group format are potentially beneficial in adolescence in terms of their capacity not only to provide knowledge and skills to manage diabetes, but also to address the participants' psychosocial needs such as attaining peer approval and fostering a sense of belonging. Despite the anticipated advantages, group interventions have been underutilized and the literature is limited in identifying and describing caveats and logistics for using group approaches with this population (Rhee, Ciurzynski & Yoos, 2008).

The current group based workshop's model was not solely based around the management of the condition, but it also focused upon the impact the condition has on a young person's life and those around them and intended to facilitate the development of potential strategies and solutions to deal with the issues they may face. This was based on the idea that it is helpful for young people to take responsibility for the management of their condition and consequently for the rest of their lives.

The Workshop was delivered in a local community centre at a weekend and was related to the patients' preferred topics, which consisted of medical, psychological and social aspects of diabetes management. Thus, the Bio-Psycho-Social (Engel, 1977) model (see Figure 4) of health psychology was employed, as it claims that health and illnesses are the product of a combination of factors including biological characteristics, behavioural/psychological factors and social conditions (Marks, Murray, Evans, Willig, Woodall et al., 2005).

One stop workshop potentially addressed both the medical issues, (e.g. injecting insulin, testing blood glucose, reducing HbA1c) of self-care and the psycho-social issues for example low mood and stress, carbohydrate awareness, exercise, smoking, pregnancy, alcohol, communication skills and problem solving (see workshop sessions for more detail). A variety of interactive activities were also designed for the workshop day, e.g. quizzes, videos, a scenario, group discussion and a prize draw contest according to the age group' needs and the reasons we wanted them to get involved in these activities, as the concept (of engaging group members) behind these activities has already been appraised by the National Diabetes Support Team (Roberts, 2007).

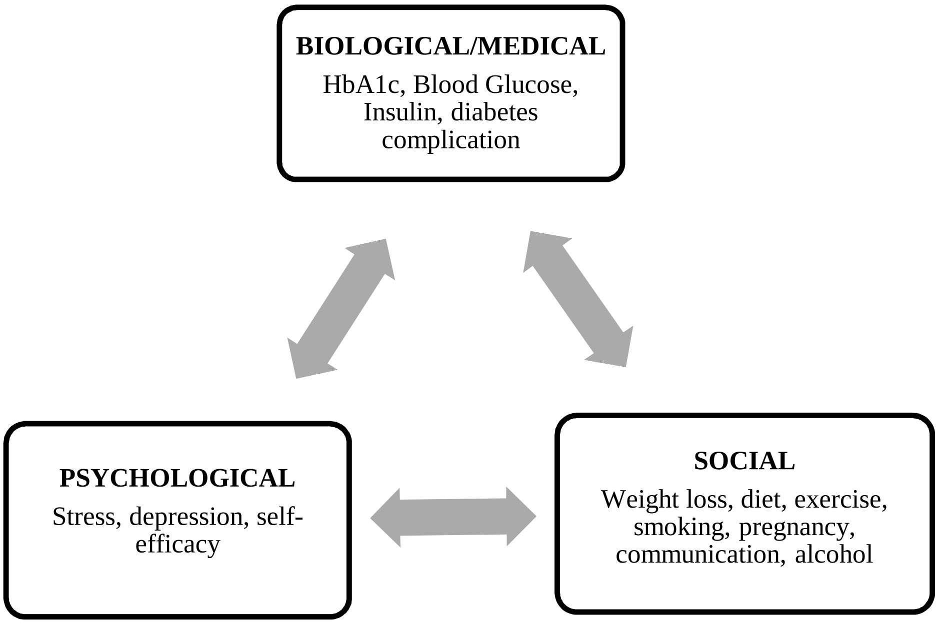

Figure 4: Integrated approach based on Biological/medical-Psychological-Social model applied in the one-stop workshop

Group learning (as mentioned in the introduction) is, however, popular in terms of cost-effectiveness and convenience for patients and providers of patient education and its advantages include: improving relationships between patients and HCPs and allowing peer interaction (Rickheim, Weaver, Flader & Kendall, 2002). It also allows the benefits of sharing experiences and social learning for people with diabetes (Diabetes UK, Care Recommendations, 2003). There is also evidence from a number of studies that group-based programmes are seen as valuable in terms of providing an opportunity to meet with other young people or parents who are in a similar situation to share experiences, information and strategies (Bruzzese, Bonner, Vincent, Shearea, Mellins et al.. 2004; Hawley, 2005; Barlow, Swanby & Turner, 2007; Trollvik and Servinsson, 2005; Salinas, 2007; Webster, 2007). These programmes fulfill both a social support and educational role and young people perceive that their self-confidence, communication skills and understanding of their long-term condition have increased as a result of participation (see evaluation section).

Workshop content

Before planning the content of the workshop, patients' perspectives were explored to ensure that the topics covered on that day were relevant and meaningful to them (please see table 3 in Appendix G). The workshop included the sessions with clear aims, method of facilitating and assessing, which served as a key point of comparison with the outcomes (please see appendix F for more detail).

Results

To assess the results of this workshop, two different types of evaluation frameworks were used. One, to assess the outcomes of the workshop day, patients' perception of the most valuable elements of the programme, intention to make changes into self-management regimens, recommendations for the future programme and service improvement and the other to identify the changes that they had made to their self-management regimens after completion of the workshop. To assess the outcomes of the workshop day, a mixed evaluative framework (consist of open ended and close ended questions) were used, which highlighted participants' perspectives related to enhancing their diabetes related knowledge and bringing some changes into their self-management regimens.

The evaluative framework (consist of close ended questions) for the post workshop allowed for verification of the impact and effectiveness of the *'one-stop workshop'* on young people' (who took part in the pilot) diabetes management related behaviour. This evaluation highlighted the positive impact on the health of those young people who took part (see follow up results), but did not set out any aims to measure the long term impact on the condition itself.

Participants valued the programme as being able to meet other young people, share experiences and learn from one another in a non-medicalised environment. They found the communication skills they developed would be useful when interacting with HCPs, parents and friends. In regards to the overall experience of the workshop, majority of the patients responded that they enjoyed the workshop. However, moderate responses were received in regards to the interactive elements of the workshop, which requires some re-consideration in the future (please see Figure 5). Increased self-confidence, self-esteem and learning about diabetes management were reported by most of the patients (please see Figure 6).The development of goal setting in consultations with HCPs was also reported.

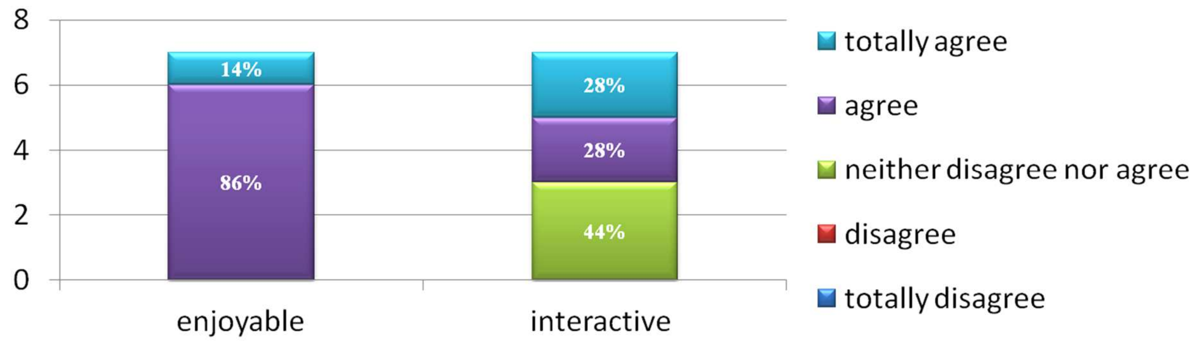

Figure 5: Workshop experiences

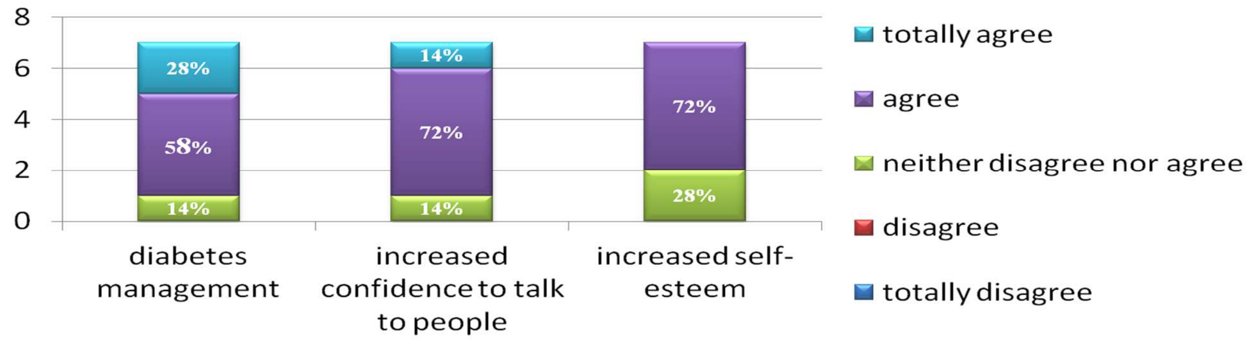

Figure 6: Workshop experiences

Most participants reported the ability to prioritise health care needs (72%) and improved confidence to communicate with the health care staff (72%, see Figure 7).

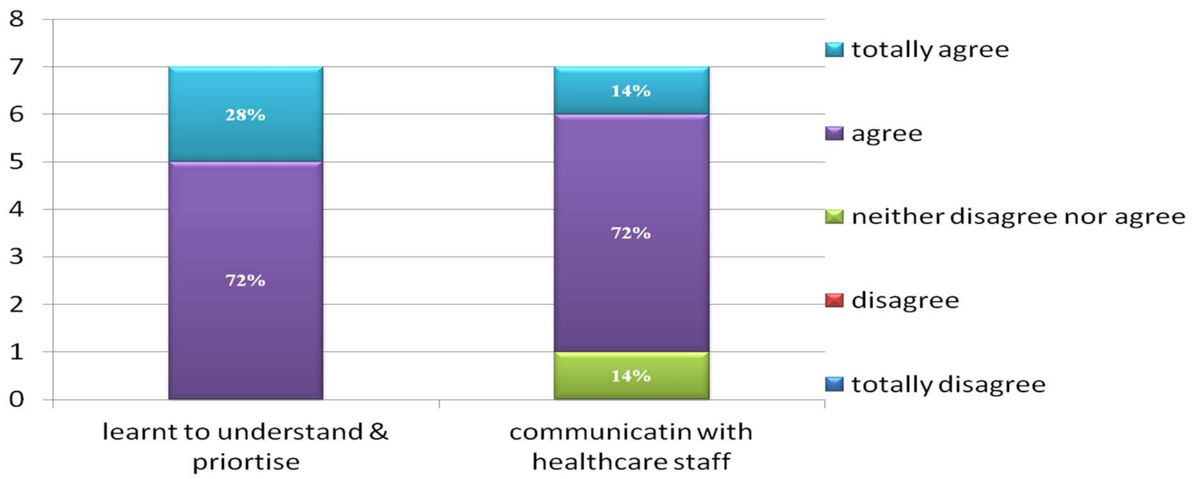

Figure 7: Workshop experiences

On the feedback sheet, patients were also asked what two things they will do differently in the future and majority of the participants reported monitoring blood glucose more often in comparison to the past (please see Figure 7).

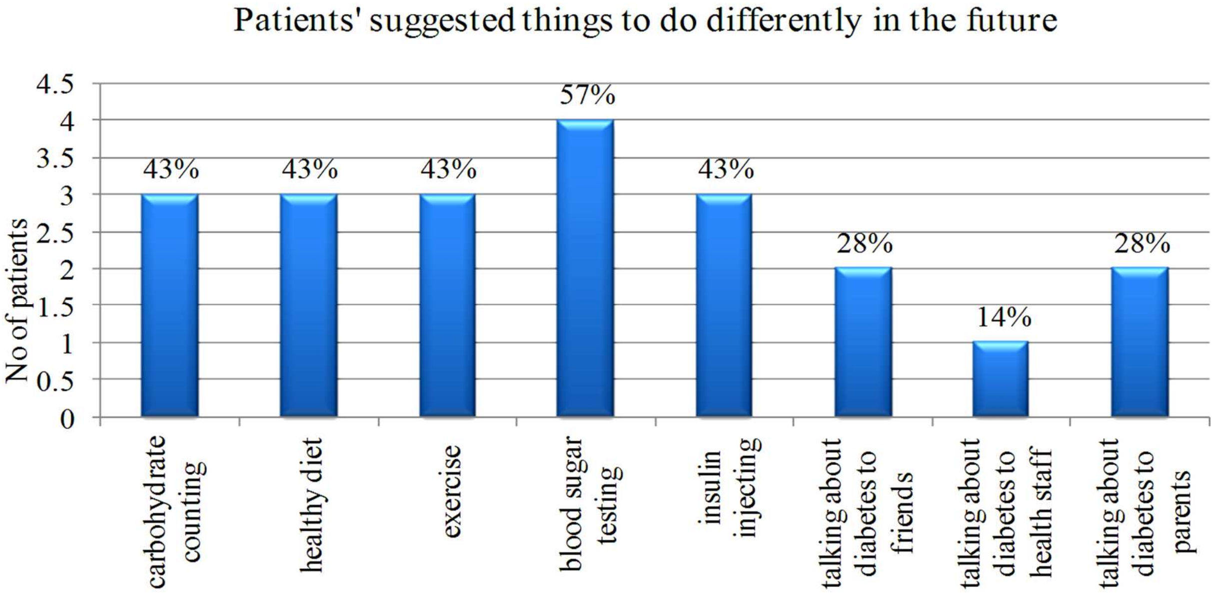

Figure 8: participants’ suggested area to bring changes in the future.

Carbohydrate awareness (or diet related) session was reported as the most favourite session on the workshop day. This response is consistent with patients’ preferences before the workshop. However, for some patients, the information provided related to pregnancy and controlling HbA_{1c} was seen ‘as shocking as well as useful’, but they mentioned that they coped up very well because of having a group of people with same illness’. It is reported that young people value being able to share experience and problems and feel understood and supported by other young people. They reported enjoying the opportunities for socialisation. In regards to conducting future workshops, a majority of the patients suggested that they would prefer to attend a shorter workshop (rather than longer than 3 hours) and at a community centre rather than the hospital (Figures 9 & 10). Some patients wanted some more fun, so they suggested including more interactive activities on the workshop day.

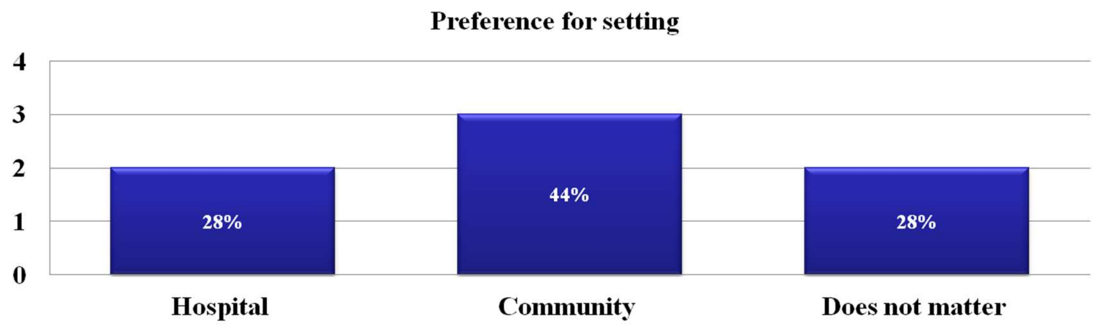

Figure 9: Future workshop format

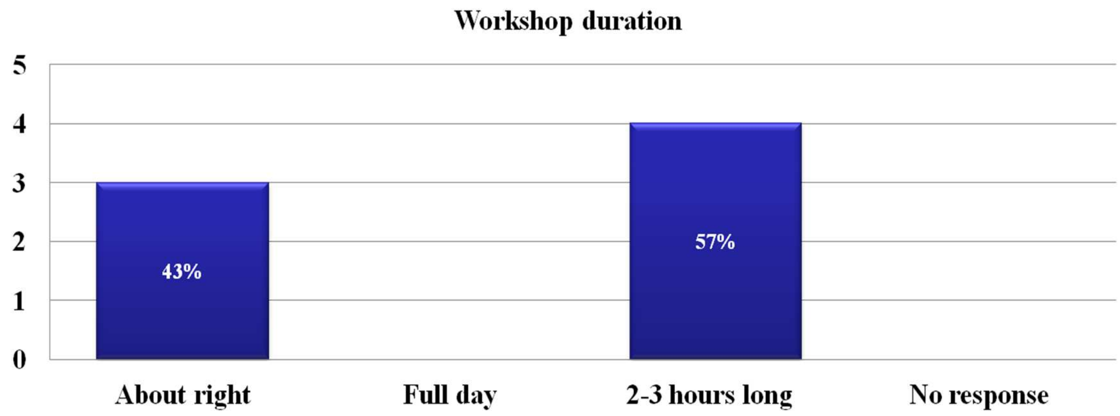

Figure 10: Future workshop format

By following the aims of this workshop, patients were also given an open option to write (anonymously) any problem they may have faced with the transition from paediatric diabetes clinics to the young adult service clinics, but no problems was reported by the patients. In addition, they were asked to rate their satisfaction on a scale of 1-10 (1= least satisfied, 10 = extremely satisfied) with the current services and majority rated 9-10 (see Figure11), which demonstrated that patients do not have any problem with the current services provided, but there may be some other issues (possibly psychosocial) behind non-attendance, dropout rate and insulin administration, which require some in-depth understanding via semi-structured or focus group interviews. The results of this workshop cannot be generalised, as the uptake of the participants was quite low on the workshop day.

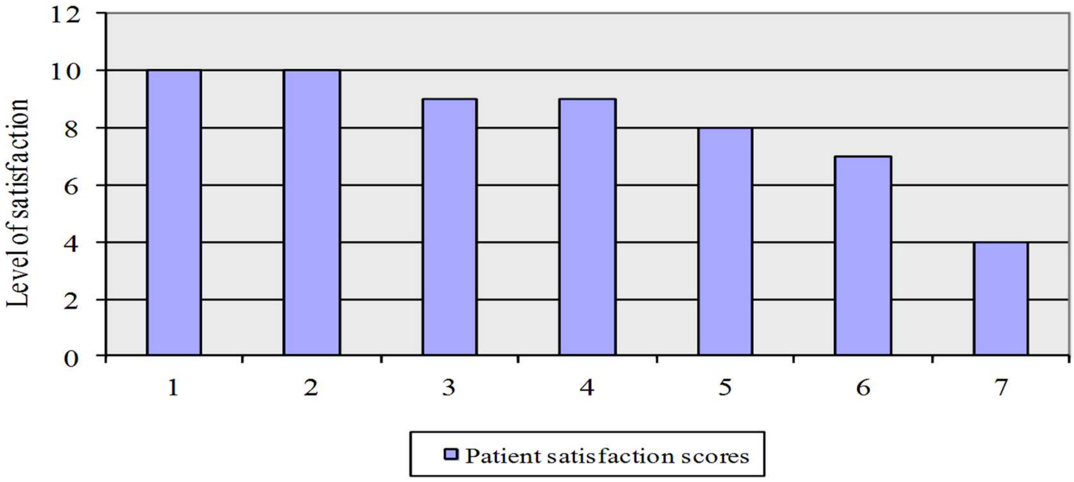

Figure 11: Participants' level of satisfaction with the services.

Nonetheless, at the end of the workshop, a summative feedback was also gained from the patients, in which they mentioned about the relaxed, informal and comfortable atmosphere to learn more about diabetes and share personal experiences related to this illness with peers. This last informal session provided the young people with time to reflect on their experiences and comment on the current workshop and developments of the future workshop. Overall a part of the evaluation process supported the need for accountability to ensure that the current workshop did had some potential positive health benefits for those young people taking part, and that those benefits would enhance their knowledge, skills and confidence to self-manage (Fawcett, 2000).

Evaluation of the post workshop outcomes

To assess the impact of the workshop on patients' health and wellbeing and implication of any changes in their lifestyle, workshop attendees were contacted by the workshop co-ordinator via posting a form to patients' homes. This form included those diabetes related areas (i.e. blood glucose testing, injecting insulin, healthy diet, communication, carbohydrate counting, smoking & alcohol), which were integrated on the workshop day with the aim of educating and enhancing patients' knowledge and skills. A positive and quick response was received from the 5 (out of 7) workshop attendees, which demonstrated some important changes in those patients' behaviour. For instance, a reasonable change was found in some patients' behaviour in terms of counting carbohydrates in their regular diet (Figure 12), testing their blood sugar (Figure 13) and communicating (Figure 14) about diabetes with the

HCPs, friends, parents and others more likely after attending the workshop in comparison to the pre-workshop. However, there were no major changes found among patients' following behaviours: eating healthy food (Figure 15), conducting physical activities or exercises (Figure 16a & 16b), administering insulin (Figure 17), stopping or quitting smoking and alcohol (Figure 18).

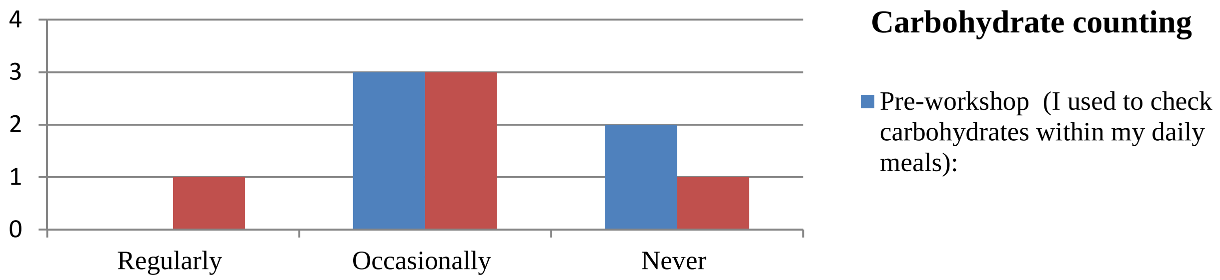

Figure 12: Comparison of the health behaviour change related to carb counting between pre and post workshop.

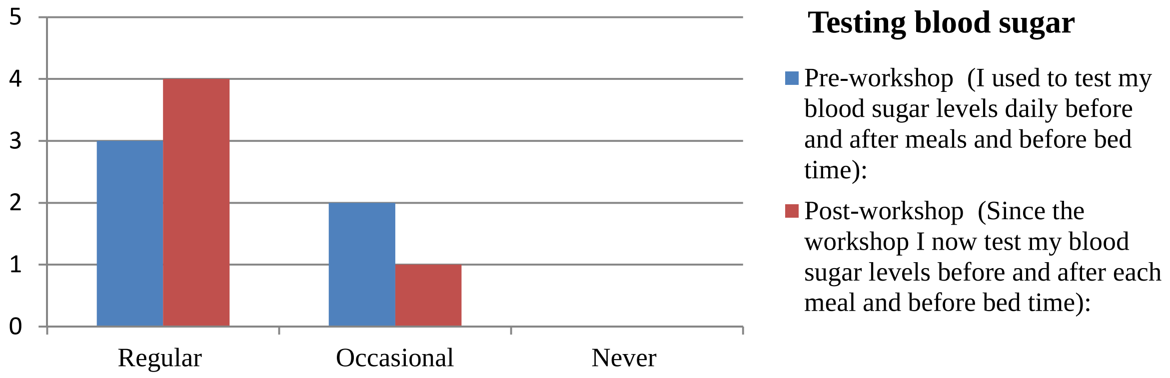

Figure 13: Comparison of the health behaviour change related to blood sugar testing between pre and post workshop.

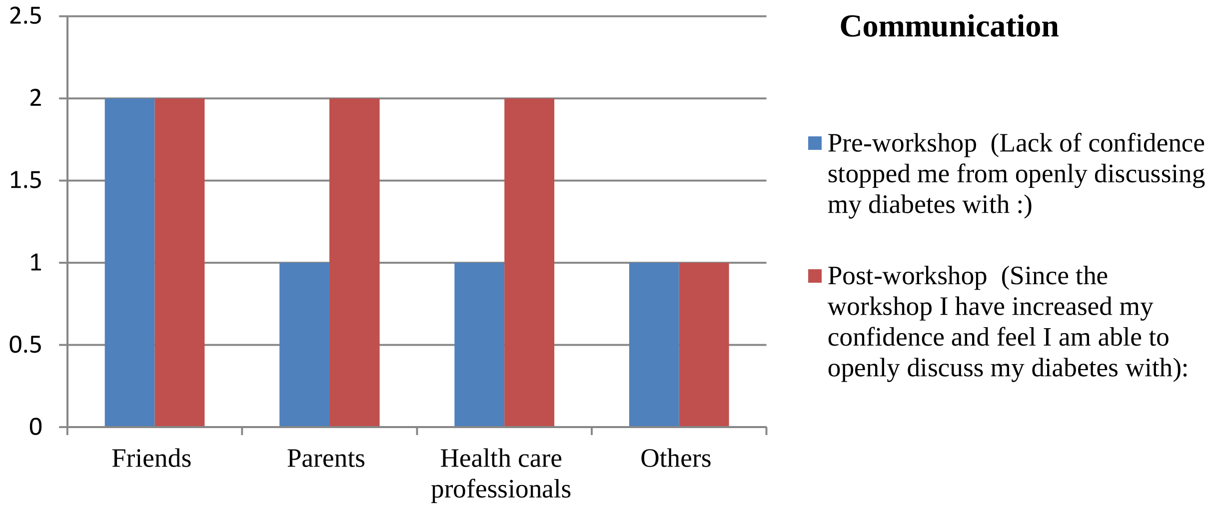

Figure 14: Comparison of patients' interaction with HCPs, friends, parents and others between pre and post workshop.

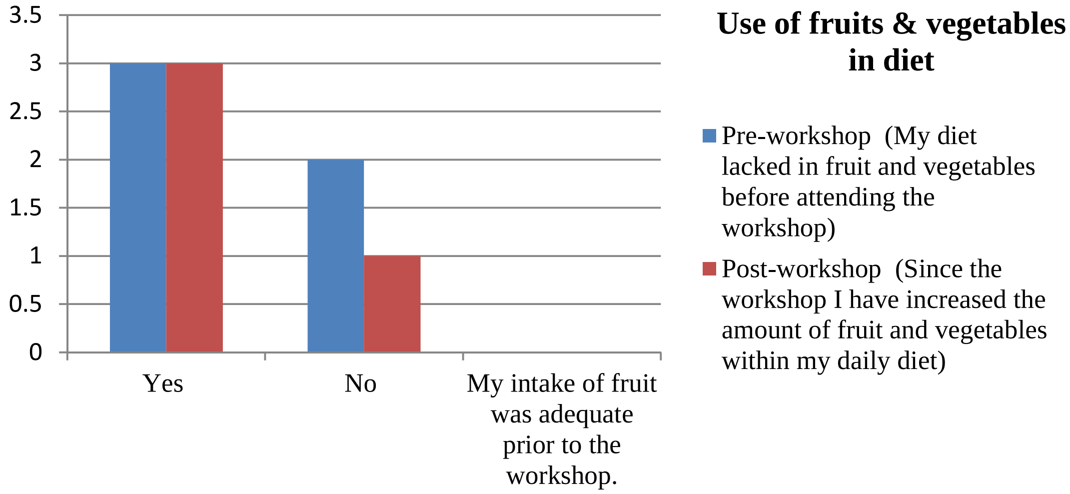

Figure 15: Comparison of the health behaviour change related to eating fruit and vegetables between pre and post workshop.

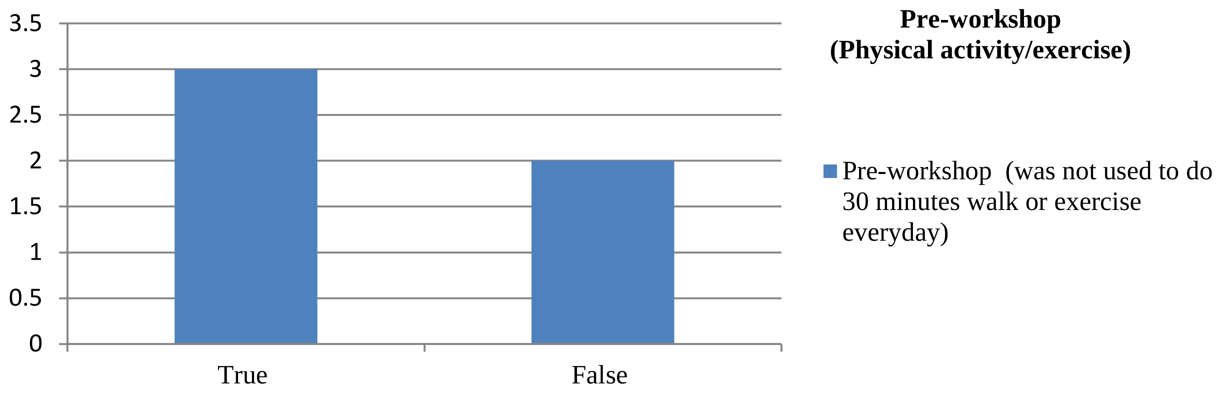

Figure 16a: Patients’ responses related to conducting a physical activity or exercise before the workshop.

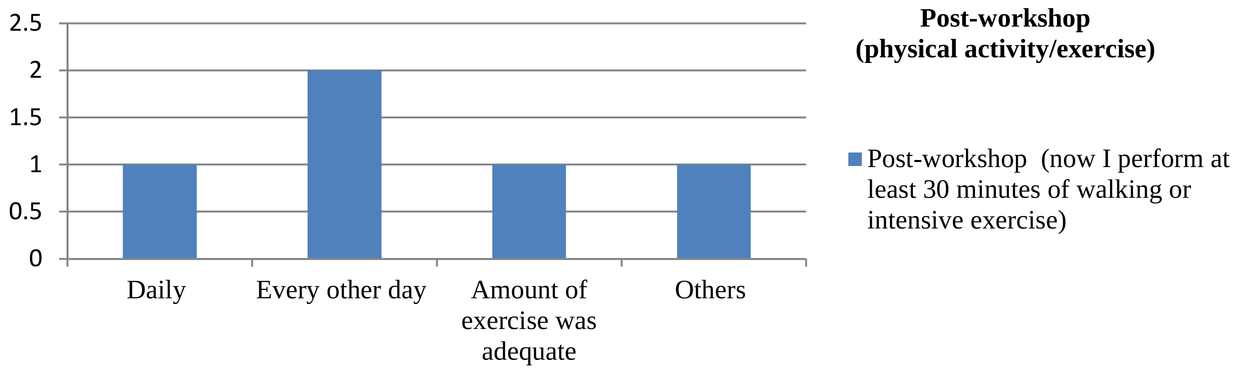

Figure 16b: Patients’ responses related to conducting a physical activity or exercise after the workshop.

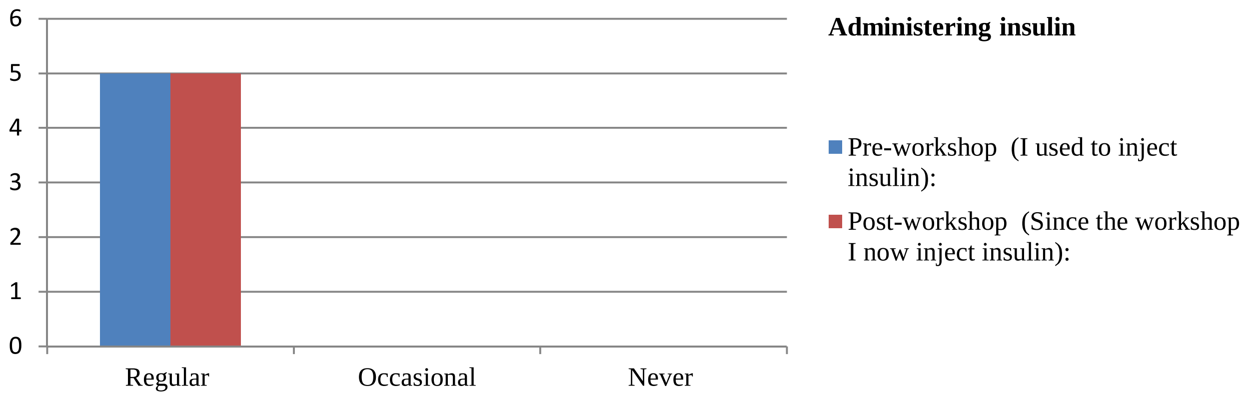

Figure 17: Comparison of the health behaviour change related to injecting insulin between pre and post workshop.

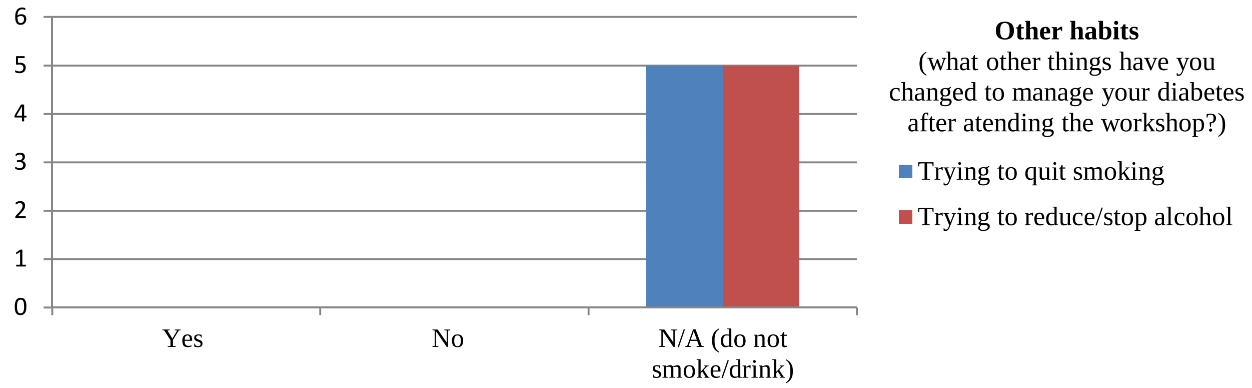

Figure 18: Patients' responses related to smoking and alcohol after attending the workshop.

Discussion

The current one-stop workshop was based on medical, psychological and social aspects of diabetes management. It focused upon increasing awareness about different aspects of diabetes self-care (e.g. carbohydrate counting, exercise/physical activity, communication, HbA1c, diabetes complications, depression, pregnancy, quitting/stopping smoking and alcohol) and equipping participants with some useful information and skills (social & psychological) to overcome some of the potential diabetes self-care related barriers, they might have at this stage. As diabetes self-management education (Mulcahy, Tomky, Maryniuk, Greene, MacDonald et al., 2003) aims to make the person with diabetes an active member of their diabetes team and to improve health status by empowering the person with diabetes to:

- Acquire knowledge (what to do)
- Acquire skills (how to do it)
- Develop confidence and motivation to perform appropriate self-care behaviour (want to do it)
- Develop problems solving and coping skills to overcome barriers to self-care (can do it)

Everett, Jenkins, Kerr and Caven (2003) suggested that information and education provide some skills that an individual can use to develop and maintain a sense of control regarding their diabetes management, but psychological skills training is required to ensure that control is maintained across all aspects of their life. Since the advent of the type 1 education network between Diabetes UK and the Royal College of Psychiatrists, it is increasingly accepted that interventions for people with type 1 diabetes should consider the social and psychological impact of living with type 1 diabetes (Knight, Bundy & Morris, 2003). This is supported by research suggesting that the emotional impact of diabetes can delay psychological adjustment and the adoption of effective self-care management skills (Plank, Kohler & Rakovac, 2004; Bradley, Todd, Gorton, Symonds & Martin, 1999). However, in the absence of severe psychological morbidity or clinically detrimental glycaemic control, support to reduce the psychological impact of diabetes is often limited (Cavan & Trigwell, 2003).

Research exploring the needs of individuals with type 1 diabetes suggests that they require skills to manage the psychological impact of diabetes that enable them to deal more effectively with the demands imposed by the condition (Cavan & Trigwell, 2003). Ellis, Naar-King, Frey, Templin, Rowland et al., (2004) and Gage et al. (2004) also concluded that the inclusion of cognitive reframing techniques and psychosocial education has made significant improvements to diabetes self-care management for adults and young people (Booker, Morris & Johnson, 2008).

Nonetheless, the current pilot workshop demonstrated quite effective outcomes in terms of engaging participants in the workshop sessions, facilitating them to bring in some potential behavioural changes in their lifestyle and informing services about what adolescents expect from the future workshops. However, there were some drawbacks in the design of this pilot workshop. For instance, no control group was included to assess the efficacy of this pilot workshop on participants’ diabetes management or behaviour change, so the outcomes observed may not be solely due to the workshop itself.

Participants’ post workshop responses were assessed via a self-reported measure rather than using qualitative methodology (i.e. interviews) to explore in-depth understanding of any potential post-workshop behavioural changes related to diabetes management. Although this pilot workshop consisted of delivering education, related to medical, psychological and social aspects of diabetes management, it lacked exploring beliefs and barriers of adolescents in diabetes management, which can be identified through qualitative psycho-educational workshops or interventions in the future.

In the literature a series of 4 workshops (not published in a peer review journal) tackling the similar area was discovered for young adult patients with type 1 diabetes, by the name of *‘getting sorted’* self care model in the Bradford NHS, teaching Primary Care Trust (Webster, 2007). In the development of these workshops, the expert patient programme[3] (EPP) or approach (endorsed by the Department of Health (DoH), 2002) was adopted in terms of using the EPP trained young workshop facilitators. However, the EPP could not be utilised due to insufficient financial and human resources to train the young adults with the diabetes management related knowledge and skills to become workshop facilitators. Nonetheless, the ethos of the ‘getting sorted’ project was to actively engage young people at every stage and for young people themselves to design and deliver the programme. The focus of the 4 workshops was to explore the impact of the condition on a young person’s life, and to encourage, support and facilitate the development of self care activities via social and interactive activities suggested by the patients. The outcome of these workshops was evaluated via focus group, which demonstrated that participants thoroughly enjoyed the experience of the workshops, but not structured or behavioural outcomes were aimed to be achieved at the end of all four workshops.

However, the findings of the current pilot workshop suggests including activities based on the medical/physical, psychological and social aspects of diabetes to enhance patients’ knowledge and skills and delivering them in interactive/collaborative ways by considering patients’ needs and perspectives. As the standard five in the National Service Framework states to provide support to young people to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development (DoH, 2002).

Challenges in implementing community-based group workshop

In this section, we will explain some of the pragmatic issues and challenges; we faced in planning the workshop with adolescents using a group format. In addition, we will offer some potentially practical suggestions to address those identified issues.

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[3] EPP: It was a generic programme, developed for adult patients with chronic illnesses. It consists of 2.5 hour long 6-8 sessions, based on group and community setting, facilitated normally by those people who have the illnesses.

Recruitment

Participant recruitment and retention is a challenge for many projects regardless of the particular workshop methods. In implementing the one stop workshop, we utilized multiple avenues to reach out to potential participants including posting information, reminder telephone calls and advertisement via distributing posters and small cards in the hospital's diabetes wards, paediatric and adult diabetes clinics and local surgeries. Of these strategies, telephone reminders were found to be most effective in comparison to other methods, as some parents responded to the telephone calls and informed their children to contact via e-mails or telephone to the workshop co-ordinator. However, this may not be an ideal option to pursue, when a project require contacting a large number of patients at least twice after sending the information by one person only. Alternatively, patients' friendly and exciting leaflets, posters or text messages (if have consent from the patients) accompanied by face-to-face verbal encouragement and reinforcement from respected adults (e.g., parents, clinicians) can be employed as a pathway to communicate to target population directly. Partnership with clinicians to encourage the target group (face to face) to attend a particular workshop can also be very effective. However, securing sustainable commitment from clinicians can also be quite challenging because of their clinical overload. In addition, posting information to a large number of patients (if they have lost the previous one) more than once was not feasible due to having a limited funding for this project. Due to this barrier, patients were sent information via e-mails, particularly to those who had given consent already to the clinics.

It is important to remember in this stage that parents are not the sole decision makers related to their teens' workshop participation. As a rule, we asked adolescents' assent along with parental consent for under 18, though this project was registered as a service evaluation. Securing adolescent assent is an important procedure in projects not only because it addresses human subject protection but because it signifies the researchers/coordinators' developmental sensitivity respecting adolescents' individuality and independence. From our own experience, most parents expressing an interest in having their adolescents participate in this workshop.

Follow-up contacts with adolescents, however, create an additional challenge as many parents were unaware of their adolescents' detailed schedule besides their routines and special events. As a result, workshop co-ordinator had to make multiple contacts with adolescents and parents until the recruitment was completed. In this workshop, it took at least 3 attempts to contact 174 patients before the confirmation of participation was received from the 17 patients. It was quite a challenging procedure to find patients available on the phone, particularly due to summer time, college exams and patients’ other commitments, such as working until 6pm during a week and away from home at the weekends. Therefore, it is important for researchers/workshop coordinators to anticipate the extended time and increased number of attempts needed to communicate for recruitment and beyond in adolescents’ programmes.

Planning the group workshop

Timing is a crucial consideration in planning a group workshop. It requires a great deal of coordination in scheduling the time for the programme in order to accommodate the availability of a target group. Many adolescents have multiple demands on their time including school, after school activities, sporting events or part-time employment. It is important to be possibly aware of the conflicting events or commitments that could affect the availability of a large proportion of the sample and to make every attempt to avoid the conflict. For example, in the UK, high schools and colleges have a fixed term from May to June for annual exams. Unfortunately, due to exam revision terms in schools and colleges, a large number of patients could not afford to attend the workshop. Therefore, summer months may be tempting to plan group workshops; however family vacations and summer school or employment can also interfere with availability to participate in a workshop. Determining the best timing is a challenge, yet careful consideration of anticipated conflicts germane to situations involving the majority of adolescents can assist co-ordinators in making informed decisions in that regard.

Although some time-related difficulties can be anticipated, weather conditions tend to be more unpredictable. Some community-centred group workshops involving outdoor activities are more susceptible to weather situations. Even when group workshops take place indoors, weather conditions can still affect participants’ motivation and ability to attend the group sessions. The weather condition that we encountered was unusually very nice for the season (i.e., middle of June in the east of England), and engaging participants in the indoor program was not a challenge, which could be due to giving them quite frequent breaks. However, it is important to take into consideration potential weather effect in scheduling and be flexible in modifying the programme sites, dates and planned activities as needed. If outdoor activities are written into the protocol, an indoor facility should be available as a backup in case untoward weather conditions interfere with the original plan.

In planning a group workshop, coordinators/researchers need to make a decision regarding how to space the program – a one day session of consecutive long hours or multiple sessions spread out over several days. Either option presents its own pros and cons. Our 'one stop workshop' was a single day program offered from 11 am to 4 pm. By adopting this strategy, we were able to address concerns for subject attrition or inconsistent attendance patterns that might have been inevitable if offered over several days. Although a few hours long workshop requires as much co-ordinations and efforts as a full day workshop, there is more probability to gain adolescents' interest to attend a few hours long workshop in comparison to a full day workshop. We observed active group dynamics and informal social networks being established among participating adolescents as they engaged in the sessions throughout the workshop.

However, we anticipated that the 4 hour long option might cause participant boredom or fatigue potentially diminishing the workshop effect. Thus, we arranged sessions of an entertaining nature to sustain participant interest and attention such as a working in teams to win a prize. Although we tried to provide as much interactive activities as we could in a limited funding, some patients verbalized dissatisfaction with available options due to their diverse range of interest and preferences. To maximize participants' satisfaction (particularly adolescents) within a limited budget, a thorough survey of their entertainment preferences in advance can be advantageous.

Location of the group workshop

Selecting a location for the group workshop is the most important process. Feasibility of a workshop depends, if not entirely, on the atmosphere that produces conduciveness to learning and group interactions. When a goal of the intervention is to capitalize on group dynamics among participants, settings of an informal nature such as community centres or camps are desirable instead of schools, or governmental facilities. It is crucial to have access to the workshop space and ensure there is enough free parking available for the patients and their parents. The workshop coordinator made a special trip to the selected community centre prior to the workshop day, to become familiarized with the facility and to ensure the proper set-up including audio-visual equipment, seating arrangements, parking access, participant drop-off and pick-up, and other details.

In regards to travelling to the workshop venue, patients were happy to make their own arrangements by their parents, relatives or friends. However, if patients require any transportation to get to the workshop venue, it is deemed important for the workshop planners to consider about the budget and allow flexibility to accommodate the high cost of reimbursing travel expenses or making transport arrangements for the patients.

Managing the group intervention

It was quite a challenging task for a single person to manage the administrative tasks, recruit patients and make arrangements for the workshop day. Therefore, it is worth considering utilizing extra personnel entirely devoted to the group event, which allows time for coordinators to focus on the scientific aspects of the group intervention.

Although, this workshop was facilitated by the HCPs, the outcome in terms of patients' interaction, involvement in the sessions, activities and discussion on the workshop day was remarkable. However, adolescents can be used as facilitators for the group workshops. As literature has supported the approach of peer education, particularly in programs targeting adolescents given it developmental relevance (Backett-Milburn & Wilson, 2000; Mellanby, Rees, & Tripp, 2000; Ozer, Weinstein, Maslach, & Siegel, 1997). The peer leader approach is developmentally salient and has important implications for group interventions targeting adolescent populations, though it can be a scrutinising process to recruit (Rhee et al., 2008).

Evaluation method

When targeting adolescents and some feedback is required at the end of a programme to analyse their perspectives or experiences, it is very important to focus upon choosing an appropriate evaluation methodology, e.g. qualitative (semi-structured or focus group interviews) or quantitative (close ended or multiple choice questions). For the current workshop, quantitative method was chosen including not only close ended questions, but also some open ended questions to find out adolescents' perspectives related to their experiences on the workshop day. This method was adopted (in comparison to interviewing adolescents) by considering about some adolescents' exam revision days and due to insufficient staff and funding.

Use of open-ended questions in the feedback sheet was not found very effective, as majority of the adolescents did not write anything to answer those questions. However, adolescents almost responded to all the questions in the feedback sheets, where they were given multiple choices to pick. So it was discovered that the workshop attendees might not be as confident in their written communication skills as in their verbal communication skills, thus to give multiple option questions in the future.

On the other hand, it was quite a challenging task to contact workshop attendees after the completion of the workshop to identify what they experienced and the changes that they had made to their self-management regimens. As attendees were contacted via telephone and e-mails by HCPs after two weeks of the workshop, but no response was received via e-mails and nobody was available on the telephone. Thus, a quantitative method (multiple choice based post workshop form) was utilised and the post workshop forms were posted to all attendees' homes with a pre-addressed and stamped envelopes to return their responses back to us. This method was found very effective in terms of a high uptake of attendees' responses. Although we suggest including quantitative format for the feedback forms, it might differ with different individuals and the current workshop' findings cannot be generalised to all adolescents as the number of attendees was quite low.

Some general key points learnt

- Non-NHS based setting with free parking
- Accessible venue
- The importance of listening and how to deal with resistance
- Reflective questioning
- Use more interactive tools to meet teenagers' needs
- Use of technology (e.g. e-mails, telephone, printed cards, posters) to inform patients and to advertise the workshop
- Use age friendly writing style
- Provide free lunch
- Give frequent breaks
- Develop some memories (group photographs after consents)
- Design a good ending (quizzes & prize draw)

Conclusion and recommendations

The current pilot workshop was based on patient-centred approach. It was developed to find out a potentially feasible and optimal methodology to deliver education by multidisciplinary team related to all aspects of type 1 diabetes (e.g. medical, psychological & social) to adolescents by considering their potential needs or requirements and to engage adolescents in discussions in a group setting. The outcome of this workshop was potentially cost-effective, as it was completed in a limited budget and was found quite effective due to a number of reasons:

- The number of attendees was reasonable on the workshop day, (as majority of the selected patients could not attend due to exam time and other commitments in summer).
- All attendees not only enjoyed the atmosphere, liked the setting, but also actively participated in the workshop.
- Patients' responses after 4 weeks within completion of the workshop demonstrated that they had developed some changes in their behaviour/lifestyle in regards to managing their diabetes, though the workshop was very short and we did not expect maintenance of the outcome on long term basis.

As majority of the patients appreciated the idea of attending the workshop with a group of people with the same illness and similar age group, a group approach can be used in the future by giving importance to peer interaction in many aspects of adolescent life. A group approach that capitalizes on group dynamic and promotes constructive interactions among participants could be a viable option for a program development of adolescents. Despite its theoretical advantages, a group programme/workshop encompasses an array of pragmatic challenges that can be addressed or overcome through precise planning.

This report not only describes experiences of developing and evaluating the pilot workshop, but it also highlights some of potential difficulties and logistics pertaining to a group approach targeting adolescents and suggests general strategies that can be adopted in undertaking such projects. When these challenges and caveats are adequately addressed, group approaches not only afford coordinators an exceptional opportunity to enhance treatment effects but also provide adolescent participants with a safe environment where they can actively engage in establishing a social network.

Overall this pilot workshop incorporated and demonstrated the value of patient-centred approach and enabling individuals to identify their own goals to change their behaviour. Findings of the current pilot workshop were quite positive and much was learnt about what young people want from a multi-component self care education based programme in terms of its setting, mode of delivery and overall environment. Although the evaluation indicated positive health outcomes for those young people who attended the pilot workshop, it is not yet known that how the current model used in the ‘one stop workshop’ will shape future service provision. Future research is also required to develop and refine the mode of delivery and the content of the workshop.

A recommendation for the future work is to deliver at least 3 individual workshops (1: diet, exercise, pregnancy, smoking, alcohol 2: metabolic control/HbA1c, diabetes complications, administering insulin, 3: communication, stress/depression, eating problems, body image, relationships, problem solving, medication adherence) rather than one workshop to tackle various needs of different individuals. In addition, a one year randomised controlled trial can also be undertaken to determine whether the individual workshops can effectively improve medical outcomes, reduce incidences of non-attendance in the clinic, reduce admission to the hospital’s Accident & Emergency department and improve self efficacy of adolescents with type 1 diabetes. Before starting any workshop, it is essential to assess a target group’s needs related to their age via semi-structured or focus group interviews, as the age group between 15 to17 might have different requirements, barriers and beliefs to self-management of diabetes in comparison to 18-20.

References

Anderson, B.J., Auslander, W.F., Jung, K.C., Miller, J.P. and Santiago, J.V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Paediatric Psychology, 15,* 477-492.

Allen, D.A., Tennen, H., McGrade, B.J., Affleck, G. and Ratzan, S. (1983). Parent and child perceptions of the management of juvenile diabetes. *Journal of Paediatric Psychology, 8,* 129–41.

Allen, C., Zaccaro, D. J., Palta, M., Klein, R., Duck, S. C. and D'Alessio, D. J. (1992). Glycemic control in early IDDM. The Wisconsin Diabetes Registry. *Diabetes Care, 15,* 980–987

Barlow, J., Swaby, L. and Turner, A. (2007). *Evaluation of a Pilot Supporting Parents Programme for Parents/Guardians of Children with Long Term or Life Limiting Conditions*. Coventry University: Coventry.

Backett-Milburn, K. and Wilson, S. (2000). Understanding peer education: Insights from a process evaluation. *Health Education Research, 15*(1), 85–96.

Bagner, D.M., Williams, L.B., Geffken, G.R., Silverstein, J. H. and Storch, E.A. (2007). Type 1 diabetes in youth: the relationship between adherence and executive functioning. *Child Health Care, 36*, 169–179.

Berg, J., Tichacek, M. N. & Theodorakis, R. (2004). Evaluation of an educational program for adolescents with asthma. Journal of School Nursing, 20, 29–35.

Betts, P., Buckley, M., Davies, R., McEvilly, E. and Swift, P. (1996). The care of young people with diabetes. *Diabetic Medicine*, *13*(4), S54–S59.

Booker, S., Morris, M. and Johnson, A. (2008). Empowered to change: evidence from a qualitative exploration of a user-informed psycho-educational programme for people with type 1 diabetes. *Chronic Illness, 4,* 41-53.

Bradley, C., Todd, C., Gorton, T., Symonds, E., Martin, A. and Plowright, R. (1999). The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: the ADDQoL. *Quality of Life Research*, *8*(1-2), 79-91.

Bruzzese, J.M., Bonner, S., Vincent, E., Sheares, B., Mellins, R.B., Levison, M.J., Wieseman, S., Du, Y., Zimmerman, B.J. and Evans, D. (2004). Asthma Education: The Adolescent Experience. *Patient Education and Counselling*. *55,* 396-406.

Butler, K. and Cooper, W.O. (2004). Adherence of paediatric asthma patients with oral corticosteroid prescriptions following paediatric emergency department visit of hospitalization. *Paediatric Emergency Care, 20*, 730–735.

Coles, C.R. (1996). Psychology in diabetes care. *Practical diabetes international, 13*(2), 55-7.

Cavan, D. and Trigwell, P. (2003). Addressing the psychological aspects of diabetes – core service or optional extra? *Practical Diabetes International*, *20*(5), 163.

Clark, N.M. and Gong, M. (2000). Management of chronic disease by practitioners and patients : are we teaching the wrong things? *British Medical Journal*, *320*, 572 - 575.

Day, J.L. (2000). Diabetic patient education: determinants of success. *Diabetes/Metabolism Research Reviews*, *16*(1), 70–s74.

Department of Health. (2002). *The Expert Patient, a new approach to chronic disease management for the 21st Century*. Department of Health. London. HMSO.

Department of Health. (2007). *Making Every Young Person with Diabetes Matter: Report of the Children and Young People with Diabetes Working Group*. London: Department of Health.

Diabetes UK, Care Recommendations. (2003). Retrieved on November 2010 from https://www.diabetes.org.uk/documents/professionals/patient_education.doc.

Diabetes Control and Complications Trial Research Group (1994). The effect of intensive treatment of diabetes on the development. *Diabetes Care*, *17*, 339-344

Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group. (2000). Retinopathy and Nephropathy in Patients with Type 1 Diabetes Four Years after a Trial of Intensive Therapy. *New England Journal of Medicine*, *342*, 381-9.

Diabetes Control and Complications Research Group. (1994a). Diabetes Control and Complications trial (DCCT): Update. *Diabetes Care, 13*, 427-433.

Diabetes UK, Care Recommendations. (2003). *Education of people with diabetes*. Diabetes UK: London.

Ellis, D. A., Naar-King, S., Frey, M., Templin, T., Rowland, M., Greger, N. (2004). Use of multi-systemic therapy to improve regimen adherence among adolescents with T1D in poor metabolic control: a pilot investigation. *Journal of Clinical Psychology in Medical Settings*, *11*,315–324.

Engel, G. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*, 129-136.

Everett, J., Jenkins, E., Kerr, D. and Cavan, D. A. (2003). Implementation of an effective outpatient intensive education programme for patients with type 1 diabetes. *Practical Diabetes International*, *20*, 51–55.

Elasy, T., Ellis, S., Brown, A. and Pichert, J. (2001). A taxonomy of diabetes educational intervention. *Patient education Councils, 43*, 121-127.

Fawcett, B. (2000). Look, Listen Learn. *Community Care*, 27th July -2nd August, 24-5.

Flack, A., Kaar, M.L. and Laatikainen, L. (1996). A prospective study examining the development of retinopathy in children with diabetes. *Acta Paediatric, 5*, 313–319.

Gage, H., Hampson, S., Skinner, T. C., Hart, J., Storey, L. and Foxcroft, D. (2004). Educational and psychosocial programmes for adolescents with diabetes: approaches, outcomes and cost-effectiveness. *Patient Education Councils, 53*(3), 333-46.

Gaudieri, P.A., Chen, R., Greer, T.F. and Holmes, C.S. (2000). Cognitive function in children with type 1 diabetes: A meta-analysis. *Diabetes Care, 31*, 1892–1897

Gibson, P.G. (2000). Educating adolescents about asthma. *Chest, 118*, 514.

Gioia, G.A., Isquith, P.K., Guy, S. C. and Kenworthy, L. (2000). Behaviour rating inventory of executive function. *Child Neuropsychology, 6*, 235–238.

Goldstein, D., England, J., Hess, R., Rawlings, S. and Walker, B. (1981). A prospective study of symptomatic hypoglycaemia in young diabetic patients. *Diabetes Care, 4*,601-605.

Glasgow, R.E., Strycker, L.A., Hampson, S.E. and Ruggiero, L. (1997). Personal model beliefs and social environmental barriers related to diabetes self-management. *Diabetes Care, 20*(4), 556-561.

Glasgow, R.E. and Anderson, R.M. (1999). In diabetes care, moving from compliance to adherence is not enough. *Diabetes Care, 22*(12), 2090–2091.

Hawley, K. (2005b). *Report on the Expert Patient Programme Parent Pilot Course January 2004-January 2005*. London: Expert Patient Programme.

Hampson, S.E., Glasgow, R.E. and Foster, L.S. (1995). Personal models of diabetesa mong older adults: Relationship to self-management and other variables. *The Diabetes Educator, 21*(4), 300-307.

Helgeson, V.S., Siminerio, L., Escoba, O. and Becker, D. (2007). Predictors of metabolic control among adolescents with diabetes: a 4-year longitudinal study. *Journal of Paediatric Psychology, 34*, 254–270.

Knight, K.M., Bundy, C., Morris, R., Higgs, J.F., Jameson, R.A., Unsworth, P. and Jayson, D. (2003). The effects of group motivational interviewing and externalizing conversations for adolescents with Type-1 diabetes. *Psychology, Health & Medicine, 8*, 149-157.

Kovacs, M., Charron-Prochownik, D. and Obrosky, D.S. (1995). A longitudinal study of biomedical and psychosocial predictors of multiple hospitalizations among young people with insulin-dependent diabetes mellitus. *Diabetic Medicine, 12*, 142–148.

Kyngas, H., Hentinen, M. and Barlow, J. (1998). Adolescents’ perceptions of physicians, nurses, parents and friends: Help or hindrance in compliance with diabetes self-care? *Journal of Advanced Nursing, 27*,760–769.

Kyngas, H. and Rissanen, M. (2001). Support as a crucial predictor of good compliance of adolescents with a chronic disease. *Journal of Clinical Nursing*, *10,*767-774.

La-Greca, A.M., Follansbee, D.S., and Skyler, J.S. (1990). Developmental and behavioural aspects of diabetes management in children and adolescents. *Children's Health Care, 19,* 132-139.

Lamb, W.H. (1997). Aetiology, epidemiology, immunology, environmental factors, genetics and prevention. In: Court, S. & Lamb, B., editors. *Childhood and adolescent diabetes.* Chichester: John Wiley & Sons.

Logan, D., Zelikovsky, N., Labay, L. and Spergel, J. (2003). The Illness Management Survey: identifying adolescents' perceptions of barriers to adherence. *Journal of Paediatric Psychology, 28,* 383–392.

McNally, K., Rohan, J., Pendley, J.S., Delamater, A. and Drotar, D. (2010). Executive functioning, treatment adherence, and glycemic control in children with type 1 diabetes. *Diabetes Care, 33*, 1159–1162.

McIntosh, A., Withers, H. and Hutchinson, A. (2000). *Systematic review on the effectiveness of patient education interventions in the management of type 2 diabetes*. Sheffield: ScHARR.

Mühlhauser, I., Bott, U., Overmann, H., Wagener, W., Bender, R., Jörgens, V. and Berger, M. (1995). Liberalized diet in patients with type 1 diabetes. *Journal of International Medicine, 237*(6), 591-7.

Marks, D.F., Murray, M., Evans, B., Willig, C., Woodall, C. and Sykes, C. (2005). *Health Psychology. Theory, Research & Practice (2nd Ed.).* London: SAGE Publications.

Morris, A.D., Boyle, D.I., McMahon, A.D., Greene, S.A., MacDonald, T.M. and Newton, R. W. (1997). Adherence to insulin treatment, glycaemic control and ketoacidosis in insulin-dependent diabetes mellitus. The DARTS/MEMO Collaboration. Diabetes audit and research in Tayside Scotland. Medicines monitoring unit. *Lancet, 350,* 1505–1510.

Mellanby, A.R., Rees, J.B. and Tripp, J.H. (2000). Peer-led and adult-led school health education: A critical review of available comparative research. *Health Education Research, 15*(5), 533–545.

Mulcahy, K., Tomky, D., Maryniuk, M., Weaver, T., Peyrot, M. and Peeples, M. (2003). Diabetes Self-Management Education Core Outcomes Measures. . *The Diabetes Educator, 29*(5), 768-803.

Norris, S.L., Engelgau, M.M. and Narayan, K.M. (2001). Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. *Diabetes Care*, *24*(3), 561-87.

Roberts, S. (2007). *National Diabetes Support Team. Improving Diabetes Services: The NSF Four Years On. The Way Ahead: The Local Challenge*. London: DH.

Onkamo, P., Vaananen, S., Karvonen, M. and Tuomilehto, J. (1999). Worldwide increase in incidence of type I diabetes—the analysis of the data on published incidence trends. *Diabetologia*, *42*, 1395-403

Ozer, E.J., Weinstein, R.S., Maslach, C. and Siegel, D. (1997). Adolescent AIDS prevention in context: The impact of peer educator qualities and classroom environments on intervention efficacy. *American Journal of Community Psychology*, *25*(3), 289–323.

Olsen, R. and Sutton, J. (1998). More hassle, more alone: adolescents with diabetes and the role of formal and informal support. *Child Health Care and Development*, *24*(1), 31–9

Plank, J., Köhler, G., Rakovac, I., Semlitsch, B. M., Horvath, K., Bock, G., Kraly, B. and Pieber, T. R. (2004). Long-term evaluation of a structured outpatient education programme for intensified insulin therapy in patients with Type 1 diabetes: a 12-year follow-up. *Diabetologia, 47*(8), 1370-5.

Rickheim, P.L., Weaver, T.W., Flader, J.L. and Kendall, D.M. (2002). Assessment of group versus individual diabetes education: a randomized study. *Diabetes Care*, *25*(2), 269–274.

Rhee, H., Ciurzynski, S. M., & Yoos, H. L. (2008). Pearls and pitfalls of community-based group interventions for adolescents: Lessons learned from an adolescent asthma CAMP study. *Issues in Comprehensive Paediatric Nursing*, 31(3), 122–135.

Salinas, M. (2007). *Evaluation Study of the Staying Positive Pilot Workshops: A Self-Management Programme for Young People with Chronic Conditions*. Department of Public Health, University of Oxford: Oxford, UK.

St Vincent Joint Task Force for Diabetes. (1999). European Diabetes Policy Group. A desktop guide to type 1 (insulin dependent) diabetes mellitus. *Diabetic Medicine*, *16*, 253–67.

Skinner, T.C. and Hampson, S.E. (1998). Social support and personal models of diabetes in relation to self-care and well-being in adolescents with type 1 diabetes mellitus. *Journal of Adolescents,* 703–15.

Skinner, T.C., John, M. and Hampson, S.E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. *Journal of Paediatric Psychology*, *25*, 257–67.

Thompson, C.J. & Greene, S. A. (1997). Diabetes in the older teenager and young adult. In: Court, S. & Lamb, B, editors. *Childhood and adolescent diabetes*. Chichester: John Wiley & Sons. p. 67–86.

Thompson, C.J., Cummings, F., Chalmers, J. and Newton, R.W. (1995). Abnormal insulin treatment behaviour: a major cause of ketoacidosis in the young adult. *Diabetic Medicine, 12*, 429–32.

Trollvik, A. and Severinsson, E. (2005). Influence of an Asthma Education Program on Parents with Children Suffering from Asthma. *Nursing and Health Sciences*, *7*, 157-163.

Weissberg-Benchell, J. and Antisdel, J.E. (2000). Balancing developmental needs and intensive management in adolescents. *Diabetes Spectrum*, *13*, 88–94.

Williams, P.G., Holmbeck, G.N. and Greenley, R.N. (2002). Adolescent health psychology. *Journal of Counselling and Clinical Psychology*, *70*, 828–842.

Wysocki, T. Greco, P. and Buckloh, L. (2003). Childhood diabetes in psychological context. In: Roberts, M., editor. *Handbook of Paediatric Psychology*. 3rd ed.. New York, NY: The Guilford Press. 304-320.

Webster, L. (2007). *Development and Evaluation of the 'Getting Sorted' Self. Care Workshops for Young People with Diabetes. Faculty of Health*. Leeds metropolitan university, Leeds. Retrieved on 9/11/10 from: www.leedsmet.ac.uk/carnegie/files/FinalSelfCareReport.pdf

Wysocki, T., Clarke, W.L., Meinhold, P.A., Bellando, B.J., Abrams, E.C. and Bourgeois, M.J. (1992). Parental and professional estimates of self-care independence of children and adolescents with IDDM. *Diabetes Care*, *15*, 43–52.

Whittemore, R. (2000). Strategies to facilitate lifestyle change associated with diabetes mellitus. *Journal of Nursing Scholarship*, *32*, 225-232.

Appendix A

Workshop invitation & information sheet

March 2011

Dear Hosp No:

Workshop for Young People with Diabetes
'One-Stop Workshop' to help you get yourself sorted

Invitation:

You are invited to take part in the 'One Stop Workshop'
This is your day and a chance to enjoy and explore
The workshop will last for about 4 hours on a Saturday
We will send you more detail about time and venue if you are interested
You will have lunch and then time to talk afterwards
You will definitely get more knowledge about Type 1 diabetes
You can share your experiences and learn from others

What to expect:

A meeting of people with similar concerns in a friendly community setting
A warm welcome from staff who you may know from [redacted]
Some 'ice breaking' interaction to get to know each other
Some useful information about Type 1 diabetes
A shared pizza lunch (or bring along something you like)
Fill out 2 questionnaires about the support from friends & family.

Who will be there?

Other young people with Type 1 diabetes with their stories to share
The workshop is for ages 15 to 20
Some people will be thinking about moving from paediatrics to the adult clinic
…and some will be attenders at the young adult clinic
Some nurses and dieticians
The project developers who are both psychologists

What you should do next: Well are you interested in coming along?
☺ **If 'YES' then send back the feedback form included with this letter…..we have given you a stamped envelope to make this super easy.**
☺ **If 'NO' and you are not interested in attending but would like to make some comments, please use the feedback form in the envelope provided.**
By the way, what if a parent or friend wants to come along to drop you off:

If this is relevant for you…..parents or maybe a friend can come along for the last hour but will be in another room to meet each other over a cup of tea or coffee. A member of staff will be there if they have informal questions.

Please reply within the next few weeks by date: **01/04/2011**

So we can fix a date for the workshop.

Contacting us:

☎

💻

Please do not hesitate to contact us and Kalsoom will be happy to answer your questions.

👍 **We look forward to hearing from you soon** 👍

[redacted], Consultant Clinical Psychologist

And

Kalsoom Akhter, Health Psychologist in Training

Appendix B

Response form

Feedback Form for 'One Stop Workshop' On Type 1 Diabetes

Please send this sheet back in the envelope provided ⇨ 🖃

☺ Thank you… this will let us know about your thoughts on this 'One Stop Workshop' we are planning

Name……………………………………………………………………………….

Address……
……………

Contact phone number…………………………………………………Contact e-mail……………………………………

Now, without making any commitment … would you be interested in coming to a Saturday 'One Stop Workshop' in a community centre in [redacted]?

'Yes' ☐ 'No' ☐

If you say **'Yes'** you will be sent further information

If you say **'No'** please tick which of the following is a problem for you

1. Weekend timing?
2. Travel to [redacted]?

3. Don’t like the idea of meeting others with diabetes to share stories
4. Not needed ‘I am satisfied with my diabetes management’

Other problems?

Please let us know……………………………………………………………………………………………….

……

If you could choose two things you feel you could learn more about your diabetes, what would they be?

1. ……

2. …….

Thank you! We are really grateful for your time taken in sending this to us at:

Appendix C

Invitation to participants (who agreed to attend the workshop)

Workshop Project Contact:
12th May 2011

Dear Hospital No:

"One-Stop Workshop for Type 1 diabetes"

Thank you for letting us know that you would like to attend the workshop for young people that we are planning in a community centre in Cambridge. I am now writing to invite you to take part in this workshop and the details are below. We hope you enjoy this experience with other young people, who have Type 1 diabetes. You will have an opportunity to discuss your thoughts about your diabetes with each other and with health professionals who will be there at the workshop (e.g. nurses, dieticians & psychologists). Some of you have already asked questions and these will be answered on the day – 11th June '11.

Please see the attached timetable and venue information for this workshop. Your parents or maybe a friend of yours can come along for the last hour of the workshop (from 3pm to 4pm). They will be in another room to meet each other over a cup of tea or coffee. A member of staff will be there if they have informal questions.

☺ Your attendance on 11th of June will help us to make our Workshop a great success!

You are welcome to contact Kalsoom, if you have any question related to this workshop.

Contacting us:

☎

💻

👍 **We look forward to meet you on Saturday, 11th of June 2011** 👍

Please contact us at least a day before, if you cannot come to attend this workshop so we can change the arrangements – we need to know how many to cater for.

NB. If you would like to bring your own lunch please feel free, but let us know.

Appendix D

Consent form

Parental/patient agreement to a workshop for a young person under 18 years of age

(Please send the form back in the attached/enclosed prepaid envelope before the workshop on 11th June 2011)

Title: One-Stop Workshop for Young People with Type 1 diabetes

Saturday 11th June 2011 – 10.45 to 3:30pm (see attached venue)

Brief description:

This workshop is being run in a local community centre in Cambridge by the health professional staff to help your son/daughter's his/her diabetes management. This workshop will help with support and exchange of information using a group discussion format with other young people who have the same condition. It will not have a clinical focus. Health professional will run the workshop: including diabetes consultants, nurses, dieticians and psychologists.

The aims of this workshop are to:

1. Increase awareness of health needs in the young adult population with Type 1 diabetes in the Cambridgeshire region.
2. Raise the profile of young people's priorities with regards successfully managing their health care needs.
3. To pilot alternative delivery of health care information in this population in a less medicalised setting.
4. Include the health care team in delivering health care information in this workshop format in a collaborative 'patient centred' way.

Name of young person attending workshop: …………………………………………….

Please tick the following:
I have read the information about the workshop on 11th June 2011 and kept a copy for my information. I understand that I can ask questions about the workshop if I need any further information.

☐

As Addenbrooke’s hospital is running this workshop I agree that relevant information from my son/daughter’s medical records will be known by staff but will be kept confidential in the workshop.

☐

I agree that my son/ daughters details can be stored on a secure computer database and will remain entirely confidential, seen only by the diabetes clinical team.

☐

I agree to/my child taking part in the workshop.

☐

☐

Parent/guardian’s

signature:...Date:

....

Name (Please write in capitals): ....
Patient’s signature if appropriate: ....Date:.............
Name (Please write in capitals): ....

Contact details:

Appendix E

Cards

NFWI

One Stop Workshop for Type 1 diabetes

Saturday, 11th June 2011 – ....am to ....pm

At .... Centre, ... Road,

Cambridge

All people aged 15-21 with Type 1 diabetes welcome!

Please give us your contact details, if you are interested in attending it:

Your e-mail:……………………………………………………………………..

Your telephone:…………………………………………………………………….

To get workshop details:

Tel:

Appendix F

Appendix F

Workshop sessions' content

Sessions	Aims & objectives	Mode of delivery	Assessment
'Getting to know each other'	3. To ensure young people feel safe and comfortable in the group setting so they can begin to work well together.	4. Informal introductory questions were shown on the computer screen to ask to the neighbours (by working in pairs) and later on introduce the neighbour.	
Personal stories & adults views about diabetes *Reflecting times*	5. To share experiences. 6. To form friendships	7. Group discussion.	
Carbohydrate awareness & exercise *Dietician-led*	8. The aim of this session was to provide a forum for discussion with the teenagers around issues that matter to them. 9. The most priority issues were described as 'carbohydrate (CHO) awareness' and 'exercise'. 10. The first 30 minutes were spent revising what CHO is and how CHO counting can be used to help better balance what is eaten with the amount of quick acting insulin injected. 11. The second 30 minutes were spent discussing exercise and	12. The mode of delivery was designed to be less formal and intended to spark discussion both between the groups as well as with the Health Care Professionals (HCPs). 13. Questions were posed to the audience to gauge what their experiences were to date regarding the value of CHO counting and to find what they have found works for them. This allowed the teenagers to learn from each other's experiences as well as from just what the HCP said. The ideas were rounded up verbally and with the use of a flip chart. The flip chart was used to illustrate more complex points.	Informal assessment of the thoughts, views and practices of the teenagers were made through verbal discussion between the groups. This was used to move the direction and pace of the session in a way that was more applicable and socially relevant to the groups.

	basic diabetes management points	14. A power point presentation was used to address the key learning outcomes for the exercise session.	
Communication, health and relationships *Trainee health psychologist-led*	15. Improve knowledge about different types of communication 16. Improve effective communication skills 17. Plan assertive communication and apply this in real life 18. Understand a link between communication, relationships and health	19. Collaborative discussion about communication problems with friends, parents or HCPs. 20. PowerPoint presentation was used to address the key areas of communication and its link with health and relationships. 21. Videos were played to help patients to learn about communication barriers and how to overcome them. 22. A written scenario was used to be read by participants and develop discussion by asking open ended questions related to that scenario. 23. A practical individual exercise (handout) was given to complete related to their communication problems. 24. Flip chart was used to demonstrate complex terms.	Assessment of the patients' knowledge and understanding was carried out throughout the session by verbal discussion and drawing some diagrams on the flipcharts. This method was used to make the session more interactive, engage the patients and make it more applicable for them.
Alcohol *Nurse-led*	25. To increase awareness about the impact of different types of alcohol on blood glucose levels.	26. Interactive session based on using a diagram to highlight the impact of alcohol on blood glucose levels and promote discussion.	
Diabetes Complications *Consultant-led*	27. To be aware of the long term effects of diabetes on health 28. To be aware of the positive outcomes of the 'Diabetes Control and Complication Trial'	29. Interactive session with power point presentation slides 30. The presentation was of 5 minutes duration to highlight the key points and rest of the session was answering questions and to promote discussion	
Smoking & pregnancy *Nurse-led*	31. To provide relevant information on diabetes in pregnancy, and smoking with diabetes. 32. For the attenders to have a basic understanding of the effect of poor diabetes control on pregnancy and the risks associated with smoking.	33. Interactive session using PowerPoint slides with the aim of developing discussion among group members and encouraging them to ask questions. 34. Leaflets were provided.	Assessment of understanding is made by questioning and also by feedback gathered at the end of the day.
Low mood and stress *Consultant clinical psychologist-led*	35. To increase awareness about the impact of stress and depression (low mood) on diabetes management. 36. To facilitate young adults to acknowledge how a specific way of thinking & feelings, emotions lead towards behaviour.	37. Collaborative session. 38. Handouts were provided.	Assessment of understanding is made by questioning and also by feedback gathered at the end of the day.

Table 1: Workshop sessions' content

Appendix G

Workshop programme

What's On!
Participants arrive – informal welcome – tea / coffee available
Introduction and 'get to know each other' Two things you need to know / get out of the day
Personal stories Young adults' views on diabetes
Lunch time – informal discussion overseen by Dieticians
Swapping stories carbohydrate awareness – overseen by dieticians Weight loss, exercise
Communication, health and relationships
Alcohol
Diabetes Complications

Smoking & pregnancy
Low mood and stress
Quiz
What do people expect from our services
Feedback related to the workshop
Finish

Table 2: Workshop's schedule programme

SECTION 3 - PROFESSIONAL PRACTICE

Section 3A: Teaching and Training one

Improving communication skills of young adult patients with Type 1 diabetes

Supervision Plan

Teaching and Training 1: Improving communication skills of young adult patients with Type 1 diabetes

Units in this area of competence	Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)	Supporting evidence to be complied for this unit of competence
4.1 Plan and design training programmes	**Setting:** A community centre at Cambridge on behalf of the **Client/ Target Group**: Young adolescents with Type 1 diabetes. **Description of work:** The issue of communication difficulties with young adult patients were introduced by some health professionals, as this issue affects the relationship between patients, health care providers and patients' health. I was responsible to tackle this issue. Therefore, a session was planned to teach and train communication skills using some interesting and interactive activities according to this group's needs. It included teaching different types	Content of the events. Training material used. Evaluation forms included.

	of communication styles, impact of communication on relationships and health and training to plan an assertive communication.	
4.2 Deliver training programmes	I delivered this teaching and training session by following the National Health Service (NHS) diabetes support team's (2007) guidelines and using some main components of the training: listening skills, observation, and group discussion, sharing experiences, exchanging/giving information, and a practical individual exercise.	
4.3 Plan and implement assessment procedures	Patients were asked to share an experience of explaining diabetes to someone else, which opened up discussion between group members. Such exercise served as an self-assessment of their learning needs followed by introducing aims and objectives. Patents were also asked some questions during the session about various communication styles as an assessment. Learning outcomes were assessed by asking some feedback at the end of each exercise.	
4.4 Evaluate training programmes	All those who received the training had the opportunity to complete the evaluation forms based on my teaching and comments were given.	

Target for completion: … June, 2011 … Workplace contact? Yes … If yes please give name: [redacted]

Background

My role in the diabetes clinic was to work on planning, designing and organising a workshop for young adult patients in a community centre. I delivered a teaching and training session that related to the impact of communication on health and relationships. A session was designed to provide an opportunity to young adult patients to enhance their communication skills, to maximise effective communication outcomes and to learn a new approach in facilitating health behaviour change. The teaching and training took place at a community centre in Cambridge rather than the hospital setting. This was due to considering young adults' needs and to provide them a non-medical or informal platform to share their views or experiences.

The issue of communication difficulties with young adult patients were introduced by some health professionals (e.g. a paediatric consultant, diabetes specialist nurses and dieticians), as this issue affects the relationship between patients, healthcare providers (Collins, Schrimmer, Diamond & Burke, 2011) and patients' health. Communication during medical interviews plays a large role in the patient adherence, satisfaction with care and health outcomes (Ngo-Metzger, Telfair, Sorkin, Wedimer, Weech-Maldonado & Hurtado, 2006). Both verbal and non-verbal communication skills are central to the development of rapport and trust between patients and health care professionals (Roter, Frankel, Hall & Sluyter, 2006). This is mainly because it could have a positive affect on their relationship and ultimately adherence to the treatment regime and satisfaction with care.

During my observations of the consultation between paediatric consultants and young adult patients with Type 1 diabetes, I noted that 15 out of 18 patients did not ask any questions. Not asking questions could indicate some potential verbal and non-verbal barriers in the clinic setting or lack of self-efficacy (passive attitude) to ask any questions. However, other patients did mention a few reasons for not sharing diabetes management related problems with their parents. This was mainly because their parents would get excessively worried about their health, which creates a barrier to communicate explicitly.

By considering the patients' perspectives, diabetes management requires the consistent implementing of adherence behaviours in a variety of settings. It is possible that for some adolescents, consistency may be difficult due to problems in communication and assertiveness. Some health professionals did draw attention towards young adult patients' verbal and non-verbal communication. For example, not responding to questions appropriately, or by not paying attention to what was explained to them. From this, a session was planned to teach and train communication skills, which included teaching different types of communication styles, impact of communication on relationships and health and training to plan an assertive communication.

Plan and design training programme

Facilitating young adults via a teaching and training session to:

- Improve knowledge about different types of communication (verbal, non-verbal & para-verbal, passive, assertive and aggressive).
- Improve effective communication skills.
- Plan an assertive communication and apply this in real life.

- Understand a link between communication, relationship and health.

Assess training needs

A formal need assessment was not carried out as the health professionals (a diabetes specialist nurse and a consultant) already identified a communication gap in these patients' knowledge and skills when seeing them in the clinic. As some patients do not ask any questions related to their health, and when they were asked any questions by their health care professionals, they only respond 'yes' or 'no' answers to their questions. So it was very important to run a teaching and training session related to communication to enhance young adult patients' knowledge and skills to get the optimal care they expect from the hospital services.

This session was conducted at a community centre as part of our first one-stop workshop for young adult patients with Type 1 diabetes from paediatric and adult diabetes services. According to adult and paediatric diabetes nurses and consultants, young adult patients with Type 1 diabetes, aged 15-20 year old, have been identified as a potentially *'hard to reach'* group. In essence, most of them don't turn up for their appointments, often end up going to Accident and Emergency due to diabetic ketoacidosis, have poor glycaemic control and don't communicate with their parents or healthcare professional when facing difficulties in managing their diabetes (e.g. high blood glucose, problems at work or loss of job), problems in relationships with parents, partners or friends or difficulties managing diabetes at college/school.

Patients in this stage go through various biological, psychological and social phases of their life. During this time, an adolescent is establishing his/her own personal identity, sense of autonomy, and sexuality. For those with diabetes mellitus, this stage is further complicated by the daily demands of a chronic disease. For instance, day-to-day management of food, insulin, physical activity and mood (mental health and wellbeing) can affect a wide range of their activities and development. These include school/college attendance and full involvement in extra-curricular activities such as trips and sports. There can also be consequences for social and family life (Department of Health, Diabetes Policy Team, 2007). For instance, risk-taking behaviour (e.g. drug, alcohol, smoking & pregnancy) amongst young people, which can have serious consequences for those diagnosed with diabetes.

Unplanned pregnancies for people with poorly controlled diabetes,or poor glycaemic control are much more likely to result in adverse health outcomes (such as higher rates of perinatal mortality and fetal malformations) than in the non-diabetic population (Dedpartment of Health Diabetes Policy Team, 2007; Magee, Schick, Donnenfeld, 1996; Temple, Aldridge, Greenwood, Heyburn, Sampson, Stanley, 2002; Casson, Clarke, & Howard,1997) .Therefore, it is advised to adolescents to contact health care providers to get some support, education and contraceptives to avoid unplanned pregnancies and to reduce the high rate of spontaneous abortions and improve infant outcome (Rosenn, Miodovnik, Combs, Khoury & Siddiqi, 1991).

Although, diabetes requires a high degree of lifelong self-management with regular health professional support (Griffin, 1998), a more effective patient-provider' verbal and non-verbal communication can lead to satisfaction with care, adherence to treatment, better self-care behaviour and improvements in health outcomes (Heisler, Bouknight, Hayward, Smith, Kerr, 2002). Patient participation in treatment decisions related to diabetes is an important component of health care that has been related to higher level of patient satisfaction, adherence to treatment (Hall, Roter, & Katz, 1988), and improved health outcomes (Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Rost, Flavin, Cole, & McGill, 1991).

Thus to enhance the young adults' communication skills, a session based on a variety of communication skills (e.g. passive, assertive and aggressive, verbal, non-verbal and para-verbal), was designed and delivered as part of a one-stop workshop. On the workshop day, eight expected patients (including one sibling) arrived, who attended the communication session as well as other sessions on the workshop day. In order to break the ice, patients were asked if somebody could share a recent or an old experience of explaining something about diabetes to someone (e.g. doctor, parents, friends or an employer and explain the outcome). Patients' responses opened up the discussion between the group members. This exercise also served as a self-assessment of the participants' own learning needs. From this exercise, patients were introduced to the aims and objectives of the session (see Appendix A, flexible enough to allow the content of the self-assessment to be included) and an assessment was carried out during the session by asking questions, when teaching and training about various communication styles.

Identify training programme structures and content

In order to deliver this teaching and training session, it was very important to design it according to the age group. For instance, using simple language, pictorial images, and videos related to adolescents' communication problems and examples relevant to this age group's problems. I allowed some flexibility in the programme based on the needs of the patients. In my planning I was mindful of the exercises chosen, (e.g. videos followed by group discussion and collaboratively drawing diagrams) and their complexity, energy and timing. In addition I had to be aware of the importance of projecting specific instructions for exercises to ensure that the aims and objectives were met. The main components of the training were listening skills, observation, and group discussion, sharing experiences, exchanging/giving information, and a practical individual exercise.

Training methods and approaches

In this teaching and training session, a patient-centred approach was applied to some extent in my delivery style in terms of facilitating them, listening and respecting their views and encouraging their efforts. I believe that my training style was consistent with the learner-centred model (Exley & Dennick, 2004). Using this model, the trainer acts as a facilitator of learning, which involves valuing the experiences, the participants bring into the session and working in a collaborative way alongside them.

The session was delivered using a variety of interactive methods by consulting with National Institute for health and Care Excellence (NICE) guidelines (NICE clinical guidelines, 2004) for young adult people to cater for a range of learning styles. This included small group exercises (reading a scenario & assertive communication practice), videos related to good and bad communication and how to tell a friend about diabetes, group discussions and a brief presentation. It was designed and structured to make it as interactive as possible, as it is suggested that adopting the *'learning by doing'* approaches are more effective than participants just listening (Roter et al., 2006).

Training materials

- PowerPoint slides with pictorial images and simple bullet points in comic San MS font style.
- Flip chart paper, stand and pens.
- Laptop & projector.

- Videos from diabetes UK & YouTube.
- Assertive communication plan on an A4 sheet.
- Gave free pens (donated by the diabetes representatives).

Delivery of the training programme

General

The training was delivered following the Department of Health Diabetes Support Team (2007) guidelines, which aim to make sessions simple and interactive for young adults and use creative media. Although to-date, I have not delivered any teaching and training session to a group of young adult patients, I felt fairly confident about delivering the training. This could be due to the fact that I had spoken to most of the young adult patients on the phone after sending them invitations related to the workshop and I had also met some of them in the transition clinic. However, I found preparing the session quite challenging, because most of the literature (Haskard, Williams, DiMatteo, Rosenthal, White et al., 2008; Casson et al., 1997) emphasises the need to improve care providers' communication skills, but not specifically improving young adult patients' communication skills. Information in the literature related to teaching and training communication skills to this age group was sparse, and there was no clear consensus on its application. However, after consulting the NICE guidelines and the literature on communication issues, the teaching and training session (see Appendix B) was developed and delivered using interactive tools suggested in the NICE for young adult patients.

Before the workshop day, I had some initial concerns regarding the size of the group, particularly concerning group dynamics. I was also concerned about the number of patients' in attendance because according to the clinic records, a majority of the patients related to this age group hadn't turn up for their clinic appointments. However, on the day, expected patients did turn up and participated actively into the session. The session was delivered in a collaborative way, asking questions, showing videos, discussing videos and drawing diagrams. Patients actively participated throughout the session.

Training challenges

One of the challenges I was faced with explaining terms/jargons and using very simple language and examples that related to diabetes by considering the age group's knowledge, understanding and requirements. Although, it was quite a difficult task to provide practical and simple examples, I overcame this issue by:

- Periodically reinforcing those diabetes related communication problems with parents, (mentioned by the young adult patients in the clinic).
- Focusing upon what was mentioned in the literature (Karlsson, Arman, & Wikblad, 2008; Wolpert, & Anderson, 2001). For example, from patients' perspectives, doctors need to identify the individual motivators for improved control and the life issues that detract from a commitment to diabetes management (Weissberg-Benchell, Wolpert, & Anderson, 2007).
- Reflecting back on presented material and answering their questions, which I hoped would then encourage them to understand the terms related to their experiences.

During the middle of the session, I noticed that some patients appeared to be struggling with certain aspects of the sessions based on their body language and facial expressions. When these instances arose, I attempted to present the material in a different way. For example, using videos (related to real-life communication problems and building up discussion among group members by asking open-ended questions) drawing some diagrams on the flipchart to explain a link between communication, health and relationships collaboratively. One of the aims of playing videos (in the session related to real life examples) was to help patients to understand, how both environmental and cognitive (e.g. embarrassment, lack of self-efficacy) factors interact to influence human learning and behaviour. This concept is linked with Bandura's social learning theory (Bandura, 1977), which focuses on learning (within a social context) by observation and modelling.

One of the other challenges was to practice the assertive communication plan with patients, which I overcame by writing an example on the flipchart related to a long-term communication problem and facilitating the patients via very short questions to overcome this problem. The outcome of this exercise was very successful, as patients filled out the blank sheets with some solutions related to their own individual communication problems.

Building self-efficacy

Some of the patients were quite shy, so to build up their confidence level and break the ice, they were given a short scenario to read in front of other patients and after that a round of applause was made to encourage their efforts, which gave them a sense of success or a robust belief in their personal efficacy (Bandura, 1994). Therefore, those patients started taking part in discussion quite actively later on in the session.

Assessing learning outcomes

During the session, an assessment strategy was used to find out the group's understanding about various communication styles, (e.g. verbal, non-verbal & para-verbal) and to see if I had met the learning objectives at various points throughout the session. To do this, I asked the patients to provide feedback on what they observed in the video related to communication styles. In addition, patients were also asked to complete the blank assertive communication plan with some questions to assess their understanding of applying this plan in real-life. This was a particularly useful way to ask patients to give feedback on their learning in a written form and also an easy way to gauge where the group were in terms of their learning communication planning.

Planning and implementation of assessment procedures

Identify assessment methods

The training was evaluated informally using a brief evaluation form for which a 10 minute time slot was allocated. The evaluation planning started with a careful analysis of the training aims/objectives. It served to evaluate the training on two levels: personal learning and applied learning (Rogers, 2002).

Evaluate such training programmes

The (45 minutes long) communication teaching and training session was evaluated using the evaluation form (see Appendix C) and assertive communication practice (see Appendix D).

Evaluate training programme outcomes

The results of the evaluation were in line with the objectives, as young adult patients did complete the assertive communication practice sheet individually by writing their communication problems related to diabetes with their parents and doctors, which indicated that patients learnt to plan and to solve communication problems assertively. On the feedback sheet, all participants (100%) demonstrated that effective communication can have a positive effect on health and relationships as well as can help them to manage diabetes when communicating effectively with the HCPs. Participants also reported that the assertive communication plan (practiced during the session) can be applied with the HCPs (70%), parents (90%) and others (20%). However, when discussing any advantages of following the assertive communication plan, 70% of responses were in favour if the problem is long term related to diabetes. Participants' reported disadvantages of such plan were that they may not think of planning communication if things are not important (30%) or if they have an urgent problem (70%). In terms of future plans to do one thing differently after attending the training session, participants demonstrated that they are more confident now to talk about diabetes to their friends than before the training. Participants reported that the trainee's presentation and training style was quite interactive and informative. In addition, the outcome of the overall feedback was also very meaningful in terms of knowing what they learnt and what went well during the session.

Identify factors contributing to training programme outcomes

Some potential contributing factors to the training session could be the use of videos, flipcharts to draw some diagrams and adolescents' scenarios (in terms of sharing diabetes related problems with their parents & friends and its potential influence on their health and relationships). Videos related to good and bad communication (http://www.youtube.com/watch?v=WHgju5HuGAs) not only grasped young patients' attention to an attractive side, but also highlighted the impact of both types of communication on relationships, which they expressed through discussion. Other videos related to telling friends about diabetes to overcome embarrassment issues (http://www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/Fun-stuff/Setting-the-record-straight/) and understanding the importance of planning the pregnancy (http://www.diabetes.org.uk/Guide-to diabetes/Living_with_diabetes/Pregnancy_and_diabetes/Rebel-Rebel-preconception-video/) were also appreciated by the adolescents.

Identify improvements for the design and delivery of training for implementation in future programmes

Having reflected upon my practice, I will make some changes to improve future training:-

- Carry out a more thorough needs assessment to screen for any specific communication problems.
- Prepare a good and bad patients-doctor communication dialogue followed by group discussion.

- Prepare the pre-post confidence self-rating scale (when communicating with others, e.g. doctors or parents), which will be related to health behaviour change.
- Prepare a list of communication problems with parents, doctors, friends and employers.

Conclusion

Overall this was a very positive experience that related to my health psychology training and developing key links with health professionals in my area of research. I felt that the teaching and training session had also been beneficial to young people with Type 1 diabetes. It is hoped that after the sessions and the developments they made that they will engage with HCPs to manage their diabetes, through communication in the future.

References

Bandura, A. (1977). *Social Learning Theory*. New York: General Learning Press

Bandura, A. (1994). Self-efficacy. In Ramachaudran, V. S (Ed.), *Encyclopedia of human behaviour* (Vol. 4, pp. 71-81). New York: Academic Press.

Casson , I.F., Clarke, C.A. and Howard, C.V. (1997). Outcomes of pregnancy in insulin-dependent diabetic women: results of a five year population cohort study. *British Medical Journal*, *315*, 275-8.

Collins, L.G., Schrimmer, A., Diamond, J. and Burke, J. (2011). Evaluating verbal and non-verbal communication skills, in an ethnogeriatric OSCE. *Patient Education Counselling*; *83*, 158–62.

Department of Health Diabetes Policy Team (2007). *Making Every Young Person with Diabetes Matter: Report of the Children and Young People with Diabetes Working Group*.

Exley, K. and Dennick, R. (2004). *Small Group Teaching. Tutorials, seminars and beyond*. Routledge Falmer. London

Greenfield, S., Kaplan, S.,Ware, J.,Yano, E., and Frank, H. (1988). Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *Journal of General Internal Medicine, 3,* 448-457.

Griffin, S.J. (1998). Lost to follow up: the problem of defaulters from diabetes clinic. *Diabetic medicine*, *15*(3), S14-S24.

Hall, J. A., Roter, D. L. and Katz, N. R. (1988). Meta-analysis of correlates of provider behaviour in medical encounters. *Medical Care, 26*, 657-75

Haskard, K.B., Williams, S.L., DiMatteo, M.R., Rosenthal, R., White, M.K. and Goldstein, M.G. (2008). Physician and patient communication training in primary care: Effects on participation and satisfaction. *Health Psychology, 27*(5), 513-522.

Heisler, M, Bouknight, R.R,, Hayward, R.A., Smith, D.M. and Kerr, E.A. (2002). The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *Journal of General Internal Medicine, 17*(4), 243-52.

http://www.youtube.com/watch?v=WHgju5HuGAs). Retrieved on May 2011.

http://www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/Fun-stuff/Setting-the-record-straight/. Retrieved on May 2011.

http://www.diabetes.org.uk/Guide-to diabetes/Living_with_diabetes/Pregnancy_and_diabetes/Rebel-Rebel-preconception-video/. Retrieved on May 2011.

Karlsson, A., Arman, M. and Wikblad, K. (2008). Teenagers with Type 1 diabetes - a phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies, 45,* 562-570.

Magee, L.A., Schick, B. and Donnenfeld , A.E. (1996). The safety of calcium channel blockers in human pregnancy: a prospective, multicenter cohort study. *Jouranl of Obstetric Gynecology*, *174*, 823-8.

Ngo-Metzger, Q., Telfair, J., Sorkin, D., Wedimer, B., Weech-Maldonado, R. and Hurtado, M. (2006). Cultural competency and quality of care: obtaining the patient's perspective. *The Common wealth Fund*, 963.

NICE clinical guidelines. (2004). *Diagnosis and management of Type 1 diabetes in children, young people and adults.* Available on www.nice.org.uk/CG015NICEguideline).

Rogers, J. (2002). *Adults Learning (4th Edition)*. University Press. Buckingham.

Rosenn, B., Miodovnik, M., Combs, C.A., Khoury, J. and Siddiqi. T.A. (1991). Pre-conception management of insulin-dependent diabetes: improvement of pregnancy outcome. *Obstetric Gynecology,* 77, 846-9.

Rost, K., Flavin, K., Cole, K. and McGill, J. (1991). Change in metabolic control and functional status after hospitalization. Impact of patient activation intervention in diabetic patients. *Diabetes Care, 14*(10), 881-889.

Roter, D.L., Frankel, R.M., Hall, J.A. and Sluyter, D. (2006), The expression of emotion through nonverbal behavior in medical visits: mechanisms and outcomes. *Journal of General International Medicine, 21*(1), 28-34.

Temple, R., Aldridge, V., Greenwood, R., Heyburn, P., Sampson, M. and Stanley, K. (2002). Association between outcome of pregnancy and glycaemic control in early pregnancy in Type 1 diabetes: population based study. *British Medical Journal*, 325, 1275-6.

Weissberg-Benchell, J., Wolpert, H. and Anderson, B. J. (2007). Transitioning From Pediatric to Adult Care: A new approach to the post-adolescent young person with Type 1 diabetes. *Diabetes care*, *30*(10), 2441-2446.

Wolpert, H.A. and Anderson, B.J. (2001). Management of diabetes: are doctors framing the benefits from the wrong perspective? *British Medical Journal*, *323*, 994–6.

Appendix A

Aims & objectives

Aims:

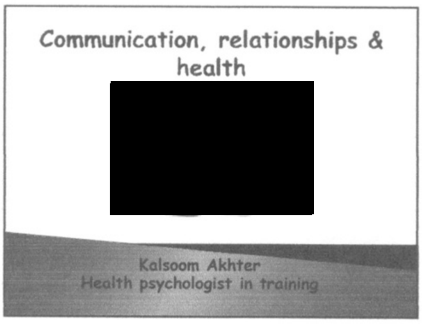
1. To determine specific communication factors, which impact upon relationships and health.
2. To learn about assertive communication
3. To enhance the young adults' assertive communication skills
4. To plan an assertive communication

Objectives:

1. To understand how communication can have an effect on your health & relationships.
2. To learn how to apply and plan assertive communication in different areas of life (i.e. hospital, home, college or work).

Appendix B

Teaching Session Slides



Communication, relationships & health

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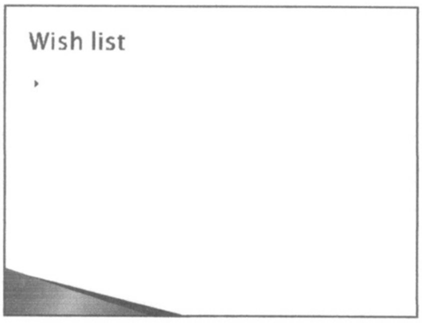
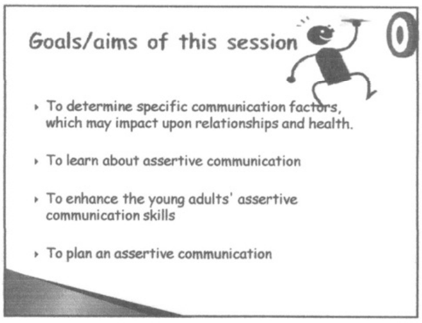
Kalsoom Akhter
Health psychologist in training



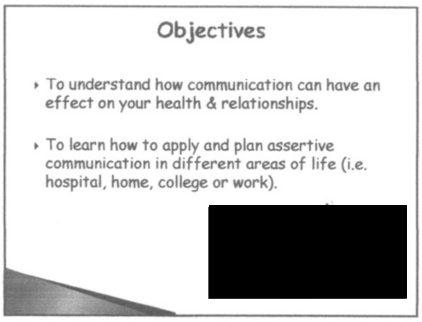
Wish list

-



Goals/aims of this session

- To determine specific communication factors, which may impact upon relationships and health.
- To learn about assertive communication
- To enhance the young adults' assertive communication skills
- To plan an assertive communication



Objectives

- To understand how communication can have an effect on your health & relationships.
- To learn how to apply and plan assertive communication in different areas of life (i.e. hospital, home, college or work).

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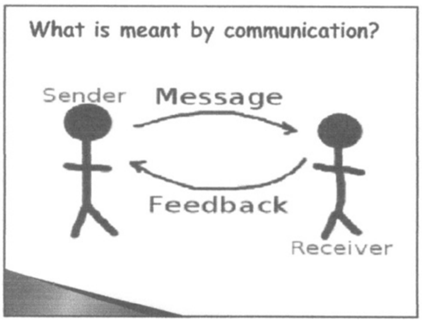
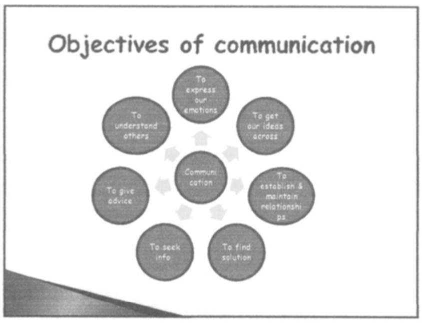


What is meant by communication?

Sender
Message
Feedback
Receiver

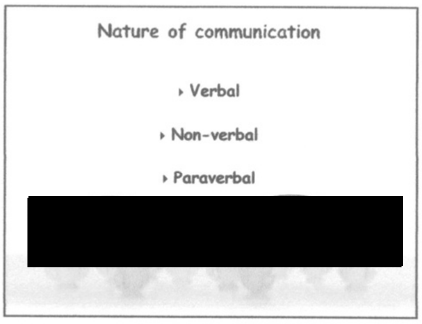


Objectives of communication

Communication
To express our emotions
To get our ideas across
To establish & maintain relationships
To find solution
To seek info
To give advice
To understand others

Communication tools

[redacted]



Nature of communication

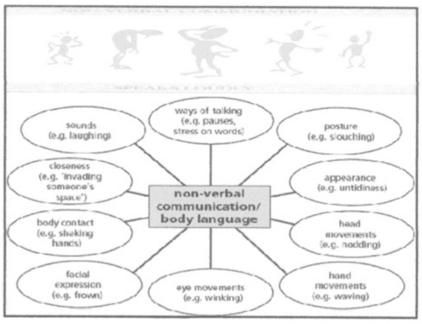
- Verbal
- Non-verbal
- Paraverbal

[redacted]

Verbal

- The words we choose

[redacted]



Paraverbal

- How we say the words

"I didn't SAY you were stupid."

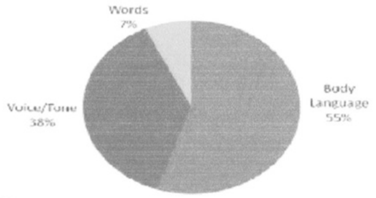
"I didn't say YOU were stupid."

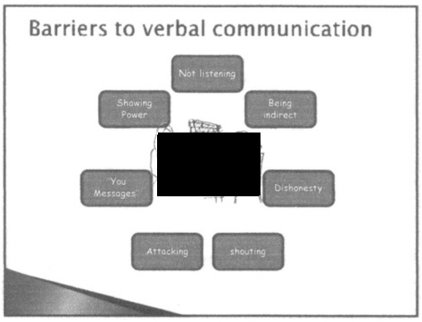
"I didn't say you were STUPID."

[redacted]

Verbal, non-verbal & paraverbal

Albert Mehrabian , 1971

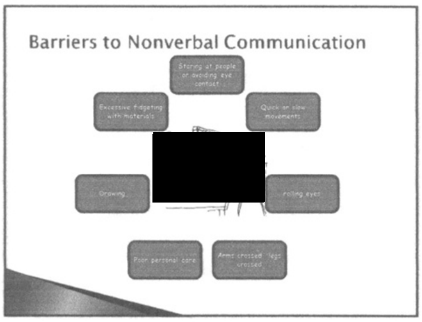




Barriers to verbal communication

[redacted]

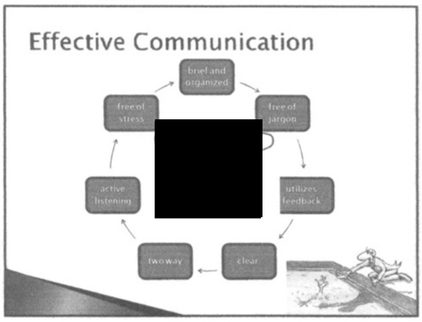
- Not listening
- Showing Power
- Being indirect
- "You Messages"
- Dishonesty
- Attacking
- shouting



Barriers to Nonverbal Communication

[redacted]

- Staring at people or avoiding eye contact
- Excessive fidgeting with materials
- Quick or slow movements
- Drawing
- rolling eyes
- Poor personal care
- Arms crossed legs crossed



Effective Communication

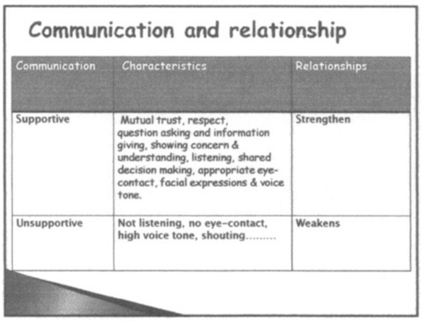
[redacted]

- brief and organized
- free of jargon
- utilizes feedback
- clear
- two way
- active listening
- free of stress

VIDEO

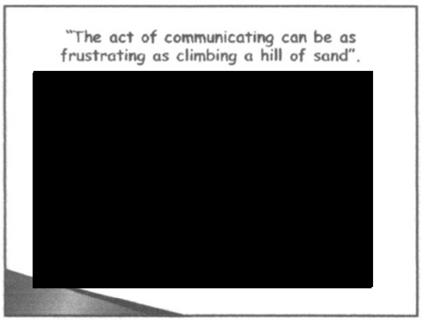
- Good and bad communication (5 min)

YouTube - Bad to Good Communications.mht



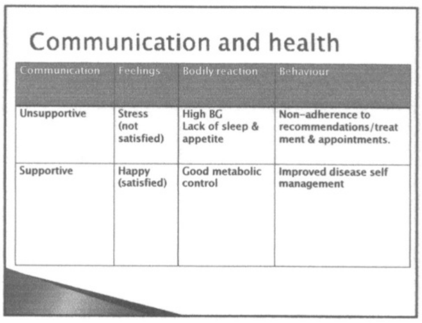
Communication and relationship

Communication	Characteristics	Relationships
Supportive	**Mutual trust, respect, question asking and information giving, showing concern & understanding, listening, shared decision making, appropriate eye-contact, facial expressions & voice tone.**	**Strengthen**
Unsupportive	**Not listening, no eye-contact, high voice tone, shouting………**	**Weakens**



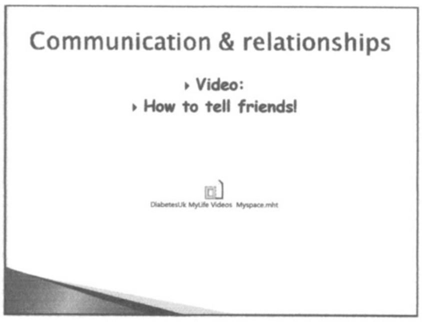
"The act of communicating can be as frustrating as climbing a hill of sand".

[redacted]



Communication and health

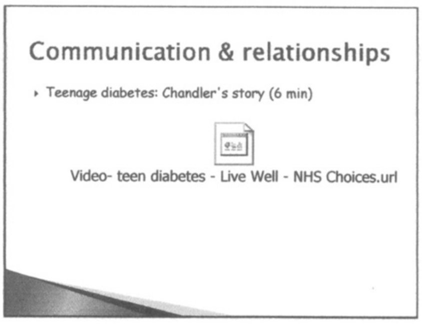
Communication	Feelings	Bodily reaction	Behaviour
Unsupportive	Stress (not satisfied)	High BG Lack of sleep & appetite	Non-adherence to recommendations/treatment & appointments.
Supportive	Happy (satisfied)	Good metabolic control	Improved disease self management



Communication & relationships

- **Video:**
- **How to tell friends!**

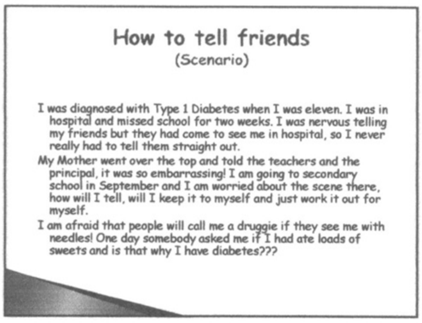
DiabetesUk MyLife Videos Myspace.mht



Communication & relationships

- Teenage diabetes: *Chandler's story* (6 min)

Video- teen diabetes - Live Well - NHS Choices.url



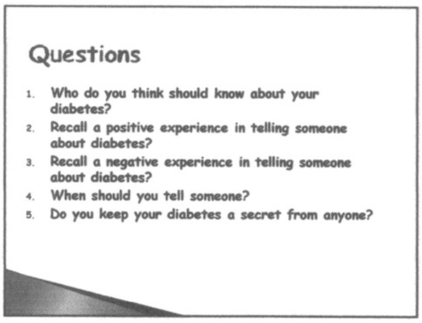
How to tell friends

(Scenario)

I was diagnosed with Type 1 Diabetes when I was eleven. I was in hospital and missed school for two weeks. I was nervous telling my friends but they had come to see me in hospital, so I never really had to tell them straight out.

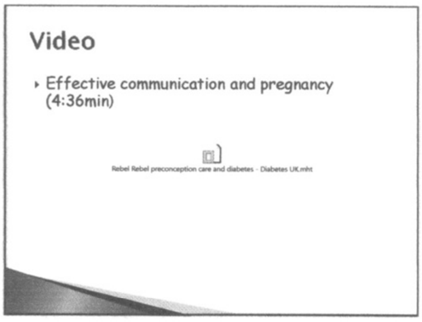
My Mother went over the top and told the teachers and the principal, it was so embarrassing! I am going to secondary school in September and I am worried about the scene there, how will I tell, will I keep it to myself and just work it out for myself.

I am afraid that people will call me a druggie if they see me with needles! One day somebody asked me if I had ate loads of sweets and is that why I have diabetes???



Questions

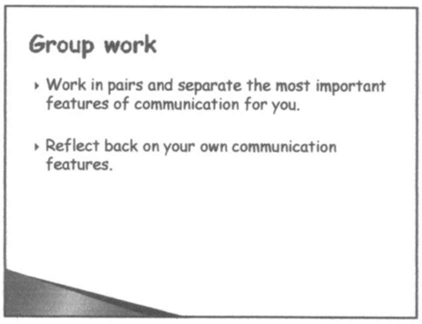
1. **Who do you think should know about your diabetes?**
2. **Recall a positive experience in telling someone about diabetes?**
3. **Recall a negative experience in telling someone about diabetes?**
4. **When should you tell someone?**
5. **Do you keep your diabetes a secret from anyone?**



Video

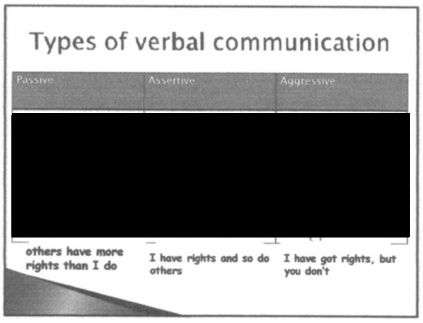
- Effective communication and pregnancy (4:36min)

Rebel Rebel preconception care and diabetes - Diabetes UK.mht



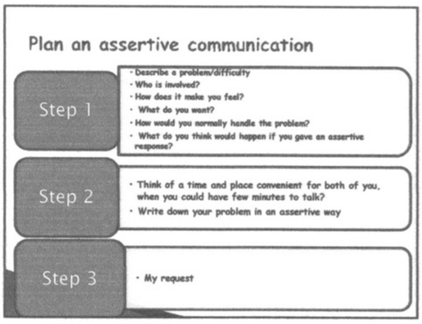
Group work

- Work in pairs and separate the most important features of communication for you.
- Reflect back on your own communication features.



Types of verbal communication

Passive	Assertive	Aggressive
[redacted]	[redacted]	[redacted]
others have more rights than I do	I have rights and so do others	I have got rights, but you don't

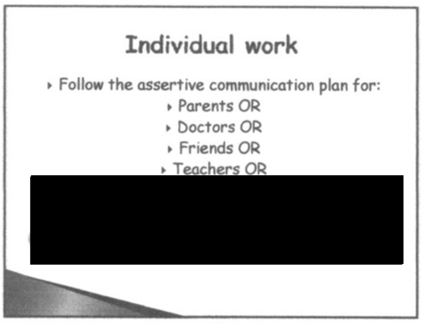


Plan an assertive communication

Step 1
- Describe a problem/difficulty
- Who is involved?
- How does it make you feel?
- What do you want?
- How would you normally handle the problem?
- What do you think would happen if you gave an assertive response?

Step 2
- Think of a time and place convenient for both of you, when you could have few minutes to talk?
- Write down your problem in an assertive way

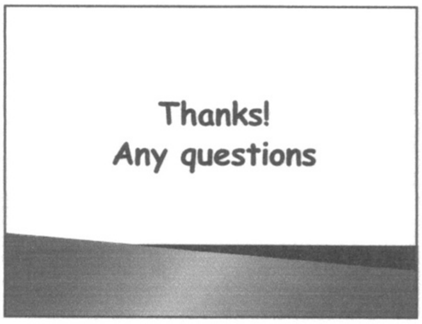
Step 3
- My request



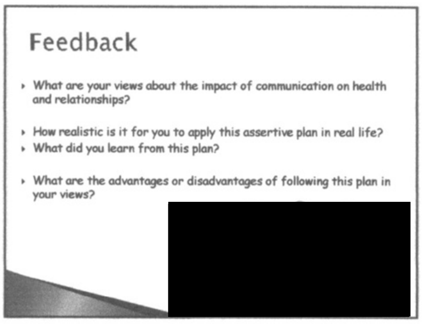
Individual work

- Follow the assertive communication plan for:
  - Parents OR
  - Doctors OR
  - Friends OR
  - Teachers OR

[redacted]



Thanks!
Any questions



Feedback

- What are your views about the impact of communication on health and relationships?
- How realistic is it for you to apply this assertive plan in real life?
- What did you learn from this plan?
- What are the advantages or disadvantages of following this plan in your views?

[redacted]

Appendix C

Evaluation sheet

Improving communication skills of young adult patients with Type 1 diabetes

How would you rate the following:

	Agree	**Disagree**	**Neither disagree nor agree**
Good communication can have a positive affect on health and relationships	8	0	0
Assertive communication plan can be applied in real life with parents	7	0	1
Assertive communication plan can be applied in real life with health care professionals	5	1	2
Assertive communication plan can be applied in real life with other people, e.g. friends, employers	2	0	6
I learnt to communicate assertively with others related to diabetes	6	0	2
Communicating effectively with health care professionals can help me to manage my diabetes	8	0	0

- **What are the advantages or disadvantages of following this plan in your views?**

Advantages	Can get proper help N = 3	Can plan if problem is long term related to diabetes N = 5
Disadvantages	Might not think of planning communication if things are not important. N = 3	Might not think of planning if I have an urgent problem N = 5

What one thing you would do differently now in these areas:

Talking about your diabetes to parents:

1. Let them know if blood is high/ if I feel ill
2. I am more confident now

Talking about your diabetes to health care staff:

1. Will be more open and focus on goal setting

Talking about your diabetes to friends:

2. More confident
3. Yes I can now

Comments on presentation style of trainers:

1- Very informative
2- Interactive
3- Very well organised

Key points learned

- The importance of listening and how to deal with resistance.
- Reflective questioning, the righting reflex and affirmations.
- Use more interactive tools to meet young adult patients' needs

Appendix D

Assertive communication plan

a) Describe a problem/difficulty

b) Who is involved?

c) How does it make you feel?

d) What do you want?

e) How would you normally handle the problem?

f) What do you think would happen if you gave an assertive response?

Write down your problem in an assertive way

My request.

Section 3B - Teaching and Training Two

Increasing Awareness and Enhancing Knowledge about some Psychological and Social aspects of managing Type 2 Diabetes Mellitus to Health Care Professionals

Supervision Plan

Teaching and Training Competence 2: Increasing Awareness and Enhancing Knowledge about some Psychological and Social aspects of managing Type 2 diabetes Mellitus to Health Care Professionals

Units in this area of competence	Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)	Supporting evidence to be complied for this unit of competence
4.1 Plan and design training programmes **4.2 Deliver training programmes** **4.3 Plan and implement assessment procedures** **4.4 Evaluate training programmes**	**Setting:** Secondary care. **Client/ Target Group**: Diabetes Health Care Professionals **Description of work:** As part of my work on a research related randomised controlled trial of peer support in Type 2 diabetes. The first part of the trial was to provide some basic education to the selected patients by the Health Care Professionals (HCPs). My responsibility was to design and deliver a teaching & training information pack based on the ethos of this trial for the HCPs. The aims of this training were to enhance knowledge and increase understanding of the HCPs about some potential psychological and social aspects of diabetes management based on health psychology perspectives. The main components of the training were listening skills, observation and group discussion, sharing experiences, exchanging/giving information, and some practical individual and group exercises. A peer-led or group-led approach was applied in my delivery style by considering and respecting the target group's expertise, listening and respecting their views. Various mini need assessments were carried out on the training day to assess HCPs' level of confidence to identify psychosocial aspects during consultations, their expectation from the training and their general knowledge about those aspects. All those who received the training had the opportunity to complete the brief evaluation forms based on the aims of teaching and comments were given. HCPs also provided a self-perception rating of their confidence to identify psychosocial aspects at the end of the training session.	• Knowledge enhancement workshop feedback form. • Training material used. • Evaluation forms included. • Brief workshop introduction. • Observational report by the University Supervisor.

Target for completion: … August, 2013 … Workplace contact? Yes … If yes please give name: Professor [redacted]

Background

In January 2012, I was offered an opportunity to work on the Randomised controlled trial of Peer Support In Type 2 diabetes (RAPSID) trial on the basis of an existing honorary research contract as a trainee Health Psychologist. RAPSID is a 12-month randomised controlled study (please see the following website for details: http://public.ukcrn.org.uk/search/StudyDetail.aspx?StudyID=6521 or Appendix A) among 1200 people with Type 2 diabetes across Cambridgeshire and neighbouring counties, assessing the effect of peer support (that is supported by other people with diabetes) on metabolic control (e.g. glucose, weight, blood pressure). The trial includes 4 groups: all receiving special educational information, 25% also receive one-to-one peer support, 25% group support and 25% both group and peer support. The ethos of this trial is that preventable complications continue to occur, often due to personal and systems barriers to implementing diabetes care. The need to overcome such barriers, so that people with diabetes are able to deal with the psychological, social and emotional issues that they face has become a major challenge. Peer support, involving experience sharing, mentoring and role-modelling, has been proposed as a way of overcoming some psychosocial barriers. The first part of this trial (after the baseline) was to provide basic Type 2 diabetes management related education to those selected patients by the healthcare professionals (e.g. diabetes specialist nurses and dieticians) at different local community centres with an assessment of pre and post-knowledge questionnaires.

My job role was to work on research related activities of this trial, which involved entering data, analysing it using SPSS, and writing up a paper for publication in one of the peer reviewed diabetes journals. In one of the meetings as part of this study, I was requested to design and deliver a teaching and training information pack based on the ethos of the RAPSID study to enhance knowledge and increase understanding of the HCPs about some potential psychological and social aspects of diabetes management based on health psychology perspectives.

It has been recognised for many years that patients with diabetes frequently fail to reach glycated haemoglobin (HbA_{1c}) targets. However, based on DAWN (Diabetes Attitudes, Wishes and Needs) survey this is often due to a neglect of the psychosocial aspects of the disease, rather than simply a failure of medical management. The DAWN survey highlighted the need for a new approach to diabetes care that looks beyond blood glucose measurements and prescribed diet and exercise routines to the person behind the disease.

The findings of the DAWN study (Conference Summit, 2004) highlighted the need for a new approach to diabetes treatment that takes into account key psychosocial issues in the lives of patients with diabetes, in conjunction with appropriate medical management. As many healthcare providers express a desire to improve their skills in this area, evidence-based tools and support materials are needed (please see the link for further details: http://novomedlink.pro/diabetes-care/diabetes-themes/Psychosocial-Aspects-of-Diabetes.aspx). In addition, to address patients' psychosocial needs properly; this required a patient-friendly clinical environment, good communications, coping-oriented self-management programmes and recognition of monitoring of well-being as an integral part of care (Conference Summit, 2004).

From a Health Psychology perspective, a number of psychosocial factors such as stress, depression, patient-practitioner communication, social support, perceived barriers and coping styles are involved in diabetes management (Weiner, Nezu, Nezu & Geller, 2003). Psychosocial barriers to diabetes management have been demonstrated in a number of studies (Glasgow, Toobert & Gillete, 2001; Lioyd, Wing, Orchard & Becker, 1993). Those barriers include: anxiety, attitudes, depression, empowerment, health beliefs, interview responses, knowledge, locus of control, motivation, outcome expectancies, personal models, problem solving, self-efficacy, self-esteem, social-support, emotional distress and coping.

Although in the RAPSID study, all the HCP facilitators are trained to provide sufficient/required relevant training to the peer support facilitators with Type 2 diabetes about the ongoing social and emotional support, active listening techniques and problem solving techniques (e.g. identifying barriers and finding ways to overcome them), it was considered very important and essential from principal investigator (of the RAPSID study)'s perspective to enhance their (HCPs) knowledge and skills regarding psychosocial areas of diabetes management from health psychology framework. In addition, HCPs also expressed an interest in developing more understanding relating to psychosocial areas of diabetes as they had not received any information in a formal setting previously.

Context

A teaching and training workshop related to psychosocial aspects of diabetes from a Health Psychology perspective was designed to enhance HCPs' knowledge and understanding, to maximise their skills to provide support to the peer support facilitators and to learn practical approaches to potentially apply in everyday consultation. The teaching and training workshop took place at a hospital setting during the week in office hours. This was due to considering HCPs' working schedule and other job commitments at the hospital. From a HCP point of view, it was feasible to attend this workshop at the hospital with other colleagues to discuss and share their views.

Plan and design training programme

The workshop was aimed to facilitating the HCPs via a teaching and training session to:

1. Enhance knowledge and understanding about some potential psychological & social factors in managing Type 2 diabetes from Health Psychology perspectives.
2. Increase systematic understanding and awareness of social and psychological knowledge.
3. Increase understanding of the appropriate application of social and psychological knowledge.

Assess training needs

A formal need assessment was not carried out as the lead diabetes consultant and a principal investigator of the RAPSID study had previously identified a gap in HCPs' evidence based knowledge and it was considered very important from his perspectives to enhance HCPs' knowledge and skills (who will be supporting peer support facilitators) to understand the psychosocial aspects of diabetes. The lead consultant discussed the idea of the workshop with his colleagues and the trainee health psychologist received e-mails from a variety of HCPs, demonstrating interest to attend this workshop.

In one of the meetings, the lead consultant appreciated the idea of engaging the HCPs in discussion and some practical group and individual exercises, as he thought it could be very useful in terms of learning in a practical way rather than just listening to the presenter and this can fulfil the gap of practical learning in the clinic setting. Thus, the trainee health psychologist prepared a draft (please see Appendix C) of their agreed date, time and length of the workshop with its aims and some information on structure, content and format of the workshop and e-mailed it to all the interested participants. The trainee health psychologist also reduced the amount of information according to the suggested length of the workshop by the HCPs.

On the workshop day, six HCPs (including three research and diabetes specialist nurses and three registrars), attended the workshop. A brief introduction of *'What is Health Psychology'* was presented just to clarify this principle of Psychology, as the trainee health psychologist was going to discuss a variety of health psychology areas later on in the workshop . Before starting the workshop, participants were asked to rate themselves on their perception of their confidence in their ability to identify psychosocial aspects during facilitation/consultation among patients with Type 2 diabetes and why, using a 0-10 (0 least confident, 10 extremely confident) confidence scale. The participants were also asked to rate themselves immediately after the training and to provide a rationale behind their self-ratings.

A mini needs assessment was conducted at the beginning of the workshop. This was in the form of gaining insight into the needs of participants by asking their expectations from the workshop which were written on the flipchart to review at the end of the workshop. The aim of this exercise was to allow the participants to form their own learning contract, which is suggested as a useful way of encouraging them to take ownership of the training and of their personal learning outcomes (Race & Smith, 1996). In addition, before clarifying the meaning of psychosocial aspects, participants' knowledge was assessed by asking *'what do we mean by psychosocial aspects of Type 2 diabetes management?'* Participants' responses opened up discussion between the group members. From this exercise, participants were introduced the aims and objectives of the workshop.

Programme structure and content

In order to deliver this teaching and training workshop to HCPs related to psychosocial aspects it was very important to design the content, structure and the format according to the target audience/group and the learning objectives. I allowed some flexibility in the workshop based on the needs of the HCPs (e.g. they may have to leave early in an emergency to see a patient). In my planning I was mindful of the exercises chosen. For example, explaining terms or principles with relevant examples followed by group activities and their complexity, energy and timing in addition to being aware of the importance of projecting specific instructions for exercises/activities to ensure that the aims and objectives were met. The main components of the training were listening skills, observation and group discussion, sharing experiences, exchanging/giving information, and some practical individual and group exercises.

The content and structure of this workshop were discussed with my university supervisor. It was considered to be aligned with the required needs of the HCPs related to the psychosocial aspects by considering and appreciating their existed experience and knowledge and providing those skills which could potentially enhance their previous knowledge and skills and improve their facilitation skills.

Training methods and approaches

In this teaching and training session, a peer-led or group-led approach (rather than using a didactic approach) was applied in my delivery style by considering and respecting the target group's expertise, listening and respecting their views. I believe that my training style was consistent with the learner-centred model (Exley & Dennick, 2004). Using this model, the trainer acts as a facilitator of learning, which involves valuing the experiences the participants bring into the session and working in a collaborative way alongside them.

The session was delivered using a variety of interactive methods to cater for a range of learning styles. This included small group exercises, which included:

- Asking participants to read the description/idea written on different cards and match them with 3 key ingredients of effective communication kept in front of the participants.
- Asking them to find the four motivational interviewing principles within the given scenario based on patient and doctor interaction
- Group discussions.

A brief presentation was provided and presentation handouts and some useful articles were given. The training materials used included:

- Flipchart paper, stand and pens
- NHS computer and projector
- Handouts
- Confidence ruler sheet
- Short group and individual activities.

Deliver such training programme

General

Although, I have delivered some teaching and training for students and patients and presented the information to HCPs at various occasions in the NHS and at professional settings (e.g. conferences or regional meetings), it was my first time to deliver any teaching and training for HCPs in the NHS. I felt fairly confident about delivering the training due to presenting various types of work in the clinic previously to the HCPs regarding behavioural and psychosocial aspects of diabetes. In addition, it was also helpful having some evidence based knowledge about the psychosocial aspects of diabetes management due to being working in the diabetes clinic. I had some initial concerns regarding the size of the group, particularly concerning group dynamics. However, I felt that training a small group may have its advantages. For example, having more time for more in-depth discussion and time to practice skills, which proved to be the case. It was also sometimes necessary to revise the timings of the exercises given the small numbers.

Training challenges

I found preparing the session quite challenging and productive, as most of the general literature related to psychosocial aspects of diabetes emphasises on depression, stress, social support, and self-efficacy (Seeman & Chen, 2002), knowledge about self treatment, coping with diabetes, identification and modification of behaviours, and dealing successfully with crises and/or problems associated with the illness (e.g. mental disorders such as depression, anxiety, and eating disorders) (Petrak, Herpertz, Albus, Hirsch, Kulzer et al., 2005). However, I was planning to design this workshop based on psychosocial aspects of diabetes from health psychology perspectives (Weiner et al., 2003), which I was able to design and deliver on the workshop day.

Before the day of workshop, I had some initial concerns regarding the size of the group, particularly concerning group dynamics. However, on that day, six expected participants did turn up and participated actively into the session by asking questions and engaging in group discussion and activities. The session was delivered in a collaborative way, asking questions, engaging participants into group discussion and individual and group activities and using flipchart to clarify different terms. Participants actively participated throughout the workshop. Few participants had to leave before the end of the workshop due to some urgent commitments, which did not interrupt the flow of the workshop too much, but it affected the group dynamic particularly in group exercises.

One of the challenges I was faced with was explaining terms/jargons, which HCPs seemed unfamiliar with, so I overcame this issue by using very simple language and real life examples. They were able to relate to their clinic experiences followed by reflecting back on presented material and answering their questions, which I hoped would then encourage them to understand the terms related to their experiences.

Avoiding the use of jargon, simplifying terms and periodically reinforcing the message (that questions and comments on the material presented) were invited throughout the training. As the time passed on that day, I also learnt to identify participants who appeared to be struggling with certain aspects of the training from their body language and facial expressions. When these instances arose I attempted to present the material in a different way (e.g. using live examples). As a facilitator it was rewarding when after successfully presenting the material differently the participants were able to understand it.

Building self-efficacy

Some participants seemed anxious about their proficiency in using some of the new techniques and strategies (e.g. identifying psychological terms/principles). To build the self-efficacy of participants following a particularly challenging exercise, I felt that it was important to highlight the fact that the training should be viewed as a learning process rather than as an event and also encouraged their efforts for identifying various concepts.

Assessing learning outcomes

During the session, an assessment strategy was used to find out the group’s understanding about various psychosocial aspects of diabetes and that I had met the learning objectives at various points throughout the session. To do this, I designed an activity at the end of each section of the workshop (e.g. communication, motivational interview). This was a practical way to gauge where the group members were at in terms of their learning as well as a very useful way of learning and practising in the workshop. In addition, when observing/assessing the exercises/activities, positive reinforcements were given before offering suggestions on how they might further improve their skills. I felt it was important to do this to avoid my suggestions being taken as a criticism.

Providing knowledge pack to strengthen participants' learning

As the training typically generates many questions, I did try to explain as much as I could with examples but also referred them to some most relevant papers to read for further guidance and information rather than providing unsatisfactory answers to their questions. By considering the busy working lifestyle of the participants, I highlighted the page numbers of those papers into the workshop just to make more feasible to read their most preferred areas, if they chose to do so in their own time.

Planning and implementation of assessment procedures

Identify assessment methods

The training was evaluated informally using a brief evaluation form for which a 10 minute time slot was allocated. The evaluation planning started with a careful analysis of the training aims/objectives. It served to evaluate the training on two levels: personal learning and applied learning (Rogers, 2002). A post-training self-perception rating of participants' confidence to identify psychosocial aspects during facilitation/consultation among patients with Type 2 diabetes and why was also formed as part of the evaluation.

Evaluate such training programmes

The whole teaching and training workshop was evaluated using the evaluation form (please see Appendix B), discussions, practical exercises and self-confidence ratings and expectations from the workshop (please see Appendix E for presentation slides).

Evaluate training programme outcomes

The results of the evaluation were in line with the objectives, as post evaluation demonstrated that participants reported an increase in their level of confidence to identify psychosocial aspects during facilitation/consultation among patients with Type 2 diabetes. Furthermore, the outcome of the overall feedback was also very meaningful in terms of knowing what they learnt and what went well during the session. For instance using motivational interview techniques was perceived very useful during consultations by the HCPs. The rating about the session related to the trainee's communication skills, enthusiasm, content, use of examples and material, presentation and facilitation skills was reported quite positive (in terms of 70% reported excellent and 30% good). Please see appendix B, question 6).

In addition, this teaching and training workshop was also evaluated by my university supervisor in terms of providing an observational report (please see Appendix D for comments) related to the training materials, teaching style and communication and presentation skills.

Identify factors contributing to training programme outcomes

Some potential contributing factors to the training programme could be the use of patient-doctor scenario when asking participants to identify motivational interviewing principles, group discussion about some key ingredients of effective communication and discussing some feasible and practical skills to use in everyday consultation/facilitation. Some HCPs were very keen to find some evidence based information related to the impact of psychological concepts into patients' behaviour and alternative treatments, so they seemed very keen to find information from the printed papers.

Identify improvements for the design and delivery of training for implementation in future programmes

Having reflected upon my practice, I will make some changes to improve future training:

- Carry out a more thorough needs assessment to screen for any specific needs/expectations of the participants.
- Design a good and bad role-play dialogue between a doctor and patient based on identifying psychosocial aspects of diabetes followed by group discussion.
- Design open-ended questions for each participant to ask. For example, which one thing you feel that you have learnt from this workshop and how you will be able to apply it in your practice?
- Ask the participants to prepare an individual short list related to those areas which they find difficult to tackle and discuss it within a group to find some feasible solutions.

Conclusion

In general, I was very pleased with the training as my first experience of interacting face-to-face with a group of HCPs and felt that the content and structure was appropriate and thus achieved the learning outcomes. It was also very encouraging to get the feedback from the participants in relation to the workshop and also the positive verbal comments received. The HCPs all commented that they had learnt new ways of communicating with patients. After the workshop I received e-mails from the HCPs who had to leave early during the workshop (due to work commitments) stating that they would like me to send them the handouts from the workshop. There was also some interest shown from the people who could not attend this workshop as they asked me whether the workshop could be run again at a later date for them to attend. I am considering running this workshop again in the near future.

References

Conference Summit. (2004). 2nd International DAWN Summit: a call-to-action to improve psychosocial care for people with diabetes. *Practical Diabetes International, 21 (5). John Wiley & Sons, Ltd.* Retrieved January 2013 from http://www.dawnstudy.com/documents/DAWN%20materials/DAWN_Publications/13_call_to_action_to_improve.pdf, conference 2004

Exley, K. and Dennick, R. (2004). *Small Group Teaching. Tutorials, seminars and beyond*. Routledge Falmer: London.

Glasgow, R.E., Toobert, D.J. and Gillette, C.D. (2001). Psychosocial barriers to diabetes self-management and quality of life. *Diabetes Spectrum, 14*(1), 33-41.

January 2013 from http://novomedlink.pro/diabetes-care/diabetes-themes/Psychosocial-Aspects-of-Diabetes.aspx

Lloyd, C. E., Wing, R. R., Orchard, T. J. & Becker, D. J. (1993). Psychosocial correlates of glycemic control: The Pittsburgh Epidemiology of Diabetes Complications (EDC) study. *Diabetes Research in Clinical Practice,* 21,187–195.

Petrak, F., Herpertz, S., Albus, C., Hirsch, A., Kulzer, B. and Kruse, J. (2005). Psychosocial factors and diabetes mellitus: evidence-based treatment guidelines. *Current Diabetes Review, 1*(3), 255-70.

Race, P. and Smith, B. (1996). *500 Tips for Trainers.* Gulf Publishing Company. Houston.

RAPSID. Retrieved January 2013 from http://public.ukcrn.org.uk/search/StudyDetail.aspx?StudyID=6521

Rogers, J. (2002). *Adults Learning (4th Edition).* University Press. Buckingham.

Seeman, T. and Chen, X. (2002). Risk and protective factors for physical functioning in older adults with and without chronic conditions: MacArthur studies of successful aging. *Journal of Gerontology Behaviour and Psychological Science and Social Sciences, 57*(3), S135-44.

Weiner, I.B., Nezu, A. M., Nezu,C. M. & Geller, P.A. (2003). *Handbook of Psychology, Health Psychology* (Volume 9). John Wiley & Sons. New Jersey.

Appendix A

RAPSID (Diabetes Peer Study)

Title: A randomised controlled trial investigating whether peer support is effective for people with Type 2 diabetes

Principal research question: RAPSID: Can peer support, delivered as a group or individual intervention, enable people with diabetes and improve their health? (A RAndomised controlled trial of Peer Support In Type 2 diabetes in Cambridgeshire, England).

Background: Diabetes related damage is often now preventable with tight metabolic control (e.g. glucose, blood pressure, and lipids), self care activities, regular review and timely intervention. However, preventable complications continue to occur (3), often due to personal and systems barriers to implementing diabetes care. The need to overcome such barriers, so that people with diabetes are able to deal with the psychological, social and emotional issues that they face has become a major challenge. Peer support, involving experience sharing, mentoring and role-modeling, has been proposed as a way of overcoming some psychosocial barriers. Previous research suggests that peer support interventions are welcomed by participants, but has not provided robust evidence for its utility across all cultures.

Sample group description: Our trial will focus on people with Type 2 diabetes across Cambridgeshire (population 587,573): Type 2 diabetes because it is more prevalent and because the experiences and needs of people with Type 1 and Type 2 diabetes differ. Diabetes was recorded among 19,579 people aged 17+ years on local General Practice registers in 2007 (49). The prevalence of diagnosed diabetes is 3.33%. The county includes over 80 towns and villages with Cambridge as the major town (population 120,000). The economic base comes from agricultural, science, educational and service industries with a large commuter population.

Outcome measure description:

Metabolic control
Quality of life
Self management behaviours Self efficacy
Reach

Appendix B

Knowledge enhancement workshop

Feedback/evaluation form

Date: ______________________

1: Do you feel this session has met your expectations?
Yes / no / don't know (please tick one option)
Why?

2: What was found to be most beneficial?

Why?

3: What was found to be least useful?

Why?

4: Any key points learnt from this session?

5: Are there any other ways this workshop could have been improved?

6: Is there anything else about the session you would like to comment upon?

---

1. How would you rate the following?

	1 **Poor**	**2** **Satisfactory**	**3** **Good**	**4** **Excellent**
The speaker's communication skills				
The speaker's enthusiasm				
Content of slides				
Examples used to assist audience to understand the points				
The organisation of the material				
The speakers ability to explain the points coherently and clearly				
The relevancy of the tasks				
The speaker's presentation skills				
The speaker's group facilitating skills				
Use of the material (e.g. PowerPoint, diagrams, flipchart)				

Thank you for your time.

Appendix C

Brief workshop

Based on psychosocial aspects of Type 2 diabetes management

What are aims/objectives of this workshop?

Aims:

To enhance knowledge and understanding about some potential psychological & social factors in Type 2 diabetes management from Health Psychology perspectives.

Objectives:

Increased systematic understanding and awareness of social and psychological knowledge.
Increased understanding of the appropriate application of social and psychological knowledge.

What this workshop involves?

Overview of psychological and social factors
Interactive activities:

1. Discussions
2. Individual and group exercises
3. Feedback/evaluation

How this workshop will benefit me?

By attending this interactive workshop, you will be gaining evidence based knowledge and enhancing you understanding about a variety of aspects of Type 2 diabetes management. You will also be provided a very useful knowledge pack (including slides and some useful papers) after the workshop to gain in-depth understanding of the evidence based information.

Duration

One and half hour

Date/Day/time

08/10/12 on Friday at 2:30pm

Appendix D

Observational report by the University supervisor

Department of Psychology
City University
Northampton Square
London EC1V 0HB
Director – Catherine Sykes
Email; [redacted]
Tel: [redacted]

Doctorate in Health Psychology

Teaching and Training Observation Report

Trainee Details

Name Kalsoom Akhter
Chartered Health Psychologist Supervisor Catherine Sykes
Audience Health care professionals
Please circle the appropriate response and make comments

Appropriate resources and material were used YES/NO

Delivery of material Poor Fair **Good** Excellent

Responded effectively to problems, queries and issues during the training **YES**/NO

Supported students through the learning programme **YES**/NO

Provided encouragement and accurate feedback to learners during training **YES**/NO

Appropriate evaluation methods were used **YES**/NO

Comments

Kalsoom produced excellent training materials for this session. She has worked on her presentation and communication skills which resulted in a very supportive teaching style. She managed to keep eye contact and the pace of her presentation was much improved.
She responded well to questions and managed to keep a mixed group of health professionals engaged in the presentation.

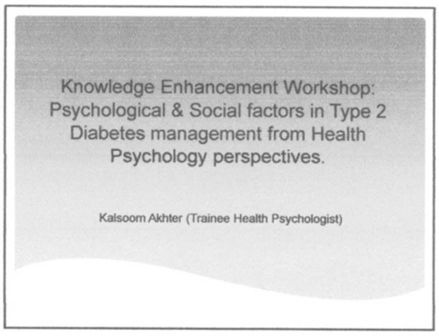
Declaration

I am of the opinion that the above named trainee has completed the teaching and training competence to a high professional standard and is able to act autonomously in this competence.

Signature: ………………………………………………………. Date: ……………………………

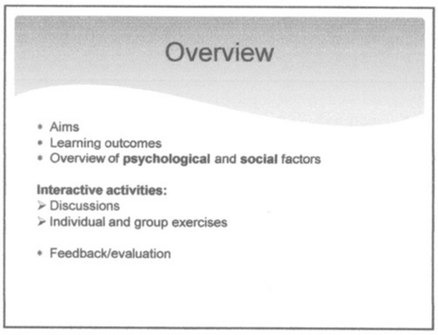
Appendix E

Presentation Slides



Knowledge Enhancement Workshop: Psychological & Social factors in Type 2 Diabetes management from Health Psychology perspectives.

Kalsoom Akhter (Trainee Health Psychologist)

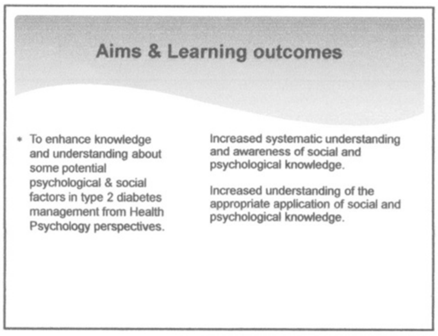


Overview

- Aims
- Learning outcomes
- Overview of **psychological** and **social** factors

Interactive activities:
➢ Discussions
➢ Individual and group exercises

- Feedback/evaluation

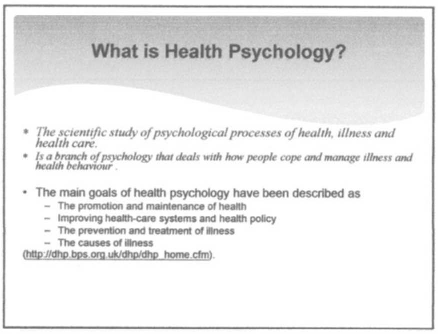


Aims & Learning outcomes

- To enhance knowledge and understanding about some potential psychological & social factors in type 2 diabetes management from Health Psychology perspectives.

Increased systematic understanding and awareness of social and psychological knowledge.

Increased understanding of the appropriate application of social and psychological knowledge.

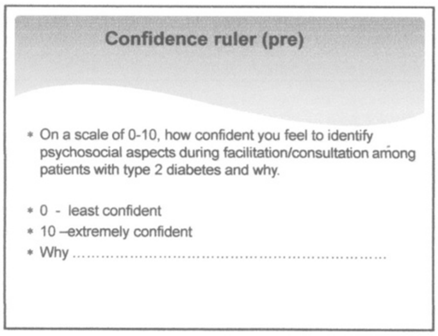


What is Health Psychology?

- *The scientific study of psychological processes of health, illness and health care.*
- *Is a branch of psychology that deals with how people cope and manage illness and health behaviour .*

- The main goals of health psychology have been described as
  - The promotion and maintenance of health
  - Improving health-care systems and health policy
  - The prevention and treatment of illness
  - The causes of illness

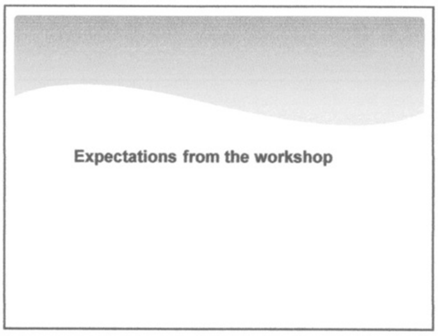
(http://dhp.bps.org.uk/dhp/dhp_home.cfm).



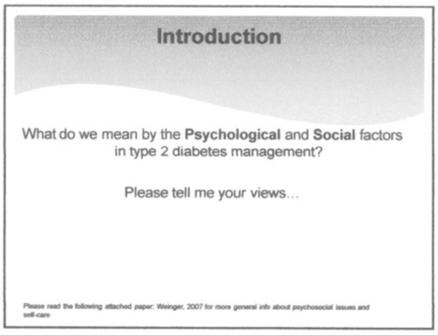
Confidence ruler (pre)

- On a scale of 0-10, how confident you feel to identify psychosocial aspects during facilitation/consultation among patients with type 2 diabetes and why.

- 0 - least confident
- 10 –extremely confident
- Why ……………………………………………………………



Expectations from the workshop

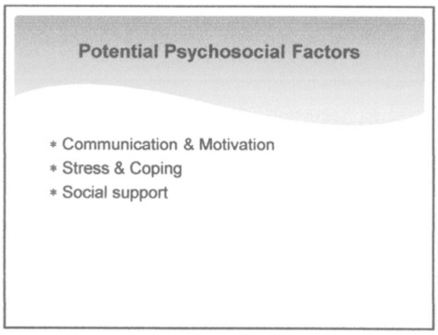


Introduction

What do we mean by the **Psychological** and **Social** factors in type 2 diabetes management?

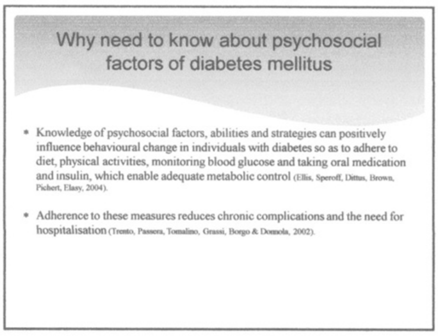
Please tell me your views…

Please read the following attached paper: Weinger, 2007 for more general info about psychosocial issues and self-care



Potential Psychosocial Factors

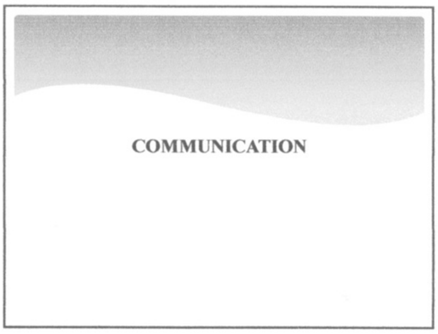
- Communication & Motivation
- Stress & Coping
- Social support



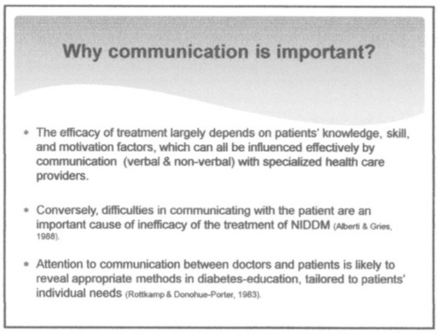
Why need to know about psychosocial factors of diabetes mellitus

- Knowledge of psychosocial factors, abilities and strategies can positively influence behavioural change in individuals with diabetes so as to adhere to diet, physical activities, monitoring blood glucose and taking oral medication and insulin, which enable adequate metabolic control (Ellis, Speroff, Dittus, Brown, Pichert, Elasy, 2004).

- Adherence to these measures reduces chronic complications and the need for hospitalisation (Trento, Passera, Tomalino, Grassi, Borgo & Donnola, 2002).



COMMUNICATION

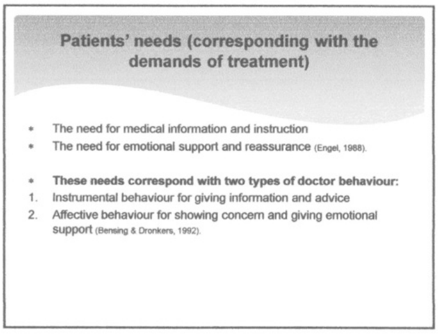


Why communication is important?

- The efficacy of treatment largely depends on patients' knowledge, skill, and motivation factors, which can all be influenced effectively by communication (verbal & non-verbal) with specialized health care providers.

- Conversely, difficulties in communicating with the patient are an important cause of inefficacy of the treatment of NIDDM (Alberti & Gries, 1988).

- Attention to communication between doctors and patients is likely to reveal appropriate methods in diabetes-education, tailored to patients' individual needs (Rottkamp & Donohue-Porter, 1983).

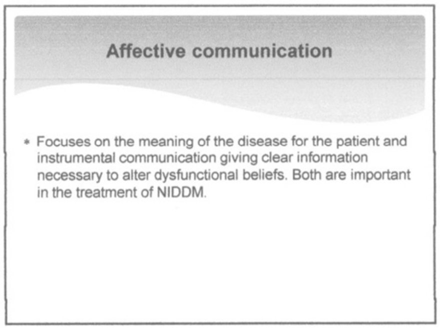


Patients' needs (corresponding with the demands of treatment)

- The need for medical information and instruction
- The need for emotional support and reassurance (Engel, 1988).

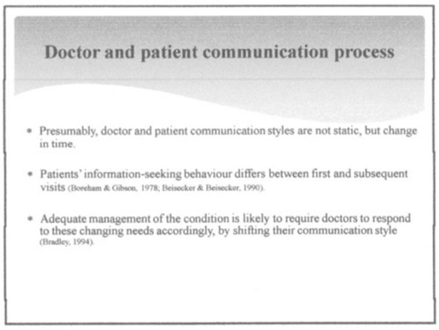
- **These needs correspond with two types of doctor behaviour:**

1. Instrumental behaviour for giving information and advice
2. Affective behaviour for showing concern and giving emotional support (Bensing & Dronkers, 1992).



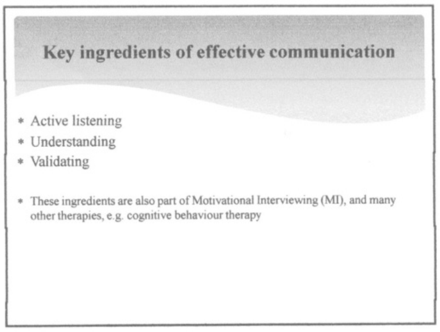
Affective communication

- Focuses on the meaning of the disease for the patient and instrumental communication giving clear information necessary to alter dysfunctional beliefs. Both are important in the treatment of NIDDM.



Doctor and patient communication process

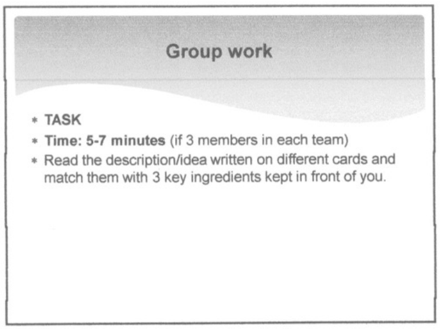
- Presumably, doctor and patient communication styles are not static, but change in time.
- Patients' information-seeking behaviour differs between first and subsequent visits (Boreham & Gibson, 1978; Beisecker & Beisecker, 1990).
- Adequate management of the condition is likely to require doctors to respond to these changing needs accordingly, by shifting their communication style (Bradley, 1994).



Key ingredients of effective communication

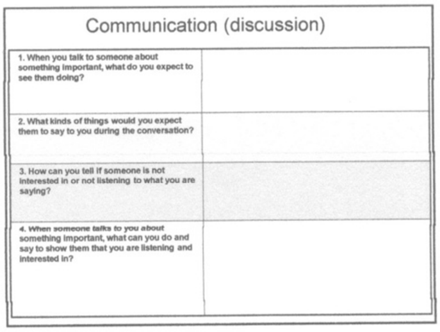
- Active listening
- Understanding
- Validating

- These ingredients are also part of Motivational Interviewing (MI), and many other therapies, e.g. cognitive behaviour therapy



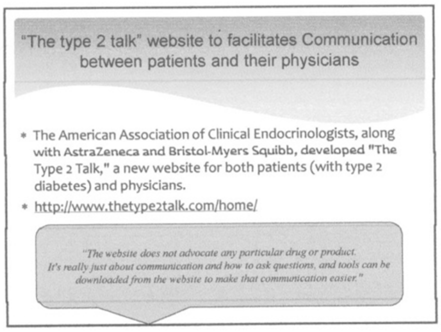
Group work

- **TASK**
- **Time: 5-7 minutes** (if 3 members in each team)
- Read the description/idea written on different cards and match them with 3 key ingredients kept in front of you.



Communication (discussion)

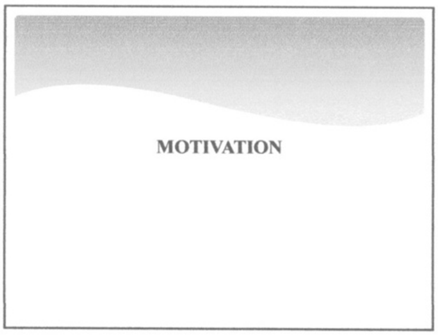
1. When you talk to someone about something important, what do you expect to see them doing?	
2. What kinds of things would you expect them to say to you during the conversation?	
3. How can you tell if someone is not interested in or not listening to what you are saying?	
4. When someone talks to you about **something important, what can you do and say to show them that you are listening and interested in?**	



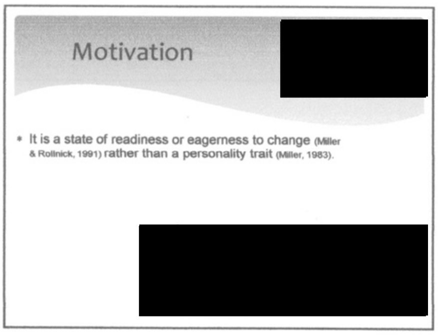
"The type 2 talk" website to facilitates Communication between patients and their physicians

- The American Association of Clinical Endocrinologists, along with AstraZeneca and Bristol-Myers Squibb, developed "The Type 2 Talk," a new website for both patients (with type 2 diabetes) and physicians.
- http://www.thetype2talk.com/home/

"The website does not advocate any particular drug or product.
It's really just about communication and how to ask questions, and tools can be downloaded from the website to make that communication easier."



MOTIVATION

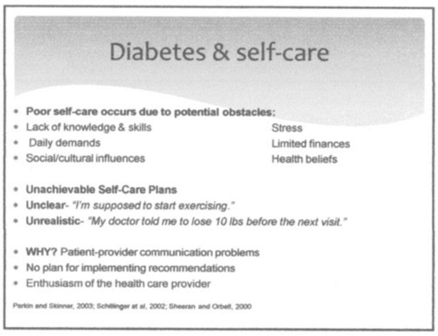


Motivation

[redacted]

- It is a state of readiness or eagerness to change (Miller & Rollnick, 1991) rather than a personality trait (Miller, 1983).

[redacted]



Diabetes & self-care

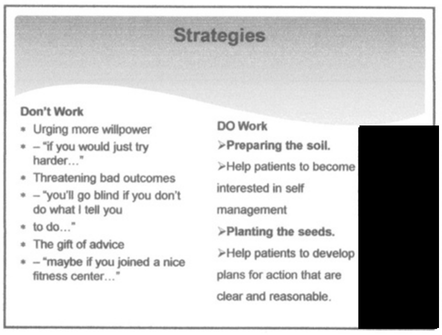
- **Poor self-care occurs due to potential obstacles:**
- Lack of knowledge & skills
- Daily demands
- Social/cultural influences

Stress
Limited finances
Health beliefs

- **Unachievable Self-Care Plans**
- **Unclear**- *"I'm supposed to start exercising."*
- **Unrealistic**- *"My doctor told me to lose 10 lbs before the next visit."*

- **WHY?** Patient-provider communication problems
- No plan for implementing recommendations
- Enthusiasm of the health care provider

Parkin and Skinner, 2003; Schillinger at al, 2002; Sheeran and Orbell, 2000



Strategies

Don't Work

- Urging more willpower
- – "if you would just try harder…"
- Threatening bad outcomes
- – "you'll go blind if you don't do what I tell you
- to do…"
- The gift of advice
- – "maybe if you joined a nice fitness center…"

DO Work

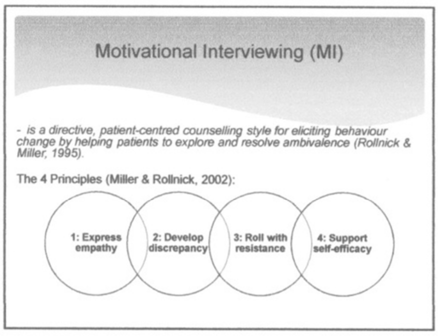
➢**Preparing the soil.**

➢Help patients to become interested in self management

➢**Planting the seeds.**

➢Help patients to develop plans for action that are clear and reasonable.

[redacted]

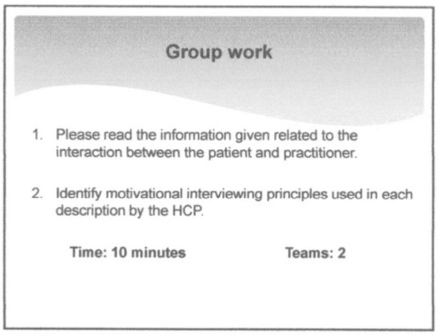


Motivational Interviewing (MI)

- is a directive, patient-centred counselling style for eliciting behaviour change by helping patients to explore and resolve ambivalence (Rollnick & Miller, 1995).

The 4 Principles (Miller & Rollnick, 2002):

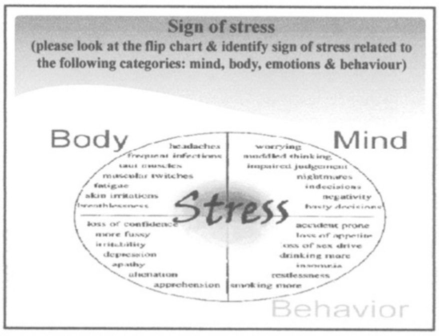
1: Express empathy
2: Develop discrepancy
3: Roll with resistance
4: Support self-efficacy



Group work

1. Please read the information given related to the interaction between the patient and practitioner.
2. Identify motivational interviewing principles used in each description by the HCP.

Time: 10 minutes **Teams: 2**



Sign of stress
(please look at the flip chart & identify sign of stress related to the following categories: mind, body, emotions & behaviour)

Body

headaches
frequent infections
taut muscles
muscular twitches
fatigue
skin irritations
breathlessness

Mind

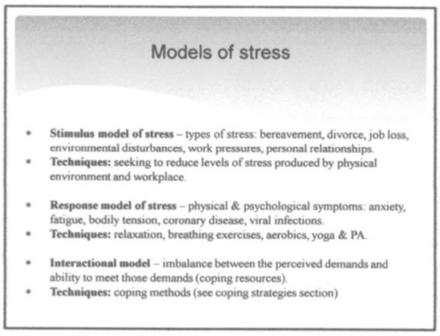
worrying
muddled thinking
impaired judgement
nightmares
indecisions
negativity
hasty decisions

Stress

loss of confidence
more fussy
irritability
depression
apathy
alienation
apprehension

accident prone
loss of appetite
loss of sex drive
drinking more
insomnia
restlessness
smoking more

Behavior

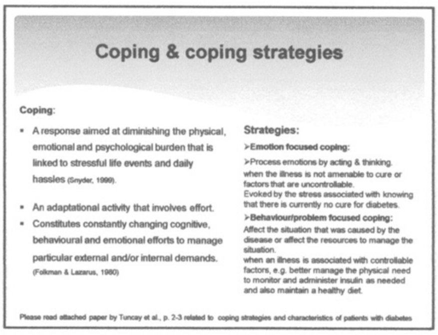


Models of stress

- **Stimulus model of stress** – types of stress: bereavement, divorce, job loss, environmental disturbances, work pressures, personal relationships.
- **Techniques:** seeking to reduce levels of stress produced by physical environment and workplace.

- **Response model of stress** – physical & psychological symptoms: anxiety, fatigue, bodily tension, coronary disease, viral infections.
- **Techniques:** relaxation, breathing exercises, aerobics, yoga & PA.

- **Interactional model** – imbalance between the perceived demands and ability to meet those demands (coping resources).
- **Techniques:** coping methods (see coping strategies section)



Coping & coping strategies

Coping:

- A response aimed at diminishing the physical, emotional and psychological burden that is linked to stressful life events and daily hassles (Snyder, 1999).

- An adaptational activity that involves effort.
- Constitutes constantly changing cognitive, behavioural and emotional efforts to manage particular external and/or internal demands. (Folkman & Lazarus, 1980)

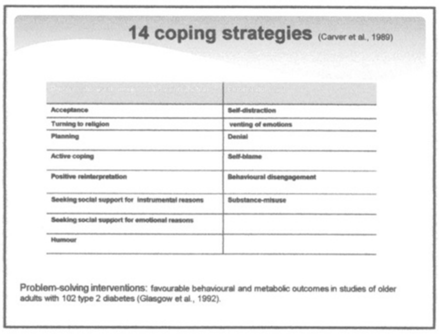
Strategies:

➢**Emotion focused coping**:

➢Process emotions by acting & thinking.
when the illness is not amenable to cure or factors that are uncontrollable.
Evoked by the stress associated with knowing that there is currently no cure for diabetes.

➢**Behaviour/problem focused coping:**
Affect the situation that was caused by the disease or affect the resources to manage the situation.
when an illness is associated with controllable factors, e.g. better manage the physical need to monitor and administer insulin as needed and also maintain a healthy diet.

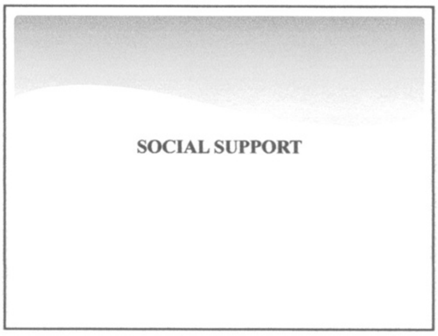
Please read attached paper by Tuncay et al., p. 2-3 related to coping strategies and characteristics of patients with diabetes



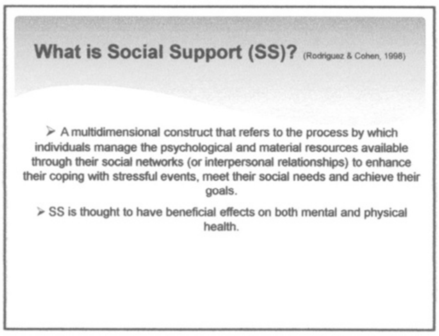
14 coping strategies (Carver et al., 1989)

Acceptance	Self-distraction
Turning to religion	venting of emotions
Planning	Denial
Active coping	Self-blame
Positive reinterpretation	Behavioural disengagement
Seeking social support for instrumental reasons	Substance-misuse
Seeking social support for emotional reasons	
Humour	

Problem-solving interventions: favourable behavioural and metabolic outcomes in studies of older adults with 102 type 2 diabetes (Glasgow et al., 1992).



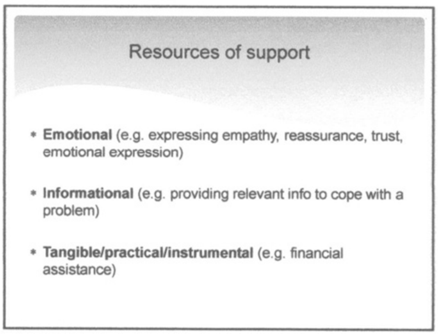
SOCIAL SUPPORT



What is Social Support (SS)? (Rodriguez & Cohen, 1998)

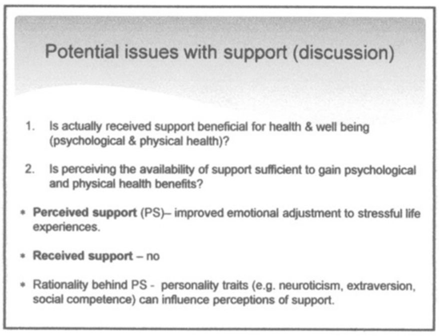
➢ A multidimensional construct that refers to the process by which individuals manage the psychological and material resources available through their social networks (or interpersonal relationships) to enhance their coping with stressful events, meet their social needs and achieve their goals.

➢ SS is thought to have beneficial effects on both mental and physical health.



Resources of support

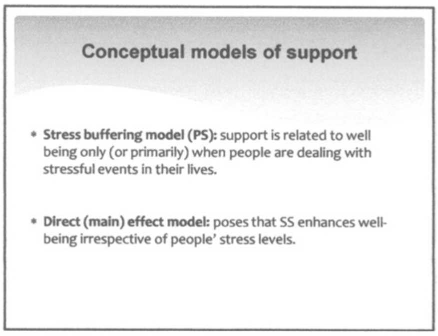
- **Emotional** (e.g. expressing empathy, reassurance, trust, emotional expression)
- **Informational** (e.g. providing relevant info to cope with a problem)
- **Tangible/practical/instrumental** (e.g. financial assistance)



Potential issues with support (discussion)

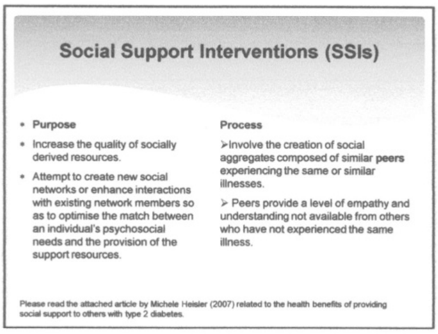
1. Is actually received support beneficial for health & well being (psychological & physical health)?
2. Is perceiving the availability of support sufficient to gain psychological and physical health benefits?

- **Perceived support** (PS)– improved emotional adjustment to stressful life experiences.
- **Received support** – no
- Rationality behind PS - personality traits (e.g. neuroticism, extraversion, social competence) can influence perceptions of support.



Conceptual models of support

- **Stress buffering model (PS):** support is related to well being only (or primarily) when people are dealing with stressful events in their lives.
- **Direct (main) effect model:** poses that SS enhances well-being irrespective of people' stress levels.



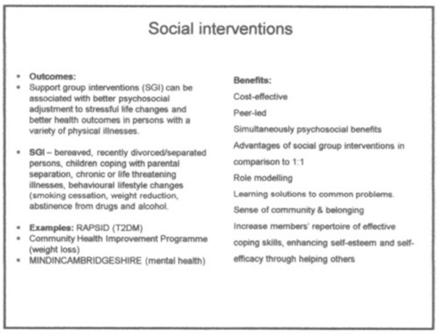
Social Support Interventions (SSIs)

- **Purpose**
- Increase the quality of socially derived resources.
- Attempt to create new social networks or enhance interactions with existing network members so as to optimise the match between an individual's psychosocial needs and the provision of the support resources.

Process

- ➢Involve the creation of social aggregates composed of similar **peers** experiencing the same or similar illnesses.
- ➢ Peers provide a level of empathy and understanding not available from others who have not experienced the same illness.

Please read the attached article by Michele Heisler (2007) related to the health benefits of providing social support to others with type 2 diabetes.



Social interventions

- **Outcomes:**
- Support group interventions (SGI) can be associated with better psychosocial adjustment to stressful life changes and better health outcomes in persons with a variety of physical illnesses.
- **SGI** – bereaved, recently divorced/separated persons, children coping with parental separation, chronic or life threatening illnesses, behavioural lifestyle changes (smoking cessation, weight reduction, abstinence from drugs and alcohol.
- **Examples:** RAPSID (T2DM)
- Community Health Improvement Programme (weight loss)
- MINDINCAMBRIDGESHIRE (mental health)

Benefits:

Cost-effective

Peer-led

Simultaneously psychosocial benefits

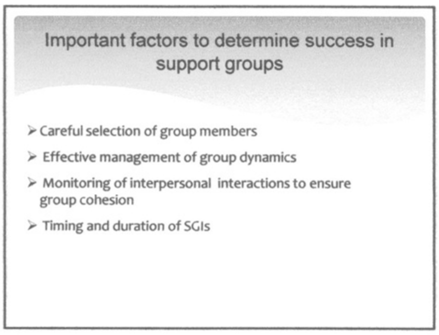
Advantages of social group interventions in comparison to 1:1

Role modelling

Learning solutions to common problems.

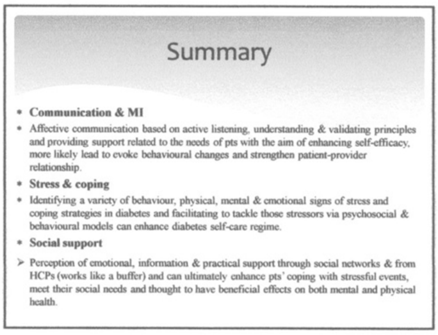
Sense of community & belonging

Increase members' repertoire of effective coping skills, enhancing self-esteem and self-efficacy through helping others



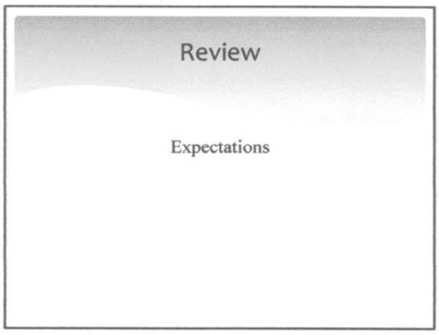
Important factors to determine success in support groups

- ➢ Careful selection of group members
- ➢ Effective management of group dynamics
- ➢ Monitoring of interpersonal interactions to ensure group cohesion
- ➢ Timing and duration of SGIs



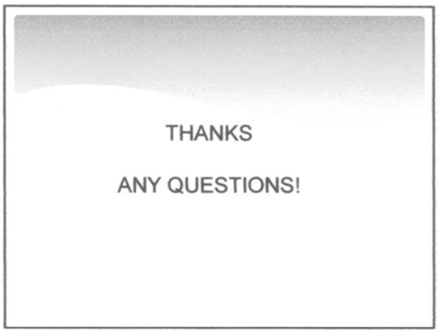
Summary

- **Communication & MI**
- Affective communication based on active listening, understanding & validating principles and providing support related to the needs of pts with the aim of enhancing self-efficacy, more likely lead to evoke behavioural changes and strengthen patient-provider relationship.
- **Stress & coping**
- Identifying a variety of behaviour, physical, mental & emotional signs of stress and coping strategies in diabetes and facilitating to tackle those stressors via psychosocial & behavioural models can enhance diabetes self-care regime.
- **Social support**
- ➢ Perception of emotional, information & practical support through social networks & from HCPs (works like a buffer) and can ultimately enhance pts' coping with stressful events, meet their social needs and thought to have beneficial effects on both mental and physical health.



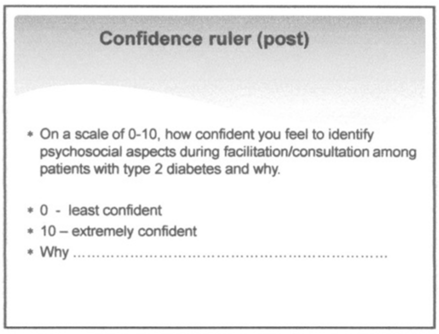
Review

Expectations



THANKS

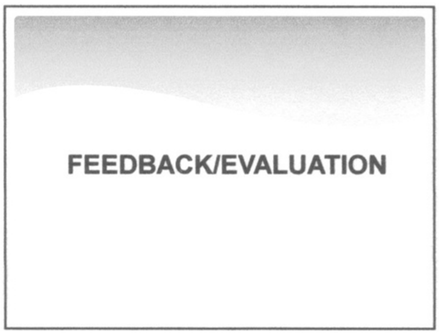
ANY QUESTIONS!



Confidence ruler (post)

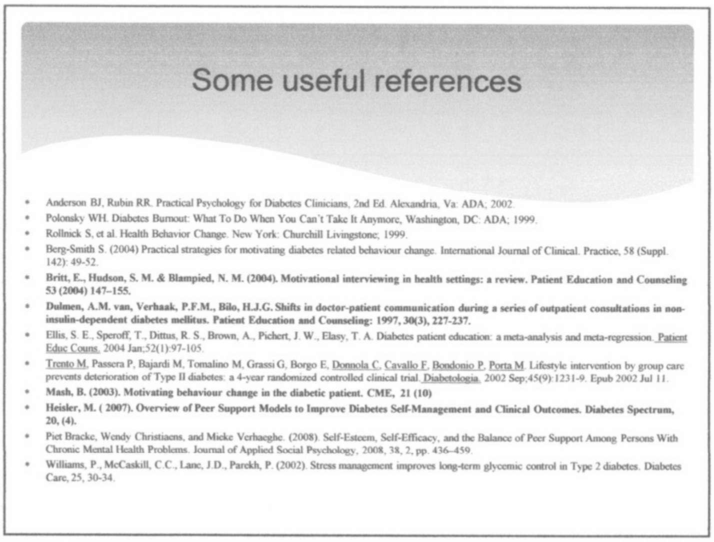
- On a scale of 0-10, how confident you feel to identify psychosocial aspects during facilitation/consultation among patients with type 2 diabetes and why.

- 0 - least confident
- 10 – extremely confident
- Why ……………………………………………………………



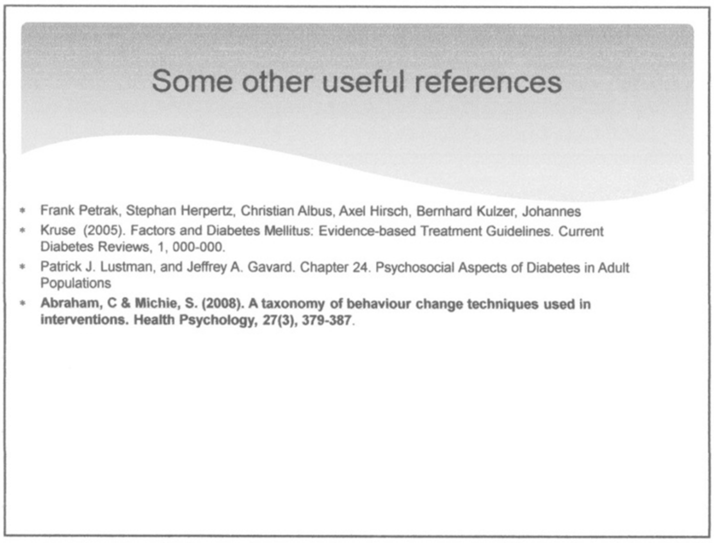
FEEDBACK/EVALUATION

THANK YOU!



Some useful references

- Anderson BJ, Rubin RR. Practical Psychology for Diabetes Clinicians, 2nd Ed. Alexandria, Va: ADA; 2002.
- Polonsky WH. Diabetes Burnout: What To Do When You Can't Take It Anymore, Washington, DC: ADA; 1999.
- Rollnick S, et al. Health Behavior Change. New York: Churchill Livingstone; 1999.
- Berg-Smith S. (2004) Practical strategies for motivating diabetes related behaviour change. International Journal of Clinical. Practice, 58 (Suppl. 142): 49-52.
- **Britt, E., Hudson, S. M. & Blampied, N. M. (2004). Motivational interviewing in health settings: a review. Patient Education and Counseling 53 (2004) 147–155.**
- **Dulmen, A.M. van, Verhaak, P.F.M., Bilo, H.J.G. Shifts in doctor-patient communication during a series of outpatient consultations in non-insulin-dependent diabetes mellitus. Patient Education and Counseling: 1997, 30(3), 227-237.**
- Ellis, S. E., Speroff, T., Dittus, R. S., Brown, A., Pichert, J. W., Elasy, T. A. Diabetes patient education: a meta-analysis and meta-regression. Patient Educ Couns. 2004 Jan;52(1):97-105.
- Trento M, Passera P, Bajardi M, Tomalino M, Grassi G, Borgo E, Donnola C, Cavallo F, Bondonio P, Porta M. Lifestyle intervention by group care prevents deterioration of Type II diabetes: a 4-year randomized controlled clinical trial. Diabetologia. 2002 Sep;45(9):1231-9. Epub 2002 Jul 11.
- **Mash, B. (2003). Motivating behaviour change in the diabetic patient. CME, 21 (10)**
- **Heisler, M. (2007). Overview of Peer Support Models to Improve Diabetes Self-Management and Clinical Outcomes. Diabetes Spectrum, 20, (4).**
- Piet Bracke, Wendy Christiaens, and Mieke Verhaeghe. (2008). Self-Esteem, Self-Efficacy, and the Balance of Peer Support Among Persons With Chronic Mental Health Problems. Journal of Applied Social Psychology, 2008, 38, 2, pp. 436–459.
- Williams, P., McCaskill, C.C., Lane, J.D., Parekh, P. (2002). Stress management improves long-term glycemic control in Type 2 diabetes. Diabetes Care, 25, 30-34.



Some other useful references

- Frank Petrak, Stephan Herpertz, Christian Albus, Axel Hirsch, Bernhard Kulzer, Johannes
- Kruse (2005). Factors and Diabetes Mellitus: Evidence-based Treatment Guidelines. Current Diabetes Reviews, 1, 000-000.
- Patrick J. Lustman, and Jeffrey A. Gavard. Chapter 24. Psychosocial Aspects of Diabetes in Adult Populations
- **Abraham, C & Michie, S. (2008). A taxonomy of behaviour change techniques used in interventions. Health Psychology, 27(3), 379-387**.

Section 3C - Consultancy

Initiatives to explore potential factors influencing non-attendance and service improvement strategies

Supervision Plan

Consultancy competence: Initiatives to explore potential factors influencing non-attendance and service improvement strategies

Units in this area of competence	Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)	Supporting evidence to be complied for this unit of competence
3.1 Assessment of requests for consultancy **3.2 Plan consultancy** **3.3 Establish, develop and maintain working relationships with clients** **3.4 Conduct consultancy** **3.5 Monitor the implementation of consultancy** **3.6 Evaluate the impact of consultancy**	**Setting:** Secondary care. **Client/ Target Group:** Type 1 diabetes patients **Description of work:** The issue of non-attendance of clinic appointments was a cause of concern for the managers and HCPs in terms of its affects on clinic services as well on patients' health. The clients demonstrated interest by asking trainee HP to provide some solutions related to this issue. The clients highlighted the needs of knowing the non-attendance rate, reasons of non-attendance and any strategies to improve the service. The hospital database was reviewed to find highest rate of non-attendance among diabetes patients. A brief telephone survey was conducted for the Type 1 diabetes patients, who missed most of their appointments. My working relationship with the contact clients was via emails and through face-to-face meetings. The aim of each contact was to maintain a good working relationship, to discuss any potential issues and the progress of the consultancy. The implementation of the consultancy was carried out via a telephone survey and keeping record of each contact with the patients (n=126). Patients' provided reasons and strategies to improve services were recorded on excel data base for analysis purposes. The clients found such work very useful after evaluating the outcome of the consultancy by focusing upon their aims. Thus, it was decided to implement patients' suggestion into the services in the form of text message reminders. I managed the whole process in terms of designing and managing it using existing resources and negotiating and disseminating it professionally in a peer review journal.	• Proposal • Assessment of request for consultancy • Brief script with the survey questions • Contract • Clinic report • Protocol for the RCT • DNA paper • DNA poster

Target for completion: … June, 2011 … Workplace contact? Yes … If yes please give name: [redacted]

Setting:	Secondary care
Primary Client:	[redacted]
Target group:	Patients with Type 1 diabetes who attend their annual review and follow up appointments in the clinic.
Contact client:	The service manager and the lead consultant Diabetologist
Consultant:	Trainee Health Psychologist

Introduction

I will describe my experience of working as a consultant on an innovative Health Consultancy project at the [redacted] to propose a potential solution for improving patients' attendance rate and assist the diabetes clinic in addressing the issue of non-attendance in the secondary care setting.

Background

The issue of non-attendance was negotiated on 27/09/ 2010 by the manager and a doctor at the diabetes clinic, as it was a cause of concern for them to manage the clinic when it gets overbooked because of giving follow-up appointments to those patients who Did Not Attend (DNA) their previous appointments. A draft plan was prepared and negotiated with the diabetes clinic to overcome this issue. The concept of this pathway was to raise the profile of self-care perception and non-attendance within the secondary care setting and to embed the process of monitoring the non-attendance of patients with diabetes into the NHS care system.

I was very keen to increase awareness amongst all health care professionals and managers about any contributing factors to non-attendance from the patients' perspectives in the diabetes. From a Health Psychology perspective, it was important to identify and understand any potential reasons, which affect care seeking behaviour at clinic appointments (Lawson, Bundy, Lyne, Harvey, 2004; Lawson, Layne, Harvey, & Bundy, 2005). In addition, one of the principles of Health Psychology is to improve patients' health by assessing their needs and implementing potential changes into services in terms of improving the health care system, for instance increasing uptake of service use (Matarazzo, 1982).

Furthermore, one of the specific aims of the Addenbrooke’s Hospital (please see the website: http://www.cuh.org.uk/cuh/profile/profile_index.html) is to improve the patients’ care by exploring their needs and prioritising them in service developments. The issue of patients’ non-attendance requires some serious concerns, as it does not only affect hospital services, but also patients’ health. For instance, patients who miss appointments also miss opportunities for detecting complications and treatment adjustments. As a result, these patients may experience poorer outcomes (Ngwenya, Van Zyl, Webb, 2009), and are more likely to return at a later stage frequently with advanced diabetes complications and risk factors than those attending regularly (Stone, Palmer, Saxby & Devaray, 1999; Simmons & Clover, 2007; Griffin, 1998). Furthermore, non-attendance at a diabetes clinic has been associated with poorer glycemic control (Jacobson, Adler, Derby, Anderson &Wolfsdorf, 1991) and attendance is associated with improved medical outcomes (Lawson, Lyne, Bundy & Harvey, 2005). Non-attendance of appointments is one of the major contributors to poor control in diabetes management (Mollentze & Koning, 2007).

In November 2010, the clients (i.e. clinic service/support manager and a lead consultant) asked me to prepare a proposal that related to exploring reasons influencing the clinic non-attendance from the patients’ perspectives, which could be beneficial for the clinic services in the future to improve patients’ non-attendance. I negotiated my proposal with the clients and they gave their consent to work on the area of non-attendance. I saw the proposed plan as a mean of assisting me to meet the aims. In addition, I felt it would be an exciting opportunity for me to influence the development of the patients care pathway from a Health Psychology perspective, but what struck me upon first seeing the draft of this plan was that it was not grounded in psychological theory. Therefore, I explored some empirical evidence in the literature (November 2010) and grounded the consultancy proposal into health psychology theoretical framework *“self regulatory theory”* (Leventhal & Cameron, 1987; Leventhal, Zimmerman, & Gutmann, 1984) Please see Appendix A for proposal that aimed to explore/understand what kind of factors control or regulate this kind of behaviour (non-attendance).

Assessing requests for consultancy

Within my capacity of working on an honorary contract as a DPsych health psychologist trainee in the diabetes clinic, clients’ requests were explored through discussion primarily. Clients mentioned one of the most concerning issues of their clinics ‘non-attendance’ and demonstrated interest by asking trainee to provide some solutions related to this issue. In this brief meeting, it was unclear as to what the client (clinic manager) was looking for. Therefore, a second meeting (1/11/10) was arranged with the contact client, in order to gain a better understanding of what the contact clients' requirements were and to discuss the finer details of the consultancy program. In this meeting clients highlighted the needs of:

1. Knowing patients' non-attendance rate
2. Reasons of not informing the clinic related to their decision of attending or not attending their clinic appointments
3. Any strategies to improve the service.

Following this meeting, the aims of the consultancy were discussed on 4th of November 2010 and it was agreed by both parties that the target group would be adult patients with diabetes, who have missed their one or more appointments in the last 12 months. In addition, I informally proposed some ideas (e.g. conducting a telephone survey or inviting patients for interviews in the clinic) to the clients to tackle this issue using patient centred approach (White & Verhoef, 2005; Stewart, 2001). This approach means involving patients in service improvements by assessing their views (in regards to not being able to attend their clinic appointments) and giving voice to the concerns of patients by applying their recommendation.

Patients' non-adherence to their appointments is an important issue for two major reasons. Firstly, the financial cost of missed appointments in the NHS has been estimated at £360 million per year (Stone, Palmer, Saxby & Devaray, 1999), most of this accounted for by non-attendance in primary care and hospital out-patient clinics (Mitchell & Selmes, 2007). Secondly, non-attendance of appointments is also considered one of the major contributors to poor control in diabetes management (Mollentze & Koning, 2007). On the other hand, from the NHS perspectives, patients' non-adherence with regularly scheduled clinic appointments can also obstruct efforts to shorten waiting lists, affect continuity of care, contribute to long waiting times (Paterson, Charlton, & Richard, 2010; Hussain-Gambles, Neal, Dempsey, Lawlor, & Hodgson, 2004; Weinger, McMurrich, Yi, Lin, & Rodriquez, 2005) and can impact successful diabetes management (Griffin, 1998). Although, numerous strategies or intervention have been implemented to reduce the non-attendance rate with varying degrees of success, (e.g. telephone (Reti, 2003), postal reminders (Henderson, 2008), e-mail reminders (Lim & Varkey, 2005) and text messaging (Downer, Meara, Da Costa &

Sethuraman, 2006), interventions to improve attendance rate in the diabetes clinic are sparse. Clients were informed about the insufficient work in this area and they were aware of some potential barriers to solve this issue (e.g. financial cost and time to spend on assessing patients' behaviour and apply some interventions).

At this stage I was acting as an *'internal'* helper, consistent with the *'Process Model'* of consultancy (Schein, 1999). This model is characterised by being both collaborative and client-centred. As proposed by Schein (1999), the consultant adopts a helping role in guiding the client through a process of discovery in which the client can identify problems on concerns within an organisation, in order for the client to ultimately make key decisions in resolving the identified problems or concerns. Within this *'helping'* role, I worked in collaboration with the clients, in developing initiatives to explore factors influencing non-attendance (or not seeking health care services) at the diabetes clinic.

The advice I gave on finding out reasons of non-attendance and any service improvement strategies was to conduct a short telephone survey, which may be more feasible and may have better outcomes in terms of finding out patients' perspectives rather than inviting them in the clinic for an interview. The clients also agreed that interviewing patients in the clinic related to their non-attendance would not have been a feasible strategy because of a number of reasons:

- Firstly, a large number of patients have missed one or more appointments since last one year
- Secondly, patients might have problem with parking or with the clinic services
- Thirdly, patients may have to arrange transport to come to the clinic or take a day off from work.

By following the above mentioned barriers, it was agreed (12/2010) to apply the survey method to find out potential reasons and service improvement strategies from patients' perspectives. Prior to preparing a written proposal, I carried out an assessment of the request for consultancy on its feasibility (please see Appendix B - Assessment of request for consultancy). Based on the requirements set out by the clients, I put together a written proposal that demonstrated how my training would fully meet the requirements of working on improving patients' attendance in the diabetes clinic. Within the proposal, I provided details of previous evidence based research, theoretical framework, aims, and a comprehensive method of conducting the requested consultancy, analysis, material/ use of existing resources and timeline. My clients suggested registering this proposal as a service evaluation project into the patient safety department of the Hospital by following a certain criterion. This innovative consultancy plan was registered at the patient safety department on the 2/2/11 and I received confirmation on 14/2/11 to start implementing the proposed initiative.

Reflection

The main challenge for the consultant at this stage of the consultancy was to develop a clear working relationship with both the primary and contact client and to have a better understanding of the service needs regarding the area of non-attendance. On reflection, the consultant realised that during the initial stages of communication with the client, it was quite difficult to establish what the primary clients' needs and requirements were. Also, in addition to this it was not very clear to understand for the consultant to ascertain what her role as a consultant was. This was because in the first meeting the consultant was faced with a number of time constraints, due to the client's limited availability which resulted in the aims and objectives of the consultancy not being properly explained. As communication progressed via meetings the consultant felt that she was now able to discuss more openly with the client regarding the uncertainties and establish the service needs of the project. On reflection, it would have been more beneficial for the consultant at the first meeting to have prepared a list of questions, in order to avoid any misunderstandings regarding the consultancy/intervention. Other learning areas were in the drafting of the proposal, the setting-up of a contract and negotiating the use of existing resources (e.g. telephone) and funding for the consultancy program. Even though the consultant was familiar with contract negotiation in her previous work-place, the design and set-up of the contract was not something she had done before. Therefore, the consultant contacted her university supervisor and accepted her suggestions on how to devise a contract template.

On further reflection, the consultant found that her own understanding related to exploring factors to non-attendance was very subjective. Therefore, in order, to design a workable consultancy/intervention, she needed to consult a variety of sources such as outpatients' departments/clinics in the hospital and journals' articles (please see references in the proposal). There was no fee required for this consultancy work, as it was based solely on an honorary contract.

Planning consultancy

My written proposal was based on the literature review (please see Appendix A), aims, methodology and analysis sections. The aims of this consultancy related to my clients' request were:

- To identify the ratio of non-attendance
- To ascertain reasons (or any contributing factors) for non-attendance and any service improvement strategies from a selected target group via a short telephone survey.

Prior to working on the aims, it was very important to select a target group of those potential patients who did not attend their clinic appointments in the last 12 months. After negotiating with the contact clients, it was decided to review the clinic databases to find out a specific group of patients (out of Type 1diabetes, Type 2 diabetes, Gestational Diabetes, Maturity Onset Diabetes of the Young, Secondary) who missed their appointment more likely in comparison to other groups. A post review analysis showed that in the last year (October 2009-September 2010), patients who missed highest number of their appointments had Type 1 diabetes. Furthermore, these patients' follow-up appointments were reviewed on the hospital databases before contacting them related to a telephone survey (in February 2011), as patients could only be contacted if they had any follow-up appointments in the future in the diabetes clinic.

Both parties worked together to discuss the questions to ask selected patients as part of the telephone survey by considering the wording and length of questions, timing to call patients during office hours (9-5) and essentially discussing the description of introducing myself to patients on the phone. I had initial concerns regarding feasibility of my planning, such as patients might not be available during working hours; may not like to stay on the phone; if I provide a long introduction, and ask more than 2 questions. In addition, it was also an important point to consider about analysing or evaluating the short telephone survey of 176 patients at this stage. To overcome these potential barriers, I negotiated my back up plan with the clients to work at weekends, if required (during implementation process) and developed and discussed a simple, brief and a clear description of my introduction (please see Appendix C of Article 2, p. 236) to patients followed by asking two questions only during the brief telephone conversation. It aimed to ensure and control the consistency in the quality and quantity of provided information to all patients on the phone. Additionally both parties discussed that it would not be feasible to analyse this telephone survey of a large number of patients via qualitative methodology, so I proposed to analyse patients' provided reasons of non-attendance and any service improvement strategies via quantitative method. As this methodology had not only has been used in many previous studies (Simmons & Clover, 2007; Mitchell & Selmes, 2007; Weinger, et al., 2005; Lawson et al., 2004; Lee, Earnest, Chen, Krishnan, 2005; Ngwenya, Van Zyl & Webb, 2009) targeting the area of non-attendance, it was also considered a feasible strategy to analyse very limited data (i.e. patients' provided information) gained from the patients via a short telephone survey. Following this meeting, it was agreed that conducting the planned initiative within the clinic was in line with the service evaluation purposes and was feasible strategy, without impacting on the quality of care, patients are receiving currently.

The consultancy was relatively straightforward and problem-free. The main challenge I faced at the initial stages, concerned finding 808 patients' type of illness (e.g. Type 1 diabetes, Type 2 diabetes, Gestational, secondary) on the hospital's databases one by one, finding the highest DNA patients' demographic and clinical characteristics and excluding those patients of 1) who belonged to endocrinology, foot and transition clinics, as these clinics were considered separate than the other regular clinics and 2) those who belonged to the following categories: discharged, moved away, deceased. The selection of an exact largest DNA group of patients since last 12 months (October 2009-September 2010) was a lengthy process, which delayed the registration of this project in the hospital' patient safety department, followed by the commencement of the telephone survey.

Overall both the consultant and the contact clients took an active role in the planning, designing the aims, objectives and establishing the learning outcomes of the consultancy. However, the primary client took a very central role and throughout the whole consultancy process and always maintained ownership of the *'problem and solution'*. Throughout the consultancy process, I was acting as an internal helper using *'process model'*, giving advice from a health psychology perspective on the development of them pathway/initiative to explore non-attendance related factors from patients' perspectives.

Reflection

Although, I have not worked in this area before on a regular basis, after conducting a literature search and negotiation with the contact clients, I was quite confident to implement the agreed planning. I felt that the process of planning this consultancy project increased my confidence to apply the health psychology principles and theoretical framework by considering about the clients and target group' needs and feasible methodology, which I was very keen to put into practice as a trainee without affecting on the care of patients and clinic services by following the ethical regulations and policies.

Establish, develop and maintain working relationships with client

My working relationship with the clients (my main contact for the consultancy), was via emails and through face-to-face contacts in the form of meetings. The aim of each contact was to maintain a good working relationship and to discuss any potential issues and the progress of the consultancy. I had already formed a close working relationship with the diabetes team prior to my involvement in this project, as I was working as a volunteer with staff members, shadowing consultants and dieticians and working at the reception since May 2010. I felt that being part of the diabetes clinic made it easier in the later stages of the consultancy when making contacts with the target group.

As the duration of the implementation of the main consultancy was relatively brief (15/2/11-30/3/11), and the nature of the consultancy (i.e. 2 questions to ask as part of the telephone survey) was straightforward and no particular difficulties arose. The only issues that arose concerned the inaccessibility of 1) some of the selected patients on the telephone during office hours (9-5) and 2) few patients' telephone numbers and 3) few other patients' up to date telephone numbers on the hospital databases. So to resolve these issues, I started working at the weekends (on Saturday with the permission of my contact clients) to speak to those patients, who were not available during the week and also started contacting patients' GPs (with the permission of my contact clients) to gain telephone numbers of those whose contact details were not found or were not up to date on the databases. This problem solving approach not only eventually resolved the potential issues, but also aided the clinic to keep contact details of the patients.

Conduct consultancy

The implementation procedure of the consultancy was commenced in the middle of February 2011 after the selection of a precise target group and despite my initial concerns the consultancy was successfully implemented within the timeframe and to majority of the patients (n = 126, 72.8%). However, 27.2% (n = 47) patients were not available on the phone, despite of working at the weekend and even three attempts were made to speak to them.

Patients provided various types of reasons and service improvement strategies from their perspectives, which I kept recording on an excel database for analysis purposes later on. During this short conversation, some patients appreciated the idea of involving them in the service improvement and provided recommendations related to their individual needs or expectations. The survey was completed at the end of the March 2011 and all the collected data was analysed quantitatively and a short report was completed until April to send it to the audit department. It was also agreed in the contract (please see Appendix C) to disseminate the outcomes to the contact clients, whole team of the diabetes clinic and to submit it to a diabetes peer review journal in the future, as it was the first service evaluation report related to diabetes patients' non-attendance from this clinic. Further decisions were taken to make patients' suggested changes into the service.

The results of this report showed that majority of the patients mentioned *'forgetfulness'* as a major reason of their non-attendance and they suggested to send a text message reminder before their appointments. Patients' related factors (e.g. neglecting diabetes, not necessary to attend an appointment, too ill, administrative problems) also indicated towards dissatisfaction with the clinic services and the contribution of psychosocial factors (e.g. perception of illness, negative emotions, communication problems, and low quality of life). These factors demonstrated some potential cognitive and emotional determinants of self regulatory theory, which control behaviour. Nonetheless, psychosocial issues related to non-attendance, described by the patients were discussed with my clients and they decided to explore them via questionnaires in a follow-up research study.

Evaluate the impact of consultancy

At the end of the consultancy, it was very important for me to evaluate this project from the contact clients' perspectives, namely to examine the feasibility and benefits of implementing the consultancy. The contact client evaluated the consultancy by focusing upon the aims and provided comments on what they found to be beneficial (e.g. finding out DNA ratio, reasons of DNA, and frequency of default), any key points learnt (e.g. how services can be improved in terms of reducing DNA rate), the implication of the consultancy (please see following paragraph for further information) and provided comments on trainee’s performance throughout the whole process (in terms of designing and managing it using existing resources and negotiating and disseminating it professionally).

The consultancy showed a behavioural change/implication at the service level in regards to objective 1 of the consultancy (to explore the diabetes clinic’s DNA rate). At the end of the consultancy, it was discovered that the diabetes clinic has the highest DNA rate in comparison to the other outpatients’ clinics at the hospital. It was decided to conduct a Randomised Controlled Trial (RCT) by sending text messages to some selected diabetes patients a week before their clinic appointments and implement a reminder system followed by evaluating the efficacy of this strategy. A power analysis was calculated (to find a sample size) on the basis of current DNA rate and expected attendance rate in the future. A new protocol was prepared in May 2011 after a meeting with the clients relating to the RCT, which required the NHS research ethic committee and Research and Development (R&D) approvals before implementing it. This RCT also required finding software to send text messages to the intervention group.

After completing/preparing all the required documents (e.g. the protocol, patient information sheet, consent form), receiving authors’ consents to use their standardised questionnaires, confirming fund, making arrangements for software and receiving required approvals. I was informed that the trust had made an announcement in one of the management meetings to implement a feasible reminder strategy first of all at the diabetes clinic for all diabetes patients to potentially reduce the DNA rates in the diabetes clinic. The management of the diabetes clinic agreed with the Trust’s suggested reminder strategies (e.g. text message, automated phone call, person phone call) by considering the reasons of missed appointments and their suggested reminder strategies.

After discussing with the clinic management and the contact clients, I had to cancel the RCT, as it was no longer valid/needed to be conducted. Nonetheless, diabetes clinic also implemented the following further changes at the end of this consultancy:

- An email site was made available to allow patients to contact the clinic about appointments
- Staffs were interviewed about ways to improve patients’ access to advice on inability to attend appointments or for support between appointments
- A standard operating procedure was introduced around answering telephones.

A summary of the consultancy results was presented to the client at a separate meeting. In addition, a short report based on service evaluation purposes was prepared which was sent to the management and the audit department (to keep in the records), who found it very useful as it was the first time in the clinic to conduct this type of project related to patients’ non-attendance. This report was highly appreciated by the contact clients and I was encouraged to submit it to the Journal of Practical Diabetes.

It was my first experience to submit the service evaluation based work into a peer-reviewed journal, which I found very useful, as it was a very good opportunity to put my previously learnt knowledge and skills (related to submitting my work to a peer reviewed journal during my master in health psychology) into practice. This process of submitting (November 2011) the manuscript online, helped me to improve my communication and writing skills in terms of preparing the covering letter and the manuscript according to the journal’s authors’ guidelines, responding to the reviewers’ comments and editors’ e-mails as a 1st corresponding author and fulfilling all the other formal requirement after acceptance of the work (February 2012). All the co-authors were kept informed throughout this process and were sent a final version of the accepted paper.

After a few months, I received an opportunity from the City University London related to a post graduate conference organised by the Division of Health Psychology at Bedford University (June 2012) to attend or disseminate any DPsych related work, which I accepted after discussing with my university supervisor to present this paper as a poster (self-funded). I also received consent from the clients after providing their requested information related to this conference. Converting a paper into a short poster (following the conference’s guidelines) was a very useful and interesting experience for me. Overall, I believe that the evaluation of the consultancy provided the client with the confidence and evidence that my input as a consultant into this project was useful, valid and met the requirements of the agreed pathway.

Conclusion

My overall experience of undertaking this innovative consultancy project was extremely positive, useful and enjoyable. It provided me with the confidence to design and to implement a consultancy project as well as a learning opportunity within a NHS organisation. This was in part due to the consultancy being well planned and structured by the client. This experience has given me the confidence to look for further consultancy opportunities within areas in which I was confident and experienced. I was also able to apply various psychological models of consultancy in practice and would like to focus on this in the future as part of my continuous professional development.

Working through the consultancy process was also useful, as it helped me to highlight my need to further develop as a consultant in the area of assessing clients' needs. In particular, a learning point during the consultancy process was to identify the needs and expectations of all the stakeholders early on. This was something that needed to improve and implement in all future consultancy work.

References

Addenbookes' hospital Cambridge. Retrieved November 2012
dhttp://www.cuh.org.uk/cuh/profile/profile_index.html

Downer, S.R., Meara, J.G., Da Costa, A.C. and Sethuraman, K. (2006). SMS text messaging improves outpatient attendance. *Australian Health Review, 30*(3), 389-96.

Griffin, S.J. (1998). Lost to follow-up: the problem of defaulters from diabetes clinics. *Diabetic Medicine, 3,* S14-24.

Hussain-Gambles, M., Neal, R.D., Dempsey, O., Lawlor, D.A. and Hodgson, J. (2004). Missed appointments in primary care: Questionnaire and focus group study of health professionals. *British Journal of General Practice, 54,* 108-113.

Henderson, R. (2008). Encouraging Attendance at Outpatient Appointments: Can We Do More? *Scottish Medical Journal, 53*(1), 9 12.

Jacobson, A.M., Adler, A.G., Derby, L., Anderson, B.L. and Wolfsdorf, J.I. (1991). Clinic attendance and glycemic control: study of contrasting groups of patients with IDDM. *Diabetes Care, 14,* 599–01.

Lawson, V.L., Bundy, C., Lyne, P.A. and Harvey, J.N. (2004). Using the IPQ and PMDI to predict regular diabetes care-seeking among patients with Type 1 diabetes. *British Journal of Health Psychology, 9*(2), 241-52.

Lawson, V.L., Layne, P.A., Harvey, J.N. and Bundy, C.E. (2005). Understanding Why People with Type 1 Diabetes Do Not Attend for Specialist Advice: A Qualitative Analysis of the Views of People with Insulin-dependent Diabetes Who Do Not Attend Diabetes Clinic. *J Health Psychology, 10*(3), 409-423.

Leventhal, H. and Cameron, L. (1987). Behavioural theories and the problem of compliance. *Patient Education and Counselling, 10,*117-138.

Leventhal, H., Zimmerman, R. and Gutmann, M. (1984). Compliance: A self-regulation perspective. In W. D. Gentry (Ed.), *Handbook of behavioural medicine* (pp. 369436). New York: Guilford Press.

Lim, L. and Varkey, P. (2005). E-mail Reminders: A Novel Method to Reduce Outpatient Clinic Nonattendance. *Internet Journal of Healthcare Administration, 3*(1), 221-228.

Lee, V.J., Earnest, A., Chen, M.I. and Krishnan, B. (2005). Predictors of failed attendances in a multi-specialty outpatient centre using electronic databases. *British Medical Council Health Services Research, 5,* 51.

Matarazzo, J.D. (1982). Behavioural health's challenge to academic, scientific, and professional psychology. *American Psychologist*, *37*(1), 1-14.

Mollentze, W.F. and Koning, J.M.M. (2007). Where have all the diabetics gone? *South African Medical Journal*, *97*, 6.

Mitchell, A.J. and Selmes, T. (2007) Why don't patients attend their appointments? Maintaining engagement with psychiatric services. *Advances in Psychiatric Treatment*, *13*, 423–434

Ngwenya, B.T., Van Zyl, D.G. and Webb, E.M. (2009). Factors influencing non-attendance of clinic appointments in diabetic patients at a Gauteng hospital in 2007/2008. *Journal of Endocrinology, Metabolism and Diabetes of South Africa*, *14*(2), 106–109.

Paterson, B.L., Charlton, P. and Richard, S. (2010). Non-attendance in chronic disease clinics: a matter of non-compliance? *Journal of Nursing and Healthcare of Chronic Illness, 2*, 63–74.

Reti, S. (2003). Improving outpatient department efficiency: a randomized controlled trial comparing hospital and general-practice telephone reminders, *New Zealand Medical Journal, 116*(1175), U458.

Stone, C.A., Palmer, J.H., Saxby, P.J. and Devaray, V.S. (1999). Reducing non-attendance at outpatient clinics. *Journal of Royal Society of Medicine. 92*, 114–118.

Simmons, D. and Clover, G. (2007). A case control study of diabetic patients who default from primary care in urban New Zealand. *Diabetes Metabolism, 33.*(2), 109-13.

Stewart, M.A. (2001). Towards a global definition of patient-centred care: The patient should be the judge of patient-centred care. *British Medical Journal*, *322*(7284), 444–445.

Schein, E.H. (1999). *Process consultation revisited. Building the helping relationship.* Addison Wesley.

Simmons, D. and Fleming, C. (2000). Prevalence and characteristics of diabetic patients with no ongoing care in South Auckland. *Diabetes Care, 23,* 1791–1793.

White, M. and Verhoef, M.J. (2005). Toward a patient-centred approach: Incorporating principles of participatory action research into clinical studies. *Integrative Cancer Therapies*, *4*(1), 21–25.

Weinger, K., McMurrich, S.J., Yi, J.P., Lin, S. and Rodriquez, M. (2005). Psychological characteristics of frequent short-notice cancellers of diabetes medical and education appointments. *Diabetes Care, 28*, 1791-1793.

Appendix A

Proposal

Exploring factors related to clinic non-attendance and service improvement strategies from Type 1 diabetes patients' perspectives.

Literature review

Diabetes is a chronic disease, requiring a high degree of lifelong self-management with regular health professional support and supervision (Griffin, 2004; Stone et al., 1999). Maintaining a near normal blood glucose level reduces the incidence of diabetic complications such as eye disease, kidney disease and neuropathy (DCCT, 1993). People receiving specialist care from hospital diabetes clinic have a better prognosis in terms of glycaemic control, diabetic complications, survival and risk of hospital admission (Deckert, Poulsen, & Larsen, 1978; Goydner, Spiers, McNally, Drucquer, & Botha, 1999; Hammersley, Holland, Walford, & Thorn, 1985). People who do not attend diabetes clinic often do not receive optimum management and are likely to return at a later stage frequently with advanced diabetic complications (Stone et al., 1999). Therefore, while nonattendance at diabetes clinic may be less prevalent than in other health care settings, the outcome may be worse in terms of morbidity and mortality (Griffin, 1998).

Patients' attendance at diabetes clinic is associated with improved medical outcomes, but significant numbers of people with type 1 diabetes choose not to attend (Lawson, Lyne, Harvery & Bundy, 2005). The financial cost of missed appointments in the National Health Service (NHS) has been estimated at £360 million per year (Stone et al, 1999), most of this accounted for by non-attendance in primary care and hospital out-patient clinics (Mitchell & Selmes, 2007). Additionally, non-attendance is a major health services research and management issue (Sharp & Hamilton, 2001) as it may lead to delayed or sub-optimal care (Frankel, Farrow & West, 1989). Yet the patients who do not attend have significantly more risk factors and complications than those who keep their appointments (Griffin, 2004).

Non-attendance and/or a delay in presentation may predispose the patient to avoidable ill health (Morton, 1995). In addition, non-adherence with regularly scheduled clinic appointments can obstruct efforts to shorten waiting lists, affect continuity of care, contribute to long waiting times, engender negative patient–provider relationships (Paterson, Charlton & Richard, 2010), reduce clinic efficiency, lower productivity (Hamilton et al., 2002), may impact successful diabetes management (Griffin, 1998) and represents one of the most costly problems in outpatient care, both in terms of economical and human resources spent (Dunbar-Jacob, Erlen & Schlenk, 2000; Moore, Wilson-Witherspoon & Probst, 2001).

The issue of non-attendance also contributes to clinic inefficiency and lower productivity (Hamilton et al., 2002) and may impact successful diabetes management (Griffin, 1998). Furthermore, non- attendance at a diabetes clinic has been associated with poorer glycemic control (Jacobson, Adler, Derby, Anderson & Wolfsdorf, 1991). Finally, health professionals may develop negative attitudes toward those patients who miss their appointments (Husain-Gambles, Neal, Dempsey, Lawlor & Hodgson, 2004), which may undermine the clinician-patient relationship (Weinger et al., 2005).

Long waiting times have often been implicated in non-attendance behaviour (Hamilton, Round & Sharp, 2002). The decision to attend for care is complex and multidimensional (Johnston, Leung, McGhee & Castan-Cameo, 2007). Patients may forget their appointment; have conflicting obligations preventing their attendance (Hamilton et al., 1999), experience a change in their health status, or seek services from other health providers (Gatrad, 1997). Numerous strategies targeting these factors have been implemented with varying degrees of success (Hamilton et al., 2002), e.g. mailed reminders (Griffin, 2004).

Previous research indicates, patients who miss appointments tend to be younger (Sharp & Hamilton, 2001; Moser, 1994) and of lower socio-economic status (Sharp & Hamilton, 2001; Barron, 1980). They often have history of failed appointments (Barron, 1980) and psychosocial problems (Cosgrove, 1990). They are also less likely to understand the purpose of the appointment (Frankel, Farrow and West, 1989). Non-attendance rates increase with increasing time between scheduling and actual appointment (Sharp & Hamilton, 2001; Moser, 1994). Longer waiting time have been shown to be related to lower satisfaction (Bower, Roland Campbell & Mead, 2003), which in turn, leads to less reliable appointment keeping (Rao, Weinberger & Kroenke, 2009).

In addition to forgetting appointments (Sharp & Hamilton, 2001; Cosgrove, 1990), patients have provided several reasons for non-attendance, which (play a key role in determining the motivation to attend routine appointments, O'Brien & Lazebnik, 1998), include: trouble getting off work (Sharp & Hamilton, 2001), child care (ibid), transportation (Bean & Talaga, 1992), cost (Mirotznik, Ginzler, Zagon & Baptsiste, 1998), inadequate communication between the clinic and patients, demographic and socioeconomic factors, and factors related to the health care provider (Bottomley & Cotterill , 1994; Can, Macfarlane, O'Brien , 2003; Canizares & Penneys, 2002; Chung, Wong & Yeung , 2004; George & Rubin, 2003), or past negative experiences with medical teams (Freed, Ellen & Irwin, 1998). In addition, both patients who felt better and patients who felt too unwell to come did not attend their appointments (Cosgrove, 1990).

Nonetheless, outpatients non-attendance has been suggested a common source of inefficiency in healthcare provision, wasting time and resources and potentially lengthening outpatient waiting times (Hardy, O’Brien & Furlong, 2001). A number of studies propose that non-attendance occurs in all age groups and in people from various social, cultural and ethnic backgrounds; if affects in all specialities and does not seem to be restricted to a particular healthcare sector (Atri, Falshaw, Gregg, Robson, Omar, Dixon (1997; Cragg, Campbel, Roland, 1994).

A variety of interventions have been tested, although none has been consistently effective (Bean & Talaga, 1992). The most popular and effective have been reminder calls or mailing (Hardy, O’Brien & Furlong, 2001). Other methods include providing transportation (Smith & Yawn, 1994), new patient education (Macharia, Leon, Roewe, Stehenson & Haynes, 1992), scheduling changes (Gatrad, 2000), and incentives or disincentives (Smoller, Mclean, Otto, Pollack, 1998).

Grover et al (1983) conducted a randomised trial of telephone and mailed reminders to assess the effect in reducing the rate of failure to keep appointments among patients new to a general medical clinic. Only 105 of the patients who received a telephone call and 125 of those who received a letter failed to keep their appointments compared with 20% of the control group. The most common reason of giving for failure to keep the appointment was lack of awareness about the appointment. Thus, Grover et al (1983) suggested that telephone or mail reminders can lower the rate of failure to keep appointments and result in greater satisfaction by patients and health care personnel.

Theoretical perspectives behind health care seeking behaviour

In regards to explain and/or predict health and illness behaviour, several social cognition models have also been used (Conner & Norman, 1996), but there is lack of theory based research related to diabetes patients' non-attendance to their clinic appointments. One study (Coates & Boore, 1998) using the Health Belief Model showed that each of the Benefits, Barriers, Severity and Vulnerability dimensions of the Health Belief Model (HBM) (Rosenstock, 1966) predicted a small amount of variance in clinic attendance.

Overall, reasons for decisions not to seek specialist help are not well understood. There has been little research amongst those who decide not to attend long-term illness related appointments, in part because these patients are an inaccessible group. Existing studies have focused primarily on barriers to attendance such as difficulty in getting to clinic, getting time off work or clinic satisfaction (Archibald & Gill, 1992; Hammersley et al., 1985; Lloyd, Sherriff, Fisher, & Burns-Cox, 1990). To understand what kind of factors control or regulate this kind of behaviour (non-attendance), this study will use the Self-regulatory Model (SRM) (Leventhal & Cameron, 1987; Leventhal, Zimmerman, & Guttman, 1984) to address this clinical problem. The model has been predictive of a range of health behaviours and adaptive outcome across illness groups (Petrie & Weinman, 1997) including medical help-seeking (Cameron, Leventhal, & Leventhal, 1993) and the employment of diabetes self-care activities (Glasgow, Strycker, Hampson, & Ruggiero, 1997; Griva, Myers, & Newman, 2000; Hampson, Glasgow, & Foster, 1995; Hampson, Glasgow, & Toobert, 1990; Skinner & Hampson, 1998). The SRM consists of three stages that regulate behaviour:

- Perception of the health threat (illness perceptions or personal models)
- The action plan or coping stage representing the individual's response to their personal model;
- The appraisal stage in which the individual evaluates the success or failure of coping actions.

Current intervention

Although, previous studies have attempted to identify demographic characteristics of patients who either did not schedule, cancelled, or did not attend appointments (Griffin, 1998; Kruse, Rohland & Wu, 2002; George & Rubin, 2003; Campbell, Staley & Matas, 1991; Dyer, Lloyd, Lancashire, Bain & Barnett, 1998; Hamilton, Round & Sharp, 2002; Karter, Parker, Moffet, Ahmed, Ferrara, Liu & Selby, 2004; Neal, Lawlor, Allgar, Colledge, Ali, Hassey, Portz & Wilson, 2001; Frankel, Farrow & West, 1989) and some literature (e.g. Hardy et al., 2001; Weinger et al., 2005) on diabetes appointment keeping does explain some optimal reasons for non-attendance, it is also important to find out non-attenders' views/perspectives related to non-attendance and any improvement strategies through an open survey, which can be very useful to design an intervention at the service level and evaluate it's impact on services and patients' satisfaction with services.

This study is designed to answer the following questions:

1) What is the non-attendance rate among high number of non-attenders at the diabetes clinic?
2) What are the reasons patients give at this clinic for not attending their appointments?
3) How diabetes clinic's services can be improved in terms of improving the attendance rate?

Process of selecting a target group

According to communication with staff, more than 2000 different types of diabetic patients (e.g. type 1 diabetes, type 2 diabetes, Gestational diabetes, MODY, secondary) are currently registered in the diabetes clinic. This number of patients was considered to be too big to use in the current study. Therefore, to select a specific target group of patients (e.g. type 1 or 2) for this intervention, who did not attend their appointments from October 2009 to October 2010, some consultants and clinics' codes were sent to the medicine departments to get DNA related patients' hospital numbers. Patients' hospital numbers were used to get some demographic information (e.g. age, gender), patients' next appointment dates and telephone numbers from the Hospital Information Support System (HISS) and DIAMOND databases.

A spreadsheet was developed based on the information collected from two databases, which showed that the number of patients with DNAs was 808, (including type 1, 2, secondary, Gestational, MODY and blank (i.e. no information about type of illness). This report was then divided into 12 individual months (i.e. October 2009-September 2010) to assess the number of non-attendance in each month on a separate spreadsheet, which showed that the number of patients who did not attend their appointments more likely were type 1 (n= 252) and majority of the appointments were missed in June and July months.

This finding was also confirmed by another analysis (when each patient's number of times of DNA in the whole year were assessed), which showed the highest number for type 1 patients in comparison to other types of diabetes (e.g. MODY, type 2 and so on). Overall, this audit data also showed that majority of the patients who did not attend were males, married and age 45. Before conducting the survey, all selected patients' current status was confirmed on the databases and it was discovered that 79 had to be excluded from this study based on following criteria: 42 had no follow up in the clinic, 2 were discharged, one was deceased, 32 were under 25 years of age (served by other clinics) and 2 moved away. Therefore 173 type 1 patients were decided to be contacted for this study.

Target group

In this study, type 1 patients attending the Diabetes Clinic will be recruited. According to the above mentioned target group selection process, 173 type 1 , males and females, aged 25 plus, will be eligible to take part in the current proposed study, who did not attend one or more appointments (as an intervention group) and were referred/scheduled for new appointments in the Clinic. Additionally, a control group of current type 1 patients, (attenders, n = 192, who had similar age group and gender to non-attenders), who attended their appointments (from October 2009 to September 2010) will also be included in this study. Both groups (attenders and non-attenders) were identified from the attendance and non-attendance recorded list of patients. In addition, both groups' clinical characteristics (e.g. BMI, HbA1c, cholesterol, blood pressure) will also be reviewed in this study. Exclusion criteria will be an inability to understand written and spoken English language.

Procedure

A telephone survey will be conducted (as part of the service evaluation) in January/February 2011 to ascertain the reasons of non-attendance and service improvement strategies. This survey will approximately take 10-15 minutes to conduct. Patients will be assured that their provided information will not affect their rights to receive services from the clinic. A brief verbal summary of the project will be given to the patients before starting the interview on the phone.

Proposed analyses

Patients’ provided information will be assessed using quantitative methodology. Statistical Package for the Social Sciences (SPSS), version 17 will be used to carry out statistical analyses: descriptive statistics and ANOVA. Microsoft excel will be used to calculate percentages related to patients’ responses.

Budget

For the current service evaluation project, no funding was required as it was conducted by trainee Health Psychologist working on honorary contract and it required contacting patients from the hospital, using clinic’s provided resources, e.g. a computer (to find out patients’ related information on the hospital data bases) and telephone (to contact relevant patients).

Time line

Proposed start date: 31/01/2011 Proposed end date: 31/09/2011

Appendix B

Assessment of request for consultancy

Who is the client?
The [redacted]

What are the questions?
The following questions were explored during this consultancy:

- What is diabetes clinic's DNA rate?
- What are the potential factors or reasons of patients' non-attendance?
- How we can improve the services?

The Diabetes clinic has not yet explored these questions before, but assured to apply patients' recommended service improvement strategies after reviewing reasons of non-attendance.

What is the background and organisational context?

This diabetes clinic covers whole County, , are register in this clinic. The purpose of this clinic is to screen (i.e. nephropathy (kidney), neuropathy (nerve) retinopathy (eye), chiropody (foot), Dose Adjustment For Normal Eating (DAFNE), young adult, insulin pump) existing and newly diagnosed patients with diabetes on a weekly, six month and annual review basis in order to pick up early on any problem that patients may be having. These can range from poor glycaemic control to retinopathy, nephropathy, neuropathy and foot ulceration to problems with obesity and diet.

The issue of non-attendance was brought to me by the managers and consultants of this clinic, (as they were finding difficult to manage the clinic when it got overbooked because of giving follow up appointments to DNA (Did Not Attend) patients). By considering the National Service Framework (NSF) standard 4 & 10 (Department Of Health, 2011):

***Standard 4**: All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.*

***Standard 10**: All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.*

And some possible consequences of untreated diabetic complications both for the individuals and for the NHS (financial consequences), I proposed a plan to management, to examine the problem more closely. As the NSF also recommends reviewing service provision, identify and follow up non-attenders. In addition, literature suggests that diabetes requires regular and structured follow up and surveillance by health professionals (Williams, 1994). Patients' attendance at diabetes clinic is associated with improved medical outcomes, but significant numbers of people with type 1 diabetes choose not to attend (Lawson, Lyne, Harvery & Bundy, 2005). Non-attendance of appointments is one of the major contributors to poor control in diabetic patients (Mollentze & Koning, 2007). Patients who miss appointments also miss opportunities for detecting complications and treatment adjustments. As a result, these patients may experience poorer outcomes (Ngwenya, van Zyl &Webb, 2009), and are more likely to return at a later stage frequently with advanced diabetic complications and risk factors than those attending regularly (Stone et al., 1999; Simmons & Clover, 2007; Griffin, 2004).

Non-attendance at hospital outpatient clinics has been a cause for concern for many years with no simple and cost effective solution to date (Cornfield, Schizas, Williams & Noorani, 2008), particularly in the adult diabetes clinic. Thus, determining factors related to non-attendance and implication of a strategy within the secondary care setting will test the feasibility and cost-effectiveness of this process. The overall aim is to embed an appointment reminder strategy within the NHS system and within patients' notes/ appointment letters. As no previous evidence was found related to determining reasons of non-attendance, implicating a reminder strategy and evaluating the effectiveness or a role of an applied strategy within this setting

Why has the client contacted you?

The [redacted] knew through meetings that I was studying DPsych health psychology and developing consultancy projects and interventions are main competences of this doctorate.

What is the timeframe for the work?

Potentially January – September 2011

IMS Institute of Metabolic Science

Appendix C

Contract

This document outlines the responsibilities of Kalsoom Akhter and [redacted] with respect to patients' non-attendance (consultancy) project undertaken by Kalsoom Akhter studying at the City University London.

Trainee's name: Kalsoom Akhter
Trainee's contact telephone number: [redacted]
Trainee's e-mail address: [redacted]
Name of department: [redacted]
Job title: Stage 2 Trainee in Health Psychology.
Client's name: [redacted]
[redacted] contact telephone number:
E-mail Address:

Both client and the trainee will maintain regular contacts via e-mails and face to face meetings as needed and in addition will meet at the end of this project, to review its outcomes.
Proposed timescale for the contract will be 9 months approximately.

Trainee's duties/responsibilities applicable to this contract:

- A full literature review will be undertaken relating to default from diabetes care.
- NHS' ethics related guidelines will be followed, when contacting patients via e-mails, telephone calls, text message or letters.
- A short report will be sent to the NHS supervisor/clients at the completion of the project.
- All information received from patients will be kept under password protected devices and both parties (trainee and clients) can access them, when necessary.
- Approximately 25 hours per week will be spent on this project.

- A paper will be drafted for submission for publication and submitted by the end of the consultancy period. All efforts will be made to obtain a peer reviewed publication from this work.
- Dr Simmons will be included as a senior co-author in any manuscript or presentation arising from the work with the need to agree to any content prior to submission.

Client's duties/responsibilities applicable to this contract:

- Provide guidance and information, when presenting this project to other health professionals in the Diabetes clinic.
- Provide information to patients, if they are contacted in regards to obtaining information related to this project.
- Contact trainee via e-mail or phone call, if anything unsatisfactory is identified (e.g. patients' complains).
- Meet in the clinic once/twice a month to discuss any potential issues or progress of the consultancy work or practices.
- Providing views on the Trainee's Performance related to this project.
- Dr Simmons will support the publication development.

Proposed Contract start date: 31/01/2011

Proposed Contract end date: 31/09/2011

Any comments…………………………………………………………………….

…………………………………………………………………………………….

…………………………………………………………………………………….

Trainee's signature:……………………………………………Date:……………

Supervisor's signature……………………………….. …….. Date:…………

Section 3D: Optional Unit one

Communicate the Processes and Outcomes of Interventions and Consultancies.

Development and evaluation of one stop workshop for young adult patients with Type 1 diabetes, aged 15-18 from the adult and paediatric diabetes clinics at a community centre in Cambridge.

Supervision Plan

Optional unit 1: Communicate the Processes and Outcomes of Interventions and Consultancies

Units in this area of competence	Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)	Supporting evidence to be complied for this unit of competence
6.3 Communicate the processes and outcomes of interventions and consultancies	**Setting:** Secondary care.[redacted] **Target Group:** Young adolescents with Type 1 diabetes **Description of work:** A workshop/intervention based on bio-psychosocial model was designed for adolescents with Type 1 diabetes to increase awareness about their healthcare needs and bring together both multidisciplinary teams (from both clinics) to deliver the education. One of the aims was to bring together two different services under one platform and also make the transitioning process (from one service to another) smoother according to patients' needs. I was responsible to plan, design, organise, manage co-ordinate and evaluate the workshop/intervention at a community centre by involving both clinics' multidisciplinary teams. Participants' provided feedback at the end of intervention as well as 8-weeks follow up outcomes were analysed on Microsoft Excel. The results of this intervention were presented to the contact clients as they wanted to implement follow-up interventions for this target group after considering funding and recruitment challenges. The contact clients were very keen to develop some follow up interventions and they also received positive feedback from the patients. The findings were presented as an abstract at the annual conference from Royal College of Paediatric Children's Health in Glasgow, 2012, followed by submitting a full report to the Clinical Psychology Forum.	• Feedback/Assessment Form • Intervention/workshop report • Feedback sheet • Structured Evaluation Form • PowerPoint presentation slides. • Workshop Poster. • Submitted report for the publication • Workshop invitation & information sheet • Invitation to participants • Consent form • Cards • Workshop sessions' content

Target for completion: … November, 2011 … Workplace contact? Yes … If yes please give name:

[redacted]

Setting: Community centre in Cambridge.
Main target group: Young adult patients with Type 1 diabetes.
Primary client: Adult and paediatric diabetes clinics at the Hospital.
Contact client: Clinical Psychologist (CP) and adult & paediatric diabetes specialist consultants.
Intermediate clients: Diabetes specialist nurses and dieticians from adult and paediatric diabetes clinics.
Consultant: Trainee Health Psychologist

Background and Context

On the 5th of November 2010, the trainee health psychologist was introduced to the client and invited for a meeting. During this meeting the client explained to me that currently there is no clear pathway within two clinics (paediatric and adult diabetes) related to transitioning services for adolescents. Furthermore, it was negotiated that designing a platform to increase awareness about young adolescents' healthcare needs and bring together both multidisciplinary teams (from both clinics) to deliver the education could be a very useful way. It would not only bring together two different services under one platform, but can also make the transitioning process (from one service to another) more smoother according to patients' needs (after meeting those personnel and gaining information about those services in an informal setting). At the end of the meeting, it was decided that a workshop should be designed for young adult patients with Type 1 diabetes at a community centre in Cambridge by involving both clinics' MultiDisciplinary Teams (MDTs).

Following this meeting, trainee health psychologist conducted a literature review to gain some in depth understanding of the required area (e.g. workshops for young adult patients with Type 1 diabetes). As a result, trainee health psychologist found some literature related to self-care of young adolescents with Type 1 diabetes (Dashiff, McCaleb, & Cull, 2006), transitioning from paediatric to adult care (Weissberg-Benchell, Wolpert & Anderson, 2007), management of Type 1 diabetes in children and young people (Nice guidelines, 2004) and a series of workshops for young adult patients with Type 1 diabetes in Bradford (Webster, 2007). Following the literature review, the trainee health psychologist prepared a short proposal and discussed this with the contact client in the diabetes clinic. Following this meeting and as a result of further correspondence between both parties (trainee and all contact clients), the timelines, budget and finer details of the workshop/intervention were discussed. It was agreed by both parties that the workshop programme will target young adults aged 15-20 at a community centre, and will be conducted for a half-day weekend event commencing in June 2011. It was also agreed by both parties that trainee health psychologist will have to provide the following:

- Plan, design, organise, manage and evaluate the workshop/intervention.
- Deliver a teaching & training session related to a health Psychology area and diabetes.
- Assess patients' needs and design interactive educational tools by considering patients' age.
- Advertise the workshop in the hospital and locally, if possible.
- Design the parental consent form for under 18 year olds, timetable, venue details, feedback forms and structured evaluation form.
- Negotiate/discuss the workshop content & mode of delivery with the multidisciplinary teams of both clinics (adult & paediatric diabetes).
- Provide estimated budget to conduct this workshop only and design the workshop accordingly.
- Co-ordinate the whole programme, make arrangements for the day in a community centre and negotiate responsibilities for the workshop day with the multidisciplinary team.
- Correspondence with patients via e-mails, telephone and post.
- Present the outcomes among HCPs in the clinics, at the regional or national level and via publication.
- Provide advice and support to diabetes nurses regarding interactive teaching methodologies (e.g. involving them in discussion, answer their questions, use diagrams or videos).
- Evaluation and communication of outcomes back to the clients at the end of the workshop.
- Register the programme as a service evaluation project at the hospital's patient safety department.

During the intervention/consultancy process, both parties worked together to negotiate the design of the various practical activities and the teaching materials for young adult patients with Type 1 diabetes to deliver at a community centre. For the development of this workshop, a patient-centred approach was employed after conducting a literature review search related to the area of illness and the age of the target group. With respect to this approach, patients are known as persons in context of their own social worlds, listened to, informed, respected, and involved in their care and their wishes are honoured during their health care journey (Balint, 1957; Entralgo, 1969; Gerteis, Edgeman-Levitan, Daley & Delbanco, 1993; McWhinney, 1985; Rogers, 1961). This approach was adopted by assessing patients' needs regarding their preferred topics by posting a feedback/assessment form (please see Appendix B in Article one, p. 281) before developing the workshop, empowering them with information, involving them in collaborative discussions to contribute ideas to help in their treatment and care and providing encouragement. Upon receiving patients' replies/responses (related to medical, psychological and social aspects of diabetes), the workshop programme was designed, which was based on the biopsychosocial model of Health Psychology (Engel, 1977). This model was considered appropriate as it takes into account biological/medical, psychological, and sociological interconnected spectrums, each as systems of the body.

At the final meeting the contact client assessed the consultancy /intervention and provided comments, on what they found to be beneficial, what they had learnt and whether they would recommend the consultancy/intervention to other clinics and continue to follow up in the future.

Prepare information for dissemination

For the one-stop workshop/intervention, the contact client had always been the main point of contact for the health psychologist. However, before the delivery process of the intervention this responsibility was transferred from the contact client to the MDTs of the adult and paediatric diabetes clinics. During this transition phase, trainee health psychologist worked closely with the MDTs by arranging individual meetings, as it was very difficult to find the whole team in one meeting to discuss the topic areas and length of their individual sessions.

The aims of the meeting were to maintain a good working relationship between the intermediate client and the consultant, and also to channel open discussions regarding the design, delivery, content and evaluation of the workshop. At this stage, trainee health psychologist was playing the role of an internal helper, consistent with the *'process model'* by collaboratively discussing the process of the intervention/consultancy based on biopsychosocial model following client-centred approach to understand the intermediate clients perspectives, and expertise in regards to tackle the target group's needs. Within this *'helping'* role, trainee health psychologist worked in collaboration with the clients, in developing initiatives to develop and evaluate a one stop workshop, which incorporated young adolescent patients' requested needs related to bio-psycho-social aspects of diabetes and involved MDTs of both clinics (paediatric and adult diabetes) into the delivery of this intervention. The advice that the trainee health psychologist gave was to design the intervention and involve the MDTs after identifying patients' needs related to the area(s) they feel that they require more understanding, knowledge and learning, as this concept links with patient-centred approach.

On reflection, trainee health psychologist realised that the outcome of all the negotiated areas in individual meetings with each healthcare professional involved a pilot intervention, which could be more effective, if all the MDT could meet together to see the final version of this programme. However, due to the restricted timelines of the programme and the teams' other work commitments, this was not possible for everyone to meet at a certain time. A lesson was learnt to find a timeslot in the future in other structured/monthly group meetings to discuss any plans for further investigation. Nonetheless, the design, content, mode of delivery, aims/objectives, assessment and evaluation of the sessions for the pilot programme was approved by the intermediate and contact clients and it was finally delivered in June 2011 in a community centre.

On completion of the programme, some feedback was gained from the target group related to their experiences on that day, recommendations for the future workshop and expectations from the current services. This feedback sheet (see Appendix A) was approved by the contact clients and the university supervisor. With caveats to the low uptake of the participants (n = 7) on the workshop day as well as the format/structure of the evaluation sheet, results were analysed via Microsoft Excel rather than SPSS. Within 8 weeks of the post workshop, workshop attendees were contacted by a nurse to find out any benefits in terms of managing diabetes, but no response was received via telephone contacts. Therefore, a structured evaluation form (see Appendix B) related to pre and post-diabetes self-care behaviours was prepared and posted to the workshop attendees' homes. This was to evaluate any changes in their lifestyle/behaviour related to the areas covered on the workshop day as well as to get any feedback related to the programme in the form of additional comments. This form was approved by the contact clients and the patient safety department of the hospital before sending it to patients’ homes.

The outcome of this evaluation was again analysed via Excel due to the format/structure of the evaluation form and it was also negotiated with the contact clients. This exercise was interesting, enjoyable and challenging. The main reason for the latter one was that to analyse each question separately rather than the whole section of the evaluation and it was agreed by the both parties. Overall, this pilot programme was completed in September 2011, including the evaluation and write-up processes. A draft of the complete report was sent to the contact clients via an e-mail and they requested to present the outcomes of the intervention in a designated meeting in October 2011 (without including too much literature). Microsoft excel was used to analyse the data due to having a small number of participants and a varied type of categorisation of the questions asked in the evaluation sheet. The trainee health psychologist felt that it would be more beneficial to catalogue and record the results in excel spread sheets and present the results based on the number of participants and percentages of responses related to each question (based on different classification, e.g. agree, disagree, true, false and so on). On completion of the data analysis, trainee health psychologist summarized the results within a power point presentation and compiled a summary report for the primary and contact clients.

Present information to individuals, groups and organisations on the processes and outcomes of psychological interventions, consultancies

The main aim of the pilot workshop from the service evaluation perspective was to evaluate the feasibility of the workshop as a mode of delivery of health care information at a community centre on a group basis. For participants, we aimed to not only to increase awareness of healthcare needs by enhancing their knowledge related to the aspects of diabetes management, but also to engage them in discussions in a community and group based setting. The results of the pilot programme/intervention were presented back to the contact client at a separate meeting. The reason why it was presented back to only the contact client was because this was an initial request made by the primary clients at the start of the programme/intervention and also they wanted to implement follow-up programmes/interventions for this target group (adolescents) close by the hospital or integrate it into one of the clinics.

Evaluate the impact of disseminated information

The presented information given to the contact clients and other regional HCPs at the Regional Paediatric diabetes meeting was very well received and appreciated. In addition, it was also a lesson learnt in terms of improving potential follow-up workshops for young adults with Type 1 diabetes. The contact client felt that the intervention was effective in terms of meeting the aims. Other regional HCPs and the contact clients also appreciated that it is a very challenging process to recruit this target group for a workshop or for any educational programme. The regional HCPs were quite surprised after knowing that patients who attended the workshop were those who normally missed their clinic appointments, as one of their comments was that the workshop attendees might be those who managed their diabetes quite well. It was also suggested by the regional HCPs to incorporate the quality of life and self-efficacy questionnaires as a pre and post-assessment method to explore any improvement in this area after the workshop. I also provided some suggestions by reflecting back on my experiences:

- In the future, it might be more effective to deliver at least 3 individual workshops (1: diet, exercise, pregnancy, smoking, alcohol 2: metabolic control/HbA1c, diabetes complications, administering insulin, 3: communication, stress/depression, eating problems, body image, relationships, problem solving, medication adherence) rather than one-stop workshop to tackle various needs of different individuals.

- A one year randomised controlled trial can also be undertaken to determine whether the individual workshops can effectively improve medical outcomes, reduce incidences of non-attendance in the clinic, reduce admission to the hospital’s Accident and Emergency department and improve self efficacy of adolescents to manage Type 1 diabetes.

- Before starting any workshop, it is essential to assess a target group’s needs related to their age via semi-structured or focus group interviews, as the age group between 15-17 might have different requirements, barriers and beliefs to self-management of diabetes in comparison to 18-20 year olds.

The contact client felt that the intervention, as per their original request needed to be both simple and interactive, and felt that trainee health psychologist had delivered all the above.

Overall the contact client felt that the intervention went well in that the young adults involved themselves in group discussions and actively participated throughout the day in all the teaching and training sessions. To engage young adults in discussion, various videos and scenarios based techniques were used followed by some open ended questions, as well as some team-based quizzes. One of the contact clients (paediatric consultant) also mentioned that he received a very positive verbal feedback from some of the workshop attendees' parents that after attending the workshop, they are seeing incredible changes in their children' behaviours in terms of monitoring blood glucose and injecting insulin accordingly.

The contact clients also mentioned that they were very keen to develop more follow-up workshops close by the hospital in a community centre and are even keen to transfer one of the clinics into a workshop to increase the uptake of patients. The contact clients commented that trainee health psychologist was both friendly and professional, used the existing resources properly to complete the project in a limited budget and they appreciated the challenges trainee health psychologist faced in terms of recruitments and design of this intervention/programme. However, they felt that it was not justified at the time because of the limited funds and staff they had available for the intervention/programme. For future work, they suggested that they would reconsider about the funding and designated staff's time carefully before implementing such a programme and such barriers might take a while to overcome. The contact clients felt that the method to present the outcomes to them was both interesting and simple to understand. They thanked trainee health psychologist for putting all the efforts and they liked the use of graphs, diagrams and brief bullet points.

After few weeks of the presentation, trainee health psychologist was contacted by the contact clients with an opportunity to present this intervention/programme's abstract in May 2012 at the Annual Conference at the Glasgow exhibition hall (organised by the Royal College of Paediatric Children's Health, RCPCH). The trainee health psychologist accepted this opportunity and presented the poster presentation on 7th February 2012. The abstract was published as a supplement in the Archives of Disease in Childhood. Please see the following website for more information:
http://adc.bmj.com/content/97/Suppl_1/A123.3.abstract?sid=ceec5db4-24ee-4737-b286-50c8a7cdddd2). The trainee health psychologist was also encouraged to submit this intervention into a peer reviewed journal or the Clinical Psychology forum magazine. Thus a

complete report was submitted to the British Psychological Society’s Clinical Psychology Forum, which was accepted and published in February 2012.

Conclusion

Upon completion of the programme/intervention, trainee health psychologist realised that even though she had thoroughly enjoyed the experience of designing, conducting and evaluating the programme, there were some areas, which required improving, especially her skills related to assessment and evaluation. These correlate with medical outcomes potentially and explore more contacts with those people who have done similar work in the past to get experts’ feedback. In addition, when designing a programme/intervention trainee health psychologist needed to be aware of all the interventions objectives/endpoints from the beginning and the end, and therefore needs to take this into account when designing relevant documents for the participants to complete. From having carried out this intervention and having presented the results back to the contact client, trainee health psychologist felt that it helped her to increase her confidence in designing and implementing a program/intervention within the local community and presenting various psychological models of consultancy used in practice. Trainee health psychologist believes that this is one kind of health behaviour change intervention that she would like to focus on in the future as part of her continuous professional development as a Health Psychologist.

References

Akhter, K., Zeffertt, A., Evans, M., AbdullaH, N. and Pesterfield, C. (2012). Development and evaluation of a pilot one-stop workshop for young adult people with type 1 diabetes. British Association of General Paediatrics/British Society for Paediatric Endocrinology & Diabetes. *Archives of Disease in Childhood*, 97:A123 doi:10.1136/archdischild-2012-301885.294. Available on: http://adc.bmj.com/content/97/Suppl_1/A123.3.short

Balint, M. (1957). *The Doctor, His Patient, and the Illness.* New York, NY: International Universities Press.

Dashiff, C.J., McCaleb, A. and Cull, V. (2006). Self-care of young adolescents with Type 1 diabetes. *Journal of Paediatric Nursing, 21*(3), 222–232.

Engel, G. (1977). The need for a new medical model: a challenge for biomedicine. *Science. 196*, 129-136.

Entralgo, P.L. (1969). *Doctor and Patient.* New York, NY: McGraw-Hill Book Company.

Gerteis, M., Edgeman-Levitan, S., Daley, J. and Delbanco, T. (1993). *Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care.* 1st ed. San Francisco, CA: Jossey-Bass.

McWhinney, I.R. (1985). Patient-centred and doctor-centred models of clinical decision making. In: Sheldon, M., Brook, J. and Rector, A., eds. *Decision Making in General Practice.* London: Stockton.

National Institute for Health and Clinical Excellence guidelines (NICE). (2004). *Diagnosis and management of Type 1 diabetes in children, young people and adults*. Retrieved January 2013 from www.guidance.nice.org.uk/cg15.

Rogers, C.R. (1961). The characteristics of a helping relationship. In: Rogers, C.R,, ed. *On Becoming a Person: A Therapist's View of Psychotherapy.* Boston, MA: Houghton Miffl in; 39-58.

Webster, L. (2007). *Development and Evaluation of the 'Getting Sorted' Self. Care Workshops for Young People with Diabetes*. Faculty of Health. Leeds metropolitan university, Leeds. Retrieved on 9/11/10 from: www.leedsmet.ac.uk/carnegie/files/FinalSelfCareReport.pdf

Weissberg-Benchell, J., Wolpert, H. and Anderson, B.J. (2007). Transitioning from paediatric to adult care: a new approach to the post-adolescent young person with Type 1 diabetes. *Diabetes Care, 6,* 2441‐6.

Appendix A

Feedback sheet (at the end of workshop)

One stop workshop

'for people with type – 1 diabetes'

Feedback sheet:

Date:

	Totally disagree	**Disagree**	**Neither disagree nor agree**	**Agree**	**Totally Agree**
I found the workshop enjoyable?					
The workshop helped me, know how to manage your diabetes better.					
The workshop experience increased my confidence in talking to people about my diabetes.					
The workshop increased my self esteem in relation to my diabetes.					
Was the workshop interactive and informal?					
Do you think you learnt some things from this workshop that helped you understand and prioritize your health care needs?					
Did this workshop help you to feel that you can communicate better with health care staff about your diabetes?					

Do you think the duration of the workshop was (please tick the response)

About right?	Should be longer (full day)	Should be shorter (2-3 hours)

If you think the workshop should be 2-3 hour long; would it be better to have it in the (please tick the response)

Morning	Afternoon	The evening	NA

About today's workshop

Which activity/ section did you like the most in today's workshop and why?

………
………
………
………

What section or activity do you think was least useful?

………
………
………
………

Please describe 2 benefits of attending this workshop in terms of looking after your health?

3. ………
4. ………

What one thing do you think you will do differently now in these areas?
Carbohydrate counting…………………………………………………………………………

Healthy diet…………………………………………………………………………………………..

Exercise……………………………………………………………………………………………………..

Blood sugar testing…………………………………………………………………………………

Insulin injecting………………………………………………………………………………………

Talking about your diabetes to friends……………………………………………….

And parents……………………………………………………………………………………………

And health staff……………………………………………………………………………………

Which other activities/ topics would you like to see in a future workshop?

………
………

Would you prefer a workshop to be at the hospital or in a community centre?

………

Would you prefer to attend the sessions with people around the same age as you?

Yes ☐ No ☐ Doesn't matter ☐

One stop workshop

'for people with Type 1 diabetes'

Feedback sheet:

Date:

Expectations from our services:

Your replies will be treated in confidence

Did you experience any problems with the transition from paediatric diabetes clinics to the young adult service clinics? Yes ☐ No ☐

If yes, please let us know what these were:

………

………

………

How do you feel about the care you receive at present on a scale of 1-10?

0	1	2	3	4	5	6	7	8	9	10
Least satisfied									extremely satisfied	

What 2 things could we do to improve the care you receive from us?

………

………

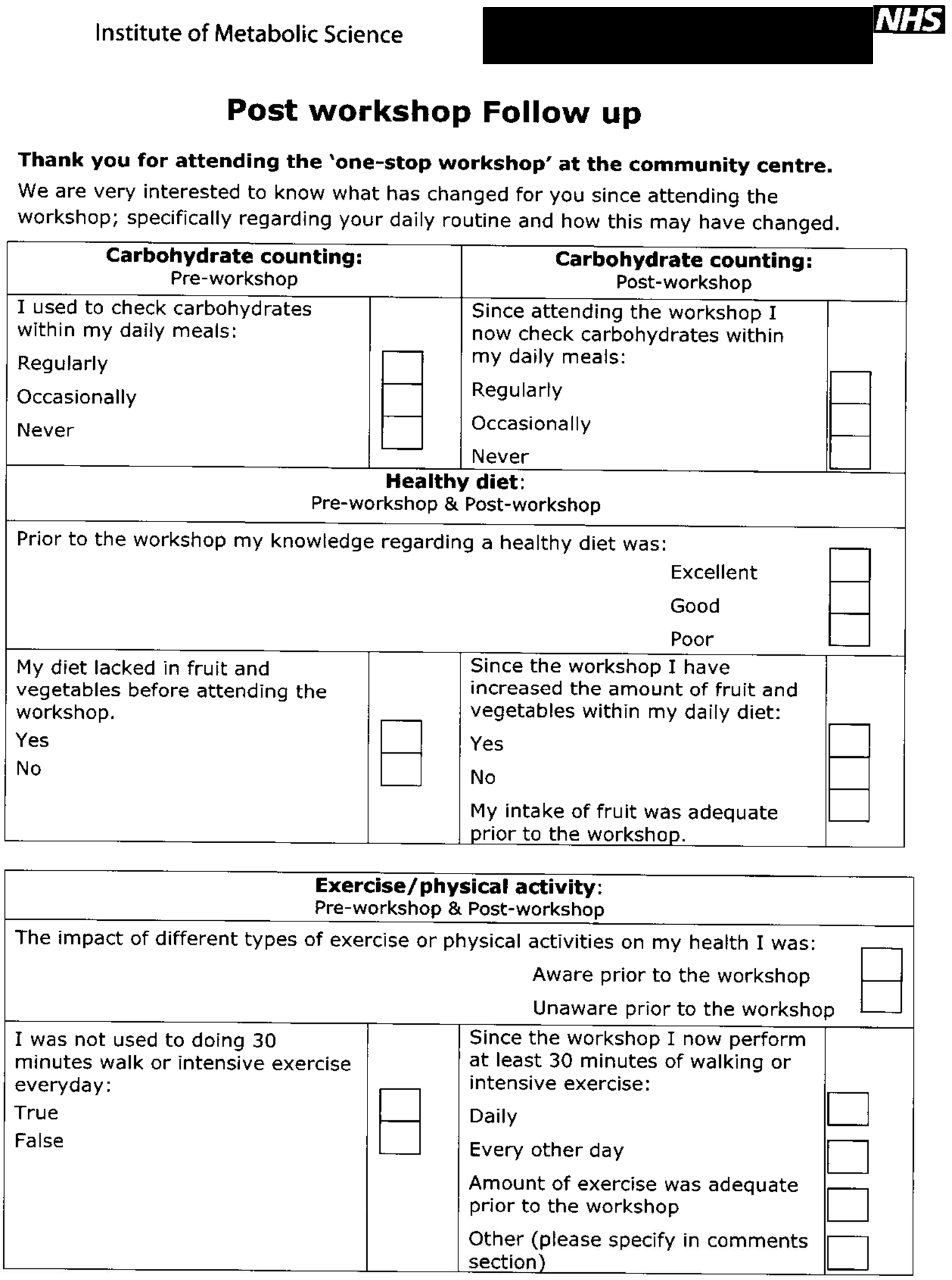
………

Thank you for taking time to fill out these questions.

We hope you have enjoyed the day.

Appendix B

Structured Evaluation Form (8-weeks post-intervention)



Institute of Metabolic Science [redacted] NHS

Post workshop Follow up

Thank you for attending the 'one-stop workshop' at the community centre.
We are very interested to know what has changed for you since attending the workshop; specifically regarding your daily routine and how this may have changed.

Carbohydrate counting: Pre-workshop		**Carbohydrate counting:** Post-workshop	
I used to check carbohydrates within my daily meals:		Since attending the workshop I now check carbohydrates within my daily meals:	
Regularly	☐	Regularly	☐
Occasionally	☐	Occasionally	☐
Never	☐	Never	☐

Healthy diet: Pre-workshop & Post-workshop

Prior to the workshop my knowledge regarding a healthy diet was:	
Excellent	☐
Good	☐
Poor	☐

My diet lacked in fruit and vegetables before attending the workshop.		Since the workshop I have increased the amount of fruit and vegetables within my daily diet:	
Yes	☐	Yes	☐
No	☐	No	☐
		My intake of fruit was adequate prior to the workshop.	☐

Exercise/physical activity: Pre-workshop & Post-workshop

The impact of different types of exercise or physical activities on my health I was:	
Aware prior to the workshop	☐
Unaware prior to the workshop	☐

I was not used to doing 30 minutes walk or intensive exercise everyday:		Since the workshop I now perform at least 30 minutes of walking or intensive exercise:	
True	☐	Daily	☐
False	☐	Every other day	☐
		Amount of exercise was adequate prior to the workshop	☐
		Other (please specify in comments section)	☐

Blood sugar testing: Pre-workshop		**Blood sugar testing** Post-workshop	
I used to test my blood sugar levels daily before and after meals and before bed time:		Since the workshop I now test my blood sugar levels before and after each meal and before bed time:	
Regularly	☐	Regularly	☐
Occasionally	☐	Occasionally	☐
Never	☐	Never	☐

Insulin injecting: Pre-workshop		**Insulin injecting:** Post-workshop	
I used to inject insulin:		Since the workshop I now inject insulin:	
Regularly	☐	Regularly	☐
Occasionally	☐	Occasionally	☐
Never	☐	Never	☐
Talking about your diabetes to your friends, parents & Health Care Professionals: pre-workshop		**Talking about your diabetes to your friends, parents & Health Care Professionals**: post-workshop	
Lack of confidence stopped me from openly discussing my diabetes with:		Since the workshop I have increased my confidence and feel I am able to openly discuss my diabetes with:	
Friends	☐	Friends	☐
Parents	☐	Parents	☐
Health Care Professionals	☐	Health Care Professionals	☐
Other (please specify in comments section)	☐	Other (please specify in comments section)	☐

What other things have you changed to manage your diabetes after attending the workshop?

Trying to quit smoking? ☐Yes ☐No ☐N/A (do not smoke)

Trying to reduce/stop drinking alcohol? ☐Yes ☐No ☐N/A (do not drink)

Please tick the clinic you are currently attending at the Addenbrookes Hospital:

☐The Wolfson Diabetes & Endocrine clinic ☐The Weston centre

Comments:

Section 3E - Optional Unit Two

Disseminate psychological knowledge to address current issues in society

Influences of social determinants on diabetes self-management: Are we doing enough?

Supervision Plan

Optional unit 2: Disseminate psychological knowledge to address current issues in society

Units in this area of competence	**Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)**	**Supporting evidence to be complied for this unit of competence**
6.8a Identify and analyse psychological components of current social issues **6.8b Present psychological analysis of current social issues**	**Setting:** [redacted] **Client/target group:** Type 1 Diabetes patients **Description of work:** The area of social issues among diabetes patients was noticed during clinic consultations and ward visits. It was thereafter important to explore those social issues in depth and any influences of those issues on patients' mental as well as physical health. I was given the responsibility to investigate this area in-depth. A literature review was conducted, which followed up designing a semi-structured interview guide for the patients as well HCPs. Two focus groups were conducted with different HCPs to explore their perspectives about the social issues. All data was analysed using thematic analysis. The exploration of such area highlighted various psychological factors of social issues affecting patients' mental as well as physical health, which linked with health determinants model. Patients provided various suggestions to improve current services. The findings highlighted the importance of considering such issues and to resolve them, providing training to clinical staff and also including social issues related data on the health care system could be beneficial. This final work will be disseminated via research articles.	Information sheet Copy of the final research article

Target for completion: … October 2013 … Workplace contact? Yes … If yes please give name:

[redacted]

Background

Health Care Professionals (HCPs) at the diabetes clinic meet patients related to various kinds of diabetes related issues or complications, but some HCPs visit the patients in the Accident and Emergency (A&E) department as well as their homes or at the community level. During consultations and visiting the patients, it was noticed quite often that most patients have social issues, which seem to affect their diabetes self-care or management.

I will describe how this project was established/initiated, implemented and submitted for peer reviewed journal for publication purposes. The outcome of this project could be beneficial for the whole diabetes team (in terms of knowing social issues from patients' perspectives and improvement strategies by considering gaps in current services) as well as for those who design strategies to support diabetes patients medically. This project can increase awareness about those social issues which lead to psychological challenges and ultimately affect diabetes self-care or management.

Awareness of service evaluation project

The area of social issues among diabetes patients was brought to my attention (while working as a research assistant) in a meeting with the lead diabetes consultant, who briefly mentioned about social issues disclosed by the patients with Type 1 diabetes during clinical consultations or ward visits. He was very keen to explore those issues further and also find out how the current services could be improved to support those patients. Most of the HCPs focus upon clinical outcomes (e.g. HbA1c and less likely on social or psychological health determinants). However, as this lifelong chronic condition requires those diagnosed to undertake a complex regimen of self-care practices, it is necessary to stave off the potential acute and long-term complications. The ultimate aim of self-care regimens is to achieve an HbA1c level of <7.5% (<59 mmol/ mol; NICE, 2004) while maintaining a good quality of life and avoiding frequent hypoglycaemic episodes (Chaney, Coates & Shevlin, 2010).

Through discussion, it was highlighted that most patients are facing various challenging situations (e.g. unemployment, housing situations, financial issues and so on), which might be affecting their diabetes management. It was noticed by the clinic HCPs and those who also work on Diabetes Ketoacidosis project (by visiting patients at their homes, meeting them in the clinic as well as in A&E department and in wards), that some patients' diabetes management routine do not seem to get better despite of providing different types of medical support and support related to lifestyle aspects. It was thereafter important to explore those social issues in depth and any influences of those issues on their mental as well as physical health. I was given this responsibility to fulfil under the service evaluation guidelines and under certain timeline by following specific topic to investigate.

The initial literature search related to the topic area demonstrated that social determinants have been defined as factors in the social environment. These being socioeconomic status, housing, transportation, availability and accessibility of health care resources, social support (Ruger, 2004), food security, and the quality of physical and social environments **(**Marmot, Wilkinson, 2000; Raphael, 2004**),** education; unemployment and job security; employment and working conditions; social exclusion; social safety network; health services; gender; and disability (Mikkonen & Raphael, 2011). Intuitively, these factors would appear to be obvious determinants of health **(**Jack, Jack, & Hayes, 2012). But, much of the literature on the causes, prevention and management of diabetes focuses on biomedical and lifestyle changes (Williamson, Vinicor & Bowman, 2004) with little if any attention given to these broader issues or to the role of Social Determinants Of Health (SDOH) in the prevention and management of diabetes (Pilkington, Daiski, Lines, Bryant, Raphael, et al., 2011).

By following the meeting, the trainee health psychologist conducted a literature search related to the influences of social determinants on diabetes management regime. Literature suggests that diabetes is known to be more prevalent among those living on a lower income (Dinca-Panaitescu, Dinca-Panaitescu, Bryant, Daiski, Pilkington at al., 2011; Brown, Ettner, Piette, 2004; Creatore, Gozdyra, Booth, 2007; Kumari, Head & Marmot, 2004; Raphael, Anstice, Raine, McGannon, Rizvi, et al., 2003). In addition, low-income populations have higher rates of diabetes-related complications and premature mortality (Wilkins, Berthelot, & Ng, 2002; Thomas, Jones, Scarinci, & Brantley, 2003). Qualitative studies of persons with diabetes living on a low income suggest that they struggle to survive, let alone manage their diabetes (Pilkington, Daiski, Bryant, Dinca-Panaitescu, Dinca-Panaitescu et al., 2010).

Current research has demonstrated that social determinants are associated with the disproportionate development of chronic conditions and challenges encountered when managing them (Bryant, Daiski, Lines, 2010; Touma & Pannain, 2011; Pilkington et al., 2010; Chaufan & Weitz, 2009; Blas, Sommerfeld, & Kurup, 2012). Clinical interventions have consistently evolved to improve disease management, particularly as a growing number of clinicians recognize the importance of social determinants of health (e.g., income, education, housing, and access to nutritious food) and their contribution to health disparities (Blas, Sommerfeld, & Kurup, 2012; Glazier, Bajcar, Kennie, & Wilson, 2006; Racial and Ethnic Approaches to Community Health, 2012).

Consultation process

Current diabetes services did not seem to have someone particular in the diabetes team to provide support to patients related to their social issues. Thus, it was suggested by the trainee health psychologist to explore this area in-depth through some focus groups and semi-structured interviews with the patients as well as the HCPs to find out their perspectives about social issues and any improvement strategies. In addition, having both parties' perspectives could be useful to gain some in-depth information to improve current services.

The trainee health psychologist realised from the previous experiences working in the clinic on different projects/studies (e.g. diabetes patients who do not attend their clinic appointments and a workshop conducted for young adolescents) that most patients were 1) less likely to take part in group discussions without any incentive and 2) some patients may not be able to come to the clinic specially for this project due to their social issues (e.g. child care or financial issues). As this project was based on service evaluation purposes rather than the research, it was not possible to get any funding to recruit patients. Thus, the potential issue of recruiting participants for this project was negotiated with some HCPs (who were aware of some potential patients facing social issues currently) in the next meeting. In addition, they were consulted with to gain their commitments to the project, in terms of informing the trainee health psychologist about the appointment dates (in the clinic) and contact numbers of those patients who they think are currently facing any social issues. Their insight to understand some of their potential patients (whether they will be available to take part in this project) and have knowledge about their current situations, (e.g. out of town or gone on holidays etc) was invaluable. They seemed to have knowledge regarding how best to target those patients.

I was also keen to discuss possibilities for their (HCPs) kind contributions to the project. For example, in gaining information via e-mails about those patients who would like to take part in this project. It was also in my mind that if some patients become unavailable for any reason (after giving consent to their HCPs to take part in this project), then whether the HCPs will continue to provide more potential patients and I was reassured about this concern. The process of finding potential patients, remembering to ask their permission and then e-mailing the trainee health psychologist about those potential patients with their contact numbers was quite time consuming process for the HCPs, but they were happy to do it due to having regular meetings/consultations with those patients. It was felt that they would be in a position to raise awareness of the initiative of this project through their direct work with patients, identify those who are currently facing social issues and available to take part in this project.

The trainee health psychologist was made aware that to protect patients' rights (related to exposing their contact details), nobody is allowed to contact them before gaining their permission and to get their permission, those potential patients' HCPs need to speak to them to ask whether they would like to take part in this project and be happy to be contacted by a trainee health psychologist.

At the end of the meeting, responsibility of contacting the patients was taken by some HCPs and it was suggested to the trainee health psychologist to prepare a brief information sheet related to this project which can be shared with the potential patients and this way they can be made aware of this project and can also be used to inform them that who will be contacting them in the near future. The trainee was also requested to provide some potential names of social issues (came across through literature review) in the information sheet just to make patients understand what is meant by social issue as well as the whole procedure and contact details of people working on this project, who patients could contact to get further information if they needed.

Approval, authentication and implementation

To initiate and implement this service evaluation project, it was very important to get authorization from the audit department of the hospital. It was discussed with the lead diabetologist that it is very important to find out from the audit department whether conducting interviews and focus groups can be permitted under the service evaluation project. This question was sent to the audit department and a confirmatory reply was received. Thus, a form was gained, completed and submitted to the audit department, which was accepted. After receiving the confirmation, the first thing to start the implementation process was the recruitment of the participants. An information sheet (please see Appendix

A) was designed (as suggested above) to start the first step for the recruitment of the participants and sent it to the HCPs to share it with their potential patients.

A reply was received from the HCPs regarding those patients who will be interested in taking part in this project. The secretary of the lead diabetologist was requested via e-mail to provide contact details of those potential patients (due to not having access to the patients' data system) contact by copying the e-mail address of those HCPs who provided the names and hospital numbers of those patients. This information was helpful for the trainee health psychologist to contact the potential patients and ask them whether they will be happy to take part in this project. The potential patients were contacted and requested whether they will be happy to participate in this project and then a brief introduction was mentioned. Some patients were already aware of this project through their HCPs. Furthermore, they were asked whether any time before or after their appointments will be suitable for them and this way an exact timeslot was arranged with the patients.

Reflection on barriers during implementation

Once the trainee health psychologist started conducting this project, various issues occurred. For example, some patients forgot to turn up for their appointment and their re-arranged appointment date was after a long time; some received cancelation of the appointment from the clinic; some did not turn up for their appointment; one could not come to the clinic due to child care problems, and some got delayed meeting them while they were in the ward due to receiving permission quite late from their diabetes consultants.

The process of meeting a patient in the ward regarding any project is to gain permission from the consultant. The trainee health psychologist was given hospital numbers, names and ward names by the HCPs (e.g. nurses or dieticians), which were sent to a secretary to find out consultants of those patients and then those consultants were e-mailed to get their permission and sometime this whole process took so long that by the time trainee got permission and reached at the ward, patients were discharged and had no recent appointments in the clinic and also not available on the phone.

Reflection

At that time, trainee health psychologist felt quite disappointed, especially when planned time was running out to complete the interviewing. However, the trainee health psychologist did not give up and after returning from the wards, she tried contacting the remaining patients to find out their appointment dates. After contacts, one said that he does not have any appointment in the next following months but he will be happy for a telephone interview next day on a certain time, which was agreed with him. As a trainee health psychologist was given the permission from the lead diabetologist to conduct interviews regarding this project in the clinic or over the phone. At various occasions, trainee was informed by some HCPs whether it is possible to meet some patients (after gaining their verbal consent regarding this project) admitted in the wards. The whole diabetes clinic team was very supportive in terms of providing patients for this project as well as finding free timeslots from their very busy schedule as a team to take part in focus groups (one with diabetes specialist nurses and other with the dieticians), which was very invaluable.

Identify, analyse and present psychological components of current social issues

The area of social inequalities and health had a strong link with health psychology (Marks, Murray, Evans, Willig, Woodall et al., 2005) in terms of identifying/exploring those social factors (or inequalities) influencing health (i.e. diabetes management) and how the clinic health care services could be improved. Social determinants of health have been associated with increased incidence, prevalence and burden of disease, and impact the health and well-being of individuals and populations (Bonnefoy, Morgan, Kelly, Butt & Bergman, 2007; Marmot & Wilkinson, 2003; Solar & Irwin, 2010). A review by the WHO investigating pathways between social conditions and health outcomes found that perceptions and experiences of individuals, including material factors, psychosocial factors, behavioral/biological factors and the health system, may influence health (Solar & Irwin, 2010).

Social determinants have been defined as factors in the social environment. These include:

- Socioeconomic status
- Housing
- Transportation
- Availability
- Accessibility of health care resources
- Social support (Ruger, 2004)
- Food security

- The quality of physical and social environments (Marmot, & Wilkinson, 2000; Raphael, 2004)
- Education
- Unemployment
- Employment and working conditions
- Social exclusion
- Social safety network
- Health services
- Sex
- Gender
- Disability (Mikkonen & Raphael, 2011).

Intuitively, these factors would appear to be obvious determinants of health (Jack et al., 2012). However, most of the literature on the causes, prevention and management of diabetes focuses on biomedical and lifestyle changes (Williamson, Vinicor & Bowman, 2004) with little if any attention given to these broader issues or to the role of SDOH in the prevention and management of diabetes (Pilkington et al., 2011).

Current research has demonstrated that social determinants are associated with the disproportionate development of chronic conditions and challenges encountered when managing them (Bryant et al., 2010; Touma & Pannain, 2011; Pilkington et al., 2010; Chaufan & Weitz, 2009; Blas, Sommerfeld & Kurup, 2012). Understanding the link between social determinants (inequalities) of health and diabetes can lead to identifying opportunities for improving or preventing negative health outcomes in communities affected by the inequitable conditions that create them (Jack et al., 2012). It can also enable practitioners to consider the implications of intervening at various points in diabetes care processes (Schuiz, Zenk, Odoms- Young, Hollis-Neely, Nwankwo et al., 2005).

During the literature search, it was noticed that the majority of studies were quantitative, using Type 2 diabetes patients and were developed in the USA or Canada. It was apparent from reviewing the literature that there was a need for more studies to be carried out among Type 1 diabetes patients and also to explore social issues and service improvement strategies from patients as well as from HCPs’ perspectives. There was also lack of literature exploring the influences of social issues on diabetes patients’ mental health in the literature, which could be due to quantitative studies. From a health psychology perspective, it was important for me to find out any influences of the social issues on patients' mental health. The concept of social determinants on health seemed to link with the health determinant model as it focuses upon individuals as well as factors surrounded by them.

The health determinants model by Dahlgren and Whitehead (1993) illustrates that places people, and their age, sex and hereditary factors, at the core of a number of layers of influences and conditions (from individual lifestyle factors, social and community influences, living and working conditions to general socio-economic, cultural and environmental conditions). It is a model that has been widely used (Ministry of Health, 2002; South Australian Council of Social Sciences, 2008; The Scottish Government, 2008) and adapted (Institute of Medicine, 2003; Barton and Grant, 2006; VicHealth, 2009), as the focus is on people and their environment. Barton's (2004) conceptual model of human settlements, which draws on the model of Dahlgren and Whitehead, is explicitly anthropocentric:

> *'People are at the heart of the model, in line with the anthropocentric view of sustainability. The health, well-being and quality of life enjoyed by people are the core purpose of settlement planning' (p. 10).*

This framework has a multi-layered structure that places the individual at the core, but surrounded by four layers of influences. From this perspective, health psychology can be structured as follows:

- Individual lifestyle.
- Social and community influences.
- Living and working conditions.
- General socio-economic, cultural and environmental conditions (Marks et al., 2005).

Dahlgren and Whitehead (1991), attempt to map the relationship between the individual, environment and disease. This framework has six characteristics:

1. It focuses upon all of the determinants of health.
2. It places the individual at the core but acknowledge the primary determining influences of society.
3. It places each layer in the context of its neighbour, reflecting the whole situation.
4. It has a true interdisciplinary flavour and not purely a medical model.

5. It makes no claims for any one discipline as being more important than others.
6. It acknowledges the complex nature of health determinants (Marks et al., 2005, p. 14).

Nonetheless, the analysis of the data demonstrated that social determinants seemed to affect patients' mental health as well as diabetes management. For instance, a variety of the following life situations left patients in a very stressful state, which affected their diabetes self-care/management:

- Having a complicated housing situation, living with in-laws in an overcrowded home and waiting to move in a council house one day as a family.
- Having leakage in the kitchen and being unable to get any support from the insurance companies.
- Going through divorce and looking after young children.
- Being unable to pay the mortgage due to sick/holiday pay.
- Constant life events or incidences after diagnosis of diabetes, (e.g. alcoholic husband, young children to look after, no job; drug addicted daughter and son in law).

These perspectives seemed to demonstrate that there is an important link between mental and physical health. Stress seemed to be an inevitable part of life, sometimes due to major life events and other times due to minor events. The government's mental health outcomes strategy '*No Health Without Mental Health*' places considerable emphasis on the connections between mental and physical health, and gives new responsibilities to Improving Access to Psychological Therapy (IAPT) services for supporting the psychological needs of people with long-term conditions or medically unexplained physical symptoms (Department of Health 2011).

Moreover, participants' perspectives in this project seemed to highlight that diabetes patients face various kinds of social issues in life, which require attention, rather than just looking after their diabetes. Therefore, when they feel overwhelmed or frustrated by issues related to housing, unemployment, and financial issues, managing diabetes or following a diabetes regime seemed to be pushed backward and efforts to solve those issues take priority on their lists.

As part of the current service evaluation project, patients and HCPs not only addressed various social determinants affecting diabetes management, but they also illustrated various suggestions to improve the current services related to those issues to some extent. For the provision of diabetes care at the hospital's outpatient practice, patients suggested that having facilities in the clinic related to their social issues, (e.g. a social worker in the diabetes team, benefits related information and a welfare officer could be supportive for them). Moreover, HCPs emphasised more likely on knowledge improvement related areas, (e.g. providing leaflets with contact numbers of services related to social issues, adding boards in the waiting area, having contact list of referral services) and improving current services, (e.g. provide peer support platform, HCPs need to work at multiple settings, opening up clinic at weekends).

Reducing social inequalities can benefit society, health systems, and clinicians from public health, ethical, and economic standpoints (National Advisory Committee on Health and Disability, 1998). To guide local, state, and national policies that address health disparities resulting from social determinants, we must first measure the non-medical factors that contribute to the development of chronic conditions (Hill, Nielsen, & Fox, 2013). On the other hand, to reduce these social inequalities requires adopting a thoroughly multilayered approach (mentioned above). Whitehead (1995) identified four different levels for tackling health inequalities:

1. Strengthening individuals
2. Strengthening communities
3. Improving access to essential facilities and services
4. Encouraging macroeconomic and cultural change (Murray and Marks, 2008, p.342).

Overall, efforts directed at the individual level have been inconclusive and small scale. This is mainly because many health determinants are beyond the control of the individual and psychological interventions aimed at individuals are likely to have limited impact on public health problems when considered on a wider scale. This suggests a need to work beyond the individual level, with families, communities, work sites and community groups.

To further challenge the underlying non-medical social and environmental contributors to chronic conditions, a focus on the individual within a systems perspective is necessary. On a systems level, this requires two vital building blocks: 1) data that accurately captures social determinants of health, and 2) policies that both intersect public health principles and practice and promote linkage of social determinants to health care delivery. Although part of the structure to fulfil these requirements already exists, the multi-factorial complexity of chronic conditions, such as diabetes, requires additional targeted activities to further advance efforts to prevent and to manage them (Hill et al., 2013).

Evaluation

Overall, the information gained throughout this project seemed to be very useful to improve clinic services. A brief report was sent to the management (as part of the service evaluation project) and the lead diabetologist to get feedback related to this work overall as well as trainee health psychologist's performance. They provided feedback and comments were along the following lines:

This project was designed and conducted to a very high standard and drew out the issues in a concrete and constructive way from those involved. This is a useful piece of work. The information sheet was clear and comprehensive and achieved the required task. The literature review was as complete as possible and has resulted in a very comprehensive and informative introduction and discussion in the report.

Trainee health psychologist always follows both the very highest NHS and professional standards. I have very much enjoyed working with her and I know that the team has been impressed with her commitment and the intensity of the work that she performs.

The qualitative data has come out very strongly to inform the final report. The report is of a high standard and with a limited amount of work can be cut down to a document worthy of submission for publication. I am happy to be a co-author on this paper.

The importance of social issues has become more clearly known by the educator staff as a result of the project. The work has enhanced knowledge, but changes in staff and funding mean that it will take some time before the full recommendations are able to be implemented.

This piece of work is at a high standard and Kalsoom is to be commended for her tenacity and skills in generating these qualitative data and associated knowledge. I look forward to us submitting the paper for consideration for publication.

A qualitative draft paper has been written to submit to a peer review journal (e.g. ‘Diabetic Medicine’) for the publication purposes.

Reflection

It will be my second experience to prepare this work to submit the service evaluation based work into a peer reviewed journal, which I find very useful as it is a very good opportunity to put my previously learnt knowledge and skills into practice. The process of submitting the manuscript online in a different journal will help me to improve my communication and writing skills in terms of:

- Preparing the covering letter and the manuscript according to a different journal’s guidelines.
- Responding to the reviewers’ comments and editors’ e-mails as a first corresponding author.
- Fulfilling the other entire formal requirement after acceptance of the work.

All the co-authors will be kept informed throughout this process and will be thanked for their support and guidance and will be sent a final version of the accepted paper.

Overall, I believe that the evaluation of this project can increase awareness (among clinic management and diabetes team lead) about the types of social issues, their influences on patients’ mental health as well as diabetes management and service improvement strategies from patients and HCPs’ perspectives. In regards to this project overall, I believe that I have developed a greater understanding and practice-based knowledge about social issues and their influence on diabetes management and mental health. This project also improved my confidence to design and develop focus group in the future as it was my first experience of conducting this type of work. In particular it has made me think more about the role that social determinants play in sustaining ill-health among diabetes patients and why it is so important to focus on both individual and social change. From this, I can see that in addressing health determinants there needs to be much more of a focus on lobbying changes at least at the service level to enable individuals to find some support, which might bring changes in their health. There was a relatively short timeline for the data collection. This factor did not allow me time to potentially involve all of the patients facing social issues (who had appointment after a very long time). In addition, I feel it would have been of benefit for me to have attended a workshop on focus groups. However, I feel that my time management skills assisted in enabling me to complete this piece of work within the allocated time given (August 2013-November 2013). In addition, I believe I have developed new skills and enhanced existing ones, including my influencing and negotiating skills.

Conclusion

My overall experience of undertaking this project was extremely positive and useful. It provided me with the confidence to design and to implement a complete qualitative project within the NHS organisation. This experience has given me the confidence to look for further opportunities within areas in which I was confident and experienced. Identifying and analysing social issues among patients with diabetes through qualitative methods and disseminating it to the wider professional audience has been a very productive experience. The importance of health psychology in addressing the above issues is invaluable. I enjoyed completing this piece of work and was pleased with the outcome of this project especially in terms of submitting it to a peer review journal in the future.

References

Barton, H. (2004). Healthy Urban Planning: The Anatomy of a WHO Healthy Cities project. In *International Planning Symposium on Incentives, Regulations, and Plans—The Role of States and Nation-States in Smart Growth Planning.* MD: University of Maryland.

Barton, H. and Grant, M. (2006). A health map for the local human habitat. *Journal for the Royal Society of Health Promotion of Health, 126*, 252-253.

Blas, E., Sommerfeld, J. and Kurup, A.S. (2012). *Social determinants approaches to public health: from concept to practice* [monograph on the Internet]. Geneva, Switzerland: World Health Organization. [cited 2012 Nov 13]. Available from: www.who.int/sdhconference/resources/SDapproachestopublichealth_eng.pdf.

Bonnefoy, J., Morgan, A., Kelly, M.P., Butt, J. and Bergman, V. (2007). *Constructing the evidence base on the social determinants of health: a guide*. Geneva, Switzerland: The Measurement and Evidence Knowledge Network (MEKM) of the WHO commission on Social Determinants of Health.

Brown, A.F., Ettner, S.L. and Piette, J. (2004). Socioeconomic position and health among persons with diabetes mellitus: a conceptual framework and review of the literature. *Epidemiology Review, 26*, 63-77. DOI: http://dx.doi.org/10.1093/epirev/mxh002.

Bryant, T., Daiski, I. and Lines, E. (2010). *Type 2 diabetes: poverty, priorities and policy: the social determinants of the incidence and management of Type 2 diabetes*. Toronto, Ontario, Canada: York University School of Health Policy and Management.

Chaufan, C. and Weitz, R. (2009).The elephant in the room: the invisibility of poverty in research on type 2 diabetes. *Humanity Society*, 33(1-2), 74-98.

Chaney, D., Coates, V. and Mark Shevlin, M. (2010). Running a complex educational intervention for adolescents with type 1 diabetes – lessons learnt. *Journal of Diabetes Nursing*, *14*, 10.

Creatore, M.I., Gozdyra, P. and Booth, R.H. (2007). Socioeconomic status and diabetes. In: Glazier, R., Booth, G., (eds.). *Neighbourhood Environments and Resources for Healthy*

Living – A Focus on Diabetes in Toronto. Toronto, ON: Institute for Clinical Evaluative Sciences. http://www.ices. on.ca. Accessed November 16, 2011.

Dahlgren, G. and Whitehead, M. (1993). *Tackling Inequalities in Health: What Can We Learn from What Has Been Tried? Working Paper Prepared for the King's Fund International Seminar on Tackling Inequalities in Health. London: The King's Fund.*

Department of Health (2011). *No Health Without Mental Health: A cross-government mental health outcomes strategy for people of all ages*. London: Department of Health.

Dinca-Panaitescu, S., Dinca-Panaitescu, M., Bryant, T., Daiski, I., Pilkington, B. and Raphael, D. (2011). Diabetes prevalence and income: results of the Canadian Community Health Survey. *Health Policy, 99*(2), 116-23.

Glazier, R.H., Bajcar, J., Kennie, N. and Wilson, K. (2006). A systematic review of interventions to improve diabetes care in socially disadvantaged populations. *Diabetes Care, 29*(7),1675-88.

Hill, J., Nielsen, M. and Fox, M.H. (2013). Understanding the Social Factors That Contribute to Diabetes: A Means to Informing Health Care and Social Policies for the Chronically Ill. *The Permananete Journal*, *17*(2), 67-72.

Institute of Medicine. (2003). *The Future of the Public’s Health in the 21st Century*. Washington, DC: National Academies Press.

Jack, L., Jack, N. H. and Hayes, S.C. (2012). Social Determinants of Health in Minority Populations: A Call for Multidisciplinary Approaches to Eliminate Diabetes-Related Health Disparities. *Diabetes Spectrum, 25*(1), 9-13.

Kumari, M., Head, J. and Marmot, M. (2004). Prospective study of social and other factors in the incidence of type 2 diabetes in the Whitehall II study. *Archives of International Medicine, 164*,1873-1880.

Marks, D.F., Murray, M., Evans, B., Willig, C., Woodall, C. & Sykes, C. (2005). *Health Psychology. Theory, Research & Practice* (2nd Ed.). London: SAGE Publications.

Marmot, M. and Wilkinson, R. (2000). *Social Determinants of Health.* Oxford, UK: Oxford University Press.

Mikkonen, J. and Raphael, D. (2011). *Social Determinants of Health: The Canadian Facts.* Toronto, ON: York University School of Health Policy and Management.

Mikkonen, J. and Raphael, D. (2010). *Social determinants of health: the Canadian facts*. Toronto, Ontario, Canada: York University School of Health Policy and Management.

Ministry of Health. (2002). *Reducing Inequalities in Health*. Ministry for Health, Wellington, New Zealand.

Murray, M. and Marks D.F. (2008). Challenging Social Inequalities in Health. In Crane, D. R. & Heaton. T. B. *Handbook of Families and Poverty*. London: Sage Publications.

National Advisory Committee on Health and Disability. (1998). The social, cultural and economic determinants of health in New Zealand: action to improve health. Wellington, New Zealand: National Health Committee

NICE. (2004). *Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults*. Clinical Guideline 15. NICE: London.

Pilkington, F.B., Daiski, I., Bryant, T., Dinca-Panaitescu, M., Dinca-Panaitescu, S. and Raphael, D. (2010). The experience of living with diabetes for low income Canadians. *Canadian Journal of Diabetes, 34*(2), 119-126.

Pilkington, F.B., Daiski, I., Lines, E., Bryant, T., Raphael, D., Dinca-Panaitescu, M. and Dinca-Panaitescu, S. (2011). Type 2 diabetes in vulnerable populations: Community healthcare providers' perspectives of health service needs and policy implications. *Canadian Journal of Diabetes, 35*(5), 503-511.

Racial and Ethnic Approaches to Community Health (REACH) (2012). Atlanta, GA: Centers for Disease Control and Prevention. Nov 6 [cited 2012 Nov 13]. Available from: www.cdc.gov/reach/about.htm.

Raphael, D. (2004). *Social Determinants of Health: Canadian Perspectives.* Toronto, ON: Canadian Scholars Press.

Raphael, D., Anstice, S., Raine, K., McGannon, K.R., Rizvi, S.K. and Yu, V. (2003). The social determinants of the incidence and management of type 2 diabetes mellitus: Are we prepared to rethink our questions and redirect our research activities? *Leadership in Health Service,16*(3), 10-20.

Ruger, J.P. (2004). Health and social justice. *Lancet* 364, 1075–1080.

Schulz, A. J., Zenk, S., Odoms-Young, A., Hollis-Neely, T., Nwankwo, R., Lockett, M., Ridella, W., & Kannan, S. (2005). Healthy Eating and Exercising to Reduce Diabetes: Exploring the Potential of Social Determinants of Health Frameworks Within the Context of Community-Based Participatory Diabetes Prevention. *American Journal of Public Health,* 95, 4.

Solar, O. and Irwin, A. (2010). A conceptual framework for action on the social determinants of health. *Social Determinants of Health Discussion Paper 2* (Policy and Practice). Geneva: World Health Organization.

South Australian Council of Social Service (SACOSS). (2008). *The Social Determinants of Health*. SACOSS Information Paper. South Australian Council of Social Service, Adelaide.

Smith, J. (2007). *Diabetes and the rise of the SES health gradient*. NBER Working Paper No. 12905. Cambridge, MA: The National Bureau of Economic Research.

Touma, C. and Pannain, S. (2011). Does lack of sleep cause diabetes? *Cleveland Clinical Journal of Medicine*, *78*(8),549-58.

The Scottish Government. (2008). *Equally Well: Report of the Ministerial Taskforce on Health Inequalities.* Vol. 2. The Scottish Government, Edinburgh.

VicHealth. (2009) *VicHealth Strategy and Business Plan 2009–2013*. Victorian Health Promotion Foundation (VicHealth), Melbourne.

Williamson, D.F., Vinicor, F. and Bowman, B.A. (2004). Centers for Disease Control and Prevention Primary Prevention Working Group. Primary prevention of type 2 diabetes mellitus by lifestyle intervention: implications for health policy. *Annals of Internal Medicine*, *140*(11), 951-7.

Wilkins, R., Berthelot, J.M. and Ng, E. (2002). Trend in mortality by neighborhood income in urban Canada from 1971 to 1996. *Health Reports*, *1*, 45-71.

World Health Organization. (2011). Social determinants of health [monograph on the Internet]. Geneva, Switzerland: World Health Organization. [cited 2011 Sep 10]. Available from: www.who.int/social_determinants/en/.

Appendix A

Information sheet

Title: Evaluation of how the Diabetes Clinic identifies and helps address social issues that impact on the self management of patients with diabetes.
Interviewer: Kalsoom Akhter (trainee Health Psychologist)
Supervisor: [redacted]

Background & purpose of this evaluation

The increasing prevalence of diabetes has been characterized as an epidemic and as such it calls for a response from health researchers, healthcare providers and people who produce policies. Much of the literature on the prevention and management of diabetes focus on lifestyle changes; less attention has been paid to the role of Social Determinants Of Health (SDOH) in the prevention and management of diabetes. SDOH include income and income distribution; education; unemployment and job security; employment and working conditions; early childhood development; childcare; shift work; food insecurity; housing; social exclusion; social safety network; health services; sex; gender; and disability .

The aim of this evaluation is to seek the views of patients with diabetes on how the diabetes service identifies and deals with social issues that can impact on the ability of a patient to manage their diabetes. This information will be used to produce a departmental policy to improve the current service provided to patients living with diabetes.

Do I have to take part?

No. It is up to you to decide to join the evaluation. If you decide not to participate, this will not affect the standard of care you receive.

What do I have to do if I want to take part in this evaluation?

The Diabetes Nurse, Dietician or Doctor will ask you if Kalsoom Akhter, who is involved in this evaluation, can contact you. If you agree, they will give your contact details to Kalsoom, who will then contact you to arrange a meeting at a mutually agreed time. This meeting needs to be held in person either at the diabetes clinic during your one of the regular visits or at home if you are receiving care at home from our Diabetes Specialist Health Care

Professionals and will involve a discussion about your experiences of, as well as thoughts on any social issues that affect your diabetes. This meeting may last up to a maximum of 1 hour and will be audio recorded to help with the evaluation.

Will my taking part in this study be kept confidential?

Yes. Information obtaining during this meeting will be stored securely and kept strictly confidential. Only Kalsoom and Dr Simmons will have access to the information. No identifying information will be included in the policy or publications following this evaluation.

What are the possible benefits of taking part?

You will help the clinic develop a policy to identify and address social issues among patients who attend the clinic. An impact of this policy might be to put health and social services under one roof to promote partnership/teamwork between healthcare professionals and those working in the social areas.

Who can I contact for further information?

If you have any questions or concerns regarding this evaluation, please do not hesitate to contact:

Kalsoom Akhter	Dr. [redacted]
Tel: [redacted]	Tel: [redacted]
E-mail: [redacted]	E-mail: [redacted]

Section 3F - Behaviour Change Intervention

Implement interventions to change
Health-related behaviour

Case study- Behavioural Intervention for Insomnia

Supervision Plan

Behaviour change case study: Behavioural Intervention for Insomnia

Units in this area of competence	Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)	Supporting evidence to be complied for this unit of competence
Implement interventions to change health-related behaviour	**Setting: Mind ( )** **Client:** Client with psychological and behavioural issues. **Description of work:** By working in a mental health charity as a well-being worker to apply CBT principles under a regular supervision on a project called ‘changing lives’, I met with an adult male client. He was referred by a GP with a diagnosis of sleep difficulties and low mood problems. An initial assessment was conducted using open-ended questions to understand this problem from his perspectives followed by standardised assessments with an evaluation and a contract form. After the assessment, a variety of cognitive (e.g. distorted thinking pattern) and behavioural determinants were explored, which related to the existence of sleep difficulties. Using a collaborative approach, some goals were identified and a plan was made to work on a prioritised goal though some home work assignments. The process of working on the selected goal was negotiated with the client based on behavioural principles first followed by the cognitive ones later on. Some barriers related to such plan as well as some overcoming strategies to achieve the goals were also explored from the client’s perspectives. The clients’ mood was reviewed after few sessions, which provided a brief update about any positive or negative changes. The client felt improvement in his mood and behaviour by stopping naps and drinking decaffeinate tea as well as by doing various other tasks. After three session, evaluation was conducted and he demonstrated improvements in his ability to cope with life, thinking positively and relaxing. The sessions were ended here due to client’s situation to move away from the UK, but he mentioned about continuing this work at his new place due to perceiving the psychological and behavioural benefits.	Training was received as part of this job role related to: • Confidentiality and professional boundaries. • Listening skills. • Lone working policy. Mental health first aid. • Equality and diversity. • Safe guarding vulnerable adults Sleep diary. Sleep Hygiene Instructions

Target for completion: … March, 2013 … Workplace contact? Yes … If yes please give name:[redacted] (   ).

Background

My current role in a mental health charity (Mind in Cambridgeshire) is to provide support to those people who have mental and behavioural problems as a well-being worker. This charity brings together the long-established organisations of Cam-mind (Cambridge) and Hunts Mind (St Neots) to provide an innovative, countywide service designed for people who have a lived experience of mental health problems. I currently work at the St Neots centre, which runs a variety of projects to support people and one of them is called '*Changing Lives Project*' (CLP). This project is a part of the Cambridgeshire wide Improving Access to Psychological Therapies (IAPT) service which is commissioned by National Health Service (NHS) Cambridgeshire. The CLP came on line in October 2010. One of the aims of this new service is to provide a stepped model of care which supports the delivery of low intensity evidence based, brief interventions that include computerised Cognitive Behaviour Therapy (CBT), guided self-help and seeing clients at their homes if this is required. As a well-being worker/trainee health psychologist, I met an adult male client (aged 60) who was referred by a local General Practitioner to the CLP team and the client was diagnosed with sleep difficulties and low mood problems.

Introduction

Poor sleep is one of the most common complaints in adults, with between 9% and 12% reporting sleep difficulties on a persistent basis. In older adults, the prevalence rates of insomnia exceed 20% to 30%, greater in frequency and severity than in any other age group (Ancoli-Israel, 2000; Foley, Monjan, Brown, Simonsick, Wallace, & Blazer, 1995; Petit, Azad, Byszewski, Sarazan, & Power, 2003). Persistent insomnia is defined as problems initiating and/or maintaining sleep at least 3 nights per week, which is accompanied by daytime distress or impairment (American Psychiatric Association, 2000; World Health Organization, 1992). It can produce an important burden for the individual and for society. Evidence suggest that this can be via by reduced quality of life, impaired day time functioning (feeling tired and being irritable, NHS Choices, 2013), increased absenteeism at work, and higher health-care costs (Breslau, Roth, Rosenthal, & Andreski, 1996; Walsh, 2004) . As such, insomnia is a heterogeneous subjective complaint that can reflect poor sleep quality or lack of restful sleep, reduced duration of sleep, or problems falling asleep or waking repeatedly through the night. Of importance, diagnostic assessment of insomnia considers that the sleep disturbance does not occur exclusively during the course of another mental or sleep disorder and is not due to the direct effects of a substance (e.g. alcohol) or a medical condition (American Psychiatric Association, 2000; World Health Organization, 1992).

Sleep problems are also associated with cardiovascular disease (Ayas, White, Manson, Stampfer, Speizer et al., 2003), mental health problems (Strine & Chapman, 2005), motor vehicle accidents (Connor, Norton, Ameratunga, Robinson, Civil et al., 2002), and overall poor quality of life (Verster, Pandi-Perumal & Streiner, 2008). The direct and indirect costs of sleep problems are substantial (Skaer & Sclar, 2010). Despite the individual and societal burden of sleep problems, most (80%-90%) remain undiagnosed (Young, Evans, Finn & Palta, 1997). Both diabetes (Laiteerapong, Karter, Liu, Moffet, Sudore et al., 2011) and sleep problems (Verster, Pandi-Perumal & Streiner, 2008) are highly correlated with poor quality of life. People with diabetes may also be at higher risk for sleep problems relative to the general population because of common risk factors for diabetes and sleep problems, including advanced age, obesity, and treatments for and complications of common co-morbid diseases (e.g. depression and cardiovascular disease). Additionally, diabetes-specific complications, such as neuropathy, could directly interfere with sleep. However, because of low rates of detected sleep disorders (Young, Evans, Finn & Palta, 1997), most people with diabetes who have sleep problems are likely to go untreated (Plantinga, Rao & Schillinger, 2012).

In older adults who are at risk for medical morbidity, the consequences of insomnia for impairments of health are especially significant. Chronic sleep disturbance also leads to disturbances in mood, energy, and performance during the day and is associated with declines in quality of life and health functioning (Ancoli-Israel, 2000; Breslau, et al., 1996; Morin, Blais, & Savard, 2002). The majority of individuals with insomnia remain untreated, despite the striking health burden of persistent sleep problems. In the primary care setting where over 50% of patients experience insomnia and only 5% seek treatment (Ancoli-Israel & Roth, 1999). The lack of treatment-seeking and/or treatment adherence is of further concern given findings from six recent meta-analyses that support the efficacy of pharmacological and behavioural interventions for primary insomnia (Holbrook, Crowther, Lotter, Cheng, & King, 2000; Montgomery & Dennis, 2003; Morin, Culbert, & Schwartz, 1994; Murtagh, & Greenwood, 1995; Nowell, Mazumdar, Buysse, Dew, Reynolds et al., 1997; Smith, Perlis, Park, Smith, Pennington et al., 2002). Meta-analyses of pharmacotherapy for insomnia show that short-term (2–4 weeks) treatments yield improvements in Total Sleep Time (TST) and reductions in sleep latency (Holbrook, et al., 2000; Nowell, et al., 1997). However, data on the maintenance of these effects in the long-term are limited with clinical management hampered by reasonable concerns about tolerance or dependence (Kupfer & Reynolds, 1997). Moreover, following withdrawal of pharmacotherapy, rebound insomnia can occur (Dement, 1992; Soldatos, & Whitehead, 1999). However, there is evidence that improvements in sleep are not sustained (Kupfer & Reynolds, 1997). Other risks with use of hypnotics include daytime residual effects, particularly in older adults, with attendant increases in the risks for falls and fractures (Wettstein, 1992).

With reference to the literature, the current client (AP) was a 60 year old man, had no major chronic illnesses and was on medications (e.g. Benzodiazepines) for sleep problems according to the referral letter. To explore and understand the context of his past experiences, personal meaning, emotions and behaviours related to this problem from his own perspectives, an initial assessment was necessary to develop meaningful insights into what may have caused this problem, what is maintaining it and what are the potential ways to restore or achieve recovery (Freeman, Pretzer, Fleming, & Simon, 2004). An ideographic assessment approach (Grant, Townend, Mills & Cockx, 2008) was used, which is concerned with understanding the person’s own characteristics that contribute to his/her difficulties rather than a broad classification of what disorder he/she might have. It is also personal rather than disease focused, which is essential in a psychotherapeutic context (Freeman, et al., 2004) and the link with the ethos of the CLP to work collaboratively with the client and try to understand his/her perspective related to the problem in order to break the vicious cycles which are sustaining or intensifying their problems (ibid).

Assess the suitability of client/s for health-related behaviour intervention

The CLP consists of conducting a comprehensive assessment initially followed by the 6 sessions (each 30-60 minutes long). As part of the job role, the first session was to assess the problem or needs related to health behaviour through some open-ended questions related to the problem and duration and development of the problem, followed by conducting the standardised assessment. This assessment was consisted of gaining demographic information (e.g. name, address, contact details, age, gender, ethnicity and employment status) and conducting a risk assessment (family history of self harm, current intent of self-harm and current medication). In addition, it also included:

- Monitoring the Activating event (A), Beliefs (B) and Consequences (C).
- Trying to gain information related to any medical or psychiatric history.
- Exploring goals or expectations from the sessions.
- Asking him to provide a summary of presenting problems.
- Completing equal opportunities monitoring form.

I also tried to give explanation of any technical language (e.g. cognitive processes, dysfunctional thinking) used during the assessment process only, as this allows the client to know precisely what I expected and to ensure that anything which might have an ambiguous meaning is clarified (Freeman, et al., 2004).

An initial CLP evaluation form was also completed by the client, which consisted of questions related to gender, waiting time, coping with life on a scale of 1-10, and expectations from the CLP. It was my first experience to see a client at his home (upon his request) to do the assessment and conduct the following sessions. However, in essence my training related to confidentiality and professional boundaries, listening skills, lone working policy, mental health first aid, equality and diversity, safe guarding vulnerable adults, strengthened my confidence to tackle any potential issues arising during this experience. It was also found very important and useful to follow the rules written on the contract form for both parties (well-being worker and client). I also felt that my previous training and experiences as a researcher helped me to explore the problem via some open-ended questions, active listening, understanding and validating.

Aims of the assessment process

I needed to work towards and be mindful of a number of overall aims throughout the assessment process. The following aims emerged from a collaborative process, which aimed to increase client’s understanding of this approach:

- Assess a detailed breakdown of the client’s problem in terms of environmental triggers, thoughts, behaviours, emotions and physiological reactions.
- Explore any potential factors from the client’s background and past which have contributed to the development of his main problem.
- Provide an account of what factors are helping to maintain the client’s problem.

- Describe the nature and strength of the therapeutic relationship via a contract (signed by client and the wellbeing worker). This contract consists of information related to the sessions, responsibilities expected from the client, environmental conditions and confidentiality.
- Define the strengths of the client.
- Provide an outline of how the wellbeing worker will be able to work with the client based on the formulation emerging from assessment in the following 6 sessions and review after 3rd and 6th session.

It was expected that as the assessment process develops, the client may start developing the ability to do as follows:

- Understand and relate to the collaboratively developing formulation of what helped to the emergence of his problem.
- Understand and relate to the thoughts, behaviours, emotional and physiological reactions that are helping maintain his problems.
- Contribute to, and understand the plan for working on problem areas.
- Understand the nature of measurement within the therapeutic process.
- Understand the collaborative nature of the therapy process and the mutual expectations within this (Freeman, Pretzer, Fleming & Simon, 2004).

Historically within the context of behaviour therapy one of the cornerstones of practice was the '*behavioural analyses*. The term was originally stressed by Skinner (1974) and was meant to distinguish the field that focuses on behaviour as a subject in its own right rather than as an index or manifestation of something happening at some other level (e.g. cognitive or emotional, Freeman, et al., 2004). Grant and colleagues (2008) suggest that it is important to determine the cause/s of unhelpful behaviour before developing an appropriate intervention. In the current case it was very important to understand the content and process of his thinking as well as what he was focusing on and attending to, as it could be useful to apply an individualised client-centred cognitive and behavioural techniques tailored to his individual needs. The assessment process continued in the subsequent sessions, as the client described various behavioural and cognitive factors, which were related to sleep difficulties. I tried to help the client to make links between his thoughts, feelings, behaviour and environment and interpersonal contexts as well as to recognise vicious cycle of factors, maintaining his difficulties by providing frequent summaries during assessment (Blackburn, James, Milne, Baker, Standart, Garland & Reichelt, 2001). These summaries enabled the client to spot some self-defeating strategies that he was using, including:

- Unhelpful beliefs (e.g. 'the sleeping tablets are not strong enough'; 'I need to go to see my GP to get much stronger tablets which can help me to sleep much better' and 'only stronger sleeping tablets can help me').
- Behaviours (e.g. drinking large amount of caffeine regularly; having naps during day time, going to bed at irregular times and not trying anything to get back to sleep).

Cognitive therapy based literature (Dalgleish, 2004; Wells, 1997) suggest that once clients are aware of these, they are more likely to be empowered towards optimism and the view that their problems are solvable. I tried to increase awareness about those internal and external factors or processes that may have not been seen as relevant to the problem and facilitate a change through a process of clarifying and differentiating the problem or problems into manageable parts (e.g. cognitive and behavioural and help to motivate the client). This led her to facilitate the client by focusing on '*what can be done*' instead of continuity of the problem and setting reasonable limits on what can be achieved. Overall this process enabled me to demonstrate understanding, warmth and empathy for the client's distress and build a collaborative relationship.

One of the important principles to remember for me was to initially concentrate on the '*here and now*' of the client's identified areas of experiences and difficulties. I found it effective to use collaborative process approach (which I was trained on) to discover the problem and asking some open-ended questions and more listening rather than firing off a rigid list of questions one after the other. Two cognitive therapists (Sanders & Wills, 2005) and authors of various CBT books have summed up the process in a clear and informed way while acknowledging that different professional groups might apply the assessment process in different ways:

The outline of assessment is not intended to be a fixed rota for therapists to stick to. Rather it is a series of coat hooks on which to hang information as it is assimilated and people will use it according to their core training (Sanders & Wills, 2005:80).

Cognitive, behavioural and situational determinants of relevant current behaviour

A part of the assessment was to find out about client's lifestyle or regular routine related to day to day activities to provide some appropriate support in the following sessions. A variety of cognitive (e.g. distorted thinking pattern) and behavioural determinants were explored, which related to the existence of sleep difficulties. The client also mentioned about not feeling physically fit to be able to do any job (due to feeling constant pain in his body) as well as not feeling he was able to go out with his family or meet other people. These symptoms (as part of sleep insomnia) give rise to emotional distress, daytime fatigue, and loss of productivity (Sateia, Doghramji, & Hauri, 2000). A variety of other common contributors to sleep disorders have also been discovered, which includes bladder or kidney disorders, odd work schedules, eating a heavy meal right before bedtime, incorrect diet for a particular body's needs, uncomfortable mattress, and caffeine, alcohol, or nicotine use late in the day (New Solutions for old Sleep Problems, 2003).

Identify and negotiate the behaviour change goals of the client/s

Behavioral therapy is more concerned with the here and now following the basic belief that behaviour is determined more by consequences than by historical fact. Behavioral and cognitive therapies are concerned with how, when, where, and what versus the why following the goals.

As the goal setting is the process of collaboratively identifying specific therapeutic outcomes for treatment. I aimed to identify goals, which must be observable, measurable and achievable and relate to cognitive or behavioural changes relevant to the client's presenting problem. I was also informed during training that identifying goals in the early stages can increase the continuity of sessions; allow for directed focused treatment, and enable the client and herself to assess the progress of therapy and identify change in an objective manner.

Although goals can be changed/modified at any point during therapy, to maximize applicability and benefit to the client, a preliminary set of goals were established and agreed upon by the end of the first session. Goal setting began with the identification of broad goals, which related to a list of few things that he would like to get out of the therapy. Once broad goals were identified collaboratively, we focused on prioritising the goals. This process involved determining the most central issues that cause concern and arranging them from most important to least important. The client was asked the open-ended questions to identify and prioritise the goal (e.g. can you identify what you want to change about your situation so we can then take steps to work on the problem).

Starting with the problem that has the best chance of being solved can help increase the client's commitment to therapy (e.g. cut down naps and caffeine and try to perform an activity during day time). A graded approach to goal was used, in which small steps were taken in service of the larger goal each week through session content or homework assignments. Identifying and sequencing action steps involves breaking each goal into smaller steps, which can help the client to know what to do at every stage of accomplishing the goal without feeling overwhelmed by a huge task.

Once the goal was identified and prioritised by the client that he would like to receive some support to improve his sleep duration at night, the process of operationalisation was discussed, which involved defining the goal and all the steps (please see the following section related to the plan/steps) that it will take to achieve it in concrete, observable/measurable, cognitive or behavioural terms (Cully & Teten, 2008). I also explored any advantages of working on or accomplishing this goal by asking *"What would be the benefits if you accomplished this goal?"*

I negotiated the behavioural/practical process of working initially on this goal following the behavioural approach as the behavioural interventions are increasingly being viewed an effective alternative to medication treatment of insomnia. Three meta-analyses support the efficacy of these behavioural approaches (Montgomery & Dennis, 2003; Murtagh & Greenwood,1995; Nowell, et al., 1997) and one comparative meta-analysis found that behaviour therapy and pharmacological treatments yielded similar improvements in sleep maintenance, TST and sleep quality with some advantage for behaviour treatments in improving sleep latency (Holbrook, et al., 2000). The strategies used in these various behavioural treatments are heterogeneous, including a range of approaches: relaxation, sleep scheduling such as stimulus control and sleep restriction, and cognitive-behavioural therapy along with sleep hygiene. Briefly, sleep hygiene teaches people about the impact of lifestyle habits on sleep, stimulus control aims to help individuals renew the association of bed and bedtime stimuli with sleep rather than sleep disruption, sleep restriction limits the time spent in bed at night and obviates sleep during the day, and cognitive therapy breaks dysfunctional beliefs and attitudes about sleep that lead to emotional distress and further sleep problems.

Gains from these various behavioural treatments are sustained for months to years following treatment, and behavioural treatment can be administered without the risk of side effects found with pharmacotherapy, making the use of these behavioural approaches highly salient for older adults (Cully & Teten, 2008).

Develop a behaviour change plan based on cognitive-behavioural principles

By considering the determinants of the problem and following the behaviour change goal set by the client, I negotiated the plan with the client to work on in the following sessions. This plan was based on cognitive (insomnia and thinking) and behavioural principles (sleep hygiene, fun and achievement activities catalogue). As the client demonstrated a variety of behavioural problems (e.g. large amount of caffeine, naps during day time, etc), thus the plan was to start the initial work with the behavioural element rather than the cognitive one as sometimes tackling those behavioural problems that can bring some positive effect on sleep. After negotiating the potential determinants of the behavioural problem of the client with the work supervisor (a psychotherapist), the sleep hygiene and fun activities catalogue were started after discussing with the client.

One of the strategies to improve sleep difficulties is called sleep hygiene. It is a term coined to describe a set of rules meant to improve sleep (Hauri, 1991). There is no single list of these do’s and don’ts about sleep and practices of everyday living. In general, sleep hygiene *‘tips’* have face validity and are consistent with everyday understanding of sleep regulation (Ebben & Spielman, 2009). Although sleep hygiene is a very useful technique, it was used with the fun activities catalogue as it is recommended that sleep hygiene can be very helpful when integrated with other techniques (Centre for Clinical Interventions, 2007). Please see Appendix B for an outline of the typical sleep hygiene instructions (Centre for Clinical Interventions, 2007).

The sleep hygiene instructions were discussed with the client and it was recommended to him to try to follow as many as he could. The client demonstrated an interest to follow a few of them (such as cut down his naps, avoid caffeine and read a book when unable to go back to sleep) to see its impact on his sleep. The client had lack of awareness about the impact of caffeine and naps on his night time sleep and also lacked knowledge about doing something when unable to go back to sleep.

Fun activities catalogue (which consists of 185 behavioural strategies for managing low mood) were also discussed with the client and it was suggested to choose two or three activities from the list in the coming week. As napping more, sitting around and doing nothing will cause the body to feel more lethargic, the mind to ruminate on negative thoughts, so this kind of activity can help him to lift his mood. A worksheet was given to him to plan ahead which activity he will do, when he will do it (date), and then rate his mood, pleasant feelings, and sense of achievement BEFORE and AFTER the activity.

In addition, a sleep diary (please see Appendix A) was also recommended for completion once a week to make an accurate assessment of how much he sleeps and other factors associated with his sleep. The aim of this exercise was to help him to identify patterns and areas for improving sleep hygiene. Also, many people who struggle with sleep difficulties make negative assumptions about their sleep and this worksheet can help the person to check if this is really the case.

A variety of homework was given to complete between the sessions, as homework is an essential and effective component of Brief CBT. Because of the condensed number of sessions in brief CBT, assignments such as readings, behaviour monitoring, and practicing new skills were given to the client to practice and use outside the sessions. Homework assignments facilitate the client’s skill acquisition, treatment compliance, and symptom reduction by integrating the concepts learned in sessions into daily life. Homework is also a key mechanism for facilitating between-session work and progress (Ebben & Spielman, 2009).

After developing the behaviour change plan, the client was also asked about the perception of any potential barriers and overcoming strategies to achieve the goal. It was very important to explore this question at this stage as sometimes there are aspects of the client's life that may facilitate or inhibit the goal. Exploring facilitators and barriers and discussing strategies can maximise the chance of goal attainment.

Ensure monitoring and support for behaviour change plan

I briefly reviewed the client’s mood and/or physical functioning and elicited responses concerning the client’s mood, and considered any discrepancies in each session. The client was also asked to provide some explanations for mood improvement or decline. This brief update allowed me to gauge how the client is progressing and identify positive and negative change. The trainee health psychologist also checked the homework and the client understands of what was discussed in the previous session. At the end of first session, the client reported that he cut down the amount of caffeine during the day and evening times. He was made aware of the potential effects of caffeine on sleep, which he was not aware of this previously, so he reported about drinking decaffeinate tea and felt slight improvements in his sleep duration. After the second session, the client stopped having a nap during the day-time by engaging himself into a physical activity (e.g. gardening). He also started going to bed on a regular time and started doing various day time pleasurable, realistic and achievable activities (e.g. went to the cinema with his family, helping his wife in home chores and reading books). Engaging in these activities not only gave his mind something else to think about or focus on, but also made him feel a sense of achievement and pleasure, as he was sleeping less during the day and feeling less lethargic and able to ruminate depressive thoughts. As a result, he started having more sleep at night time and feeling less tired during the day.

Reinforcing what the client has learnt in past sessions was essential to the improvement that the client has made outside the therapeutic relationship. Sometimes, some of the issues discussed as part of the monitoring phase became very important from the client’s perspective to add into the session’s agenda (e.g. reading a book if unable to get back to sleep). Furthermore, at the end of each session, a brief summary related to the session was provided and feedback was exchanged about the session and on the progress of therapy. At this stage, I also encouraged and motivated the client to continue working towards change.

Evaluate outcome

According to the set contract, a brief review was conducted when reached at the minimum number of sessions (i.e. three) to get client’s feedback to monitor and evaluate how he is finding it to working on the behaviour change plan. He illustrated his responses on a structured review form in terms of reporting that now he feels his ability to cope with life generally is 4 on a scale of 1 to 10. This score demonstrates improvements in his abilities at this stage in comparison to the initial stage when he gave himself a score of one (please see Figure 1). He also reported that CLP helped him to focus on thinking positively, relaxing and to develop some coping mechanisms. Overall he reported that this project has changed his behaviour and therefore stated he would like to continue with it.

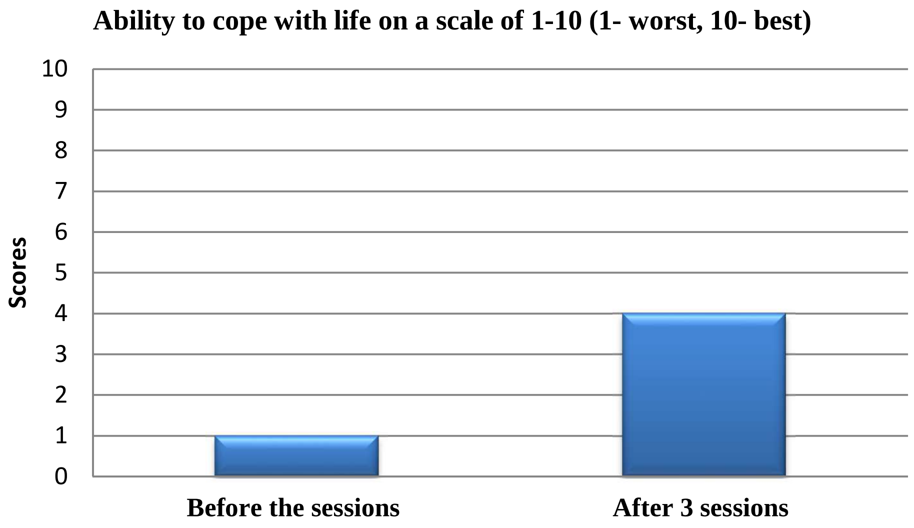


Figure 1: Client's self-reported scores before and after the sessions

Negotiate completion, follow-up or referral as appropriate

At the end of third session, the client had to move his house to another part of the United Kingdom; therefore, he was unable to carry on the remaining sessions. However, he mentioned through telephone conversation that he found many psychological and behavioural benefits from this therapeutic project, thus he would like to continue it at his new place after negotiating it with the GP. According to the requirements of this project, I sent a letter to his previous local GP to inform him about the client's progress and his involvement in the sessions. Now it was client's responsibility to register at his new local surgery and request to his GP for continuing this therapy again as part of the CLP.

Conclusion

Overall, the client demonstrated various cognitive and behavioural determinants/factors influencing sleep difficulties (e.g. distorted thinking pattern, not feeling like going out or feeling in a low mood, using of large amount of caffeine during day and before sleeping hours, having naps during day time and so on). After exploring the problem and assessing its potential determinants, some behaviour change goals were set by negotiating with the client using the CBT approach. The client's problem seemed to link mostly with behavioural problems, which he did not seem to be aware off previously. Thus, identifying and increasing awareness about those factors and providing reassurance and education seemed to work for him effectively, which was monitored in each session and evaluated in third session. The client started seeing benefits of this approach by understanding those determinants and trying to bring some behavioural changes into his lifestyle, which improved his coping mechanism, mood and physical health, sleep patterns and strengthened his relationship with his family. He also gained knowledge about some potential causal factors of sleep difficulties, which he lacked awareness of previously. In a limited time, he progressed quite well in terms of his overall improvements. However, it could be more useful for the client to learn various other cognitive and behavioural strategies to tackle this problem more effectively in the future. Due to a sudden change in his life ‘moving house to another part of the UK’, it was not feasible to continue any further sessions, which was negotiated collaboratively between both parties (the client and the well-being worker) and this work ended by wishing the client good wishes for his future.

References

Adamson, J. and Burdick, J. A. (1973). Sleep of dry alcoholics. *Archives of General Psychiatry*, *28,* 146-149.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.). Washington, DC: Author.

Ancoli-Israel, S. (2000). Insomnia in the elderly: A review for the primary care practitioners. *Sleep*, *23,* S23–S30.

Ancoli-Israel, S. and Roth, T. (1999).Characteristics of insomnia in the United States: Results of the 1991 National Sleep Foundation Survey: I. *Sleep*, 22, S34–353.

Ayas, N.T., White, D.P., Manson, J.E., Stampfer, M.J., Speizer, F.E., Malhotra, A. and Hu, F.B.l. (2003). A prospective study of sleep duration and coronary heart disease in women. *Archives of Internal Medicine*, *163*(2), 205-9.

Blackburn, I.M., James, I., Milne, D., Baker, C.A., Standart, S., Garland, A. and Reichelt, F.K. (2001). The revised cognitive therapy scale (CTS-R): psychometric properties. *Behavioural and Cognitive Psychotherapy*, *29*, 431–446.

Breslau, N., Roth, T., Rosenthal, L. and Andreski, P. (1996). Sleep disturbance and psychiatric disorders: A longitudinal epidemiologic study of young adults. *Biological Psychiatry*, *39,* 41–48.

Centre for Clinical Interventions. (2007). *Centre for Clinical Interventions*. Retrieved February 2013 from http://www.cci.health.wa.gov.au/

Connor, J., Norton, R., Ameratunga, S., Robinson, E., Civil, I. and Dunn, R. (2002). Driver sleepiness and risk of serious injury to car occupants: population based case control study. *British Medical Journal*, *324*(7346),1125.

Cully, J. A. and Teten, A. (2008). A Therapist's Guide to Brief Cognitive Behavioural Therapy. *Educational product developed through the South Central MIRECC*. Manual available: http://www.mirecc.va.gov/VISN16/clinicalEducationProducts.asp

Dalgleish, T. (2004). Cognitive approaches to posttraumatic stress disorder: The evolution of multi-representation theorizing. *Psychological Bulletin, 130*(2), 228–60.

Dement, W.C. (1992).The proper use of sleeping pills in the primary care setting. *Journal of Clinical Psychiatry,53S,* 50–56.

Ebben, M. R. and Spielman, A. J. (2009). Non-pharmacological treatments for insomnia. *Journal of Behavioural Medicine, 32*(3), 244-254.

Foley, D., Monjan, A., Brown, S., Simonsick, E., Wallace, R. and Blazer, D. (1995). Sleep complaints among elderly persons: an epidemiologic study of three communities. *Sleep, 18*(6), 425-432.

Freeman, A., Pretzer, J., Fleming, B. and Simon, K. (2004). *Clinical applications of cognitive therapy, Second edition*. New York: Springer Publishing Company

Grant, A., Townend, M., Mills, J. and Cockx, A. (2008). *Assessment and Case Formulation in Cognitive Behavioural Therapy.* Sage Publications Ltd, London

Hauri, P. (1991). Sleep hygiene, relaxation therapy, and cognitive interventions. In Hauri, P. (Ed.), *Critical issues in psychiatry: Case studies in insomnia* (pp. 65–84). New York: Plenum Medical Book.

Holbrook, A. M., Crowther, R., Lotter, A., Cheng, C. and King, D. (2000). Meta-analysis of benzodiazepine use in the treatment of insomnia. *Canadian Medical Association Journal, 162,* 225–233.

Karacan, I., Thornby, J.I. and Anch, M. (1976). Prevalence of sleep disturbance in a primarily urban Florida County. *Social Science and Medicine*, *10,* 239-44.

Kupfer, D.J. and Reynolds, C.F.(1997). Management of insomnia. *New England Journal of Medicine, 336,* 341–346.

Laiteerapong, N., Karter, A.J., Liu, J.Y., Moffet, H.H., Sudore, R. and Schillinger, D. et al. (2011). Correlates of quality-of-life in older adults with diabetes: The Diabetes & Aging Study. *Diabetes Care*, *34*(8), 1749-53.

Montgomery, P. and Dennis, J. (2003).Cognitive behavioural interventions for sleep problems in adults aged 60_. *Cochrane Database Systematic Review* (1), CD003161.

Morin, C.M., Culbert, J.P. and Schwartz, S.M. (1994). Non-pharmacological interventions for insomnia. *American Journal of Psychiatry, 151,* 1172–1180.

Morin, C.M., Blais, F. and Savard, J. (2002).Are changes in beliefs and attitudes about sleep related to sleep improvements in the treatment of insomnia? *Behaviour Research and Therapy, 40,* 741–752.

Murtagh, D.R., and Greenwood, K.M. (1995). Identifying effective psychological treatments for insomnia: A meta-analysis. *Journal of Consulting and Clinical Psychology, 63,* 79–89.

New Solutions for old Sleep Problems, 2003 *New Solutions for old Sleep Problems*. (2003, February). Retrieved April 10, 2008, from Health alternatives 2000.com: http://www.healthalternatives2000.com/sleeplessnesssolution. html

NHS Choices. (2013). *NHS Choices.* Retrieved February 2013 from http://www.nhs.uk/Conditions/Insomnia/Pages/Symptoms.aspx

Nowell, P.D., Mazumdar, S., Buysse, D.J., Dew, M. A., Reynolds, C.F. and Kupfer, D.J. (1997). Benzodiazepines and zolpidem for chronic insomnia: A meta-analysis of treatment efficacy. *Journal of the American Medical Association,278,* 2170–2177.

Petit, L., Azad, N., Byszewski, A., Sarazan, F. F. and Power, B. (2003). Non-pharmacological management of primary and secondary insomnia among older people: Review of assessment tools and treatments. *Age and Aging, 32,* 19–25.

Plantinga, L., Rao, M.N., and Schillinger, D. (2012). Prevalence of self-reported sleep problems among people with diabetes in the United States, 2005-2008. *Previous Chronic Disability, 9,* E76.

Sanders, D. and Wills, F. (2005). *Cognitive therapy*: *An introduction,* 2nd ed. London. Sage

Sateia, M., Doghramji, K. and Hauri, P. (2000). Evaluation of Chronic Insomnia. *An American Academy of Sleep Medicine, 23*(2), 243-308.

Skaer, T.L. and Sclar, D.A. (2010). Economic implications of sleep disorders. *Pharmaco Economics*, *6,* 28(11), 1015-23.

Skinner, B.F. (1974). *About Behaviorism*. New York: Knopf.

Smith, M.T., Perlis, M.L., Park, A., Smith, M.S., Pennington, J. and Giles, D.E. (2002). Comparative meta-analysis of pharmacotherapy and behaviour therapy for persistent insomnia. *American Journal of Psychiatry, 159,* 5–11.

Soldatos, C.R. and Whitehead, A.(1999).Tolerance and rebound with rapidly eliminated hypnotics: A meta-analysis of sleep laboratory studies. *International Clinical Psychopharmacology, 14*, 287–303.

Strine, T.W. and Chapman, D.P. (2005). Associations of frequent sleep insufficiency with health-related quality of life and health behaviours. *Sleep Medicine, 6*(1),23-7.

Verster, J.C., Pandi-Perumal, S.R. and Streiner, D. (2008). *Sleep and quality of life in clinical medicine*. Totowa (NJ): Humana Press.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders. Clinical descriptors and diagnostic guidelines.* Geneva, Switzerland: Author.

Wettstein, A.(1992). Falls as a side-effect of drugs [Sturz als Nebenwirkung von Medikamentan]. *Schweizerische Rundschau fur Medizin Praxis,81,* 1383–1387.

Walsh, J.K. (2004). Clinical and socioeconomic correlates of insomnia. *The Journal of Clinical Psychiatry*, *65*(S8), 13-19.

Wells, A. (1997). *Cognitive therapy of anxiety disorders: A practice manual and conceptual guide*. Chichester, UK: Wiley.

Young, T., Evans, L., Finn, L. & Palta, M. (1997). Estimation of the clinically diagnosed proportion of sleep apnea syndrome in middle-aged men and women. *Sleep*, 20(9), 705-6.

Section 4 - Generic Professional

‘Reflection on Professional Journey to Chartered Status’

4.1- Supplementary report summarising reflections on professional practice, development and training needs.

Supervision Plan

Generic professional: Supplementary report summarising reflections on professional practice, development and training needs

Units in this area of competence	**Area of work in which unit will be covered (asterisk any units to be covered outside of normal work)**	**Supporting evidence to be complied for this unit of competence**
1.1 Implement and maintain systems for legal, ethical and professional standards in applied psychology. **1.2 Contribute to the continuing development of self as a professional applied psychologist.** **1.3 Provide psychological advice and guidance to others.** **1.4 Provide feedback to clients.**	**Settings:** [redacted] [redacted], [redacted] [redacted]. **Clients/ Target Groups**: Diabetes patients, Health Care Professionals, clinic managers and mental health related clients. **Description of work:** Whilst working as a trainee health psychologist on all DPsych related competences, I have consistently followed the British Psychological Society (BPS) and Health Professional Council's (HPC) ethical and professional standards. During g my research and service evaluation/improvement related projects, I ensured that I stored the data securely, and when analysing the data and writing the report for the clinic and a paper for the peer review journal, ensured that participant confidentiality and anonymity were maintained. To ensure that I was adhering to professional standards, whilst leading on this workshop initiative, I sought advice from the R&D department of the hospital whether ethical approval was required. I have attended a series of City University Health Psychology Doctorate workshops, including teaching and training, supervising others, consultancy, professional skills – ethics, Cognitive Behavioural Therapy (CBT) skills for Health Psychology, research methods in Health Psychology, conducting systematic reviews, motivational interviewing and qualitative research methods (by Dr Carla Willig). Consultancy work was published in the 'journal of practical diabetes' and the first optional unit was published in the 'clinical psychology forum'. Abstract posters were presented at the annual conference of Royal college of diabetes and children's health and the health psychology symposium in Bedford university. Various others courses/training days were attended: mental health first aid training, Motivational interviewing, Brief solution focused therapy, smoking cessation training and pro-health, weight loss programme. By working with the multidisciplinary team of HCPs, psychological advice, feedback and guidance were provided to the HCPs in the design and development of one-stop workshop/intervention and various other service improvement projects.	

Target for completion: … April, 2015 … Workplace contact? Yes … If yes please give name: [redacted]

[redacted]

4.1.1- Introduction

I will describe and reflect upon my professional practice as a trainee health psychologist over a three year period by working as a trainee health psychologist and consultant on various projects for the Cambridge University Hospitals (CUHs). During my training, I also worked at the Medical Research Council Epidemiology Unit, Cambridge and Mind in Cambridgeshire (mental health organisation). I will also reflect upon how I have developed professionally as an applied health psychologist. This will include an account of how I have developed a range of skills in the areas of: teaching and training, writing proposals for the National Health Service (NHS)' Research & Development (R&D) department, Research Ethic Committee (REC), conducting behaviour change intervention and research and applying psychological principles to areas of my work. I will also demonstrate skills achieved through various training programmes, attending conferences, publications in peer review journals and in the Clinical Psychology Forum. In addition, how I have provided psychological advice and guidance to others, provided feedback to others and how I have implemented and maintained systems for legal, ethical and professional standards in applied psychology.

4.1.2- Background

Initially, I started working in the adult diabetes clinic on an honorary contract in October 2010 as a trainee health psychologist. My main role was to design interventions or some projects based on service evaluation/improvement purposes, conduct literature search, design material, and implement them using health psychology models. It was also included in my responsibilities to evaluate the outcomes and disseminate them among the professional audience. Working on a project as a consultant was also part of my journey in the NHS, as well as conducting some teaching and training days for the patients as well as for the HCPs. Later on I worked on a quantitative study and was given a job to work as a research assistant, when I established my qualitative and quantitative skills by working on various studies. During my DPsych journey, I also gained various opportunities to work at different organisations (e.g. Medical Research Council Cambridge, Mind , paediatric diabetes clinic).

4.1.3- Implement and maintain systems for legal, ethical and professional standards in applied psychology

Whilst working as a trainee health psychologist, I have consistently followed the British Psychological Society (BPS) and Health Care Professional Council's (HCPC) ethical and professional standards. For example, when carrying out my consultancy work for the diabetes clinic at the CUH related to patients' non-attendance I was contracted to carry out a quantitative piece of work, to assist the service in better understanding the reasons of non-attendance and strategies to improve current services. I ensured that I stored the data securely, and when analysing the data and writing the report for the clinic and a paper for the peer review journal, ensured that participant confidentiality and anonymity were maintained.

I was also successful in achieving the approval from the NHS Health research Authority, National Research Ethics Service (NRES) Committee, East of England - Cambridge East, NHS's R&D approval, Site Specific Assessment and the City university Ethic committee for my research in August 2012 respectively. In addition, over the past three years (2010-2013, 2015) I have maintained supervision logs documenting my practice.

4.1.4- Development and evaluation of a *'One-Stop Workshop'* for adolescents with Type 1 diabetes

I was responsible for leading the one-stop workshop in my first year of DPsych in diabetes clinic at the CUH. It was a service evaluation project based on involving two clinics' (paediatric and adult diabetes) multidisciplinary teams and young adolescent patients under one platform. A systematic review of Randomized Control Trials (RCT) of diabetes self-management training concluded that collaborative interventions were more successful than didactic ones. Therefore, a brief pilot and group based collaborative workshop/intervention was developed in a community centre first time after reviewing the literature and following the needs assessment. The selected target group was identified as potentially *'hard to reach'* with the older teenagers in the paediatric setting sometimes finding difficulty transitioning to the young adult's clinic setting within the adult department. The aim of this workshop was to evaluate its feasibility, increase participants' awareness of their healthcare needs [(e.g. medical, psychological and social) by enhancing confidence, knowledge and skills related to diabetes self-care], as well as engage them in collaborative discussions in a community and group based setting and to model problem solving through discussion. My role was to:

- Plan, design, organise, manage and evaluate the workshop (based on collaborative/ patient-centred model & increasing awareness about healthcare needs via improving knowledge and skills about diabetes management)
- Deliver a teaching & training session related to a health Psychology area and diabetes
- Assess patients’ needs and design interactive educational tools by considering patients’ age
- Advertise the workshop in the hospital and locally, if possible
- Design the parental consent form for under 18 year olds, timetable, venue details, feedback forms and structured evaluation form
- Negotiate / discuss the workshop content & mode of delivery with the multidisciplinary teams of both clinics (adult & paediatric diabetes)
- Provide estimated budget and design the workshop accordingly
- Co-ordinate the whole programme, make arrangements for the day in a community centre & negotiate responsibilities for the workshop day with the multidisciplinary team
- Correspondence with patients via e-mails, telephone and post
- Disseminate the outcomes among health care professionals in the clinics, at the regional or national level and via publication
- Provide advice and support to diabetes nurses regarding interactive teaching methodologies.
- Evaluation and communication of outcomes back to the clients at the end of the programme/workshop
- Register the programme as a service evaluation project at the hospital’s patient safety department.

A variety of tools were developed for this workshop. For example, a simple assessment form, information sheet, parental consent form, post workshop evaluation forms, small cards, quizzes (approved by the consultants) and feedback sheets. The first four tools were approved by the patient health and safety department before they were sent to patients’ homes by following the service evaluation guidelines. It also included the questionnaires and feedback sheets in a format which could be analysed easily and in a correct format. It was also my responsibility to send an invitation letter (on behalf of the lead diabetes team) with the workshop related information sheet to all the parents/carers/guardians. A further responsibility was to ensure that the data collected at the community centre from the patients was safely kept at the clinic's locked draw as well as on the password protected computer. I was also responsible for ensuring that all data collected was anonymised, collected on encrypted data sticks and stored securely, in accordance with the Data Protection Act (1998). This piece of work involved working closely with personnel from the diabetes specialist nurses, dieticians and consultants.

Upon introducing the plans and topics to cover on the workshop day to both of the diabetes teams individually, there was initial resistance in terms of who will cover from which clinic and which topic and what method to use to prepare that work. This was overcome by first acknowledging what patients suggested to cover on that day (during the assessment part) followed by discussing nursing related topics to one of the paediatric nurse (as she was aware of the activities of this workshop) and topics regarding food, physical activity were discussed with the adult diabetes dieticians and similarly HbA1c, biomedical topics with a diabetes consultant. To resolve the methodology issue, it was explained to the dietician and the nurse about using quite interacting (rather than just PowerPoint slides) and collaborative style by considering the age group of the participants. I also pointed out that all of the material designed for this project/intervention will be kept in the clinic as a resource to potentially use in the future workshop.

Some HCPs discussed their concerns about the attendance of the participants on that day as this age group less likely attend their clinic appointments. I resolved this issue by pointing out (what patients suggested about the venue in the assessment part) various potential strategies: conducting the workshop in a community centre rather the NHS setting and providing this age group's potentially favourite lunch (e.g. pizza from a particular place). This way they could gain knowledge about the carbohydrate counting in a pizza (and how much they need to inject insulin accordingly) by the dieticians, which could make the session interactive and collaborative as well. On the workshop day, only some patients could attend and most could not due to their exams (as they mentioned in their reply slips and some through e-mails).

To ensure that I was adhering to professional standards, whilst leading on this workshop initiative, I sought advice from the R&D department of the hospital whether ethical approval was required. As no standardised questionnaires or interview method was used in this workshop, this was not deemed to be necessary. However, I was suggested to seek advice from the audit department regarding this service evaluation project. Upon contacting, they advised me to seek their guidance after preparing the information sheet, invitation letter, parent consent form and all of the other material, as everything needs to verify before it is posted to patients' homes according to the hospital policies. Thus, their confirmation was gained regarding all of the written material. Despite this, I ensured that in conducting, analysing, evaluating and writing this workshop that legal, ethical and professional standards were adhered to at 24 times (please see Appendix A regarding my NHS line manager's comments related to following professional and ethical standards).

4.1.5- Contribute to the continuing development of self as a professional applied psychologist

Over the past three years I have continued to develop as an applied psychologist. I have attended a series of City University Health Psychology Doctorate workshops, including teaching and training, supervising others, consultancy, professional skills – ethics, Cognitive Behavioural Therapy (CBT) skills for Health Psychology, research methods in Health Psychology, conducting systematic reviews, motivational interviewing and qualitative research methods have enhanced my professional development. These sessions encouraged me to reflect upon my practice as a health psychologist which often led to a change in my practice as outlined in examples given later on within this competence.

Sharing experiences with my peers on the Doctorate programme has also helped me to develop professionally, both formally within workshops and on a more informal basis. I have also attended numerous conferences and training courses/workshops and events, which have enabled me to further enhance my knowledge and to develop a range of skills. For example, in the areas of writing various project proposals for the NHS Research Ethic Committee, the NHS Audit department, consultancy work and working on behaviour change interventions.

4.1.5.1- Working at the Medical Research Council (MRC) & Mind (non-NHS based practices)

In January 2012, I received an opportunity to work in the MRC at the Cambridge University Hospitals to evaluate a complex theory based behavioural intervention. I accepted this opportunity to improve my knowledge and practical skills, as it linked with the health psychology theories and it required writing a qualitative report and evaluating fidelity assessment designed for this intervention. It was also useful to develop more transferable skills in terms of writing qualitative papers and gaining knowledge about the complex behavioural theory based interventions, which help to change government policies regarding the babies' feeding guidelines. Working at the MRC improved my knowledge about the use of theory based behavioural interventions via conducting some literature research.

I found very useful to work in the MRC epidemiology unit on evaluating a theory based complex behaviour change intervention, which aimed to prevent obesity in children (called baby milk study). This experience not only improved my knowledge, but also skills to evaluate complex behaviour change interventions, understand theoretical importance and its link with behaviour change techniques, evaluate the delivery of intervention and fidelity criteria and provide implications.

While I was working in the MRC, I also explored an opportunity at the MIND Cambridge (February 2012) to work as a volunteer wellbeing worker, which required supporting people with mental illnesses using guided self help CBT principles. This opportunity not only provided various types of training (e.g. lone working policy training, quality and diversity, safe guarding vulnerable adults and mental health first aid) including some basic training to see clients at their homes under regular supervision (by a psychotherapist), but also provided some shadowing with a therapist at the clients' home as well. I found this experience very useful to develop more confidence to apply the CBT principles when see the clients at their homes. All the shadowing and meetings with the supervisor before seeing the clients independently was very useful as it became very effective when I started seeing the clients independently.

Once I started working on seeing the clients at their homes I was slightly nervous. However, I had more confidence due to having shadowing previously and various types of training. I was also provided regular supervision after seeing the clients, where I was suppose to feedback the whole process of meeting the clients and discuss any issues arose. After seeing clients related to various challenging situations, I choose one client to write up a case study (called *'Implement interventions to change health-related behaviour'*) as this case was related to Health Psychology area, which was called *'Behavioural Intervention for Sleep Insomnia'*.

The role of a well-being worker gave me some insight in terms of designing theory based behavioural interventions and helped me to develop confidence to see the clients independently. This experience was very useful not only to fulfil one of the DPsych competences, but also contributed towards my professional development as a trainee as well as for my future CBT course, which I intend to do after my DPsych.

4.1.5.2- Publications ad conferences

During my first year of DPsych working as a trainee health psychologist in the NHS on a consultancy project, my NHS supervisor brought to my attention to publish this work in a diabetes peer-review journal on its completion. I was slightly nervous initially by accepting this offer, as it was my first experience in DPsych to prepare a manuscript, but he kept demonstrating confidence on my work, which increased my confidence level and I accepted it. After completing the consultancy, a report was written to submit to the management as well as the audit department followed by writing an article according to the guidelines of the *'Journal of Practical Diabetes'*. Before submitting this article, some feedback was received from my work supervisor and it was accepted on 29 November 2011 and published on 09 February 2012 entitled 'E*xploring factors influencing nom-attendance at the diabetes clinic and service improvement strategies from patients' perspectives'*. This was my first publication to a peer-review journal as an academic article. It provided me with the experience of submitting to a peer review journal and managing all the professional formalities in terms of completing various publication related forms. This included writing covering letter and responding to the editors and reviewers' comments. Having the article accepted which in turn boasted my confidence and inspired me to submit my other academic work in the future. This article was also presented as poster presentation at the *'Health Psychology Symposium at Bedford University'*.

A further opportunity for a publication arose in May 2012 after completing an intervention entitled '*Development and evaluation of a One-Stop Workshop' for adolescents with type 1 diabetes.* During a meeting with a paediatric diabetes consultant, I was suggested to submit an abstract of this workshop to the '*Royal College of Paediatrics and Child Health'*s Annual Conference in Glasgow. I submitted the abstract to present as a poster presentation by following the guidelines of this conference and it was published in the 'Archives *of Disease in Childhood', volume 97, supplement (May 2012).* After this conference, I submitted my work *in 'Journal of Diabetes Care for Children and Young People',* but unfortunately this did not suit their publication criteria. Although it was not a pleasant experience, I found reviewers' comments very useful to improve my skills in the future interventions, e.g. all of aims should match the outcomes. This workshop was also presented at the *'East Anglian*

Paediatric Diabetes Network Group' (Cambridge, 2011). Now in 2015, I am presenting two pieces of my DPsych work at the Division of Health Psychology conference in London. The first one is the systematic review presenting as a poster under the following category: review/theoretical and practice applicable poster. The second piece of work is my research thesis presenting as a poster 'Work in Progress'.

From the initial stages of this workshop, I worked with a clinical psychologist, who suggested that I submit it in *'The Clinical Psychology Forum*', where there is more scope for this kind of preliminary work in comparison to a peer review medical journal due to a small number of participants. She acknowledged and appreciated all of my efforts for this workshop, provided some feedback and was very pleased with the format and writing style of this work. This decision was accepted by me and the whole team (who worked on this workshop). Agreeing on who would lead on this article went smoothly, as everyone acknowledged all of my efforts (from design to write up) and suggested that I be the lead author followed by those who were senior in terms of their expertise and provided support as a team on this workshop. Some feedback was received from a Clinical Psychologist and a diabetes consultant through some face-to face meetings and regular e-mails. Thus, it was submitted as suggested and accepted for the clinical Psychology Forum in December 2012, whereby I was sent a complimentary copy of the magazine where the article was published in February 2013. I feel that the experience and skills gained from writing this article have been invaluable and transferable.
I will continue to develop as an applied psychologist. I would like to attend those training and practical courses designed to enable participants to conduct or commission research to build insight into target audiences and learn how to use these to engage with hard to reach groups.

4.1.5.3- Continuous Professional Development courses/training days

During my DPsych, a variety of courses and training days were attended to improve my professional development and gain knowledge to put into practice. For example, good clinical practice (Cambridge, 2011) related to conducting research in the NHS, MRC Epidemiology Scientific research day (Cambridge 2012) related to 'Genetic & Lifestyle Determinants of Obesity', mental health first aid training (Cambridge, 2012), Motivational interviewing (London, 2011), Brief solution focused therapy (London, 2011), smoking cessation training – Level 1 (April 2013) and pro-health, Community Health Improvement Programme (CHIP) or a weight loss programme (February 2012).

4.1.5.4- Developing my skills as a consultant

In October 2010, when I started working in the NHS (diabetes clinic) as a trainee health psychologist, my main responsibilities were to design, develop and implement a consultancy project related to diabetes patients' non-attendance in the clinic. The aims of this consultancy work were to identify the ratio of non-attendance and ascertain reasons (or any contributing factors) for non-attendance and any service improvement strategies from a selected target group via a short telephone survey, which could be beneficial for the clinic services in the future to improve patients' non-attendance. So first of all, a draft plan was prepared in November 2010 and negotiated with the diabetes clinic to overcome this issue. The concept of this pathway was to raise the profile of self-care perception and non-attendance within the secondary care setting and to embed the process of monitoring the non-attendance of patients with diabetes into the NHS care system.

From a Health Psychology perspective, it was important to identify and understand any potential reasons which affect care seeking behaviour (e.g. clinic appointments). This perspective linked with one of the principles of Health Psychology, which was to improve patients' health by assessing their needs and implementing potential changes into services in terms of improving the health care system. It was an exciting opportunity to influence the development of the patients care pathway from a Health Psychology perspective. It involved using a Health Psychology theoretical framework *"self regulatory theory"* to explore/understand what kind of factors control or regulate this kind of behaviour. Various meetings were conducted with the clients to clarify the target group and it was agreed by both parties that the target group would be adult patients with diabetes, who have missed their one or more appointments in the last 12 months.

In addition, I informally proposed some ideas (e.g. conducting a telephone survey or inviting patients for interviews in the clinic) to the clients to tackle this issue using patient centred approach. For this project, I used the *'Process Model'* of consultancy. This model is characterised by being both collaborative and client-centred. By following my role as an internal helper, I worked in collaboration with my clients, in developing initiatives to explore factors influencing non-attendance at the diabetes clinic.

Prior to preparing a written proposal, I carried out an assessment of the request for consultancy on its feasibility. Based on the requirements set out by the clients, I put together a written proposal that demonstrated how my training would fully meet the requirements of working on this project. In addition, a written contract was also set up before starting this work with a proposed completion timeline. The work started by reviewing the hospital database, which demonstrated that the highest number of patients who missed their appointment had type 1 diabetes (n=176). According to the proposed plan, I conducted a brief telephone survey by considering the wording and length of questions, timing to call patients during office hours (9-5) and essentially discussing the description of introducing myself to patients on the phone. Overall, the consultancy was successfully implemented within the agreed time frame. All the data was analysed quantitatively as a feasible strategy to analyse such a large data. Some feedback was received from the clients related to this work.

The outcomes were disseminated to the contact clients as well as to the wider professional audience as requested in the contract. The evaluation of this consultancy demonstrated a behavioural change at the service level in terms of starting a RCT regarding what patients suggested to improve this situation. I also established, developed and maintained a very good working relationship with my client through face-to-face meetings and e-mails on a regular basis to discuss any potential issues and the progress of the consultancy. This project was very well acknowledged by the clinic management and the clients, who found it very useful for improvising the clinic services and disseminating the outcomes of this project in the Trust meetings to bring new changes into the clinic to improve clinic services from patients' perspectives.

This consultancy piece was a very exciting and a challenging piece of work, especially in terms of my first experience of undertaking this type of project. The consultancy was relatively straightforward and problem-free. The main challenge I faced at the initial stages, concerned finding 808 patients' type of illness (e.g. type diabetes, type 2 diabetes, Gestational, MODY, secondary) on the hospital's databases one by one, finding the highest Did Not Attend (DNA) patients' demographic and clinical characteristics and excluding those patients 1) who belonged to endocrinology, foot and transition clinics, as these clinics were considered separate than the other regular clinics and 2) those who belonged to the following categories: discharged, moved away or deceased. The selection of an exact largest DNA group of patients since last 12 months (October 2009-September 2010) was a lengthy process, which delayed the registration of this project in the hospital' patient safety department (audit department), followed by the commencement of the telephone survey.

I feel that despite my lack of experience in undertaking this type of consultancy that I dealt well with the challenge I faced, as there was no other way of tackling this issues at that time. However, one of other issues that arose concerned the inaccessibility of some of the selected patients on the telephone during office hours, which was resolver via working at the weekends. Although, I have not worked in this area before on regular basis, after conducting some literature searches and negotiation with the contact clients, I was quite confident to implement the agreed planning. I also feel that with more experience in this area, and having attended the City University Doctorate workshop on Consultancy, that I am now more able to conduct this type of work more appropriately and was very pleased that I did not underestimate the time it would take to carry out the consultancy for an outpatient clinic in the NHS.

4.1.5.5- Teaching and training

My experience in delivering teaching and training has largely been for the diabetes patients and health care professionals. In June 2011, I delivered a teaching and training session related to the impact of communication on health and relationships. This session was designed to provide an opportunity to young adult patients to enhance their communication skills, to maximise effective communication outcomes and to learn a new approach in facilitating health behaviour change at a community centre at Cambridge. From this experience I learnt that when training different audiences that the delivery style needs to be adapted to meet the needs of the participants.

In October 2012, I delivered a teaching & training information pack to enhance knowledge and increase understanding of the HCPs about some potential psychological and social aspects of diabetes management based on health psychology perspectives as part of the *‘RAndomised controlled trial of Peer Support In type 2 Diabetes (RAPSID)’*. The session was entitled *‘Knowledge Enhancement Workshop: Psychological & Social factors in Type 2 Diabetes Management from Health Psychology Perspective’* and focused upon a number of psychosocial factors involved in diabetes management (e.g. stress, depression, patient-practitioner communication, social support, perceived barriers and coping styles). It was designed to enhance HCPs’ knowledge and understanding, to maximise their skills to provide support to the peer support facilitators and to learn practical approaches to potentially apply in everyday consultation. My experience of delivering this session/workshop was positive and

I would like to deliver further training to HCPs in the future. My confidence has increased as I have worked more regularly within a consultancy and teaching and training role. Once I complete my Doctorate I aim to continue to gain more experience within this area.

4.1.6- Provide psychological advice, feedback and guidance to others

I have provided psychological guidance to the multi-disciplinary teams of HCPs in the design and development (as well as monitoring and overseeing) of a '*one stop wor*kshop' for adolescents with Type 1 diabetes in terms of incorporating psychological, social and behavioural elements (not only just medical) as well as Health Psychology models. In regards to the workshop, some guidance was provided relating to the overall design and development as well as setting, room organisation, delivery of the information, use of interactive material, incorporating interesting elements throughout the day, aims of the day/expectations and outcomes. It was very important to increase awareness about these aspects from patients' perspectives (as there was no one working full time from Psychology background in the diabetes clinic) and provide advice and guidance on various service improvement/evaluation initiatives based on what/how to explore/implement.

An information pack was designed for the HCPs related to psychological and social factors in Type 2 diabetes management from Health Psychology perspectives, which was delivered through a workshop. HCPs were provided some guidance in terms of utilising/applying various psychological techniques during their consultations related to communication, motivation, stress and coping and social support, which they found quite useful.

4.1.7- Lessons learnt

During my training as a DPsych trainee health psychologist, one of the key lessons learnt was in the area of exploring a research topic. At the beginning of my DPsych, my initial chosen area to conduct research thesis was related to Type 2 diabetes among south Asian population (questionnaire based research) and a proposal was prepared in August 2010 to present during the DPsych interview (before starting the DPsych). However, this idea had to be cancelled (in November 2010), as some of the questionnaires were valid for anyone population (e.g. Indian) but not others (e.g. Pakistani or Bangladeshi). I also could not be successful to find some validated questionnaires for all the target populations. I started writing another proposal (related to exploring beliefs and attitude related to type 2 diabetes management among south Asian population) in December 2010.

To find the participants for this research, I started contacting researchers or health care professionals at various places, e.g. Peterborough (HCPs at hospitals and surgeries), Luton (diabetes nurses), Leicester (established researchers), London (Newham hospital, Nurses), Cambridge (local surgeries), but received no positive reply regarding my request. However, it was useful to know that a student from City University (under Dr Renata Pires's supervision, in December 2011) has already completed his thesis related to my area of interest and methodology. So due to having resemblance of my work related to another student's completed work, I had to cancel this plan as well (December 2011).

At that time, I was shadowing the Gestational Diabetes Mellitus (GDM) related clinics to gain more understanding before designing a short workshop for the GDM ladies, as I was requested from the HCPs. However, I had to stop this plan later on after discussing with the lead dietician and a consultant due to some barriers (e.g. lack of staff's time to run the workshop on continuous basis and I was not qualified to tackle the medical side of GDM as well as some potential funding issues).
Although, I could not carry on designing the workshops for the GDM ladies, I explored affects of social support during pregnancy by sitting in those clinics. Thus, I conducted some literature search related to that area and found that current research suggest to work on this area, as no previous research was found exploring meanings related to social support during pregnancy from GDM women's perspectives. Therefore, I started writing another proposal (January 2012) related to that area and submitted to my supervisor in February 2012.

My teaching and training skills have developed over the past three years. I believe that my skills in this area have improved greatly following attendance at a Teaching and Training workshop through the Doctorate programme. I learnt that detailed planning is required, in the form of a lesson plan, when delivering training in addition to the need to set clear aims, objectives and learning outcomes for each component of it, a practice that I have now fully adopted. Prior to attending the workshop when delivering teaching/training I found that my failure to plan in detail often led to me running out of time, which resulted in me having to rush through the delivery of some components of the session. However, having changed my practice, I no longer experience this.

4.1.8- General

Over the past three years I have put much effort into promoting health psychology within my Department and amongst a range of health professionals, in highlighting the contribution health psychology can make to health practice and health-related research. This has led to an increased interest in psychology and behaviour change techniques within my work place (diabetes clinic) and the MRC department.

Further skills, that I believe, I have enhanced most in is my ability to impart my knowledge in the area of health psychology to others. For example, in stressing the importance of assessing health related needs and designing projects according to a theoretical framework. In addition, working as a consultant and researcher, designing service improvement/evaluation projects and managing all of their aspects (from the initial idea to the implementation, communication, evaluation, monitoring, analysing, presenting and disseminating) my confidence has improved when writing peer review articles and in public speaking.

4.1.9- Conclusion

Having consolidated my learning over the past three years, I feel more self confident in my ability to work unsupervised as a health psychologist once my training period ends. I also feel that I am more reflective in my practice which has resulted in me adapting the way that I work based on this process, which has resulted in me developing into a more skilled and effective applied psychologist. As my confidence has grown, I feel that I am now more proactive. For example, seeking opportunities to apply psychology to relevant areas of health within the NHS and also in opportunities to work within a consultant capacity in areas where I am competent.

My journey as a trainee health psychologist have made me think about how Health Psychology can be applied when undertaking my role as a researcher, project developer/manager/consultant, or a well-being worker. I feel that I have been fairly successful in raising the profile of Health Psychology across the NHS, which has been reflected through publishing and presenting a variety of work to a highly professional audience as well as developing a resource pack for the clinic (as part of the intervention/workshop). I was also instrumental in highlighting and putting forward the rationale for the need to train health professionals in the area of communication skills in order for the care pathway to be implemented successfully.

Achieving skills and improving confidence was a very valuable, exciting and effective experience for me through:

- Presenting work at the conferences
- Designing a variety of posters
- Submitting abstracts at the conferences
- Following deadlines
- Corresponding with the editors and provide responses to reviewers' comments regarding publications in peer review journals
- Designing professional PowerPoint presentations to present work in the NHS and at the national regional meeting
- Writing proposals for the NHS R&D and the NHS Ethic Committee, attend the R&D meetings to justify my proposals.

I have gained experience in working within multi-disciplinary teams, including diabetes specialist nurses, dieticians, diabetes consultants, receptionists, managers and mental health workers, which is important when workings as an applied psychologist. My experience of working as a trainee health psychologist over the past three years has been both challenging and rewarding and I look forward to working as a health psychologist within a Chartered capacity in the near future.

Appendix A

NHS line manager’s e-mail

Name and the e-mail address has been annonymised

Dear Kalsoom,

I can confirm that you worked here during your training for DPsych and during this time you showed yourself to be very professional and dedicated to the work that you were doing. You were very thorough and appreciated the many demands on the staff, and always found a way to work with them in a manner that reduced the burden on them wherever possible. You went out of your way to also ensure that the patients that you were seeing were made to feel as comfortable as possible, and you fitted in with their schedule. You showed yourself to be collaborative with the consultant and wider team whilst designing your projects and audit forms. You were diligent in your literature reviews and ensuring that you adhered to the Trust’s confidentiality protocol’s. The combined effort of this meant that you were able to have a paper signed off and put forward for submission for publication.

We wish you the very best in the future.

Service Manager
Tel: