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Health Psychology
in Renal Care

Submitted in fulfilment of the requirements of
the degree of

Professional Doctorate in Health Psychology

By

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DECLARATION

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ABBREVIATIONS

Abbreviation	**Meaning of the abbreviation**
ACT	Acceptance and Commitment Therapy
AD	Advance Directives
BPS	British Psychological Society
CBT	Cognitive Behaviour Therapy
CKD	Chronic Kidney Disease
CPD	Continuing Professional Development
ESRD	End Stage Renal Disease
HCPC	Health & Care Professions Council (previously HPC)
HPC	Health Professions Council (changed to HCPC in 2012)
IPA	Interpretative Phenomenological Analysis
MeSH	Medical Subject Heading
NHS	National Health Service
NICE	National Institute of Clinical Excellence
PD	Peritoneal Dialysis
QoL	Quality of Life
RPSG	Renal Psychological Services Group
RRT	Renal Replacement Therapy
UK	United Kingdom

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SECTION A: PREFACE

Health Psychology in Renal Care

1. Health Psychology in Renal Care

This portfolio demonstrates the experiences, skills, knowledge and expertise that developed throughout the course of completing the doctorate in health psychology. The majority of the key competencies were completed while working as a Senior Assistant Psychologist for a London-based National Health Service (NHS) Renal department. This is reflected in the theme of chronic physical health that runs concurrently throughout the competencies, with a specialism in the area of renal disease. In addition to working as a Senior Assistant Psychologist, the author's training as a health psychologist also involved working as a research assistant, an honorary assistant research psychologist and undertaking various opportunities as a health psychologist trainee.

1.1. Overview of Portfolio Competencies

This portfolio consists of the research thesis, two publishable papers, competencies that relates to evidence professional practice and a systematic literature review. The competencies demonstrate the broad range of responsibilities, skills and the different professional roles (i.e. researcher, consultant, lecturer, presenter, clinician, healthcare professional) that have been adopted within the remit of the role of a Health Psychologist in training. The following section will briefly introduce each of these competencies.

SECTION B: Research Thesis

The subject of the research study focused on the exploration of people's experiences of being a parent receiving hospital-based haemodialysis for treatment of end stage renal disease. Knowledge in the field of renal care developed throughout the researcher's doctorate in Health Psychology training while employed in a renal department at one of London's leading hospitals. By working closely with renal patients, in particular those receiving or soon to start hospital-based haemodialysis, it was evidently clear how complex and demanding the different renal replacement therapies can be for patients. Previous studies that have investigated the impact of chronic illnesses on parents have found that such illnesses can have an adverse effect on the parental role and people's experiences of being parents (Altschuler & Dale, 1999; Barlow, Cullen, Foster, Harrison & Wade, 1999; van Mens-Vershulst, Radtke & Spence, 2004). To date, however, there has been very limited empirical research on the experiences of parents with end stage renal disease receiving hospital-based haemodialysis.

Ten participants, six mothers and four fathers, who met the inclusion criteria were recruited for this qualitative research study. The inclusion criteria included (i) patients currently receiving hospital-based haemodialysis treatment and (ii) be the parent of at least one child that was under the age of 16 years. Data was collected through semi-structured interviews that were audio recorded and transcribed verbatim. The data was analysed using Interpretative Phenomenological Analysis (IPA) to explore people's experiences of being a parent receiving hospital-based haemodialysis. Two major themes emerged from the data: (1) the haemodialysis experience and (2) the lived experience of parents with end stage renal disease. The model of findings formed a Venn diagram with the intersection of the two major themes capturing the specific aspects of the researched phenomenon.

In addition to the model, three key findings also presented themselves through the research. These were: (i) the impact of haemodialysis time demands on parenting, (ii) the impact of haemodialysis side-effects on parenting, and (iii) parenting and haemodialysis is more challenging when parenting younger children. It is hoped that through its findings this research study can offer a valuable contribution to the field of health psychology to other healthcare professionals and also inform and inspire future research into this vastly under-researched phenomenon. The findings inform Health Psychologists on the impact that intensive and frequent treatment regimes, such as haemodialysis, can have on the fine balance between patient and parental roles. The insights from this study also have the potential to provide a valuable understanding that could assist in the development of programmes for haemodialysis patients to support them through the complex challenges in their treatment journey. Health Psychologists and researchers are well placed to aid in the development and evaluation of the effectiveness of patient support programmes and other interventions that could greatly lessen the adverse psychological and social effects of intensive treatment regimes.

SECTION C: Publishable Papers

In accordance with the requirements of City University's Doctorate in Health Psychology programme, two publishable papers totalling more than 10,000 words were produced with the intention of submitting them for publication in peer reviewed journals. The first article, written in compliance with the requirements of the Journal of Renal Care was based on a systematic literature review into the effectiveness of peer support interventions in renal care. The Journal of Renal Care was chosen as an appropriate publication for the revised, shortened version of this portfolio's systematic literature review. The primary reason for choosing this journal is that it is predominately targeted towards professionals working within renal multidisciplinary teams and therefore enhances the review's potential contribution to improving patient care and clinical practice.

The second article, a qualitative study exploring the experiences of renal patients, was written in the structure and style required for publication in the Journal of Health Psychology. The journal was identified as being ideally placed in disseminating the research findings within the field of health psychology and informs professionals of the psychological implications that living with a chronic health condition can have on individuals. The study, entitled *parents' journey with end stage renal disease: an interpretative phenomenological analysis,* used data that was collected as part of the main research thesis, however the major theme, along with the subordinate themes, presented in this publication emerged independent to the findings of the main research thesis. The article presented the major theme and discussed the clinical and research implications of the study.

SECTION D: Professional Practice

Generic

The Generic Professional competency reflects the training journey towards becoming a Health Psychologist. It demonstrates the adherence to the British Psychological Society's (BPS) Code of Conduct from 2009 through to 2018 (2009; 2018 respectively). It also shows how the Health Professions Council's (HPC) Standards of Conduct, Performance and Ethics (2008) and the updated Health & Care Professions Council's (HCPC) Standards of Conduct, Performance and Ethics (2016) were followed in establishing a legal, ethical and conscientious approach to research and psychological practice throughout training that has laid the foundation to a developing career. It outlines the breadth of experience gained from working for the NHS, providing consultancy work and conducting studies as a researcher.

One's growth as a Health Psychologist in training has been enhanced by investing in challenging and appropriate continuing professional development (CPD) training workshops and programmes. Being a member and regular contributor to the Renal Psychological Services Group, which is a CPD and professional support group of renal allied healthcare professionals, provided one such opportunity and the chance to share and learn from the experiences of best practice from other professionals. Opportunities arose throughout training to provide psychological advice and guidance to other professionals and clients, such as providing consultancy, facilitating training and workshops, and working clinically with patients.

Consultancy

A consultation in the form of a needs assessment was provided to a NHS Renal Department's Peritoneal Dialysis (PD) service. The consultation opportunity arose through a discussion with the department's Lead PD Clinician and was conducted independently and separate from the consultant's existing employment within the Renal department. Adopting an expert model approach (Schein, 1999), the aims and objectives of the consultancy were agreed with the client, the Lead PD Clinician. The agreed overall aim for the needs assessment consultancy was to identify *'best quality'* care in PD, with particular focus on the support and training that PD patients receive. The needs assessment was structured into four parts: (i) using process mapping to gain a better understanding of renal patients' care within the department; (ii) conducting a thorough literature review of relevant research findings, guidelines and recommendations of PD training; (iii) benchmarking the client's PD service with similar services within and outside the NHS Trust, and (iv) the production of the final Needs Assessment Report that detailed the consultation's findings and recommendations. Upon receipt of the Needs Assessment Report the client advised that the findings and recommendations would be taken into consideration and form part of a planned review of the service.

Behaviour Change Intervention

As part of the treatment for end stage renal disease, patients undergoing renal replacement therapies are generally required to adhere to a prescribed medication regime, especially as medication helps to support the body in regulating hormones and breakdown chemicals that the body is unable to do efficiently due to the loss in kidney function (Tonelli, Pannu & Manns, 2010). Despite this, it has been suggested that nonadherence to prescribed medication occurs in between 15.4% to 50.2% of haemodialysis patients, which increases the risk of hospitalisation and mortality (Matteson & Russell, 2010).

This behaviour change competency describes a case study of a 25-year old male that had been diagnosed with end stage renal disease three years previous and had been receiving haemodialysis since diagnosis. The patient was seen within the Renal Psychology

Department for a total of 23 face-to-face sessions to address the patient’s non-adherence to medication, which was a requirement for him to be considered for the kidney transplant list. Working collaboratively with the patient, the treatment adopted a behaviour change plan that was based on the principles of motivational interviewing and cognitive-behavioural therapy. Through the course of therapy the patient was able to improve his medication adherence sufficiently to be referred to the Renal Transplant Assessment Team.

Teaching and Training

The teaching and training competency was met by two case studies. The first case study documents the development and delivery of a three-hour lecture on *Health Promotion in Renal Care* to MSc Health Psychology students as part of a module on Health Promotion. The lecture was developed in accordance to the training needs of the students and focused on meeting the objectives of the module by applying Kolb’s (1984) experiential learning cycle model. The content covered three main areas: (i) the role of health psychology in renal care, (ii) the physical and psychological aspects of living with end stage renal disease, and (iii) the theories on behaviour change, health promotion and interventions. The lecture was delivered with use of a PowerPoint presentation and a vignette that encouraged the students to participate in developing an appropriate intervention for the presented scenario. The feedback from both the students and the Module Lead was broadly positive, in particular with regards to the interactive structure and delivery of the lecture.

The second case study, meeting the training segment of the competency, details the design and provision of a whole-day workshop to healthcare professionals working in an NHS Renal Department. The one-day workshop, entitled *Improving Patients Experiences: Communication and the Patient-Partnership Model*, was delivered on five separate occasions with the intention of enabling a wider dissemination of the workshop. The workshop focused on exploring the impact of renal failure on people’s quality of life, the importance of communication in the nurse-patient relationship, and an exploration of nurse-patient communication with the use of vignettes. Once again, the feedback from the attendees was overwhelmingly positive and highlighted how the informative and interactive delivery of the workshop enhanced the attendees learning

Optional

The main research thesis provided the material in which the author was able to provide expert advice and opinion to fellow Health Psychologists and other healthcare professionals. The findings from the research, investigating people's experiences of being a parent receiving haemodialysis, were disseminated through presentations on four separate occasions and across two different settings (professional conferences and CPD sessions). The first was a one-hour oral presentation at a CPD session for the Renal Psychological Services Group, which is a group of renal allied healthcare professionals working in renal care (including psychologists, counsellors, psychotherapists and assistant psychologists). The group members meet three times a year for CPD and the sharing of expertise and experiences from clinical practice. A further CPD presentation was to senior nursing staff working in the field of renal care. Both CPD presentations involved the development and delivery of PowerPoint slides that succinctly summarised the basis of the research (i.e. existing literature and methodology), the model of findings along with the key findings from the research and its implications for clinical practice and research.

The research was also presented at two conferences. It was firstly presented by means of a moderated poster presentation at the UK Kidney-Week conference and subsequently with an oral presentation at the Annual Health Psychology Conference. Similar to the CPD presentations, the conference oral presentation used PowerPoint slides to assist in communicating the main points of the study to the audience. The moderated poster presentation provided the presenter with an opportunity to graphically display the research findings in an easy to follow and engaging arrangement. The four presentations provided the opportunity to disseminate the research to a broad yet relevant audience of healthcare professionals. In addition, it also enabled the presenter to develop and grow important presenting skills during their transition towards becoming a Health Psychologist.

SECTION E: Systematic Literature Review

The final competency of this portfolio is a systematic literature review that examined the effectiveness of peer support interventions within renal care. Peer support has become a useful aspect of patient care in the management of challenging and chronic health conditions (Doull, O'Connor, Welch, Tugwell & Wells, 2008), which is likely to become an increasingly important intervention due to a growing population of people with chronic illnesses (Embuldeniya, Veinot, Bell, Bell, Nyhof-Young, Sale & Britten, 2013). Despite the growing provision of peer support in the field of renal care (Wood, 2015), there had been no recent systematic review of literature that has evaluated the effectiveness of the intervention the use of pre and post evaluation data. Given this, the aim of this systematic review was to assess the effectiveness of peer support interventions in renal care. In total, four studies were identified as meeting the inclusion criteria. The review found that peer support interventions were effective in supporting renal disease patients in developing self-transcendence (Milani, Amiri, Vejdani, Salehiniya & Malek-khahi, 2017), self-efficacy and various psychosocial elements of quality of life (St. Clair Russell, Thomson, Southerland, Meyer, Huff & Lynch, 2017; Sattoe, Jedeloo & Van Staa, 2013). It also found that peer support within palliative care for renal patients increased engagement with advance directives as patients' entered end of life care (Perry, Swartz, Brown, Smith, Kelly & Schwartz, 2005). The limitations of the review and its implications for future practice are also discussed.

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SECTION B: RESEARCH

The Experience of Being a Parent Receiving Hospital-Based Haemodialysis Treatment: A Qualitative Study

Abstract

Background: The prevalence rate for Chronic Kidney Disease in England has increased in recent years, with an estimated 6.1% of adults affected by the condition. From those people requiring Renal Replacement Therapy; 41% receive life-sustaining haemodialysis treatment. Studies have found that haemodialysis treatment has a marked impact on people's physical and psychological well-being, including the negative effects it can have on people's quality of life, and intimate and social relationships. To date, the investigation of people's experiences of being a parent that receives haemodialysis treatment has been an area that has received little attention.

Research design and aim: A qualitative research study was employed to gain an in depth understanding of the lived experiences of parents that receive haemodialysis treatment.

Methods: Ten parents who received hospital-based haemodialysis treatment were recruited through a National Health Service Trust. From the ten parents, six were mothers and four were fathers with a median age of 41.9 years. Data was collected through semi-structured interviews that were audio-recorded and transcribed verbatim. Transcripts were then analysed using Interpretative Phenomenological Analysis.

Findings: Two themes emerged from the data. The first theme, '*the haemodialysis experience*' explores the experience of living with the demands, necessity and the process of haemodialysis treatment. It describes people's lived experience of being on the haemodialysis ward, the professional care they received, and the effects from the physical side-effects of the treatment. The second theme, '*the lived experience of parents with end stage renal disease*', captures the different facets of being a parent. It explores the parents' perception of their children's experience of having a parent with end stage renal disease, people's thoughts of their own mortality and the impact chronic illness has on family life.

Discussion: The study emphasises the complex and multifaceted challenges faced by parents receiving haemodialysis treatment. The significance of these findings contributes to the field of Health Psychology by providing a valuable insight of the main difficulties this client group experience, including how the challenges of parenthood and chronic illnesses are managed. The findings provide a resource that can inform clinical practice for Health Psychologists and other Healthcare Professionals.

1. Introduction

1.1 Chronic Kidney Disease and End Stage Renal Disease

Chronic Kidney Disease (CKD) is defined as *"a gradual loss of kidney function over time. The kidneys become less effective at filtering waste products from blood; water, waste and toxic substances therefore accumulate in the body"* (National Health Service Kidney Care, 2012, p.5). CKD is sub-divided into five stages reflecting the severity of the kidneys' functioning and the extent of evident kidney damage. Stages one and two are classed as indicating normal to a slight decrease in blood filtration in the kidneys with some indication of kidney damage. Stages three and four are described as moderate to a severe decrease in blood filtration, with or without further evidence of kidney damage. Stage five also shows severe decrease in blood filtration in the kidneys and indicates established renal disease, also known as End Stage Renal Disease (ESRD) (National Health Service Kidney Care, 2012).

A report published by Public Health England (2014) stated that the estimated prevalence rate for adults over the age of 16 years with CKD, in stages three to five of this disease, is over 2.6 million in England alone. This is an estimated 6.1% of adults in England. The report estimated that the number of adults in England with CKD is expected to increase to 3.2 million by the year 2021. It also stated that CKD is more common in females than males, with there being a negative correlation between aging and kidney function. It has been suggested that the rising prevalence of people with CKD has been due to an aging population, the increase of other chronic illnesses, such as diabetes and hypertension, and lifestyle choices leading to obesity that are all associated risk factors for the development of CKD (National Health Service Kidney Care, 2012).

The National Institute for Health and Care Excellence (NICE) published guidelines for CKD (NICE, 2014) and recommend that suitable changes to an individual's lifestyle, such as regular physical exercise, obtaining and maintain a healthy body weight, cessation of tobacco smoking and effective management of blood pressure and diabetes can delay further kidney function decline. Once kidney function has deteriorated to stage five of CKD, indicating ESRD, changes to lifestyle and diet, as well as management of pharmaceutical medication should be continued (Warwick, Mooney, Russon & Hardy, 2014). At this stage, the onset of ESRD, patients are likely to be provided with the opportunity to discuss appropriate Renal Replacement Therapy (RRT) options. Clinical

Guidelines, published by the United Kingdom (UK) Renal Association, recommended involving clinicians, the patient and the patient's family members in determining the most appropriate RRT treatment available to the patient. This determination should also take into account considerations that include the patient's general physical and psychosocial well-being and the impact the different RRTs could have on the person's well-being and current lifestyle (Warwick, et al., 2014).

The currently available RRT choices for adults with ESRD include kidney transplantation and dialysis. Kidney transplantation involves replacing the diseased kidney with a functioning kidney from a recently deceased or living donor (NICE, 2015). Dialysis involves two types of treatment: peritoneal dialysis (PD), which is usually self-administered away from the hospital, and haemodialysis, which can either be hospital or home based. As of 2015, out of the 41% of people receiving haemodialysis treatment in the UK only 2% received haemodialysis treatment at home (MacNeil & Ford, 2017). The NICE guidelines for PD (NICE, 2011) and haemodialysis (NICE, 2002) both state that dialysis involves the removal of excess fluid, waste products and toxins from the body, which would usually be performed by well-functioning kidneys. There a number of differences between the two dialysis types, including the means used to access the body and the method in which waste products are removed. Prior to starting dialysis treatment patients are required to have dialysis access points created, for PD a PD catheter is implanted into the abdomen. Whereas, for haemodialysis treatment usually an arteriovenous fistula is fitted, most commonly in the forearm (NICE, 2015). The method of PD involves introducing dialysate, a cleansing fluid, through the catheter into the peritoneum. The fluid absorbs toxins, waste products and excess fluid from the membrane's blood supply by means of osmosis and diffusion, with the fluid subsequently drained out of the body (Dring & Hipkiss, 2015). Haemodialysis treatment involves the person being connected to a dialysis machine, usually via the created arteriovenous fistula. The haemodialysis machine, which contains a semi-permeable membrane, pumps the person's blood across the machine's membrane into dialysis fluid. This process retains the collected waste products, while pumping the cleaned blood back into the person's body (NICE, 2002).

The UK Renal Registry Annual Report (MacNeil & Ford, 2017) highlighted that in 2015 53% of patients receiving RRT were transplant recipients, with 41% receiving haemodialysis treatment and only 6% receiving PD. Of those adults receiving dialysis treatment, kidney transplantation was the preferred RRT choice for approximately 40% of patients (NICE, 2011). A metanalysis on RRT and Quality of Life (QoL), conducted by Landreneau, Lee and Landreneau, (2010), found that from the different RRTs kidney transplantation was reported to result in an overall better QoL compared with that of PD and haemodialysis. Despite this, approximately a third of patients are considered unsuitable for organ transplant (NICE, 2002). Furthermore, the All Party Parliamentary Kidney Group hosted a manifesto to increase transplantation in 2017. The report produced by the National Kidney Federation of that manifesto stated that between 2013 to 2017 the number of living donors in the UK have decreased year on year, a drop of nearly 9% in the four-year period (National Kidney Federation, 2017). With ESRD being a lifelong chronic disease RRT patients are likely to require one or more changes in treatment modalities throughout the course of their lifetime based on clinical and personal circumstances (NICE, 2011). For similar reasons some people choose to either never start or cease dialysis treatment in favour of conservative care for symptom management with medication and palliative care (Noble, 2008).

1.2 Haemodialysis Treatment for End Stage Renal Disease

RRT, including haemodialysis, are life-sustaining procedures for people with ESRD. Dialysis treatment however replaces only an approximate 10% of normal renal function (Loghman-Adham, 2003). Due to the only partial replacement of kidney function provided by dialysis the rate of morbidity and mortality for people with ESRD remains high, with people commonly experiencing many other health problems, including salt, water and phosphate retention (Loghman-Adham, 2003), cardiovascular disease (Levey & Eknovan, 1999), hypertension (Malliara, 2007) and diabetes (Lok, Oliver, Rothwell & Hux, 2004). The survival rates for dialysis patients receiving either PD or haemodialysis in the first year of starting treatment was 88.3% in 2014 (Methven, Steenkamp & Fraser, 2017), with one of the main causes of death for people receiving dialysis being cardiovascular disease (Locatelli, Marcelli, Conte, D'Amico, Del Vecchio, et al., 2001). The United Kingdom Renal Registry 19th Annual Report (Methven, et al., 2017) recorded cardiovascular disease as accounting for 23% of deaths, with infection and treatment withdrawal each accounting for 21% of deaths for dialysis patients.

To address the medical problems common to people receiving haemodialysis, treatment usually requires patients to adhere to a regime that includes four aspects: medication adherence, fluid restrictions, dietary restrictions and treatment attendance (Wolcott, Maida, Diamond & Nissenson, 1986). Dialysis patients are likely to be prescribed various medications as part of their pharmacotherapy, these include blood pressure tablets, diuretics, blood-thinning medication, phosphate binders, cinacalcet, erythropoietin stimulating agents, and vitamin D and iron supplements (Day, 2017). Loghman-Adham (2003) highlighted that difficulties that some patients might experience in adhering to medication intake could be related to the required frequency and high quantity of medications, particularly phosphate binders that also have an unpleasant taste and need to be taken with food. Needing to follow a medication regime that is complex and lifelong might also lead to non-adherence (Carter & Erlich, 2007).

A further aspect of the haemodialysis regime is fluid restrictions. The set limit of fluid intake could vary from person to person as it depends on the amount of fluid the individual is able to pass in their urine. For some people receiving haemodialysis their fluid intake limit could be set to a total of 500ml daily (Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, et al., 2007). Another element of the haemodialysis regime involves following a strict diet that restricts the intake of sodium, fluid, potassium, and phosphorus (Durose, Holdsworth, Watson, & Przygrodzka, 2004). Dietary restrictions in relation to food types high in water content (i.e. soups) and the intake of sodium, which can cause thirst, are important considerations in managing fluid restrictions (Cristóvão, 2015). Durose, et al., (2004) found that more than 33% of people receiving haemodialysis treatment did not adhere to at least one of the four dietary restrictions, with potassium being the most adhered restriction and phosphorus the least.

Non-adherence to treatment attendance, the final aspect of the haemodialysis regime, can be classified as missed treatment and shortened treatment time (Denhaerynck, et al., 2007). In the UK the vast majority of haemodialysis patients receive hospital-based treatment three times per week, with dialysis sessions lasting between four to five hours (MacNeil & Ford, 2017). Adherence to the four aspects of the haemodialysis regime is crucial in improving treatment outcomes and reducing the side-effects of haemodialysis treatment, particularly as nonadherence to the regime has been found to increase morbidity and mortality rates (Denhaerynck, et al., 2007).

1.2.1 Side-Effects of Haemodialysis

As well as comorbidity with other chronic diseases and illnesses, people on haemodialysis are also likely to endure a range of side-effects including fatigue (Jhamb, Weisbord, Steel

& Unruh, 2008), low blood pressure (Luther & Golper, 2008), sepsis (Johnston, Zalunardo, Rose & Gill, 2007), muscle cramps (Panchiri, Joshi & Dumbre, 2017), skin itchiness (Prabahar, Anusha, Periasamy, Boddu, Ramanathan, et al., 2017), bone and joint pain (Weisbord, 2016), sexual dysfunction (Palmer, 1999), sleep difficulties (Gul, Aoun & Trayner, 2006) and mental health deterioration (King-Wing & Kam-Tao, 2016; De Sousa, 2008).

Jhamb and colleagues (2008) in a review of the definitions, measures and contributing factors of fatigue in dialysis patients reported that one of the most common side-effects experienced by dialysis patients is fatigue. Murtagh, Addington-Hall and Higginson (2007) found in a systematic review of literature exploring the symptoms experienced by dialysis patients that fatigue had a mean prevalence of 71%, with the prevalence of some other symptoms being: pain 47%, sleep disturbance 44%, anxiety 38%, nausea 33%, restless legs 30% and depression 27%. Studies have shown that fatigue in dialysis patients is a complex yet all too common debilitating phenomenon that contributes to an impaired quality of life for the individual (see Jhamb et al., 2008; Bossola, Vulpio & Tazza, 2011; Anees, Hameed, Mumtaz, Ibrahim & Khan, 2011). Jhamb and colleagues (2008) indicated four contributing factors to ESRD related fatigue: physiological, psychological and behavioural, sociodemographic, and dialysis-related factors. Physiologic etiologies include a host of possible haemodialysis side-effects, such as uraemia, anaemia, hyperparathyroidism, malnutrition and medication side-effects. Coexisting chronic conditions and restrictions to fluid and diet could also be factors. The psychological and behavioural factors include sleep disorders, substance use and mental health issues, such as depression, anxiety and stress. The patient’s age, gender, ethnicity, employment and marital status, education and social support are all possible sociodemographic contributing factors. In line with Jhamb and colleagues’ (2008) conclusions, a number of studies have shown that the haemodialysis schedule (i.e. frequency and duration of treatment) (Letchmi, Das, Halim, Zakariah, Hassan, et al., 2011), dialysis adequacy (Cha & Min, 2016) and post-dialysis fatigue (Gordon, Doyle & Johansen, 2011) are all contributing factors to fatigue.

Sklar, Riesenberg, Silber, Ahmed and Ali’s (1996) cross-sectional study of haemodialysis patients’ experiences of post-dialysis fatigue found that 65% of patients reported that symptoms were experienced after the first dialysis treatment and that an average of 4.8 hours of sleep or rest was required to overcome the post-dialysis fatigue symptoms. They also concluded that depression is highly associated with post-dialysis fatigue and that it is a common, incapacitating condition. Gordon and colleagues (2011) reported prevalence of 86% of haemodialysis patients experience symptoms of post-dialysis fatigue, which is 21% higher than Sklar, et al.'s (1996) findings. Gordon and colleagues (2011) also found that patients that were more physically active reported fewer symptoms of post-dialysis fatigue. They reasoned that physical activity could have a protective effect against the psychological aspects of post-dialysis fatigue (i.e. depression) or alternatively a higher level of physical fitness could aid a greater resilience to the pathophysiological factors of dialysis.

1.2.2 The Haemodialysis Machine and Treatment Environment

A fundamental component to receiving haemodialysis treatment is the haemodialysis machine. Due to the purpose and function of the haemodialysis machine it forms an essential and inseparable part of the patients' lives (Hatthakit, 2012). Nagle (1998) referred to the relationship between the patient and haemodialysis machine as a reluctant yet necessary partnership in life. Hagren, Pettersen, Severinsson, Lutzen and Clyne (2002) qualitative study exploring the experiences of hospital-based haemodialysis patients found in their first theme, *the haemodialysis machine as a lifeline*, that the dialysis machine formed an actual and symbolic lifeline. The findings highlighted that the lifeline that sustained patients' lives also came with the cost of restricted freedom, caused by the confinement imposed by the haemodialysis machine and the dependence on nursing staff that monitored treatment and provided care. Indeed, as patients are physically connected to the dialysis machine there are notable restrictions on patients' ability to engage in certain pastimes, which can give rise to feelings of anger, frustration, impatience and uneasiness (Moran, Scott & Darbyshire, 2009). Hagren et al., (2002) concluded that the loss of freedom experienced as a result of being dependant on the haemodialysis machine as a lifeline was the primary area of suffering for patients, with the time-consuming and exhaustive dependency having a detrimental effect on the individuals' social life and family system.

Similar to Hagren and colleagues (2002), Giles (2005) found in his interpretive phenomenological analysis (IPA) study that dependency on the haemodialysis machine to survive can deny agency and foster a sense of powerlessness in the patient. He described a paradoxical nature in the relationship between the machine and patient where there is a dehumanising and objectification of the lived-body and a personification of the haemodialysis machine. Giles (2005) refers to this dynamic as a struggle between the machine and body. He proposes that healthcare givers should discuss this dynamic with patients and assist the patient to become more empowered to recover their sense of independence and self-agency.

The environment of hospital-based dialysis is a challenging one. Prezerakos, Galanis and Moisoglou's (2015) study on the environment of hospital-based haemodialysis and its impact on nurses and patients found that the environment was unfavourable and likely to have an impact on nursing staff's well-being and patient outcomes. Patients can feel an emotional distance to caregivers, feeling dehumanised and an object of care with little empathy for their life-situation felt from nursing staff (Hagren, Pettersen, Severinsson, Lutzen & Clyne, 2005). In the findings of Nagle's (1998) qualitative research study one of the themes, *enduring the treatment environment*, described patients' loss of agency in their own care and a lack of individualised care. Participants reported having a desire to have their opinions heard and accepted and then incorporated in the decisions process concerning their own care. Yet, Pereira, Chemin, Menegatti and Riella (2016) found that in 76.3% of cases the choice of treatment modality for patients was made solely by doctors. Finnegan-John and Thomas (2013) stated, however, that many patients from their study on the psychosocial experience of patients with ESRD expressed the importance of self-care treatment, including insertion of the haemodialysis needle into their fistula and preparing the haemodialysis machine. This was deemed especially important for enabling the patient to develop a sense of independence and autonomy of the treatment, which in turn can aid coping with the treatment regime.

Nagle (1998) also indicated how the majority of participants expressed being part of a community on the dialysis unit, despite reporting that the design of the treatment environment interferes with interactions with other patients and care providers. The study recognised that the treatment environment did not make the experience of receiving haemodialysis easier. A further environmental challenge in dialysis units is noise. James (2008) stated that significant noise is generated by the Unit's heavy reliance upon machinery, most notably the haemodialysis machines. Noise generated by the haemodialysis machines is not only caused by the mechanisms of the machines (e.g. motors, pumps and fans) but also the alarm system, which alert staff to problems. The alarms, which have auditory and visual indicators, can be intermittent or constant in nature and vary in frequency and intensity. Additional contributors to noise disruptions on dialysis units include human generated sounds, air conditioning, televisions, radios and other patient-orientated equipment (James, 2008). Nagle (1998) recommended that by involving patients in the design and structure of the treatment environment would have the potential to make the surroundings more endurable and easier.

Due to the repeated, high-frequency and potential long-term nature of haemodialysis treatment transportation to and from hospital is essential for some patients (Smith, Fortnum, Ludlow, Mathew & Toy, 2015). A lack of, or poor, transport can severely undermine good dialysis treatment and as a consequence have a major impact on the person's QoL (NICE, 2014). Smith and colleagues (2015) found that many patients struggle with securing assisted transportation to and from their dialysis units and that some of those without assisted transportation experience the additional cost of either paying for parking during the duration of their treatment, the need to self-fund private transportation (e.g. taxis) or the use of public transport. All of which has the potential of contributing additional stressors and impacting negatively on patients' QoL (Smith, et al., 2015).

1.2.3 Psychosocial Aspects of End Stage Renal Disease and Haemodialysis

The QoL experienced by people with ESRD is seriously affected by the disease, with it infringing on patients' social, financial and psychological well-being (Anees, et al., 2011). Finnegan-John and Thomas (2013) investigated the psychosocial experience of patients and its impact on QoL. Their findings indicated that ESRD has a considerable impact on QoL, with an increased psychological burden particularly prevalent among patients. Depression and anxiety are the most common psychological problems among haemodialysis patients. In a study into the prevalence of depression and suicide risk in haemodialysis patients, depression and anxiety were robust indicators of suicidal ideations with 35% of patients reporting depressive symptoms and 21.5% with suicidal ideations (Chen, Tsai, Hsu, Wu, Sun, et al., 2010). Finnegan-John and Thomas (2013) stated that in addition to depression, anxiety and suicidal ideations, patients also reported having feelings of grief for the loss of their kidney. This appeared to be particularly evident for those with a failed kidney transplant, which accompanied feelings of dread at returning to dialysis treatment. In contrast to Chen, et al., (2010), AlDukhayel (2015) found a much higher prevalence of depression (83.5%) in his study population of haemodialysis patients. He reasoned that the high prevalence of depression in the study resulted from the studied population presenting with multiple risk factors of depression, including low monthly income (65.4%), unemployment (48.9%) and low education (61.3%). A number of potential protective factors from depression in haemodialysis patients have been identified, including age (Hung, Wu, Chen, Ma, Tseng, et al., 2011), cultural differences, and social and professional support (Chan, Steel, Brooks, Heung, Erlich, et al., 2011). The high prevalence of depression in haemodialysis patients is a concern as it has been shown that patients with depression are three times more likely to not adhere with treatment (DiMatteo, Lepper & Croghan, 2000), with depression associated with non-adherence to dietary and fluid restrictions (Khalil, Frazier, Lennie & Sawaya, 2011). Anees and colleagues (2011) highlighted that patients with low QoL are more likely to not adhere and withdraw from dialysis treatment. Despite the high prevalence of depression, the similarities in the symptoms of depression and those of uraemia (which affects emotional, intellectual and physical functioning (Nichols & Springford, 1984)) may contribute to difficulties in appropriately identifying and treating the early onset of depression for haemodialysis patients (Kimmel, Weihs & Peterson, 1993).

ESRD and haemodialysis treatment have been shown to have an impact on social and intimate relationships. The psychological impact from receiving haemodialysis can be highly destructive to both the individual and their families (Nichols & Springford, 1984). Finnegan-John and Thomas (2013) reported that issues such as fatigue, low mood, weight gain, scarring, and physical changes, for example from the instillation of a catheter, can all contribute to a deterioration of confidence and self-esteem. Furthermore, infertility and sexual dysfunction can put additional stress on intimate relationships. Palmer (2003) stated that sexual dysfunction is a common feature for both male and female patients. Both genders are likely to experience a decreased libido and fertility, with the increased occurrence of erectile dysfunction in men and menstrual abnormalities in women.

The fertility rate for both genders with ESRD is usually very low (Higgind, 2011). Despite this, the use of contraception for female patients is advised (Higgind, 2011) as pregnancy when receiving haemodialysis treatment carries an increased risk of complications for both mother and baby (Davison, 1991). During the early stages of CKD fertility is less affected, however in the event of pregnancy some medications may need to be reviewed to reduce developmental risks to foetus and to the mother's health (Higgind, 2011). Fertility usually improves for both genders with successful kidney transplantation and termination of haemodialysis treatment, although pregnancy after transplantation is still categorised as a high-risk pregnancy (McKay & Josephson, 2008). To reduce the potential risk of pregnancy after transplantation medications may need adjustments and the pregnancy closely monitored by healthcare professionals (Kovacs, Szabo, Jenei, Fedor, Zadori, et al., 2015).

The psychological consequences of the life restrictions that patients experience, along with an increased dependency on their partner, have been shown to have a changing effect on one's identity (Nichols & Springford, 1984). Nichols and Springford (1984) found that patients can experience a perception of being a failing sexual partner, being burdensome to their family, and also an erosion of their role as a parent. Their study also found that 61% of partners experienced depression as a result of changes in their ill spouse, with more than one in two partners feeling exhausted by the efforts of coping.

The time-consuming nature of the haemodialysis schedule and the physical and emotional demands of the treatment can greatly reduce the patients' sociability (Finnegan-John & Thomas, 2013). The reduced opportunities for recreation can result in increased dissatisfaction for patients (Ginieri-Coccossis, Theofilou, Synodinou, Tomaras & Soldatos, 2008). Finnegan-John and Thomas (2013) stated that all of the 118 patients in their study of the impact of ESRD on QoL mentioned that the restrictions to leisure activities due to their ill-health and treatment were considered significant losses. The daily restrictions to diet and fluid intake greatly impacted on social interactions and leisure activities, especially as adherence to the recommended restrictions requires much in the way of daily forward planning and organisation. Patients may also experience challenges in travelling and going on holiday as the location of the holiday would be restricted to holidays where dialysis services are readily available, which would make remote and rural areas particularly challenging (Sims, Bennett, Ockerby, Ludlow, Fairbaim, et al., 2017). The complex challenges and changes faced by haemodialysis patients may also lead to increased anxiety about death (Niu & Liu, 2016). Calvey and Mee (2011) described how patients conveyed a powerful realisation of their own mortality and the fragility of life. They found that patients initial fear of death led to a development of respect for the haemodialysis treatment and machine.

1.3 Parenting and Ill-Health

Over the years the prevalence rate of people in the UK with long-term health conditions has been increasing (Department of Health, 2012). Alongside the increasing prevalence in long-term conditions there has been a rise in the number of dependent children living with families in the UK. The Statistical Bulletin on Families and Household also reported that in 2005 there were 7.5 million families with dependent children in the UK, which increased to 7.9 million in 2015 (Office for National Statistics, 2015). Considering the increase prevalence of long-term health conditions and the number of dependent children living with families in the UK it is perhaps important to consider the implications of being a parent with ill-health, which to date is an under researched phenomenon.

Altschuler and Dale (1999) explored through a clinically-based project at an outpatient Child and Family Mental Health Clinic, how ill parents manage the role of being a parent and a patient. Three themes emerged from their findings: (i) the struggle to recognise parental competence when ill; (ii) past parental trauma; and (iii) pacing self-care with caring for others. The first theme, the struggle to recognise parental competence when ill, highlights the fears parents might hold in that their illness could render them less fit and competent in meeting the needs of their children. Altschuler and Dale (1999) described how the ill parent could struggle to retain an identity as a competent parent and may instead perceive themselves as a danger to their children. In their findings they highlighted one participant that felt that her worth as a mother had been disqualified as a result of her illness. A number of conditions and symptoms, including pain, fatigue, physical incapacity, anxiety and absence, were noted as having the potential to impair on parents' capabilities to meet their children's needs. Parents' perceptions on how these symptoms adversely impact on their ability to meet their own parental expectations have the potential to manifest feelings of guilt, frustration and anger (Barlow, Cullen, Foster, Harrison & Wade, 1999). In order to negate such feelings, parents might overextend themselves to compensate for how they believe their illness negatively impacts on their children. This in turn has the potential to adversely affect their treatments and worsen their condition (van Mens-Verhulst, Radtke & Spence, 2004). Altschuler and Dale's (1999) first theme also captured the feelings of responsibility that parents might experience for the impact their illness has on their children's childhood, particularly by exposing their children to uncertainty, grief and pain. The children's uncertainty and confusion could be further compounded by the disruption caused to the children's regular routine. Many of the parents that participated in Altschuler and Dale's (1999) paper expressed preferring to hide their distress from their children and experiencing feelings of shame when unable to do so. Paradoxically, parents' attempts to protect children by not demonstrating their distress could risk them withdrawing from their parental role and subsequently limiting their children's access to a person that could help them make sense of their experiences. Despite the dilemma that parents face regarding the extent to which they inform their children of their parent's illness, Dale and Altschuler (1999) found that there was little difference in the children's knowledge of their parent's illness regardless of the amount of information shared.

The second theme from Altschuler and Dale's (1999) paper, past parental trauma, suggests that past trauma can exacerbate the difficulties patients experience with being a parent. They found that enduring a severe illness can trigger symptoms relating to past traumatic or stressful life events. Past traumas, if left unresolved, could affect parents' ability to manage anxiety and stress effectively, which has the potential to limit the family's ability to cope with adversity. Alonzo (2000) suggested that the cumulative burden of adversities that can accompany chronic diseases, such as pain and demands, have the potential to trigger past traumatic experiences and develop symptoms of post-traumatic stress disorder. Altschuler and Dale (1999) added that having the opportunity to explore and resolve past traumas may allow the individual, and the family system, to cope differently with the impact of parental illness.

Pacing self-care with caring for others, the third theme, demonstrates the struggle parents with illnesses have in balancing self-care and responding appropriately to the needs of others (Altschuler & Dale, 1999). Contrary to caring for another, parents with severe or chronic illnesses potentially find themselves dependent on others and needing to prioritise their own needs over the needs of others. This dilemma between self-care and caring for others has the potential to challenge one's beliefs and identity as a parent, especially as maximising survival and healing could mean limiting their parental role and their children's access to parental care. Children's ages and their level of dependency also have the potential to influence the dilemma that parents can experience in balancing their parental responsibilities and meeting the demands of their illness and treatments (Barker, Moses & O'Leary, 2017). Herbert (1998) commented that older children tend to be more independent with more predictable needs than younger children. As such, parents of younger children as opposed to adolescents could experience greater challenges in prioritising their own needs over the demands of their children's, which in turn could adversely affect their adherence to their treatment regimes (Barker et al., 2017). Altschuler and Dale (1999) emphasised the importance of addressing the implications that illness can have on parenting, especially considering the increased distress that can be experienced by chronically ill parents when their identity as a parent is threatened.

1.3.1 Chronic Kidney Disease, Treatment and Parenting

To date the number of published research papers exploring the experience of parents who have ESRD and undergoing haemodialysis treatment is very limited. Only three papers were found that investigated this specific phenomenon. Smith and Soliday's (2001) questionnaire-based study on *the effects of parental chronic kidney disease on the family*, posed a question that asked United States of America-based parents with CKD: My illness has affected me and my family in the following ways. 107 questionnaires were fully completed, returned and analysed. Four main themes were presented in their findings: (i) financial burden, (ii) no energy or feel tired, (iii) gender specific issues, (iv) family issues. The first aspect, financial burden, included the participants' limited ability to continue with employment and the addition financial costs of medication. Their second theme, no energy or feel tired, covered the participants' experiences of feeling limited in their ability to carry out chores for their family and adversely impacting on the time they spend engaging in activities with the children. Limited ability to work was reported as being influenced by the experience of fatigue, which had implications on participants' financial burden, as mentioned above. Their third theme on gender specific issues covered, for mainly mothers, the reduced ability to care for their family and their children. Whereas, for fathers, issues relating to participants' reduced ability to support the family financially were highlighted. The fourth theme, family issues, discussed the worry that the participants described for the impact that their illness has on their ability to spend time with their children and family. They also expressed concern that their children could be affected by worrying about their ill parent's mortality. Some people expressed hope that the adverse events experienced by their children in relation to the parents' illness could help prepare their children for the possible challenges faced in adulthood (Smith & Soliday, 2001).

Wadd, King, Bennett and Grant's (2011) literature review on 'being a parent on dialysis' found only Smith and Soliday's 2001 study to have met their inclusion criteria. As such, the review was extended to include papers whose participants were haemodialysis patients of child-bearing age, although the age range that deemed whether participants were of child-bearing age was not specified in their literature review. In the end, a total of 17 studies were included and their findings were categorised into five major themes, which were: (i) restricted lives, (ii) relationships, (iii) adjustment, (iv) consequences of the disease, and (v) future outlook. Wadd and colleagues' (2011) first theme, restricted lives, describing the different restrictions that are common to haemodialysis treatment, including restrictions on finances and employment. The second theme, relationships, encapsulated the impact of their illness on relationships, such as on their children, family and friends. This also included the ill parents' own evaluation of their current parenting skills and changes in their parenting role. The third theme, adjustment, described the effort to maintain a level of normality by trying to function as normal as possible. This also included making adjustments to the haemodialysis regime by trying to keep treatment interference with other life aspects restricted to a minimum. The fourth theme, consequences of the disease, described the impact of haemodialysis side-effects (such as fatigue and tiredness). They highlighted that patients might experience a loss in their sense of agency and a deterioration in their mental health and emotional wellbeing, including an increased prevalence of depression and suicidal ideations. The fifth theme identified, future outlook, captured participants' feelings of uncertainty regarding their future and hope for a future kidney transplant (Wadd, et al., 2011).

The third study found was conducted by Wadd, Bennett and Grant (2014) in Australia on mothers requiring dialysis. They conducted semi-structured interviews with four mothers, of which three were receiving home-based haemodialysis and one hospital-based haemodialysis treatment. Their research data lead to four emerged themes: (i) fitting everything in, (ii) internal family challenges, (iii) lost connections and (iv) striving for normality. Their first theme, fitting everything in, described the challenges of caring for others and for oneself, while still managing the side-effects of haemodialysis treatment. Those aspects were also mentioned by Smith and Soliday (2001) and Wadd, et al., (2011). The second theme, internal family challenges, captured the limited time available to care and spend with their children, for example coming together for family meals. Changes in the activities they engaged in with their children were also reported, with examples shared of choosing low energy activities due to fatigue. The third theme, lost connections, mentioned how haemodialysis treatment impacted on the patients' connections with extended family. Examples mentioned by patients included, having restricted time to visit extended family or friends due to the time demands of the haemodialysis treatment, resulting in reduced social support connections. The fourth theme, striving for normality, concerned patients desire to be perceived and treated as a 'normal' person despite needing haemodialysis treatment. The drive for normality was also evident in the participants' reluctance to discuss their illness with their children, regardless of their children's anxieties of their parent's mortality (Wadd, et al., 2014).

Smith and Soliday's (2001) study illustrated the experiences of parents with ESRD. Overall, it has highlighted the impact of parental illness on the whole family system and the changes that can occur in the family members' identity and roles. For example, the impact of the illness on household chores, childcare, employment and finances. Smith and Soliday (2001) also highlighted the impact that fearing for the parent's mortality could have on the child. Wadd, et al., (2011) listed a number of restrictions endured by haemodialysis patients, mentioned earlier in this chapter, and how these restrictions have been shown to impact on the person's QoL. Wadd, et al.'s (2014) research explored more niched areas on the struggle between managing the demands of childcare, household chores and their own physical and mental health.

1.4 Aim of this Research Study

The impact haemodialysis treatment on patients' QoL (Anees, et al., 2011; Finnegan-John & Thomas, 2013), especially in relation to their physical (Jhamb, et al., 2008) and psychological (Chen, et al., 2010) wellbeing, has been widely documented. Research has explored experiences of being a parent with chronic illness (Altschuler & Dale, 1999), however there is limited existing literature that has investigated the lived experiences of parents, mothers and fathers, that receive hospital-based haemodialysis treatment. This research study aims to gain an insight into an under-researched phenomenon by answering the following research question: *How do patients experience being a parent who receives hospital-based haemodialysis treatment for ESRD?*

2. Methodology

2.1 Overview

The intention of this chapter is to provide a clear description and rationale of the process when exploring and answering the following research question: *How do patients experience being parents who receive hospital-based haemodialysis treatment for end stage renal disease?*

This chapter will explain the rational for choosing the employed research design and chosen methodology for data analysis. The section on research methodology will set-out the inclusion criteria used in the recruitment of a homogenous sample. Ethical considerations throughout the research process will be described in detail, as will the sampling, process of recruitment and the participants demographics. A transparent and coherent description of the research procedure will be provided, including the materials used during the research process, and the steps taken to analyse the collected data. Finally, the quality markers for qualitative research that have been adhered to throughout this study will be discussed.

2.2 Research Design

The aim of this qualitative research study was to explore people's experiences of being a parent when receiving hospital-based haemodialysis treatment. The data was collected by employing a semi-structured interview approach that involved digitally audio-recording the interviews and transcribing them verbatim. The transcripts were then analysed using the approach of Interpretive Phenomenological Analysis (IPA).

2.3 Qualitative Methodology

The application of qualitative research methods in the field of psychology is expanding in both use and interest (Smith, 2015). Qualitative research is concerned with exploring the meanings that people attach to experienced phenomena in a naturalistic description or interpretation of that experience (Langdridge, 2007). Although quantitative approaches are commonly interested in the numeric occurrences or the size of associations between entities, qualitative methods generally engage with exploring, describing and interpreting the experiences and thoughts of participants to provide rich descriptive accounts of the studied phenomenon (Smith, 2015).

Reflexivity, in an important part of qualitative research methods and as such it was an integral part of this study. Willig (2008) states that qualitative methods acknowledge that the researcher is an important and inevitable influencer in the research process. Similarly, Smith (2015) refers to qualitative research as *"a joint product of researcher and researched"* (Smith, 2015 pp.20). Considering the relationship between the research and the researcher, reflexivity is important as it encourages the researcher to reflect on their implications on the study and findings as well as their personal reactions to the research process (Willig, 2008).

2.3.1 Rationale for Interpretative Phenomenological Analysis

Developed by Jonathan Smith in 1996, IPA is a qualitative research method that is dedicated to the exploration of personal meanings and lived-experiences, especially in relation to how people make sense of their personal and social world (Smith, 2015). Smith, Flowers and Larkin (2009) explained that people try to make sense of major events experienced in their lives and IPA researchers are interested in exploring how a person makes sense of such experience. IPA has three main areas of philosophical knowledge: (i) phenomenology, (ii) hermeneutics, and (iii) idiography.

Phenomenology in IPA is interested in the human experience, especially in what constitutes towards people's lived world. Drawing on the work of four leading phenomenological philosophers, Husserl, Heideggar, Merleau-Ponty and Sartre, IPA focuses on trying to gain an understanding of experiences that are embodied by the person's perspectives, meanings, and relationship with the world. As such, IPA is necessarily interpretative in its attempt to understand and make meaning of the other person's experience and view of the world (Smith et al., 2009). This is why hermeneutics, the theory of interpretation, is the second important influence of IPA. In an attempt to understand and get close to the other person's world IPA researchers engage in an interpretation process referred to as double hermeneutic. This involves the researcher trying to make sense of the participant's world through the participant's attempts of making sense of their own world (Smith, 2015). A further important aspect in hermeneutic theory is the hermeneutic circle. The concept of the hermeneutic circle is concerned with the dynamic relationship between the part and the whole (Smith et al., 2009). For example, the meaning of a word (the part) takes shape when considered in the context of the sentence or conversely, the meaning of the sentence (the whole) when considering the meaning of individual words (the part); or the meaning of the individual interview (the part) in relation to the research study (the whole) and vice versa (Smith et al., 2009). The third and final key theoretical underpinning of IPA is idiography, which is concerned with the study of the particular. Idiography in IPA is interested in the sense of detail and as such an in-depth, systematic and thorough analysis of the data. It is additionally interested in understanding a particular phenomenon from the perspective of particular people, in a particular context. As such, IPA employs the use of relatively small, purposive and homogenous sampling (Smith et al., 2009).

In Smith's (1996) seminal paper on IPA, he introduces IPA as an important and useful analytic method in the field of health psychology. Since the introduction of IPA there has been a wealth of qualitative studies in health psychology that have applied IPA (such as Arroll & Senior, 2008; Osborn & Smith, 1998; Bramley & Eatough, 2005). As this research is concerned with the phenomena of the experiences of parents that receive hospital-based haemodialysis treatment and attempting to gain an understanding of these experiences, adopting a qualitative methodology using IPA was considered the most appropriate.

2.3.2 The Researcher's Epistemological Stance

Epistemology, a strand of philosophy that is concerned with the theory of knowledge, aims to draw conclusions to the question: *"how, and what, can we know?"* (Willig, 2001, p2). Langdridge (2007) states that epistemology is concerned with determining what can be known about the world and the relationship between the knower and the known. The methodology that is adopted for a research study therefore would likely be informed by the researcher's epistemological stance. Willig (2008) argues that despite the fundamental assumptions and beliefs people have about the world that it is important for researchers to explicitly recognise and own their epistemological position. To aid this process, Willig (2001) proposes three questions for researchers to consider to help identify their epistemological stance. These exploratory questions are: (i) what kind of knowledge does the research methodology aim to produce? (ii) what kind of assumptions does the research methodology make about the world? and (iii) how does the research methodology conceptualise the role of the researcher in the research process?

As mentioned, the aim of this research study to investigate the experience of being a parent receiving haemodialysis treatment. It intends to gain an understanding of the world from the participants' perspective and to capture the meaning they make about the self, the world they live in and the experiences they encounter. As such, the researcher makes no assertions on whether the participants' accounts are globally true and can be applied to the outside world. It is however accepted that the participants' accounts are a reflection of the participants' reality. The ambition of the researcher is to understand the participants' real world, while accepting that the data collected may have difficulties fully accessing this reality. Willig (2001) refers to this position as critical realist.

From a social constructionism standpoint the human experience is influenced by historical, cultural and linguistic factors, with such experiences being a result of the reading of environmental conditions rather than a direct reflection of those conditions. It therefore proposes that there are 'knowledges' as opposed to 'knowledge' (Willig, 2001). In other words, social constructionism allows for the existence of unique differences between individuals while at the same time acknowledging the essence of sameness that unifies people (Ashworth, 2003). People that experience a phenomenon can describe it in different ways based on their own perceptions and interactions with that phenomenon, yet it does not necessarily mean that any of those descriptions are incorrect or less valued.

The researcher's epistemological position is in line with the analytic methodology of this study, IPA, and takes the form of a critical realist perspective, with a moderate form of social constructionism. Furthermore, as IPA accepts that insights from analysed data is gained through a process of interpretation the researcher aims to maintain a reflexive attitude throughout the research process.

2.4 Research Methods

The following section discusses the process in which this research was conducted. It sets out the method of participant recruitment, data collection and data analysis. The method of participant recruitment includes the inclusion criteria, considerations in ensuring the research met ethical standards and the appropriate sampling steps taken. The process of data collection describes the materials used and the procedures employed in recording the pre-analysed data. Finally, a step-by-step guide as to how the collected data was analysed using an IPA approach will be discussed along with the quality control markers of qualitative research that were adhered to in this study.

2.4.1 Inclusion/Exclusion Criteria

The inclusion criteria for this research study consisted of four components: (i) age, (ii) child's/children's age, (iii) current renal replacement therapy (RRT) modality received and (iv) comprehension of the English language.

Firstly, participants were required to be 18 years or older. There was no upper age limit exclusion criterion, as long as participants met the remaining inclusion criteria. The second criterion, child's/children's age, required participants to be the parent or guardian of a child (or children) under the age of 16 years at the time of the interview and for the child (or children) to live with them at home on either a permanent or occasional basis. The rational for defining a child as being below the age of 16 years is aligned with the definition of a child in the Education Act 1996: *"any person who is not over compulsory school age shall be deemed to be a child"* (legislation.gov.uk, 1996, pp. 315). The compulsory school age in England is 16 years (Family and Parenting Institute, 2007).

The third element of the inclusion criteria required participants to be undergoing hospital-based haemodialysis treatment for ESRD at the time of the interview. There was no exclusion criterion for previously received RRT modalities, such as kidney transplantation, peritoneal dialysis and home-based haemodialysis. Due to the nature of ESRD being a lifelong chronic disease, with RRT modalities designed for life-sustainability as opposed to cure, it is likely that patients would change treatment modalities during the course of treatment based on clinical and personal reasons (NICE, 2011).

The final criterion required participants to have a reasonable comprehension of the English language. There were no exclusion criteria based on ethnicity, country of origin, or main language spoken, yet as data would be collected through an audio recorded semi-structured interview a reasonable understanding and use of the English language was deemed necessary.

2.4.2 Ethical Considerations

Ethical considerations were taken into account for this research study and ethical approval was gained through three ethics committees, which were; (i) the Health Research Authority for the National Health Service (NHS) (Regional specific) (Appendix 1 and 2), (ii) Local Research and Development department for the NHS (Trust specific) (Appendix 3) and (iii) City, University of London (Appendix 4). In addition, the research process also followed the British Psychological Society's (BPS) 2009 and 2018 Code of Ethics and Conduct (2009; 2018 respectively).

This study was carried out under the supervision and support of a Chartered Health Psychologist throughout the research process. All ten participants were recruited through a hospital's Renal department of the NHS. In accordance with the three ethics committees and the BPS (2009) requirements and guidelines all participants' identifiable personal details were treated confidentially and anonymously. All data collected, including the signed consent forms, demographic forms and the initial contact forms, were stored in a secure, lockable cabinet. The audio recordings were transferred to a password protected NHS computer and on an encrypted memory stick, which was stored in a lockable location separate from other research data. The audio files were subsequently deleted from the digital Dictaphone. Each participant was assigned a pseudonym that was used throughout the research process, including anonymising their relevant transcript. All other identifiable information on the transcript, for example location names, were also anonymised to maintain confidentiality. To ensure confidentiality was adhered to the interviews were conducted in a discrete hospital-based consultation room that was separate from other patients. It was explained to all participants, on the research information sheet, consent form and verbally, that their identity and data provided would be anonymised and treated confidentially.

It was also taken into consideration that due to the potentially emotive nature of the topic explored in this qualitative research study participants were debriefed verbally and in writing at the end of the interview. Participants were also provided with information and contact details of NHS and charity support services should they feel distressed by the subject discussed in the research. In addition, the researcher's skills and knowledge working with people who have ESRD in their role as a senior assistant psychologist and trainee Health Psychologist meant that the researcher was able to assess for any potential risk in the participants' presentations and manage the situation appropriately and make an appropriate referral to other agencies, if necessary. Participants were made aware that they could withdraw from the study at any time, with all collected data and identifiable data deleted, without prejudice or judgement and with no subsequent impact on their ongoing clinical care. At the end of the study participants were also given the opportunity for a copy of the research findings to be sent to them on request.

2.4.3 Sampling and Participant Recruitment

IPA aims to use purposive and homogeneous sampling to recruit participants that share an experience (Langdridge, 2007). The reason for using this sampling approach is in an attempt to gain a greater understanding of that phenomenon that is being studied (Creswell, 2013). Adhering to this approach to sampling that is most appropriate for IPA, participants for this study were recruited purposively.

A recruitment flyer (Appendix 5) was developed, which included brief information regarding the research, three of the four aspects of the inclusion criteria (age, child's/children's age and receiving hospital-based haemodialysis treatment), the researcher's contact details and the research supervisor's contact details. The intention of providing the research supervisor's contact details were so that participants could raise any concerns they may have had about the researcher or the research study directly to the research supervisor and/or the University. The research flyers were distributed strategical at several appropriate venues across the NHS Trust, such as haemodialysis units, satellite sites, and Renal Department waiting rooms and reception areas. A further recruitment strategy involved the assistance of members of the Renal Healthcare Team. Patients that met the inclusion criteria were approached by a member of their direct healthcare team and were provided with a research information sheet (Appendix 6) and an accompanying letter from the Haemodialysis Matron (Appendix 7). The letter clearly stated that patients were under no obligation to participate and any decision to partake or not would have no bearing on the care and treatment they receive.

Interested patients were initially asked to contact the researcher directly. After receiving feedback from members of the healthcare team regarding their experience of the recruitment process, many expressed that patients reported a preference for the researcher to contact them directly. Following this feedback, an amendment to the NHS Ethics Form was submitted and agreed upon that requested permission to provide interested patients with an Initial Contact Consent Form sheet (Appendix 8). The Initial Contact Consent Form allowed patients to give consent to be contacted directly by the researcher to discuss their potential participation further. Once the researcher received the returned Initial Contact Consent Form the participant was contacted by telephone to explain the research further and, if interested, arrange a suitable date and location to conduct the research interview.

2.4.4 Participants

From the eleven individuals that initially expressed an interest in participating in this research, ten met the inclusion criteria and agreed to take part. The eleventh individual that initially expressed an interest in the research did not partake due to changes in his personal and clinical circumstances. Since his initial contact, the individual subsequently received a recent kidney transplant and terminating his haemodialysis treatment. All participants that took part in the research received hospital-based haemodialysis treatment under the care of the same NHS Trust. Therefore, the ten participants consisted of six mothers and four fathers, aged between 28 years to 49 years with a mean age of 41.9 years (participants' demographic and background information can be found in Table 1 of the Findings Chapter). In describing their marital/relationship status eight of the participants reported being married, one identified as being widowed and one participant referred to themselves as a single mother. The highest number of children that the participants reported having were seven children, with the lowest being one child. The mean number of children of all ten participants was three. The youngest child of all ten participants at the time of the interviews was eight months old and the eldest being 28 years old. Please see appendix 9 for brief biographies of each of the ten participants.

2.4.5 Materials

This research study used a number of different materials. For ease of explanation the materials used have been categorised into two stages of the research process: (i) recruitment and (ii) the interviews.

Recruitment

The research flyer (Appendix 5) was developed for the purpose of participant recruitment. The flyer briefly mentioned the research topic, two of the four participant inclusion criteria (to be a parent with at least one child under 16 years that lives at home and the current RRT modality received) and the researchers contact details should they be interested in participating.

Patients that were identified as meeting the inclusion criteria were given an invitation letter (Appendix 7) that briefly informed recipients of the research topic, the studies inclusion criteria and the researcher's contact details, if more information was required. The letter also informed the recipient that participation was optional and should they decide to not participate or withdraw from the process at a later date that they would not be discriminated against.

Accompanying the invitation letter when it was passed to appropriate patients were an information sheet (Appendix 6) and an initial contact consent form (Appendix 8). The information sheet provided patients with details of the research's aims, the inclusion criteria, information on confidentiality and the ethical care of the collected data, and the contact details of persons and organisations should the participant want to discuss the research process further. The initial contact consent form enabled participants to provide formal signed consent to be contacted by the researcher to discuss their possible participation in the research.

The interviews

Materials taken and used during the interview process were a Dictaphone, notepad and pen, consent form, demographic information and background information questionnaire, the debrief form and the interview schedule.

A digital Dictaphone was used to record the audio data from the interview, which would be later downloaded onto an encrypted memory stick and NHS secured computer. A paper notepad and pen were also taken into the interview for the purpose of any note taking.

The consent form (Appendix 10) was devised for participants to give their informed consent for the collection and use of data for the purpose of this research study. The form informed participants that their involvement in the study was voluntary and they maintained the right to withdraw at any time.

The demographic information and background information questionnaire (Appendix 11) asked participants to provide details that included their age, gender, ethnicity, along with questions on their parenting status, health status and RRT history.

At the end of the interview all participants received a debrief sheet (Appendix 12). The debrief sheet thanked participants for their involvement in the study and provided a reminder of the participants' right to withdraw consent at any time. They were reminded that their anonymity would be treated confidentially throughout the research process. As the participants were speaking about their experiences that could have the potential to be sensitive and elicit a strong emotional response information was provided of organisations and resources that would be able to provide the necessary support.

Interview schedule

Smith and Osborn (2015) recommends the use of a flexible interview approach when collecting data for IPA. Usually, a semi-structured interview style has been employed in IPA studies as it promotes a dialog between the participant and the researcher. This style of interviewing allows the researcher to modify initially prepared questions and adapt them in relation to the participants' responses. This enables the researcher to explore some appealing areas raised by the participants that the researcher may not have previously considered, which fits nicely with IPA (Smith, 2015).

In accordance with the above recommendation, this study developed an interview schedule that used semi-structured interview questions. To aid the flow of the interviews, the questions were developed in advanced to provide a broad and specific account of the participants' experiences. The developed interview schedule covered five topics: (i) the experience of living with ESRD; (ii) experience of haemodialysis; (iii) outside haemodialysis treatment; (iv) experience of being a parent; (v) experience of being a parent and a patient. In total, there were nine open-ended questions with prompts accompanying the majority of them, to be used if required (Appendix 14).

2.4.6 Procedure

During the recruitment process interested participants were offered the opportunity to meet at either the NHS Trust's main Renal department or at one of the six Trust's haemodialysis satellite units for the purpose of the research interview. The consulting rooms at each of the venues were chosen as they would provide a confidential space suitable for conducting audio recorded interviews.

Out of the ten participants, one preferred to be seen on a non-dialysis day at the main Renal department and the remaining nine participants chose to meet at the same location of their haemodialysis treatment. From the nine, four participants opted to be interviewed before their haemodialysis treatment and five chose to meet afterwards. All participants were met at their chosen location's reception area and were escorted to the available consulting room. The participants were reminded of the purpose of the research interview and were provided with a copy of the consent form (Appendix 10). The consent form was read through and discussed with the participants, with any questions raised by the participant answered. On agreement to proceed with the interview the consent form was signed by myself and the participant. Prior to the interview starting the demographic information and background questionnaire (Appendix 11) was given to the participant to complete. Again, any support or questions that the participant had were managed to the best of my ability. Prior to commencing with the interviews each participant was informed about the interview process, that there were a number of prepared questions for the interview but that they would be used only as a guide as I was interested in hearing about their experiences. I emphasised that there were no right or wrong answers to the questions I would be asking and that they could stop the interview at any time. All participants stated that they were happy to proceed and agreed for their interview to be audio recorded. At this point the digital recorder was activated. The duration of the ten interviews varied between 34 minutes to nearly 90 minutes in duration. At the end of the interview each participant was given the opportunity to reflect on their experience of the interview, to raise any questions or concerns they may have. A debrief sheet (Appendix 12) was given to each participant and discussed. All participants were thanked for their time in participating in the research and their willingness to share their stories.

2.4.7 Data analysis

2.4.7.1 Transcription

Using the digital audio recording of the interviews, each recording was transcribed verbatim to provide an accurate representation of the actual flow and dynamic of the interview. All identifiable information, such as names and specific locations, were anonymised to maintain confidentiality and adhere to an ethical research practice.

For the purpose of anonymising the transcripts each participant was assigned a pseudonym. The pseudonyms were chosen randomly from a baby names book (Bolton, 2013) and assigned using names that began with the letter A to J. The first transcript analysed was assigned a name beginning with the letter ‘A’, the second transcript given a pseudonym beginning with the letter ‘B’, the third with a name starting with the letter ‘C’ and so forth. The pseudonyms assigned to the participants are: Ari, Boris, Cara, Demi, Emma, Flora, Gina, Henry, Isaac and Janet. In preparation for data analysis all ten transcripts followed the same format. As well as using the same font and font size, each line of the text was chronologically numbered and the left and right margins were widened to provide sufficient space for notations.

2.4.7.2 Analysis Stages

Smith and Osborn (2015) refer to IPA as not having a prescriptive methodology. They do however describe a step-by-step approach to the analysis that researchers can use as a guide and adapt as appropriate. For the purpose of this research study I have adopted Smith and Osborn's (2015) step-by-step guide to IPA, with the flexibility to adapt the process accordingly to aid my engagement with the data. For this section, in an attempt to provide a coherent and transparent description of the process of analysis for this research study the steps used are presented below:

(i) Reading and re-reading

Following Smith and Osborn's (2015) suggested approach, it was important to read and re-read the transcripts a number of times to improve familiarity with each one. The first read through of the transcript was accompanied with the playing of the audio recording of the interview. This was done with the intention of helping the researcher to become more immersed with the data, which Smith, Flowers and Larkin (2009) propose as an important process to enable a more complete analysis.

(ii) Initial noting

Having read and re-read the transcript, the next step involved making initial notations in the left-sided widened margin of the text (Appendix 14). The notations reflected the participant's use of language and captured semantic content to further develop my familiarity with the text. I approached the initial notations with an open mind, being aware of the participant's descriptive, linguistic and conceptual comments. As Smith and colleagues (2009) described these three categories of commentary as a useful analytic tool to explore the richness of the participant's account.

(iii) Developing and tabling emergent themes

Following completion of the initial notations, which were made in the left-side of the margin, the aim was to reduce the volume of data while concurrently maintaining the complexity of the participant's account and the initial notes. Using the space in the right-side margin the identified emergent themes were noted (Appendix 14). The themes that emerged aimed to reflect a deep understanding of the participant's lived experience.

On completion of identifying the emergent themes on the right-side margin, the themes were then transferred into a three-column table. The right column displayed the emerged themes, with the supporting quotation from the transcript in the middle column. The left column showed the transcript location of the supporting quotation, with the participant's pseudonym initial and the line number(s) from the transcript used as coding for the location (Appendix 15).

(iv) Grouping emergent themes

The initial three steps of the analysis followed an idiographic approach of working from the initial notations through to the tabling of emergent themes for each transcript before moving onto the next. After all ten transcripts were analysed with their emergent themes tabled, the tables were then cut into individual strips. Each strip of paper contained an emergent theme, the corresponding supporting quotation and the location code. The separated strips of the first three tables were combined and then spread out using a large vacant floor area. The use of the individual strips of paper and the large floor area utilised my preference for considering connections using a spatial and visual method. The individual strips were then clustered together with similar emergent themes and appropriately labelled as to describe the commonality of the grouped themes.

On completion of clustering the emergent themes of the first three transcripts, the remaining cases were introduced one transcript at a time until all ten had been introduced and clustered. As each new case was introduced the researcher attempted to remain mindful that the strips represented the subjective lived experience of another person and therefore would not be overly influenced by the themes that had previously emerged. The clustered themes evolved into two major themes, with their subordinate themes, and formed the thematic model of the analysis (see Diagram 3 in Discussion Chapter).

2.4.8 Quality Markers

Whereas quantitative research is evaluated by the criteria of validity and reliability, qualitative research relies on a framework of set principles. Yardley (2000) proposed a set of four core quality control principles. These are: (i) sensitivity to context, (ii) commitment and rigour, (iii) coherence and transparency, and (iv) impact and importance. Smith, et al., (2009) stated that Yardley's (2000) guidelines provide the necessary means to establish and assess the validity and quality in qualitative research.

Sensitivity to context

There were several ways that the researcher attempted to remain sensitive to context. Firstly, the researcher immersed the self in the theoretical and empirical literature in order to gain an in-depth understanding of the studied phenomena. Throughout the process an awareness of the interactional nature of the data collection stage of this study was kept in mind. A sensitivity towards the participants' subjective accounts was upheld, especially through the employment of the researcher's professional therapeutic experience to empathise with the individuals and put them at ease enough to share their stories. This approach also assisted in being sensitive to the sociocultural setting, especially considering the specific physical and mental health challenges this population face. Furthermore, this research study received ethical clearance from the NHS and City University and adhered to the guidelines of the BPS (2009) on Code of Ethics.

Commitment and rigour

Throughout the process of data collection, analysis and reporting the researcher remained engaged and committed with the explored phenomenon and the telling of the participants' stories. The researcher's competence and abilities as a qualitative researcher were greatly enhanced and developed during every phase of the study. The researcher rigorously attended to each step of the analysis process, returning to the original data (audio recordings and transcript) when necessary to ensure a deeper understanding of the data and in so doing, rise above a basic or superficial understanding.

Coherence and transparency

It was the researcher's intention to provide a coherent and transparent representation of all relevant stages of the research process. A comprehensive account of every aspect of the data collection and analysis is presented in this chapter, with the outcome of the analysis discussed in the Findings and Discussion chapters, which are to follow. Also, a reflexive account of the experiences and motivations that led the researcher explore the phenomenon of this study will be included. The intention of having a clear and transparent approach to this research study was to enable the reader to follow and discern the steps taken to achieve the overall thematic model of analysis.

Impact and importance

The impact and importance of this study is discussed in more detail in the Discussion chapter. It is hoped however that this study will provide an invaluable contribution to the field of health psychology by providing an empirically driven perspective of an under-researched phenomenon: the experience of parents that receive hospital-based haemodialysis treatment.

3. Findings

This chapter intends to illustrate an insight into the lived experiences of parents who have been diagnosed with end stage renal disease (ESRD) and are receiving haemodialysis treatment. The participants' willingness to share their stories and experiences during the interviews produced a large quantity of data. The rich depth of data collected was perhaps as a result of the pervasiveness of the demands and impact that receiving haemodialysis treatment has on the participants' lives and their role of being a parent. In order to refine the data so that it is directly focused on answering the research question, challenging decisions were made during the analysis process to best capture the themes that are unique to this population. Following the analytic process described in the methodology chapter, two major themes were identified, with each of the major themes comprising of a collection of subordinate themes (Appendix 16). These will be described in more detail within this chapter. The two master themes are: (i) the haemodialysis experience and (ii) the lived experience of parents with end stage renal disease. The two major themes follow the premise of a Venn diagram. The two themes intersect to capture the experience of being a parent receiving haemodialysis for the treatment of ESRD which will be elaborated further in the discussion chapter.

Direct verbatim extracts from the interviews are presented throughout this chapter in an attempt to bring the reader closer to the experiences of the ten parents and to support the major themes and subordinate themes. The extracts are accompanied by the participant's assigned pseudonym and the line number where the text originates from the corresponding transcript. The organisation strategy that this chapter follows is in line with one suggested by Smith (2015), in that themes will be presented with supporting extracts and the researcher's interpretative commentary. The findings will then be discussed with extant literature in the Discussion chapter.

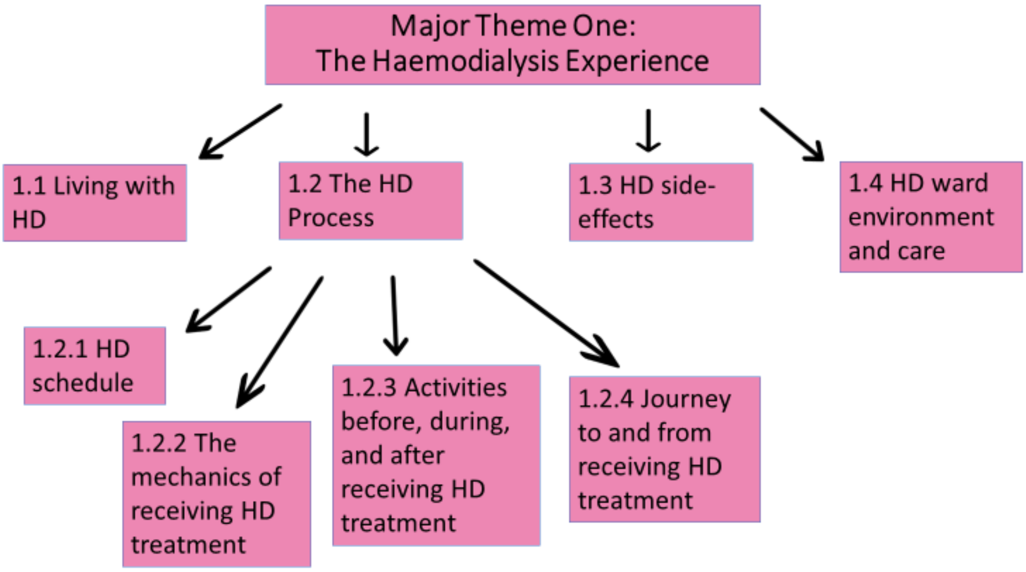
In a further attempt to bring the reader closer to the accounts from the ten participants, detailed summaries of each participant have been provided (Table 1 and Appendix 9). Before exploring the two major themes in detail, a brief synopsis will be presented followed by an in-depth exploration of the research findings.

Table 1: *Participants' demographics and background information*

Participants' pseudonyms	**Gender and age**	**Number of children and their ages**	**Time of ESRD diagnosis**	**Previous kidney transplant**	**Marital status**
Ari	Male 44	3 children age: 9 to 16	About 18 months ago	No	Married
Boris	Male 49	7 children Age: 18 months to 26	About 22 years ago	Yes - twice	Married
Cara	Female 49	6 children Age: 13 to 28	About 3 years ago	Yes - once	Married
Demi	Female 41	1 child Age: 13	About 12 years ago	No	Widowed
Emma	Female 35	3 children Age: 8 to 15	About 3 years ago	No	Married
Flora	Female 45	3 children Age: 15 to 21	About 20 years ago	Yes	Married
Gina	Female 43	1 child Age: 12 years	About 23 years ago	Yes - once	Single mother
Henry	Male 28	1 child Age: 8 months	About 14 years ago	Yes - twice	Married
Isaac	Male 39	2 children Aged 9 to 14	About 12 years ago	Yes - once	Married
Janet	Female 46	3 children Aged 13 to 17	About 6 years ago	No	Married

(i) *The Haemodialysis Experience*

All of the participants shared their experience of life on haemodialysis for the treatment of ESRD. They spoke at length about the process of receiving haemodialysis. This included the frequency and duration of haemodialysis treatment, their relationship with the haemodialysis machine, their activities before, during and when not receiving treatment, and their journey to and from hospital. The participants also described the various side-effects common to haemodialysis treatment, in particular the physiological effects and the impact it has on their parenting. The final subordinate theme explores the participants' perception of the Haemodialysis Units and the care they receive from the medical staff on the ward.



<u>Diagram 1:</u> *Diagram of Major Theme One and subordinate themes.*

(ii) *The Lived Experience of Parents with End-Stage Renal Disease*

Throughout the interviews the participants spoke of what being a parent means to them and how the commonly experienced haemodialysis side-effects impact on their parenting. Within the subordinate theme of *being a parent* the participants also spoke about their experiences of being absent from their children when attending hospital for treatment of ESRD and the implications their illness has on their ability to holiday with their children. The participants described how their children experience their parent's illness, their children's awareness of their illness and the means in which their children have been exposed to their parent's chronic illness. The majority of the participants expressed the strength and support they receive from their children and how their children remain a motivator to continue with treatment. Finally, how the participants make meaning of their own mortality is explored.

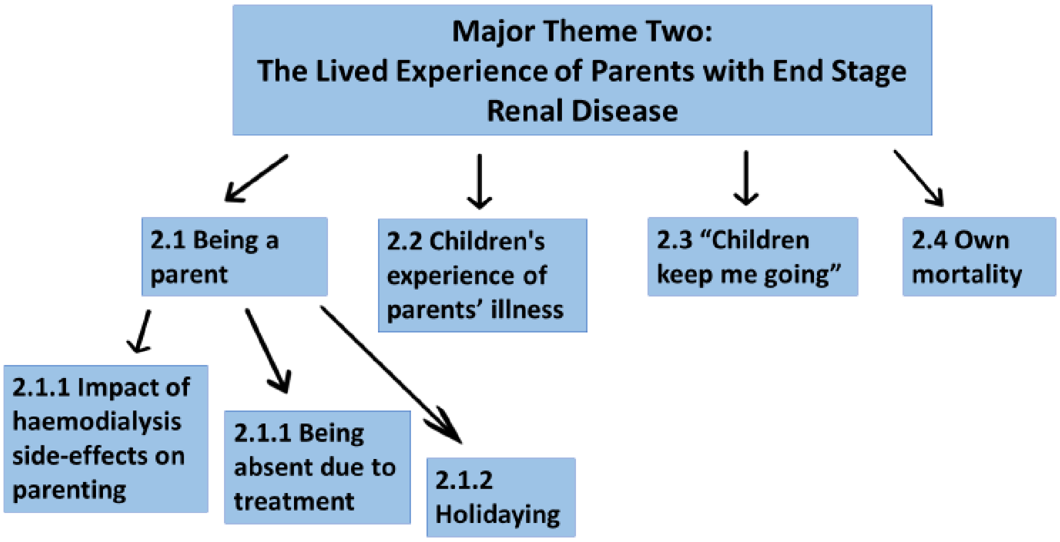


Diagram 2: *Diagram of Major Theme Two and subordinate themes***.**

3.1 Major Theme One: The Haemodialysis Experience

3.1.1 Living with Haemodialysis

The first subordinate theme illustrates how participants' make sense of requiring haemodialysis treatment to sustain their lives. The majority of participants shared their experience of what it's like receiving haemodialysis treatment and how it has become a significant aspect of their lives. Ari indicated the central role dialysis takes in one's life:

> *"Your life will revolve around dialysis"* (Ari, 1383-1384).

Ari's statement that *"life will revolve around dialysis"* could perhaps be as a result of the all-encompassing nature of haemodialysis, including the need to attend regular treatment sessions three to four times per week for several hours for each session. The frequency and duration of receiving haemodialysis seemingly has a substantial impact on different facets of patients' lives. In discussing the role dialysis has in his life, Ari described it as occupying a significant part of his life:

> *"Instead of dialysis being a small part of my life, it has become the major part of my life"* (Ari, 915-916).

Similar to Ari, both Henry and Janet referred to haemodialysis in exactly the same manner in that it has become a part of their lives, with Isaac also perceiving dialysis as part of his existence:

> *"It's part of my life"* (Henry, 163; Janet, 636).

> *"I see it as part of my life"* (Isaac, 707-709).

Whereas other participants described haemodialysis as being a part of their lives, Gina's sadness that *"this is my life"* highlights the comprehensive affect haemodialysis and ESRD has on her quality of life:

> *"I cry and cry and I feel unhappy, I feel very sad that this is my life"* (Gina, 882-883).

Other participants expressed being affected by their experience of receiving haemodialysis. Ari and Flora both described feeling negatively towards their renal replacement therapy:

> *"I hate it"* (Ari, 185).

> *"I have had a lot of bitterness towards dialysis"* (Flora, 1163-1164).

The hatred and bitterness that Ari and Flora feel is typical to how others similarly expressed feeling towards haemodialysis, however Flora's use of the word *"had"* appears to refer to her bitterness in the past tense. This perhaps suggests a process in which she has transcended the negative feelings she formerly had for haemodialysis. Flora, who first experienced receiving haemodialysis almost 20 years ago, is one of the participants with the earliest experience of the treatment having been diagnosed with ESRD shortly before starting dialysis. Ari however, was diagnosed with ESRD 18 months ago and started haemodialysis soon after. The difference in the period of time that has elapsed between Ari and Flora's first experience of haemodialysis to the present day may indicate a process of change that has occurred in how one feels towards the treatment.

Ari later spoke of feeling resentful towards the necessity of needing to attend and endure hospital-based haemodialysis:

> *"I resent the fact that I'm coming here and I have to be subjected to this"* (Ari, 438-439).

Ari's use of the words *"...I have to..."* highlights the necessity of the treatment and suggests a lack of agency that he may feel. Many of the participants, in talking about how they live with requiring haemodialysis treatment, spoke of their experiences between sessions. Cara described occasionally feeling despondent, possibly due to the combination of the haemodialysis schedule and the numerous fluid and dietary restrictions:

> *"You do get fed up sometimes"* (Cara, 51).

Gina on the other hand shared how she feels apprehensive about attending haemodialysis sessions due to the physical effect it has on her:

> *"The thing is, I worry about dialysis and how it makes me feel"* (Gina, 463-464).

As mentioned previously, Ari expressed his feelings of hatred towards haemodialysis, however he also later added feeling conflicted towards the treatment:

> *"I feel angry towards dialysis, even though I shouldn't be"* (Ari, 436-437).

Ari's declaration that he should not feel angry highlights the contradiction between the feelings felt by the majority of the participants towards haemodialysis and the function of haemodialysis in sustaining their lives. One potential reason for feeling negatively towards haemodialysis was suggested by Boris:

> *"It puts a bind on what you can do and what you can't do"* (Boris, 8-9).

Boris' comment typified the impact that haemodialysis can have on different aspects of one's life. He described in his interview how constraining he finds his haemodialysis schedule and the restrictions associated with the treatment. A minority of the participants however, including Boris, expressed having a pragmatic perspective to their treatment:

> *"When you look at it logically it is not a big deal having dialysis, […] you have your dialysis and then you go, it's not a big deal"* (Boris, 1212-1217).

Boris' pragmatic view of haemodialysis was similar to an opinion expressed by Emma:

> *"It's not too bad, it's only three times a week so you can do something during that time, so I don't see it as a big issue"* (Emma, 433-435).

Using the time effectively during the period that she is receiving haemodialysis appears to help Emma manage haemodialysis and perceive her experience on haemodialysis as *"not too bad"*. She described using her time productively whilst on the haemodialysis unit, such as completing necessary responsibilities (e.g. paying utility bills), with the intention that she would conversely have more available time to spend with her family on non-haemodialysis days. The activities that the participants engage in during their haemodialysis sessions are discussed later in this chapter.

Despite the comprehensive effect that haemodialysis has on different aspects of the participants' lives, both Emma and Henry consider themselves to be comparable to others:

> *"I'm like a normal person, only I'm on dialysis"* (Emma, 102-103).
>
> *"The only difference now is that I'm on dialysis, I'm going to hospital three days a week"* (Henry, 69-70).

Isaac shared his view that haemodialysis was less of a strain when procedural and treatment advice were adhered to, including dietary and fluid restrictions:

> *"Dialysis is not that difficult here if you follow correctly whatever they say"* (Isaac, 910-911).

Originating from the Asian continent, Isaac has experienced receiving haemodialysis in the country of his birth. He described the contrast between receiving treatment in the country of his birth in Asia to that in the UK as being vastly different. He expressed in his interview that his current treatment in the UK has impacted on his life to a far less extent, which he partly attributed to the greater accessibility he has to treatment in the UK compared with his country of birth.

All of the participants verbalised that they were acutely aware of the necessity of haemodialysis treatment in sustaining their lives. Ari typified this shared knowledge by stating:

> *"You hear every day all the people here are getting this treatment because if they didn't have it, they'd be dead. This is just a fact"* (Ari, 1166-1169).

Ari seems to suggest that people's knowledge on the importance of haemodialysis to sustain life is reinforced by the repetitiveness of information received when on the Haemodialysis Units. Both Gina and Janet relayed having a similar understanding, with Janet mentioning her knowledge that *"you would be dead if you don't have it"* as a means of accepting the treatment:

> *"I come here, to dialysis, to survive and I know it keeps me alive"*
> (Gina, 464-465).

> *"You have to have it, you would be dead if you don't have it, so you get on with it"* (Janet, 212-214).

Ari also expresses accepting the need for him to receive haemodialysis as it keeps him alive, this is despite of his dislike and, as stated earlier, his hatred for the treatment:

> *"I don't like it but I have to go through it, it's keeping me alive"*
> (Ari, 191-193).

Acceptance that haemodialysis is needed to treat their failing kidney function was widely reported by the participants. Whereas others discussed the importance for them to accept their haemodialysis treatment, Henry explained how it was actually important for him to attend his haemodialysis sessions for him to accept that he has a chronic health condition:

> *"If I don't come then I will not be facing my problems and then I can't be there for my baby, that's what it is"* (Henry, 192-194).

Henry highlighted his role as a father to his eight-month old son as a motivating factor to adhering to his haemodialysis schedule. Henry seems to suggest that his survival or at least his physical wellness would be affected if he did not attend haemodialysis, which would subsequently mean that he would not be there for his child.

As explained, the participants spoke of their awareness that non-attendance to haemodialysis is likely to result in death. In addition, some participants expressed that non-adherence to the frequency and duration of haemodialysis sessions would result in the deterioration of their physical health and lead to potential infections:

> *"I'm thinking, if you don't keep going to dialysis other infections are going to happen"* (Emma, 1051-1052).

> *"If you don't come here you're just going to get very ill, it's as simple as that"* (Boris, 1363-1365).

Both Emma and Boris verbalised their awareness that non-adherence to their haemodialysis treatment regime would likely have an adverse effect on their physical well-being. They described feeling distressed when considering the possible consequences of their chronic illness without their current haemodialysis treatment or other RRTs. Emma expressed her unease when she thinks about the potential for death or illness if her physical health deteriorated further by not adhering to her haemodialysis regime:

> *"I don't like to think about it, if I think about it I'll get upset and so because of that I don't think about it"* (Emma, 1060-1062).

Boris exclaimed that he manages his frequent anxieties about the potential consequences of non-adherence to his haemodialysis, and the possible future prognosis of his ESRD, by continuing to follow his haemodialysis schedule:

> *"It's something I deal with and I deal with it every day, so I just try to put it on the back burner and come to dialysis as a natural fact"*
> (Boris, 13-16).

Boris continued by explaining that he attempts to approach his haemodialysis treatment pragmatically, and in so doing accept the negative aspects of the treatment in return for its main function, which is to keep him alive:

> *"To be honest dialysis is dialysis, you come here for a reason, it's not worth moaning about"* (Boris, 1362-1363).

Boris' apparently matter of fact comment that *"...dialysis is dialysis…it's not worth moaning about…"* were echoed by other participants. Cara and Emma also expressed that they manage the reality of haemodialysis treatment by accepting that the treatment is necessary for their relative wellness:

> *"It's just life isn't it, you just have to get on with it"* (Cara, 125-126).
>
> *"I can't do nothing about it, so I just take it how it is"* (Emma, 115-116).

Cara's comment that *"...you just have to…"* and Emma's *"I can't do nothing…"* indicates a possible lack of agency or choice felt by both women regarding them receiving haemodialysis, yet also suggests that acceptance of their situation may be essential in managing the affect from their illness and treatment.

As briefly mentioned earlier, several of the participants spoke of developing greater acceptance requiring haemodialysis to be part of their lives. The majority of participants indicated there being a process of adjustment from when they first received haemodialysis through to the present day. After returning to haemodialysis following the failure of a transplanted kidney, Flora reported slowly adjusting to the change in RRT by recognising the ability of haemodialysis to keep her alive. She explained in her interview that she initially found the period when she returned to haemodialysis treatment challenging as she hoped the organ transplantation would have lasted longer:

> *"I slowly started accepting it because here are people who are alive because of dialysis who have not even been as fortunate as me who had a transplant for seven years"* (Flora, 225-229).

Similarly, Emma, who started haemodialysis three years ago, and Boris, who initially first received haemodialysis approximately 15 years ago, both highlighted a process where they adjusted to the treatment and the impact it has on their lives:

> *"Now that I've been doing dialysis for three and a half, three years, I've become used to this lifestyle now"* (Emma, 55-57).
>
> *"I'm now so used to it"* (Boris, 512).

Isaac also expressed adjusting to the treatment. He mentioned initially worrying excessively about receiving haemodialysis, yet over time his perception has altered to him now viewing the treatment as an aspect of his life:

> *"I was worried about it a lot back then but now I think of it as part of my life"* (Isaac, 235-237).

Identifying with haemodialysis as *"part of my life"* is a perception that Isaac shares with the majority of the other participants, as presented earlier in this section. Henry also expressed that since his initial experience of haemodialysis 14 years ago he has developed an acceptance of the treatment and now sees it as *"part of his life".* He continued by stating that haemodialysis does not interfere with him enjoying life:

> *"It's part of my life, that's the way I see it because dialysis doesn't stop me from enjoying my life"* (Henry, 760-762).

3.1.2 The Haemodialysis Process

This subordinate theme captures the process involved in receiving haemodialysis. It describes the participants' accounts of following their haemodialysis regime, their experiences of receiving haemodialysis and the journey to and from receiving treatment.

The participants described the different ways that they anticipate their haemodialysis treatment. Ari spoke with apparent sarcasm concerning how he regards the anticipation of his treatment during the week, especially on the morning of a haemodialysis session:

> *"Waiting for dialysis, the highlight of my week"* (Ari, 654).

Whereas Ari referred to the waiting period in the morning of his sessions, Cara described the repetitiveness of her haemodialysis schedule and her apprehension about attending:

> *"When it gets to like tomorrow evening I'll be thinking to myself, 'oh no, I've got to go there again tomorrow morning and it starts all over again' and then I think, 'oh, I don't want to'"* (Cara, 903-906).

In Cara's interview she stated that she frequently relies on the encouragement and persuasiveness of her husband on the occasions when she feels reluctant to attend her scheduled haemodialysis sessions. She highlighted the repetitive nature of dialysis, which requires her to attend treatment sessions three times per week. Cara’s apathy towards her haemodialysis was mirrored by Henry’s feelings towards his treatment:

> *“Sometimes you don’t feel like going in and getting needled and sitting there for four hours”* (Henry, 95-97).

In contrast to other participants, Gina spoke about a different reason for an increased anticipation for attending her next haemodialysis season. She explained that on Sunday evening she usually looks forward to receiving treatment the next day as her previous session would have been before the weekend:

> *“I cannot wait for dialysis, like on Sunday nights, when it’s been Saturday and Sunday without dialysis”* (Gina, 589-591).

Gina described her general physiological condition towards the end of the weekend after she has not dialysed for three days. Her narrative captures the physical necessity of haemodialysis treatment to partly replace the functionality of her failing kidney and highlights the physiological demands haemodialysis patients also experience on non-treatment days:

> *“Three days of not passing any urine whatsoever, everything I drink is inside me and my heart doesn’t feel too good and I feel very short of breath, and I felt like my body isn’t strong enough to go on for much longer”* (Gina, 470-474).

Similar to the accounts of other participants when discussing the anticipation they feel before attending treatment, Boris spoke of his experiences on the mornings that he receives haemodialysis, before he leaves to attend hospital. He stated that he has an arrangement with the healthcare team on the Haemodialysis Unit he attends for treatment that they would inform him in the morning if an earlier slot becomes available for him:

> *“It’s the sitting about waiting, it’s like every day when I get up and it’s a dialysis day I’m waiting for a phone call, I can’t settle”* (Boris, 46-48).

Boris described the waiting process that exists for him on each morning of his treatment sessions, which he finds unsettling. Despite feeling unsettled in the morning, he noted that he feels highly appreciative when the opportunity arises for him to attend hospital earlier as it allows him to collect his children from school and spend an extended period of time with them. The majority of the participants mentioned the process of waiting and anticipation for their treatment as being a common feature of living with receiving haemodialysis. Ari spoke about how the waiting process continues on the haemodialysis unit:

> *"I can tell you exactly what it's like, I can go through the whole process of the dialysis experience: you turn up, you sit in the reception, sometimes for five minutes, sometimes for an hour, sometimes for two hours, waiting there, just sitting and waiting"* (Ari, 225-230).

Ari's depiction suggests a lack of agency that he experiences with the waiting process, from needing to wait from five minutes to a possible two hours. He continued by describing the lack of agency that exists throughout the process of receiving haemodialysis, including attending the Haemodialysis Unit, to starting the treatment session through to disconnecting from the haemodialysis machine:

> *"You go through the initial process of waiting for a long time and then its rush-rush-rush-rush "we need do this we need to get you onto the machine, we need to get you onto the machine because x-x-x-x needs to happen", everyone gets onto the machines and then nothing happens for a few hours obviously, then it's time to get off and the rushing process starts again"* (Ari, 236-243).

Ari's description captures the periods of waiting and the times of high activity that patients receiving haemodialysis can experience on treatment days. He again describes a lack of personal agency, with the waiting process largely dictated by the renal nursing staff and the availability of haemodialysis treatment stations. Considering the irregular waiting periods and the anticipation of having treatment from the evening before, as described by some participants, in addition to the duration and frequency of haemodialysis treatment it is perhaps unsurprising that the majority of participants spoke about the time demands that come with haemodialysis:

> *"It's time consuming"* (Boris, 7-8).

In response to a question on what she found most challenging about living with receiving haemodialysis, Emma responded:

> *"It's only the time"* (Emma, 382).

In addition to the waiting process experienced by the majority of participants, several individuals discussed the impersonal nature of their time on the Haemodialysis Units when receiving treatment. Ari typified this experience by referring to it as similar to patients being a piece of meat in a sausage factory:

> *"It's a factory system, a sausage factory, you get patients in, you stick them in and you get them out"* (Ari, 205-207).

A contributing factor to the impersonal nature of receiving hospital-based haemodialysis treatment is likely to be the lack of agency that several of participants mentioned feeling in relation to their treatment, as stated by Ari earlier in this chapter. Ari and Cara both neatly summarised their feelings about the experience of receiving haemodialysis:

> *"I do not like my dialysis, it is not a pleasant experience"* (Ari, 193-195).
>
> *"I hate it"* (Cara, 70).

In contrast, several of the participants verbalised having neutral or positive feelings towards the experience of receiving haemodialysis. Henry, Emma and Boris all stated being largely unaffected during the process of receiving their treatment:

> *"It's fine, it's not a problem"* (Henry, 149).
>
> *"It's not too bad"* (Emma, 426).

Boris, whom had first received haemodialysis about 15 years ago, described feeling so unaffected by the treatment process that he would frequently sleep throughout the duration that he was connected to the haemodialysis machine:

> *"Someone puts a needle in you and you go to sleep and then they wake you up to go home"* (Boris, 1281-1283).

Whereas Henry, Emma and Boris each expressed feeling relatively neutral towards the experience of receiving treatment, Gina illustrated having a more positive experience. Gina, whom had previously mentioned feeling physically distressed the evening before certain haemodialysis sessions due to fluid retention, spoke of the relief she feels soon after commencing her treatment:

> *"One hour after I have started dialysis I feel relieved"* (Gina, 797-798).

Whilst Gina described the physical sensations and the relief she feels soon after starting her haemodialysis sessions, several participants articulated what they experience upon completion of a treatment session. Cara, for example, expressed feeling elated and great relief when she disconnects from the haemodialysis machine:

> *"It's like all the Christmases come at once"* (Cara, 406).

> *"Oh, it's absolutely brilliant, it really is, as soon as I disconnect myself I feel like, I don't know, like the whole...like everything is lifted off my shoulders"* (Cara, 410-412).

Cara continued by describing the physiological change that occurs soon after she disconnects from the haemodialysis machine as a result of her body temperature regulating:

> *"You can feel the change after about ten minutes, like I feel nice and warm again"* (Cara, 424-425).

The jubilation expressed by Cara on when her treatment session completes and she disconnects from the haemodialysis machine was similarly shared by both Emma and Gina. They both spoke of feeling happy and positive, despite being or appearing fatigued:

> *"I'm so happy, I want to go home and have a sleep"* (Emma, 454-455).

> *"I know my body looks tired but I feel good inside"* (Gina, 804-805).

Conversely, other participants portrayed a less favourable experience after they have disconnected from the haemodialysis machine. Henry, who had previously said about receiving haemodialysis as it being *"fine, not a problem"*, stated that he finds the period after receiving treatment to be particularly challenging:

> *"The problem is what happens after dialysis, during dialysis I'm fine"* (Henry, 150-151).

During his interview, Henry mentioned frequently feeling physically unwell and fatigued after haemodialysis sessions. A common symptom of haemodialysis, Henry spoke of occasionally experiencing hypotension after treatment with feelings of nausea and dizziness that would be severe enough to prevent him from driving home immediately after completing his session. Similarly, Demi and Flora both mentioned feeling physically unwell and unsettled after treatment:

> *"It's not nice, it's not a nice feeling after dialysis, you feel rotten"* (Demi, 534-536).

> *"After dialysis you're really not right"* (Flora, 982-983).

Despite feeling a sense of relief and elation immediately after disconnecting from the haemodialysis machine, Cara also shared that occasionally the aftereffects of receiving haemodialysis, particularly fatigue, significantly impedes her functionality:

> *"Sometimes I feel so useless"* (Cara, 199).

3.1.2.1 Haemodialysis Schedule

All of the participants discussed their haemodialysis schedule and the impact it has on different aspects of their lives. For the majority of participants, the frequency of their treatment schedule was found to be challenging:

> *"Coming to dialysis three times a week makes for a very tough life"* (Gina, 1878-1880).

Gina explained throughout her account how the routine and continuous cycle of her haemodialysis schedule made for *"…a very tough life…"* for her. Likewise, Ari also spoke about how impactful the repetitive nature of his haemodialysis schedule can be:

> *"'Oh, what's happening this week?' well, I have got dialysis three times a week and everything then works around dialysis"* (Ari, 903-905).

Ari's depiction that other interests and activities *"…work around dialysis…"* aligns with Isaac's account that other activities need to fit with his haemodialysis schedule commitments:

> *"If I go anywhere I have to remember that I have to go to dialysis"* (Isaac, 246-247).

For many of the participants, there seemed to be a routineness and possible monotony of living life in line with their haemodialysis schedule. Similar to Ari's account ("*oh, what's* *happening this week? well, I have got dialysis three times a week"*), Demi described the start of her week as the beginning of her weekly haemodialysis treatment:

> *"Oh, it's Monday morning again, back to the hospital"* (Demi, 336-337).

The two consecutive days that Demi has at weekends where she does not receive haemodialysis appears to provide her with precious respite from the relentlessness of her treatment schedule:

> *"You get fed up but you have one extra day off at weekends"* (Demi, 335-336).

The participants also spoke about the impact that their haemodialysis schedule has on their everyday lives, particularly as it tends to limit the time they have available to spend with their children and families. For many participants, it was important to find a manageable balance between their treatment and their parental and family responsibilities. Cara stated that she prefers to dialyse as early in the day as a possible, to allow her a short period of time in the afternoon to rest before her children return from school.

> *"I like to get here early so I can leave early"* (Cara, 22).

Participants expressed the importance of minimising the effect that attending their haemodialysis treatment has on their children and the time they have available to meet their parental responsibilities. Whereas Cara spoke about her desire to continue with the timings of her current treatment slots, Boris verbalised how the timing of his regular dialysis slot hinders him from meeting his paternal responsibilities and from him fully supporting his wife in caring for their children on his treatment days:

> *"I would like to go onto an earlier shift, so I can pick up the kids from school"* (Boris, 791-793).
>
> *"It would be a lot more helpful if I was there"* (Boris, 86-87).

The majority of the participants spoke about the significant impact that their haemodialysis treatment schedule has on most other aspects of their lives, including minimising the time and availability they have with family and friends, and the effect it has on their work and social commitments. Isaac, one of the participants that had attempted to maintain employment when he first started receiving haemodialysis, recalled finding the balance of attending his treatment sessions and managing the usual side-effects against his work commitments to be particularly challenging. Despite ultimately finding continuing with work too difficult, he said that the healthcare personnel on the Unit were very accommodating in changing his treatment slot for the period that he was still working at the same time as receiving haemodialysis:

> *"Sometimes I called them and asked if there was a place for me to go in the evening instead, there wasn't any problem with that"* (Isaac, 814-816).

The adverse impact the haemodialysis schedule has on family and friendship relationships was further highlighted by Henry. He indicated that the frequency and duration of his haemodialysis treatment was the main contributing factor to his dissatisfaction for not spending enough time with his family and friends. As a consequence, he stated that there were occasions when he was younger when he did not adhere to his schedule and missed haemodialysis sessions to be with family and friends:

> *"I wanted to spend more time with my family and my friends like other people would and being on dialysis three days a week and going to hospital you don't get the time"* (Henry, 199-202)**.**

Missing treatment sessions and not adhering to his haemodialysis schedule resulted in the deterioration in Henry's health that required him to be hospitalised. Henry's account further underlines the necessity for patients to follow their haemodialysis schedule, as well as the challenges that many patients may experience in managing the impact it has on other aspects of their lives.

3.1.2.2 The Mechanics of Receiving Haemodialysis Treatment

As part of the process of receiving haemodialysis participants explored different aspects of that experience. In this section, the participants discussed the various mechanics of receiving haemodialysis treatment. The mechanical aspects consist of the haemodialysis machine and the components required for patients' connection to the haemodialysis machine, namely the creation of the fistula and connecting to the haemodialysis machine through insertion of a needle into the fistula.

Fistula creation for haemodialysis treatment

It is usual for patients that are to commence haemodialysis to undergo a surgical procedure to create a fistula in order to connect to the haemodialysis machine. Janet's depiction of having her first fistula created illustrated a painful procedure that she found largely unpleasant:

> *"The first time when I had the fistula done it really hurt"* (Janet, 269-270).

She continued by sharing the traumatising experience of having her fistula surgically created without sufficient anaesthesia:

> *"The anaesthetist left the room and I was just left there laying on the table on my own with them still working on my arm and I could feel everything, I was in agony"* (Janet, 684-687).

Similar to Janet, Gina and Henry spoke of experiencing complications in the surgical procedure to create their fistulas. Gina's account that she was required to have four separate surgical procedures in an attempt to create a fistula highlights how challenging the procedure can be:

> *"The fistula, it didn't work too good and they had to try again four times"* (Gina, 949-950).

Akin to Gina's account, Henry portrayed a difficult surgical procedure to create a new fistula to replace his original fistula that had since degraded. Henry's experience further explains the challenging nature of creating fistulas, which are an important component to receiving haemodialysis treatment:

> *"They tried to do another fistula on my left arm but they couldn't find a big vein on the x-ray yet they decided to still operate on it to see if they could do it but there was no progress"* (Henry, 281-283).

The accounts of Janet, Henry and Gina highlights the challenges involved in creating and maintaining fistulas that are crucial for haemodialysis. Contrary to these accounts several participants reported having fistulas that had been created without much difficulty and had remained viable for many years. Isaac, who originated from Asia and had developed ESRD before immigrating, stated that his original fistula had continued to function 12 to 13 years since its creation:

> *"This fistula was done back home in (Country of birth) which is quite old, about 12/13 years old now, I don't know but it's still functioning"* (Isaac, 289-292).

Likewise, Flora referred to her current fistula, which she has had for approximately two years, as being *"…very stable…"*:

> *"Thank God that for quite a few years, at least two years I think, I've not had any of those problems, my fistula is very stable and I mean I know that anything can happen at anytime with dialysis it could clot, anything could happen"* (Flora, 656-661).

Flora's account emphasises the potential volatility of fistulas and her awareness of potential complications. Her use of the term *"…thank God…"* stresses her appreciation that she had not experienced such complications with her current fistula. Concern about the possible complications with fistulas was an anxiety shared by the majority of participants, especially as it would involve another surgical procedure and disrupt their haemodialysis treatment. Ari mentioned being aware of the seriousness of complications with the fistula through the experience of another patient whose fistula failed. He stated that knowing of his fellow patient's experience brought to light the seriousness of haemodialysis and the need to maintain his fistula:

> *"There was another chap whose fistula burst when he was at home and then I realised that even though I might just make light of it, it's quite serious"* (Ari, 1156-1159).

As if following on from Ari's account, Henry verbalised the importance of treating his fistula with care and consideration. He said that being the father of an infant child presents challenges in protecting his fistula, especially as any plaster or covering of his fistula would likely gain the attention of his eight-month old child:

> *"When my baby sees the plasters or anything on my arm it will go for it, he tries taking it off and that's really bad because after dialysis there can be a bit more bleeding, so you must be careful"* (Henry, 263-267).

Henry mentioned that following receipt of haemodialysis there can be further bleeding from the fistula, which is the connection point onto the haemodialysis machine. He continued by explaining that manipulation of the fistula increases the risk of possible infection and fistula failure:

> *"When there is new bleeding or something on the fistula it could get infected and then I probably would need to have another surgery to make another fistula to put my dialysis through, so I need to be really careful of that"* (Henry, 1019-1024).

In his interview, Henry spoke about the difficulties he faces in spending time with his infant child when he returns home from receiving haemodialysis. He mentioned that factors that contribute to it being difficult include feeling physical fatigued and having a lack of strength in the arm that he has the fistula. He also added that he tends to be highly cautious in protecting his fistula, which impedes his freeness when being with his child.

Needling: connecting the fistula to the haemodialysis machine

The procedure of creating the fistula and living with having the fistula was described by many of the participants as a challenging aspect of haemodialysis. The functionality of the fistula for haemodialysis treatment was also mentioned as being problematic by participants. For connection to the haemodialysis machine a large needle is required to be inserted through the fistula. Both Isaac and Boris commented on the size of the needle:

> *"They are very big"* (Isaac, 283-284).

> *"When you see them needles you think, 'woah, hold on a minute!'"*
> (Boris, 1298-1299).

Boris' *"...woah..."* response illustrates his astonishment at seeing the size of the needles. The process of the needle insertion through the fistula was generally depicted as an unpleasant experience by many of the participants. Emma stated that the needling aspect of haemodialysis was the main factor in her feeling apprehensive about commencing and continuing with haemodialysis:

> *"The needling, that's the main thing why I didn't want to come here"*
> (Emma, 358-359).

For Emma, it was the physical pain she associated with the needle insertion as opposed to a needle phobia that was the reason for her apprehensiveness and fear towards haemodialysis:

> *"I was so scared when they did the needling, I mean I didn't like to come for dialysis, that's the only reason I didn't want to come to dialysis because of the needling pain"* (Emma, 315-319).

Ari gave a paralleled description to Emma's account in referring to the needling process as *"…a painful process…"* (Ari, 315). Ari, who has type II diabetes, said that despite being used to needles due to self-administering regular insulin injections he found the needle insertions for haemodialysis to be a painful and unpleasant experience:

> *"I still hate when the needles go in, I haven't got a fear of needles, I'm diabetic so I am used to needles but it just hurts"* (Ari, 1349-1352).

Preparing the area surrounding the fistula for needle insertion was portrayed as a further cause of pain. Ari, whose interview took place immediately after receiving haemodialysis, reported feeling some discomfort in the area surrounding his fistula during his interview. This was as a result of the nursing staff on the Haemodialysis Unit needing to open up his fistula entry point in order to connect him to the haemodialysis machine:

> *"They've got to open up the wound, they pick my scab and they pick it and they pick it and they pick it and that hurts, it's sore now"* (Ari, 1352-1355).

As mentioned, many of the participants considered the needling aspect of dialysis as a painful and generally unpleasant experience. Isaac however was the only individual that mentioned the suggested use of an anaesthetic cream to help manage the pain from the needle insertions. Despite stating that he also found the needling aspect to be painful and that he was aware that anaesthesia would be available to manage the pain, Isaac reported that for an unexplained reason he chooses not to use the available anaesthetic cream:

> *"It's just the needling that is painful but they even give you cream for it"* (Isaac, 916-917).

Both Boris and Ari made assertions that either the needling aspect of haemodialysis was not as painful as others have depicted or that it had been suggested to them that it was not painful. Boris commented that he was aware that other patients complain about how painful the needling for haemodialysis was, even though this was in stark contrast to his personal experience and declaration that it is actually quite painless:

> *"I know a lot of patients complain that, "oh, I have got to have dialysis", "oh, the needles hurt", "oh, aww, all aches" and all that but that's all rubbish because it doesn't hurt"* (Boris, 23-27).

Boris continued by clarifying that when he initially started haemodialysis treatment about 15 years ago and each time he has returned to haemodialysis or had a new fistula created that the process of having the needle inserted has been painful:

> *"If somebody asks me I'd say first, "it bloody hurts, don't get me wrong but after a period of time your skin gets so hard that you don't feel it anymore""* (Boris, 1300-1303).

Boris' explanation suggests a period of adjustment that may occur as the site surrounding the fistula heals, which could lead to a reduction in the level of pain experienced by patients. In contrast to Boris, Ari was one of the participants with the least experience of haemodialysis and was one of the more vocal in expressing his displeasure at needing to endure the needles insertions. Whereas Boris had experiential knowledge of the physical sensations and pain associated being inserted with a needle for haemodialysis, Ari spoke on the frustration he feels when healthcare professionals on the Haemodialysis Units, that may not have similar lived experiences, inform him that the needling process is painless:

> *"They tell you that it doesn't hurt but I defy the nursing staff to be stabbed with two-inch needles, how many times a week? Three times a week and say it doesn't hurt because I'm telling you it does hurt"* (Ari, 320-324).

The accounts of Boris and Ari highlight the potential helpfulness in providing patients with peer support programmes that encourage the sharing of experiential knowledge between ESRD patients, which could be particularly beneficial in preparing newer patients to the various and complex aspects involved in receiving haemodialysis treatment. Similar to Boris, Janet and Cara also shared that the needling process necessary for haemodialysis is a process that they have adjusted to:

> *"It is a matter of you having to get used to it, you don't have an option so you just get on with it"* (Janet, 283-284).

> *"I've become very pain tolerant, I can suffer any pain"* (Cara, 1222-1223).

To mitigate the pain from the needle insertion and to provide patients with increased autonomy, patients have the opportunity to learn and deliver their own needle insertions. Emma and Cara discussed their personal experiences of being able to deliver their needle insertions. Emma mentioned that being able to insert the needle into her fistula allows her to dictate the position of the needle to help manage any discomfort:

> *"When you do the needling you know where it goes because your body knows the pain"* (Emma, 339-341).

Similarly, Cara stated that having the responsibility to insert the needles for her haemodialysis treatment allowed her to make subtle adjustments to reduce the pain she felt:

> *"I prefer to put the needles in because some of the nurses they don't care, they just shove it in but when you put it in yourself you can feel and you can twiddle it and get less pain"* (Cara, 305-309).

Both Cara and Emma commented on taking over the responsibility of inserting the needles from nurses on the Haemodialysis Units. Whereas Cara claimed that *"...some of the nurses don't care, they just shove it in..."*, Emma implied that occasionally nurses unintentionally incorrectly insert the treatment needle:

> *"Sometimes the nurses they don't know how to, they're doing a good job of course, but when they do it sometimes they put it in a different place but when you do it you know where exactly to go with the needle and that makes the blood flow quite easy and that gives you a good clearance as well"* (Emma, 341-347).

The commentary from Cara and Emma on their experiences of having the nursing staff administer the needle insertions may further explain Ari's earlier statement that nursing staff displayed a lack of understanding or empathy on the painfulness of frequent haemodialysis needle insertions. Despite the frustration and pain that Ari experiences in relation to his needle insertions he had decided to continue with assisted needle insertions, unlike Cara and Emma who both opted to receive training to self-administer their treatment. Emma stated that she was permitted adequate time to learn the necessary aspects to enable her to self-administer her treatment:

> *"They gave me time to learn and they didn't rush it"* (Emma, 1330).

The self-administered treatment extends beyond learning how to self-insert the haemodialysis needles to also learning how to function the haemodialysis machine. Cara expressed that she initially struggled with self-inserting the needles:

> *"The only thing that I had problems with was at first when I started doing the needling, when I started putting the needles in yourself but after a little while it just becomes so easy"* (Cara, 1209-1213).

Cara and Emma explained that after the initial period of learning how to administer the needles the process generally became easier, with them both feeling more at ease with their treatment:

> *"When you do your own needling and when you know about the treatment you're getting, it makes you feel more relaxed"*
> (Emma, 333-335).

The haemodialysis machine

In addition to sharing their views and experiences of their fistulas and needle connections, several of the participants spoke about another important component of their renal replacement therapy, the haemodialysis machine. Gina, who had previously explained that she feels physically uncomfortable and unwell in the lead up to certain haemodialysis sessions due to fluid retention, stated that she relies heavily on the haemodialysis machine to improve her physical wellness:

> *"I desperately need the machine, I know it will make me feel better"*
> (Gina, 814-815).

> *"It helps me feel relieved, the machine helps me"* (Gina, 516-517).

Gina's account highlights the necessity and functionality of haemodialysis to partly replace the function of patients' diseased kidney(s). For Gina, the haemodialysis machine was perceived as essential in helping to relieve the physical discomfort she experiences between treatment sessions. Ari described being connected to the haemodialysis machine for the duration of treatment as a dualistic process, where the patient becomes almost subservient to the machine for that time:

> *"It's almost like a dualistic thing where you lose yourself and for those five hours a day you become dependent totally on that machine"*
> (Ari, 324-327).

During his interview Ari articulated that he tends to personify the haemodialysis machine, perceiving it as another entity and having a personality:

> *"I almost personify the machine, almost think I've given it a personality"*
> (Ari, 470-471).

Ari also mentioned in his interview that he considered the overall haemodialysis experience to be dehumanising, where he relinquishes much of his independence, freedom and ability to live the life that he would prefer to have. This loss of self and dependency on a mechanical entity is evidently met with some resistance:

> *"Sometimes I feel like it is a battle of will between me and the machine"*
> (Ari, 475-476).

Despite being dependent on haemodialysis Gina described experiencing difficulties with the haemodialysis machine extracting excessive fluid amounts. Her following statement that *"…the machine gives me a hard time…"* possibly implies that, similar to Ari, she too feels submissive to the haemodialysis machines:

> *"The machine gives me a hard time, taking out too much fluid and making me feel weak with high blood pressure or low blood pressure"*
> (Gina, 443-446).

Similar to Gina's experience of hypertension and hypotension during receipt of haemodialysis, Flora expressed feeling physically restless when connected to the haemodialysis machine. She reasoned that her restlessness was caused by the functionality of the machine:

> *"When I'm dialysing, that blood pump on the machine, the pump is going, it's pumping the blood so what happens is that all that pumping, pumping, pumping it seems to make me really very restless"* (Flora, 1223-1227).

In contrast to the accounts of other participants, Boris declared that he notices no adverse sensations while connected to the haemodialysis machine:

> *"Nothing, don't feel anything, seriously I don't"* (Boris, 510).

3.1.2.3 Activities Before, During and After Receiving Haemodialysis Treatment

As part of the process of receiving haemodialysis treatment, which as discussed also covers the haemodialysis schedule and the mechanics of the treatment, all of the participants shared how their treatment influences the activities they engage in before, during and after attending hospital.

Activities before receiving haemodialysis

Emma and Flora stated that they attempt to complete certain duties and chores prior to leaving home to attend hospital for haemodialysis. Emma described undertaking duties such as housework and cooking her family's evening meal in the morning before attending her treatment:

> *"Before I come here I'll do the cooking and everything"*
> (Emma, 507-509).

> *"My slot is always afternoon, after twelve o'clock, so before I come at twelve o'clock I cook"* (Emma, 522-523).

Emma suggested in her interview that her identity as a parent was closely associated with her emotional wellbeing and that her identity had been threatened since her diagnosis with end stage renal disease. Maintaining what she perceives to be her parental responsibilities, such as cooking and housework, is perhaps vital for her psychological and emotional well-being. Similarly, Flora talked about preparing food for her family and carrying out regular household tasks. She also described ensuring that her children attend school before leaving for haemodialysis:

> *"I would do a little bit of my housework, make the sandwiches and everything then send them to school or take them to school and then go off again to dialysis and I wouldn't be back until 6 or 7 o'clock at night and they would be home by then"* (Flora, 487-492).

The homebased activities, namely cooking and housework, that Emma and Flora say that they complete before attending treatment would require a certain amount of energy. Considering that fatigue is a common side-effect that many patients experience as a consequence of haemodialysis it is possible that both Emma and Flora prioritise completing certain duties that directly influence their families while their energy levels were higher.

The majority of participants that had regular morning or afternoon haemodialysis sessions spoke about either taking their children to school or ensuring that they were able to get to school by other means. Isaac stated that on the days that he receives haemodialysis he routinely takes his son to school, then attends church before going for treatment:

> *"My normal routine is that I drop off my son to school and then I go to church, I go every day to mass"* (Isaac, 372-375).

Demi explained that her priority before leaving home to attend haemodialysis is making certain that her daughter is either taken to school or is ready to leave and attend school by her own means. She stated that on the days where she feels too low in energy to take public transport she would tend to arrange for a taxi to drive her to hospital. On such occasions Demi's daughter would often accompany her in the taxi to be taken to school. Demi expressed concern about her daughter's well-being when she takes her to school by taxi as it means that she arrives almost an hour before her school opens:

> *"I have to drop her early so she's in school, she don't have to be in the classroom until 8.40 and I'm dropping her off at 7.45 in the morning and she'll be standing in the cold"* (Demi, 369-372).

On the mornings when Demi goes to dialysis by bus, she explained how she ensures that her daughter is prepared for school beforehand:

> *"I can't leave her too early in the morning because she just wouldn't get ready, she'd just sit there and watch the telly, so I have to make sure that she's got her uniform on and everything"* (Demi, 379-383).

Demi's account highlights the challenges many of the participants describe in balancing their haemodialysis treatment with the care and needs of their children. It also indicates an aspect of the impact that haemodialysis has on the children of parents who have ESRD.

Activities whilst receiving haemodialysis

Patients receiving hospital-based haemodialysis spend approximately 12 to 20 hours per week on Haemodialysis Units, excluding waiting and journey times. All of the participants reported the various different ways in which they tend to use the time while on the Units receiving treatment. Emma stated that when she first started attending hospital-based haemodialysis she would frequently feel inpatient and unsettled by being stationary for the three to four hours of treatment:

> *"In the beginning it was a bit hard for me, to sit in one place and I'd be looking at the time all the time, I'd just want to go home"* (Emma, 420-423).

To ward off impatience and boredom while connected to the haemodialysis machine Boris recommended that fellow patients could remain stimulated with the use of electronics:

> *"When you're there just try to chill out, just get a little computer* or *little game console or DVD player, something to keep your mind occupied because a lot of people get bored"* (Boris, 1309-1214).

Boris' statement *"…when you're there just try to chill out…"* perhaps suggests that he believes that it is important to accept the necessity of the treatment and duration that each sitting usually takes. The use of electronic devices, such as game consoles and DVD players, might act as an effective distraction from the monotony of the hours connected to the haemodialysis machine, as well as the reality of their situation. Ari expressed that he believed that patients' attempts to remain preoccupied by various means while receiving treatment, for instance with reading, was in order to distract from the general experience of haemodialysis:

> *"For most people I think they are trying to ignore it and they pretend that it's not happening by reading a book and doing what they can"*
> (Ari, 328-331).

Ari later exclaimed that the environment on Haemodialysis Units tended to make it difficult to ignore the difficulties associated with receiving haemodialysis treatment, particularly with frequent interruptions by alarms from the haemodialysis machines. The environment of Haemodialysis Units is discussed later in this chapter. Despite of the environment, several other participants described being able to sleep during their treatment:

> *"Have a sleep if you can, some people are always snoring in there anyway"* (Janet, 292-293).

> *"I come here and go to sleep most of the time, I'll doze off and they have to wake me up to go home"* (Boris, 27-29).

Unlike Janet and Boris, other participants explained that falling asleep when connected to the haemodialysis machine does not come easy to them. Cara and Emma both reported that they feel too uncomfortable and stressed to sleep during treatment:

> *"I know some people can sleep but I can't"* (Cara, 112-113).

> *"I'm not relaxed enough to sleep, so I always keep awake"* (Emma, 480-481).

Similarly, Henry explained that the reason that he finds it difficult to sleep on the Haemodialysis Units during treatment is due to his awareness of having the needle inserted through his fistula and his anxiety of possible complications if the needle and fistula connection would become dislodged:

> *"I find it difficult to sleep because the needle is in my hand"* (Henry, 341-342).

Emma expanded on her earlier statement that she does not feel relaxed enough to sleep during receipt of treatment. She described feeling anxious that if she was to sleep and complications with her treatment were to occur then it may not be noticed by the nursing staff on the Units:

> *"Sometimes I think, 'oh, maybe if I sleep and if something happens no one's going to notice'"* (Emma, 458-460).

The accounts of both Henry and Emma highlights the acute awareness of the possible complications that can occur on haemodialysis, in addition to the general anxieties felt by being connected to the haemodialysis machine via the needling of the fistula. Ari reported having personally lived through a distressing experience while receiving haemodialysis. He stated that he suffered an episode of severe hypotension early in his treatment that resulted in unconsciousness, emergency medical attention and subsequent feelings of shame, loss and anxiety. Ari expressed fearing that if he was to sleep while receiving haemodialysis that he could experience a similar unfortunate episode again:

> *"I have to admit I find it quite difficult sleeping in there, that every time I might sleep that that could happen again"* (Ari, 705-707).

The apprehensiveness towards sleeping during treatment, as depicted by the likes of Cara, Henry, Emma and Ari, indicates a preference by some participants to maintain as much agency as possible to manage their anxieties. It also shows the challenges patients may face in following advice similar to Boris' earlier assertion that patients should *"…try to chill out…"* during treatment by engaging in certain pastimes.

Cara stated that she occasionally queries how effectively she uses the hours that she is connected to the haemodialysis machine:

> *"Sometimes I sit there and I think to myself, 'well I'm sitting here and this is so useless' but it's not useless"* (Cara, 167-169).

Cara's comment that *"…it's not useless…"* perhaps demonstrates her awareness that, although many hours is spent receiving haemodialysis, the primary function and purpose of haemodialysis is to sustain her life. She continued by explaining that she tries to use the time that she is connected to the haemodialysis machine by reflecting on her life. She stated later in her interview that she takes comfort during her treatment from remembering her deceased parents and fantasising on what they would be like if they were still alive:

> *"It's nice having the time to sit there and think"* (Cara, 383-384).

Having time to think was also mentioned by Flora and Demi. Both parents mentioned that their children remain their primary focus during treatment. Flora said that she worries that her children are being well cared for by family members while she attends treatment, whereas Demi stated that she thinks of her daughter and worries for her well-being while she is at school:

> *"You're thinking, 'I hope they're OK and nothing has gone wrong'"* (Flora, 939-940).
>
> *"Worrying if she's OK"* (Demi, 952).

Emma, who earlier described being too anxious to sleep whilst receiving haemodialysis, said that she prefers to use the time that she is on the Unit constructively. She explained that she is motivated to use the time to complete certain responsibilities, such as paying utility bills or replying to correspondence, as it creates additional time between her treatment sessions to spend with her family. This use of time seems particularly important considering the side-effects common to haemodialysis, especially fatigue, and how it is not only the duration and frequency of treatment sessions that limits patients' availability and engagement with their family:

> *"Now, I take that time to do something important and do something with that time"* (Emma, 416-418).
>
> *"Things I have to do at home I can save the time by doing it here, so I can spend more time with my family"* (Emma, 410-412).

For many of the participants, time on the Haemodialysis Units while connected to the machines was passed using electronic devices, such as laptops and tablets, or by reading books or magazines. Janet and Isaac shared that they use electronic devices that were gifted to them by family members:

> *"I have an iPad my husband bought me, so I normally bring that"* (Janet, 289-290).
>
> *"I bring my laptop, which is connected to the internet too, my brother bought it for me and I have a lot of things to watch on there"* (Isaac, 304-306).

With Henry passing the time by watching movies on and Cara frequently reads magazines or watches a show on the televisions that the Unit she receives her treatment at has available:

> *"I usually take my iPad in and watch movies"* (Henry, 342-343).
>
> *"I either read a magazine or I watch the TV because I can't sleep in there"* (Cara, 111-112).

Similarly, both Gina and Janet prefer to read while receiving haemodialysis:

> *"I prefer reading, when I read whilst on dialysis I don't notice the time"*

> (Gina, 833-834).

> *"I used to bring books in but now I have my iPad I have just download them onto there"* (Janet, 297-298).

Demi also explained that she attends her treatment sessions with sufficient reading material:

> *"I buy these magazines and I'm not even reading them, I just look through them and put them back in the bag or leave them on the side for somebody else to read, I mean I must spend about £20 to £30 a week on magazines, it's ridiculous"* (Demi, 456-460).

It is worth reflecting on the financial burden that patients may experience in engaging in pastimes during the hours that they receive haemodialysis, from the cost of reading materials to the cost of electronic devices, such as tablets. All of the participants explained that maintaining employment with haemodialysis as their renal replacement therapy had not been possible, and as a consequence many described experiencing financial restrictions. It is possible that financing the activities that help to manage the tedium of being connected to haemodialysis machines could contribute to the financial burden that many of the participants described experiencing.

Hunger and fantasising about food happened to be an experience that both Flora and Henry discussed having while they are receiving haemodialysis. Flora mentioned that she enquired with one of the nursing staff on the Units for the reason why she feels so hungry while on haemodialysis:

> *"On dialysis I get really hungry and I have to bring food with me to have on dialysis. I asked one of the nurses, "why do I feel really hungry during dialysis?" and she said, "it is because all of your organs are working hard on dialysis so you need to eat to keep up with it""* (Flora, 1233-1237).

For similar reasons, Henry expressed that he frequently fantasises about food when connected to the haemodialysis machine. Both Flora and Henry spoke about bringing food onto the Units to eat during their sessions. This seems particularly important for Henry as he later explained that he tends to feel too exhausted to eat after sessions:

> *"During dialysis I think, 'I would love to eat this, I would love to eat that'"* (Henry, 364-366).

Cara, Demi and Ari all described the environment of the Units in relation to their fellow patients. Cara and Demi illustrated there being a communal connection with other patients, which lends to enabling them to develop relationships with their fellow patients:

> *"Everybody is quite talkative and so you just chat to pass the time away"* (Cara, 147-148).

> *"It's not too bad, you get to know people"* (Demi, 334).

Ari's experience of his fellow patients on the Haemodialysis Units is very different to those expressed by Cara and Demi. He referred to the experience of receiving haemodialysis as *"…a very lonely process…"* with little meaningful human contact:

> *"There is no real interaction, so it can be a very lonely process"* (Ari, 243-245).

According to Ari, the lack of interaction with other patients on the Units contributes to receiving haemodialysis being a lonely and isolating experience. Ari suggested that the apparent isolating nature of haemodialysis is the reason for patients to engage in solitary activities during their treatment:

> *"I've noticed that very little conversation actually takes place there. People seem to be very isolated, that is why people tend to either sleep or they have headphones on or read a book but there is no real communication"* (Ari, 245-249).

Activities after receiving haemodialysis

In this section participants share how they are and what they tend to do following haemodialysis treatment. Tiredness and fatigue were reported as common features experienced by all of the participants after receiving haemodialysis. For Henry, returning home to rest immediately after leaving hospital was important to him:

> *"Once I get out of dialysis I go straight home, I don't stop at any shop or anything, I just go straight home and relax"* (Henry, 362-364).

As with Henry, Gina also spoke of requiring rest in a peaceful, quiet environment after treatment:

> *"I need nothing but quiet, I need quiet and not care about much else"* (Gina, 1531-1532).

Despite Gina's desire to recuperate after haemodialysis in a restful and undemanding setting, she mentioned that this was often difficult to achieve as she would need to care for her son when she returned home from hospital. This is explained further later in this section. Other participants also spoke about requiring rest in the immediacy following treatment. Emma expressed that she prefers to not schedule any additional commitments or activities on the days that she receives haemodialysis in an attempt to manage her tiredness:

> *"On dialysis days I don't book any other work or anything on those days because after I go from dialysis I'm a too tired to do any work"* (Emma, 503-506).

Similar to Emma, Cara describes feeling exhausted when she returns home from hospital after treatment. She stated that she tends to limit her activities, with cooking for her family often being the only activity she feels able to manage:

> *"When I get indoors like the most I can do is cook for the day and that's it, me finished, can't do no more"* (Cara, 172-174).

Cara added that her family, particularly her husband and her older children, also take on the responsibility of preparing food for her family on her treatment days. She expressed that the support she receives from her family on the days she receives haemodialysis is important for her in managing her fatigue. Likewise, Flora conveyed that her family's understanding and support had been integral in enabling her to rest after haemodialysis:

> *"Most of the time my family is quite understanding, so when I go home I can relax, I can rest, I can have a bite to eat and then I can just rest"* (Flora, 666-671).

Being the parent of younger, more dependent children was highlighted as being particularly challenging for haemodialysis patients. The participants that were parents to young children expressed that the opportunity to use the remainder of the day to recuperate from haemodialysis was frequently not possible due to their parental responsibilities. Flora expanded on the extract above that she was able to return home and relax following haemodialysis with far greater ease now that her children were older. Demi and Cara, who were both mothers to school-aged children, stated that they tend to return home after treatment for a brief rest before either being ready for their children to return home from school or leaving to collect them from school:

> *"I go home, have a sleep and then by the time I wake up she's just coming back from school and the same on Wednesdays, same on Fridays"* (Demi, 341-344).

Cara spoke about how she at times feels ashamed that she has not always been present for her children, especially her two younger children, due to her attending haemodialysis:

> *"Even when I do dialysis and I've had a couple of hours sleep, it doesn't matter how things have gone, I'll go and pick them up from school because then I don't feel so bad"* (Cara, 628-632).

Here, Cara captures the delicate balance between being a patient on haemodialysis and meeting one's parental responsibilities, particularly with regards to the feelings of guilt and shame that may accompany not meeting one's expectations of being a parent. She explained in her interview how important it is to her that she attempts to maintain an air of normality with regards to her children by continuing with certain tasks, such as collecting her children from school, regardless of her physical condition after haemodialysis. By the same token, Emma's priority after her return home from treatment is to care for her children rather than to recuperate as other participants described doing:

> *"I can't just go and sleep in bed, I have to look after my children"* (Emma, 126-127).

Whereas Flora previously stated that she tends to return home to rest after she receives haemodialysis, she explained in her interview that this had not always been the case. She expressed that when her children were younger she would need to leave her children in the care of a childminder while she attended hospital and collect them when her session finished:

> *"After dialysis it was very difficult to go and pick up the kids, take them home and see to them because after dialysis you're just not right"* (Flora, 1008-1011).

Flora portrayed a very arduous journey on public transport that she would routinely need to do to collect her children from the childminder's. She noted that her physical condition and her fatigue after haemodialysis were the main reasons for it being so difficult. She stated that regardless of the degree that she felt unwell and tired after her treatment she would still need to use different types of public transport to collect her children and continue to care for them once they returned home, all without having the opportunity to recuperate. This, she said, changed as her children became older and would either be at school as she attended hospital or in later years they became more independent:

> *"I remember being knackered afterwards and I had to go to get the kids after dialysis, pick them up from the childminders, take the bus and then bring them home and then see to them as well, they were very young, that was very difficult, it was very, very difficult"* (Flora, 992-998).

Similar to other participants, Gina, who is a single mother of her young son, explained previously that after treatment she frequently feels the need to return home and be in a peaceful environment with no demands placed on her. She also described however the dilemma she experiences in managing her fatigue and dealing with the demands from her son:

> *"He says to me, "I want you to cook something" and I say, "I cannot cook tonight I am so tired, I cannot cook anything, I need somebody to cook for me" and he says "but mummy I need this, this and that""* (Gina, 372-376).

Both Henry and Emma described spending time with their family when they return home from treatment:

> *"After dialysis when I get home I do spend some time with my baby and my wife and my family"* (Henry, 468-470).

Henry stated that he enjoys spending time with his family, including his infant child, after he has had adequate rest following haemodialysis. Emma, who expressed that she often does not have the opportunity to sleep or rest when she returns home after treatment, said she considers it important that she speaks with her children individually and demonstrate her interest in their well-being:

> *"I talk quite a lot with them after I go home from dialysis"*
> (Emma, 826-827).

Activities on non-treatment days

All of the participants spoke of the differences, and in some cases the similarities, between the activities they engage in on the days that they receive haemodialysis compared with the days that they do not. Emma verbalised feeling more relaxed on non-treatment days:

> *"When I wake up in the morning and say "oh, I don't need to go to dialysis today" I feel a bit more relaxed"* (Emma, 500-502).

Emma's comment highlights the relationship between her realisation of it being a non-treatment day and a reduction in her stress, which conversely suggests that she possibly experiences heightened stress on the days that she receives haemodialysis. Both Cara and Henry spoke of feeling *"...brilliant..."* and *"...good..."* on non-treatment days:

> *"The days I don't do it I feel absolutely brilliant"* (Cara, 52-53).

> *"I feel really good"* (Henry, 449).

Flora also spoke of feeling positive on non-treatment days:

> *"When I'm not on dialysis and at home I'm happy"* (Flora, 646-648).

One reason that Flora provided for feeling more positive on non-treatment days was that she would not be *"...tied up to the* [haemodialysis] *machine"*:

> *"It's very nice, just relaxing and I can do whatever I want, I can cook and I'm not being tied up to the machine"* (Flora, 648-650).

Flora's comments of *"...not being tied to the machine..."* and that she can *"...do whatever I want..."* implies that when she does not receive haemodialysis she feels freer and by the same token receiving haemodialysis perhaps restricts what she can do. Henry and Isaac both spoke about being incapable of fitting all the activities they were unable to do on treatment days into non-treatment days:

> *"I feel like doing everything that I can't do on dialysis days, although there is not enough time"* (Henry, 449-451).

> *"Sometimes a day is not enough for me to do everything"* (Isaac, 465-466)

For several of the participants non-treatment days were the days they used to complete household chores, such as cleaning and cooking:

> *"The days that you are not here are the days that you do the housework"* (Cara, 174-176).

> *"I'm at home doing some housework and like a normal person I do everything"* (Emma, 488-489).

> *"When I'm well I do my own housework, cook for my son, cleaning and everything"* (Gina, 983-985).

Gina continued by saying that she often starts the weekdays that she does not receive haemodialysis by helping her son to get ready for school:

> *"I get my son ready for school"* (Gina, 897).

Likewise, Janet helps her children to get ready for school before using the remainder of the day to rest or complete everyday tasks at home:

> *"I just potter about in doors or go back to bed because I get up early to set the kids off to school"* (Janet, 340-343).

Like Gina and Janet, Cara described planning her activities on non-treatment days around her commitment to collect her children from school:

> *"If I've got any shopping to do I'll go and do the shopping and by the time I've done everything the kids are in from school or it's time to go and collect them"* (Cara, 828-831).

Boris, who earlier explained that he would frequently enquirer about rescheduling his haemodialysis slot to an earlier time so that he could help support his wife with caring for their children, stated that he tends to use the time on non-treatment days to be with his wife or visit other family members:

> *"I've got a big family as well, so we go see my mum, go and visit my wife's mum and nan or whatever but really that can only happen on Tuesdays and Thursdays, which are also the only days of the week where me and my wife can go shopping or whatnot"* (Boris, 568-573).

In addition to spending time with his wife, Boris spoke about using the time on non-treatment days to engage in different activities with his children. Being in the company of their children appears to have been an activity that the majority of the participants described enjoying on their non-treatment days:

> *"I do stuff with the kids"* (Boris, 560).

> *"On days I'm not on dialysis I spend a lot of time with my baby"* (Henry, 401-402).

Henry spoke passionately about having the opportunity to be with his infant child and attend to his needs when not receiving haemodialysis:

> *"I get to see him cry, laugh, he is watching telly as well, so he's sitting there sucking his thumb watching telly with me, I get to change his nappies and everything, feed him, it's lovely"* (Henry, 406-408).

Using the time they have on non-treatment days to be with their children seems particularly important for the majority of the participants. This is potentially because on treatment days all of the participants are absent from their children for significant periods of time. This is in addition to them experiencing side-effects from haemodialysis that impacts on their ability to be present with their children and be the parents that they would ideally prefer to be. Both of these reasons contribute to the participants having less available time with their children on treatment days. Cara conveyed that she makes a conscious effort to not only be with her children on non-treatment days but to also plan enjoyable activities with them:

> *"I make that a point, I have to spend time with them, I have to"* (Cara, 751-752).

> *"When I'm at home I try to do extra, try to do things with them, so tomorrow no doubt we'll have an adventurous day somewhere"* (Cara, 1175-1177).

Cara mentioned earlier that when she returns home from haemodialysis on treatment days she ensures that she collects her children from school to negate any feelings of guilt for how her illness or treatment may affect them. Cara's assertion that *"...I make a point, I have to spend time with them, I have to..."* perhaps demonstrates her desire to minimise any negative effect that her haemodialysis treatment, particular her absence from home and subsequent fatigue, could have on her children. Henry stated that although adequate rest after receiving haemodialysis is helpful for his recuperation, he stills experiences the weakening effect of his treatment on non-haemodialysis days:

> *"Even the day after dialysis sometimes you will feel weak and you don't want to go out"* (Henry, 202-204).

Similar to Henry, Ari expressed having little energy on his non-treatment days:

> *"I just want to sleep"* (Ari, 1249).
>
> *"I spend a lot of time sleeping during the daytime if I can, yeah, I just potter about doing stuff I like to do which is often nothing much"* (Ari, 650-653).

Ari reported that he generally experiences low energy levels regardless as to whether it is a treatment or non-treatment day. He however expressed that he can feel particularly fatigued in the immediacy after treatment. Throughout his interview Ari alluded that he had found the adjustment of having a chronic illness and requiring haemodialysis a difficult transition to make. He mentioned his illness had altered his appraisal of himself as a father and a husband and had triggered characteristics that are symptomatic of depression. As to whether Ari's desire to sleep and his general apathy was as a result of fatigue or his general emotional state was undetermined during the interview:

> *"Nothing, absolutely nothing, I do nothing at all"* (Ari, 590).

Conversely, Cara stated that she purposefully does not sleep during the day on non-treatment days:

> *"I do not sleep, I do not go to bed on the days that I don't do dialysis, I've made that a point"* (Cara, 739-740).

3.1.2.4 Journey To and From Receiving Haemodialysis

Journeying to and from hospital to receive haemodialysis treatment was highlighted by the majority of the participants as a significant aspect of the haemodialysis process. Two factors were noted as being particularly influential with regards to the journey to and from hospital: firstly, the additional demands it puts on participants' time and the time that they are away from their children; secondly, the impact the side-effects of haemodialysis has on their journey.

Boris described the journey he would make to a Haemodialysis Unit where he used to receive treatment. He mentioned that after attending the same Haemodialysis Unit for eight years he had adjusted to the regular travelling:

> *"I spent, must be nearly eight years travelling backwards and forwards to (hospital name), which was three times a week and it was just a matter of life, I just got on with it"* (Boris, 201-204).

For a minority of the participants, they found travelling to and from hospital by their own means removed some of the strain of the journey. Isaac mentioned that he found the journey to hospital to be *"…very simple…"* as he was able to drive himself for treatment:

> *"It is very simple because I drive to come here"* (Isaac, 72-73).

Henry also preferred to drive to hospital by his own means. He mentioned however, that on a few occasions he had suffered hypotension as a result of haemodialysis that prevented him from traveling home immediately after treatment:

> *"There are certain times when it happened to me after dialysis when I was going home, whilst driving and my blood pressure might go low, gets low, so I have to stop, take a rest and drive again as it can be really dangerous"* (Henry, 249-254).

Henry's experience highlights the difficulties the side-effects of haemodialysis can have on driving from hospital following treatment. Cara stated that she felt unable to drive herself to and from hospital due to how she often feels physically unwell immediately after treatment:

> *"Some people can come here and they park their car and they drive home, I can't do that"* (Cara, 193-195).

Cara continued by explaining that as she does not drive herself to hospital, on the occasions when she feels unwell after haemodialysis, she contacts her older children or husband to enquire whether they are able to drive her home:

> *"If I finish from dialysis and if I don't feel well and if somebody is at home they'll come and pick me up"* (Cara, 489-491).

Further to Henry's and Cara's descriptions, Demi mentioned that she would tend to arrange a taxi to take her home after haemodialysis as opposed to traveling on public transport when she feels unwell. Demi's account highlights the additional financial cost placed on patients:

> *"Some days I don't bother getting a bus, I just, if I'm feeling really, really drained then I just take a cab and I'll go home, that's like £7 a time, it's a lot of money"* (Demi, 360-363).

Remembering the period when her kidney transplant failed, Flora expressed feeling bitterly disappointed at needing to return to haemodialysis as her renal replacement therapy. She stated that the additional travelling and being absent from her children while she attended hospital were the main reasons for her disappointment:

> *"When I went back on dialysis there was a lot of travelling I was having to do again and again I had to leave the children behind"*
> (Flora, 482-484).

The additional travelling that Flora mentions was in part due to the Haemodialysis Unit where she received treatment at the time being far from her home:

> *"I was finding that when I was very far away at (hospital name) and I would have to come back, walk to the station then take the train, it was a long journey home and it was something I used to feel bitter about"*
> (Flora, 1040-1045).

Similar to Flora's bitterness towards the travelling to and from hospital that she would need to do, Janet vocalised her displeasure at needing to take several different forms of public transport to her haemodialysis:

> *"I had to get public transport, train, buses"* (Janet, 257-260).

> *"Horrible, horrible experience, hated it"* (Janet, 235-238).

Janet's journey time reduced dramatically once she was able to secure a transfer to a Haemodialysis Unit nearer her home. The move nearer to her home also enabled her sons to visit her when she was on the Unit and allowed her to spend the time that she would have been travelling with her family:

> *"To be nearer the boys, if they need me, they can walk over here and see me if they want to"* (Janet, 758-759).

Both Flora and Janet complained that they were required to undertake such a regular and gruelling journey in order to receive haemodialysis. Both participants stated that they had requested support with patient transportation but were unable to secure additional help. Flora expressed that she felt *"…bitter…"* that she was not granted additional support with transport:

> *"I felt bitter that after dialysis I had to make that trek on my own, I used to feel bitter that they didn't give me transport, I was asking them but they said "no sorry you are young, you should be doing it yourself""* (Flora, 1045-1050).

Likewise, Janet spoke about not being granted transportation support. She expressed feeling angry that additional help was not provided:

> *"I turned around and said to her, I tell you what, you live for one day my life and then tell me that I don't need transport"* (Janet, 247-249).

The provision of additional support with transportation was noted by Flora as an essential accompaniment to care for parents that receive haemodialysis:

> *"When they have kids they should be given transport"* (Flora, 1039-1040).

The additional demands travelling to and from hospital for haemodialysis, particularly when the location of the Haemodialysis Units are far from the patient's home, and the extra strain that the side-effects have on patients seem to contribute significantly to the challenges faced by a number of participants.

3.1.3 Haemodialysis Side-Effects

Some of the side-effects common to haemodialysis were reported by all of the participants as having a frequent presence in their lives. Ari referred to the side-effects that accompany the end of his haemodialysis sessions as *"...unpleasant..."*:

> *"It has unpleasant aftereffects"* (Ari, 196).

Ari recalled that he first experienced adverse physical symptoms by the time he attended his second haemodialysis session. He explained that following his second treatment session he experienced the onset of mobility difficulties and intense limb pain that continued for approximately two months:

> *"By the second dialysis treatment I had I couldn't walk and my leg, I just couldn't walk, I was on crutches and hobbling, had intense pain in my legs and this dragged on for about two months"* (Ari, 200-204).

Emma also associated the occurrence of back and leg pain with being a side-effect of her haemodialysis:

> *"Sometimes when my calcium goes down I get this back pain and the leg pain, apart from that I'd be OK"* (Emma, 307-309).

In addition to Ari and Emma, Flora and Isaac shared their experiences of the physical effects of haemodialysis. Flora commented that following her treatment sessions she frequently feels physically restless:

> *"After dialysis you find that you're really, your whole body feels restless"* (Flora, 1240-1241).

Whereas, Isaac explained that when he first started on haemodialysis in his Country of birth he would repeatedly feel unwell following his treatment:

> *"It is very difficult, I don't know the reason but back there I was getting nausea and everything"* (Isaac, 77-79).

Isaac's account and description that *"...it is very difficult..."* typifies the general portrayal by all of the participants that the side-effects intensify the challenges that are faced by receiving haemodialysis. One of the more common side-effects that a number of the participants reported enduring was hypotension. For Isaac, although he had experienced hypotension while he has been receiving haemodialysis, it had been a far less frequent occurrence than it had been for other participants:

> *"I have been dialysing for nearly seven years now but apart from one, two, maybe three days when I went a bit low, that's it, otherwise I've been OK"* (Isaac, 80-82)

For Henry, hypotension was a more frequent by-product of haemodialysis that would result in exhaustion:

> *"After dialysis my blood pressure goes low and I'm exhausted"* (Henry, 245-246).

Henry had previously mentioned that hypotension following haemodialysis had on occasions prevented him from driving home from hospital. Both Demi and Cara shared that hypotension during and after haemodialysis have led to them both feeling physical unwell. For Demi, hypotension was noted as the main cause of her feeling unwell after haemodialysis:

> *"Only when my blood pressure is really low I feel dog rough after dialysis"* (Demi, 442).

While Demi cited that for her hypotension mainly occurs after haemodialysis, Cara explained that it is during the final period of being connected to the haemodialysis machine that her blood pressure goes low:

> *"My blood pressure drops and then I feel really rough, which tends to be in the last hour an half or so"* (Cara, 76-79).

Hypotension during the course of treatment for both Cara and Ari had resulted in each of them losing consciousness while on the Haemodialysis Unit. Cara, who had lost consciousness twice while connected to the haemodialysis machine, explained that she remains apprehensive that it could happen again:

> *"A couple of times I've blacked out on the machine, so I think that's always at the back of your mind"* (Cara, 97-99).

Ari's account of experiencing hypotension on the Haemodialysis Unit details an episode that he found to be highly *"...traumatic..."* and a *"...horrible..."* experience:

> *"I went low and when I came back around I heard everyone around me shouting "Ari", machines bleeping away, I was in the recovery position and I had soiled myself and vomited all over myself and it was a very traumatic experience"* (Ari, 701-705).

> *"That really, really was a horrible experience"* (Ari, 708-709).

Ari continued by stating that the episode of him suffering hypotension on the Haemodialysis Unit resulted in feelings of shame and humiliation, especially as it involved him losing control of his bladder and bowels:

> *"All resemblance of pride had gone just like that"* (Ari, 800-801).

In addition to hypotension, the majority of the participants spoke about the incapacitation they have experienced as a result of fatigue following haemodialysis. Demi reported experiencing periods when she feels drained of energy:

> *"Some days you're like, 'oh my God, where's the energy gone?', it's like somebody's sucked it out of you"* (Demi, 539-541).

Both Cara and Emma mentioned that they frequently feel fatigued once they have disconnected from the haemodialysis machine:

> *"You know you're going to be tired when you come off the machine"* (Cara, 935-936).

> *"I only get the tiredness after I come off dialysis"* (Emma, 304-305).

Henry illustrates being too debilitated by fatigue following haemodialysis that he struggles to muster even sufficient energy to eat:

> *"When I get home there is no energy, I can't even eat because when I'm biting into food I just feel exhausted"* (Henry, 257-259).

As mentioned previously, the majority of the participants attempt to manage their fatigue when they return home from treatment by recuperating with sleep. For a minority of the participants however this was not always an option due to their childcare commitments. Flora advised that now that her children were older, having the opportunity to sleep and rest following haemodialysis was sufficient in managing the effects of fatigue:

> *"It lasts until I've gone to sleep and I wake up refreshed, then I feel OK"* (Flora, 1249-1250).

Contrary to Flora's account, Janet suggested that fatigue has a constant presence in her life and that it worsens following her haemodialysis sessions:

> *"It makes you very tired but you are tired anyway"* (Janet, 187-188).

3.1.4 Haemodialysis Ward Environment and Care

The environment on the Haemodialysis Units and the care they receive while on there was noted by the participants to be important elements of their overall experience in receiving haemodialysis. Ari somewhat simplified his perception of the Haemodialysis Unit by referring to it as *"...a challenging environment..."* (Ari, 1358-1337). He expanded on his impression of the Haemodialysis Unit environment with an enlightening illustration. He mentioned the apparent efforts made with the interior design of the Unit he is attending to create a more tranquil environment:

> *"They try, you know, it's a nice, pretty building with nice blue clouds and sun covered with candescent fluorescent lights"* (Ari, 1337-1340).

Despite the apparent decorative efforts, Ari stated that it did little to change the overall sense he feels when on the Haemodialysis Units. He named the different aspects of the environment that contributes to it being such a challenging space to be in, including the aforementioned mechanical components of haemodialysis:

> *"The whole clinical nature of it and the needles and the machinery and the bleeping and the noise and the smell of death in the ward"*
> (Ari, 189-191).

Ari continued by powerfully emphasising the connection he makes between haemodialysis, the hospital environment and death:

> *"It is what it is, it's a morgue waiting to happen, delaying death"*
> (Ari, 1340-1341).

Death was a reoccurring topic for the majority of the participants, from a general awareness of the primary function of haemodialysis to sustain life through to being exposed to the death of other haemodialysis patients. The subject of mortality is explored in further depth later in this chapter. Ari was not alone among the participants to have witnessed or heard about a fellow patients' death. The experience, he said, sends *"...a shiver down my spine"*:

> *"Since I've been here on dialysis, a number of patients have died"* (Ari, 1148-1150).
>
> *"When I see somebody on the ward die, that does send a shiver down my spine"* (Ari, 1312-1315).

As though referring to Ari's description of the Haemodialysis Unit environment as resembling a mortuary and the temperature of a mortuary, Cara spoke about how inhospitable she finds the climate on the Units:

> *"In there it's freezing"* (Cara, 428).

The *"...freezing..."* temperature on the Units appears to be so uncomfortable for Cara that she finds it a challenge to regulate her temperature enough to be comfortable, regardless of her efforts:

> *"I'll have two, three blankets in there and it's still not enough"* (Cara, 426-427).

As well as the uncomfortable climate on the Units, the participants portrayed an environment that is noisy and frequently disturbed by the sounds produced by the haemodialysis machines:

> *"The whole dialysis experience it's always punctuated by bleeps and whistles and alarm sounds"* (Ari, 331-333).

Ari spoke of his worry and the anxiety caused when he first heard the alarms ring out from the haemodialysis machines. His reaction likely highlights his general unease with receiving haemodialysis, particularly during the early stages, which perhaps contributed to a more hypervigilance state and his alert response to hearing the machine alarms:

> *"The first few times when this happened to me I was asking, "what's wrong? What's wrong? What's wrong?""* (Ari, 343-345).

As the haemodialysis machine alarms are an audible indicator to that machine or the connected patient requires attention, it is perhaps understandable that many of the participants were able to speak about witnessing other patients encountering difficulties while on the Units. Flora suggested that she observes other haemodialysis patients having difficulties and in distress while receiving treatment:

> *"When I look around me when I'm dialysing, most of the time what I see is that people are having lots of problems, their lines are not working or something is wrong"* (Flora, 653-656).

Additionally, Ari described being on the Units and observing when other patients suffer hypotension and the reaction of the medical team when it happens:

> *"When somebody gets low everyone's rushing about and crash carts get introduced. It's like watching something out of ER"* (Ari, 1325-1327).

The above descriptions illustrate a highly challenging environment that the participants are exposed to three times a week for an estimated four hours per session. The participants' appraisals of the care they receive while on the Units varied, with some participants expressing being satisfied with their care and others being less so. Ari mentioned the impersonalised nature of the care that patients receive when on the Units:

> *"I think the person gets forgotten about here because you are just a patient"* (Ari, 503-505).

He reasoned that the impersonalised care received was as a result of tendency to focus on the treatment of the disease, rather than the well-being and inclusion of the patient:

> *"Because of the whole epidemiological way of looking at medicine, patient treatment and whatnot, they have clinicised the patient as opposed to working with the person"* (Ari, 498-503).

Similar to Ari, Gina and Janet also spoke about being displeased with the nursing care received on the Units. Gina, like Ari, described believing that the care she received on the Units was largely impersonal and was especially evident in her interactions with the nursing staff:

> *"It's staff, they talk to me like, I don't know, like I am nothing but I am something"* (Gina, 738-740).

Gina believed her treatment schedule, with frequent attendance to the Haemodialysis Units, was a factor for nursing staff speaking to her uncompassionately:

> *"Sometimes I think if they wouldn't see me all the time maybe they would not talk to me like that"* (Gina, 744-746).

Gina's reasoning for receiving the care she has from the nursing staff on the Units suggests that the intensity of haemodialysis and the *"challenging environment"* of the Units not only adversely impacts patients but also the staff that work there. It is worth considering the impact of the treatment environment on the well-being of the healthcare staff and how this in turn intensifies patients' experiences. Janet spoke of receiving a lack of empathy from nursing staff when she informed them that she was feeling unwell towards the end of one of her treatment sessions:

> *"I thought that this was very unprofessional and when you get smart remarks like that, you think to yourself why bother"* (Janet, 250-252).

Despite the above account, Janet said that she generally considered the nursing staff on the Unit she is attending for her treatment to be caring and compassionate professionals:

> *"The nurses are lovely and you do get on with everyone"* (Janet, 309-310).

Likewise, other participants spoke positively when speaking about the nursing staff on the Units. Both Demi and Ari used the term *"…lovely…"* when describing them:

> *"They're lovely here though, they're really nice"* (Demi, 471-472).

> *"The nurses are lovely"* (Ari, 1422-1423).

In addition to the other positive comments, several other participants spoke in glowing terms when speaking about the Units nursing staff. Flora, Emma and Boris shared how they considered the support and care they received directly from the medical staff to be positive:

> *"I'd say that the nurses are generally good"* (Flora, 1106-1107).

> *"They've given me really good support"* (Emma, 1319).

> *"I have got the upmost faith in the doctors and everything at (hospital name), they are really good at what they do"* (Boris, 1174-1176).

Boris continued by explaining that the *"...upmost faith..."* that he has in the medical staff at the hospital leads him to feel secure and safe in their care:

> *"To me, the staff, all of them, they know what they are doing and I do feel safe"* (Boris, 1392-1394).

The sense of security described by Boris appeared to ease the burdensome nature of haemodialysis for him. He went on to talk more about the people he shared the Haemodialysis Units with over the years particularly his experience in regards to this at a previous unit. Along with Janet, Boris shared their feelings of connection to staff and patients on the Units to such an extent that they described at like being part of an extended *"...family..."*:

> *"It was almost like a big family and that was good, that was really good"* (Boris, 1410-1415).

> *"It is like a little second family...you get to know everyone and yeah it's really good, well not good but it's nice"* (Janet, 307-309).

Flora explained that being on the Haemodialysis Unit and observing other patients that appear to be more effected by their condition helps her to appreciate her current situation and reduce the possibility of self-pity:

> *"When I look around me people are worse off than me, I'm alright, I'm stable, so I just have my dialysis and I go home and rest"* (Flora, 661-664).

One of the features of receiving treatment alongside other patients that displeased both Boris and Ari was the tendency for some patients to complain about their haemodialysis experience. Boris, who stated that he had been feeling part of a large family at the unit he had received treatment, expressed that he believed that other patients had little reason to complain:

> *"I look at people out here and think, 'you're moaning, no you have no reason to moan'"* (Boris, 689-691).

For Ari, hearing negativity from other patients while on the Units was mentioned as the primary reason why he isolates himself from other patients, despite referring to haemodialysis as a lonely experience:

> *“Because of the amount of time they spend whinging I’m not interested”* (Ari, 919-920).

3.2 Major Theme Two:

The Lived Experience of Parents with End Stage Renal Disease

3.2.1 Being a Parent

Throughout the interviews, the participants discussed what being a parent meant to them. For each of them being a parent was core to their identity, with some participants describing a change to that identity and their role as a parent since developing end stage renal disease. The meaning attached to being a parent was described as wholly positive among the participants. For example, both Henry and Ari expressed the love they have for fatherhood:

> *“It’s lovely to be a parent”* (Henry, 720).

> *“Being a dad, I love it”* (Ari, 925-926).

For Cara and Emma, there was no aspect of being a mother that they did not find pleasurable:

> *“Everything about parenting is good”* (Emma, 854).

> *“I enjoy everything about it”* (Cara, 1039-1041).

Cara added that simply being a part of her children’s lives as their parent, from birth through to adulthood, was what she enjoys the most about being a mother:

> *“It’s everything, from the time they’re born to the time that they get married”* (Cara, 990-991).

The above account and use of the words *“…it’s everything…”* highlights what it means to Cara to be a mother and how central it is to her identity of self. Henry also spoke about how he enjoys his role as a parent and the different responsibilities that come with it:

> *“I enjoy most things about having a kid, changing his nappies, looking after him, playing with him, when he cries you just look at him and laugh*

> *because usually he cries for no reason, they even cry when they want to go to sleep, that's what I love, it's lovely"* (Henry, 746-751).

Another father, Isaac, often referred to the importance of his faith in God in helping him to manage the complex challenges that come with his illness and receiving haemodialysis.

His religious faith was described as a vital element in his life, with his two children also considered to be a divine gift:

> *"I've got two kids, which is a gift of God"* (Isaac, 628-629).

As with the accounts of other participants, both Demi and Janet expressed that their children mean everything to them:

> *"She's my world, absolutely she's my world"* (Demi, 934).
>
> *"They are my life"* (Janet, 221).

The above extracts further illustrate how central being a parent is to the participants' self-identity. Demi's comment that her daughter is *"…my world…"* and Janet's remark that her children *"…are my life…"* highlights the absoluteness of what being parents mean to them. With this in mind, it is worth considering to what extent receiving an intensive form of treatment, in this case haemodialysis, could affect people's concept of what it means to be a parent. This will be explored further throughout this chapter.

Gina noted that the day she gave birth to her son remained one of the happiest of her life:

> *"The happiest days of my life were when I had my baby and when I had the kidney transplant"* (Gina, 27-29).

Gina's account that her son being born and her receiving a kidney transplant were the happiest moments of her life suggests that being a parent and her chronic health condition occupy much of her attention and are highly significant to her. For some of the participants their parental role was described to have changed since becoming unwell. Ari mentioned that he no longer considered being a parent to be his greatest achievement, not because he had achieved something that he viewed as greater but because his role as a father had changed since developing end stage renal disease:

> *"Best thing that I ever did, or used to be"* (Ari, 935).

Both Janet and Ari made associations between the change in their parental roles and the development of their illnesses:

> *"It is different, it is different because you are ill"* (Janet, 556).
>
> *"It's all a different role now, it's a different situation now, isn't it?"* (Ari, 930-932).

An aspect of his parental responsibilities that Ari considered to have changed since becoming unwell was his role as a disciplinarian to his sons. He mentioned that he believed that the role of the father in a family system was to instil a sense of authority and to generally govern his children. Since the development of his illness he perceived that he was no longer adequately capable to fulfil this role:

> *"As the father, it was "my word is law" but now I don't think my word is law anymore"* (Ari, 945-947).

He elaborated by describing how his perception of this change was challenged when he recently overheard an interaction between his wife and their sons where he was mentioned as a source of discipline:

> *"There was a situation the other evening when they were all fighting and their mother, I could hear her from the lounge and their mother said to them, "you know, if you don't stop I am going to tell your dad". One of them I heard saying, "oh, why do you have to bring dad into this", so perhaps with regards to me backing off, I am still performing that role, who knows? Perhaps I am still performing it at some level for them"* (Ari, 1020-1029).

Ari's comment that since being unwell he has been *"…backing off…"* perhaps gives an indication as to why he believes his role as a father has changed. At other times in his interview Ari described a general abandonment of various responsibilities since developing end stage renal disease, these included passing the responsibilities of the household finances to his wife and taking a step back from joining his sons in certain pastime activities. His account suggests that his withdrawal from aspects of his parental role had in part been influenced by his appraisal of what his illness means to him as a father, as opposed to the physical restrictions it had imposed on him. Ari stated that he was no longer as active with his children as he had been previously:

> *"I would take him to the park, run and kick a ball about previously but we are not doing much anymore"* (Ari, 1233-1235).

He explained that as a consequence his sons now spend more time with their uncles rather than him:

> *"He tends to go out more with his uncles now"* (Ari, 1217-1218).

As well as Ari's withdrawal from his parental role due to how he perceives his role as a father with a chronic illness, the complex demands and side-effects of haemodialysis was also noted to influence the activities that the participants were able to share with their children. Many of the participants mentioned mostly engaging in low energy activities with their children. Boris, Demi and Janet all mentioned that their preference was to remain at home with their children and spend time with them doing activities that require little energy:

> *"I spend most of the time at home with the children because that suits me"* (Boris, 608-609).
>
> *"Sitting in doors"* (Demi, 906).
>
> *"When they sit and have a conversation with me"* (Janet, 551-552).

For other participants, they talked about taking their children to places that again exerted little energy. For Gina and Cara, the cinema was an ideal activity where they could conserve energy while at the same time their children would be sufficiently entertained:

> *"We go to the movies together"* (Gina, 1142).
>
> *"They say, "oh mum lets, come on let's go to the pictures""*
> (Cara, 449-450).

Similarly, Isaac identified outings to his local library as suitable activity in addition to the cinema:

> *"I take my son to the library and to the cinema"* (Isaac, 595-596).

All of the participants reported that caring for their children and meeting their own expectations as a parent was made more challenging due to their chronic illness and their receipt of haemodialysis. Demi stated that despite the additional challenges, it had not diminished the pleasure she feels from being a mother:

> *"Maybe I find it more difficult because of my illness but I enjoy every moment of it"* (Demi, 726-727).

Likewise, for Cara and Gina, having end stage renal disease made meeting the demands of their parental responsibilities highly challenging:

> *"It's hard work and it's very demanding"* (Cara, 1011-1012).

> *"I show him that I do my best but it's very tough for me, very, very tough for me"* (Gina, 1152-1154).

Gina believed that despite her best efforts to manage her parental responsibilities alongside her illness and the demands of haemodialysis it was not good enough for her or her son:

> *"I try my best but it's not very good, it's not good enough for him and it's not good for me"* (Gina, 1581-1583).

She suggested that the predominating factor that adversely prevented her from being the mother that she ideally would have liked to be were the limited available time and energy she has for her son due to the demands and side-effects of haemodialysis:

> *"There's not enough time for me to give to him and what he needs is time and energy"* (Gina, 1134-1135).

Similarly, Demi explained that as she becomes increasingly fatigued due to the effects of haemodialysis she is less able to take her daughter out and enjoy different activities with her. She suggested that this was not only felt by her but also by her daughter:

> *"I got from her the other day "you don't take me out, you do nothing with me no more" because I'm getting more and more tired now and she said, "you don't take me or do nothing with me no more""* (Demi, 638-642).

Flora, who was already a mother of two children before receiving a diagnosis of end stage renal disease, explained that she became pregnant unintentionally with her third child after she had received a live donor kidney from her mother. After a period of uncertainty and much debate with her husband whether to continue with the pregnancy due to fears it could lead to the rejection of her kidney transplant, she decided against the wishes of her extended family and continued with the pregnancy following the advice of her renal doctors. Flora subsequently gave birth to her third child and sometime later returned to haemodialysis after her kidney failed for unrelated reasons. She described her husband's frustrations at the challenges they experienced in caring for a young child while undergoing the intense demands of haemodialysis:

> *"There were times when it was difficult with the baby and then my husband would sometimes get angry and say, "now where are those doctors?""* (Flora, 422-426).

A minority of the participants articulated how they use the illness and need for haemodialysis as a tool in parenting their children. Janet described two distinctly different uses of mentioning her treatment in her interactions with her children. Firstly, she illustrates using her children's awareness and empathy towards her requiring haemodialysis to manipulate their behaviour:

> *"When they play up I say to them, "tomorrow I'm not going to go to dialysis, OK kids?", but they say, "no, no, sorry mum you've got to go, you've got to go""* (Janet, 503-505).

Janet then explained that she would use the evident challenges that she experiences on haemodialysis as a method to motivate and teach her children that they too can overcome adversity:

> *"You need to show your kids that life can go on, that if you come to a difficult point that you need to go through it"* (Janet, 630-631).

Equally, Demi described discussing with her daughter the value and importance of continuing to commit to certain activities, even if there is a lack of motivation to do so. In her interaction with her daughter, Demi compared her commitment to attend haemodialysis to her daughter's need to continue to attend school:

> *"I say, "we all have to do things in life we don't like doing, I mean I don't like going to dialysis but I have no choice if I want to be with you, I have no choice, I have to go, so you have to go to school""* (Demi, 871-877).

3.2.1.1 Impact of haemodialysis side-effects on parenting

Many of the participants, especially those that are parents of younger children, conveyed how the side-effects of haemodialysis impacts on their ability to parent their children.

Fatigue was reportedly the side-effect that unfavourably hindered parenting more than any other side-effect. Gina, a single parent, explained the challenge she faces in attending to her son's needs and giving him adequate attention when she returns home from haemodialysis:

> *"He needs attention, he needs that but he doesn't get a lot of attention from me when I'm too tired coming home from dialysis"* (Gina, 441-443).
>
> *"Sometimes I cannot listen to him because of how tired I am"*
> (Gina, 1497-1498).

Here, Gina illustrates the mismatch between her son's need for attention and her struggle to provide that attention when she returns home from haemodialysis feeling fatigued. She said that she has attempted to explain how her tiredness restricts her capabilities to her son:

> *"I say to him, "I'm so tired today, please I cannot do that" and he says, "but do it for me, I want it" but I say "but mummy cannot do it" but he doesn't listen, it's my tiredness"* (Gina, 363-366).

The challenge in meeting their children's needs that some of the participants illustrate was described by Demi as being particularly difficult when she feels fatigued:

> *"It's hard when I don't feel well and I want to do things with her"*
> (Demi, 979-980).

The disparity mentioned by Gina and Demi between their physical capabilities when fatigued and their desire to be active with their children and meet their needs suggests an additional struggle that parents receiving haemodialysis might experience. Henry spoke about how his lack of energy after treatment leads him to be less active with his wife and infant son:

> *"I can't take them out because I'm feeling low in energy"* (Henry, 470-472).

Henry further explained that his lack of energy and hypotension following haemodialysis means that he is often too exhausted to be attentive to his son. Taking time to get the necessary rest after treatment appears to further limit the opportunity available to Henry to spend time with his son:

> *"Picking up the baby or sitting down playing with the baby, you can't do that because you have to lay down until your blood pressure goes up again and you feel exhausted and you need to get back the energy"* (Henry, 100-104).
>
> *"There are some days, by the time I get my full energy back, my baby is asleep so I cannot really do anything about it"* (Henry, 112-114).

Furthermore, Henry also complained that the pain he experiences around the area of his fistula creates a weakness in that arm. The pain and the weakness means he requires the assistance from others for him to hold his son:

> *"Because you just had dialysis the pain is still on your arm because of the needles, so I have to ask someone to give my baby to me so that I can carry him"* (Henry, 259-263).

Being dependent upon others to help him to hold his infant son evidently causes Henry some emotional distress:

> *"I do feel quite sad because I can't do it myself"* (Henry, 300).

3.2.1.2 Being Absent Due to Treatment

One of the main features of haemodialysis is the frequency of the sessions and the duration of time each session takes. This feature was noted by the participants as one of the most challenging in terms of how it impairs their ability to parent their children. Having a strong presence in his children's lives was one characteristic that Ari believed to be vital in being a good father:

> *"What is it to be a dad? Somebody who is always there for their children. Is there more than that?"* (Ari, 954-956).

Ari's concept of what being a good father means seems to run contrary to the likely implications that comes with adhering to regular haemodialysis sessions, which involves at least three hospital-based treatments per week with each treatment lasting approximately four hours. This excludes the additional travelling and waiting times.

Demi, Gina and Emma all stated how difficult they find being separated from their children each time they attend hospital to receive treatment:

> *"It's horrible being a parent having to come to hospital every other day, it's not nice, it's hard, very hard"* (Demi, 945-947).
>
> *"It is very tough, very, very tough, it is very painful for me, when I say it is painful it's because I'm not there for him"* (Gina, 1475-1477).
>
> *"It's very hard"* (Emma, 663).

Demi described the heart-breaking experience of being separated from her young daughter during periods of hospitalisation. She explained that she would find the separation from her daughter to be highly distressing and that it would lead her to question her capabilities to be the mother she expected herself to be:

> *"I'd just stand there and I just used to sob thinking, 'I shouldn't be here, it shouldn't be happening to me, I should be there bringing her up and having fun and that', but that was hard, really hard"* (Demi, 772-775).
>
> *"It used to break my heart it did"* (Demi, 767-768).

Similar to Demi, Flora and Henry illustrated the challenge of being apart from younger children for long periods of time while they attend treatment. Speaking about the time that she is separated from her children when she attends hospital-based haemodialysis, Flora noted the additional challenges that come with being apart and *"…far away…"* from younger children:

> *"With dialysis you're far away when you're having your treatment, especially when my children were younger, that's what mostly comes to*

> *mind that when I'm having my treatment that I am not with them for many hours"* (Flora, 928-933).

Whereas Henry stated that the nature of the schedule of haemodialysis results in him having far less time available to spend with his infant child:

> *"There is less time that you can spend with your baby when you are on dialysis"* (Henry, 820-821).

The haemodialysis schedule, in particular the timing of the sessions, was also a cause of frustration for Ari as it meant there would regularly be days that he would not see his children due to returning late from treatment:

> *"My kids would come home from school and I would disappear and they would not see me until often after they came back from school the next day"* (Ari, 667-670).
> *"I would be getting back at 1am, 2am in the morning from coming in and they would be going to school at 8am, so often I wouldn't see them and it would feel like I was losing out"* (Ari, 670-674).

As with Ari, Henry also expressed his disappointment that the time demands of haemodialysis took him away from his son. He described his worry that the limited time he has available for his son could severely impact on the closeness of their relationship:

> *"I want to give more time to my baby, so that he recognises me as his father and not just another man who goes and comes back"*
> (Henry, 119-122).

Similar frustrations to Ari's and Henry's were also expressed by Gina and Demi. They both stated that they recognised the importance of spending time with their children but how the need to attend hospital for haemodialysis significantly reduced their availability:

> *"Of course, I want to be with him but I have to come here"*
> (Gina, 1224-1225).

> *"I get fed up keep coming, coming here and leaving my daughter"*
> (Demi, 265-266).

Janet described that it used to *"…kill me…"* to not be at home to greet her children when they returned from school, as she would still be at hospital receiving treatment:

> *"I used to do afternoons here and not be there when they come in from school and that used to kill me"* (Janet, 833-835).

Cara stated that being regularly absent from her son as she continues to receive hospital-based haemodialysis has led her to question her role as a mother and whether she is good enough for him. She expressed feeling distressed for not being able to be the mother she hoped to be:

> *"You do get upset because I think, 'oh, I'm neglecting them'"*
> (Cara, 662-663).
>
> *"I think to myself, 'oh, I'm a terrible mum, I'm not there for him, so I can't do his breakfast'"* (Cara, 579-580).

As with Janet and Cara, Gina also described how difficult it has been for her to be apart from her child. She added that not only is it upsetting for her but also hugely challenging for her son:

> *"Being away from him is painful, painful for both of us"*
> (Gina, 1262-1263).

As separation from their children while attending hospital for haemodialysis was reported by all of the participants to be distressing it is perhaps understandable that for some it was important to maximise the quality of their time when with their children. Flora shared that she frequently thought of her children while receiving treatment and would be eager to return to them:

> *"You can't wait to get home and you want to be with them and do things for them"* (Flora, 937-939).

For Cara, she also mentioned having a desire to make the most of the time she spends with her children due to how she feels about being separated from them while she prioritises her treatment:

> *"I feel guilty but then I do make it up to them in other ways"* (Cara, 728-729).

Children's reaction to parents' absence

Many of the participants spoke of how their children react to them attending hospital regularly for treatment. Emma stated that during the period of school term her two older children would largely be unaffected by her frequent hospital attendance due to the scheduling of her haemodialysis sessions:

> *"They don't notice that I went for dialysis"* (Emma, 898).

> *"During the time between me and them getting home they just wash and as soon as they come out from the washroom and are ready I'll be at home too"* (Emma, 894-897).

Both Ari and Boris said that they believed that their children were largely unaffected by their absences. Ari stated that although his sons' notice that he is often not at home they tend to behave in a manner that would suggest that they are unaffected, with little disruption to their usual activities:

> *""Where is daddy?", "he has gone to dialysis""* (Ari, 664-665).

Likewise, Boris described a scenario where him leaving home to attend haemodialysis had seemingly become an accepted norm for his children:

> *""Dad is going to dialysis, see you later, ta-ra, bye", they're not worried at all"* (Boris, 1096-1097).

Boris' above account suggests an impassive response from his children to him leaving for treatment. This is in contrast to Demi, who expressed that her daughter frequently displays feelings of anxiety and being worried for Demi's well-being. She stated that her daughter often likes to stay close to her in the morning on treatment days, as though wanting to make the most of the limited time they have available with each other:

> *""But I want to sit with you until you go" she said, I was like, "oh, all right then""* (Demi, 404-405).

In addition to the parents being reluctant to leave and be separated from their children, Cara and Gina mentioned that their children also expressed being hesitant in being parted from their mothers. Both parents stated that their children have at times attempted to persuade them to miss their treatment sessions to stay with them:

> *"When I come in the mornings they say, "oh, mum please, do you have to go today?""* (Cara, 178-179).

> *"When I come to dialysis he says, "mummy, I want you to stay here with me""* (Gina, 335-336).

Gina continued by adding that her son has been explicit in explaining to her his feelings of upset when she attends hospital:

> *"He told me, "mummy, when you are not here on those days I'm not happy""* (Gina, 1175-1177).

Providing a specific occasion when her son expressed wanting Gina to remain at home with him rather than for her to attend dialysis, Gina described an incident when it was her son's birthday and her son was very disappointed that his mother seemingly prioritised attending her treatment over remaining at home to celebrate with him:

> *"He said, "you know it's my birthday, right? You have to stay, my birthday is more important than anything else" but I was coming here for dialysis and couldn't change it"* (Gina, 1195-1198).

As mentioned earlier, Demi shared being highly distressed when she was separated from her daughter during a period of hospitalisation. Here she recalls her daughter's visible distress on the same occasion. She provides an account that describes a time when she was hospitalised on a Ward where her young daughter at the time would come and visit her:

> *"I'd be in (hospital name) with the long corridors, it was in (name) Ward, she was only two, three, four years old and I used to kiss her bye and she used to cry all the way up the corridor"* (Demi, 768-771).

Childcare arrangements

To accommodate their need to attend haemodialysis all of the participants relied heavily on the support of others to care for their children while they are at hospital. Emma explained that the main consideration for her when she attends haemodialysis is who would care for her child in her absence:

> *"The only issue that I think of when I come here is who's going to look after my child"* (Emma, 631-633).

Many of the participants reported that they depend on the support of other family members for the provision of childcare. Gina stated that her former husband, the father of her son, takes responsibility for their child until she returns from treatment:

> *"He looks after his son when I'm here, he comes to look after his son"* (Gina, 298-299).

Emma was another participant that talked about their partner taking care of the children to allow her to spend the required hours at hospital to receive haemodialysis:

> *"Sometimes my husband looks after my daughter but when he is at work no one is there, so I have to leave her with my neighbour as I have to come here"* (Emma, 637-639).

Whereas Emma relied on her neighbour at times to look after her daughter, Demi said that her mother, who was also her neighbour, would often watch over her daughter while she was at hospital:

> *"I live next door to my mum, so my mum pops in if I'm not there and if my daughter is asleep indoors she'll pop in"* (Demi, 278-280).

Grandparents played an important role in providing childcare to some of the participants. Flora also relied on her children's grandparents, her in-laws, to aid her need to attend regular haemodialysis by providing childcare to her children when they were younger:

> *"My parents-in-law were at home, so they would be with them when I was not there and I would come home in the evening at about 7pm"*
> (Flora, 592-594).

As demonstrated, many of the participants counted on family members to care for their children, including spouses, grandparents, parent's siblings and the children's older siblings. Gina and Emma both mentioned that other family members ensure that their childcare needs are met when their usual childcare arrangements are unavailable. Gina expressed that her sister and brother-in-law care for her son, while Emma's older children look after their younger siblings during school holidays:

> *"When his father sometimes goes on holiday and I come to hospital, my sister looks after him, well my sister and her husband"* (Gina, 1671-1673).
>
> *"During their holidays my older children, they look after the little one, so it's OK"* (Emma, 685-686).

Similar to Emma, Flora also said that her older children help to provide childcare cover. She shared that her two eldest used to collect the youngest sibling from school and care for them until Flora returned home from haemodialysis:

> *"The youngest one was 6, so they used to pick him up on days when I was on dialysis, they would pick him up and bring him home, so that's how it worked"* (Flora, 588-591).

Janet's husband would usually take responsibility to collect their youngest child from school. This would often be needed to allow Janet addition time to return home from hospital:

> *"Then (youngest child's name) normally gets picked up by my husband on his way home"* (Janet, 843-844).

Several of the participants spoke of the struggle they occasionally experience in finding adequate childcare cover. Emma stated that she relies on her neighbour to help look after her daughter when other arrangements cannot be made, including changing her haemodialysis session slot to accommodate the lack of childcare:

> *"I still sometimes struggle with my eight-year-old because I have to leave her with my neighbour when I come here or ask her to pick her up after school"* (Emma, 626-629).
>
> *"Sometimes I ask the nurse to give me a different slot, sometimes they do but sometimes they say, "no", so then I have to find someone"*
> (Emma, 688-690).

Meanwhile, Janet described the support she has received from her son's school on at least two occasions when her husband has been unavailable to collect their son due to work and Janet has been occupied attending haemodialysis:

> *"Their schools have been absolutely brilliant with me, both of them"* (Janet, 800-801).

> *"He was in Year Five and they're not allowed to walk home on their own until they are in Year Six but I would speak to the Headmistress and she kept coming around to see me, to see how I was and she said, "he is fine as long as you are OK with him walking home alone I will authorise it""* (Janet, 806-812).

The second instance involved Janet's son's school unexpectedly closing at the same time as her being at hospital receiving haemodialysis. She explained that her son's school's Headmistress offered to provide much needed emergency childcare until Janet was able to finish her treatment and return home:

> *"I didn't know that they would shut the school because of snow and I wasn't at home to let him in, so I said to her, "what can we do?" and she said, "don't worry, if it comes to it I will take him home with me and I will take him back to yours after""* (Janet, 817-822).

The need to organise adequate childcare on a regular basis appeared to be a trigger of high anxiety and stress for a number of the participants. Both Flora and Emma explained that ensuring childcare is in place is source of worry for them. For Flora, making sure that her children were cared for when they were younger was mentioned as being more challenging than haemodialysis itself:

> *"What was stressing me out at the time, it wasn't the fact that I was on dialysis, I seem to have accepted that, but the stress was from thinking that the children, they needed looking after"* (Flora, 85-90).

The uncertainty on who would care for Emma's children during a period of hospitalisation was described by her as being highly distressing and was her main concern at the time, more so than the reason for her hospital stay. She disclosed that it was particularly distressing as her children were of a young age and dependent on her care:

> *"I was so upset and I was in the hospital for 10 days, I didn't know what to do about my children I didn't know who's going to look after my children"* (Emma, 1121-1123).

In the event of there being no available persons to provide childcare a couple of the participants stated that they have little option but to leave their child unattended at home.

As mentioned previously, Demi's daughter would at times remain at home whilst Demi attended her haemodialysis sessions. This arrangement however would be negated by the fact that Demi's mother lived in the neighbouring home and would *"...pop in..."* to check on Demi's daughter's well-being. Another participant, Janet, explained her dilemma when she needs to attend hospital and there being no available persons to care for her youngest child after they return home from school. She shared that in managing such occasions her youngest child had been provided with a key to their home where either he or both of their sons would be expected to care for themselves until either Janet or her husband returned home from hospital or work respectively:

> *"There were times when they had to be left on their own because I had to go dialysis and my husband couldn't give up work...there were times when (youngest child's name) had to have a key to mine to let himself in"* (Janet, 455-459).

A common theme that emerged throughout the interviews involved the significance of children's ages on the challenges faced by parents with end stage renal disease. The age of the participants' children appeared to be particularly significant with regards to the need to organise childcare for when the participants attending hospital-based haemodialysis. This is perhaps due to younger children being far more likely to be dependent on their parents and/or caregivers than older, more independently able children. Flora expressed that parenting younger children while requiring haemodialysis created additional challenges and distress, which eased as her children became older and she was less reliant on childcare:

> *"Back then I went through a difficult time but now it's easier because the children are now grown up so I don't need to stress that somebody has to be looking after them"* (Flora, 734-738).

Flora explained that even though she received support with childcare when her children were younger from husband’s parents it would frequently add an additional strain on her already fragile relationship with her parent-in-laws. To ease her reliance on her parent-in-laws, she said that she requested childcare support through her local authority, which she was subsequently turned down for on the basis that she had existing support from her parent-in-laws:

> *“They seemed to think that, ‘oh, because you've got somebody in the house to look after them that should be enough’”* (Flora, 72-77).

Flora expressed her deep frustration that childcare support was not readily available and offered to haemodialysis patients, especially to parents of younger, more dependent children.

> *“They should give help with childcare straightaway…you shouldn’t have to push them or beg them, they should be able to see that childcare is needed when you've got young kids”* (Flora, 1034-1038).

> *“For people that have got young children and they’re on haemodialysis, you know normal haemodialysis, you don’t feel right after dialysis and they should be helped more, they should have more support”*
> (Flora, 1168-1172).

All of the participants indicated how the provision of childcare is an essential element that enables them to attend haemodialysis treatment. When childcare has not been readily and consistently available through the support of family, friends or childcare professionals many of the participants highlighted the additional worry and stress they endured in making necessary alternative arrangements. Although none of the participants mentioned that a lack of childcare provision had interfered with their ability to adhere to their treatment schedule, it is clear that a number of the participants needed to compromise the care they ideally wanted their children to receive in order to attend treatment. It is perhaps reasonable to also argue that a lack of adequate childcare could create a dilemma for parents on whether to prioritise their own care or the needs of their children, which could lead to the parent’s nonadherence to treatment and severe deterioration in their health.

3.2.1.3 Holidaying

The majority of the participants also spoke about how living with end stage renal disease and needing to attend regular hospital-based haemodialysis sessions adversely impacts on their capability to take holidays with their children. Gina explained how the regularity of her haemodialysis treatment prevented her from having the time to go on holiday.

> *"I come here several times each week and you don't have time to go anywhere else, you don't have two days to go anywhere, just on weekends of course but you don't have time to go on holiday"*
> (Gina, 717-722).

Demi and Janet both succinctly highlighted their difficulties of holidaying while on haemodialysis:

> *"I can't go on holidays"* (Demi, 266-267).

> *"The only thing I don't like is that I cannot take them on holidays"*
> (Janet, 567-568).

Demi also mentioned that being a hospital-based haemodialysis patient prevented her from being spontaneous in arranging holidays, which she regarded as being usual behaviour for people that do not receive haemodialysis. Her account suggests that the different aspects of her haemodialysis regime, including the treatment schedule, create a bind that makes spontaneity difficult:

> *"You cannot go and be like a normal person, get up and say, "oh go on, let's book a holiday, let's go", you cannot do nothing like that"*
> (Demi, 27-30).

For Boris, haemodialysis meant that holidaying was an *"...awkward..."* and unfamiliar challenge:

> *"The only downside I can think of with it to be honest is that holidays are awkward"* (Boris, 768-770).

> *"It's just an unknown quantity and I like to know what's going on"*
> (Boris, 838-840).

One reason for holidaying being *"…awkward…"* could perhaps be related to how vital it is for patients to commit to a regular treatment regime for haemodialysis to be effective. Holidaying enforces a break from that regime and removes the patient from familiar settings. Henry pointed out that haemodialysis restricts his freedom to choose possible holiday destinations. Any holiday destination would need to be able to cater for patients

needing haemodialysis to be able to continue their hospital-based treatment and to adhere to the different restrictions of end stage renal disease and haemodialysis:

> *"Because you are on dialysis you cannot go on holiday, there are certain destinations you would like to go but you cannot"* (Henry, 831-833).

Due to the perceived challenges that come with holidaying while continuing to receive haemodialysis the majority of the participants said that they had not holidayed since having to rely on hospital-based haemodialysis treatment:

> *"I don't know how it would be for dialysis and all that, I don't know anything about it"* (Demi, 287-289).

Boris explained that he worries about how hospital-based haemodialysis overseas would be different from the treatment that he has received in the United Kingdom that he is familiar with:

> *"I'm a bit worried about it to be honest, I've never been abroad to a dialysis unit so I don't know how they work, I only know how the English ones work"* (Boris, 800-803).

Both Gina and Demi discussed how their children are affected by them not freely being able to holiday. They shared how their children have expressed their dissatisfaction at being unable to holiday with their mothers:

> *"He says "mummy, when can we go visit (name) in (Country)?", my friend invites us but I've told her I can't go because I have to stay and keep going to hospital"* (Gina, 1235-1238).
>
> *"She got a bit upset, so I said, "I will take you soon""* (Demi, 289-290).

Gina and Demi added that her children feel upset by their apparent exclusion from holidaying, particularly when they are aware that other family members go on holiday together:

> *"He feels jealous when my mother, my sister and her kids go on holiday together but I cannot go with him"* (Gina, 1726-1728).
>
> *"My mum went to Spain a few years ago and she really felt it because they all went, my little nephews and that, everyone went apart from us two"* (Demi, 284-287).

A minority of the participants stated that on occasions other family members have taken on the responsibility of taking their children on holiday while they remain at home to continue their hospital-based haemodialysis treatment. Boris described feeling grateful that his children had the opportunity to go on holiday with the help from his wife's parents:

> *"I'm lucky in the respect that my kids sometimes go away with my in-laws…they are still young so they don't mind going, which is good because otherwise they wouldn't get a holiday"* (Boris, 793-799).

In much the same way, Gina shared that while she has remained home to continue with her treatment her son has been on trips overseas with his father and aunt:

> *"He has been to Africa twice with his father and his aunty but I wasn't with him"* (Gina, 1228-1230).

Despite Gina's son having the opportunity to travel, Gina said that they have both found the time apart from each other to be difficult. She spoke about her son expressing his desire to holiday with her, and Gina herself also shared that hope with the aim to be in a position to make that happen at some stage in the future. Gina mentioned in her interview that she places a lot of hope on receiving another kidney transplant and how that would enable her to improve her and her son's quality of life, which perhaps also includes the possibility of going on holiday together with her son:

> *"He says, "mummy you never fly with me, you never have" and I say, "don't worry, one day I will""* (Gina, 1230-1232).

> *"Sometimes when he has a school holiday he wants to go on holiday with me"* (Gina, 1227-1228).

The reliance on childcare was given as one of the reasons that contribute to the difficulties balancing haemodialysis with holidaying. Demi, a single parent, stated that the lack of childcare while on holiday means that she is unlikely to go on holiday with her daughter

unless either the haemodialysis units permits children to accompany their parent for treatment or for a family member or friend to join them on holiday:

> *"I could go on holiday but I'd have to take someone else with me because I can't leave my daughter by herself if I'm on holiday"* (Demi, 267-270).
>
> *"It would be nice if all these dialysis units would let the kids in because I would love to just go on holiday and just take me and (daughter's name) on holiday"* (Demi, 1139-1142).

Demi stated that being accompanied on holiday by her sister enabled her to go on holiday with her daughter whilst being able to continue with her haemodialysis treatment:

> *"We did go away for two weeks a few years ago"* (Demi, 296-297).
>
> *"We went to (location in England) for two weeks, my big sister had paid for the chalet and she came with us"* (Demi, 301-303).

Several of the participants discussed how they manage the demands of hospital-based haemodialysis and the challenges of holidaying with their children. Janet stated that her family holiday is held in the United Kingdom, where she can more easily maintain her treatment regime. She also advised that since the deterioration in her health the type of holiday she has with her family has changed:

> *"We do go on holiday, we used to do camping but I find that too hard now, so we had to get rid of that and now we're looking for a caravan…they don't mind because as long as they have the sea, we bought them a boat, so they're happy"* (Janet, 568-574).

Isaac also claimed that holidaying as a family is possible while continuing with haemodialysis treatment. To minimise the impact on his treatment and to remove the need to haemodialysis in unfamiliar settings, Isaac stated that he prefers to have shorter breaks with a slight amendment to his treatment schedule:

> *"When we go after my dialysis, we go for a weekend or for a long weekend, then it's easier. Otherwise you have to dialyse there which is difficult so you better dialyse on Friday early then go and come back on Tuesday"* (Isaac, 390-394).

Conversely, Demi stated a dislike of having shorter breaks with her preference of having a slightly longer holiday with her family. This would however require Demi to continue her hospital-based haemodialysis in less familiar settings and for her to arrange the provision of childcare, as mentioned previously:

> *"Not just like on a Friday and come back on a Monday and then come straight to dialysis but go on holiday for a week, spend a week together"* (Demi, 1142-1148).

A further consideration for haemodialysis patients when holidaying is the location of the nearest Haemodialysis Unit in relation to their accommodation. Demi highlighted this point be describing her experience of holidaying with her sister, where she found the transportation costs to and from the Haemodialysis Unit to be substantial:

> *"When you come out of the hospital, because sometimes they did dialyse me at different times, in the dark, in the middle of nowhere this hospital, I was terrified, so I was getting cabs and that was costing me £21 each time, so each time I went dialysis it was costing me £42 because it was so out of the way, I didn't realise how far it would be"* (Demi, 306-313).

Demi continued by outlining the different factors patients on hospital-based haemodialysis should consider before planning a holiday overseas:

> *"If you're abroad and you book a hospital, if it's far, I don't drive, how am I going to get there? How am I going to get back? You know, it's all them things you have to consider"* (Demi, 320-323).

Isaac reiterated the challenges patients face in dialysing while on holiday. He stated that when he has travelled back to his place of birth on the Asian continent, he has found the experience of continuing his treatment to be highly challenging:

> *"I have only been back home twice and even though I had booked everything before going it was very hard, dialysis there is very hard"* (Isaac, 429-435).

Isaac noted that factors that included high temperatures and long journey times due to the remoteness of the Haemodialysis Unit contributed to his haemodialysis while there being *"...very hard..."*.

3.2.2 Children's Experience of Parents' Illness

The previous major theme and subordinate themes mainly focused on the direct experiences of the participants on being a parent living with end stage renal disease and receiving haemodialysis as their current renal replacement therapy. This subordinate theme explores the children's experience of their parents' illness, as perceived and experienced by their chronically ill parent. The vast majority of the participants spoke about the impact of their illness on their children. Ari and Cara expressed feeling greatly affected that their children are inadvertently adversely affected by their illness:

> *"I feel for them because I love them, they're my boys"* (Ari, 1121).

> *"You feel bad because you don't want to keep putting them through it"* (Cara, 491-493).

Cara's account that she does not want to *"...keep putting them through it..."* suggests that the children of chronically ill parents endure the effects of that illness to a similar extent as their parents. Similar to Cara's disappointment that she perhaps lacks agency in being able to prevent her children from being affected by her illness, Demi described being unable to keep her effects of her illness isolated from her child. To make amends for how her child experiences her illness she attempts to *"...make up for it..."*:

> *"I thought, 'this child has been through enough', she has to keep going through this, that's why I take her out and things, to make up for it"* (Demi, 783-786).

Both Cara's and Demi's accounts state that their children *"...keep..."* experiencing the adverse effects of their illness. The use of the word *"...keep..."* highlights the enduring nature of the participants' illness and how much the extent of living with end stage renal disease is experienced by members of their family, namely their children. Akin to Cara and Demi, Gina articulated that the repeated frequency of her hospital-based haemodialysis sessions makes it difficult for her son despite him being aware that it helps to prevent her health from deteriorating further:

> *"It is very tough on him and it's not just once but it's three times a week it happens to him"* (Gina, 1533-1534).

> *"He knows I'm alive and OK but it's hard for him me not being there"* (Gina, 1260-1262).

Demi expressed feeling distressed and responsible for the adverse effect her illness has on her daughter's life:

> *"Sometimes I do apologise to her. I sit and cry, I say, "it's not much of a life for you, me being ill"* (Demi, 736-737).

Cara explained that her younger children greatly dislike the fact that their mother needs to endure haemodialysis on a regular basis:

> *"It's hard on my two younger ones though, I know that they are 14 and 13 but they hate it"* (Cara, 176-178).

> *"They were quite upset because they hated that I have to come on the machine"* (Cara, 603-604).

Cara's above account shines a light on her children's empathy for her need to receive haemodialysis. She also mentioned that her children welcome her non-treatment days, yet it was unclear from her interview whether this was as it allowed them to have more time with her or because it meant that their mother would not need to endure haemodialysis on that day:

> *"They are so happy when I don't do it on my days off, they are so happy"* (Cara, 180-181).

Gina stated that her son accepts her need to continue with her haemodialysis, despite his preference to not be separated from her:

> *"He wants to be with me but he knows I come here to survive"* (Gina, 1225-1226).

Several of the participants spoke about the worry their children experience for their parents' well-being. Both Janet and Cara stated that their children express feeling anxious about their parents' health. Janet said that her illness has been difficult for her children and that her children notice how challenging it has been for their mother, which at times lead them to support their mother by taking on the responsibilities of household chores:

> *"It's been hard for them I think, they worry, they are very worried"* (Janet, 465-466).

Whereas Cara described an occasion when she was hospitalised and her children were evidently too worried to leave her in fear of her health deteriorating:

> *"They didn't want to leave me and I'm sure they must have thought, you know, in case anything happened to me"* (Cara, 1094-1096).

Likewise, Demi said that her daughter worries about her mother's well-being. This is particularly the case when they are separated, for example when Demi attends haemodialysis or when her daughter is at school:

> *"I think she doesn't like going to school because it must play on her mind that, 'if I come home mum isn't going to be there, mum's going to go up to hospital or mum is not going to be well, if I'm with her everything's going to be all right'"* (Demi, 865-870).

Demi explained that her daughter too experiences regular episodes of illness, which results in absences from her school. Demi reasoned that her daughter's stress and anxiety for her mother's health is the main factor for her absences from school:

> *"She gets ill a lot though, I don't know if it's worry but she gets ill a hell of a lot"* (Demi, 389-390).

She continued by saying that she was uncertain of the exact reason for her daughter's worry, whether it was due to her concern for the effect of her treatment or her illness:

> *"I don't know if it's worry of me coming here or worrying about me not being well"* (Demi, 414-415).

Participants shared that their children's awareness of their parent's illness was a source of concern for many of their children. Gina said that her illness is a trigger for her son's unhappiness. She mentioned that this seems to be especially the case during family celebrations when he attends with other family members while his mother is absent in order to attend haemodialysis:

> *"When he is unhappy it's often because he remembers that his mother isn't well"* (Gina, 282-285).

Emma explained that her children also feel anxious and worry about her wellness, yet seemingly attempt to hide their distress from her:

> *"I know they are worried about me but they don't want to show that to me in case I'll get upset"* (Emma, 1024-1025).

Ari on the other hand stated that he believes that his sons are largely unfazed by his illness. This account is however slightly contradicted by Ari's recognition that his sons' behaviour has changed since he developed end stage renal disease. The differences in Ari's accounts could be caused by the subtleness in how outwardly his sons have been affected by his illness, where the affect has been more evidently shown in their behaviours rather in what they say:

> *"I don't think it bothers them, they're boys. Boys tend to be very self-centred"* (Ari, 164-165).

> *"I do think the children, I haven't given them credit before, I think sometimes I've noticed that their behaviour has adapted"* (Ari, 933-935).

Nonetheless, Ari continues by stating that his sons have seemingly accepted their father's chronic condition and his need for haemodialysis as they are aware that it is necessary to sustain his life:

> *"I think they just accept it. Dad is still there, dad goes to hospital, dad comes back from hospital"* (Ari, 170-172).

Communicating or disclosing the parent's illness to their children

Several of the participants discussed their views on how to manage their children's exposure to their parents' illness and the extent in which they communicate about it with their children. Isaac and Janet advised that their children were aware and had a good understanding of their parents' illness:

> *“They understand”* (Isaac, 37).

> *“They are fine with it”* (Janet, 495-496).

Participants shared their different perspectives on the value of discussing the extent of their illness and the different aspects of their treatment. Janet expressed her strong belief that it is important to inform children of the details and ongoing status of their parent’s illness and treatments, regardless of the child’s age:

> *“Let the kids know, don’t keep the kids in the dark, let the kids know what is going on, no matter how young they are you still got to let them know what is happening”* (Janet, 824-827).

Aligned with Janet’s recommendation, Boris, Cara and Demi all reported that they have engaged in an open dialogue with their children when it comes to speaking about their illness and the treatments received:

> *“I just said, “look dad’s got to go onto dialysis”, “what’s dialysis?”, so I told them everything”* (Boris, 1071-1077).

> *“They know everything, I have told them all, they all know”*
> (Cara, 598-599).

> *“She knows everything, everything that goes on I tell her, she knows everything”* (Demi, 60-61).

Boris and Demi added that even though they believe that it has been important to be open with their children that it has been equally important that discussions with their children were appropriate in tone and delivery in terms of their children’s ages:

> *“They know what it entails, obviously the baby doesn't get it but the other two know”* (Boris, 1094-1095).

> *“She was explained it all when she was little and when she grew up in more detail”* (Demi, 71-72).

Several of the participants implied that they, as their children’s parents, were best placed to be the ones to inform their children of the details of their illness. The also suggested that by ensuring that they were the main source of information they were able to maintain a sense of agency over the type of details their children receive regarding end stage renal disease and the different renal replacement therapies:

> *"I believe in honesty with her, it's no good hiding things from her, she'll only find out some other way, so I'd rather she finds out from me than somebody else"* (Demi, 63-66).
>
> *"There is no point lying to them"* (Janet, 514).
>
> *"They both have laptops and they're both always on them and the information they want to know I suppose they are going to get whether it will be the truth or not"* (Janet, 514-517).

Demi explained that she has been confronted by individuals that have disagreed with her approach of maintaining an open dialogue with her daughter when it comes to discussing her illness and the treatments she receives. Her response to such queries suggests that she believes that informing her daughter of her illness both educates and perhaps helps to prepare her for whatever the future holds:

> *"People ask me, "why does she know all that?", I just say, "she's got to learn""* (Demi, 61-63).

Conversely, Emma and Gina hold a different belief and approach in how much information to share with their children. They both said that they prefer to limit the amount of information they share with their children regarding their illness:

> *"They only know a little bit about dialysis, I don't talk to them about it all"* (Emma, 1003-1004).
>
> *"He knows Monday, Wednesday and Friday something happens and he needs to go somewhere"* (Gina, 1201-1203).
>
> *"I cannot explain to him every little thing about my illness"* (Gina, 1575-1576).

In addition to the above accounts, Ari mentioned that his illness is a largely ignored topic of conversation within his family, despite his children being fully aware that he has end stage renal disease and receives haemodialysis:

> *"I don't want to say it's the elephant in the room because it's bigger than that"* (Ari, 672-674).

Although Emma does speak to her children about her illness and matters concerning her haemodialysis treatment, she shared that she chooses to self-censor the seriousness of receiving haemodialysis. Emma explained that when she speaks with her children she

tends to play down how difficult she finds living with haemodialysis and the associated risks:

> *"I say, "I'm OK, dialysis is not a big thing for me", I know that dialysis is a big thing but I don't tell them that, it makes it very hard for me but I just tell them that it's not a big thing"* (Emma, 935-938).
>
> *"I don't talk about any of the risks in having dialysis, I never tell them because they will get upset"* (Emma, 993-994).

Emma continued by explaining that she attempts to shield her children from the serious risks associated with her disease and haemodialysis. She implied that she does this with the intention of protecting her children from unwanted worry and distress, despite her own concern about the risks and anxiety about her personal mortality:

> *"If somebody passes away in the Unit I never go and tell them, they will get upset"* (Emma, 1003-1004).
>
> *"There are things that worry me but I don't show it"* (Emma, 1019-1020).

Similar to Emma, both Cara and Ari expressed their reluctance to display their distress and upset in front of their children. Cara explained that during a period of hospitalisation she would receive regular visitations from her children. She said that her children's visits would tend to be quite prolonged due to their concern for her and fear that her health could quickly deteriorate. She stated that she would often try to suppress her own distress until after her children had left her bedside:

> *"Not in front of them but when they've gone I used to get really tearful, really tearful"* (Cara, 1099-1100).

For Ari, he also described moments of feeling upset and tearful. Similarly, he also felt that it was important to not show distress and cry in front of his children. He mentioned that his role as a father is to be authoritarian and a protector for his children, it is perhaps reasonable that being congruent by displaying his distress in front of his children may threaten his role as a father:

> *"Sometimes I do feel like crying. They never see me cry and I never want them to see me cry"* (Ari, 151-152).

As well as speaking to their children about their illness, some of the participants disclosed that their children have witnessed them receiving haemodialysis on the Units. Janet and Boris both explained that their children have observed them on the Units while they receive treatment:

> *"They have come up here before and seen me being put on and being taken off"* (Janet, 486-488).
>
> *"She has seen it all before"* (Boris, 1091).

The above extraction from Boris suggests that his children have been fully exposed and made aware of haemodialysis treatment, which could be similar to Janet's children. By having the opportunity to observe her on haemodialysis, Janet stated that her children have expressed sympathy for her having to endure the needling aspect of connecting to the haemodialysis machine:

> *"They just feel sorry for me because they say, "mummy, this must really hurt""* (Janet, 492-493).

The sentiment of Janet's account was repeated by Emma. She explained that her children commented on the noticeable needle markings that had been caused by the regular connections to the haemodialysis machine. She said that her children had expressed concern for the pain she seemingly endures as a result of her receiving haemodialysis:

> *"They think when I do my needling and everything, they think I suffer a lot, they say, "you can't take the needle all the time, look at your hand, it's getting sore", they are worried about that"* (Emma, 926-929).

Demi and Cara also disclosed that their children have visited them on the Haemodialysis Units while they receive treatment or while being an inpatient. Some of the participants suggested that their children spend time with them on the Units because they miss being with them due to the regular absences that are needed for the participants to attend haemodialysis:

> *"She came here Wednesday, last time she come, she came around 9:30-10:00 and she sat with me until we left"* (Demi, 177-179).
>
> *"I used to say to them, "go home" because it isn't nice them just sitting there and they would say, "no mum, we want to sit here, we want to be close to you""* (Cara, 1085-1088).

Cara added to her above account by recalling a time when she was hospitalised and required temporary dialysis. She shared that her children had visited her while hospitalised and saw her with dialysis tubes connected through her neck, which she referred to be distressing for her children to see:

> *"I feel bad because they've seen me when I have been in hospital when the kidney failed and also doing dialysis"* (Cara, 1061-1063).
>
> *"I had the temporary dialysis, you have all these tubes coming out of your neck and it's not a nice thing for them to see"* (Cara, 1075-1077).

The reasons mentioned above by Cara and a number of the other participants were similar to what gave Ari just cause for not wanting his sons to visit him during hospitalisation and on the Haemodialysis Units. For Ari, not allowing his sons to visit him was also deemed important in maintaining his perceived role of a father being 'strong' as opposed to being seen as vulnerable:

> *"I did not actually want my children to come and visit me as I did not want them to come and see me sick in hospital like that"* (Ari, 36-39).
>
> *"I was laid low, so I didn't want them to see me that vulnerable, I still don't"* (Ari, 144-146)

Ari said that he was grateful that his wife understood and adhered to his desire of preventing his sons from witnessing him at hospital:

> *"I said "no", my wife understands me so luckily, she respected my decision"* (Ari, 157-158).

In light of the struggles and challenges faced by all of the participants, the majority of the participants mentioned that their children expressed their desire for their parents' health to improve. Gina said that she believed her son desired for her to be healthier as the impact from her illness is too great:

> *"He wants his mother to be healthier, especially as he misses out on a lot of things"* (Gina, 1679-1681).

Emma advised that her children expressed their hope that her receiving a kidney transplant would remove from her the burden of continuing to receive haemodialysis:

> *"They say, "mum, you can't be on dialysis forever, you have to get a transplant and you will be OK then and you don't have to have dialysis then""* (Emma, 924-926).

3.2.3 "Children Keep Me Going"

All of the participants described their children as being one of their primary motivators in them continuing to do all that they are doing to remain alive. They shared that their approach to living with end stage renal disease and needing to undertake the rigours of haemodialysis would be vastly different if their children were not in their lives. In typifying the importance of their children in remaining committed to continuing with haemodialysis both Janet and Boris commented that their children give them reason to live:

> *"I live for my kids"* (Janet, 374).
>
> *"I think they keep me going"* (Boris, 1135-1136).

Likewise, Demi reported that without her daughter being present in her life she believed with certainty that she would not have continued with her haemodialysis treatment and simply accepted the consequences, which would have likely resulted in death. In addition to being a motivation to continue to adhere to a demanding treatment regime, Demi's account also suggests that her daughter provides her with the support and strength to cope with the challenges that her illness has brought into her life:

> *"If I didn't have her I would've gave up by now, without a doubt, I would've given up, I wouldn't bother coming to dialysis no more and just let happen whatever happens happen but she keeps me going…I definitely*

> *wouldn't be here now, 100% I wouldn't be here now, as I said I don't think I'd be able to cope, she keeps me going, bless her"* (Demi, 792-799).

Janet and Boris added to their previous statements by claiming that, similar to Demi, without their children in their lives they would have chosen to cease their haemodialysis:

> *"I only do it for my kids anyway, if I did not have them I would not do it, I would give up"* (Janet, 214-216).

> *"A couple of times I thought about rather than do this I could just finish it and if it weren't for the kids I probably would have"* (Boris, 1137-1141).

As with Janet, Boris and Demi, Emma also stated that without her children she would likely not adhere to the various aspects of end stage renal disease treatments, including fluid and dietary restrictions:

> *"If it was just me and my husband only I don't think that I would look after myself like this and I would just let go"* (Emma, 724-726).

The responsibilities of caring for a dependent child(ren) that accompanies the role of being a parent was noted by the participants as a significant factor in them adhering to the demands of their treatment and doing all they can to stay alive. Gina and Demi, both single parents, mentioned that as mothers it was their responsibility to do all they can to remain alive for their children:

> *"Because I am a mother, I am responsible for another person, so I had to go back on dialysis"* (Gina, 53-55).

> *"I've got to be there for her, it's only me there for her"* (Demi, 803-804).

Gina and Demi's accounts mirrored Emma's statement that in being a mother Emma believed that her role in her children's lives was essential and therefore, for the sake of her children, it was vital that she tries to prolong her life for as long as possible:

> *"They need a mother and because of the children we should live longer"* (Emma, 754-755).

As well as being one of the main reasons for the participants being willing to endure the burdensome nature of haemodialysis, the children were also portrayed as a protective factor against the development of depression. Depression has been cited as one of the primary mental health conditions among end stage renal disease and haemodialysis patients. Cara, among other participants, stated that her children prevent her from developing depression:

> *"If I was to sit down and never have the kids around me and the place was completely, like completely quiet I think to myself that I would then get depressed"* (Cara, 714-717).

The emotional and practical support that the participants receive from their children was described as being invaluable by many of the participants. For example, Gina and Demi shared that their children assist them with shopping and lifting when they feel weakened by post-dialysis fatigue:

> *"He helps me really, he seems grown up when I say, "I cannot take this" and he says, "mummy, I take it" when I am not feeling well"*
> (Gina, 1037-1039).

> *"She helps me to do the shopping or carry the bags for me"*
> (Demi, 613-614).

Similarly, both Emma and Janet spoke about the support and care they receive from their children while at home:

> *"They know that there are certain things I can't do and they support me"*
> (Emma, 218-219).

> *"They always say, "mum, mum don't do that, sit down, don't touch that, don't bend, we can do that, I can make you a cup of tea""*
> (Janet, 474-476).

The above accounts highlight the awareness that Emma's and Janet's children have of their parents' chronic health and the limitations it has created for both participants. Isaac suggested that his children seem perhaps protective of him in ensuring that he does not over-exert himself while at home, especially due to his fistula in his arm:

> *"They don't let me lift anything because they know I've got a fistula on my arm, so they help when they are at home"* (Isaac, 48-50).

The participants talked about how their children take on additional chores and duties within the family, such as cooking the evening meal for the family or older siblings providing childcare for the younger siblings, as a way to support their ill parent. The participants also shared how attentive their children are to their needs, especially

following treatment or when feeling unwell. Emma spoke of the care she receives from her daughter when she returns home from hospital feeling the after-effects of haemodialysis:

> *"When I go to sleep my daughter, she comes and she asks me, "are you feeling okay? Do you want a cup of tea? Shall I make you a cup of tea?", that feels nice"* (Emma, 885-888).

Echoing Emma's account, Demi advised that her daughter provides her with practical and emotional support when she returns home feeling unwell following haemodialysis:

> *"If I go home she'll make me lunch or if I don't feel well she'll look after me or she says, "are you all right mum?", she'd sit with me or helps if I need anything"* (Demi, 94-97).

Following on from her earlier description of how her daughter cares for her after returning home from treatment, Emma said that her son is also very attentive when she is affected by how challenging her life has become. When mentioning the attention that her son gives to her, Emma talks about it with seeming unexpected surprise at her son's gesture:

> *"Even my son, he comes and talks to me, my daughter she comes and talks to me, if I feel, like, if I'm a bit upset they come and talk to me"*
> (Emma, 220-222).

Despite the apparent unexpectness of her son's actions, it is clear from Emma's description how highly she regards and draws strength from the love and support she receives from her children:

> *"They say "mum, don't worry, we're always with you, you will be OK one day", so they give me support like that"* (Emma, 227-228).

Demi also spoke touchingly of her daughter's display of love and affection towards her, which gives added weight and clarity to her earlier comment that her daughter *"...keeps me going..."*:

> *"She writes me little notes and cards telling me how much she loves me every day"* (Demi, 739-741).

Gina epitomised the care that the participants felt that their children provided them by describing the practical and emotional support that her son gives to her:

> *"Sometimes I am vomiting he gives me a bowl to vomit in, he is so good, my goodness, he helps out, he is very helpful...he says, "poor mummy" and just gives me a hug"* (Gina, 1041-1043).

In addition to the support that the participants children provided them in terms of helping their parents emotionally and with more practical household type chores, a minority of the participants mentioned that their children provide care with regards to their renal replacement treatment. Boris stated that his daughter would occasionally join him on the Haemodialysis Unit and help with certain aspects of his treatment:

> *"You can bring my daughter down here and she'll help the nursing staff, she's really good"* (Boris, 1077-1079).

This was similar to Demi and her daughter, who would also take over the nursing responsibility of the needle insertions to connect to the haemodialysis machine as well as other aspects of Demi's care:

> *"I say to them, "don't worry, she'll take it out for me" and she'll put it in and she tapes it up and she'll put the blood pressure thing around"*
> (Demi, 188-191).

In fact, Demi's daughter had been directly involved in supporting Demi with her renal replacement therapies from a young age. Demi explained that she previously received peritoneal dialysis at home, which required significant input and care from her husband. It was Demi's husband that had learned the process and procedural aspects of the treatment, which meant that Demi was heavily dependent on him to care for her. Sadly, Demi's husband died suddenly and following his death Demi's then six years old daughter took on some of the manual responsibilities of Demi's treatment. One aspect of Demi's treatment that her daughter would assist with would be to dispose of large fluid bags that would be a by-product of Demi's peritoneal dialysis. Not long after her husband's death Demi changed her renal replacement therapy to hospital-based haemodialysis:

> *"After he'd gone she'd carry them, those big fluid bags, she'd drag them to the bath, from my bedroom to the bathroom near the sink, she'd drag them at the age of six years and empty them down the toilet for me when I was ill"* (Demi, 83-87).

The attachment between Demi and her daughter was clearly demonstrated throughout her interview. She explained that her daughter is a carer for her, especially when Demi is feeling unwell, which seems to create a sense of longing when they are separated:

> *"She's really good and she looks after me now if I don't feel well"*
> (Demi, 88-89).

> *"I do miss her in the day, especially if I'm not feeling well"*
> (Demi, 429-430).

The strength and motivation to do all they can to prolong their lives that the participants gain from their role as parents was evident in their interviews. Cara considered her children's compassion and empathy for her to be a validation of her own parenting achievement:

> *"You feel so good in yourself because you think, 'well, at least I must have done right by bringing them up because they care for me'"*
> (Cara, 976-979).

3.2.4 Own Mortality

The seriousness of end stage renal disease was not lost on the participants. As discussed previously, all of the participants were able to vocalise their awareness that end stage renal disease is a chronic condition that if not treated appropriately is likely to result in death. For many of the participants, thoughts of their own mortality were never too distant and would often accompany feelings of fear and anxiety:

> *"I could pretend that I'm OK and that I'm not worried about death constantly"* (Ari, 1312-1315).

A distressing awareness that death was a possibility due to end stage renal disease was also shared with Cara, who mentioned that *"...I want to survive..."*:

> *"I worry about my health because I want to survive, as everybody does"* (Cara, 1131-1132).

As discussed in the previous subordinate theme, the participants described their children as an enough of a reason to continue to undergo the rigours of haemodialysis in order to stay alive. Conversely, the thought of their own mortality and not being alive for their children was a cause of great distress for the participants. Demi said that thoughts of her death and not being alive to share the life of her daughter was *"...horrible..."*:

> *"It's not fair at all, I'm getting upset now, it's horrible but what can you do? It's life, isn't it?"* (Demi, 822-823).

Similarly, Cara added that she worries about the possibility of dying and being unable to share future significant moments in her children's lives:

> *"I think, 'oh, I might not ever be around them, I might never see them get married'"* (Cara, 1125-1126).

Both Emma and Ari commented on the inevitability of death as a result having end stage renal disease.

> *"It's going to happen one day, we can't hide from death"* (Emma, 1074-1075).

Here, Emma's factual statement provides a generalised comment that death is unavoidable for all. Although in the context in which she made the comment, where she was speaking about haemodialysis and other patients, the *"...we..."* appears to relate to haemodialysis patients. It is therefore perhaps reasonable to paraphrase Emma's comment to mean that despite the primary aim of haemodialysis being to sustain life, death is not something that haemodialysis patients can ultimately prevent. This account links with Ari's statement that regardless of the different renal replacement therapies, end stage renal disease will likely result in death:

> *"They can't delay it forever, you've got kidney failure. It's going to get you in the end"* (Ari, 1341-1343).

Emma’s and Isaac’s approach to death was expressed as something natural and inevitable, which neither seemed to fear:

> *“I'm not scared of dying, everybody’s got to die sooner or later”* (Cara, 1160-1161).

> *“When the time comes for me I have to go, don’t worry”* (Isaac, 497-498).

Isaac continued by suggesting that his faith in God and his held beliefs in what happens after death appears to allow him to have a general acceptance that death is something that he has no agency over. This is similar to Emma’s account, where she speaks about death as being an inevitability that she has no control over:

> *“I believe in God, so say if God wants us to come we have to go”* (Isaac, 499-451).

> *“That’s up to God, what He decides let Him decide”* (Emma, 1076-1077).

As mentioned, Cara expressed that she was not fearful of death but more saddened by the thought of leaving her children. She later mentioned that she puzzles over what the experience of death would be like to her:

> *“I am not really scared but sometimes you think to yourself, ‘oh, what will it be like at the end’”* (Cara, 1161-1163).

As with Cara, many of the participants worried about what impact their death could have on the lives of their children. Gina expressed although she is worried about her own mortality it is the concern she has for the effect of her death on her son that equally occupies her mind:

> *“I’m worried about my life and I’m worried about my little boy that he might lose his mother”* (Gina, 858-860).

Many of the other participants reiterated Gina’s concerns and spoke emotively about their fears on how their children’s lives and well-being would be impacted on in the event of their death:

> *“I was thinking, ‘what if I die, what's going to happen to my children?’. That was my main worry”* (Emma, 1123-1125).

> *"Sometimes I do get tearful now and I think to myself, 'oh, if anything happens to me what's going to happen to them?'"* (Cara, 1102-1104).
>
> *"'What's going to happen to the kids, oh blimey!'"* (Boris, 409-413).
>
> *"The only thing which crosses my mind is what would happen if I pass away or whatever, what would happen to her?"* (Demi, 817-819).

The above accounts highlight how the uncertainty of what impact their death could have on their children underpins much of their death anxiety. Isaac embodied this in stating that he worries about how his children would cope without their father in their lives and how this might influence their future:

> *"I worry about my children's future"* (Isaac, 182).
>
> *"I was thinking, 'how are they going to cope?'"* (Isaac, 198).

As if in an attempt to develop a degree of certainty on how their children could be impacted by their death, several participants spoke about having a clear idea or plan on who would care for their children when they die. Demi named her mother, sister and other family members as being the likely guardians of her daughter in the event of her death. However, she implied that despite having family members that would care for her daughter, that she was irreplaceable as her mother and therefore it was important to do all she could to remain alive:

> *"All right she's got my mum, my sister, extended family but she's only got one parent which is me"* (Demi, 804-806).

It seemed clear though that Demi gained comfort from knowing that her daughter would be cared for and loved just like a daughter by Demi's sister:

> *"I know for a fact my sister would look after her and bring her up like one of her own"* (Demi, 819-821).

In essence, Demi's account was similar to Gina's. Gina expressed that despite her son's father being there to care for their son if she was to die, that she was irreplaceable in her role as her son's mother in the way she cares and looks after him:

> *"I know he has his father but the way I care about him and look after him, well he doesn't care for him the same way, so he needs me"*
> (Gina, 860-862).

Cara also mentioned that despite her husband, the father of their children, being there to care and parent their children, he would other responsibilities that would challenge his capabilities to care for their children as a widower:

> *"I know my husband is there but he's still got to work"* (Cara, 1134-1136).

As mentioned previously in this chapter, the participants discussed how aware their children were with regards to the nature and prognosis of their illness. Ari, who mentioned that his illness had become the *"…elephant in the room…"* for his family, explained that he was uncertain of how aware his children were of the probability of death for people with end stage renal disease. Despite this, Ari mentioned that he was fully aware of death being a possibility and he saw as his duty to prepare his children in future for life without him:

> *"I'm not sure if they realise that but I know it's a realisation for me*
> (Ari, 1146-1147).

> *"I might have a conversation with them and say you need to know this stuff for when I, maybe, one day when I'm not here"* (Ari, 1143-1145).

Cara too described her desire to prepare her family for how life could be after her death, this includes her desire for how her children would be parented and cared for by other:

> *"I like to because then everybody knows what is what if anything happens to me"* (Cara, 1148-1449).

In light of all the challenges associated with living with end stage renal disease and the numerous complexities that come with the different renal replacement therapies, especially haemodialysis, Ari symbolised the resilience and determination shown by all of the participants in his firm statement:

> *"I am still here, I am not dead yet"* (Ari, 135-136).

4. Discussion

4.1 Overview

This study aimed to explore the phenomenon of being a parent with ESRD receiving haemodialysis treatment as their RRT. The aim intended to gain an insightful understanding of the impact that living with a chronic health condition has on a person's parental role and their identity as a parent. Existing literature indicates that patients receiving haemodialysis as their RRT can experience a range of complex challenges that adversely impacts on the person's quality of life. To date, there has been limited research into the specific experiences of parents that receive hospital-based haemodialysis. The findings of this study suggest that parents receiving haemodialysis are faced with additional challenges in managing the demands of parenting and their renal replacement therapy. The particular challenges highlighted by the participants included the impact that the frequency and duration of hospital-based treatment sessions and the side-effects of haemodialysis has on their ability to fulfil their expectations of being a parent. The findings also highlighted that for many of the participants being a parent to their children remained a strong motivator for adhering to their treatment requirements.

The structure of this chapter provides a detailed overview of this research study and is divided into the following four sections. Firstly, an overview of the analysis will be discussed, including the presentation of the analysis model and the study's key findings. The second section demonstrates how this study attempted to follow Yardley's (2000) quality control principles for qualitative. Here some transferability issues will also be reviewed. The third section discusses the contribution the findings of this study can make to clinical practice, with particular focus to the field of health psychology. The final section presents suggestions of possible future research areas that could follow this study, followed by concluding comments.

4.2 Overview of the Analysis

This quantitative study ventured to gain an understanding of the experiences of parents receiving hospital-based haemodialysis and the meaning they attach to being a chronically ill parent. As presented and discussed in the Findings chapter, through the analysis of the collated data by using IPA two major themes emerged:

1. The haemodialysis experience
2. The lived experience of parents with end stage renal disease

The formation of the thematic model that emerged from the analysis demonstrates an interesting overlap of the two major themes that is highlighted in the graphic presentation of the model as a Venn diagram (see Diagram 3). The intersection of the two major themes captures the multi-layered experiences of parents with ESRD that receive haemodialysis.

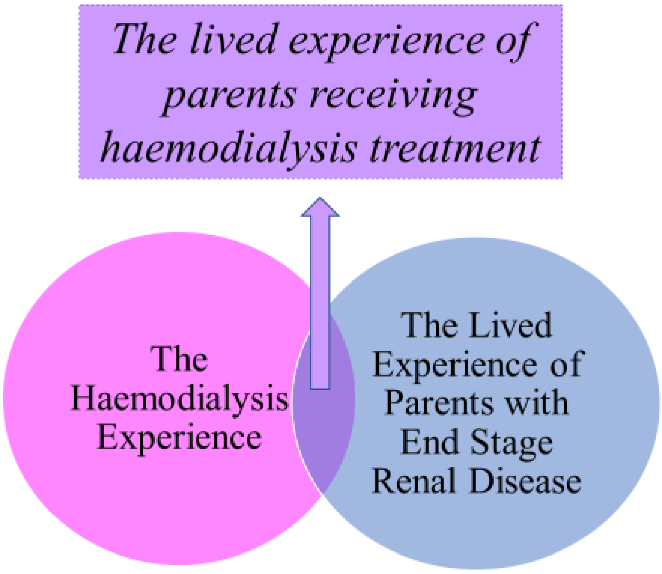


Diagram 3: *Thematic model of findings.*

The first major theme, the haemodialysis experience, captures the various aspects of living with and receiving haemodialysis treatment. It attempts to shine a light on the complexities of the treatment and the all-encompassing nature that it appears to have within the lives of the participants. The first major theme shows how physically and emotionally demanding, time-consuming and restrictive haemodialysis as a RRT can be for patients. All the participants depicted a clear recognition that their haemodialysis treatment is critical to sustaining their lives. Conversely, most participants reported having feelings of bitterness and distain that haemodialysis had become an essential part of their lives. One of the reasons for the expressed negativity towards haemodialysis could be due to the restrictions that such a treatment has on people’s lives. The limitations that are common in the lives of people receiving haemodialysis, including restrictions on employment and finances, have been shown to have serious impact on patients’ QoL

(Wadd, et al., 2011) and in turn infringe on their social and psychological well-being (Anees, et al., 2011). A loss of spontaneity and freedom, that has been found to be present in the lives of chronically ill patients and their families (Golics, Khurshid, Basra, Salek & Finley, 2013), could also be a contributing factor for the participants expressed dissatisfaction, especially considering how time-consuming and demanding haemodialysis is as a treatment. Similarly, the relationship between patients and haemodialysis machines can create a dependency that comes at the cost of generating restrictions on patients' freedom and ability to engage in certain activities (Hagren, et al., 2002). Several of the participants of this study spoke about their absolute dependency on the haemodialysis machine, yet how their reliance on the haemodialysis machine and the frequency and intensity of their treatment schedule also adversely effects their quality of life.

The accounts from a minority of the participants illustrated a dehumanising aspect that is apparent within the haemodialysis experience, from patients' lack of agency in their treatment to the machine-patient relationship and the general haemodialysis hospital environment. These findings are akin to previous studies (Giles, 2005; Prezerakos, et al., 2015; Nagle, 1998). Hagren, et al., (2002) found that the loss of agency and the exhaustive dependency on haemodialysis can have a detrimental effect on patients' family systems. One suggested method of improving patients' overall haemodialysis experience and to nurture a greater sense of agency was noted by a few of the participants in this study. Some of the participants shared that by self-administering their treatment, including being responsible with connecting and disconnecting from the haemodialysis machine, their general haemodialysis experience improved along with an increased sense of self-agency.

The second major theme, the lived experience of parents with end stage renal disease, encapsulates how the participants made meaning of their role as a parent while living with a chronic illness. The findings highlight the changes that occurred in the parental role for several of the participants as a result of being diagnosed with ESRD and undergoing RRT. Living with ESRD and receiving haemodialysis has been shown to be destructive for patients and their families, which can erode the person's parental role within the family system (Nicols & Springford, 1984). The impact of their chronic illness and associated treatments on their parental role can lead to patients re-evaluating their parenting skills (Wadd, et al., 2011), competence (Altschuler & Dale, 1999) and having their identity as a parent threatened (Vallido, Wilkes, Carter & Jackson, 2010). Similarly, factors that contributed to changes in the participants' parental identity and their role as a parent included how the side-effects of haemodialysis (e.g. fatigue) and treatment attendance impeded on their ability to be present for their children. These factors meant that the participants' expectations of what it means to be a parent were often unable to be met, which were associated with intense feelings of guilt, regret and having their identity as a parent threatened. Studies have found that parents living with a chronic illness report being unable to consistently meet their children's needs, which induce increased anxiety and feelings of frustration, anger and guilt that they are unable to fulfil their expectations of what it means to be a parent (Zadinsky & Boyle, 1996; van Mens-Verhulst, et al., 2004; Barlow, et al., 1999; Altschuler & Dale, 1999). Carter and McGoldrick (1989) noted that anxiety produced by stressors during an individual's and family's lifespan, including unpredictable life events such as chronic illnesses, can be exacerbated by additional stressors (e.g. expectations and stigmatism). As such, the threat to parental identity that the parents within this study depicted were intensified by their perceived inability to match the own expectations of being a parent and/or their concern of being seen as adequate by others.

Most of the participants expressed feeling responsible and having a strong sense of remorse for the perceived adverse effect their illness has on their children's QoL. They provided descriptions of their children's behaviour that highlighted their children's worriedness and anxiety concerning their parents' health and well-being, such as their children's reluctance to be separated from their parent and frequent enquires by the children on their parents' well-being. Altschuler and Dale (1999) noted that the chronically ill parent may feel responsible for exposing their children to uncertainty, grief and pain. Parents may look to negate the adverse impact their illness has on their children by making efforts to achieve a sense of normality, for example implementing adjustments to their haemodialysis regime to reduce interference with other life aspects (Wade, et al., 2011). For the participants, this meant requesting adjustments to their haemodialysis schedule to either minimise the overlap between the time they attend their hospital-based treatment and the time that they could spend with their children or schedule their treatment to attend to home-based tasks. The participants' attempts to integrate their parental role with adaptations required due to their illness management fits with one aspect of the relational theory of coping, which highlights parents' developing beliefs and expectations as a parent with a chronic illness (Kayser, Sormanti & Strainchamps, 1999).

The participants' descriptions of their adjustment to the challenges of following their treatment schedule while meeting their family related responsibilities demonstrate their evolving beliefs and expectations of being a chronically ill parent.

The findings of this study found that children are intentionally and unintentionally exposed to different aspects of their parents' illness, which increased the children's awareness of their parents' illness. Intentional exposure included communication between the parent and child concerning the different aspects involved in living with ESRD, children accompanying or visiting parents at hospital, and children's involvement in their parents' treatment and care. Whereas, unintentional exposure captured the consequences of children witnessing the parent enduring the side-effects from haemodialysis, the visibility and restrictions of parents' fistula, adherence to the pharmaceutical treatment regimes and the frequent absence of the parent for them to attend hospital. Children being unintentionally exposed to their parent's illness, or the distress the illness causes their parent, could lead to the parent experiencing feelings of shame and potentially withdrawing from their parental role (Altschuler & Dale, 1999). A desire to limit children's exposure to the full implications of their parents' illness was found in this study, for example participants reported being reluctant to discuss or disclose the full extent and restrictions of their illness to their children. This approach could have been driven by the participants' desire for normality and their felt need to be perceived as 'normal' parents (Wadd, et al., 2014). However, helping children to understand the extent of the limitations imposed by a chronic illness can make the role of parenting easier (Barlow, et al., 1999).

Many of the participants spoke about the dilemma of discussing the extent of their illness with their children. The participants appeared split between either the importance of discussing their illness with their children or preferring to limit how much their children are exposed to their illness and treatment. The apprehensiveness of informing their children of details regarding their illness seemed to be related to the appraisal that it would distress and worry their children. Not establishing an open dialogue between the unwell parent and the child threatens the parents' full involvement in their parental responsibilities (Altschuler & Dale, 1999). This mirrors the account of a minority of the participants that described withdrawing from their parental responsibilities and delegating different aspects of their parental role to nuclear and extended family members. Improving communication within the family system, giving space to listening to the concerns of each individual, has the potential to help parents to maintain their parental identity despite the challenges of living with a chronic illness (Altschuler & Dale, 1999). In addition to this, children would benefit from information and support that would better enable them to understand and cope with life as a child of a chronically unwell parent (Berggren & Hanson, 2016).

An adjunct to the restrictive nature of haemodialysis, that has been mentioned earlier, was highlighted by major theme two's subordinate theme, Holidaying. As a result of being dependent on haemodialysis to maintain physical equilibrium, going on holiday, particularly to another Country, was noted as being an anxiety provoking and rarely ventured pastime. Familiarity with their current treatment regime, anxiety and uncertainty of the accessibility and possible differences of another Country's haemodialysis treatment, transportation concerns and reliance on childcare emerged as the main reasons that contributed to the participants being wary of holidaying in another Country. The findings of this study are akin to Golics and colleagues (2013) findings that living with a chronic illness can severely impair a patient's ability to holiday with family members. Their study suggested that the patient's need to attend hospital appointments/treatment, feeling too unwell and worrying about food abroad were the most common factors that made holidaying difficult. For those patients that manage to holiday in another Country, the location of their holiday would likely be restricted to areas where dialysis services are readily available, which would ultimately make visiting remote or rural locations particularly challenging and unlikely (Sims, et al., 2017). Reliance on additional childcare support was also found by this study to be an essential factor in enabling patients receiving haemodialysis to holiday with their children, which appeared to be particularly the case with the participants of this study that were single parents or lacked family support. The need for adequate childcare arrangements seems evidently clear given the frequency and duration of haemodialysis sessions, as well as the, at times, debilitating side-effects common to the treatment.

Children were noted as being a great source of emotional strength and practical support for the participants. Indeed, positive family relationships have been found to optimise chronic disease management (Lewis, 1990). In this study, children were considered by many of the parents to be the primary motivating factor for them to continue attend and adhere to the requirements of their treatment, and consequently endure the often-debilitating side-effects of haemodialysis. Children being identified as a dominating motivator mirrors other studies that have explored impact of chronic illnesses on parenting (Barker, et al., 2017; vans Mens-Verhulst, et al., 2003; Barlow, et al., 1999). In a study into the experiences of parents with cystic fibrosis, Barker, et al., (2017) found that having children led patients to attempt to optimise their health and demonstrate a keen motivation to adhere to challenging and time-consuming treatment for the sake of their children. Similarly, the findings of this current study found that parents' have a strong desire to continue with their haemodialysis treatment in order to survive and be there for their children. Interestingly, being there for their children appears contrary to the nature of hospital-based haemodialysis which involves regular attendance to haemodialysis units and subsequently meaning parents are frequently absent from their children.

Parents receiving haemodialysis and living with the complex challenges common to the treatment can lead to an increased death anxiety (Niu & Liu, 2016). The subject of mortality and death seemed to be a pervasive feature in the participants' consciousness. Rolland (1987) described three phases of the illness timeline, crisis phase, chronic phase and terminal phase. Whereas the crisis and chronic phases are concerned with the period between initial disease onset through to readjustment to living with a chronic illness, the terminal phase occurs when death becomes apparent. The participants expressed that despite being aware that haemodialysis serves to prolong their lives, it had a mortality and morbidity prevalence where death was a high probability. They spoke of their expectation that ESRD, or a resulting complication, would result in their eventual death. Despite an apparent acceptance that death was inevitable, participants expressed feeling anxious for not only their own mortality but the effect that their death would have for their children. This finding reflected the outcome of Smith and Soliday's (2001) study, who also reported that children could be adversely affected by worrying about their parent's mortality. Despite the concerns for their children's worry, parents may be reluctant to discuss the implications of their illness and their own mortality (Wadd, et al., 2014). Similarly, some of the participants of this study expressed their reluctance to discuss the subject of death with their children.

4.3 Significant Findings in Relation to Research Topic

This section discusses the key findings that emerged from this research study in relation to previous literature. Three key findings will be presented here, these are: (i) the time demands of haemodialysis versus parenting; (ii) the impact of haemodialysis side-effects on parenting; and (iii) being a parent living with haemodialysis: it's more difficult with younger children.

4.3.1 Time Demands of Haemodialysis Versus Parenting

One of the main findings that emerged in this study characterised the difficulties that parents might experience due to the time intensive nature of haemodialysis. The participants all reported following the recommended hospital-based haemodialysis schedule of treatment, which is four to five-hour sessions for three-times per week (MacNeil & Ford, 2017). The parents of this study shared a clear understanding of the importance of adhering to their haemodialysis schedule in order to fully utilise the treatment's effectiveness. They reported being acutely aware that non-adherence to their haemodialysis regime would likely increase morbidity and mortality (Denhaerynck, et al., 2007). The findings stressed how challenging frequency and duration of haemodialysis treatment is for the parents of this study, particularly as attending treatment conversely meant being absent from their children for long periods on a repeated regularity. Feelings of sadness, guilt and a strong sense of loss and separation were noted as consequential by the participants for being apart from their children so regularly, which for some was counter to their parental expectations of being present and available to their children. These findings support previous research that suggest that parents with a chronical illness are subject to powerful internal and external expectations of being a parent and a patient, and prioritise one role at the expense of the other can result in feelings of guilt, anxiety and loss (Barker, et al., 2017).

Achieving the delicate balance between self-care and meeting the needs of others has been shown to be particularly challenging for parents with chronic illnesses. The findings of this study highlighted the compromises that parents need to make in receiving haemodialysis. Patients' needing to prioritise their own care over the needs of their children can potentially threaten their parental identity and their concept of what it means to be a parent (Altschuler & Dale, 1999). The participants stated that the time demands involved in adhering to their haemodialysis schedule meant that they were less present and therefore less able to meet their children's needs. As mentioned, the apparent need to prioritise their own self-care seemed to threaten the participants' identity as a parent to the extent they perceived themselves as being neglectful, terrible parents. This mirrors Wadd and colleagues' (2014) findings that mothers receiving dialysis experience a significant challenge to their mothering and their strong desire to be perceived as being a good mother to their children. Although differences between mothers and fathers were not specifically explored by this study, fathers have been found to more easily accept the need to prioritise their own treatment over the needs of their children. Two reasons could explain this gender difference, firstly that fathers may consider the short-term cost of not spending time with their children against the longer-term benefits of possibly having more time to spend with their family, and secondly, that fathers may not position themselves as the principle caregiver and therefore feel that their parental identity is less threatened by prioritising their own needs (Barker, et al., 2017).

Being regularly absent from their children meant many of the participants adapted their routine to ensure that they were still able to achieve their perceived parental responsibilities. For example some of the participants expressed a preference for their haemodialysis slot to be later in the day to allow time to clean their home or cook their family’s evening meal before leaving for treatment, whereas others were more inclined to have an earlier slot so they could collect their children from childminders/school or be home for when their children arrive from school. Despite these adaptations, parents receiving haemodialysis may worry about the lack of time they have available to spend time with their children (Smith & Soliday, 2001) and how that may impede on family time, for example coming together as a family at mealtimes (Wadd, et al., 2011).

A reliance on social support to help care for children while parents attended treatment was presented by the findings. The chronically unwell individual would often take a central position within a family system, where nuclear and extended family members surround the individual to provide both support and structure (Newby, 1996). Most participants in this study reported being dependent on the support of their family system, in addition to outside help, for them to balance their role as a parent and a patient. Childcare support was essential for some of the participants, with childcare being provided by the other parent, grandparents, older siblings, neighbours, professional childminders or by the child’s school if treatment was received during school hours. The heavy and regular reliance on childcare that was necessary for parents to receive their haemodialysis treatment resulted in some parents feeling that they were abdicating their parental responsibilities or putting undue demands onto others. Being absent from younger children seemed particularly challenging, which will be discussed in more depth in the third key finding.

4.3.2 Impact of Haemodialysis Side-Effects on Parenting

The side-effects of haemodialysis played a central role in the overall experience of receiving haemodialysis for all the participants. Jhamb and colleagues (2008) found that the most commonly reported side-effect from haemodialysis is fatigue, which they stated has a mean prevalence of 71% among patients. The most widely occurring side-effects that were reported by the participants of this study were similarly post-dialysis fatigue and hypotension. All the participants bar one described in detail the debilitating nature of their experienced side-effects, with post-dialysis fatigue being the most prevalent and severely incapacitating side-effect.

The experience of living with the effects of post-dialysis fatigue was reported as the side-effect that has had the most adverse influence on the participants' QoL. Several of the participants mentioned that having the opportunity after haemodialysis to recuperate with sleep was essential in managing the effects of fatigue. Sklar, et al., (1996) suggested that an average of 4.8 hours of sleep or rest was generally required to adequately recover from the symptoms of post-dialysis fatigue. Post-dialysis fatigue can adversely impede on parents' capability to sufficiently care for their children (Altschuler & Dale, 1999). Likewise, this current study found that being a parent greatly hinders the possibility of freely resting after receiving haemodialysis in order to overcome the symptoms of post-dialysis fatigue. The parents of preschool or school-aged children explained that their priority following haemodialysis was to either collect their children from the arranged childcare or from their children's school and then subsequently care for their children's needs. Having inadequate time or a lack of opportunity to recuperate after haemodialysis meant that parents were less engaged with their children and less able to meet their needs.

To manage the impact that haemodialysis side-effects has on parenting, the parents of this study described predominately deploying low energy activities with their children after receiving treatment. The parents that described being solely responsible for their children on their treatment days all returned home following treatment, either after collecting their children from their arranged childcare or before their children returned home. Relationship-focused coping, such as using low energy activities, can be effective in responding to children's needs while also providing temporary respite from parenting (White, et al., 2009). As a means of managing post-dialysis fatigue the majority of participants spoke of completing more energy intensive activities either before attending treatment or on non-treatment days, these included completing housework chores and preparing future meals for their children and spouses. This enabled the participants to focus exclusively after their treatment on their recovery and caring for their children.

Symptoms of fatigue, pain and impaired mobility have been found to impinge on parents' perception of their own ability to fulfil their parenting role. The perceived impairment that these symptoms have parents' parental expectations can manifest feelings of guilt, frustration and anger (Barlow, et al., 1999). Many of the participants spoke of being affected by the extent in which the side-effects of haemodialysis prevent them from performing their parental role. Several participants described foregoing a sufficient rest period in order to care for their children. This was often motivated by the participants feelings of guilt and their desire to align themselves closer to their own parental expectations. Similar reactions are akin to the suggestion that parents living with a chronic illness may attempt to compensate for missed opportunities with their children by overextending themselves. This in turn has the potential to worsen their symptoms (van Mens-Verhulst, et al., 2004).

4.3.3 Being a Parent Living with Haemodialysis: It's More Difficult with Younger Children

One of the subtler key findings that arose from this study indicates that parents receiving haemodialysis are likely to endure additional challenges if they are the parents of younger children as opposed to parents of adolescents or older children. The two previously presented key findings have shone a light on the likely impact that the time demands and the side-effects of haemodialysis can have on parenting. Both of these dominating elements of haemodialysis were highlighted by the participants as being considerably more demanding when they coincide with parenting younger children. The findings demonstrated that being absent from younger children due to the frequency and duration of the haemodialysis regime creates a heavy reliance on arranging childcare, which either involved the cooperation from family members and friends or meant accruing the financial cost of professional childcare. For some of the participants, the reliance on childcare support continued post-dialysis due to the prevalence of the treatment side-effects and the participants need for rest, whereas for others the lack of childcare provision meant that parenting their young children while managing their post-dialysis fatigue became a significant challenge.

For the parents of younger children within this current study, their focus shifted from attending to their own needs (i.e. receiving haemodialysis) to acting towards meeting their parental responsibilities soon after completing their treatment session. For example, some of the participants reported collecting their children from childcare immediately after receiving haemodialysis which meant they were unable to have the 4.8 hours sleep or rest recommended as enough to overcome the effects of post-dialysis fatigue (Sklar, et al., (1996). Parents meeting their parental responsibilities appeared to result in them rarely having the opportunity to adequately rest and overcome the effects of post-dialysis fatigue. Post-dialysis fatigue presented challenges for parents being physically and psychologically well enough to attend to the needs of younger children. Fatigue and a lack of mobility have been shown to have a greater adverse impact on parents of younger children. The practical elements involved in the parenting of younger children can contribute to the challenges experienced by chronical ill parents, such as carrying an infant or engaging in play or meeting the child’s primary needs (Barlow, et al., 1999). Being physically and emotionally less available to their children contributed to feelings of guilt, shame and regret for many of the participants.

Rolland (1987) argued that when the onset of a parent’s chronic disease coincides with a period of parenting young children in the family life cycle, referred to as a centripetal period, there can be vital consequences for both the individual and the family unit. The addition of a new infant family member and the occurrence of a chronic illness within a family are both centripetal periods that exert an inward focus on the family system. When a parent is the family member with the chronic illness and it occurs while there are young children to care for in the family it can severely impede a family’s ability to manage the additional demands. This was highlighted by this study’s findings, with the parents of young children finding it particularly challenging to balance their parental expectations and the demands of their illness and haemodialysis treatment.

Participants that were parents of older children that were more independent appeared to be more able to prioritise their own care and were able to more fully recuperate from post-dialysis fatigue symptoms. One reason could be that older children tend to be less dependent on their parents and have needs that are more predictable than younger children (Herbert, 1998), which may allow the unwell parent to prioritise their own needs more so than if parenting younger children (Barker, et al., 2017). In addition to parents with older children being more able to sufficiently recuperate after receiving haemodialysis, some of the participants described how their older children would take on extra responsibilities, such as cooking the family meal or caring for their younger siblings, which in turn would aid their parents' convalescence.

The current study did not look specifically at differences between parenting with a chronic illness for mothers and fathers, mothers of younger children all reported needing to undertake their parental responsibilities soon after completing their haemodialysis session. This contrasted with the few fathers who were parents to young children, who implied that they were more able to rest after their treatment while others (e.g. partners) cared for their children. It has been previously suggested that chronically ill mothers are more likely to experience greater difficulties when caring for infants and toddlers, whereas fathers find it more challenging when their children reach school age (Barlow, et al., 1999). One potential reason for this gender difference is that fathers may be less likely to perceive themselves as their child's primary caregiver and as such will feel more able to prioritise their own needs (Barker, et al., 2017) when the child is young. The physical aspects of parenting young children would therefore more likely fall on mothers, while fathers may struggle with the physical demands once the child reaches the age of five years (Barker, et al., 2017). The parents of this study generally managed the impact of their side-effects by reducing the physical demands of parenting by employing low energy activities with their children. Other studies have also identified that parents with chronic conditions reduce the physical demands of the activities with their children as a means of illness management (Katz, Pasch & Wong, 2003; Barlow, et al., 1999).

The participants also depicted the role that their older children play in providing practical and emotional support. This includes them receiving direct practical support from their children, sharing responsibilities of household chores, their children becoming a carer for their parent and a source of emotional comfort. The support received from older children likely follows Piaget's (1973) stages of cognitive development where children from the age of 7 years (concrete operational stage) are more able to think logically about concrete concepts and children from the age of 12 years (formal operational stage) tend to think more logically, abstractly and flexibly. Thus, older children are more likely to have the cognitive and emotional maturity to grasp their parents' incapacitation caused by their chronic illness. The children of the parents in this current study were not only described as being supportive but also a great motivator to their parents' adherence to their haemodialysis regime, this was particularly the case with younger children. The participants expressed feeling saddened and worried about the devastating impact that a deterioration in their physical health or death would have on their children, especially younger children. Their strong desire to survive and be alive for milestone events in their children's lives appeared to be a significant enough motivation to endure the difficulties common to haemodialysis. Indeed, younger children have been found to be a strong motivator for chronically unwell parents to maintain their wellness yet due to a maternal desire to fulfil ideals of being a mother and their role as the primary caregiver mothers could frequently be confronted with the dilemma of needing to put their children's needs above their own (Barker, et al., 2017). This may explain why the mothers of younger children in this study found the balance between meeting their parental responsibilities and managing the side-effects of haemodialysis difficult.

The number of additional challenges experienced by parents receiving haemodialysis who have young children signifies the potential need for parents of younger children to be further supported by healthcare teams and other professional services. A desire that was shared by many of the participants of this study was that parents on haemodialysis, particularly those with younger children, require more comprehensive support. Parents with chronic illnesses are likely to benefit from practical and psychological support from healthcare teams to help in managing their parental responsibilities in conjunction with their illness demands. Adopting a more flexible approach to treatment may also assist parents' in prioritising their needs with those of their children (Barker, et al., 2017).

4.4 Transferability and Limitations of the Study

As with most other research, this study has its strengths and limitations. Following Yardley's (2000) characteristics of good qualitative research, this research study attempted to adhere to four core quality control markers to enhance this study's transferability. Yardley's (2000) four quality control markers are: (i) sensitivity to context, (ii) commitment and rigour, (iii) coherence and transparency, and (iv) impact and importance.

4.4.1 Quality Markers

4.4.1.1 Sensitivity to Context

The researcher remained sensitive to the context of this study by reviewing and remaining familiar with theoretical and empirical literature relevant to the researched phenomenon of parents that receive haemodialysis. Having a personal and professional knowledge of parental illness and experience of working closely with haemodialysis patients the researcher remained mindful of their own biases and influences through personal reflections and use of a research diary. Throughout the research process, from the recruitment stage to beyond analysing the data, the researcher remained sensitive to the personal accounts of the ten participants of this study. This was particularly evident in approaching each interaction with compassion and professionalism, and then handling all collected data ethically and sensitively in accordance with the guidelines of the BPS (2009) on Code of Ethics.

4.4.1.2 Commitment and Rigour

A thorough commitment to this study was required throughout each phase to ensure the research met the highest quality of empirical research. The researcher's commitment was evidenced through their rigorous engagement with the literature in gaining an in-depth knowledge of the researched topic, the process of data collection and analysis, and ensuring the retelling of the participants' stories remained true to their accounts. The researcher stayed committed to a thorough and rigorous exploration of the data throughout each stage of the analysis process, returning to the original data when necessary and reviewing the emergent themes to ensure a deeper understanding. Commitment to the well-being of the participants of this study was demonstrated by the researcher's desire to appropriately attend to recommended professional and ethical standards throughout the research process.

4.4.1.3 Coherence and Transparency

The researcher strived to provide a coherent and transparent representation of the different stages of the research process, as the Methodology and Findings chapters demonstrate. A clear and thorough account of each phase of the research process has been presented in the Methodology chapter, including: a coherent rationale for the inclusion/exclusion criteria; the considerations and steps taken during recruitment and data collection; a clear guide through the analytic process; and a transparent explanation of the researcher's ethical considerations. The Findings chapter further evidences the researcher's transparent use of the collected data through the use of explanatory commentary that accompanies the original data extracts and in the final analysis thematic model. Furthermore, the brief biographies of each participant (Appendix 10) were provided to enhance the cohesiveness of the Findings and bring the reader closer to the participants.

The intention of presenting a coherent and transparent account of the researcher's role in this study was to provide clear guide of the path taken to achieve the overall thematic model of analysis and to encourage elements of transferability.

4.4.1.4 Impact and Importance

A fundamental aspect of this study is that it has explored a phenomenon that has previously received only limited research exposure. By adhering to the aforementioned quality markers of qualitative research this study illuminates the experiences of ten parents that are undergoing hospital-based haemodialysis treatment for ESRD and shines a light on what meaning they make of being a parent receiving haemodialysis. This exploration of an area that has received limited attention previously has gained an insightful and rich understanding of a phenomenon that is hoped will provide an important impact with other researchers, healthcare professionals and in the field of Health Psychology.

4.4.2 Limitations

This study, as with most empirical research, has its limitations. Here, the methodological and the procedural limitations of this study will be discussed along with recommendations for possible improvements, where appropriate.

4.4.2.1 Methodological Limitations

In accordance with its suitability to qualitative research methodology, in particular IPA, this study used a small purposive sample of ten participants. By adopting a small sample size it may prohibit the generalisability of the findings to a wider population. Despite the limitations associated with exploring the experiences of a small homogeneous sample, the chosen sample size permitted a deeper, meaningful engagement and analysis of the rich wealth of data that was collected from the ten participants. Therefore, what might seem to be a limitation, using a small sample size could also be seen as one of this study's main strengths.

IPA relies on the assumption that language provides individuals with the tools to communicate and express the meanings they make of their experiences and the world around them (Willig, 2008). With this in mind, it is worth noting that even though all of the participants showed a good comprehension of the English language, English was not the dominant language for a number of participants. In recognising the importance of language, one of the inclusion criterion required that participants have a sufficient grasp of English, which all of the participants were able to demonstrate. It is important to consider however that non-native English speakers may be restricted in articulating a full picture of their experiences.

4.4.2.2 Procedural Limitations

Two main procedural issues arose during the data collection phase of this research study, which concerned the location and timings of the interviews. Firstly, all of the interviews were conducted in consultation rooms within Haemodialysis Units where participants regularly received their treatment. Considering the physical and psychological demands that patients might endure during their haemodialysis treatments it is possible that patients would form negative associations with being on Haemodialysis Units. Conducting the interviews in the same environment where the participants receive haemodialysis could have affected them during the data collection phase and potentially influenced how they responded to the interview schedule.

The second procedural limitation concerns the timing of the interviews in relation to when the participants received their haemodialysis. All except one of the interviews were conducted on the participants' treatment days, either before or shortly after receiving haemodialysis. As discussed at great length in the Findings and earlier in this chapter, the side-effects common to haemodialysis have the potential to be debilitating for the majority of the participants. Some participants mentioned feeling physically uncomfortable before haemodialysis due to fluid retention, whereas post-dialysis fatigue and the effects of hypotension were also reported. It is fair to consider whether the adverse physical conditions that the participants experienced pre and post-dialysis could have influenced their interviews and limited the data collected.

Despite the few methodological and procedural limitations of this study, the quality markers that the researcher adhered to throughout the research process has ensured that this study remains robust and provides a valuable insight for professionals working in the health psychology field.

4.4.3 Personal Reflexivity

(This section is written in the first person as it is the personal reflections of the researcher)

The decision to explore the experiences of parents receiving haemodialysis for the treatment of ESRD originated from my time working in a renal department's psychology service as a Senior Assistant Psychologist/Trainee Health Psychologist. During my time working clinically with the patients of the renal department, and in particular haemodialysis patients, I became increasingly aware of the multiple challenges that this population frequently experienced. I witnessed in many of the haemodialysis patients the inspiring durability and resilience needed to regularly endure the complex demands of the treatment. What became increasingly apparent were the difficulties parents experienced in balancing their parental responsibilities and their dedication in meeting the demands of haemodialysis. Through exploring and becoming more familiar with the available literature on parents receiving haemodialysis, it quickly became clear that it was an area that had received little previous attention.

My interest in exploring the experiences of the chronically ill parent was not only influenced by my professional clinical work but also my personal experiences of being a child to a parent with a chronic physical health condition. Since my formative years I grew up within a family where my mother, the matriarch of our close family, lived with chronic pain. During these early years, and beyond, I developed a deep understanding and appreciation for how a parent's illness can have wide reaching effects on the person and their whole family. My personal experience was formed from the perspective of a child who was witnessing their mother in frequent pain and discomfort, while still managing to care lovingly for her children, stay on top of our household chores and, later in life, maintain employment. Taking the pain and suffering away from my mother was one of my strongest desires but as she had learnt to live with her pain so did I. In having a very close relationship with my mother I had been able to discuss with her during my adult years how she experienced living with her chronic pain while parenting my brother and I, especially during our younger years when our needs were more dependent on being met by our parents. My personal and professional experiences, in addition to being guided by the lack of available empirical research, were highly influential factors in my decision to conduct this qualitative study into the phenomenon of being a parent receiving haemodialysis.

I also became a mother for the first time during the course of this research. It was during the analysis phase of the study that I became pregnant and gave birth to my daughter. I was aware that I not only had personal knowledge of being a child of an unwell parent but was also now a parent conducting research on the experiences of other parents. Taking up a new position of sameness with the participants increased the need for me to remain aware of my own beliefs and possible biases in my role as the researcher of this study. This seemed particularly relevant considering that I became a mother during the analysis and write-up stages, where any unchecked biases would have the potential to adversely influence the findings and final thesis. Although qualitative research accepts that the researcher is an active member in the research process it is also important that the researcher remains aware of their biases. I endeavoured to stay mindful of my own inner view of the world through frequent reflexivity and by keeping a reflective diary throughout the research process.

In my clinical work as a Senior Assistant Psychologist/Trainee Health Psychologist during the course of my doctorate in Health Psychology I have conducted a number of initial assessments and provided psychological support to a large host of patients. The skills gained though my clinical work helped to inform my development as a more reflective and self-aware health professional. These skills proved to be valuable throughout the data collection and analysis stages of this study, especially in helping me to remain aware of my own biases and belief systems.

4.5 Implications for Clinical Practice

This study has the potential to make a valued contribution to the field of health psychology and to the broader healthcare field by shining an illuminating light on an under-researched subject area and thus increasing the understanding on the experiences of parents receiving haemodialysis. It also provides a valuable insight into the challenges that parents with chronic illnesses experience in balancing their needs as patients receiving an intensive form of treatment with their responsibilities of being parents.

The findings of this current study have the potential to inform clinicians and healthcare services of the complex challenges that parents with ESRD face by undergoing regular haemodialysis and enduring the side-effects commonly associated with the hospital-based treatment. The findings of this current study could be applied to the Capability, Opportunity, Motivation and Behaviour (COM-B) model (Michie, van Stralen & West, 2011) to assist in the formulation and implementation of behaviour change interventions to ease the burden of balancing the demands between being a parent and patient receiving haemodialysis treatment. For example, based on the findings, a person’s physical capabilities could be impeded by the incapacitating nature of the treatment's side-effects and the demands of their parental role. With a lack of knowledge or insight into their illness and treatment adversely impacting on their psychological capabilities. Likewise, the treatment frequency and duration alongside the haemodialysis side-effects could greatly reduce patients' opportunities to suitably meet both their own and their children's needs. Health psychologists, clinicians and renal healthcare services are well positioned to develop behaviour change interventions that improve patients' capabilities (e.g. provide subsidised childcare support in the community to promote the need for parents to recover from post-dialysis fatigue; develop psychoeducation workshops, peer support services and provide psychological therapy to improve psychological capacity) and opportunities (e.g. reduce travel time to and from treatment by providing transportation for parents; individualise haemodialysis schedules for parents by prioritising their preferred treatment slot to optimise their ability to meet their role as a patient and as a parent). The children of haemodialysis patients emerged through the findings as the primary motivator that encouraged patients to continue to endure such an intensive and taxing treatment regime. By creating behaviour change interventions to improve patients' capability and opportunity while tapping into parents' rich form of motivation could have substantial positive implications for assisting patients in managing the complex dual role of being both a patient and a parent.

Parents with a chronic illness can often struggle with the decision as to how or whether to disclose and discuss their illness with their children (Rolland, 1999). Many of the parents of this research study indicated being similarly uncertain on how to communicate with their children, with some expressing concern that their children would be unnecessarily distressed if they were more aware of their parents' illness. Rolland (1999) stated however, that blocked communication fuelled by the parent's own vulnerabilities and sense of devastation about their own mortality could trigger greater anxieties and threat of loss in their children. Providing patients with psychological support, through the method of psychoeducation workshops and psychotherapies, would help guide them through their personal distress and support them in developing age-appropriate strategies to enable them to communicate with their children.

One of the key findings of this current research study highlighted that parenting younger children further complicates the patient's haemodialysis experience and QoL. Older children, however, were identified by those participants with older children as taking on additional responsibilities within the family system, including looking after younger siblings and taking on more of a carers role for their unwell parent. What this current study signifies is that parents receiving haemodialysis and their children (of any age) require extensive support appropriately structured to their individual needs. Involving health psychologists in the provision of valuable service development consultation, with the aim to identify the importance of the parent/child relationship on patients' and the child's psychological well-being, could help lessen the impact of haemodialysis on the parent, the child and their relationship. The findings from the consultancy could help guide the development of support groups for young carers, respite care programmes for parents and older children, and peer-focused family activity events within the renal community.

4.6 Future Research

The findings from this study brought to the surface a number of areas that would benefit from further exploration. An area of interest that warrants further research follows on from the third key finding of this current study that highlights the additional challenges that parents of younger children may experience in their attempts to balance the demands of their haemodialysis treatment and their desire to meet their parental responsibilities. Further qualitative research that specifically looks to gain a greater understanding of the significant additional stresses that parents of younger children are under merits greater attention. To the author's knowledge, there has been little research to date that has explored the experiences of haemodialysis receiving parents and how those experiences differ in line with children's cognitive, emotional and social development. Gaining an in-depth understanding of this area through empirical research has potential to have implications on not only parents' QoL but also inform and improve children's experiences of living with a parent with a chronic illness undergoing an intensive and frequent treatment regime.

Considering the complex and far-reaching psychosocial demands associated with haemodialysis treatment that were evident in the findings of this current study, an in-depth assessment of the illness trajectory of ESRD (including received RRTs) and the impact it has on the family system would be necessary to further understand how patients and their families adapt through each transitional period. Using Rolland's (1987) Time Line and Phases of Illness model as a framework to explore the trajectory of ESRD and the impact the illness has on the family system would help to expand on the study's findings by shining a light on the journey that patients and their families experience living with a chronic illness, through the 'crisis', 'chronic' and 'terminal' phases. As discussed previously in the findings of this study, haemodialysis treatment is a life sustaining treatment that has side-effects that can be incapacitating for patients, with many participants of this study also revealing their awareness and anxieties of the terminal aspect of ESRD. Future research has the potential to build on the current findings by investigating how parents with ESRD, patients' family systems and the children of chronically ill parents appraise and react to the transitional periods within ESRD (from diagnosis to death, including the numerous transitions through different treatment modalities). In so doing, it could have wide-reaching implications for patients and their families by helping to inform clinicians that provide essential renal, systemic and palliative care.

Although this study was intentionally interested in gaining a greater understanding of the experiences of living with ESRD and receiving haemodialysis from the perspective of being a parent, what emerged from the findings were the parents' beliefs that their illness has a substantial effect on their children's QoL and emotional well-being. Future research could therefore attempt to explore the phenomenon of being a child to a parent receiving haemodialysis, with particular attention to the manner in which children make sense of their parents' absence due to attending regular treatment sessions and how they perceive the side-effects their parents' experiences from receiving haemodialysis.

5. Conclusion

In summary, this study aimed to explore the phenomenon of parents receiving haemodialysis using a qualitative methods approach. The ten participating patients, aged between 28 to 49 years of age, participated in semi-structured interviews that were analysed using IPA. From the analysis two major themes emerged: (i) the haemodialysis experience and (ii) the lived experience of parents with end stage renal disease, which in the intersection of a Venn diagram captured the complex experiences of parent that receive haemodialysis. The findings of this study have provided an in-depth and meaningful account of what it means to be a parent living a life that involves regular haemodialysis treatment. This study has the potential to inform the work of health psychologists and other health professionals in their clinical practice working with parents receiving haemodialysis and also parents that live with having other chronic illnesses. It also has the potential to guide future research towards areas of possible exploration that could stem from this study.

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Appendices

1. Ethical approval letter from the Health Research Authority for the National Health Service (Regional specific)
2. Amended ethical approval letter from the Health Research Authority for the National Health Service (Regional specific) following recommendations
3. Ethical approval letter from the Local Research and Development department for the National Health Service (Trust specific)
4. Ethical approval letter from the City, University of London’s Research Ethics Committee
5. Research flyer
6. Information sheet
7. Invitation letter
8. Initial contact consent form
9. Brief biographies of the participants
10. Consent form
11. Demographic information and background questionnaire
12. Debrief sheet
13. Interview schedule
14. Extract of initial analysis stages – initial notations and emergent themes from individual transcript
15. Example extract of table with emergent themes from individual transcript
16. Table of Major Themes, subordinate themes and extract location

Appendix 1: Ethical approval letter from the Health Research Authority for the National Health Service (Regional specific)

NHS
Health Research Authority

23 August 2012

Ms Maria Tziggili
Trainee Health Psychologist
Psychology Department
City University London
Northampton Square
London

Dear Ms Tziggili

Study title: **Exploring people's experience of being a parent with End Stage Renal Disease receiving Haemodialysis treatment**

REC reference:

Thank you for your letter of 14 July 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).

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

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).

Approved documents

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

Document	*Version*	*Date*
Advertisement	2	14 July 2012
Covering Letter		25 May 2012
Evidence of insurance or indemnity		07 July 2011
Interview Schedules/Topic Guides	1	25 May 2012
Investigator CV		
Letter from Sponsor		16 May 2012
Letter of invitation to participant	2	14 July 2012
Other: Summary CV for supervisor (Dr Pires-Yfantouda)		
Other: Appendix 5 - Debrief Sheet	2	14 July 2012
Participant Consent Form: Appendix 4 - Consent Form	2	14 July 2012
Participant Information Sheet: Appendix 3 - Information Sheet	2	14 July 2012
Protocol	2	14 July 2012
Questionnaire: Appendix 1 - Demographic Information and Background Questionnaire (non-validated)	1	25 May 2012
REC application	IRAS 3.4	25 May 2012
Referees or other scientific critique report		
Response to Request for Further Information		14 July 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

[redacted]	**Please quote this number on all correspondence**

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

Yours sincerely

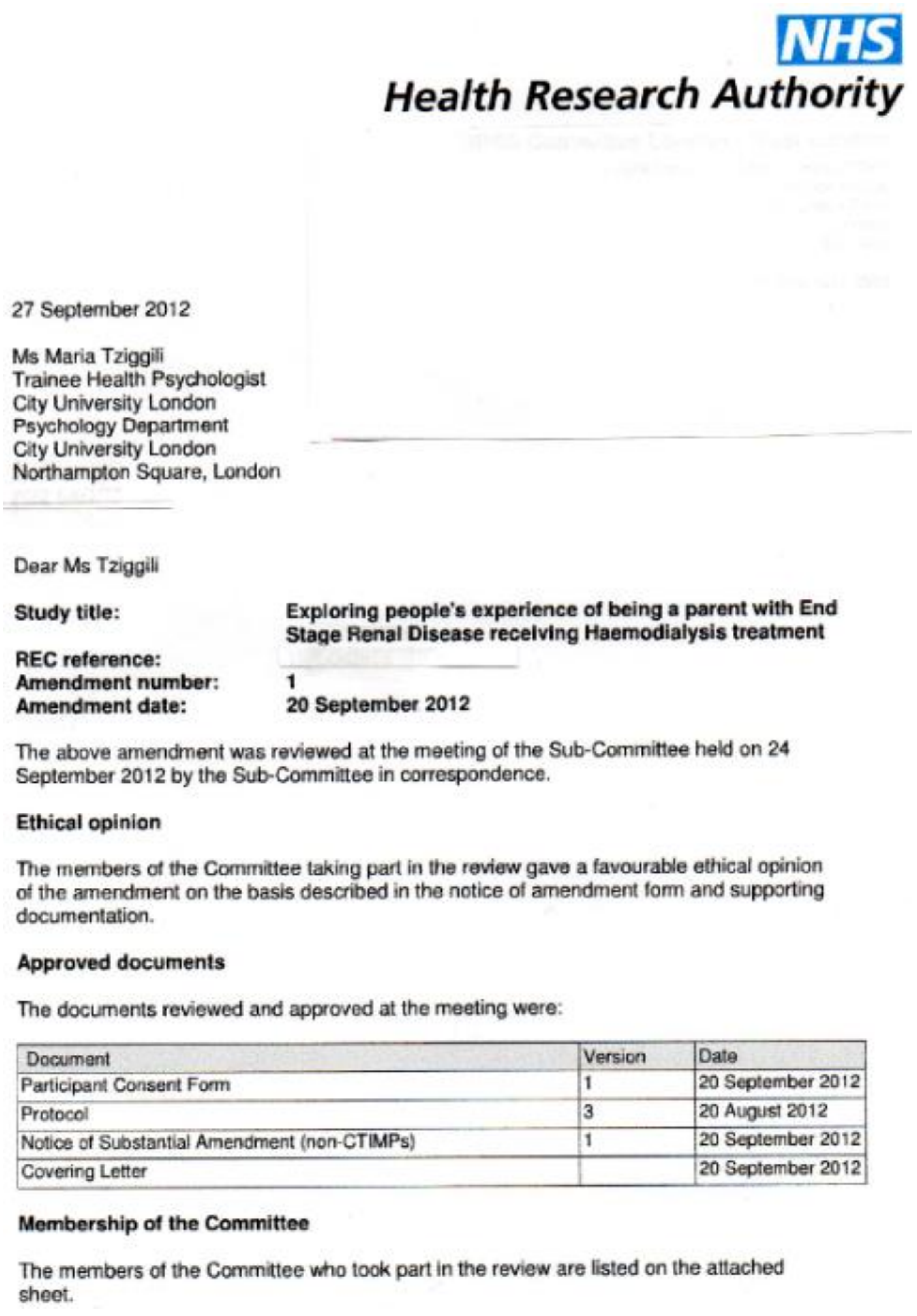
[redacted]

Email: [redacted]

Enclosures: "After ethical review – guidance for researchers"

[redacted]

Appendix 2: Amended ethical approval letter from the Health Research Authority for the National Health Service (Regional specific) following recommendations



Health Research Authority

27 September 2012

Ms Maria Tziggili
Trainee Health Psychologist
City University London
Psychology Department
City University London
Northampton Square, London
[redacted]

Dear Ms Tziggili

Study title: **Exploring people's experience of being a parent with End Stage Renal Disease receiving Haemodialysis treatment**
REC reference: [redacted]
Amendment number: **1**
Amendment date: **20 September 2012**

The above amendment was reviewed at the meeting of the Sub-Committee held on 24 September 2012 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form	1	20 September 2012
Protocol	3	20 August 2012
Notice of Substantial Amendment (non-CTIMPs)	1	20 September 2012
Covering Letter		20 September 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

[redacted]	**Please quote this number on all correspondence**

Yours sincerely

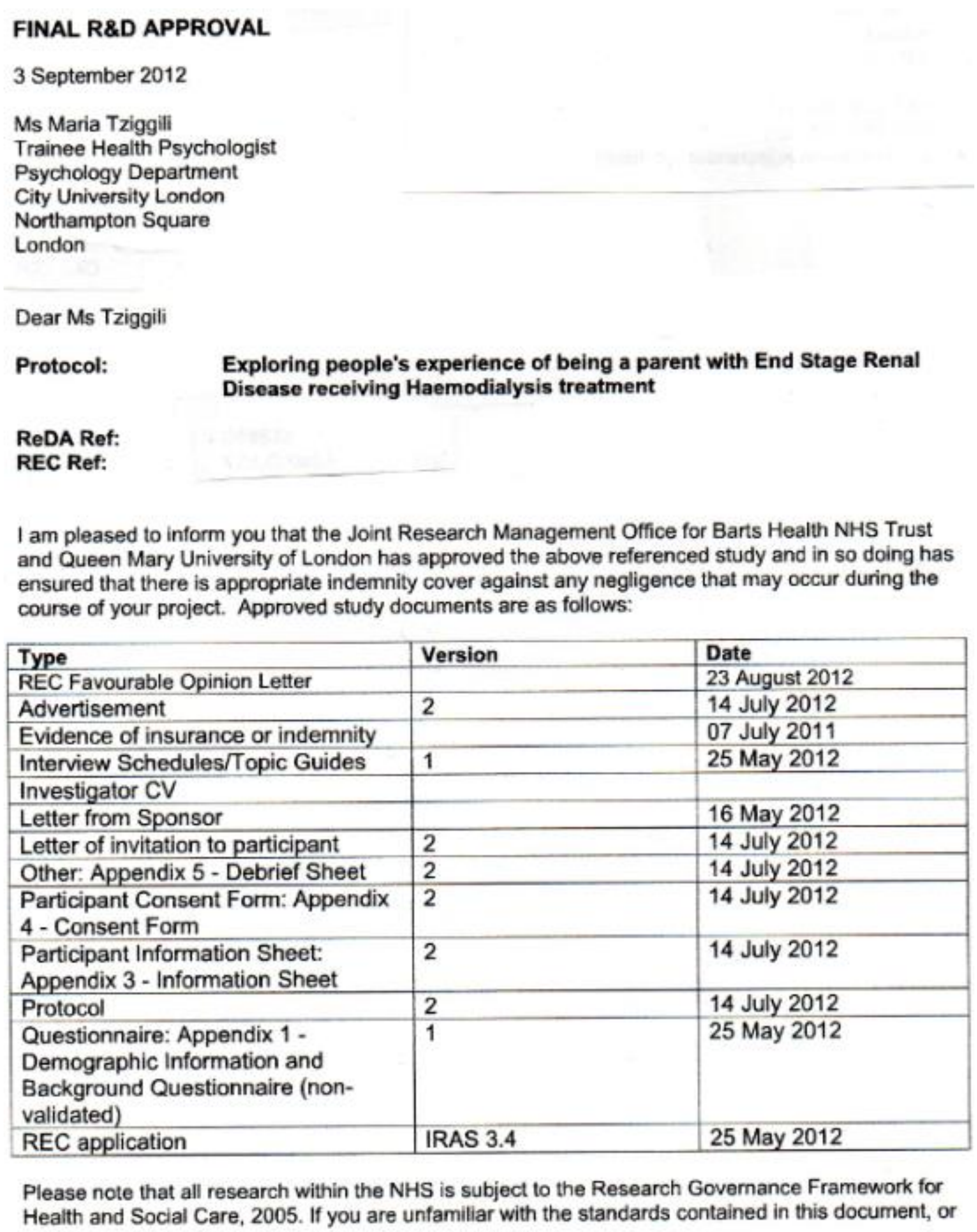
[redacted]

E-mail: [redacted]

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [redacted]

Appendix 3: Ethical approval letter from the Local Research and Development department for the National Health Service (Trust specific)



FINAL R&D APPROVAL

[redacted]

3 September 2012

Ms Maria Tziggili
Trainee Health Psychologist
Psychology Department
City University London
Northampton Square
London
[redacted]

Dear Ms Tziggili

Protocol: **Exploring people's experience of being a parent with End Stage Renal Disease receiving Haemodialysis treatment**

ReDA Ref: [redacted]
REC Ref:

I am pleased to inform you that the Joint Research Management Office for Barts Health NHS Trust and Queen Mary University of London has approved the above referenced study and in so doing has ensured that there is appropriate indemnity cover against any negligence that may occur during the course of your project. Approved study documents are as follows:

Type	Version	Date
REC Favourable Opinion Letter		23 August 2012
Advertisement	2	14 July 2012
Evidence of insurance or indemnity		07 July 2011
Interview Schedules/Topic Guides	1	25 May 2012
Investigator CV		
Letter from Sponsor		16 May 2012
Letter of invitation to participant	2	14 July 2012
Other: Appendix 5 - Debrief Sheet	2	14 July 2012
Participant Consent Form: Appendix 4 - Consent Form	2	14 July 2012
Participant Information Sheet: Appendix 3 - Information Sheet	2	14 July 2012
Protocol	2	14 July 2012
Questionnaire: Appendix 1 - Demographic Information and Background Questionnaire (non-validated)	1	25 May 2012
REC application	IRAS 3.4	25 May 2012

Please note that all research within the NHS is subject to the Research Governance Framework for Health and Social Care, 2005. If you are unfamiliar with the standards contained in this document, or

the BH and QMUL policies that reinforce them, you can obtain details from the Joint Research Management Office or go to:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

You must stay in touch with the Joint Research Management Office during the course of the research project, in particular:

- If there is a change of Principal Investigator
- When the project finishes
- If amendments are made, whether substantial or non-substantial

This is necessary to ensure that your R&D Approval and indemnity cover remain valid. Should any Serious Adverse Events (SAEs) or untoward events occur it is **essential** that you inform the Sponsor within 24 hours. If patients or staff are involved in an incident, you should also follow the Trust Adverse Incident reporting procedure or contact the Risk Management Unit on 020 7480 4718.

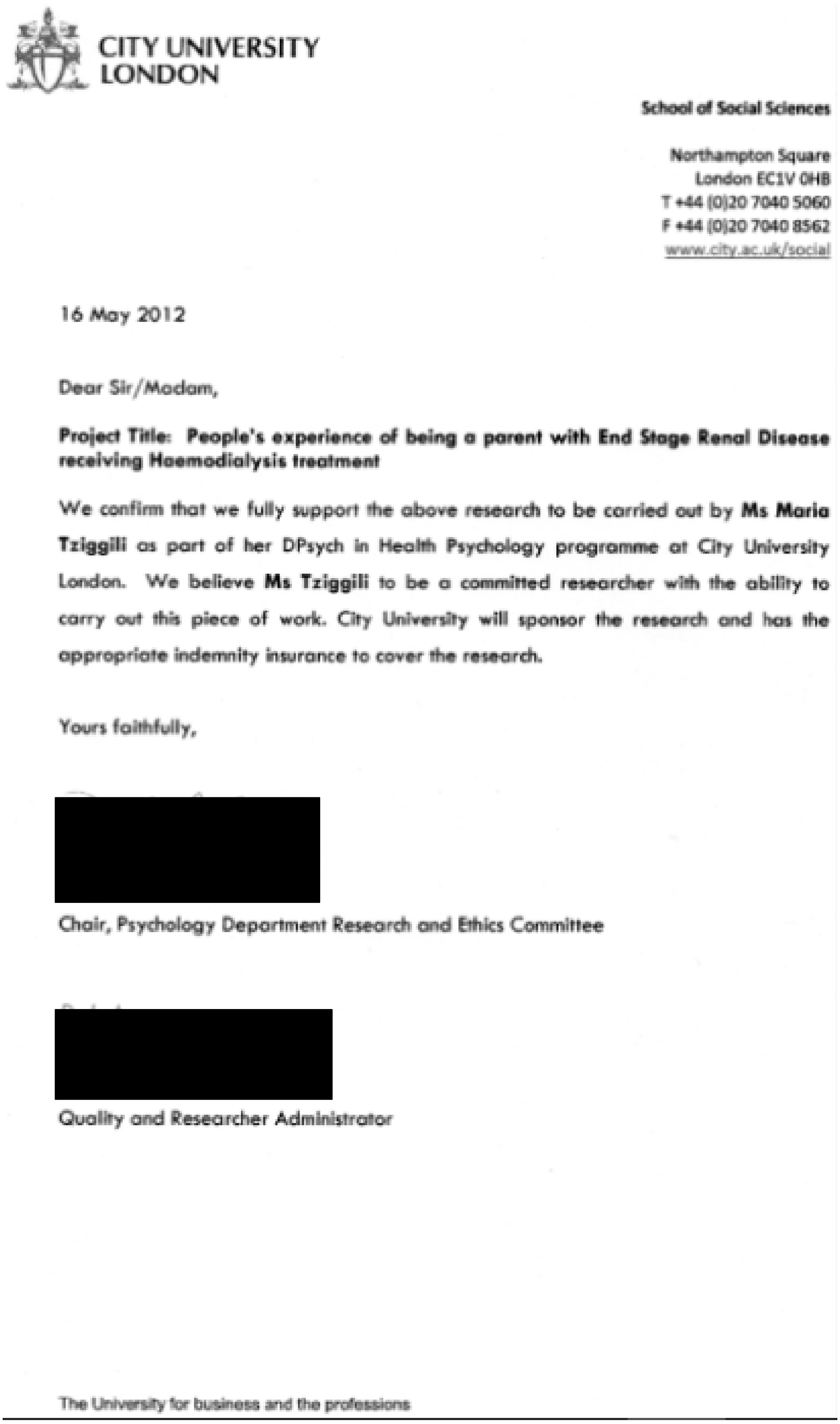
We wish you all the best with your research, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

[redacted]

[redacted], Head of Research Resources

Copy to: [redacted]

Appendix 4: Ethical approval letter from the City, University of London’s Research Ethics Committee



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School of Social Sciences

Northampton Square
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www.city.ac.uk/social

16 May 2012

Dear Sir/Madam,

Project Title: People’s experience of being a parent with End Stage Renal Disease receiving Haemodialysis treatment

We confirm that we fully support the above research to be carried out by **Ms Maria Tziggili** as part of her DPsych in Health Psychology programme at City University London. We believe **Ms Tziggili** 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]

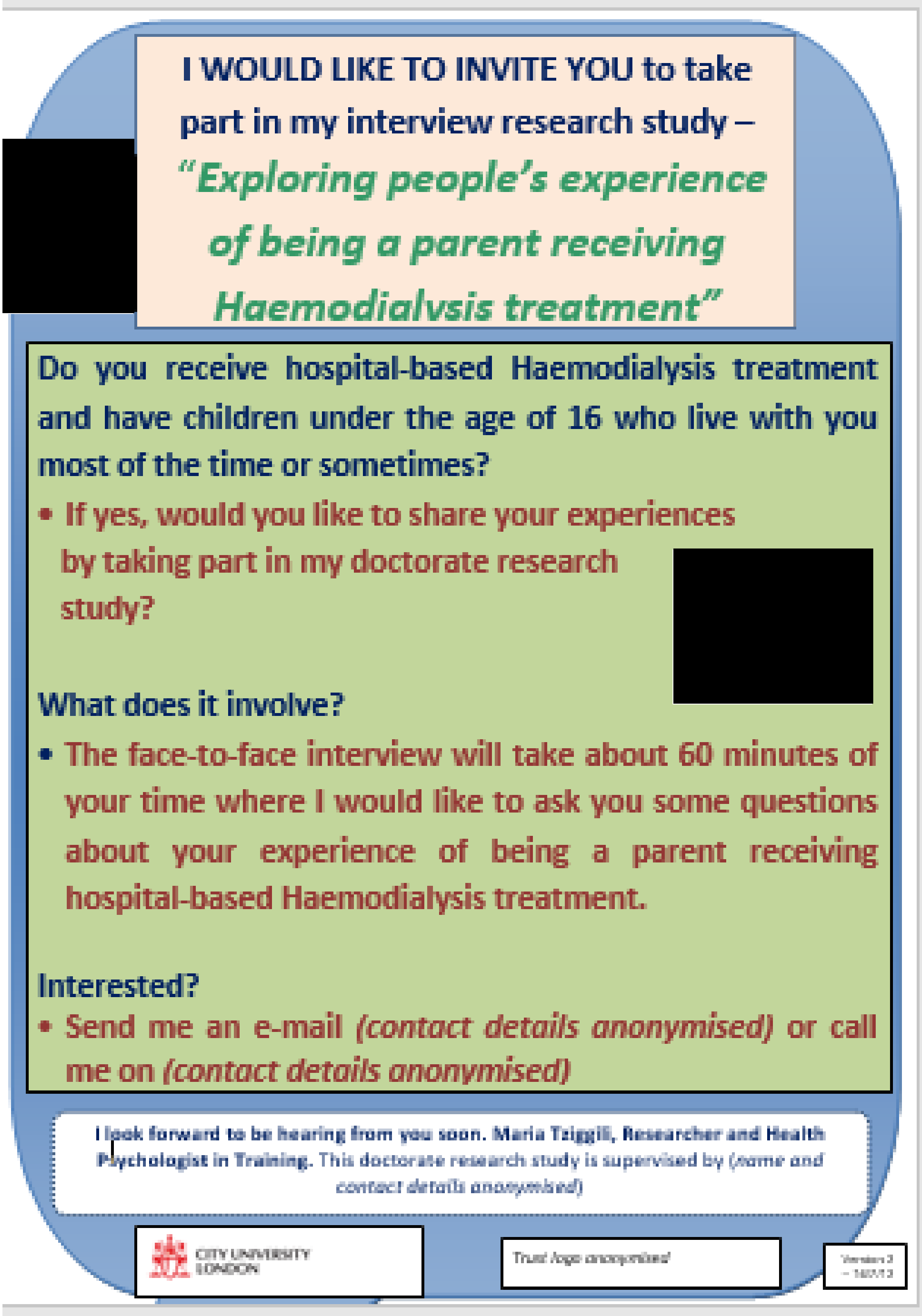
Chair, Psychology Department Research and Ethics Committee

[redacted]

Quality and Researcher Administrator

The University for business and the professions

Appendix 5: Research flyer



[redacted]

I WOULD LIKE TO INVITE YOU to take part in my interview research study – ***"Exploring people's experience of being a parent receiving Haemodialysis treatment"***

Do you receive hospital-based Haemodialysis treatment and have children under the age of 16 who live with you most of the time or sometimes?

- If yes, would you like to share your experiences by taking part in my doctorate research study?

[redacted]

What does it involve?

- The face-to-face interview will take about 60 minutes of your time where I would like to ask you some questions about your experience of being a parent receiving hospital-based Haemodialysis treatment.

Interested?

- Send me an e-mail *(contact details anonymised)* or call me on *(contact details anonymised)*

I look forward to be hearing from you soon. Maria Tziggili, Researcher and Health Psychologist in Training. This doctorate research study is supervised by *(name and contact details anonymised)*

CITY UNIVERSITY LONDON

Trust logo anonymised

Version 2 – [illegible]

Appendix 6: Information sheet

CITY UNIVERSITY
LONDON

NHS Trust's logo anonymised

Researcher & Health Psychologist in training
Ms Maria Tziggili
Contact details anonymised
Research Supervisor
Name and contact details anonymised

INFORMATION SHEET

Exploring people's experience of being a parent receiving haemodialysis treatment

You are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Talk to others about the study if you wish. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of this study is to explore people's experience of being a parent who receives hospital-based haemodialysis treatment. In particular, parents who have children younger than 16 years of age who are living with them.

Do I have to take part and can I get further information?

It is up to you to decide whether you would like to take part in this research study. I will describe the study to you and go through this information sheet with you. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the care/ support you receive from the hospital staff.

Why have I been chosen?

You have been chosen to take part at this study as you expressed an interest in taking part in response to one of the posters placed at the haemodialysis units and waiting areas displaying information regarding this study, heard about it by your direct health care team or/ and received a letter via post informing you about this study.

Who can take part in the study?

Adults (aged above 18) who have end stage renal disease, currently receive hospital-based haemodialysis treatment and have children younger than 16 years of age. Also, a reasonable good understanding of the English language is necessary as the interviews will be hold in English.

What's involved?

You will be asked to participate in a one-to-one interview which will last approximately 60 minutes and which will be conducted in person. The interview will consist of questions exploring your experience of having End Stage Renal Disease, receiving hospital-based haemodialysis and parenthood.

Are there any possible disadvantages or risks involved?

As you are being asked to describe personal experiences of being a parent who receives hospital-based haemodialysis treatment it is possible that it may raise experiences that are distressing to you. This is by no means the aim of the study and all efforts will be taken to avoid it. If, however, you do become distressed, you have the choice to carry on with the interview, to have a break or to draw the interview to a close. The interviewer will stay with you to make sure that you are alright and will give you information about where you can seek further support if you wish to do so.

Will my taking part in this study be kept confidential?

Yes, ethical and legal practice will be followed at all times. All information which is collected about you during the course of the research will be kept strictly confidential, and any personal information (e.g. name and/or address) will be removed so that you cannot be identified. Furthermore, your personal details as well as any information you provide will be used for research purposes only and will be stored on a secure file.

What will happen to my interview data?

The interview will be audio taped and then transcribed so that your descriptions can be reported accurately. The digital recording will be stored on a secure, password-protected file. However, no details that could identify you will be used in the transcript or in any research write-up.

What will happen to the results of the research study?

When the study is finished it will be written up and submitted as part of my doctorate thesis. The thesis and any possible publications or presentations of this study and its findings may include anonymous quotes from your and other people's interviews, at no point, however, will individuals or individual responses be identifiable. Please let me know if you would like to receive a brief summary of the findings.

What if there is a problem?

If you have a concern about any aspect of this study, you can contact me via e-mail (*contact details anonymised*) or phone (*contact details anonymised*), my Research Supervisor, *details anonymised* at City University London, e-mail: *contact details anonymised* and we will do our best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Local Patient Advice and Liaison Service by phone (*contact details anonymised*) or e-mail (*contact details anonymised*).

Who has reviewed the study?

This research gained Ethical approval by the Health Research Authority contact details anonymised.

Thank you for taking the time to read this information sheet which is yours to keep. If you are interested in participating in this study or have any questions, please contact me by email (*contact details anonymised*) or phone (*contact details anonymised*).

Yours Sincerely,

Maria Tziggili

Appendix 7: Invitation letter

CITY UNIVERSITY
LONDON

NHS Trust's logo anonymised

Address and contact details anonymised

September 2012

Dear Patient,

RE: Research study "Exploring people's experience of being a parent receiving Haemodialysis treatment"

We would like to inform you that currently we are conducting a research study exploring people's experience of being a parent receiving Haemodialysis treatment" at *Trust name anonymised*. The aim of this research study is to gain a better understanding of people's experience of being a parent who receives hospital-based Haemodialysis treatment, in particular, parents/ guardians who have children younger than 16 years of age living with them at home most of the time or sometimes.

If you would like to know more about this research study, are a parent/ guardian of a child/ children who is/ are younger than 16 years of age and who live with you at home most of the time or sometimes please take the time to read the enclosed information sheet carefully. Also, talk to others about the study if you wish to or/ and contact Maria Tziggili via e-mail *details anonymised* telephone *details anonymised* for more information and/ or for expressing your interest in taking part in this research study.

This research study consists of a one-to-one interview which will take approximately 60 minutes of your time and questions around people's experience of having End Stage Renal Disease, receiving hospital-based Haemodialysis treatment and parenthood will be asked. Maria Tziggili is a Health Psychologist in training who is conducting this piece of research as part of her professional doctorate at City University London. This research study received NHS Ethical approval from the *details anonymised* and the joint Research Management Office for *details anonymised*. However, you are not in any way obliged to take part at the above-mentioned study and your decision in taking part or not taking part in this study will not affect the care you receive at the hospital.

If you are interested in taking part please contact Maria Tziggili within 3 weeks of receiving this letter. Maria is looking forward to be hearing from you.

Thank you very much for your time.

Yours Sincerely,

details anonymised

Haemodialysis Matron

Appendix 8: Initial contact consent form

CITY UNIVERSITY
LONDON

NHS Trust’s logo anonymised

Ms Maria Tziggili
Contact details anonymised

Research Supervisor
Contact details anonymised

Initial Contact Consent Form

Study: Exploring people’s experience of being a parent receiving Haemodialysis treatment

Please insert your initials in the boxes below to indicate agreement:

1	I confirm that I have been given the invitation letter and information sheet (both dated 14/7/12 Version 2) for the above study.	
2	I confirm that I am interested to find out more about the above-mentioned research study and to potentially take part in the study	
3	I give consent to the researcher, Maria Tziggili, to get in touch with me directly using the given contact details below	

Name of person interested to find out more about the research study: ________________ ________________	Contact details: __________________ __________________	Date: _____/_____/2012	Signature: _________________

<u>Appendix 9:</u> Brief biographies of the participants

ARI:

Ari is a 44-year-old married male who described his ethnicity as Caribbean. He is a father to three boys with their age ranging from nine to 16 years of age. Ari reported that he used to work in a high-pressured managerial position prior to starting RRT. He had been diagnosed with ESRD 18 months ago and had started haemodialysis treatment six months after his diagnosis. In addition, Ari also stated that he has other health comorbidities, including diabetes and hypertension. Ari described his identity prior to his illness as “the breadwinner”. However, his sense of identity significantly changed after his diagnosis of ESRD, especially in relation to his identity as a father and as a husband.

BORIS:

Boris is a British 49-year old married male with seven children. The age range of his children is from 18-months to 26 years of age. Boris described himself as a physically very active person after years of martial arts training and previously serving in the military. Boris stated that he was diagnosed with ESRD approximately 22 years ago. He explained that since being diagnosed he has experienced all available RRTs, including peritoneal dialysis, kidney transplant and haemodialysis treatment. He reported that due to his physical fitness prior to his ESRD diagnosis, starting RRT did not impact on his employment status as he was able to continue working until a few years ago. The reason for needing to stop working was as a result of cardiological health issues that required him having a pacemaker fitted. Boris explained that in the past two years he has noticed a marked deterioration in his physical fitness.

CARA:

Cara is a married 49-year old mother of six children, whom described her ethnicity as white Asian. The age range of her children is 13 to 28 years of age. She was diagnosed with ESRD approximately three years ago. Since her diagnosis she reported having experienced all three available RRT, from peritoneal dialysis (PD) to kidney transplant and haemodialysis treatment. She explained that she was taught by the Renal nursing staff how to self-care on haemodialysis. She stated that the fact that she can connect and disconnect herself from the haemodialysis machine has helped her overall well-being. She informed me that her father also had ESRD and that he died several years ago. Similar to Cara, three out of her six children have been diagnosed with polycystic kidneys. She expressed her desire that her children would not develop ESRD.

DEMI:

Demi is a 41-year old British widow and the mother of her 13-year-old daughter. She explained that her daughter was born nine weeks premature and that she was not able to hold her for the first few days after her birth. Demi stated that she was diagnosed with kidney failure sixteen years ago, which progressed to ESRD and she subsequently started on RRT eight years ago. During her time on RRT she experienced receiving PD before moving onto haemodialysis treatment. The change of RRT, from PD to haemodialysis, occurred soon after her husband died unexpectedly at home and was discovered by her then four-year-old daughter. Prior to his death Demi's husband assisted Demi with her PD treatment at home. During the period between her husband's death and switching to haemodialysis treatment, Demi's daughter took on more responsibility in supporting Demi at home with her PD treatment.

EMMA:

Emma is an Asian 35-year old married female with three children, from the ages of eight to 15 years. She reported that she was diagnosed with ESRD three years ago and start haemodialysis treatment immediately following diagnosis. Emma explained that after receiving haemodialysis treatment for a period of time she was asked by the Renal nursing staff whether she would be interested in learning how to self-care on haemodialysis. Emma explained that learning how to self-care on haemodialysis at the hospital has helped her cope and adjust with the haemodialysis treatment.

FLORA:

Flora is an Asian 45-year old married mother of three children. The age of her children ranges from 15-years to 21-years of age. She was diagnosed with ESRD nineteen years ago. Flora stated that she initially started dialysis treatment soon after receiving diagnosis and has received all available RRT modalities since her diagnosis. Flora expressed how difficult it has been for her to manage the balance of childcare and attending hospital for haemodialysis treatment, even though there have been periods when extended family has lived at the same home as her, her daughter and her husband.

GINA:

Gina is an African 43-year old single mother, having divorced from the father of her 12-year-old son two years ago. She stated that she was diagnosed with ESRD twenty-three years ago and started RRT immediately after diagnosis. She said that since diagnosis she has received haemodialysis treatment, as well as having received a kidney transplantation that subsequently failed. She stated that when she received the diagnosis of ESRD she was determined to receive a kidney transplant, which she said was principally to increase the possibility of her being able to have children. She described the day she received a kidney transplant and the day of her son's birth as the two happiest days in her life.

HENRY:

Henry, an Asian married 28-year old male, is the father of his eight-month-old son. He reported that he was born with one kidney and that his second kidney had failed when he was 14 years old. His experience of RRT have involved the receipt of two kidney transplants and receiving haemodialysis treatment. To attend haemodialysis treatment, Henry drives himself to and from hospital. Even though he was currently unemployed, he was able to maintain employment when he first started haemodialysis treatment and when he had received a kidney transplant.

ISAAC:

Isaac is a 39-year old Asian married father of two children. His two children are aged nine and 14-years of age. He reported that he had been diagnosed with ESRD 12 years ago. Since then, the RRT he has experienced are haemodialysis treatment and he has also received a kidney transplant. Prior to his diagnosis with ESRD Isaac had maintained employment, however since his diagnosis he has felt unable to sustain employment due to the demands of the haemodialysis schedule and work. He is currently studying to become an accountant, with the hope that accountancy would be an industry that he could more easily combine the frequency and time-demands of haemodialysis treatment. Isaac also expressed the importance of his religious beliefs in helping him and his family manage the physical and psychological demands of ESRD.

JANET:

Janet is a 46-year old British married mother of two children. Her two sons are aged nine and 14-years old. Janet was diagnosed with ESRD four years ago and started haemodialysis treatment soon after. The RRT she has received since her diagnosis include PD and haemodialysis treatments. Janet also mentioned that she has other health comorbidities. These include high blood pressure and osteoporosis, which impacts negatively on her mobility. She stated that she usually only leaves home by using her electronic scooter.

Appendix 10: Consent form

NHS Trust's logo anonymised

CITY UNIVERSITY
LONDON

Researcher & Health Psychologist in training
Ms Maria Tziggili, *contact details anonymised*
Research Supervisor, *contact details anonymised*

CONSENT FORM

Exploring people's experience of being a parent receiving Haemodialysis treatment

Study Number: _________________ Participant Identification Number: __________

Please insert your initials in the boxes below to indicate agreement:

1	I confirm that I have read and understood the information sheet dated .... (version........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected	
3	I understand that I need to complete both parts of the study (a brief questionnaire collecting some background information and the interview).	
4	I understand that the interview will be digitally audio recorded and that my data provided will be stored in a secure file.	
5	I understand that while information gained during this study may be published, I will not be identified and my personal details will remain confidential.	
6	I understand that relevant sections of the data collected from me during the study may be discussed with responsible individuals from City University London (e.g. the research supervisor), where it is relevant to my taking part in this research. I give my permission for these individuals to have access to this information	
7	I understand that while anyone reading the completed research paper/ report will not be able to identify me I may be able to recognise some of my own comments. I understand if any of my comments are directly quoted, then an alternative name will be used in the report to protect my anonymity.	
8	I agree to take part in the above mentioned study.	

Name of participant	**Signature of participant**	**Date**
Name of researcher	**Signature of researcher**	**Date**

Appendix 11: Demographic information and background questionnaire

NHS Trust's logo anonymised

CITY UNIVERSITY
LONDON

Exploring people's experience of being a parent with End Stage Renal Disease receiving

hospital-based Haemodialysis treatment

Demographic Information & Background Questionnaire

This is a brief questionnaire to collect some additional information before we start with the interview. This data will only be used for the purpose of research and therefore will not be linked back to you as your identity will be anonymous. ***Instructions: Please tick the relevant boxes below or write your answer on the space provided where appropriate.***

II. Interview Date: ……………………		II. Interview Code:	
1.Gender: ……………………	2.Age: …….......................	3.Marital status: ………………………	4.Employment: ....……………

5.Ethnicity: **>White** ☐ British ☐ Irish ☐ Any other White Background **>Mixed** ☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other Mixed Background	**>Asian or Asian British** ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Any other Asian Background **>Black or Black British** ☐ Caribbean ☐ African ☐ Any other Black Background	**>Chinese or other ethnic group** ☐ Chinese ☐ Any other ethnic Background

6.To how many children are you a parent or a guardian to? (please give ages) ☐ None ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ more than 5	7.If you are a parent or a guardian, do the children live with you at home? ☐ Yes ☐ No ☐ Sometimes – please specify when or how often ....
8.When were you diagnosed with End Stage Renal Disease?.............................	9.When did you start hospital-based haemodialysis treatment?..................
10.Were you ever on a different dialysis treatment regime or have you ever received a kidney transplant? ☐ Kidney Transplant ☐ Peritoneal Dialysis ☐ Home-based Haemodialysis	
1.Does anybody else in your family have kidney disease? ☐ No ☐ If yes, please specify……….	12.Do you have any other chronic health conditions? ☐ No ☐ If yes, please specify……………………………..

Appendix 12: Debrief sheet

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Researcher & Health Psychologist in training
Ms Maria Tziggili
contact details anonymised
Research Supervisor
Name and contact details anonymised

DEBRIEF SHEET

Study: Exploring people's experience of being a parent receiving haemodialysis treatment

Thank you very much for taking part in this interview study. Your help is very much appreciated. The aim of this study is to gain a better understanding of people's experience of being a parent who receives hospital-based haemodialysis treatment. Previous research has looked into the experiences of people receiving hospital-based Haemodialysis or how people with other chronic health conditions experience being a parent with a chronic health condition. However, to my knowledge not much emphasis has been put yet in exploring people's experience of being a parent receiving haemodialysis treatment and what this really means to them. Therefore, this piece of work aims to provide a better understanding and to inform and improve Renal Care practices and services where possible.

If you have any questions regarding this study please feel free to contact me via email at *contact details anonymised* and I will be happy to answer any questions and/ or receive any comments. I would like to take this opportunity to remind you that all information you have provided will be used purely for research purposes and your personal details will not be included in this process. All research outcomes that will be published are done so anonymously. However, you still have the right to withdraw your responses as your participation is completely voluntary. To do this, simply email me and I will withdraw your responses from this study.

If you would like to talk to someone or find out information about where you can receive help for any emotional or health related problems or difficulties, the below listed registered agencies may be useful to you and you can always go to your GP and ask for a referral to a psychological support service in your area.

Samaritans - Provide confidential emotional support 24 hours a day via phone or e mail.

Tel: 08457 90 90 90; **Web:** www.samaritans.org

NHS Direct - The NHS 24-hour helpline => **Tel:** 0845 4647; **Web:** www.nhsdirect.nhs.uk

Renal Psychology Service – *contact details anonymised.*

Again, I would like to thank you for your time and for your participation.

Yours Sincerely, Maria Tziggili

Appendix 13: Interview schedule

CITY UNIVERSITY LONDON

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Exploring people's experience of being a parent with End Stage Renal Disease receiving Haemodialysis treatment

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SEMI-STRUCTURED INTERVIEW QUESTIONS

A) Experience of Kidney failure:

1) What is it like for you having kidney failure/ end stage renal disease?

>Prompts: What does it mean to you? How does it make you feel? What was it like for you when you were told that you have end stage renal disease?

B) Experience of Haemodialysis:

2) What is it like for you to receive haemodialysis treatment?

>Prompt: What is your experience of haemodialysis? How does it make you feel? What does it involve? What is it like for you when you are connected onto and disconnected from the haemodialysis machine? What goes through your mind? What was it like when you started haemodialysis treatment?

C) Outside Haemodialysis Treatment:

3) What is it like for you when you are not on haemodialysis?

>Prompt: What do you do? How do you feel?

4) How would you describe yourself as a person?

>Prompt: How do you feel about yourself?

D) Experience of being a parent:

5) What is it like for you being a parent?

>Prompt: What does it mean to you? How do you feel about being a parent? Is parenthood as you imagined it to be? What aspects do you enjoy most and what least of parenthood?

E) Experience of being a parent and a patient:

6) What is it like for you being a parent who has end stage renal disease*?*

>Prompt: What does it mean to you? How does it feel? What is it like for you being a parent receiving hospital-based haemodialysis?

F) Reflection & Closing question:

7) Are there any experiences which have stood out for you since you were diagnosed with end stage renal disease which you would like to share with me?

>Prompt: Anything particular surprising? Was something more or less difficult than expected?

8) Thinking back to the time when you were diagnosed with end stage renal disease, and knowing what you know now, what would you have liked to have been told yourself or feel others who are in a similar position to you should know? (being a parent on haemodialysis)?

>Prompt: From your experience now, what would have been helpful to have known? In your experience what did you find helpful and not as helpful? Is there something you feel that could have been helpful to you? What would you have liked to be different?

9) Is there anything else you would like to add?

Appendix 14: Extract of initial analysis stages – initial notations and emergent themes from individual transcript

[redacted]

Appendix 15: Example extract of table with emergent themes from individual transcript

Emergent Theme	**Transcript Extract**	**Line No.**
What is it like to have ESRD?	That's quite a hard, broad question *Q: What is it like for you to have ESRD?*	A13
Reaction to ESRD diagnosis	it was strange because I was warned by...at the renal clinic that I was heading this way but when the actual diagnosis came that I had to have dialysis it was a big shock	A16-19
Diagnosis of ESRD was a significant moment	It was almost, I wouldn't say it was an epiphany but it was definitely a epoch-making moment in my life	A23-24
Reaction to receiving diagnosis of ESRD	it made me sit and take stock	A25
Depression after ESRD diagnosis	I became very depressed	A25-26
Uncertainty about future after ESRD diagnosis	I did not know that much about dialysis and what the long-term prognosis and outcomes would be	A26-28
Belief that ESRD diagnosis = death	I thought 'oh my life is over'. That's it	A28-29
Uncertainty about what happens after ESRD diagnosis	I thought "what happens now?"	A29-30
Emotional reaction to ESRD diagnosis	I was very sad	A30
Process leading to diagnosis	I was in this hospital initially when they took me and told me because I was not feeling well and they had to check my blood pressure and they did a test and I had to come in straight away	A30-34

Appendix 16: Table of Major Themes, subordinate themes and extract locations

Master Theme	Subordinate Themes		Location of quotes
The Haemodialysis (HD) experience	1.1 Living with HD		Ari, 1383-1384, Ari, 915-916, Henry, 163; Janet, 636, Isaac, 707-709, Gina, 882-883, Ari, 185, Flora, 1163-1164, Ari, 438-439, Cara, 51, Gina, 463-464, Ari, 436-437, Boris, 8-9, Boris, 1212-1217; Emma, 433-435; Emma, 102-103; Henry, 69-70; Isaac, 910-911; Ari, 1166-1169; Gina, 464-465; Janet, 212-214; Ari, 191-193; Henry, 192-194; Emma, 1051-1052; Boris, 1363-1365; Emma, 1060-1062; Boris, 13-16; Boris, 1362-1363; Cara, 125-126; Emma, 115-116; Flora, 225-229; Emma, 55-57; Boris, 512; Isaac, 235-237; Henry, 760-762;
	1.2 The HD Process		Ari, 654; Cara, 903-906; Henry, 95-97; Gina, 589-591; Gina, 470-474; Boris, 46-48; Ari, 225-230; Ari, 236-243; Boris, 7-8; Emma, 382; Ari, 205-207; Ari, 193-195; Cara, 70; Henry, 149; Emma, 426; Boris, 1281-1283; Gina, 797-798; Cara, 406; Cara, 410-412; Cara, 424-425; Emma, 454-455; Gina, 804-805; Henry, 150-151; Demi, 534-536; Flora, 982-983; Cara, 199;
		1.2.1 HD schedule	Gina, 1878-1880; Ari, 903-905; Isaac, 246-247; Demi, 336-337; Demi, 335-336; Cara, 22; Boris, 791-793; Boris, 86-87;

			Isaac, 814-816; Henry, 199-202;
		1.2.3 The mechanics of receiving HD treatment	Janet, 269-270; Janet, 684-687; Gina, 949-950; Henry, 21-283; Isaac, 289-292; Flora, 656-661; Ari, 1156-1159; Henry, 263-267; Henry, 1019-1024; Isaac, 283-284; Boris, 1298-1299; Emma, 358-359; Emma, 315-319; Ari, 1349-1352; Ari, 1352-1355; Isaac, 916-917; Boris, 23-27; Boris, 1300-1303; Ari, 320-324; Janet, 283-284; Cara, 1222-1223; Emma, 339-341; Cara, 305-309; Emma, 341-347; Emma, 1330; Cara, 1209-1213; Emma, 333-335; Gina, 814-815; Gina, 516-517; Ari, 324-327; Ari, 470-471; Ari, 475-476; Gina, 443-446; Flora, 1223-1227; Boris, 510;
		1.2.3 Activities before, during and after receiving HD Treatment	Emma, 507-509; Emma, 522-523; Flora, 487-492; Isaac, 372-375; Demi, 369-372; Demi, 379-383; Emma, 420-423; Boris, 1309-1214; Ari, 328-331; Janet, 292-293; Boris, 27-29; Cara, 112-113; Emma, 480-481; Henry, 341-342; Emma, 458-460; Ari, 705-707; Cara, 167-169; Cara, 383-384; Flora, 939-940; Demi, 952; Emma, 416-418; Emma, 410-412; Janet, 289-290; Isaac, 304-306; Henry, 342-343; Cara, 111-112; Gina, 833-834; Janet, 297-298; Demi, 456-460; Flora, 1233-1237; Henry, 364-366; Cara, 147-148; Demi, 334; Ari, 243-245; Ari, 245-249; Henry, 362-

			364; Gina, 1531-1532; Emma, 503-506; Cara, 172-174; Flora, 666-671; Demi, 341-344; Cara, 628-632; Emma, 126-127; Flora, 1008-1011; Flora, 992-998; Gina, 372-376; Henry, 468-470); Emma, 826-827; Emma, 500-502; Cara, 52-53; Henry, 449; Flora, 646-648; Flora, 648-650; Henry, 449-451; Isaac, 465-466; Cara, 174-176; Emma, 488-489; Gina, 983-985; Gina, 897; Janet, 340-343; Cara, 828-831; Boris, 568-573; Boris, 560; Henry, 401-402; Henry, 406-408; Cara, 751-752; Cara, 1175-1177; Henry, 202-204; Ari, 1249; Ari, 650-653; Ari, 590; Cara, 739-740;
		1.2.1 Journey to and from receiving HD treatment	Boris, 201-204; Isaac, 72-73; Henry, 249-254; Cara, 193-195; Cara, 489-491; Demi, 360-363; Flora, 482-484; Flora, 1040-1045; Janet, 257-260; Janet, 235-238; Janet, 758-759; Flora, 1045-1050; Janet, 247-249; Flora, 1039-1040;
	1.3 HD side-effects		Ari 196; Ari, 200-204; Emma, 307-309; Flora, 1240-1241; Isaac, 77-79; Isaac, 80-82; Henry, 245-246; Demi, 442; Cara, 76-79; Cara, 97-99; Ari, 701-705; Ari, 708-709; Ari, 800-801; Demi, 539-541; Cara, 935-936; Emma, 304-305; Henry, 257-259; Flora, 1249-1250; Janet, 187-188;
	1.4 HD ward environment and care		Ari, 1337-1340; Ari, 189-191; Ari, 1340-1341; Ari, 1148-1150; Ari,

			1312-1315; Cara, 428; Cara, 426-427; Ari, 331-333; Ari, 343-345; Flora, 653-656; Ari, 1325-1327; Ari, 503-505; Ari, 498-503; Gina, 738-740; Gina, 744-746; Janet, 250-252; Janet, 309-310; Demi, 471-472; Ari, 1422-1423; Flora, 1106-1107; Emma, 1319; Boris, 1174-1176; Boris, 1392-1394; Boris, 1410-1415; Janet, 307-309; Flora, 661-664); Boris, 689-691; Ari, 919-920;
The lived experience of parents with end stage renal disease	2.1 Being a parent		Henry, 720; Ari, 925-926; Emma, 854; Cara, 1039-1041; Cara, 990-991; Henry, 746-751; Isaac, 628-629; Demi, 934; Janet, 221; Gina, 27-29; Ari, 935; Janet, 556; Ari, 930-932; Ari, 945-947; Ari, 1020-1029; Ari, 1233-1235; Ari, 1217-1218; Boris, 608-609; Demi, 906; Janet, 551-552; Gina, 1142; Cara, 449-450; Isaac, 595-596; Demi, 726-727; Cara, 1011-1012; Gina, 1152-1154; Gina, 1581-1583; Gina, 1134-1135; Demi, 638-642; Flora, 422-426; Janet, 503-505; Janet, 630-631; Demi, 871-877;
		2.1.1 Impact of haemodialysis side-effects on parenting	Gina, 441-443; Gina, 1497-1498; Gina, 363-366; Demi, 979-980; Henry, 470-472; Henry, 100-104; Henry, 112-114; Henry, 259-263; Henry, 300;
		2.1.2 Being absent due to treatment	Ari, 954-956; Demi, 945-947; Gina, 1475-1477; Emma, 663; Demi, 772-775; Demi, 767-768; Flora, 928-933; Henry,

			820-821; Ari, 667-670; Ari, 670-674; Henry, 119-122; Gina, 1224-1225; Demi, 265-266; Janet, 833-835; Cara, 662-663; Cara, 579-580; Gina, 1262-1263; Flora, 937-939; Cara, 728-729; Emma, 898; Emma, 894-897; Ari, 664-665; Boris, 1096-1097; Demi, 404-405; Cara, 178-179; Gina, 335-336; Gina, 1175-1177; Gina, 1195-1198; Demi, 768-771; Emma, 631-633; Gina, 298-299; Emma, 637-639; Demi, 278-280; Flora, 592-594; Gina, 1671-1673; Emma, 685-686; Flora, 588-591; Janet, 843-844; Emma, 626-629; Emma, 688-690; Janet, 800-801; Janet, 806-812; Janet, 817-822; Flora, 85-90; Emma, 1121-1123; Janet, 455-459; Flora, 734-738; Flora, 72-77; Flora, 1034-1038; Flora, 1168-1172;
		2.1.3 Holidaying	Gina 717-722; Demi, 266-267; Janet, 567-568; Demi, 27-30; Boris, 768-770; Boris, 838-840; Henry, 831-833; Demi, 287-289; Boris, 800-803; Gina, 1235-1238; Demi, 289-290; Gina, 1726-1728; Demi, 284-287; Boris, 793-799; Gina, 1228-1230; Gina, 1230-1232; Gina, 1227-1228; Demi, 267-270; Demi, 1139-1142; Demi, 296-297; Demi, 301-303; Janet, 568-574; Isaac, 390-394; Demi, 1142-1148; Demi, 306-313;

			Demi, 320-323; Isaac, 429-435;
	2.2 Children’s experience of parents’ illness		Ari, 1121; Cara, 491-493; Demi, 783-786; Gina, 1533-1534; Gina, 1260-1262; Demi, 736-737; Cara, 176-178; Cara, 603-604; Cara, 180-181; Gina, 1225-1226; Janet, 465-466; Cara, 1094-1096; Demi, 865-870; Demi, 389-390; Demi, 414-415; Gina, 282-285; Emma, 1024-1025; Ari, 164-165; Ari, 933-935; Ari, 170-172; Isaac, 37; Janet, 495-496; Janet, 824-827; Boris, 1071-1077; Cara, 598-599; Demi, 60-61; Boris, 1094-1095; Demi, 71-72; Demi, 63-66; Janet, 514; Janet, 514-517; Demi, 61-63; Emma, 1003-1004; Gina, 1201-1203; Gina, 1575-1576; Ari, 672-674; Emma, 935-938; Emma, 993-994; Emma, 1003-1004; Emma, 1019-1020; Cara, 1099-1100; Ari, 151-152; Janet, 486-488; Boris, 1091; Janet, 492-493; Emma, 926-929; Demi, 177-179; Cara, 1085-1088; Cara, 1061-1063; Cara, 1075-1077; Ari, 36-39; Ari, 144-146; Ari, 157-158; Gina, 1679-1681; Emma, 924-926;
	2.3 “Children keep me going”		Janet, 374; Boris, 1135-1136; Demi, 792-799; Janet, 214-216; Boris, 1137-1141; Emma, 724-726; Gina, 53-55; Demi, 803-804; Emma, 754-755; Cara, 714-717; Gina, 1037-1039; Demi, 613-614; Emma, 218-219; Janet, 474-476;

		Isaac, 48-50; Emma, 885-888; Demi, 94-97; Emma, 220-222; Emma, 227-228; Demi, 739-741; Gina, 1041-1043; Boris, 1077-1079; Demi, 188-191; Demi, 83-87; Demi, 88-89; Demi, 429-430; Cara, 976-979;
	2.4 Own mortality	Ari, 1312-1315; Cara, 1131-1132; Demi, 822-823; Cara, 1125-1126; Emma, 1074-1075; Ari, 1341-1343; Cara, 1160-1161; Isaac, 497-498; Isaac, 499-451; Emma, 1076-1077; Cara, 1161-1163; Gina, 858-860; Emma, 1123-1125 Cara, 1102-1104; Boris, 409-413; Demi, 817-819; Isaac, 182; Isaac, 198; Demi, 804-806; Demi, 819-821; Gina, 860-862; Cara, 1134-1136; Ari, 1146-1147; Ari, 1143-1145; Cara, 1148-1449; Ari, 135-136;

Article One:

Peer Support Interventions in Renal Care

&

Article Two:

Parents’ Journey with End Stage Renal Disease: An Interpretative Phenomenological Analysis

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Area of competency:

Generic Professional Practice

D1. Generic Professional Practice: Health Psychology in Renal Care

Description of work:	The journey of becoming a chartered Health Psychologist
Setting:	NHS hospital out-patient setting and University setting
Target group:	Adults, adolescents, healthcare professionals and students

Implement and maintain systems for legal, ethical and professional standards in applied psychology

The four ethical principles set out in the British Psychological Society's (BPS) Code of Conduct (2018), namely respect, competence, responsibility and integrity, formed an essential guide that I adhered to throughout my training and in my development towards becoming a health psychologist. Following BPS's Code of Conduct from 2009 through to 2018 (2009; 2018 respectively) whilst implementing and maintaining systems for legal and ethical standards was important in my role as an applied psychologist in training in the National Health Service (NHS) and in university settings. Every effort was made to ensure the highest standard of conduct when working directly and indirectly with clients and research participants. For example, all individuals were treated with the upmost respect and integrity, while taking necessary measures to ensure confidentiality was maintained where appropriate.

The main research project explored people's experiences of being a parent receiving hospital-based haemodialysis and participants were recruited through the NHS. This required applying and gaining ethical approval from three ethics committees (i.e. national NHS research authority, regional NHS Trust's Research and Development department, and City, University of London). The reason for applying and gaining ethical approval from the City, University of London ethics committee in addition to NHS approval was to ensure that, if required, participants could also be recruited from outside the NHS. Obtaining ethical approval from three separate ethics committees encouraged me to gain a clear understanding and familiarity with the required security systems, especially with regards to consent and confidentiality. In accordance to the agreed ethics applications, all ten of the participants provided signed consent for their participation and for use of the data collected for the purpose of the research project. Once all identifiable data had been anonymised, further security systems were applied to ensure confidentiality was maintained, such as guaranteeing that digital recordings, transcripts and signed consent forms were securely stored. These security systems were regularly reviewed to ensure that confidentiality was maintained and all access to information was appropriately controlled. These considerations and measures remained in place throughout the research process and were evident in the preparation and presentation of the research findings at two conferences (i.e. Annual Health Psychology conference and the Kidney Week UK conference) and two renal healthcare Continuing Professional Development (CPD) sessions, where all supporting extracts from the interviews remained anonymised and used appropriately. It also struck me as highly important to consider the ethical implications of exploring a potentially emotive phenomenon with the participants, which could elicit some distress for the individuals. Countermeasures were established to safeguard against unnecessary distress for the participants, such as informing them that they could withdraw their consent at any time with no prejudice and having relevant information available to signpost the participants to psychology or support services, if necessary.

Working ethically, legally and with integrity throughout the research process mirrored other areas of my practice as a health psychologist in training and in my work with clients. For example, an aspect of my role working within an NHS Renal Department's Psychology Service was the provision of individual face-to-face sessions with renal patients, usually with the focus of work being to facilitate behaviour change. This would routinely involve the handling of patient data (e.g. session notes, patient's name and NHS number) in accordance with the Trust's information governance policies and procedures, the BPS' Code of Conduct (2009; 2018), the Health Professions Council's (HPC) (2008) Standards of Conduct, Performance and Ethics and the updated Health & Care Professions Council's (HCPC) Standards of Conduct, Performance and Ethics (2016). As a matter of course, I ensured that patients were also made aware of the terms of confidentiality and the circumstances in which I would have a duty of care to breach confidentiality in an attempt to reduce the potential of risk to the individual or to others. The management of risk issues would often involve working closely with the patient, and when appropriate other professionals, and relying on an ethical and conscientious approach.

In addition to working individually with patients, my work as a Senior Assistant Psychologist and as a Health Psychology trainee also presented me with different opportunities to develop and facilitate groups for adults and adolescents, as well as CPD workshops for other healthcare professional. One such opportunity arose early in my training and involved developing and facilitating a weight management group with a dietician for an adolescent client group. It was my intention to work collaboratively with the attendees in constructing a safe and secure environment by highlighting the importance of confidentiality and establishing group boundaries. This provided the experience that laid the foundation for future group work. For example, when facilitating nurse-patient communication workshops for renal nurses it was important to provide a safe learning environment that encouraged colleagues to share experiences from their professional practices that could be confidential in nature.

Working closely with other healthcare professionals and clients has been an essential element in my training as an applied psychologist. Being a member of the multidisciplinary team within a renal department required the sharing of patient information with other professionals directly involved in the care of that patient. I have placed significant value on the importance of adhering to the systems in place within the NHS Trust on protecting patient data confidentiality, whilst at the same time practicing to the standards that are fundamentally entwined within my professional identity and mirror the guidelines set out by the BPS and HPC.

Contribute to the continuing development of self as professional applied psychologist

Throughout my journey as a trainee health psychologist I have placed great value on the importance of eliciting the feedback from others and evaluating it with the intention of using it to continue my professional development and enhance the quality of care and service that I am able to provide. For example, in working therapeutically with renal patients on a one-to-one basis I would routinely seek feedback from patients during the course of treatment for their general experience of the sessions. This would tend to facilitate opportunities to not only refocus therapy if there had been any drift away from the patients' goals but also provided me with the chance to learn from the therapeutic process and gain an understanding of the effectiveness of different interventions. In addition to discussions during the course of therapy, patients would be provided with an anonymised evaluation form at the point of discharge and asked for their valuable feedback, which they could submit confidentially.

Evaluation forms have also been used to collect feedback when delivering workshops, lectures and when providing talks at seminars and CPD sessions. When delivering lectures to MSc Health Psychology students and presenting the findings of my main doctoral research study to other healthcare professionals, eliciting feedback through the use of evaluation forms, discussions and visual recordings has been invaluable in my ability to continually monitor my growth towards becoming a health psychologist and help to identify areas in which I could develop further. The improvement in my self-awareness and willingness to learn through feedback has been instrumental in my growing maturity as a reflective practitioner. Early in my training I would at times feel sensitive to receiving feedback due to my insecurities and inexperience working within the field. Whereas, as I developed and learned to appreciate the value of receiving constructive feedback throughout my training it has helped me to flourish and become a more confident professional.

Having the ability to be open to learning from others has been a vital aspect in my personal and professional development. One area where this was demonstrated was during the period when I applied and subsequently gained NHS ethics approval for the main research study. As it was the first time that I went through the process of applying for NHS ethics I was understandably unfamiliar with the requirements of the procedure. Appreciating my need to learn more about the necessities of the process I decided to utilise the professional relationships I had formed in academic and NHS settings to improve my knowledge of what would typically be required. Such discussions, which included initiating contact with the Trust's Research and Development Team for advice, led to developing a comprehensive research plan that provided a clear and thorough review of the study's ethical considerations. Having successfully gone through the process of securing NHS ethics approval it will no doubt help to inform future research and highlights the importance of utilise the access I have, and would have, to other professionals for competent consultation and advice.

Additionally, when I took on a consultancy role to conduct a Needs Assessment for a Peritoneal Dialysis (PD) Consultant to explore best quality care in PD training delivery I initiated contact with a Consultant Clinical Health Psychologist to enquire about the possibility of her providing supervision for this piece of work. I recognised early in the work that organising appropriate supervision would be important to offset my lack of consultancy experience at the time. In doing so, I was able to enjoy a reflective space where the progress of the consultancy, including its challenges, could be explored and relevant professional advice could be received to further develop my skills in a previously unfamiliar role.

Investing in my continuing development as a health psychologist has been a constant feature throughout my training. The process has involved undertaking mandatory training through my place of work, attending academic lecturers and workshops, and taking responsibility to initiate various CPD opportunities. Engaging in mandatory training and relevant academic teachings helped to inform my clinical and research practice with regards to establishing, maintaining and reviewing security systems and the importance of controlling any access to confidential and sensitive information. Being part of different CPD groups, attending different CPD workshops and receiving regular supervision by qualified psychologists has contributed enormously to my development as an applied psychologist. By being a member of three CPD groups (Renal Psychological Services Group, the Clinical Health Psychology Group and the Affect Regulation Therapy study group) that met regularly, where most of the time I was the sole member that was still in training, I was exposed to a rich depth of clinical experience from the other members that I could learn from. Attending those CPD sessions also helped to foster a sense of belonging among Applied Psychologists and other healthcare professionals which felt important in enhancing my identity as a health psychologist in training.

The CPD groups promoted the exploration of theory and practice. For example, the Affect Regulation Therapy study group encouraged members to rotate the responsibility of presenting theory and facilitating discussions on its application in practice. Taking on the occasional role of group facilitator meant I learned over time to trust my theoretical knowledge, clinical experience and general worth to the group and to the profession. Receiving appropriate and regular supervision in relation to my applied and university work was another arena where I actively linked theory and practice. My role working in a renal department allowed me to think creatively of ways in which I could bring health psychology more into the field of renal care. This is evidenced by the opportunities I had in meeting the competencies of the doctorate in health psychology through my place of work. In addition to the CPD sessions and workshops offered as part of the doctorate in health psychology training, I also attended a number of CPD sessions that predominately discussed areas in improving patient care and the application of different therapeutic approaches and behaviour change. CPD training courses included ‘Foundations of Health Psychology Clinical Practice’, ‘Health Psychology interventions in Practice’, counselling skills workshop, Cognitive Behavioural Therapy (CBT) training to different presentations, introduction to Acceptance and Commitment Therapy (ACT), existential psychotherapy, Compassion Focused Therapy and Mindfulness, and an introduction to Interpretative Phenomenological Analysis (IPA). Each of these CPD trainings, as well as others not mentioned here, equipped me with opportunities to broaden my knowledge and expertise that has been reflected in my clinical and research work.

Overall, keeping up to date with relevant literature, guidelines and recommendations through CPD, as well as being a member of different professional bodies and study groups has enabled me to expand my knowledge and skills in the field of psychology. Being in a position where I am able to incorporate theory into practice while continuously assessing, evaluating and being reflective in my work provides the key ingredients that enable my continuing development as a health psychologist.

Provide psychological advice and guidance to others

Working as part of the renal department’s multiciliary team and having worked in the department for a number of years allowed me to build professional relationships across different healthcare professionals which has been important for improving the holistic care of patients. It has also been helpful in creating opportunities to promote the merits of health psychology. For example, an opportunity arose following discussions with renal dieticians where they expressed unease in working with patients’ that presented in emotional distress or those that present with issues of risk. Following these discussions, I proposed the development and delivery of a CPD training session to the renal dietetic team on assessing and managing risk. Upon agreement, the renal psychology medicine team, this comprised of me, a Clinical Psychologist and a Consultant Psychiatrist, delivered a one-hour session. The attendees’ feedback was wholly positive, with comments made with regards to the relevance and transferability of the training to their practice. Attendees also expressed that it would be useful to have a second-part to the training where the theoretical aspects of the training could be applied experiential in a safe environment. A second-part of the training was subsequently delivered to consolidate the learning from the initial training. Both sessions were well received by those in attendance, with the renal psychological medicine team being invited to facilitate further CPD training sessions to provide psychological advice on various topics from health promotion to managing patient distress.

Psychological advice and guidance was also provided through a series of different lectures, workshops and in my day-to-day work. In my role as a Senior Assistant Psychologist I provided psychological advice on an informal basis to various healthcare staff and students. Conversations ranged from providing information on the common psychological and social challenges experienced by people living with end stage renal disease (ESRD) to providing guidance on the referral process for patients to access the renal psychological medicine service and information on what services the team provides. More formally, further opportunities have included the provision of whole-day workshops to nursing staff on nurse-patient communication workshops, which presented theory with experiential elements, and being involved in the low clearance education programme that works closely with patients that have either been recently diagnosed with ESRD or are expected to commence dialysis in the near future.

Separate from my duties as a Senior Assistant Psychologist an opportunity arose to conduct consultancy work for a Peritoneal Dialysis (PD) Consultant who sought a consultant to carry out a Needs Assessment to determine the best quality PD training for patients. The needs assessment consisted of process mapping, a thorough literature review on PD training, and conducting a benchmarking exercise with other PD services and training providers. Upon conclusion, the client was presented with a Needs Assessment report that detailed the outcome of the consultancy. Written and verbal feedback from the client included his intention to disseminate the findings to senior staff members of the PD team and implemented as appropriate.

Similarly, further opportunities outside of my employment as a Senior Assistant Psychologist arose by being approached by Module Leads of a MSc Health Psychology programme to deliver two lectures to MSc Health Psychology students. One lecture focused on ‘health promotion in renal care’ and a further lecture discussed the theme of ‘living with ESRD’. Both lectures aimed to provide psychological advice by combining health psychology theory and applied psychology, with experiential elements. Both lectures were received well and provided me with the opportunity to inform MSc Health Psychology students of an area that they might previously have had limited knowledge of. It also gave me the opportunity to develop my lecturing and group facilitation skills that are a key aspect of my progress in becoming a health psychologist.

Provide feedback to clients

My role as a Senior Assistant Psychologist at a Renal Department provided me with numerous opportunities to work on a one-to-one basis with patients who live with having end stage renal disease. The work has involved working with patients throughout the psychological care pathway, from conducting initial assessments through to providing psychological interventions and behaviour change support. As part of the provision of treatment, patients would be asked to complete psychometric outcome measures (i.e. Patients Health Questionnaire – 9-Items, General Anxiety Disorder Assessment – 7-Items) at the time of the initial assessment and again at their closing session. The outcome measures would provide an opportunity to provide and discuss feedback to patients at the end of treatment and evaluate the areas where additional support could be useful.

In addition to the measures mentioned above, patients would routinely receive regular verbal or written feedback concerning a review of our work together. Patients would also receive a closing letter summarising the main points from treatment and any relevant future recommendations. When possible, the closing letter would be presented at the final session and discussed as an effective means of reviewing the work and exploring issues of relapse prevention. Generally, patients have expressed finding this method of feedback to be both collaborative and highly helpful in providing a review and a visual reference that could be referred to in the future to remind patients of interventions that could help to maintain positive changes.

Through my work in renal care I have had regular opportunities to provide feedback to clients of different professions. For example, part of the agreement with a Haemodialysis Matron for me to deliver nurse-patient communication workshops to staff members was to provide an evaluation report on completion of the series of workshops. The evaluation report comprised of a synopsis of the workshops and a summary of the collated feedback from those in attendance, including the attendees' perspective on the relevance of the workshops to their practice. Following receipt of the evaluation report, the Haemodialysis Matron requested the delivery of further workshops to enable more staff members to attend.

The provision of feedback to clients has the potential to make up a significant aspect of the professional duties of an applied psychologist. Being involved in conducting annual audits for the Renal Psychology Service formed an integral part of my role as a Senior Assistant Psychologist during certain periods of the year. Part of my responsibilities during these periods included collecting, analysing and presenting the findings visually in a brief report to be disseminated to Service Managers. The report would also consist of patient feedback that would be collected annually by sending out service evaluation forms to those patients that had used the Service during the previous year.

Reflections

My journey as a health psychologist in training has rarely been an easy or straightforward path, with numerous challenges being presented along the way. These challenges, all though creating some discomfort, had enabled me to develop professionally and personally on many different levels. During my training I was exposed to several opportunities that I had no or very limited previous experience of, such as providing consultancy, working clinically with patients, and delivering workshops and lectures. Without these opportunities it is perhaps unlikely that I would have progressed as much as I have in fulfilling my ambition of becoming a health psychologist and working in a field that I feel passionately about.

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Area of competency:

Consultancy

D2. Consultancy Competency: Needs Assessment in Peritoneal Dialysis

Description of work:	Conducting a needs assessment on Peritoneal Dialysis training.
Setting:	NHS Hospital setting - Renal department
Client/target group:	Renal Consultant specialised in Peritoneal Dialysis

Context

A consultation in the form of a needs assessment was provided to a National Health Service's (NHS) Renal Department's Peritoneal Dialysis (PD) service. The National Institute for Health and Care Excellence (2011) recognises PD as one of the treatment modalities available to patients with End Stage Renal Disease (ESRD), which is a chronic and irreversible failure of kidney function. This dialysis treatment allows patients to dialyse daily at home with the purpose of sustaining life (Chow & Wong, 2010). Patients and family members are usually trained by a PD service in the application and regime of PD that is tailored as much as possible to their individual needs and lifestyle (Russo, Manili, Tiraboschi, Amar, De Luca, et al., 2006). The PD service that this needs assessment was provided for supported more than 170 patients undergoing treatment for ESRD. The PD service requested an exploration of *'best quality'* care in PD training through the review of existing literature and benchmarking against other PD services with the intention of supporting a review of the training and service they were providing.

Assessing request of consultancy and review of the literature

The Lead of the Renal Psychology and Counselling Service was approached by the PD Lead Clinician enquiring about the possibility of conducting short-term consultancy work. She recommended speaking to me, the Senior Assistant Psychologist/Health Psychology trainee, as she believed that I had the required expertise. I was subsequently informed of the opportunity and took the intuitive of contacting the PD Lead Clinician to request a meeting. During the meeting the PD Lead Clinician set out the initial ideas for the consultancy work, which seemed to suit my existing experience of working in renal care and would offer me the opportunity to develop my skills in conducting consultancy work. I informed the clinician of my experience in research and how my expertise would be beneficial and appropriate in meeting the requirements of the consultancy. It was agreed for me to be the Lead Consultant in this needs assessment and that it would be a standalone piece of work, unconnected to my current role as Senior Assistant Psychologist.

During the consultation the client expressed many ideas that could be explored in this Needs Assessment. Through discussion we were able to identify and prioritise four main areas that the client wanted to investigate, these were:

(i) To identify *'best quality'* training offered to PD patients and, if required, to improve the PD service's own patient training
(ii) Investigate the application and effectiveness of PD patient training in groups and in one-to-one interviews
(iii) To explore how PD training could be tailored to meet the potential needs of patients that require additional support, including the elderly, patients with cognitive impairment, and patients with a limited understanding of the English language
(iv) To investigate the PD trainers' competence in delivering PD training to patients and, if required, identify potential areas of development for trainers.

The client's desire to provide *'best quality'* care to PD patients in the service came across strongly during the initial discussions. Due to the ambitiousness of the client's request, it was necessary to narrow the scope of this consultancy to ensure the feasibility of its completion within the time frame available. Through an open dialogue with the client, we negotiated the specific areas that this needs assessment could address. It was agreed that it would be important to identify what constitutes *'best quality'* care. We decided that this could be achieved by benchmarking the patient care and training provided by different PD services, along with a review of relevant existing literature. Following the conclusion of the initial discussions with the client a proposal listing the outline and planned delivery of this needs assessment was submit to the client via email for review and agreement.

Review of the literature

The literature was reviewed for relevant advice on conducting a consultancy piece of work. Lee (2002) states that consultancy is traditionally seen as a relationship between two parties where one person, or a group of people, provide support to another person or group of people. Schein (1999) describes three consultancy concepts: (a) *'Expert Model'*, where the consultant provides the client with information that the client is looking for;

(b) *'Doctor-Patient Model'*, where a consultant is brought into an organisation to explore possible areas of improvement, as well as providing the client with a recommended plan to implement any changes; and (c) *'Process Consultation Model'*, which puts an emphasis on the consultant supporting the client to help themselves.

The *'Expert Model'* approach seemed appropriate for this needs assessment as the client was interested for the consultant to explore different areas regarding PD training. The client expressed his ideas during the initial meeting, which were discussed and refined. In this model the client gives autonomy to the consultant once the client's needs are expressed and agreed upon. It was then important for the consultant to abide by the agreed aims and objectives. Failure to do so may cause a potential mismatch between the client's need and the outcome of the consultancy (Schein, 1999).

Plan consultancy and produce implementation plans

The outline of the proposed needs assessment was modified with mutual agreement with the client via email (Appendix 1). It was agreed that the needs assessment would be conducted over four months, based on working one and a half days per week during this period. Project budgeted for this consultancy work is listed in Appendix 2. The agreed overall aim for this Needs Assessment was to identify what *'best quality'* care in PD consists of especially with regards to the support and training PD patients receive. There were four objectives for this needs assessment:

a) Using process mapping to enable a better understanding of renal patients' hospital journey in the renal department
b) Conducting a literature review of relevant research findings, guidelines and recommendations regarding PD training
c) Benchmarking the PD service with similar institutions to gain a better understanding of the training provided to PD patients
d) Producing a needs assessment report displaying findings and recommendations to the client

The implementation plan for this needs assessment included carrying out a brief *'process mapping'* exercise. Trebble, Hansi, Hydes, Smith and Baker (2010) proposed that process mapping has been found to be beneficial in enabling a better understanding of patients' treatment pathways using a workflow diagram. Producing a visual representation, such as the workflow diagram, of the renal patients' hospital journey would allow for a better understanding of the different renal teams involved in the patients' care, before and during PD treatment.

Conducting a literature review was also proposed in the implementation plan to enable the identification and review of relevant guidelines and recommendations regarding PD training. For example, by exploring relevant renal publications made by the NHS and the National Institute of Clinical Excellence (NICE). A further rationale for this was to enable the gathering of recent research findings in PD training in terms of context, delivery and evaluation. Due to their relevance different psychological and medical electronic databases were proposed for this literature review, including: PsycINFO; MEDLINE; BNI; EMBASE; and CINAHL. Proposed search terms included *'Peritoneal Dialysis'* or/and *'Continuous Ambulatory Peritoneal Dialysis'*; and *'Training'* and/or *'Education'*, with the aim to identify research papers evaluating different PD training programmes. The proposed inclusion criteria for this literature review were: (a) research findings published between 2000 to 2012; (b) national and international articles, providing they were published in the English language and the full article was accessible, as available resources would not cover translation or article purchase costs. Due to limited resources grey literature and theses were excluded.

The implementation plan also included conducting benchmarking to identify what the client's service and different PD services offer to their patients. Stapenhurst (2009) states that benchmarking is an effective tool, that can be used to compare and learn from similar services, by evaluating services strengths and weaknesses. The National Health Service Benchmarking Network's website (as per 2013) defines Benchmarking as *'the use of structured comparisons to help define and implement best practice'* and states that benchmarking is a recognised and effective way to improve performance. It also highlights that benchmarking is a process where it is important to understand the client's service first before exploring the merits of other relevant services, which can help inform recommendations for change. To enable a more systematic process of collecting data from the different PD services, it was proposed to develop a semi-structured questionnaire based on relevant PD training recommendations and guidelines. As part of the implementation plan it was agreed that the client would be provided with a report of the findings and recommendations on conclusion of this needs assessment.

Establish, develop and maintain working relationships as well as develop and maintain consultancy contracts with clients

Initial contact with the client was established in-person following a discussion between the Renal Psychology and Counselling Service Lead and the Lead PD Clinician regarding a piece of consultancy work. Following the initial consultation meeting, changes to the needs assessment proposal were subsequently made following feedback from the client and agreed upon via email, which also acted as the consultancy contract (Appendix 1). Even though the *'Expert Model'* approach was employed in this needs assessment the client was kept informed of any progress through emails and in-person meetings. Keeping the client informed of the project's progress helped to develop and maintain a professional working relationship. The client was also encouraged to provide feedback on the project and relationship at the end of the consultancy by completing an evaluation questionnaire (Appendix 3). It was also necessary to develop and maintain professional working relationships with other services and individuals involved in this consultancy. PD professionals from within and outside the trust were contacted with the intention of gaining a better understanding of their PD services. Visits were arranged to PD training providers and PD services of other trusts to observe and discuss their training and practices. Contact was maintained through discussions via email and telephone when necessary. Due to the nature of this needs assessment it was essential to form and maintain good working relationships with other PD professionals. As such, it was important to encourage an open and non-judgemental environment where other PD professionals could share their expertise and experiences. Contributors received a summary of their information relevant to their own service (Please see Evidence folder, Section 10, p.39-54). This was with the intention of being transparent and to encourage feedback. Although the working relationship was not evaluated as such, the PD professionals reported on the helpfulness of receiving a summary of their PD service.

Conduct and close consultancy

The planned procedures of the consultancy, as stated above, were conducted as follows:

1. **Process Mapping:**

Process mapping was executed by arranging in-person meetings with professionals from the renal department's multidisciplinary team, with the aim of mapping renal patients' hospital journey. Having collected the relevant information a visual diagram was created and then reviewed by members of the multidisciplinary team to ensure the presented illustration was accurate (Please see Evidence folder, Section 10, p.11).

2. Review of available literature and publications:

The literature search was conducted as proposed and followed the steps as listed in Table 1. which generated hundreds of articles. Nine articles ultimately met the inclusion criteria and were identified as appropriate to this needs assessment. However, due to the focus on different aspects of the PD training it was not possible to compare all nine articles as a whole. This resulted in subdividing the articles into four sub-groups: (a) different approaches employed in PD training; (b) a private sector renal education centre versus hospital PD training delivery; (c) home visits and home visit assessment questionnaire(s); and (d) international and a national survey of PD training programmes (Please see Evidence folder, Section 10, p.12-21).

Table 1: *Procedure of literature review*

Steps	**Action**
1st Step	Electronic database search using proposed search terms
2nd Step	Read through generated articles to identify relevance to this Needs Assessment
3rd Step	Exclusion of duplicates, non-relevant and not accessible articles
4th Step	Read through relevant articles critically regarding their appropriateness and relevance to the inclusion criteria
5th Step	Identified articles which were meeting the inclusion criteria
6th Step	Identified and explored similarities and differences across the included studies
7th Step	Summary of findings

3. Conducting benchmarking

The benchmarking process included gathering information from the PD professionals from within and outside the Trust. A semi-structured questionnaire schedule, based on the International Society for Peritoneal Dialysis recommendations (Bernardini, Price & Figueiredo, 2006) was developed and followed during in-person or telephone meetings with the PD professionals (Appendix 4). Thirteen aspects of PD training and delivery emerged from the benchmarking data collection. These were:

- Delivering Continuous Ambulatory Peritoneal Dialysis and/or Automated Peritoneal Dialysis training
- Teaching qualification of trainers
- Learner
- Training duration
- Training location
- Brief training outline
- Trainers and number of learners
- Booklets/handouts
- Evaluation of patient's knowledge
- Home visits after training completion and after training assessment
- Offer of retraining
- Evaluation/satisfaction questionnaire
- Most challenging and least challenging parts of training delivery

Each service received a table of the thirteen aspects of PD training reflecting the information gathered about their service (Please see Evidence folder, Section 10, p.39-54). The table was provided for their information and also to allow each service the opportunity to comment and feedback on any necessary changes. The finalised needs assessment report presented the thirteen aspects of PD training, both service specific and an overall summary (Please see Evidence folder, Section 10, p.22-32 & p.39-54)). The fourth section of the implementation plan consisted of producing a needs assessment report displaying the findings and recommendations. The finalised needs assessment report was produced and emailed to the client, along with a hand delivered hardcopy for the client's perusal (Please see Evidence folder, Section 10, p.1-57). Prior to the closure of the consultancy, the client was given the opportunity to discuss the final needs assessment report and was provided with an *'Evaluation of the Consultancy Process'* questionnaire (Appendix 3). The client completed the questionnaire and reported being satisfied with the consultancy. At this stage it was agreed with the client to close the consultancy.

Monitor the implementation of consultancy

The consultancy was conducted according to the implementation plan with the main aim and the four agreed objectives achieved (Appendix 1). Monitoring processes were put in place throughout the different stages of this consultancy to help identify and implement any necessary changes in meeting the set aim and objectives. These processes were also applied to implement quality assurance and control mechanisms throughout the consultancy. The client's expectations, needs and requirements within the consultancy were collaboratively explored and agreed through a number of negotiations. In accordance with the *'Expert Model'*, once the focus of the project, its aim and objectives were set with the client subsequent monitoring processes involved discussions with other renal professionals. This was achieved by requesting feedback on the summary tables that each contributor received on the collected data to monitor the accuracy of the collected information. This resulted in making appropriate amendments to the collected data where necessary with a final version of their service summary distributed via email. Towards the end of the consultancy the client was sent the '*Evaluation of the Consultancy Process'* questionnaire (Appendix 3) with the final report (Please see Evidence folder, Section 10, p.1-57). The client's feedback was overall highly positive, for example he strongly agreed that the needs assessment met the enquiry and that the recommendations would be considered in the service delivery, especially in how PD training is delivered to patients and/or relatives. The consultancy was conducted under the clinical supervision of a Consultant Clinical Health Psychologist who was external to the renal department. Regular supervision meetings were used to facilitate reflection and to monitor the consultancy's progress and evaluation. At the start of the consultancy the client was also provided with the supervisor's contact details if he had any questions concerning the ethical regulations regarding my work, if needed.

Evaluate the impact of consultancy

The main aim of this consultancy was to identify what constitutes '*best quality'* care in PD, especially with regards to PD training, and how this can be delivered whilst maintaining *'best quality'* patient care. The consultancy objectives were met by conducting a literature review and through carrying out benchmarking with other services and providers delivering PD training. The findings and recommendations were presented in a needs assessment report with the intention of it being used as an aid for discussion within the client's PD team when reviewing the service provided. With the submission of the needs assessment report, and in receipt of the completed *'Evaluation of the Needs Assessment Report'* (Appendix 3) from the client, the consultancy contract was ended in agreement between both parties. Prior to the closure of the consultancy a debrief meeting with the client took place to discuss the findings and recommendations. The client expressed that the report would be taken into consideration during their service review. It was also discussed how the findings could be best disseminated to the client's PD team to aid discussion and reflection on their service. It was recommended to present the consultancy findings to the PD team. However, due to service challenges, such as staff shortages and high clinic demands, it was only possible to discuss the findings with designated senior members of the nursing team in individual meetings. It was subsequently agreed, upon one of the senior nurse's request, that the *'PD Training Evaluation Questionnaire'* for patients/carers (Please see Evidence folder, Section 10, p.55-56) developed as part of this consultancy would be used by the PD team going forward to collect patients' feedback on the PD training received.

Overall reflection on consultancy

This consultancy was both challenging and rewarding in equal measure. It was the first consultancy piece that I had undertaken. This increased the challenge in delivering a project whilst needing to acquire new skills and knowledge. During the different stages of the consultancy I faced many demands. For example, the client initially requested a project with a very broad scope, which struck me as too ambitious for this consultancy. My role here was to negotiate a more specific focus that could be realistically achieved with the resources available. At first, I found this process especially challenging as I felt intimidated exploring an achievable project with a senior clinician. However, utilising the counselling and motivational interviewing skills that I had acquired through my clinical work enabled me to manage my discomfort and gain confidence in my role as a consultant.

Conducting the literature review presented a significant challenge in the work. Even though I had previous experience of searching existing literature, I found the process of searching for literature for this consultancy difficult due to the limited availability of relevant articles. This resulted in the literature review taking more time than initially anticipated and required me to organise the relevant articles into sub-groups to present a clearer picture of the information. Doing this enabled me to overcome my sense of feeling stuck, yet also brought up anxiety as I felt under increased time pressure.

The questionnaire I developed as part of the benchmarking aspect of this project, which was based on the International Society for Peritoneal Dialysis recommendations by

Bernardini, et al., (2006) on PD training, worked particularly well. Without a questionnaire, it would have been difficult to capture and compare the collected information systematically that was essential for this stage of the consultancy. By including areas listed in the International Society for Peritoneal Dialysis (2006) enabled me to explore how the recommendations are put into practice. Conducting the questionnaire with PD nurses about their PD services was both interesting and rewarding. Gathering first-hand accounts from PD staff on the frontline of providing PD care allowed me to gain an appreciation of the complexity of their work. Additionally, I believe that my previous academic and work experience in the health field enabled me to provide a non-judgement environment that aided data collection.

Overall, conducting this consultancy project was highly informative on a personal and professional level. The challenges that I faced throughout this period exposed me to opportunities that developed my skills and knowledge as a consultant. This piece of work showed me that the implementation plan may need to change and therefore it is important to remain flexible in my approach to the work in order to adjust to any obstacles that may occur. A further learning experience that will help to inform my future work is the benefit of being aware of the need to take a step back at times and objectively see the bigger picture to remain focused on the overall aim of the project. Drawing on the experiences and positive feedback from the client has given me an increased confidence in delivering further consultancy work in the future.

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Appendices

Appendix 1: Agreed project outline/consultancy contract

The agreed project outline for this Needs Assessment formed the consultancy contract. A brief implementation plan and the completion time for this project were agreed between the client and the consultant via email. Please see agreed needs assessment aims as outlined below:

1. Process mapping – brief description of PD patient training
    a. From when patients have their PD catheter inserted or when their 'buried' catheter is externalised.
    b. To include patients' experiences of receiving PD training (organisation, structure, material, delivery, involvement of others, such as relatives whom also took part in the training). Satisfaction and evaluation questionnaire of patients' experiences*.
2. Literature review - looking at the relevant literature and PD training guidelines
    a. Search the literature.
    b. Read through guidelines, recommendations and articles.
    c. Write a brief summary.
3. Benchmarking – to get an understanding of what other hospitals offer in their PD training
    a. To identify 2 to 3 other London based hospitals providing PD services.
    b. To arrange meetings with the identified services and explore the PD service and PD training they are offering to their patients.
4. Brief summary report
    a. Produce a finalised report of the Needs Assessment.
    b. Include recommendations for future steps.

*Additional notes to point 1b:

Even though included in the Needs Assessment and requested by the consultant it was not possible to include patients' experience in this piece of work. As during the time of the data collection only patients on assisted PD received training by the PD staff. It was felt that due to its very short training (not comparable to the full PD training) it would not have informed this piece of work. However, I developed a '*Peritoneal Dialysis Training Questionnaire'* for the service which could be used for the purpose of training evaluation in the future.

Appendix 2: Project budget

Time scale:

- Proposed time scale = 19th June 2012 to 19th October (4 months = 25 ½ days in total, working 1½ days a week)

- Actual time scale = 19th June 2012 to 22nd November 2012 (5 months = 33 days in total, working 1½ days a week)

Table II: *Display of proposed and estimated project costs.*

Costs	**Per unit**	**Amount**	**Total sum**
PROPOSED time scale - Salary for consultant (me)	£11.15 per hour = £83.63 per day	x 25 ½ days	£2132.44 (Proposed time scale)
ACTUAL time scale - Salary for consultant (me)	£11.15 per hour = £83.63 per day	x 33 days	£2759.63 (Actual time scale)
Supervision costs	£60 per hour	x 6 sessions	£360
Telephone costs *	7.95 pence per minute	x 75 minutes (in total 2 phone calls)	£5.97
Photo copies	3 pence per sheet	83 sheets (25 sheets for Questionnaire + 58 sheets for Final Report and Appendixes)	£2.49
****Travel costs**	£11 per day	X2	£22
PROPOSED time scale – Total			£2522.90 (Proposed time scale)
ACTUAL time scale – Total			£3150.09 (Actual time scale)
ADDITIONAL INFORMATION: *Telephone costs (BT Estimate as per 2012): http://www.productsandservices.bt.com/consumerProducts/displayTopic.do?topicId=25512 **Travel cost (Transport for London as per 2012): http://visitorshop.tfl.gov.uk/travelcards/1-day/product/day-anytime-travelcard.html			

Appendix 3: Client's assessment and evaluation of the consultancy process

APPENDIX 3 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

Appendix 4: PD training questionnaire for PD training staff used for the data collection of the benchmarking process

1) **In Brief, what was the patients' PD pathway like before starting the training?**

Answer:………………….

2) **Who delivers the PD training?**
    - The nursing staff?
    - Do they have experience to train others/ patients?
    - Do they have formal training in training others received/ attended or learned through experience?

Answer:…………………..

3) **What is the role of the Physician in the PD delivery/ training?**
    - At what stage of delivery/training does the physician get involved?

Answer:…………………..

4) **Do you use pre-assessment tools/ questionnaires before or during PD training?**
    - Do you assess environmental factors e.g. available space for PD exchanges and the storage of the PD bags?
    - Do you assess patients cognitive functioning and motor ability?
    - Is a psychological assessment carried out?

Answer:…………………..

5) **Who is the learner?**
    - Patients
    - Carers
    - Both
    - Others

Answer:…………………..

6) **Where does the training take place?**
    - At a specially assigned training room?
    - At patients' homes?

Answer:…………………..

7) **Do the patients/ relatives know what to expect from the training?**
    - Are they provided with an agenda of the Day and/ or of the whole week?

Answer:…………………..

8) **Is the PD programme structured/ unstructured/ flexible training programme/ agenda followed?**

Answer:…………………..

9) **The PD programme: what is taught/ what does it involve?**
    - What materials are used? What material can patients take home with them?
    - What is the duration of training (length)?
    - Is the PD training delivered in groups, 1:1 or both?

Answer:…………………..

10) **What are the learning approaches they follow?**
    - Do the patients receive class room style (listening only) training?
    - Experiential learning?
    - Is information provided on one time or more often?

Answer:…………………..

11) Does the training include motor skill practises?

- What does it look like?
- E.g Bag exchanges etc?

Answer:…………………..

12) What happens at the end of the training?

- Do you evaluate patient’s knowledge and skills gained?
- Are the patients given a quiz?
- Do you observe patients’ competence?
- Do you follow a check list?

Answer:…………………..

13) Is Re-training offered to the patients?

- If yes to whom/ how often/ when?

Answer:…………………..

14) Do you assess the patients periodically on their PD technique?

- During clinics?
- During home visits?
- Pre arranged appointments?

Answer:…………………..

15) From your experience…

- What is the most challenging part of delivering PD training?
- And what do you find is least challenging?
- Do you think there are parts/ sections of the PD training that could be delivered in groups or should everything be delivered on a 1:1 basis?

Answer:…………………..

16) Do you use end of training questionnaires?

- Patient evaluation/ satisfaction questionnaires or something similar for patient’s feedback of training?

Answer:…………………..

17) Any other comments?

Answer:…………………..

Area of competency:

Behaviour Change Intervention

D3. **Behaviour Change Intervention:** Non-Adherence to Medication

Description of work:	A behaviour change intervention with the aim to increase a client's medication intake practices by reducing non-adherence
Setting:	NHS hospital out-patient setting
Target group:	Adults with End Stage Renal Disease (ESRD)

Literature and guidelines regarding non-adherence to prescribed medication in patients with long term conditions

Horne, Weinman, Barber, Elliott, and Morgan (2005) describes adherence as *"the extent to which patients' behaviour matches agreed recommendations from the prescriber"* (p12). The National Institute of Clinical Excellence (NICE) guidelines (2009) state that between 33% and 50% of medications prescribed to patients with long-term conditions are not adhered to as recommended. Non-adherence has been suggested to fall into two categories: intentional non-adherence and unintentional non-adherence (Horne, et al., 2005). Horne, et al., (2005) refers to intentional non-adherence as occurring from patients' beliefs, attitudes and expectations, which can impact on their motivation to start and continue with treatment plans. Unintentional non-adherence is denoted as arising from patients' individual constraints (e.g. memory, dexterity) and environmental factors (e.g. difficulties accessing prescriptions, competing demands). The NICE guidelines (2009) highlight the importance of identifying factors that have the potential to impact on non-adherence and providing patients with the necessary support to improve their adherence. They recommend that adherence can be improved by: (i) healthcare professionals working collaboratively with the patient; (ii) increasing patients' involvement in decision making; (iii) improving understanding of patients' perspectives; and (iv) providing relevant information to patients on their condition and treatment. Patients could be further supported by healthcare professionals assessing and frequently reviewing their adherence to medication and by considering alternative interventions.

To date a general recommended intervention has not been proposed by NICE (2009). However, the importance to investigate patients' reasons of non-adherence and to provide a tailored intervention specific to their needs has been highlighted. Haynes, Ackloo, Sahota, McDonald and Yao's (2008) 'Cochrane Review' suggests that adherence to prescribed medication seems to be more effective, particularly in long-term regimes, when a combination of different approaches are used such as counselling, reminders, self-monitoring, feedback, and physiological therapy. Adherence to prescribed medication, particularly in renal care is very important as some of the medications prescribed support the body to regulate hormones and breakdown chemicals that the body is unable to do due the lost kidney function (Tonelli, Pannu & Manns, 2010). Regular medication intake is also crucial in maintaining a transplanted kidney to prevent organ rejection. It has been suggested that about 15.4% to 50.2% of haemodialysis patients do not take their medications as prescribed, even though non-adherence increases the risk of hospitalisation and mortality (Matteson & Russell, 2010).

Assess the suitability of client/s for health-related behaviour intervention

The client, addressed here by the pseudonym Leo for the purpose of anonymity, was referred into the Renal Psychology and Counselling Service by his Nephrologist. The referral stated that the client wanted to address difficulties in adherence to his medication, which had implications on him being placed onto the kidney transplant list. Leo attended an initial assessment with the Renal Counselling Psychologist to identify his suitability for the service and any apparent risk issues. Leo was considered suitable for the service with no suicidal, self-injurious, or other risk factors identified, apart from adherence problems. He noted friends, family, and his religious faith as protective factors. The Renal Counselling Psychologist recommended for the client to be seen by me in my role as a Senior Assistant Psychologist, primarily based on his presenting issues relating to end stage renal disease (ESRD) and the low risk identified. The initial intention in me being allocated to the client was to conduct a further assessment of his needs and to provide psychological input.

Leo was a 25-year-old male that had been on haemodialysis for three years since being diagnosed with ESRD. Leo lived with his father. He stated that his ESRD and treatment regime led to his withdrawal from university due to him feeling physically unable to continue. Leo expressed fearing being stigmatised by others, including his friends and family, for having ESRD. Leo described feeling anxious at taking his medication away from home as he feared that he could vomit in front of others, which would lead to feelings of shame. However, Leo said he usually adhered to taking his medication when at home as he felt better equipped to manage his nausea. Leo also expressed his understanding that non-adherence to his medication was jeopardising his chances of receiving a kidney transplant (Appendix 1 and Appendix 2).

It was agreed with Leo to meet fortnightly. The total number of sessions was not set at the start of therapy, in accordance with the service guidelines, yet it was agreed with Leo that therapy would be reviewed regularly to assess progress and his needs. The work was supervised by the Renal Department's Healthcare Professions Council (HPC) registered Chartered Counselling Psychologist.

Identify and negotiate the behaviour change goals of the client

During the initial sessions Leo talked about his medication intake behaviour; his fears of potential implications on his health, and possible future treatment options. Working in an empathetic and non-judgemental manner a collaborative therapeutic relationship was established early on. Padesky and Greenberger (1995) proposed that the establishment of a positive therapeutic relationship and the application of Socratic guided discovery are fundamental clinical processes central to cognitive and behavioural practice. Appling these principles enabled the identification of Leo's therapy goals. Leo's main aim for therapy was identified as wanting to improve and sustain a regular medication intake.

Using Prochaska and DiClemente's (1982) Stages of Change Model, Leo appeared to be at the *'Preparation'* stage as he was motivated to make changes (for further explanation on Prochaska and DiClemente's model see Appendix 3). To explore Leo's intention to change his medication intake, Ajzen and Madden's (1986) Theory of Planned Behaviour model (TPB) was considered an appropriate model to use as it addressed the social and environmental factors, and took into account Leo's past experiences that seemed influential in the formulation of his presentation (Appendix 2). Applying the TPB model, Leo believed that regular medication intake would impact positively on his health, such as by reducing his physiological pain that limited his mobility (*attitude towards the behaviour*). He believed by taking his medication regularly he would become eligible to be put onto the kidney transplant list (s*ubjective norm*). Leo mentioned that having learned to take his medication at home, he felt encouraged that he could learn to take it in other environments (*behavioural internal control*). He also identified occasionally forgetting to collect his prescription from his General Practitioner in time, resulting in him being without medication (*behavioural external control*) (Appendix 4). Padesky and

Greenberger (1995) argued the importance of establishing goals that are specific, manageable and realistic. Smaller, more immediate goals were negotiated with Leo, with the intention of helping him to work towards changing his behaviour. For example, minimising the likelihood of Leo running out of medication. Gollwitzer (1993) proposed with his *implementations intension* that an increased likelihood of executing a goal directed behaviour can be achieved with detailed planning, such as when, where and how a behaviour would be carried out. Collaboratively planning and scheduling specific behavioural changes became an integral part of Leo's therapy, as did exploring possible obstacles and barriers that could hinder behaviour change.

Assess the cognitive, behavioural and situational determinants of relevant current behaviour

The assessment of Leo's cognitive, behavioural and situational determinants of relevant current behaviour was an ongoing process. With time, we started exploring at a deeper level what was going on and how things were interlinked with each other (Appendix 4). Leo believed that having ESRD greatly impacted on his mortality. He said that *"with ESRD, death is expected".* Leo stated that he was experiencing a relief from the distress he feels towards his condition when distracted by enjoyable activities. He said that *"when you have too much fun you forget about everything, you just forget that you are ill",* yet he also described avoiding social situations due to his illness and *"not having much fun since being ill"* that seemed contrary to his statement to the way he was managing his distress.

Leo spoke about having experienced feelings of shame towards having ESRD. He stated that he assumed that *"if people know that I am unwell, then they would treat me differently and I do not want that".* Leo described being self-conscious about the appearance of his fistula (a surgically created connection required for haemodialysis treatment) due to how others may perceive it, saying *"if people see my fistula, then they would find it disgusting*". This also seems to coincide with an earlier experience where Leo interpreted his mother's initial reaction to seeing his fistula in his arm as disgust. Leo expressed feeling disappointed with himself, considering himself to be *"a failure"* and *"abnormal"* for struggling with his medication intake. He stated that *"if I was normal, then I would be able to take my medication like everyone else"*. Leo described the way he viewed his illness greatly influenced his behaviour and his reaction to certain situations. Leo said he was managing his feelings of shame about having a fistula in his arm by only wearing long sleeve shirts in order to prevent it from being seen. Leo also mentioned that if his friends visited him unexpectedly at home, at a time when he was feeling unwell, he would say he was ill with a cold/flu rather than disclose that he had ESRD. He associated this to his fear that he would be treated differently and would *"no longer fit in"*. Furthermore, Leo's fear as to how others would perceive him for being unwell had meant that he had only disclosed his illness to one friend and immediate family members. This also illustrated his dilemma of either staying at home or going out as it impacted on his medication intake behaviour. Leo stated that sometimes he had avoided attending communal gatherings, including going for prayers and celebrations, as he worried about vomiting after medication intake. This had impacted on his adherence to medication as he stated that he was more likely to take medication when at home.

Develop a behaviour change plan based on cognitive-behavioural principles (not necessarily CBT)

Having identified his current behaviour and cognitions towards his illness and medication intake therapy progressed to developing a plan to support him in improving his adherence to his medication. The behaviour change plan for Leo was developed by including regular monitoring of his medication intake behaviour, relaxation techniques, cognitive restructuring, and the development and implementation of behavioural experiments (Table 1):

Table 1: *Components of the Behaviour Change Plan.*

1. *Sharing the formulation with Leo to increase understanding of his presenting difficulties*
2. *Monitoring his medication intake behaviour*
3. *Relaxation: Deep breathing*
4. *Cognitive restructuring*
5. *Behavioural experiments*
6. *Relapse prevention*
7. *Involvement of Renal Dietician*

Sharing the formulation: Collaboratively, developing and working with Leo to formulate his presenting difficulties in adhering to his medication formed an important part of the behaviour change plan. Sanders and Wills (2005) suggested that sharing a formulation, especially when presented as a diagram, helps the therapist and client consider how things are interlinked and consider where interventions and change can start. The formulation was frequently referred back to and amended during the course of therapy (Appendix 2).

Monitoring medication intake: Leo reported during his assessment, and in the early stages of therapy, that he was uncertain about the frequency of his medication intake (i.e. when, frequency, and whether medication was taken). Diary records were considered a useful means of monitoring his behaviour on a daily basis (Appendix 5). Sage, Sowden, Chorlton, and Edeleanu (2008) emphasised that keeping written records was an integral aspect of most cognitive behavioural practice, to increase the client's awareness of their current behaviours and also as a source of reference. Furthermore, homework was used throughout therapy as it provided Leo with the opportunity to experience behavioural and cognitive therapeutic change while also practicing, maintaining and experimenting with new techniques and behaviours. Beutler, Malik, Alimohamed, Harwood, Talebi, et al., (2004) found significantly better therapy outcomes when homework was used.

Relaxation techniques: Leo expressed experiencing feelings of anxiety before medication intake. Part of his behaviour change plan included the application of relaxation techniques, such as breathing exercises and progressive muscle relaxation. Wilding and Milne (2008) suggested that relaxation techniques can help to ease the physical sensations and psychological components of anxiety.

Cognitive restructuring: Challenging Leo's cognitions and affect towards having ESRD and his medication intake was central to the behavioural change plan. The plan included challenging his cognitions by exploring his thoughts towards his medication intake and his assumptions about other people's perception of him and his illness. Padesky (1993) identified the usefulness of *'Socratic guided discovery'* in exploring and challenging cognitions. Behavioural experiments were also incorporated into the behaviour change plan, with the intention to further explore existing and alternative cognitions.

Behavioural experiments: As stated above, Leo's behaviour change plan consisted of the implementation of behavioural experiments. Bennett-Levy (2003) argued that behavioural experiments can encourage greater change in a client's behaviour, their cognition and affective state in comparison to therapy without the inclusion of behavioural experiments. As well as using behavioural experiments with the intention to challenge cognitions, behavioural experiments were also employed within the plan to explore new behaviours (e.g. experimenting with different methods to assist medication intake and scheduling reminders) helpful to achieving Leo's aim of improving medication adherence.

Relapse prevention: Kyrios (2009) argued for the importance of including a relapse prevention plan during therapy, usually towards the end of treatment. The intention was to discuss possible issues of relapse collaboratively with Leo including reviewing the learning points from therapy, acquired skills, and looking at Leo's social and professional support network.

Input from the Renal Dietician was included as part of the treatment plan as Leo expressed that he would benefit from receiving specific dietetic information, namely that the medication he had difficulty in taking (phosphate binders) were closely interlinked with his dietetic needs (phosphate-controlled diet). Haynes, et al., (2008) argued that the involvement of the multidisciplinary team is important when working with people with long-term health conditions.

Ensure monitoring and support for behaviour change plan

The developed behaviour change plan was explored throughout the course of therapy, with the aspects of the plan monitored and collaboratively designed with Leo. The specific practicalities and the implementation of the behavioural experiments were also agreed. Reviews of the behavioural experiment homework were conducted at the start of each session to monitor their outcome, with the intention of assessing Leo's progress and also to highlight any potential difficulties and achievements made. By regularly reviewing the behavioural experiments allowed for appropriate modifications to be made or for a new behavioural experiment to be designed. The behavioural experiments included setting a reminder for picking up his prescription in time from his General Practitioner, trying medication intake with different types of food and drinks, and identifying and confronting feared situations. One way of monitoring any changes in Leo's medication intake behaviour was with the use of a daily diary (Appendix 5), with the intention of highlighting any progress made and/or obstacles faced. Establishing a positive therapeutic relationship was central in supporting Leo towards working on his behaviour change. The therapeutic relationship provided Leo with a non-judgemental, empathic, and encouraging environment that monitored and supported him in his process. Therapy also looked at exploring possible external social and professional support, including identifying and developing relationships with friends and family that would support him in aspects of his behaviour change. Additional professional support was provided by including the Renal Dietician in individual and combined sessions with the Leo's therapist.

Evaluate outcome

Different methods were used to evaluate the outcome of Leo's behaviour change intervention. These included objective and subjective measures. One of objective measures employed in monitoring Leo's progression was through the routinely taken monthly blood samples. This was monitored by the Renal Dietician and by Leo's Nephrologist. Leo and his Renal Dietician kept me informed of any changes in his blood samples as this could be an indication of the effectiveness of the medications taken and help evaluate improvements in his adherence. During therapy Leo expressed that with the support he was receiving, and the changes he had been making, he felt less anxious about receiving his blood test results as a frequent trend of improvement was appearing.

One of the subjective measures used involved Leo answering the following question on a 10-point Likert scale: "*How likely do you currently feel about taking your medication as prescribed?*". The Likert scale was rated from one to ten, with one representing *'not likely'* and ten representing *'very likely'*. The question was asked at the beginning of therapy to gain a baseline measurement and at the end of treatment to evaluate potential change. Leo recorded his baseline measure as two, whereby his after-therapy measure had increased to an eight (Appendix 6). When asked what could have made the eight a ten, Leo explained that even though he had developed helpful skills and techniques he still felt a bit apprehensive about their durability when feeling physically too unwell. However, he expressed feeling optimistic that in time he would become more confident in the changes he had achieved. Leo also expressed hope that the learned skills could be transferable in supporting him in taking other medication he may have difficulties with in the future.

Leo expressed understanding why he had not been put onto the transplant list. At the beginning of therapy he said that he did not feel confident in his ability in taking the necessary medication as required by transplant patients. However, by the end of therapy Leo reported that he believed he had made significant progress with his adherence and felt ready to be put onto the transplant list. He also shared that his family noticed an increased sense of responsibility and ownership in how he approached his medication intake. Leo described feeling more self-confident and having an increased hopefulness for his future, which included him considering returning to university.

Reflecting on Leo's engagement during therapy, Leo had frequently not attended appointments during the early part of therapy. When asked, he stated that he either forgot about appointments or had been feeling physically too unwell to attend. As therapy, and our therapeutic relationship progressed, Leo's attendance improved. He seemed to engage more in sessions and more willing to experiment with different methods to improve his adherence. He also began to cancel his appointment rather than not showing when feeling physically too unwell to attend.

Negotiate completion, follow-up or referral as appropriate

I saw Leo over an 18-month period for counselling and behaviour change sessions. Throughout the course of therapy Leo's progress and difficulties with regards to his adherence were regularly reviewed and discussed. Towards the end of therapy Leo and I negotiated the completion of our work together and agreed an end date. The final few sessions focused on reviewing his progress, exploring relapse prevention techniques and providing information about re-accessing the service. It was agreed that a follow-up appointment would not be arranged but that Leo would self-refer back into the service if he felt it necessary in the future. Leo was offered a closing letter summarising our work together and the progress he made during therapy. He expressed being interested in receiving the letter with the opportunity to discuss its content during our last session. During the discussion of the letter, Leo stated that reading the letter reminded him of the difficulties that initially brought him to therapy and helped him to recognise the significance of the changes he had made. He also mentioned that due to the changes made, and discussions with his Nephrologist, it was agreed for him to be sent to the Renal Transplant Assessment Team. Leo agreed for the closing letter to be copied to his referrer (his Nephrologist).

Personal overall reflection

Leo was seen in the early stages of my posting within the renal department. My previous role as a Stop Smoking Advisor for the NHS enabled me to develop and apply the necessary skills and experience (e.g. Motivational Interviewing techniques and counselling skills) in working with patients on a one-to-one basis in addressing behaviour changes. Even though I was initially anxious in working with Leo, given my limited experience working with renal patients at that time, I was looking forward in transferring my existing skills and gaining new experiences in working with this client group.

For me, the work with Leo was a great learning experience. It demonstrated that each individual has their own pace of doing things and that they will make a change once they feel ready to do so. In addition, the importance of a good therapeutic relationship was highlighted during my work with Leo. Developing the therapeutic relationship seemed to help ease Leo’s initial anxieties and fears of being judged and/or criticised. Working in a collaborative and non-judgemental manner worked well for Leo. During our sixth session a significant turning point was reached when Leo voluntarily disclosed his fistula, which he previously said he felt highly self-conscious about and that he was fearful that others might be disgusted by it.

Despite the positive changes in Leo’s presentation during the course of our work together, on reflection I believe that the interventions applied could have been further developed by broadening the theoretical models used. One such model is the Necessity-Concern Framework (NCF) (Horne, Chapman, Parham, Freemantle, Forbes & Cooper, 2013). The NCF presents a model that is categorised into two groups: (i) a patient’s personal belief of the necessity of their treatment and (ii) the patient’s perception or concern for that treatment’s possible adverse effect on them. In Leo’s case, he reported having a clear understanding that any nonadherence to his prescribed medication would jeopardise his chances of being placed on the kidney transplant list and have an adverse effect on his physical well-being. In spite of Leo recognising the necessity of his treatment he expressed having a number of concerns that impeded his adherence, such as being perceived differently from others if his treatment was noticed (e.g. the likelihood of vomiting after taking his medication) and people will feel disgust if his fistula is visible, which would result in him being stigmatised.

The work with Leo followed a CBT approach and although it did not explicitly use the NCF, the cognitions that were identified and challenged during our work together would fit within the NCF. That said, it is possible that by using the NCF along with a modified version of the Belief about Medicines Questionnaire devised by Horne, Weinman and Hankins (1999) early in our work together that Leo’s perception of his treatments could have been identified sooner, which may in turn have helped to bring about a positive change at an earlier stage of his therapy.

Furthermore, it could have been helpful to present Leo with a graphical record of his medication intake during the course of his therapy. At the last session, whilst discussing the closing letter, he expressed how surprised he was about the extent of his overall change and on reflection the graph might have supported him in recognising the changes earlier. One tool that was very successful was the regular use of a daily diary, which gave an essential insight into Leo’s adherence behaviours throughout the period that we worked together. This enabled a regular discussion which seemed to help increase Leo’s awareness of his own adherence behaviour.

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Appendices

Page

Appendix 1: Information gained during the initial assessment with Leo.

Physical Health/Illnesses

- Diagnosed with Kidney Failure in 2007 and started haemodialysis shortly after.
- High blood pressure.

Reason of referral

- Request for support to address medication intake and increase confidence in taking medication.
- Non-adherence to medication impacts negatively on possibility of being on the kidney transplant list.

Family and friends

- Described family as “large” and “close”.
- Reported living with his father, spending majority of time with extended family.
- Mother and siblings live overseas.
- Described friendships as good, but only disclosed illness to one of his friends.

Hobbies

- Enjoys playing musical instruments.
- Likes spending time with his friends and family.
- Used to enjoy playing football until becoming unwell.

Employment/education

- Used to go to university but stopped due to illness.
- Currently unemployed due to effects of illness.

Risk factors

- No suicidal, self-injurious, or other risk factors reported, except for difficulties with adherence to medication.
- Protective factors noted as friends, family and religious faith.

Future sessions

- Collaboratively agreed to be seen as an outpatient on a non-dialysis day at the Renal Psychology and Counselling Service.
- Appointments to be scheduled bi-weekly for one-hour sessions.
- Preferred to be seen in the afternoon.

- Total number of sessions were not set in accordance with the service guidelines, yet it was agreed with Leo that therapy would be reviewed regularly to assess progress and his needs.

Appendix 2: Leo's case formulation

Early Experience

- Grew up in a "close family"
- Aunt died from End Stage Renal Disease (ESRD) when he was young

Core beliefs and Dysfunctional Assumptions

- "With ESRD death is expected"
- "I'm a failure for being unwell"
- "If I was brave I would be able to take my medication"
- "If people know I'm unwell that they will treat me differently"
- "If people see my fistula then they will find it disgusting"

Critical Incidents

- Diagnosed with ESRD when 22 years of age
- Mum seemed to react with disgust when initially shown fistula
- Becoming nauseous when taking medication
- Left University when diagnosed as felt physically too unwell.

Negative Automatic thoughts

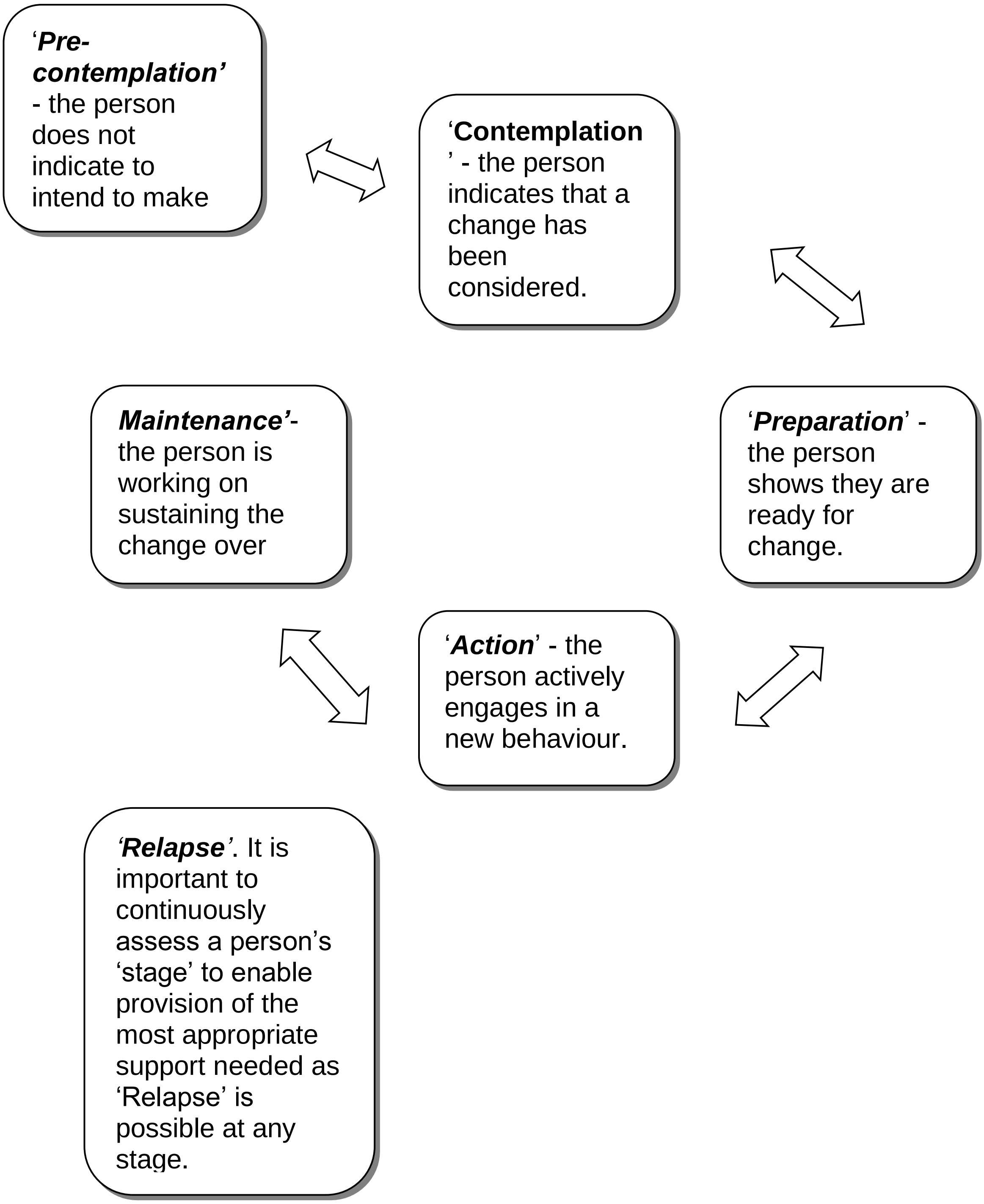
- "I will no longer fit in if people know I'm unwell"
- "People will know I'm unwell if I vomit"

Symptoms

Behavioural	Emotional	Physical
• Avoiding taking medication when away from home • Avoiding social events • Only wearing long sleeves shirts to hide the fistula • Using excuses to hide ESRD symptoms	• Anxiety • Fear • Shame • Embarrassment	• Feelings of nausea and occasional vomiting • Feeling physically tired or unsettled

Appendix 3: Brief explanation of Prochaska and DiClemente’s (1982) Stages of Change Model

Using Prochaska and DiClemente’s (1982) Stages of Change Model, Leo appeared to be at the *‘Preparation’* stage as he was motivated to make changes. This model displays five different stages:



‘***Pre-contemplation’*** - the person does not indicate to intend to make

‘**Contemplation**’ - the person indicates that a change has been considered.

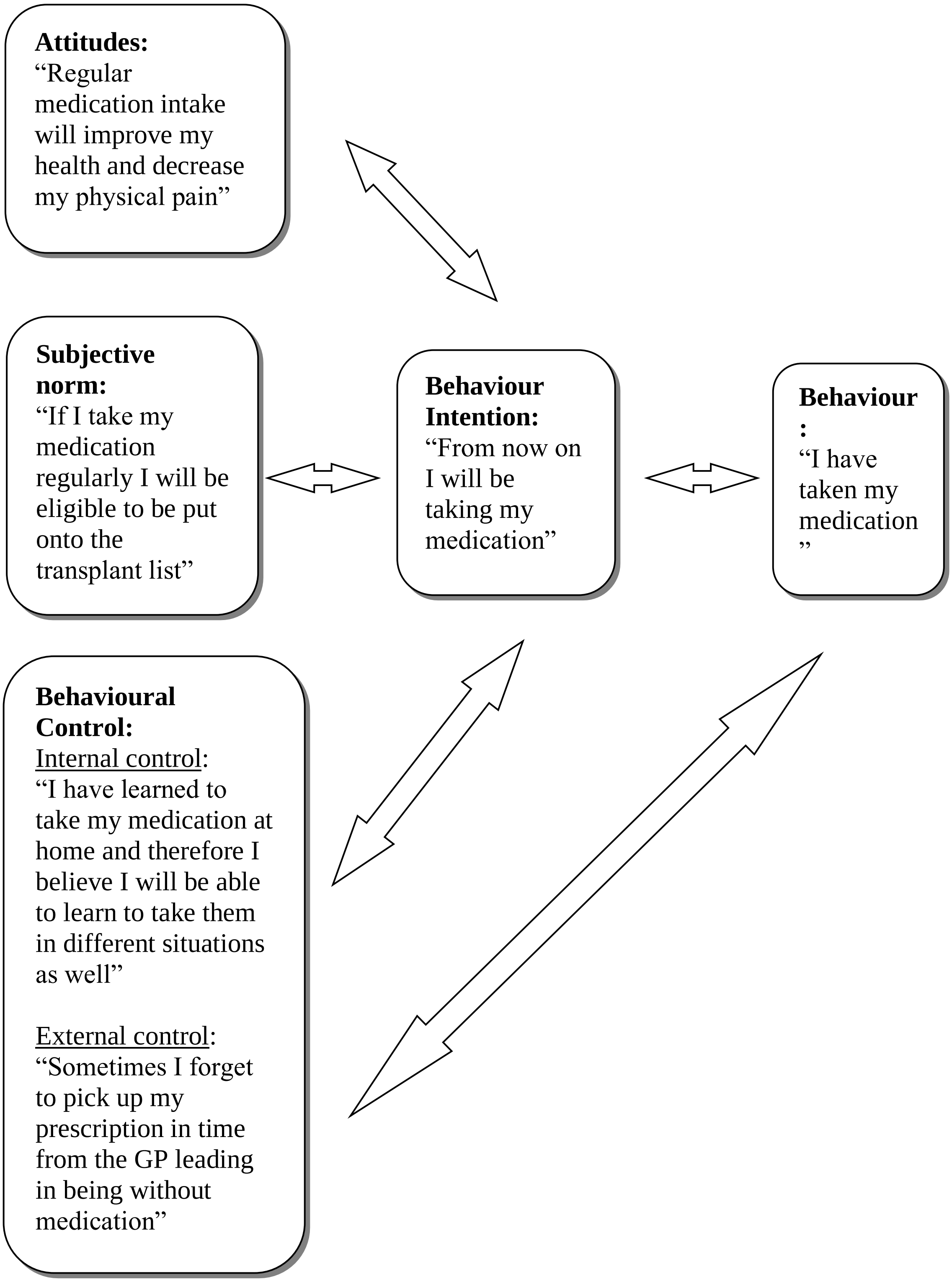
‘***Preparation***’ - the person shows they are ready for change.

‘***Action***’ - the person actively engages in a new behaviour.

Maintenance’- the person is working on sustaining the change over

*‘**Relapse**’*. It is important to continuously assess a person’s ‘stage’ to enable provision of the most appropriate support needed as ‘Relapse’ is possible at any stage.

Appendix 4: Leo’s intention to change his medication intake behaviour. Theory of Planned Behaviour Model (Ajzen & Madden’s, 1986)



Attitudes:
“Regular medication intake will improve my health and decrease my physical pain”

Subjective norm:
“If I take my medication regularly I will be eligible to be put onto the transplant list”

Behaviour Intention:
“From now on I will be taking my medication”

Behaviour:
“I have taken my medication”

Behavioural Control:
Internal control:
“I have learned to take my medication at home and therefore I believe I will be able to learn to take them in different situations as well”

External control:
“Sometimes I forget to pick up my prescription in time from the GP leading in being without medication”

Appendix 5: Recording calendar of medication intake - example taken over a three-week period

The daily diary of medication intake consisted of a table subdivided into seven columns, one for each day of the week. Each day was subdivided into three sections representing the three different times Leo was scheduled to take his medication. Below is an example over a three-week period:

Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
√	-(V)	- (HD)	√	√	√	-(V)
- (HD)	-(V)	-(O)	√	- (Out)	- (Out)	√
-(O)	-(V)	√	√	- (HD)	- (Out)	√
Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
√	- (Out)	- (HD)	√	√	√	√
- (HD)	- (Out)	√	√	√	√	√
-(O)	- (Out)	√	√	- (HD)	√	√
Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
√	√	- (HD)	√	√	√	√
- (HD)	√	√	√	√	√	√
-(O)	√	√	√	- (HD)	√	√

Key:

Symbols	**Explanation of symbol**
√	Medication taken
‘(-V)	Medication taken but vomited out
(-HD)	Medication not taken as on HD
(-Out)	Medication not taken as not at home
(-O)	Medication not taken due to other reasons e.g. run out of medication

Appendix 6: Pre and post therapy questionnaire

Leo was asked the following question at the start and at the end of therapy ‘How likely do you currently feel about taking your medication as prescribed?’. His responses are displayed below:

- **Leo’s response given at the beginning of therapy**

How likely do you currently feel about taking your medication as prescribed?

1	[✓ 2]	3	4	5	6	7	8	9	10

⇧ Not likely

⇧ Very likely

- **Leo’s response given at the end of therapy**

How likely do you currently feel about taking your medication as prescribed?

1	2	3	4	5	6	7	[✓ 8]	9	10

⇧ Not likely

⇧ Very likely

Area of competency:

Teaching and Training

D4. Teaching and Training Competency

Case Study One: Lecture on Health Promotion in Renal Care Delivery to MSc Health Psychology Students

Description of work:	Delivering a three-hour lecture on ‘*Health Promotion in Renal Care’*
Setting:	City, University of London
Client/ Target Group:	27 MSc Health Psychology students

Context

A three-hour lecture on *‘Health Promotion in Renal Care’* was designed and delivered to 27 MSc Health Psychology students at City University London as part of their Health Promotion module. I was approached by the module lead to deliver a lecture on health promotion due to my experience in working with people that have end stage renal disease (ESRD).

Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices

The World Health Organisation (2016) defines health promotion as *“the process of enabling people to increase control over, and to improve, their health”*. Beattie (2002) presents a structural analysis, which generates four strategies for health promotion. The four strategies are subdivided into *‘individual’* and *‘collective’* interventions. The two strategies based on an individual basis are: (a) *‘health persuasion’*, which highlights the practitioner’s role in offering advice and information in order to encourage individuals in adopting a healthier lifestyle; and (b) *‘personal counselling’*, which involves practitioners providing counselling and education to empower individuals to develop skills and gain confidence in taking more agency over their health. The remaining two strategies are encapsulated in the collective approach, these are: (c) *‘legislative action’* sets out the practitioner’s role in making healthier options for the population available through policy work and lobbying; and (d) *‘community development’* involves practitioners enabling groups and communities through community development projects and action work to identify how social factors may impact on their lives.

As Beattie (2002) details there are different approaches in promoting health, both on a more individual and a collective basis. In my role as a Senior Assistant Psychologist at a hospital based Renal Department my duties involve working on an individual basis with patients, supporting them with their management and adjustment of living with ESRD. Part of this work consists of providing short and long-term personal counselling to patients to explore their physical and mental health needs. This often includes a collaborative investigation of the patient's adherence to medication and to their overall recommended treatment regime. For example, this can be achieved by patients keeping an adherence diary and also providing psychoeducation on relevant health issues, if appropriate.

Due to my experience in the health field and working with people with ESRD, I was approached by the MSc Health Promotion Module Lead to deliver a lecture to MSc students on *'Health Promotion in Renal Care'.* Upon agreement, discussions were held with the Module Lead to ascertain the students' training needs, existing knowledge, and to explore how the relevant module objectives could be met by the lecture. Receiving the module outline (Appendix 1) from the Module Lead, and in conjunction with the held discussions, I was able to recognise the main learning outcomes for the students. These included, (i) gaining a better understanding of health promotion theories; (ii) increase knowledge of the complexities of living with a chronic health condition; and (iii) to explore ways of incorporating theory into practice by planning, designing, and evaluating a health promotion intervention.

Having a clear understanding of the main learning outcomes for the students helped in the planning of the structure and content of the lecture and in putting a lecture outline together (Appendix 2). The lecture was designed to be presented over a three-hour period, with a 15-minute break midway through, with the content covering:

- the role of health psychology in renal care
- the physical and psychological aspects of living with ESRD
- theories on behaviour change, health promotion and interventions

The lecture consisted of a didactic and an experiential method of teaching to enhance students learning. Kolb (1984) stated that learning is *"the process whereby knowledge is created through the transformation of experience"* (Kolb, 1984, p.38). Furthermore, Kolb's (1984) *experiential learning cycle model* proposes that learning is a recursive process that consists of four parts, (i) Concrete Experience: experiencing by putting learning into practice, (ii) Reflective Observation: reflecting by objectively analysing the learning, (iii) Abstract Conceptualisation: thinking by reviewing conceptual understanding of learning, and (iv) Active Experimentation: acting by experimenting to find solutions. The lecture was designed to present theory and to include reflective discussions and group exercises. The exercises were intended to encourage students to experience, reflect, think, and act on their learning.

The training material developed for the lecture composed of a PowerPoint presentation (Please see Evidence Folder, Section 11, p.2) and a vignette (Appendix 3) of a scenario where the students would be asked to design and develop an intervention. These were discussed with the Module Lead to confirm that the proposed training content and material met with the learning objectives and would be appropriate for the students' level of understanding. Having received confirmation from the Module Lead about the appropriateness of the material, I arranged with the Course Administrator for the PowerPoint lecture slides (Please see Evidence Folder, Section 11, p.3) and three relevant articles (Appendix 4) to be distributed to the students ahead of the lecture. It was confirmed with the Module Lead that a computer and projector would be available for the delivery of the lecture, as well as a flipchart where different comments and contributions from the students could be captured where appropriate. The case vignette was designed to be given to the students before the small group exercise.

Delivering the training programme

I had arranged with the Education Support Team to meet with a technician prior to the lecture to assist in setting up the Lecture Capture System and the other appropriate electronic media. The Lecture Capture System was used to record the presentation for evaluation purposes. The lecture was able to start close to the scheduled time and was delivered to 27 MSc Health Psychology students in one of City, University of London's lecture rooms. The lecture was designed to encourage interaction and student participation throughout. Students were encouraged to apply the presented and discussed material to different scenarios and to a case study vignette. Students were also given opportunities to reflect on their personal experiences and to consider the possible impact of living with a chronic illness could have on an individual and their family.

With the lecture designed to allow for student participation, students were encouraged to raise questions and were given the opportunity of working in small groups. During the small group exercises students were encouraged to collaboratively work together and exchange ideas. It also provided me with the opportunity to move between the individual groups to offer relevant support and address any queries the groups may have had. Working with the smaller groups allowed me to observe that some students seemed more willing to feedback their ideas and ask questions compared with when working as a group as a whole. Some of the ideas and questions raised from the small group exercises were later shared to the whole group, which seemed useful in enhancing the group's learning.

Plan and implement assessment procedures for the training programme

In line with the initial discussions with the Module Lead regarding the overall module objectives the material covered by the lecture was designed to be a precursor to one of the module assessments, which required the students to design and present a health promotion intervention focused on a specific health issue or illness. This formed a way of assessing the students' learning of the material covered by the lecture. Within the lecture the students' knowledge and understanding of the material covered was explored and put into practice by the case study vignette towards the end of the lecture. This small group exercise required the students to design, plan and evaluate a health promotion intervention for a young renal patient who was not adhering to the prescribed medication.

The teaching style adopted encouraged students to ask questions, reflect on their understanding, and to engage with the lecture material. With the process of the lecture moving between whole group and small group exercises allowed more individuals to express their ideas, which in turn helped to develop thoughtful discussions and enhance peer learning. Dividing the students into small groups allowed me to move around the individual groups and provide additional support where required. It also helped me to gauge and assess the students' understanding of the task and material covered. The assessment methods and overall teaching style used in the lecture fitted with Kolb's (1984) experiential learning model. Through the whole and small group discussions and exercises students were prompted to reflect and put their learning into practice and to review their conceptual understanding of the material covered. They were also encouraged to experiment with possible solutions, particularly when asked to develop a health promotion intervention. I developed an evaluation questionnaire (Appendix 5) that was based on the lecture evaluation questionnaires used at City, University of London.

The questionnaire used a 5-point Likert scale that varied from *'strongly agree'* to *'strongly disagree'*. Students were presented with the questionnaire at the end of the lecture and were asked for their feedback on the lecture's content, their gained understanding, and about the lecture's delivery.

Evaluate the training programme

The feedback received from the students on the evaluation questionnaire was generally very positive (Appendix 5). The questionnaire asked the students to rate their learning outcome, the content, and the delivery of the lecture. Two-thirds of students *'strongly agreed'* that they had gained a better understanding of health promotion in patients with chronic health conditions and its complexity. Almost all students either *'strongly agreed'* or *'agreed'* that their understanding of planning and evaluating a behaviour change intervention had improved following the lecture. When asked to evaluate my performance as a speaker, the vast majority of students either 'strongly agreed' or 'agreed' that I was able to demonstrate my knowledge about the topic and also presented the lecture in a clear and interactive manner. All students rated my teaching style as approachable and also noted that the presentation was well paced with sufficient opportunities given for questions.

The evaluation questionnaire also included open-ended questions to give the students an opportunity to express what they had found most and least helpful from the lecture. Many of the students that commented stated that the presentation of theory and its application had been particularly helpful, especially when working in small groups such as the case vignette exercise. However, the feedback from one of the students noted that it could have been more helpful if some of the models were presented by drawing on real life examples. Taking the student's feedback into consideration I would endeavour to include more real-life examples in future presentations as my own clinical experience progresses.

In summary, I feel that the presentation was delivered as intended and that the learning objectives identified with the Module Lead were appropriately addressed. This was evidenced by the feedback received by the students that they had gained a better understanding of health promotion theories, improved knowledge of the complexities of chronic illness, and the incorporation of theory into practice. Following the lecture, I was invited to deliver an adaptation of this health promotion lecture to another cohort of 14 MSc Health Psychology students, as part of their Behavioural Medicine module on

'Living with end-stage renal disease' (Appendix 6). The experience and feedback received from designing and delivering the lecture on '*Health Promotion in Renal Care'* helped greatly to inform my preparation and presentation of the lecture for the Behavioural Medicine module.

Overall reflection

Even though I had some previous experience of giving presentations to students at a secondary school and university level, this was the first time I had sole responsibility for designing and delivering a three-hour lecture. Initially I felt anxious, yet excited to have the opportunity of delivering a lecture on health psychology theory that also included my clinical experience I had gained from working in renal care.

It was very helpful to have had the opportunity to discuss the overall module objectives and the students' current level of understanding with the Health Promotion Module Lead. These discussions were informative and provided me with a good basis to develop a suitable lecture that I was confident would meet the students' needs. When designing the lecture structure and content I not only drew on my personal experiences of presenting but also my experiences of being a recipient of university-based lectures. Reflecting on these experiences encouraged me to develop a lecture that facilitated a didactic and a more experiential teaching style. It was pleasing to receive feedback from a number of the students that highlighted how useful they found the interactive aspects of the lecture and how it helped to consolidate their learning.

The evaluation feedback from the students stated that they felt comfortable in being able to ask questions and contribute to the lecture, which was observable particular when I moved between the small groups during the vignette exercise. I noted that moving between groups allowed me to engage with more students, especially with the students that seemed more reluctant to share their ideas to the whole group. Having had the opportunity to hear their ideas I was able to gently encourage them to relay their valuable contribution to the whole group to aid peer learning, if they felt comfortable in doing so. Creating the opportunity to divide the whole group into smaller groups for certain exercises seemed to be quite a freeing experience for some students. Going forward I intend to consider designing lectures that include different learning platforms and to draw on my own clinical experience where appropriate with the intention to enhance students learning.

References

Beattie, A. (2002). Chapter 7. Knowledge and control in health promotion: a test case for social policy and social theory. In Gabe, J., Calnan, M., and Bury, M. (Eds.). *The Sociology of the Health Service,* pp.162-202. London: Routledge.

Kolb, D.A. (1984). *Experiential Learning: Experience as the Source of Learning and Development*. Englewood Cliffs: Prentice-Hall, Inc.

World Health Organisation. (2016). *Health topics: Health promotion. World Health Organisation* website http://www.who.int/topics/health_promotion/en/ - found online on 07/05/1016.

Appendices

Appendix 1: Health Promotion module outline, as received from the Module Lead

PSM404 HEALTH PROMOTION

Health promotion's goal is to enhance health and prevent disease. Its main focus has been on the prevention of physical disorders such as coronary heart disease, cancer and sexually transmitted diseases. An aim associated with health promotion has been to change individual behaviour, attitudes and beliefs in order to promote better health and enhance population health.

- Introduction to health promotion
- Models in health promotion (Beatties, Bartholomew Intervention Mapping Approach, Social cognitive models, social marketing) i.e. The Beattie Model allows us to map and evaluate different approaches to health promotion. It is divided into two dimensions (top and bottom) with two boxes (paradigms) in each dimension. Each paradigm contains a description of different approaches that are delivered in an authoritarian ‘top down’ fashion: health persuasion and legislative action. The two paradigms in the bottom dimension describe ‘bottom up’ approaches: personal counselling and community development. The ‘top down’ approaches aim to inform about unhealthy behaviours and risk, or to impose change at national level. The aim of the ‘bottom up’ approaches is to empower individuals and / or communities to make healthier choices. Beattie’s model fits well with the current political climate; increasingly active communities bring about sustainable changes to reduce health inequalities.
- Health Inequalities – a critical psychology discussion of the benefits and disadvantages of targeting specific groups (i.e. HIV/AIDS – targeting homosexual groups increasing stigma and giving a sense of insusceptibility to other groups – historical review). Lottery post codes, community impact initiatives amongst Afro Americans in the US, Whitehall studies are presented and discussed.
- Applied health promotion – discussion of different projects and initiatives including community initiatives, one-to-one support, legislation in context of different chronic illnesses – i.e. efficacy of a project targeted at the South Asian community to promote healthy eating amongst adults with type 2 diabetes. A discussion of the previous approaches, implementation of the project and results from the pilot study and

outcomes and evaluation/recommendations. Harm reduction perspective in drugs and alcohol services/smoking cessation campaigns are also discussed.

- Evaluating Health Promotion

Students' assignment is twofold – They need to design a group campaign addressing a specific health style issue or illness. They need to justify the materials vis-à-vis the audience, the theoretical basis underpinning the campaign (health promotion models), design materials and present to the class.

They also need to write a 2000 words essay. The essay topics require students to engage in critical thinking – i.e. consider the relevance and the extent of the applicability of social cognitive models in the context of a specific intervention – for instance reducing harm amongst intravenous drug users. Students are expected to demonstrate a good understanding of the issues and challenges in applied health promotion and sound and critical understanding of the applicable theories - good/current and relevant literature review, reflectivity, critical thinking and ethical approach to service users.

Appendix 2: Health Promotion Lecture Outline

Introduction and Objectives **Approx: 15 minutes**

- Brief introduction of self
- Outline briefly the aims and objectives of today's lecture
- Describe in a bit more detail my career so far and the Renal Service where I currently work

Information about Kidney Disease and Treatment **Approx: 20 minutes**

- What do healthy kidneys do?
- The Five Stages of kidney disease
- The different treatment modalities for End Stage Kidney Disease (ESKD)
- The prevalence rates of chronic kidney disease across populations

The Impact of Kidney Failure on People's Lives **Approx: 25 minutes**

- Classroom exercise: work in pairs (10 minutes)
- The psychological impact of kidney disease (group discussion and taught element)

Health Promotion in Kidney Care **Approx: 25 minutes excl. break**

- Why is health promotion an important aspect in kidney care?
- Defining compliance and adherence in medicine taking
- NICE guidelines on medication adherence

<15 minute Break>

- Supporting adherence (NICE guidelines) and interventions for enhancing medication adherence (Cochrane review)

Behaviour Change Models, Theories and Approaches **Approx: 25 minutes**

- Theory of Planned Behaviour (Ajzen, 1991)
- Transtheoretical Model (Prochaska and DiClemente, 1982)
- Behaviour Gap (Gollwitzer, 1993)

- Motivational Interviewing techniques
- Engaging patients to self-manage their care

<u>Planning and Intervention</u> **Approx: 15 minutes**

- Intervention mapping
- Precede/Proceed model

<u>Health Promotion in Kidney Care</u> **Approx: 30 minutes**

- Putting it into practice – developing an intervention (small group exercise – approximately five students per group)
- Evaluating an intervention

<u>Ending</u> **Approx: 10 minutes**

- Summary of the main aspects discussed throughout the day and answering any outstanding questions
- Post-lecture evaluation questionnaire (to be completed by each student)

Appendix 3: Case study vignette used during the lecture as group exercise

Health Promotion in Renal Care

Case study:

Tina is a 27 year old young woman who has been on haemodialysis for the past two years. The doctor talked to her about her non-adherence to the prescribed medication and discussed with her whether she would like to be referred to the Renal Psychology Service. Tina agreed to the referral as she herself would like to be able to take the prescribed medication without difficulties. In addition, she knows that she will not be able to get onto the transplant list as long as she does not take her medication regularly.

Some additional information:

Physical = most of the time Tina feels nausea after taking her medication

Psychological = Tina feels anxious before taking her medication as she worries about being sick

Social = Tina has a good social support network, however, not many people know about her kidney condition

Appendix 4: Pre-lecture reading sources for students

Three articles relevant to the Health Promotion lecture sent to the module lead and the course administrator prior to the lecture as pre-reading material for the students

Haynes, R.B., Ackloo, E., Sahota, N., McDonald, H.P. Yao, X. (2008). Interventions for enhancing medication adherence (Review). *The Cochrane Library, issue 4. The Cochrane Collaboration.* John Wiley & Sons, Ltd. Apr 16;(2).

Karamanidou, C., Clathworthy, J., Weinman, J. & Horne, R. (2008). A systematic review of the prevalence and determinants of nonadherence to phosphate binding medication in patients with end-stage renal disease. *BioMed Central Nephrology* 2008, 9:2.

Kok, H., Schaalma, H., Ruiter, R.A.C. & Van Empelen, P. (2004). Intervention Mapping: A Protocol for Applying Health Psychology Theory to Prevention Programmes. *Journal of Health Psychology, 9*, 85-98.

Appendix 5: Evaluation questionnaire of lecture, including students' feedback

Table 1: *Students' quantitative feedback.*

As a result of today's lecture, I feel that…	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
I have a better understanding of health promotion in patients with chronic health conditions in particular patients with end stage renal disease	17 (63%)	9 (33%)	1 (3.7%)	0	0
I have a better understanding of the complexity of chronic health conditions (in particular end stage renal disease) in relation to behaviour change	18 (66.6%)	8 (29.6%)	1 (3.7%)	0	0
I have a better understanding of patients' non-adherence to prescribed medication	17 (63%)	9 (9%)	1 (3.7%)	0	0
I have a better understanding of how to put theory into practise when planning a behaviour change intervention	12 (44.4%)	14 (51.8%)	1 (3.7%)	0	0
I'm more aware of the importance to evaluate behaviour change interventions (one person did not give an answer)	13 (50.1%)	11 (42.6%)	2 (7.70%)	0	0
CONTENT/GROUP TASK(S)	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
The lecture was relevant to my course	21 (77.7%)	5 (18.5%)	0	1 (3.7%)	0
The complexity of the information was appropriate	16 (59.2%)	10 (37%)	1 (3.7%)	0	0
The group tasks were helpful	13 (48.10%)	8 (29.6%)	5 (18.5%)	1 (3.7%)	0
SPEAKER	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
The speaker was knowledgeable about the topic	22 (81.4%)	4 (14.8%)	1 (3.7%)	0	0
The speaker spoke clearly	23 (85.1%)	3 (11.1%)	1 (3.7%)	0	0
The speaker presented the information at the right pace	20 (74%)	7 (25.9%)	0	0	0
The speaker interacted well with the audience	24 (88.8%)	2 (7.4%)	1 (3.7%)	0	0
The speaker was approachable	24 (88.8%)	3 (11.10%)	0	0	0
The speaker gave opportunities for questions	25 (92.5%)	2 (7.4%)	0	0	0

STUDENTS' QUALITATIVE FEEDBACK

Q15) What did you find most helpful?

The content of the lecture:

- "Information on complexity of illness didn't know before"
- "It was actually an application of theory to practice"
- "The application of health psychology theories into practical setting"
- "The case study activity encouraged us to apply the concepts in a real setting"
- "Strategic case planning"
- "Intervention mapping and case study"
- "Group work and the case study"
- "Group work"
- "The group tasks"
- "The group work was great"
- "A lot of time for group tasks throughout the lecture"

The lecturer:

- "Very approachable speaker, took a lot of time to make sure we were all taking info in and engaged"
- "The speaker's knowledge and experience in the field itself"
- "Very interesting, friendly, open manner"

Other:

- "Being able to ask questions, group activities"
- "Overall very helpful"
- "Exploration of job role, exploration of kidney disease, thought providing"
- "The lecturer's own story of how she got her job and what she actually does in her job"

Q16) What did you find least helpful?

The content of the lecture:

- “Perhaps would have liked even more detail about the technicalities of the disease and treatment process (although I did arrive late, so maybe I missed this!)”
- “The models were a little dry could apply them more to real life”
- “I find the group work would have been great to do all together as one group than in groups of 5 in the lecture”
- “Too much reading from slides sometimes”

Other:

- “Everything seemed very important and relevant”

Q18) Any other comments?

The content and lecturing style:

- “Maria is a great lecturer, I really enjoyed her lecture and learnt a lot”
- “I really like the teaching approach of the lecturer”
- “Very good lecturing style :-)”
- “Great presentation skills, clear, concise and very informative”
- “Lovely lecturer. Good clear slides and info”
- “Very interesting and well presented”
- “Very well thought out lecture and very knowledgeable”
- “Great lecture. These lectures are much better than all our lectures last semester put together! Thank you!! :-)”
- “Much better than many presentations including from the professors!
- “Generally enjoyed the lecture”
- “Very interesting. Thank you”
- “Less time on the group thought process - we do a lot of these. Thanks - really good lecture!”

Appendix 6: Lecture outline submitted to the Module Lead and Course Administrator prior to the lecture

Before I delivered the lecture on '*Living with End Stage Renal Disease'* for the Behavioural Medicine module I was asked by the Module Lead and the Course Administrator to provide them with: (i) a summary of the lecture to display what I was planning to deliver, (ii) an essay question which could be used as an option for the students overall module assessment, and (iii) three articles the student could read before the lecture. Prior to this I had received the Behavioural Medicine module outline by the Course Administrator: Please see material displayed below:

BEHAVIOURAL MEDICINE MODULE OUTLINE

This module has been designed to examine clinical application of psychobiological approached in: the evaluation and management of health-related disorders, health risk factor modification, and disease prevention. Students will be introduced to basic principles of cognitive behavioural assessment, case formulation, interventions and outcome evaluation as related to specific case work examples.

Brief summary of the lecture on *Living with End Stage Renal Disease*

The number of people diagnosed with kidney failure has been rising over the last years, especially as hypertension, diabetes, obesity, smoking and socio-economic statuses are dominating risk factors for kidney disease. People diagnosed with chronic kidney disease tend to need to be monitored routinely as kidney function is likely to decline rapidly over time for some people. When the kidney function has reached below 15%, also known as end stage renal disease (ESRD), people have to decide whether to go for dialysis, kidney transplant, or supportive care by taking into consideration their physical, psychological and social aspects of their lives. It is a challenging decision to make as different factors have to be taken into consideration, while still adjusting to the diagnosis of ESRD.

Amongst many other psychological factors, depression and anxiety are most commonly found in this client group. In addition, people with ESRD need to follow a strict treatment regime, including fluid intake allowance and diet, regular medication intake and hospital attendance. Not following those guidelines can impact on the patient's physical well-being. Since people have to change their lifestyles and everyday activities to accommodate the guidelines, patients often find following those treatment regimes quite challenging. Supporting people with ESRD from a psychological perspective on aspects around adjustment to ESRD, adherence to the different treatment regimes and end of life support have been found to be helpful. Usually different psychological approaches are applied and offered by the different psychology and counselling services depending on the patient's needs.

The aim of the lecture 'Living with End Stage Renal Disease' is to get a better understanding of patients who are living with chronic health conditions such as ESRD. To think about the complexity of ESRD in relation to behaviour change and adherence to prescribed medication by taking into account different research studies, NICE guidance, behaviour change models and theories and to start thinking about how this translates into practice.

***Suggested Essay Question**:*

> *'Review and discuss psychological approaches in End Stage Renal Disease.'*

Suggested papers to be read by the students before the lecture:

Cukor, D., Cohen, S.D., Peterson, R.A. & Kimmel, P.L. (2007). Psychosocial Aspects of Chronic Disease: ESRD as a Paradigmatic Illness, *Journal of the American Society of Nephrology*. *18*(12), 3042-3055.

KhaKhalil, A.A., Frazier, S.K., Lennie, T.A. & Sawaya, B.P. (2011). Depressive symptoms and dietary adherence in patients with end-stage renal disease. *Journal of Renal Care*, *37*(1), 30–39.

Levenson, J.M. & Glocheski, S. (1991) Psychological Factors Affecting End-Stage Renal Disease: A Review. *Psychosomatics. The Journal of Consultation and Liaison Psychiatry*, *32*(4), 382–389.

D4. Teaching and Training Competency

Case Study Two: Workshop on Nurse-Patient Communication Delivered to Renal Nursing Staff

Description of work: Delivering a one-day Nurse-Patient Communication workshops, with the aim to enhance patients' experiences by exploring and building on healthcare staff's communication skills.

Setting: NHS Hospital setting.

Target group: Haemodialysis nursing staff, including healthcare assistants (Band 3) up to junior nurses (Band 6).

Context

The Renal Psychology and Counselling Service was approached by the Haemodialysis Matron with the task of enhancing nursing staff's communication skills. Therefore, I delivered a one-day workshop on *'Improving Patients' Experience: Communication & the Patient-Partnership Model'* to a total of 30 Healthcare Assistants/Junior Sisters working in Renal Care offering haemodialysis treatment. The interactive workshop was delivered on five different dates with the intention of enabling a manageable release of different staff members to attend.

Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices

McCabe (2002) found in her study of nurse-patient communications that a positive nurse-patient relationship and high-quality nursing care is more likely to occur when nursing staff adopt a person-centred approach, as opposed to being task-oriented, when caring for patients. She argued that nurses' communication with patients and patients' experiences of care received improves when nurses use a person-centred approach. In a review by Bridges, Flatley and Meyer (2010) they also highlighted the importance of positive nurse-patient relationships to improve patients experience of the care they receive.

Having been approached by the Haemodialysis Matron with the opportunity to develop and deliver a one-day workshop on enhancing nurse-patient communication, discussions took place between myself and the Matron to assess the training needs of the haemodialysis Healthcare Assistants/Junior Sisters. Through the discussions, she provided useful example and incidences of poor nurse-patient communication and in conjunction with my personal experience and knowledge of working in the hospital-based Renal Department, the provisional structure, content and desired learning outcomes were agreed.

To inform appropriate staff of the workshop, I produced and distributed an information poster at the different Haemodialysis Units (Appendix 1). The finalised structure of the workshop was designed to run for six hours (Appendix 2). The content of the workshop covered five main topics:

- What being a ‘nurse’ means
- The impact of Renal Failure on people’s well-being and life
- Communication: how do we communicate and what is considered ‘good communication’
- The ingredients of working in partnership with patients
- Exploring the role of nurse-patient communication with the use of vignettes

The workshop’s main aim was to build on and develop on the attendees existing communication skills, providing a space to reflect on the role of communication in their clinical practice and the care their patients receive. To enhance attendees learning a combination of a more dialectic approach as well as an experiential approach were employed. This followed Kolb’s (1984) argument that learning can be enhanced when information is provided in different ways, with opportunities to consolidate information, for example through discussions, group work and with the use of vignettes.

With the intention of creating an environment that attendees would feel secure and comfortable to share their personal experiences the room was arranged in an informal formation, with chairs placed in a semi-circle facing the projector screen. Some light snacks were also provided. To make the workshop as interactive as possible different media was used to deliver specific aspects of the workshop. A computer and projector were used to present the main body of the taught aspects of the workshop through the use of a PowerPoint presentation. Other media used for the individual and group exercises included a flip-chart, a research article and vignette handouts.

Deliver such training programmes

At each of the five days that the workshop was hosted, four to six different attendees were present (Appendix 3). All attendees received a handout of the PowerPoint presentation (Please see Evidence Folder, Section 11, p.20) and other relevant handouts at the start of the workshop (Appendices 4, 5 & 6). The attendees were encouraged to engage with the material covered by interacting during the workshop, firstly by asking questions and secondly by participating in the different individual, pair and group exercises. The small group of attendees also helped encourage attendee participation and had the intention to further facilitate learning, with the attendees able to share their professional experiences with other attendees and apply their experiences to the taught materials.

Plan and implement assessment procedures for such training programmes

I decided that an appropriate method of assessing the attendees' learning of the workshop material would be through the group discussions of the provided vignettes (Appendix 6). This form of assessment seemed suitably effective considering the small number of attendees in each group. The vignettes were designed following initial discussions with the Haemodialysis Matron and were modelled on fictional and also anonymised real-life examples. Printed copies of the vignettes were disseminated among the attendees and discussed towards the end of the workshop. Attendees were asked to individually present one or two of the vignettes, depending on the group size on the day, and identify and discuss the possible aspects of poor nurse-patient communication and suggested methods of improvements. Enabling each attendee to present the vignettes and the group discussions that followed formed an effective method of assessing the attendees' learning and understanding of the material covered by the workshop. Further to the vignettes, the attendees were each given a pre-workshop questionnaire (Appendix 7) to rate their own communication abilities and also a post-workshop questionnaire (Appendix 8) to assess the attendees learning and their evaluation of the effectiveness of the workshop.

Evaluating such training programmes

The pre/post-workshop questionnaires included sections for the attendees to rate their communication skills prior to the workshop and following the workshop they were asked whether they believed their learning had been enhanced to the extent of informing their care delivery to patients. The post-workshop questionnaire also asked about the structure, content, delivery and method of the overall workshop (Appendix 8).

All attendees who completed the post-workshop evaluation form reported that the workshop met their training needs and had provided useful reflections and insights that they could immediately apply in their clinical work. Attendees expressed that several exercises were particularly constructive, such as exploring nursing care from the patient's perspective, discussions on effective verbal and nonverbal communication and the use of vignettes to stimulate individual learning and group discussions (Appendix 8). The attendees' feedback was also taken into account to help inform slight amendments to the workshop material and slide order between the delivery of the second and third workshop, with the intention of helping the overall flow of my delivery.

A workshop evaluation report (Appendix 9) and the evaluation data (Appendix 7 & 8) were submitted to the Haemodialysis Matron on completion of the five workshop days. The Haemodialysis Matron reported being highly satisfied with the outcome of the workshop and the feedback received by the attendees. She expressed her desire to repeat the workshop to allow more staff the opportunity to attend. Subsequently, an additional five date block of the same workshop were offered (Appendix 10) with an overall total of 60 nurses and Healthcare Assistants attending.

Despite the wholly positive feedback from the attendees, in retrospect I would recommend including a follow-up assessment for attendees to rate their communication skills in the workplace six weeks after the workshop. This would serve to further evaluate the effectiveness of the attendees learning and help inform possible changes to future programmes.

Overall reflection

Developing and delivering this workshop was an exciting opportunity, especially considering that I had very little similar experience of doing so before. For the initial workshop I experienced the addition challenge of trying to manage my own anxiety at the same time as attempting to engage the attendees with the workshop material. I found that after a short period however the informal setting of the room not only worked to provide a comfortable environment for the attendees but also eased my own nervousness and developed a shared enjoyable experience. The success of the first workshop certainly helped increase my confidence in my own presentation skills and also the quality of the workshop material.

Even though the same workshop was delivered on five separate dates each workshop was different in its own right. This was partly due to the depth of expertise the different attendees brought to the workshop, as well as the different dynamics of each group. I tried to use these individual differences to the betterment of the workshop by incorporating the attendees' professional experiences while relating it to the workshop objectives and materials, which worked well.

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Kolb, D.A. (1984). *Experiential Learning: Experience as the Source of Learning and Development.* USA, Englewood Cliffs: Prentice-Hall, Inc.

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Appendices

Page

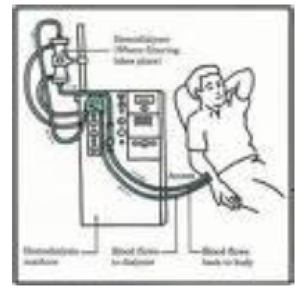
Appendix 1: Workshop poster for the first block of dates (18th May to 27th July 2011)

The Picker Project

An interactive Workshop on Nurse-Patient Communication in Haemodialysis Care & the Patient Partnership Model

The one day workshop is offered on the following Wednesday's

May '11	June '11	July '11
18th (room 2)	8th (room 3)	13th (room 4)
	15th (room 4)	27th (room 5)
	29th (room 2)	



http://health.kosmix.com/topic/Haemodialysis

From 10am – 4.30pm

At TRUSTS NAME – PLACE AND ADDRESS OF WORKSHOP

We look forward to be seeing you there.

The Renal Psychology Team

Appendix 2: Structure of the one-day workshop

>Pre-workshop questionnaire:

- to be completed by each attendee prior to the start of the workshop

>Introductions:

- myself and the workshop outline
- each attendee

>Defining the term ‘Nurse’:

- partly in group discussion and taught elements

>The impact of renal failure on people’s lives:

- partly via individual process, group discussion and taught elements

>Communication - how do we communicate and examples of good communication:

- partly through group work and taught elements

<Break for lunch>

>Nurse-patient communication:

- McCabe, 2004 article: individual process, group discussion and taught elements
- Bridget, et al., (2009). Best practice for older people in acute care setting booklet: taught element

>The patient partnership model:

- Taught element

>Qualities and skills of a nurse:

- Partly through group discussions and taught element

>Putting it into practice with the use of vignettes:

- Partly through individual process and group discussions

>Ending:

- Summary of the main aspects discussed throughout the day and answering any outstanding questions

>Post-workshop evaluation questionnaire:

- to be completed by each attendee at the end of the workshop and submitted

Appendix 3: Table of workshop attendees and attendees' bandings

Table 1: *Workshop attendees and attendees' bandings.*

Workshop Date	**Attendees Banding**	**Total Number Attended**
18th May 2011	Band 3 = 1 attendee Band 4 = 0 attendees Band 5 = 2 attendees Band 6 = 1 attendee Not stated = 1 attendee	5
8th June 2011	Band 3 = 0 attendees Band 4 = 0 attendees Band 5 = 2 attendees Band 6 = 2 attendees Not stated = 1 attendee	5
15th June 2011	Band 3 = 0 attendees Band 4 = 0 attendees Band 5 = 5 attendees Band 6 = 0 attendees Not stated = 1 attendee	6
26th June 2011	Band 3 = 2 attendees Band 4 = 0 attendees Band 5 = 0 attendees Band 6 = 0 attendees Not stated = 2 attendees	4
13th July 2011	Band 3 = 1 attendee Band 4 = 0 attendees Band 5 = 1 attendees Band 6 = 0 attendees Not stated = 3 attendees	5
27th July 2011	Band 3 = 0 attendee Band 4 = 0 attendees Band 5 = 0 attendees Band 6 = 1 attendee Not stated = 4 attendees	5

<u>Appendix 4:</u> Abstract of McCabe's (2004) article

(The full article was disseminated to the workshop attendees)

ISSUES IN CLINICAL NURSING

Nurse–patient communication: an exploration of patients' experiences

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Submitted for publication: 20 November 2002
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McCABE C. (2004) *Journal of Clinical Nursing* **13**, 41–49

Nurse–patient communication: an exploration of patients' experiences

Background. Patient-centred communication is a basic component of nursing and facilitates the development of a positive nurse-patient relationship which, along with other organizational factors, results in the delivery of quality nursing care. Nurses are frequently described in the literature as poor communicators, however, very few studies have examined patients' experiences of how nurses communicate.

Aims and objectives. The aim of the study was to explore and produce statements relating to patients' experiences of how nurses communicate.

Design. A qualitative perspective using an hermeneutic phenomenological approach was considered to be the most appropriate methodology for this study.

Methods. Using purposeful sampling, eight patients in a general teaching hospital in the Republic of Ireland were interviewed. Data were collected using unstructured interviews. Data analysis was a reflective process and the findings were presented through the description and interpretation of themes and sub-themes.

Results. Following data analysis four themes emerged. These were, 'lack of communication', 'attending', empathy' and 'friendly nurses'.

Conclusions. The findings of this study indicate that, in contrast to the literature that suggests that nurses are not good at communicating with patients, nurses can communicate well with patients when they use a patient-centred approach. However, health care organizations do not appear to value or recognize the importance of nurses using a patient-centred approach when communicating with patients to ensure the delivery of quality patient care.

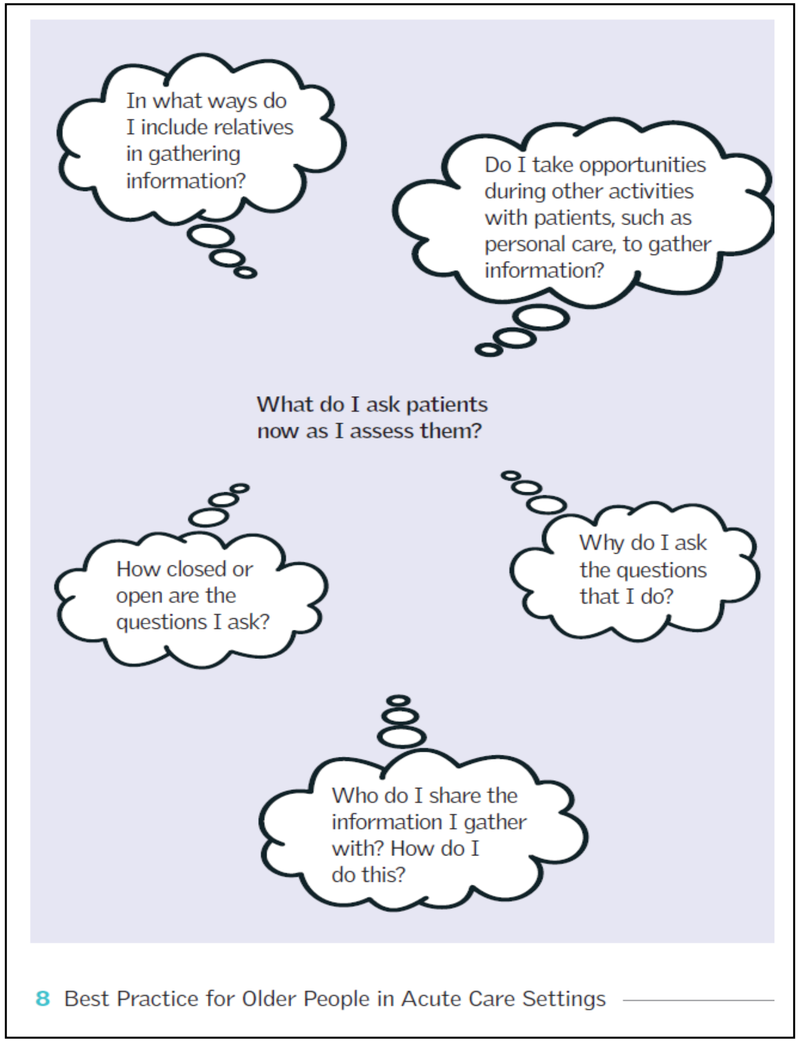
Relevance to clinical practice. The implication of these findings for clinical practice is that the task-centred approach to patient care that is associated with nursing in the past, appears to be alive and well. If health care management want to ensure that patients receive quality nursing care, they will need to consider patient-centred communication to be essential to encourage and support nurses to communicate in this manner.

Key words: communication, empathy, nurse–patient communication, patient satisfaction, phenomenology, socialization

Appendix 5: Extract from the *Best Practice for Older People in Acute Care Setting (BPOP): Guidance for Nurses (2009)*

(the booklet was disseminated to each of the workshop attendees)

[redacted]



In what ways do I include relatives in gathering information?

Do I take opportunities during other activities with patients, such as personal care, to gather information?

What do I ask patients now as I assess them?

How closed or open are the questions I ask?

Why do I ask the questions that I do?

Who do I share the information I gather with? How do I do this?

8 Best Practice for Older People in Acute Care Settings

Appendix 6: Vignettes used during the workshop

QUESTIONS

The following two questions were asked to be answered for each scenario:

1.What would you do?

2.How do you think this would improve the patient's experience?

SCENARIO 1

a) A patient finished with the HD for the day and is waiting to be disconnected. As time passes by she becomes more and more stressed but the staff member who connected her to the HD machine is busy helping somebody else whilst one of the other nurses is talking to a colleague.

b) On one of the HD wards two staff members are making a bed and they are having a conversation in a foreign language whilst patients are dialysing next to them hearing their conversation.

SCENARIO 2

a)A patient is calling "Nurse, nurse, nurse!!!" One of the staff members goes to the patient and says "What do you want?"

b) A staff member is helping one of the patients to connect to the HD machine whilst he is discussing the events of the

SCENARIO 3

a) The doctors are currently doing their ward round. One of the patients is very tearful and she is hiding partly under her blanket.

b)A nurse went to one of the patients and with a raised voice said "Why have you not been taking your medication?"

SCENARIO 4

a) A staff member serves sandwiches to the patients by leaving them on their bedside tables. One of the patients table is at the foot of the bed away from the patient.

b) A staff member is seen walking around aimlessly whilst patients' bedsides are full of dirt and clutter.

SCENARIO 5

a)A patient who is suffering from peritonitis (after being on PD for the past 5 years) had to be moved onto HD and it is his first time at the satellite unit but he does not get orientated to the environment.

b) A patient admitted through LCC is very tearful. Recently she was told that her kidneys were failing and that she had to be put on HD as soon as possible. This is her first time on HD.

Appendix 7: Pre-workshop questionnaire, including attendees' responses

APPENDIX 7 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

Appendix 8: Post-workshop evaluation form, including attendees’ responses

APPENDIX 8 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

Appendix 9: Evaluation report of the workshop, submitted to the Haemodialysis Matron

EVALUATION REPORT: An interactive nurse patient communication workshop for nurses and healthcare assistants working in haemodialysis care

What it is about:

A nurse-patient communication workshop was offered by the Renal Psychology team and carried out by Maria Tziggili (Senior Assistant Psychologist/Health Psychology Trainee) to nurses and healthcare assistants working in haemodialysis care.

AIM: The aim of the workshop was to enhance patients' experiences by exploring and building on healthcare staff's communication skills. This was done by creating a place for discussion, to look at good practice by using peer experiences and reflections from professional experience, in addition to the use of role plays and evidence-based knowledge.

PROCEDURE: The Haemodialysis Matron and the Ward Managers based at the main HOSPITAL NAME and at the satellite units HOSPITAL NAME, HOSPITAL NAME and HOSPITAL NAME agreed to send some of their staff (Band 3s – Band 6s) to the one-day workshop. In total, thirty nurses and healthcare assistants attended the one-day workshop at NAME OF TRAINING PLACE which ran on five different occasions between May 2011 and July 2011.

Before the start of the workshop all 30 attendees were asked some questions in relation to their current communication with patients and after the workshop they were asked to evaluate the workshop they just had attended.

Pre-workshop evaluation data:

Out of the 30 attendees, 28 completed the pre-evaluation questionnaire:

- One of the questions asked before the workshop was 'how people feel they are currently communicating with patients?' On a scale from 1 '*poorly*' to 6 '*very well*'. Out of those who answered the question, all rated their communication above 3, with most people (36%) rating their patient communication with 5 on the 6-point Likert scale.

- When people were asked '*how often they sit with and listen to their patients?'* on a 5-point scale starting from '*never*' (1) to '*all the time'* (5), most people (49%) answered with FREQUENTLY (4 on the scale) followed by some people (8%) with OCCASIONALLY (point 3 on the scale).
- Attendees were also asked '*whether they struggle at times communicating with patients'* when the patient is challenging. Out of the people who responded, 64% answered with a YES and 36% with a NO.
- When asked '*what type of training would be helpful for them in challenging situations?'* Two of the most common answers were around communication skills training and how to deal with challenging/difficult patients. Both of these were attempted to be covered during the workshop by looking at communication skills as well as looking into the challenges patients are facing once diagnosed with kidney failure.

Post workshop evaluation data:

After the workshop all 30 attendees were asked to evaluate the workshop by completing a further anonymous questionnaire from which nearly all attendees did:

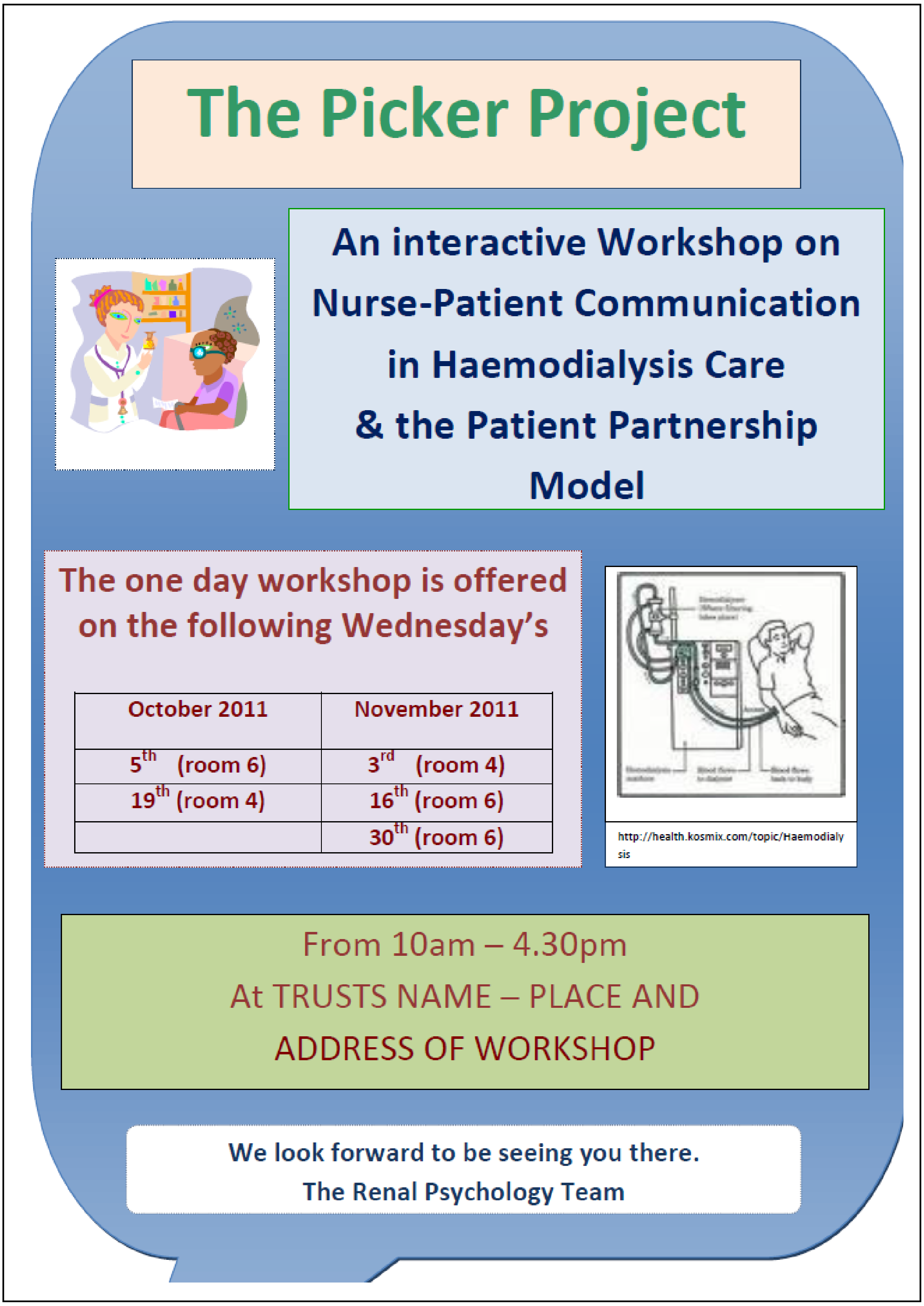
- When asked *'how well the workshop met their needs and expectations?'* On a 6-point scale varying from 1 '*poorly*' to 6 '*very much'*. All attendees who answered gave a rating above 3. Over half (55%) of the attendees gave the highest rating (point 6 = '*very much'*) followed by a 5 on the rating scale (26%) and a 4 (14%).
- The attendees were also asked how they found the *'pace and style used at the workshop'.* Most people (86%) describing the workshop as ENJOYABLE, followed by MOTIVATING (69%) and ENCOURAGING (62%). Some people made some additional comments, such as "*the trainer discussed the topic in a comprehensive way and related scenarios in our day to day work", "it was a very good interactive session",* and *"I think that it is very enjoyable and other nurses/ HCA's will benefit from this*".
- All Attendees who completed the evaluation form also stated that *the 'material and exercises used'* during the workshop were found useful. Some of the additional comments made by the attendees were: "*very appropriate*", "*encouraged to think*", "*learnt through speaking to colleagues – group exercises*", and "*realising the things you do automatically and think about which could help or not help the patients*".

- All people who responded also agreed that the workshop gave them ideas to take back to work ("*it gives us a different perspective on how we do things and can be done better", "eye opener to understand patients feelings*", "*yes it inspired me to change the way I see patients – not only as a patient but as a whole individual" ...),* also that they feel that the workshop will help them to improve patients' experiences *("the workshop will help me to know how to communicate efficiently with my patients and to involve them in their care").*
- Furthermore they also agreed that they feel that the workshop will have a positive effect on how they communicate with patients *("even little time spend listening to the patients is worthwhile – it has a positive affect", "It has shown me other ways of dealing with patients and their needs", "I can use this workshop at my workplace which helps a lot", "as I will always remember their psychological side, though we all do it but this study day helped me to up-date it").*

Future objectives:

The nurses seemed to have enjoyed the workshop and people have been asking for new workshop dates since they would also like to attend. A brief conversation with the Haemodialysis Matron sounded encouraging and some provisional dates will be put forward very soon by the Senior Psychology Assistant (probably for October to November 2011). The aim is for all nurses and healthcare assistants (from Band 3s – Band 6s) who are working in haemodialysis care at the HOSPITAL NAME, at NAME and at the satellite units at HOSPITAL NAME, HOSPITAL NAME and HOSPITAL NAME to attend the interactive nurse-patient communication workshop, if possible.

Appendix 10: Workshop poster for the second block of dates (5th October to 30th November 2011)



The Picker Project

An interactive Workshop on Nurse-Patient Communication in Haemodialysis Care & the Patient Partnership Model

The one day workshop is offered on the following Wednesday's

October 2011	November 2011
5th (room 6)	3rd (room 4)
19th (room 4)	16th (room 6)
	30th (room 6)

http://health.kosmix.com/topic/Haemodialysis

From 10am – 4.30pm
At TRUSTS NAME – PLACE AND ADDRESS OF WORKSHOP

We look forward to be seeing you there.
The Renal Psychology Team

Area of competency:

Optional

Provide expert opinion and advice, including the preparation and presentation of evidence in formal setting (Option F).

D5. Optional Competency

Provide expert opinion and advice, including the preparation and presentation of evidence in formal settings (*Option F*)

Description of work:	Oral presentations of doctorate research findings, through the use of different media, including PowerPoint slides and a conference poster.
Setting:	Various settings, consisting of two continuing professional development (CPD) group sessions and two separate conference settings.
Client/Target Group:	Healthcare professionals working in renal care and healthcare professionals working in health psychology.

Introduction:

This competency was primarily met by presenting my doctorate research, a qualitative study on people's experience of being a parent receiving hospital-based haemodialysis treatment, to healthcare professionals on four occasions (Appendix 1) and by providing expert opinion on the possible implications that the research could have on clinical practice. The competency is separated into four sections: (i) the nature of the information request and decision to disseminate expert opinion; (ii) the provision of an appropriate response to information request; (iii) the production and presentation of psychological material, and (iv) testimony of providing expert advice and opinion. In keeping with the reflective nature of the competency, this report will be presented in the first person, from the perspective of the author.

The nature of the information request and decision to disseminate expert opinion

My expertise in the field of renal care has developed and expanded over the past eight years while working as a Senior Assistant Psychologist in a Renal Department and training to become a Chartered Health Psychologist. During the eight years my duties working in a Renal Department have included: the development and delivery of workshops for different healthcare professionals such as junior doctors and nursing staff and the assessment and provision of one-to-one psychological support sessions to renal patients. Throughout my employment I have worked with patients receiving different renal replacement therapies and at different stages of their treatment, including pre-dialysis, receiving dialysis, and pre and post kidney transplantation. Working in the renal department provided me with the opportunity to not only work closely with patients but also to be a member of the multidisciplinary team and promote the most appropriate holistic care for the patients. Being part of the multidisciplinary team at the renal department, I attended meetings with other healthcare professionals, who offered psychological support to patients across different renal sites and attending renal specific conferences and Continuing Professional Development (CPD) sessions which has further enhanced my understanding and knowledge of the physical and psychological complex issues that renal patients may experience.

My particular area of interest, which is the exploration of people's experiences of being a parent receiving haemodialysis treatment has been further informed by my doctoral research that explored this phenomenon. A total of ten mothers and fathers were interviewed with their interviews being audio recorded, transcribed verbatim and analysed using interpretative phenological analysis (IPA). Gaining a thorough familiarity of the existing literature in the field of renal care and becoming immersed in the rich and detailed accounts of the ten participants greatly further enhanced my knowledge and understanding of renal care.

The experience gained during my time working in renal care, including my doctoral qualitative research study, has provided me with an invaluable insight into the experiences of people living with end stage renal disease (ESRD), particularly those receiving haemodialysis as their renal replacement therapy (RRT). It is hoped that the findings from the qualitative research study will help to inform future practice of health psychologists and other healthcare professionals when working with this particular client group. Exploring opportunities to disseminate my research findings and inform other healthcare professionals and colleagues will be discussed next.

The provision of an appropriate response to information request

I had the opportunity to present my research findings and share my expertise on four separate occasions, across two different settings (conferences and CPD sessions) and to different healthcare professionals. I presented my doctoral research at two separate CPD sessions, firstly to allied healthcare professionals and then on another occasion to senior renal nursing staff. The research was also presented in different formats at two health-related conferences, firstly at a renal specific conference (UK Kidney-Week) and later at the Annual Conference of Health Psychology. The lead up to each presentation will be discussed here:

CPD session delivery – to Allied Healthcare Professionals (One-hour slot):

The research findings were firstly presented at the Renal Psychological Services Group CPD session. The Renal Psychological Services Group, which I am also a member, consists of renal allied healthcare professionals (psychologists, counsellors, psychotherapists and assistant psychologists) that offer psychological support to renal patients, predominately in London and the surrounding areas. The meetings occurred three times a year and usually consisted of a general meeting in the morning and one or two CPD sessions in the afternoon. The aim of the group was to share experiences and expertise from clinical practice among the healthcare professionals and to encourage the enhancement of knowledge when working in different renal care settings. This partly takes place through the dissemination of research, information on service development, service evaluation projects and through the provision of peer support with the intention to further professional development and reflective practice.

The opportunity to present the findings from my doctorate research at the group's CPD session materialised after a discussion between the group's chairperson and myself, followed by a broader conversation with the other group members. After I presented a brief synapsis of my research, the group members agreed that I would present during the next CPD session. I proposed, with the agreement of the group, that the oral presentation would be delivered for the duration of a one-hour CPD session alongside a PowerPoint presentation. Sufficient time would also be reserved for questions and peer-discussion, where the group members would be invited to bring their own experience from clinical practice into the discussion in light of the presented research findings. This was considered particularly valuable as the research explored the phenomenon that had previously received limited empirical attention.

CPD session delivery – Senior Nursing Staff (20-minute slot):

The Renal Psychological Medicine Team, which consists of a psychologist, a psychiatrist and an assistant psychologist, facilitates a 20-minute CPD slot at the renal departments monthly Haemodialysis Senior Nurses meetings. Previous CPD presentations have discussed different psychological issues, such as anxiety and depression. I enquired with the Senior Nurses whether they would be interested to receive a presentation of my research on the experience of parents receiving hospital-based haemodialysis during their next CPD session. They expressed a keen interest in the research presentation, especially considering the direct relevance of the research to the core aspect of their nursing role in working closely with haemodialysis patients.

Oral Abstract Presentation - Annual Health Psychology Conference (20-minute slot):

The British Psychological Society Division of Health Psychology website states that the 2018 conference theme was on *Celebrating Health Psychology*. It invited people from different settings and countries to attend (British Psychological Society, 2018a). I chose to apply to present at the Annual Health Psychology Conference as it would provide an invaluable platform to disseminate my research findings to a variety of professionals working within Health Psychology, including Chartered Health Psychologists, Trainees and Researchers. The process of applying involved submitting an abstract (Appendix 2) of my research to the Division of Health Psychology Scientific Conference Committee. The abstract was written in line with the conference's guidelines (British Psychological Society, 2018b) and I was subsequently accepted for an oral presentation, with confirmation received by email (Appendix 3).

Moderated Poster Presentation - UK kidney-Week 2018 conference (seven-minute slot):

The UK Kidney-Week Conference, which was jointly organised by the Renal Association and the British Renal Society, was a standout opportunity to further disseminate my research to an appropriate audience. The chairs of both organisations described the conference as an opportunity to network with other healthcare professionals and share examples of best practice (O'Donoghue & Tall, 2018). In line with the conference guidelines (Appendix 4) and similar to the procedure of the Annual Health Psychology conference, I submitted an abstract outlining my research study to the UK Kidney-Week's panel to be considered for a moderated poster presentation (Appendix 5), which was subsequently accepted (Appendix 6).

The production and presentation of psychological material

CPD session delivery to Allied Healthcare Professionals

The PowerPoint slides for the presentation at the Renal Psychological Services Group's CPD session were organised into four sections: (i) study background and existing literature; (ii) demographics of participants; (iii) research findings, and (iv) conclusions (Please see Evidence Folder, Section 11, p. 32). The findings of the study were presented by providing attendees with the overall model of the findings in addition to a detailed exploration of each of the two major themes. Each of the major themes was graphical presented with their subordinate themes and supporting extracts from the participants. Additional contextual information was provided verbally to the attendees to enhance their understanding of the researched phenomenon.

The session structure involved presenting the research for the first 45 minutes of the CPD slot, with the remaining 15 minutes open to invite attendees to ask questions and to share their own expertise working with this client group in relation to the presented research. Before the CPD session came to an end all attendees were asked to complete an evaluation form to provide their assessment of the research study and the presentation (Appendix 7). All 13 attendees completed the form and also provided valuable and predominately positive feedback verbally. On the whole, the verbal feedback received reflected the attendees written responses (Appendix 7). In addition to the group's verbal and written feedback, one of the attendees was invited to complete an observer report regarding my performance as a presenter (Appendix 8).

CPD session delivery to Senior Nursing Staff

The PowerPoint slides developed for this CPD session consisted of 17 slides and, as with the previous CPD session, was structured into four parts: (i) existing literature; (ii) methodology and participants demographics; (iii) research findings, and (iv) conclusions (Please see Evidence Folder, Section 11, p. 44). The presentation was designed with due consideration being given to the fact that the presentation would be limited to 15 minutes, with five minutes at the end open for questions and completion of a brief feedback form. As such, the presentation needed to be concise with a brief overview of the findings. The major themes were each presented with six supporting quotes, which were specifically selected to provide the attendees with a broad description of the research findings. In the final section of the presentation, the conclusions, the relevant slides were designed to be specific to the area of renal care and the attendees' professional expertise. In the final few minutes of the session attendees were asked to complete a brief evaluation form that included questions concerning the relevance and value of the research to their daily work, as well as my performance as a presenter. Additional feedback was also received via an observer report which was completed by a Clinical Psychologist (Appendix 9).

Oral Abstract Presentation at the Annual Health Psychology Conference

As per the Annual Health Psychology Conference Guidelines (BPS, 2018a) a PowerPoint presentation was designed taking into consideration the time slot allocated for oral presentations in the programme, 20-minute slots with 15 minutes for the presentation and five minutes for audience questions. The PowerPoint slides presented at the event were similar to the ones delivered at the Senior Nursing Staff CPD session mentioned above. This was in part due to the same period of time made available for the oral presentations at both events. The main adjustment to the slides was to the *conclusion* slides, where the slides presented were amended to reflect the research's relevance to the wider field of Health Psychology (Please see Evidence Folder, Section 11, p. 50). A feedback form, consisting of five questions on the research and my performance as a speaker at the Annual Health Psychology Conference, was developed, distributed and completed by a designated Chartered Health Psychologist that was in attendance (Appendix 10).

Moderated Poster Presentation at the UK Kidney-Week 2018 Conference

Soon after receiving confirmation that the abstract had been accepted by the UK Kidney-Week panel for a moderated poster presentation I set out designing an informative and engaging poster (Appendix 11). The poster was organised into five sections: (i) background literature and research aim; (ii) research design, including participants and analysis method; (iii) findings; (iv) conclusion; and (v) acknowledgements. Due to time and space restraints common to presenting a moderated poster I decided to include the overall model of findings with ten supporting quotes from the participants to best illustrate the research findings. The models of the two individual major themes, which displayed the subordinate themes, were presented to the attendees via a handout (Appendix 12) and were disseminated during the poster presentation.

Even though it is not usual practice, I developed a short feedback form of the poster quality and my poster presentation skills (Appendix 13). Following the presentation, I enquired with the attendees, which included the two poster moderators, whether they would be willing to complete the short feedback form. All of the attendees expressed being happy to complete the evaluation form, with a total of ten responses collected (Appendix 13).

Testimony on the experience of providing expert advice and opinion through presentations of research

Having the opportunity to present my research to different audiences (renal specific vs non-renal specific professionals) and in different settings (CPD vs Conference settings) provided an exciting challenge. Prior to the presentations my experience as a public speaker was limited, especially in academic and professional settings, which added to the challenge. Another challenging factor was the pressure I felt, which was self-manifested, to clearly convey the qualitative research that I had invested an abundance of time, energy and belief into. It also felt very important to deliver presentations that were competent enough to be vessels that enabled the participants' voices to be heard in a way that the research could have positive implications for clinical practice and future research. However, as this research had not previously been presented, it was difficult to know whether audiences would find the researched phenomenon and the findings as enlightening and interesting as I have. The aforementioned factors contributed to a dual sense of apprehension and excitement to share the research with Health Psychologists and healthcare professionals.

In choosing which opportunities to pursue when disseminating my research findings, I considered it important to select occasions where the audiences represented broad yet appropriately relevant attendees such as Health Psychologists and Researches as well as healthcare professionals that work in renal settings. The process of securing the opportunities to present at the conferences and the CPD sessions relied on different attributes and abilities. For example, submitting the two abstracts for the conferences provided the chance to develop on my previous experiences of writing research abstracts for academic papers with the addition of structuring them to specific guidelines for the conferences. For the CPD sessions, it was important to rely on my interpersonal skills in initiating and building new or existing professional relationships. Being accepted for all four presentations reinforced my confidence in the research and the appropriateness of it within the fields of health psychology and renal care.

Having been accepted for the four presentations I set about developing the appropriate PowerPoint slides, handouts, evaluation forms and a conference poster. In developing the PowerPoint slides it was essential to strike the correct balance between providing sufficient information to allow attendees to get a decent flavour of the research, especially the findings, and manage the timings of the different presentation slots by ensuring the presentations were concise and relevant. It was my intention to create slides that were well structured, succinct, and appropriately emotive in order to encourage audience interest and engagement. This was achieved by subdividing the slides to demonstrate relevant existing literature, methodology, findings and conclusions. Appropriate extracts from the participants' accounts were also included that best illustrated the findings, which it was hoped would also serve to be engaging for the audience members.

Similarly, I deemed it important to design a research poster that was suitably appealing and informative. Having no real previous experience of developing research posters, I relied on an extensive review of other poster examples online. This enabled me to develop structure that was an appropriate fit for my research that would provide a visually attractive representation of the study. Settling on a clear and colourful poster design, which embodied the research in question, enhanced my confidence as a presenter and, based on the feedback received, achieved the aim of being both informative and appealing to those in attendance.

The occasion of delivering the first oral presentation to the Allied Health Care Staff at their CPD session was an empowering and encouraging experience. The feedback received was overall positive (Appendix 7), with attendees expressing that they were able to relate to the research with regards to their clinical work. Being a relatively inexperienced public speaker and presenter however, I was perhaps understandably anxious. This consequently led to an increased rate of speech that admittedly I was not fully aware of at the time. The nominated observer at the presentation noted in her evaluation that despite a generally clear and engaging delivery style the presentation could at times be aided further by a slow rate of speech. For the subsequent presentations, being mindful of my rate of speech and taking measures to calm my rate through breathing techniques proved to be highly effective and helpful in developing a more skilled delivery.

The observation report from the Health Psychology conference also provided an invaluable learning opportunity with feedback from the observer in attendance. Due to my anxieties I developed a safety behaviour of having paper notes that I could refer to if needed during the presentation. Although I did not read directly from the notes, it was noted by the observer as the only possible area of improvement that could help to engage the audience further. I took this feedback on board and recognised that as a developing Health Psychologist it was important to develop a different method of managing my anxieties. With this in mind, I invested time in being exposed to practicing without any paper notes in preparation for the remaining presentation to Senior Haemodialysis Nurses, which helped to positively reinforce my belief in the strength of the study and my abilities as a presenter without the reliance on the notes. By the time of the actual presentation I was suitably proficient enough in speaking without notes that the presentation went extremely well, with a seemingly more intuitive and easy flow. This was reflected in the feedback received from the nominated Clinical Psychologist in her written observation report (Appendix 13).

Reflecting on the overall experience of disseminating my research to Health Psychologists and other Healthcare Professionals, there was an incremental improvement of my developing skills as a presenter and my confidence as a public speaker with each passing presentation. Each occasion supplied opportunities to develop and grow in preparation for the next presentation and my transition in becoming a Health Psychologist. The verbal and written feedback from the presentation audiences also provided validation of the confidence that I have had on the impactful possibilities of the research. In addition to the clinical implications and possible areas of future research that were included in the presentation the audience members also suggested their own reflections on the study’s potential. Some of the suggestions mirrored my own proposals for the need to design, implement and evaluate the effectiveness of possible interventions to support parents receiving haemodialysis. The feedback highlighted how essential this study has the potential to be in informing practice and influencing future research and service developments.

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Appendices

Appendix 1: Table of dates and settings of research presentations

Table 1: *Table of dates and settings of research presentations.*

Date	**Duration of presentation**	**Different settings research presented at**
24th January 2018	1 hour	Renal Psychological Services Group meeting
21st June 2018	About 7 to 10 minutes	UK-Kidney Week 2018 Conference
7th September 2018	20 minutes	Annual Health Psychology Conference
20th September 2018	20 minutes	Band 7 Senior Haemodialysis Nurses CPD session

<u>Appendix 2:</u> Abstract submitted to the Annual Health Psychology Conference panel

The experience of being a parent receiving haemodialysis treatment: A qualitative study

Objectives: Research into the impact of treatment of End Stage Renal Disease has increased in recent years in line with escalating prevalence rates of people with the illness. Studies have indicated that haemodialysis treatment has a bearing on people's quality of life. To date, the exploration of parents' experiences receiving haemodialysis treatment has been an area that has received little attention. The research aim is to gain an understanding of the impact of haemodialysis on parenting and to help inform clinical practice in the field of Health Psychology.

Design: A qualitative study employing Interpretative Phenological Analysis (IPA) to explore the lived experiences of parents receiving haemodialysis treatment

Methods: Ten parents who received hospital-based haemodialysis treatment and were known to an NHS Trust participated in audio-recorded semi-structured interviews that were transcribed verbatim. Interviews were then analysed using the method of IPA.

Results: Two superordinate themes developed from the analysis:

Theme 1: The Haemodialysis Experience

Living with the demands, the necessity and the process of receiving haemodialysis treatment

Theme 2: The Lived Experience of Parents with End Stage Renal Disease

The impact the illness and its treatment have on the identity and role of being a parent

Conclusions: This research highlights the challenges experienced by parents receiving haemodialysis treatment. The significance of these findings helps to inform current clinical practice. It contributes to the discipline of Health Psychology by providing an insight of the main difficulties this client group faces and how the complexities of parenthood and chronic illness are managed.

Appendix 3: Acceptance email received from the Annual Health Psychology Conference panel

Sent: Friday, 11 May 2018 14:32:15

Subject: DHP Annual Conference - Submission Decision

This email contains important information about your submission for the Division of Health Psychology Annual Conference in Newcastle Gateshead (05-07 September 2018)

Ref: 774

Thank you for your submission **The experience of being a parent receiving haemodialysis treatment: A qualitative study** as an Empirical Oral Presentation, I am pleased to inform you that your above submission has been accepted as **Empirical Oral Presentation**.

Appendix 4: UK-Kidney Week 2018 abstract submission guidelines

- Work that has been accepted for publication before the abstract deadline date may not be submitted
- All abstracts must be submitted electronically via this site by completing the form below
- Abstracts are invited from all members of the multidisciplinary team
- UKKW will accept case report abstracts for consideration for poster presentation. Case reports that are based on clinic-pathological (kidney biopsy) findings will be eligible for inclusion in the clinic-pathological conference session. Case Reports should show one or more of the following: unexpected or unusual disease presentations; unreported or unusual side effects; patient safety considerations; findings of relevance to pathogenesis; unusual events during treatment or follow-up; presentation and management of very rare diseases. Reports can also comprise: N of 1 trials, meta-analyses of published case reports, retrospective studies that include case-specific information (age, sex and ethnicity).
- Authors are reminded to take particular care to ensure that the submitted case report includes no potential patient identifiers
- The uploaded abstract document should only include the text of the actual abstract do not include authors or hospital names in the document or document name
- Before continuing to the next screen, you should ensure that you have saved your abstract as a Word document with extension .doc or .docx.
- This document must fit on one side of an A4 sheet. Additional sheets will be rejected
- Font should be Times New Roman, size no smaller than 11pt
- Use Margins size of 3cm top, bottom & sides
- If you have used any scientific symbols you should select "embedded fonts" when you save your document
- Please ensure that you submit your abstract without track changes showing
- Abstract selection will be the responsibility of the Programme committee
- The submitting author of each abstract will be contacted by Friday 2nd March to the email address given on the submission (unless a different email address is provided)

Appendix 5: Abstract submitted to the UK-Kidney Week 2018

Exploring peoples' experiences of being a parent with End Stage Renal Disease receiving haemodialysis treatment: A qualitative Study

Background: The prevalence rate of people with End Stage Renal Disease (ESRD) has increased over the years, with the impact of the illness and its treatments gaining attention more recently. Research has shown that receiving haemodialysis treatment impacts on most aspects of peoples' daily lives. One area that has received less attention has been exploring peoples' experiences of being a parent who receives haemodialysis treatment.

Aims: The objective of this study was to explore and gain an understanding of the lived experiences of patients that are parents and receive haemodialysis treatment for ESRD.

Methods: Ten parents who received haemodialysis treatment were interviewed using a semi-structured interview protocol. The interviews were then transcribed verbatim and then analysed using the method of Interpretative Phenomenological Analysis (IPA).

Results: Six mothers and four fathers were represented in this study, ages ranging between 28 to 49 years of age and with a median age of 41.9 years. Two Master Themes emerged from the data. The first Master Theme, *'The Haemodialysis Experience'*, explores what it is like to live with the demands, necessity and process of haemodialysis treatment, as well as the side-effects of the treatment and the participants' experience of the haemodialysis ward environment and professional care received. The second Master Theme focuses on *'The Lived Experience of Parents with End Stage Renal Disease'*, which captures different aspects of being a parent; their perception of their children's experience of having a parent with ESRD and their considerations on their own mortality and impact on family life.

Conclusion: Receiving haemodialysis treatment, along with its associated challenges, has been shown to impact on the person's role and identity of being a parent. This research provides a valuable insight for Renal Care Professionals into the challenges experienced by parents receiving haemodialysis treatment, especially those with young children. Furthermore, it also provides health care professionals with ideas on how to support parents receiving haemodialysis treatment to ease the challenges and demands they are facing as a parent and as a person with ill health.

Appendix 6: Acceptance email received from the UK-Kidney Week 2018 Conference panel

Subject: UKKW Poster Presentation Information

UKKW
UK Kidney Week 2018

UK KIDNEY WEEK CONFERENCE 2018
19th - 21st June
Harrogate Convention Centre, Kings Road, Harrogate, HG1 5LA

Dear Maria,

Please find below the details of your poster presentation. Please read through these carefully and let us know if you feel any of the information is incorrect.

Guidelines
Please find a copy of the poster presentation guidelines attached.
Contact us:
If you require any further information or have any questions, please contact the UKKW Events Team on:

Contact: [redacted]
Email: [redacted]
Telephone: [redacted]

We look forward to welcoming you to the UKKW Conference in Harrogate.
UKKW Events Team

Speaker Presentations

Title	Exploring peoples' experiences of being a parent with End Stage Renal Disease receiving haemodialysis treatment: A qualitative Study
Paper Status	Accepted – Poster
Session Details	Moderated Poster Session - Thursday Jun 21, 2018 2:00 PM - 3:00 PM

Appendix 7: Evaluation form and feedback received from the Renal Psychological Services CPD session

APPENDIX 7 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

Appendix 8: Observer report for the presentation at the Renal Psychological Services CPD session

APPENDIX 8 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

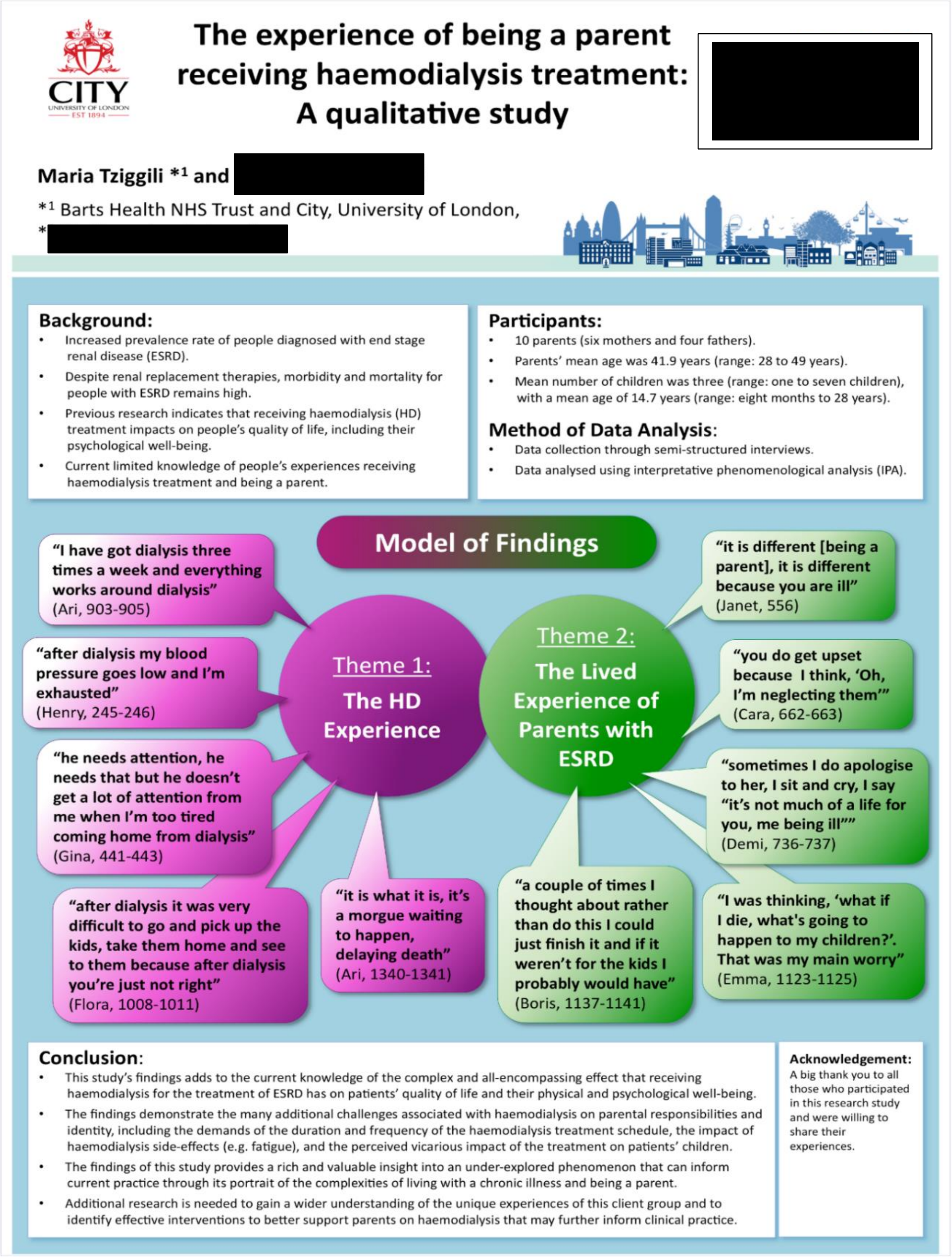
Appendix 9: Observer report for the presentation at the Senior Haemodialysis Nurses

APPENDIX 9 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

Appendix 10: Observer report for the presentation at the Annual Health Psychology Conference

APPENDIX 10 HAS BEEN REDACTED FOR CONFIDENTIALITY PURPOSES

<u>Appendix 11</u>: Poster presented at the UK-Kidney Week 2018 Conference



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The experience of being a parent receiving haemodialysis treatment: A qualitative study

[redacted]

Maria Tziggili *[1] **and** [redacted]

*[1] Barts Health NHS Trust and City, University of London,
* [redacted]

Background:

- Increased prevalence rate of people diagnosed with end stage renal disease (ESRD).
- Despite renal replacement therapies, morbidity and mortality for people with ESRD remains high.
- Previous research indicates that receiving haemodialysis (HD) treatment impacts on people's quality of life, including their psychological well-being.
- Current limited knowledge of people's experiences receiving haemodialysis treatment and being a parent.

Participants:

- 10 parents (six mothers and four fathers).
- Parents' mean age was 41.9 years (range: 28 to 49 years).
- Mean number of children was three (range: one to seven children), with a mean age of 14.7 years (range: eight months to 28 years).

Method of Data Analysis:

- Data collection through semi-structured interviews.
- Data analysed using interpretative phenomenological analysis (IPA).

Model of Findings

<u>Theme 1:</u>

The HD Experience

"I have got dialysis three times a week and everything works around dialysis" (Ari, 903-905)

"after dialysis my blood pressure goes low and I'm exhausted" (Henry, 245-246)

"he needs attention, he needs that but he doesn't get a lot of attention from me when I'm too tired coming home from dialysis" (Gina, 441-443)

"after dialysis it was very difficult to go and pick up the kids, take them home and see to them because after dialysis you're just not right" (Flora, 1008-1011)

"it is what it is, it's a morgue waiting to happen, delaying death" (Ari, 1340-1341)

<u>Theme 2:</u>

The Lived Experience of Parents with ESRD

"it is different [being a parent], it is different because you are ill" (Janet, 556)

"you do get upset because I think, 'Oh, I'm neglecting them'" (Cara, 662-663)

"sometimes I do apologise to her, I sit and cry, I say "it's not much of a life for you, me being ill"" (Demi, 736-737)

"I was thinking, 'what if I die, what's going to happen to my children?'. That was my main worry" (Emma, 1123-1125)

"a couple of times I thought about rather than do this I could just finish it and if it weren't for the kids I probably would have" (Boris, 1137-1141)

Conclusion:

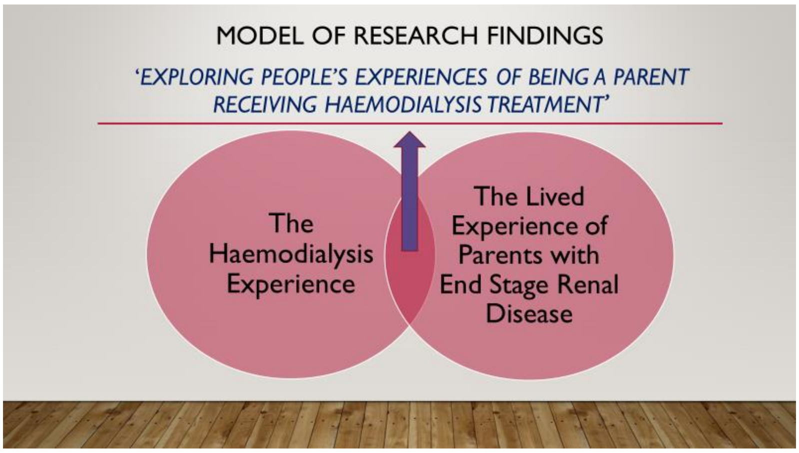
- This study's findings adds to the current knowledge of the complex and all-encompassing effect that receiving haemodialysis for the treatment of ESRD has on patients' quality of life and their physical and psychological well-being.
- The findings demonstrate the many additional challenges associated with haemodialysis on parental responsibilities and identity, including the demands of the duration and frequency of the haemodialysis treatment schedule, the impact of haemodialysis side-effects (e.g. fatigue), and the perceived vicarious impact of the treatment on patients' children.
- The findings of this study provides a rich and valuable insight into an under-explored phenomenon that can inform current practice through its portrait of the complexities of living with a chronic illness and being a parent.
- Additional research is needed to gain a wider understanding of the unique experiences of this client group and to identify effective interventions to better support parents on haemodialysis that may further inform clinical practice.

Acknowledgement: A big thank you to all those who participated in this research study and were willing to share their experiences.

Appendix 12: Handout used at the UK-Kidney Week Conference

UKKW 2018

Handout accompanying poster presentation on
'Exploring people's experience of being a parent receiving Haemodialysis treatment'

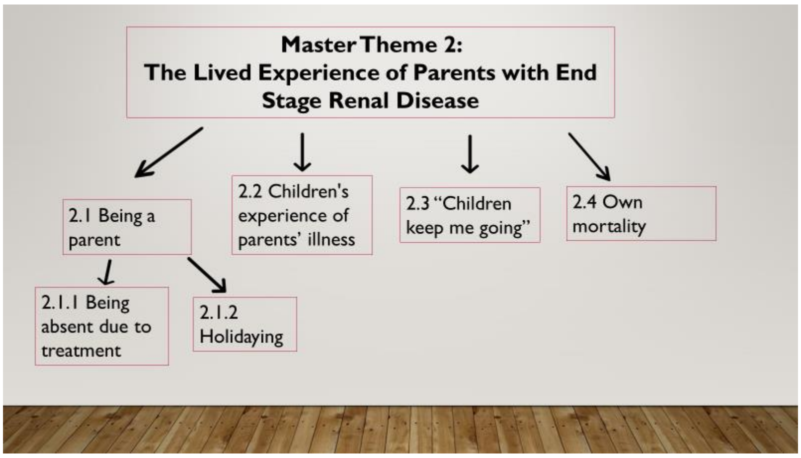


MODEL OF RESEARCH FINDINGS

'EXPLORING PEOPLE'S EXPERIENCES OF BEING A PARENT RECEIVING HAEMODIALYSIS TREATMENT'

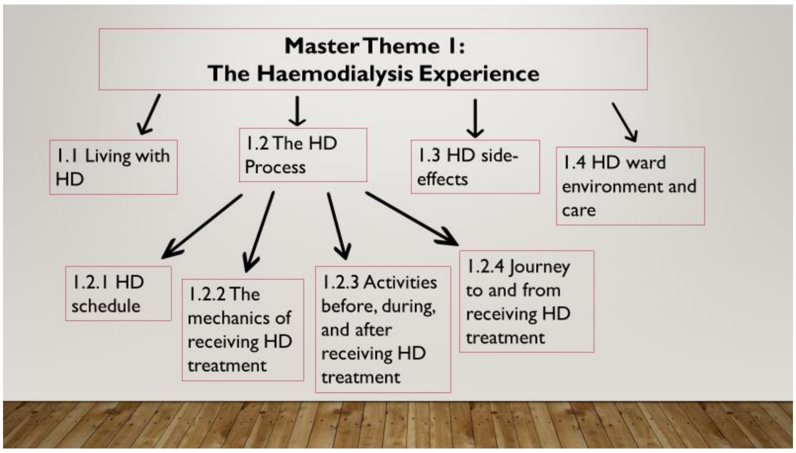
The Haemodialysis Experience

The Lived Experience of Parents with End Stage Renal Disease



Master Theme 2:
The Lived Experience of Parents with End Stage Renal Disease

- 2.1 Being a parent
  - 2.1.1 Being absent due to treatment
  - 2.1.2 Holidaying
- 2.2 Children's experience of parents' illness
- 2.3 "Children keep me going"
- 2.4 Own mortality



Master Theme 1:
The Haemodialysis Experience

- 1.1 Living with HD
- 1.2 The HD Process
  - 1.2.1 HD schedule
  - 1.2.2 The mechanics of receiving HD treatment
  - 1.2.3 Activities before, during, and after receiving HD treatment
  - 1.2.4 Journey to and from receiving HD treatment
- 1.3 HD side-effects
- 1.4 HD ward environment and care

Appendix 13: Evaluation form and feedback received for presentation at the UK KidneyWeek 2018 Conference

UKKW 2018

Evaluation form of poster presentation

'Exploring people's experience of being a parent receiving Haemodialysis treatment'

Please can you complete the following anonymous evaluation form.

Please can you state your occupation here: Doctor (I); Renal Social Worker (I); Psychologist (I); Consultant (I); Health Psychologist (I); Not stated (II);

Table 4: *Feedback on content of the presentation and speaker.*

CONTENT of the poster:	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
a) The information on the poster was appropriate	5	2	0	0	0
b) The information on the poster was clearly structured	6	1	0	0	0
c) The information on the poster was readable and easy to follow	6	1	0	0	0
CONTENT of the presentation:	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
d) The research findings presented expanded my knowledge on people's experience of being a parent receiving haemodialysis treatment	5	2	0	0	0
e) The information presented was appropriate for the audience present	5	2	0	0	0
f) The information presented by the researcher added to the poster content	5	2	0	0	0
SPEAKER:	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
g) The speaker was knowledgeable about the topic area	5	2	0	0	0
h) The speaker spoke clearly	6	1	0	0	0
i) The speaker presented the information at the right pace	6	1	0	0	0
j) The speaker interacted well with the audience	6	1	0	0	0
k) The speaker gave opportunities for questions	6	1	0	0	0
GENERAL:					
Any other comments: • **Great presentation – important area** • **Food for thought**	• **Interesting** • **Very interesting – thank you**				

Thank you very much for your time and feedback!

SECTION D: SYSTEMATIC LITERATURE REVIEW

The Effectiveness of Peer Support Interventions in Renal Care: A Systematic Literature Review

Abstract

Background: Peer support interventions have been identified as being beneficial additions to the care of people with chronic health conditions. There is growing evidence that such interventions are also helpful to patients in renal care. To date there has been no systematic review of the existing literature, which would inform future research and clinical practice in the field of renal care.

Objectives: To systematically retrieve studies that conducted peer support interventions in renal care and to investigate the effectiveness of such interventions.

Method: Six different databases were systematically searched to retrieve peer-reviewed English language articles on peer support interventions in renal care, between the years of 1998 to April 2018. The online databases employed were: *CINAHL*; *MEDLINE Complete*; *PsycINFO*; *Web of Science*; *Cochrane library*; and *PubMed*. A variety of similar terms to *end stage renal disease* and *peer support* were employed in the search.

Results: Four articles met the inclusion criteria from which two were randomised control trials, one was a quasi-experiment and the fourth study followed a mixed method approach. All four studies proposed that peer support interventions are beneficial to patients with end stage renal disease, which was reflected in some of their findings.

Conclusion: The review found that peer support interventions are effective additions to treatment in renal care at different stages of patients' illness, particularly in developing greater self-transcendence, self-efficacy, improved quality of life and increased engagement in advanced directives as patient's enter end of life care. The review also concluded, in line with existing literature, that improving the awareness and engagement of clinicians for peer support programmes could markedly enhance the utilisation of this positive and low-cost addition to patient care. Further empirical evidence would however be required to help inform and expand the awareness and integration of such programmes within the renal services..

1 Introduction

1.1 Peer support

A growing number of studies have explored the role of peer support in healthcare (Ghahramani, 2015; Heisler, 2006; Hughes, Wood & Smith, 2009). Despite this however, there has been a limited consensus towards a defining concept of peer support. Dennis (2003) concept analysis of peer support in a healthcare context aimed to provide a conceptual basis from which peer support interventions could be developed, implemented, evaluated and compared. She defined peer support linguistically as *"the giving of assistance and encouragement by an individual considered equal"* (Dennis, 2003, p.323). Through her in-depth literature review three critical attributes of peer support emerged and are evident to some degree in all peer interventions, these are: emotional support, informational support, and appraisal support. *Emotional support* refers to the provision of empathy, attentive listening, reassurance, and expressions of caring and encouragement. These qualities aim to foster feelings of acceptance, respect and validation in individuals despite the personal difficulties people with chronic diseases experience. *Informational support* is the supply of problem-solving knowledge that is often required when difficulties cannot be readily overcome or existing knowledge is lacking (e.g. when making an informed decision between treatment modalities). Finally, *Appraisal support* aims to nurture positive future assumptions by providing interactions that include motivation aspects that encourage persistence in problem-solving, optimism and support in enduring frustrations. Dennis (2003) also highlighted *instrumental support* as a further attribute of peer support. Instrumental support can be defined as providing practical assistance or tangible aid to peers. However, whereas emotional, informational and appraisal support repeatedly occur in peer interventions, instrumental support appears less frequently and is therefore not considered to be a defining attribute. Referring to Dennis' (2003) description of peer support, McCarthy (2017) stated that peer support is different to expected interactions with other patients (e.g. in waiting rooms, on hospital units), as peer support provides planned contact with patients by individuals that have received training to provide such support.

Peer support has become a useful strategy within healthcare settings to assist in the management of increasingly complex and chronic diseases (Doull, O'Connor, Welch, Tugwell & Wells, 2008). Embuldeniya and colleagues (Embuldeniya, Veinot, Bell, Bell, Nyhof-Young, et al., 2013) suggest that peer support will likely become an increasingly important aspect of care for the growing population of people with chronic diseases. Patients diagnosed with a chronic illness often experience various challenges in their daily lives that impact on lifestyle and socialisation. Such challenges include issues relating to medication and treatment adherence, reduced activity, and stress (Doull, et al., 2008). Mentoring by trained peers is an effective intervention in providing individualised care to patients with a chronic condition. The provision of peer support that includes patient-centred information, decision-making and self-management support have been shown to improve treatment outcomes for chronically ill patients (Ghahramani, 2015). One of the reasons peer support has been found to be so effective is the non-hierarchical, reciprocal nature of the peer relationship, as opposed to the dynamic that may be found in the relationship between healthcare professional and patient. The reciprocal nature of peer support relationships has the additional benefit of supporting both the peer support receiver and the peer support volunteer, especially as patients with chronic conditions can feel isolated and lack sufficient social support (Heisler, 2006). However, there are several formats in which peer support in a healthcare setting could be delivered, including peer coaches, face-to-face self-management programmes, group visits, telephony and online peer support (Green & Boulware, 2016).

1.2 Peer support in renal care

In the field of renal care, peer support is a growing adjunct to the care that patients receive (Wood, 2015). Peer support has the ability, through experiential learning, to provide renal patients with emotional, social and practical assistance (Green & Boulware, 2016). Hughes, Wood and Smith’s (2009) qualitative study exploring the experiences of patients with kidney disease that had received peer support found that patients had an overwhelmingly positive reaction to the support received. Six main benefits to receiving peer support were identified: (i) talking to someone ‘who’s gone through what you’re going through’; (ii) answers to questions and practical information; (iii) reassurance, encouragement and increased confidence; (iv) support with coming to terms with starting treatment; (v) help making or confirming treatment decisions; and (vi) hope for the future (Hughes et al., 2009, p.403). Their study also indicated that the individuals living with kidney disease identified with their peer supporters and regarded them as positive role models that were able to help normalise their experiences of their illness and treatment. This positive peer relationship seems to have the potential to contribute to an increased sense of empowerment and self-agency (Hughes et al., 2009). However, Taylor, Gutteridge and Willis (2015) found in their study into the barriers to peer support for patients with end-stage kidney disease, that there is potential for individuals to feel resistant to peer support if there is a perception of them being a passive recipient. Their findings highlighted peer support relationships that are reciprocal and mutual in nature as being essential characteristics in encouraging engagement and preservation of the person's dignity and self-esteem.

Despite the complex life challenges associated with chronic kidney disease (CKD), especially in the advanced stages, adolescents with the condition may experience impediment on their peer interactions as a result of the demands of the care received and diminished energy levels (Nicholas, Koller & Picone, 2004). Young adults with end stage renal disease (ESRD) tend to be geographically scattered and, with haemodialysis being the most likely treatment modality, are commonly restricted in their ability to travel (Zheng, Newman, Veinot, Hanratty, Kim, et al., 2010). Due to this, adolescents may be left with limited social networks, social isolation and a lack of close peer relationships (Nicholas, Koller & Picone, 2004). Nicolas and colleagues (Nicholas, Picone, Vigneux, McCormick, Mantulak, et al., 2009) developed a pilot study of a six-month online peer support network for adolescents with CKD. The results of the study indicated that online peer support can, in part, help to mediate the various challenges and concerns that adolescents with CKD may experience. Nicolas et al., (2009) concluded that the benefits of online peer support are enhanced by its accessibility, ease of communication, connection with peers and a sense of privacy. Young adult renal patients involved in peer support programmes have the potential to alleviate their feelings of isolation, loneliness and insecurity at the same time as facilitating the reciprocal sharing of shared ideas, concerns, emotions and future aspirations with peer support volunteers (Kapron, Perry, Bowman & Swartz, 1997). In addition, peer support effective in improving the care received by patients with CKD, even though some studies have illuminated that peer support volunteers also benefit from peer support relationships. In a study exploring the psychological well-being of renal peer support volunteers the findings indicated that peer support volunteers had high levels of psychological well-being and an increase in personal growth and general well-being. The study also found that peer support volunteers benefited from developing new and meaningful relationships with other volunteers and engagement in a challenging and a productive role. Through involvement in peer support schemes volunteers also have the potential to gain a greater acceptance of their own chronic illness being a part of their lives (Brunier, Graydon, Rothman, Sherman & Laidsky, 2002). Peer support volunteers are in an invaluable position in being able to offer a unique perspective into the substantial impact that ESRD may have on quality of life (QoL) and can contribute significantly in addressing these issues by working directly with the patient (Kapron, Perry, Bowman & Swartz, 1997).

The role that clinicians take in patients accessing peer support has been described as crucial, especially with regards to how encouraging clinicians are towards patients engaging with peer support (Taylor et al., 2015). Wood (2015) argued that renal peer support programmes could be negatively impacted upon by inadequate clinician engagement, conversely improvement in clinician engagement could maximise the benefit of such programmes for patients. Wood (2015) found that many renal care units in the United Kingdom (UK) experienced low participation rates despite investment of time and resources in establishing peer support programmes. She proposed that active advertisement and education of peer support services focused specifically at clinicians can significantly increase clinician referrals and patient participation in the schemes. In a follow-up to her 2015 study, Wood (2018) found similar low referral rates into peer support schemes, particularly from less experienced healthcare staff. The main obstacles to clinician engagement with the programmes included poor knowledge of the practicalities of peer support services, forgetfulness and erroneous beliefs regarding whom the service may be appropriate for.

McCarthy and Mastin’s (2016) paper on the development and delivery of a diverse peer support programme for renal patients reported that any peer support scheme would require service wide buy-in from the onset. They suggested that individuals that have a preference and commitment to providing peer support should receive appropriate training from nursing leads. Their suggestion aligned with Wood’s (2014) recommendation that it is crucial for peer support volunteers to receive training in order to provide a safe and high-quality service. Peer support volunteers should also receive adequate support, with easy access to a peer support clinician and other support mechanisms (e.g. regular group meetings). The development and delivery of peer support programmes may also be important interventions for young adult renal patients transitioning from paediatric services to adult care (Harden & Sherston, 2013) and patients entering end-of-life care (Perry, Swartz, Kelly & Brown, 2003).

Peer support interventions for people with chronic health conditions have been identified as being beneficial in providing patients with emotional support, social support and illness management support. There is limited but growing evidence that peer support in renal care is an effective adjunct to patient treatment. This systematic literature review was conducted to gain a better understanding of the existing peer support interventions in renal care and how future research and clinical practice could be informed to the betterment of patients with ESRD.

The objectives of this review were:

(i) To identify peer support interventions carried out in renal care.
(ii) To evaluate the effectiveness of peer support interventions in renal care.

2 Methods

A systematic literature review on peer support interventions for people with ESRD was carried out. This section will cover the inclusion and exclusion criteria for the studies, the search strategy and terms used to retrieve relevant studies. It also demonstrates the process of data collection, including the process of quality assessment for each of the included research articles. For the purpose of this review, the term *haemodialysis* will be used rather than the treatment's alternative spelling, *hemodialysis*, which was used by some authors.

2.1 Inclusion criteria

The inclusion criteria used in the article searchers were:

Participants

Individuals who were diagnosed with ESRD and were receiving outpatient, rather than inpatient care by a renal department.

Intervention

Interventions that focussed on offering peer support to patients with ESRD, meaning renal patients offering support to renal patients.

Outcomes

Peer-reviewed articles that used pre-post intervention measures to evaluate the effectiveness of their peer support intervention.

Setting

There was no restriction regarding the setting that the peer support took place (e.g. in a hospital, social or private setting). The method of which peer support was offered was also not restricted, allowing communication to be in the form of face-to-face, telephony or by text or email messaging.

Study design

There were no restrictions set on the type of study design, as long as pre-post measures were used to either partly or fully evaluate the effectiveness of the peer support study.

2.2 Search strategy

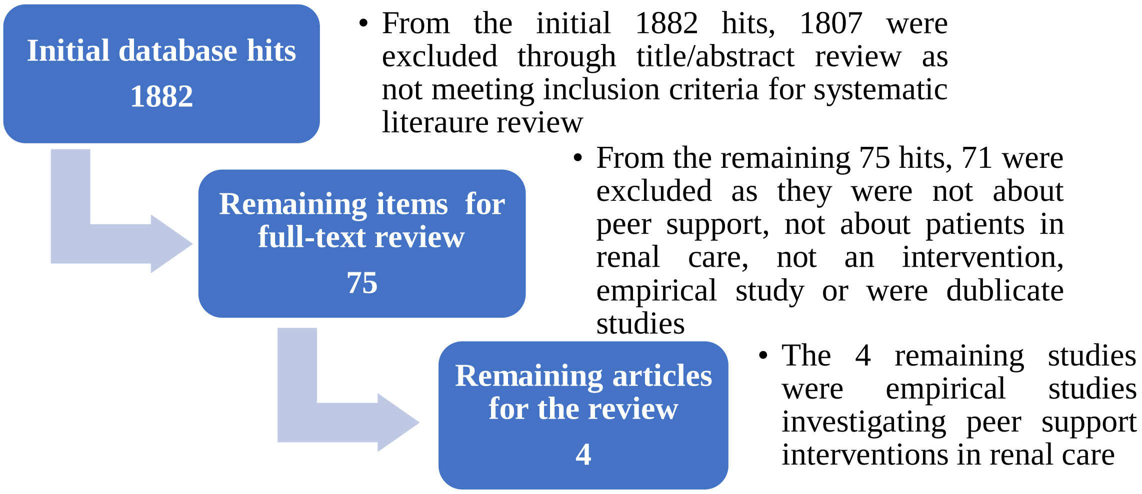
Relevant literature was identified on the 15th of April 2018 through searches on six different databases. The databases employed were: CINAHL; MEDLINE Complete; PsycINFO; Web of Science; Cochrane library; and PubMed.

Initial search terms, such as *end stage renal disease* and *peer support*, were expanded by reviewing and including derivative terms (e.g. kidney failure) and associated words (e.g. haemodialysis, kidney organ transplant). Sources such as a thesaurus, MeSH (Medical Subject Heading), suggested subject terms, other relevant systematic literature reviews, and the researcher's own knowledge of specific terminology in renal care were used to identify alternative words to expand the literature search. The final version of search terms used in this systematic literature review are displayed in Table 1 below. (An example of actual search can be found in Appendix 1).

Table 1: *Search terms used for the systematic literature review in the databases.*

Renal	Combination Word	Peer Support	Limiters
Nephrology OR "Renal disease" OR "Renal failure" OR "Kidney disease" OR "Kidney failure" OR ESRD OR ESKD OR ESRF OR ESKF OR “Renal replacement therapy” OR “Renal treatment” OR Haemodialysis OR Hemodialysis OR “Peritoneal dialysis” OR “Kidney transplant*” OR “Kidney organ transplant*” OR “conservative care” OR “conservative management”	AND	Peer* OR Peer group* OR Peer support* OR Peer counsel* OR peer intervention*	-English (published in English) -published between 1998 and March 2018

An additional search for appropriate articles took place though hand searching the reference lists of relevant articles. All searches were set to retrieve articles written in the English language and were published between 1998 and March 2018. Abstracts for meetings and conference proceedings, dissertations and theses were excluded, as well as grey literature.



- From the initial 1882 hits, 1807 were excluded through title/abstract review as not meeting inclusion criteria for systematic literaure review
- From the remaining 75 hits, 71 were excluded as they were not about peer support, not about patients in renal care, not an intervention, empirical study or were dublicate studies
- The 4 remaining studies were empirical studies investigating peer support interventions in renal care

Figure 1: *Display of search hits, number of excluded and remaining articles.*

2.3 Data collection process

All 1882 articles retrieved from the six different databases were explored for their relevance to this systematic review by reviewing their title and abstract. Articles that were deemed initially relevant for this review based on the article's title and abstract, and articles where further information was required to assess their relevance, were selected for further review and full-text retrieval. This process reduced the initially retrieved articles from 1882 to 75. The next selection process of articles to be included into this systematic review involved excluding articles that appeared as duplicates, not relevant to this specific systematic review, not empirical studies and/or not published in peer reviewed journals. Topics of excluded articles included papers that focused on exploring future peer support programmes rather than investigating the effectiveness of a peer support intervention. Further exclusions included articles that explored peer support volunteers' experiences and psychological wellbeing from providing peer support, and investigations into patients' decision-making processes for choosing a treatment modality. Through this process four articles were identified.

Quality assessment procedure

The remaining four articles that met the inclusion criteria for this systematic review were assessed on a self-developed quality assessment tool. The assessment tool included ten questions with a three-point scoring scale (0=No; 1=Partly; 2=Yes), with a higher score indicating a better quality (Appendix 2). The quality assessment questions were:*?*

1) *Is the aim of the study clearly stated?*
2) *Is the overall design of the study appropriate for answering the research question?*
3) *Was an intervention used in this study?*
4) *Has a clear description of the intervention been provided?*
5) *Is there a control group?*
6) *Has demographic data of participants been collected and presented?*
7) *Have pre-post questionnaires been used?*
8) *Does the study use standardised data collection tools?*
9) *What was the 'drop-out' percentage rate of participants in this study? <15%=2 points; <30%=1 point; >31%=0 points*
10) *Are the limitations of the study mentioned?*

Each article was assessed on the quality assessment tool by two researchers independently. Once both researchers completed their assessment of each of the four articles, a review of the scores took place to discuss any difference between the researchers'. The score differences between the two researchers were between zero to one point. For an overall score the individual totals for each article were combined and divided by two. The overall score for all four articles totalled to between 16 ½ to 18 ½ out of a possible score of 20 (Appendix 3). These scores were then converted into percentages, with 80% considered to represent a high-quality mark. As all four articles achieved a score of over 80%, all four articles were included in this systematic literature review.

3 Results

3.1 Overview

The four articles of which this systematic literature review was conducted on focused on the effectiveness of peer support in renal care. The aim of the first study, Milani, Amiri, Vejdani, Salehiniya, and Malek-khahi (2017), focused on assessing the impact of peer support on self-transcendence for patients undergoing haemodialysis treatment. The intention of Perry, Swartz, Brown, Smith, Kelly and Schwarz (2005) was to compare the effectiveness of peer support and other interventions on end-of-life decision making. They also aimed to identify whether demographic differences impacted on the effectiveness of peer support interventions. The study by St. Clair Russell, Thomson, Southerland, Meyer, Huff and Lynch (2017) looked at evaluating the impact of peer to peer support on the health outcomes of haemodialysis patients. The final study, Sattoe, Jedeloo and Van Staa (2013), aimed to understand the effect of peer support on self-management for young people with end stage renal disease.

A variety of terminology was used by the different study authors to describe those involved in the peer support programmes. Perry et al., (2005) referred to peer support volunteers as *peer mentors* and peer support receivers as *participants/patients.* In the study by St. Clair Russell et al., (2017), peer support volunteers were called *mentors* and peer support receivers were called *mentees*. Different terms were used by Sattoe et al., (2013), whom used the terms *buddies* and *attendees* to identify the peer support volunteers and the peer support receivers respectively. Milani et al., (2017) did not separate peer support volunteers and peer support receivers in their intervention study. All those taking part in the peer support group intervention study were referred to as *participants/patients*. For the purpose of this review, the author will refer to the patients who offer peer support as *peer support volunteers* and the patients who receive the peer support as *peer support receivers*.

The included articles of this systematic review will be explored and compared on their similarities and differences across the studies. The data will be synthesised and written narratively, however it was not possible to conduct a meta-analysis on the reviewed studies as each study used different measures to evaluate their interventions.

1.2 Details of included studies

Table 2: *Characteristics of Milani et al., (2017) study.*

<table>
<tr><td colspan="5">**Full Title**: Milani, M.J., Amiri, P., Vejdani, M., Salehiniya, H., & Malek-khahi, A. (2017). The effect of peer support group on self-transcendence in patients undergoing haemodialysis. *Biomedical Research & Therapy*, *4*(3), 1198-1209.

Study conducted in Iran.</td></tr>
<tr><th>Design</th><th>Participants</th><th>Description of Intervention</th><th>Pre-post measures used</th><th>Results</th></tr>
<tr>
<td>Quantitative research study

Randomize control trial (RCT)

Block randomisation method used for group allocation

2 groups:

-1x Control (CG) receiving standard care

-1x Intervention Group (IG) receiving peer-support (in a group)</td>
<td>**Number of participants:**
-55 (CG=27; IG=28)

Mean age & Standard deviation (SD) where available:
-47,54 (CG=48.04+/-13.0); IG=47.04+/-13.29)

Age range = not specified

Diagnosis:
-end stage renal disease

Treatment modality:
-Haemodialysis

Study withdrawal:
-14% of participants</td>
<td>1x Intervention Group

Weekly 2-hour peer support group for 8 weeks

Limitations/other:
-Does not clearly state who is facilitating the peer support group</td>
<td>**Time frame between pre and post data collection**:
-Not specified

Questionnaires used for pre and post evaluation:
-Reeds 15-item Self-transcendence scale</td>
<td>**Statistical tests used:**
-ANOVA and T-test

Main findings:
-Significant improvement of self-transcendence was found pre-post the intervention period for the IG (p<0.0001) and the CG (p=0.006)
-Statistical difference was also found between intervention and control group when comparing post intervention data on self-transcendence (p<0.0001)</td>
</tr>
</table>

Table 3: *Characteristics of Perry et al., (2005) study.*

Full title: Perry, J., Swartz, J., Brown, S., Smith D., Kelly, G., & Schwartz, R. (2005). Peer mentoring: A culturally sensitive approach to end-of-life planning for long-term dialysis patients. *American Journal of Kidney Disease, 46*(1), 111-119. Study conducted in the US across 21 dialysis units				
Design	**Participants**	**Description of Intervention**	**Pre-post measures used**	**Results**
Quantitative research study Randomize control trial (RCT) Random lots randomisation method used for group allocation 3 groups: 1x control group (CG) receiving standard care 1x intervention group (IGa) receiving one to one peer support 1x Intervention Group (IGb) receiving printed material **Other:** Peer support volunteers and receivers as well as social workers,	**Number of participants:** -237 patients **Study withdrawal:** -34 patients (27.5%) **Demographics of all participants (CG, IGa and IGb):** -age range 19 to 83 years of age, 49% were females; 38% were African American **Demographics for each group**: **-CG:** mean age 45; 46% females, 37% African American **-IGa**: Mean Age: 44, 54% female; 39% African American **-IGb**: mean age 44, 46% females, 39% African American	**2x intervention groups:** -1 included printed material and 1 involved peer support **Duration of intervention:** -2 to 4-month study period **Frequency of intervention:** -8 meetings **Method of peer support interaction:** -5 telephone and 3 face-to-face meetings **Training for peer support volunteers**: -peer support volunteers attended a state wide 16-hour training program fostered by the National Kidney Foundation prior to the intervention	**Duration between pre- and post-evaluation data:** -2 to 4 months **Questionnaires used for pre and post intervention:** **Psychosocial measures used:** -included adapted version of the Hopkins Symptom Checklist including "depression, subjective well-being (rated on 5 statements), death acceptance (rated on 5 statements), anxiety (2 items assessing symptoms), and suicidal thinking (1 question)" (p.112) **Post evaluation measure:**	**Statistical tests used:** - Logistic regression model, ANOVA and T-test **Main findings:** **Advance directive (AD) completion and comfort in discussing AD:** -participants from the IGa were significantly more likely to complete an AD ($p<0.05$) and felt significantly more comfortable in discussing the AD ($p<0.01$), -there was a significant interaction between race (African Americans & Caucasians) on AD completion

received a modest payment for their participation in the full study	**Number and demographics of peer support volunteers**: -17 Peer support volunteers, age range 29-81 years of age, 11 whites and 6 African Americans	(training included learning active listening and problem-solving skills as well as human development and mental health) **Additional support for peer support volunteers** (and social workers): -regular AD workshops offered by research study	-number of AD's completed	when in IGa (p<0.01) -African Americans were more likely to complete an AD when in IGa in comparison to when in one of the other two groups (IGb & CG) whilst for the Caucasians a big difference was not found between attendance in either of the two intervention groups (IGa & IGb) **Psychosocial Markers:** -significant findings on the psychosocial markers included increase in subjective wellbeing in American Africans in the IGa (p=0.05) and decrease in suicidal ideation in Caucasians in the IG2 (p<0.05)

Table 4: *Characteristics of St. Clair Russell et al., (2017) study.*

Full title: St. Clair Russell, J., Thomson, M., Southerland, S., Meyer, K.B., Huff, E.D., & Lynch, J.R. (2017). A peer-to-peer mentoring program for in-centre hemodialysis: A patient-centred quality improvement program. *Nephrology Nursing Journal, 44*(6), 481-489. Conducted in the US (one in-centre haemodialysis facility in Virginia with 249 patients)				
Design	**Participants**	**Description of Intervention**	**Pre-post measures used**	**Results**
Quantitative research study Single arm, repeated measurement quasi-experimental design **1 group:** 1x Intervention Group (IG) receiving individual peer to peer support >**matching peer support volunteers and receivers**: -mentees and mentors were paired together who attended the same shift and where possible additionally matched on different characteristics with the input of the application forms and by	**Number of peer support receivers:** -22 completed the study *(23 originally recruited for which the demographics were provided for)* **Gender:** -12 male and 11 females **Mean age and Standard deviation:** -56 years of age; SD=12.85 **Race:** -21 African Americans and 2 Caucasian **Diagnosis**: -end stage renal disease **Treatment modality:** -Haemodialysis **Study withdrawal**: -6.5%	**Length of total intervention:** -4 months (March to June 2015) **Intervention:** -ongoing one to one peer support interactions in between 2 group meetings, a kick-off mixer (at the start of the intervention) and a final celebration mixer (at the end of the intervention) **Ongoing meetings:** -advised to meet 4 times per month, with at least twice a month meeting in person **Training for peer support volunteers**: -a five-hour training session	**Frequency of evaluation measures taken:** -three times (pre, mid and post-intervention) **Outcome measures used:** **-psychosocial health** (via questionnaires); self-efficacy, knowledge, perceived social support, health related quality of life, dialysis self-management **-physiological health** (from patients' health records)**;** phosphorus, interdialytic weight gain, missed treatments, shortened treatments and hospitalization	**Statistical tests used:** -ANOVA & Friedman's test **Main findings:** -statistically significant improvement in most **psychosocial markers** were found, including self-efficacy (p<0.01), knowledge (p<0.01), perceived social support (p<0.01), and dialysis social support (p<0.01). -significant improvement in one **physiological marker** was found which was the reduction of missed haemodialysis treatment

taking int consideration opinions of health care staff **Other:** -peer support pairs entered a monthly $25 gift card per individual if they followed suggested frequency of contact -plus, a $100 gift card per person which could be won at the final celebration event at the end of the intervention	**Peer support volunteers:** -21 completed the study *(23 originally recruited for which the demographics were provided for)* **Gender:** -7 males and 16 females **Age:** Mean age 57 years and SD=15.49 **Race:** -17 African American; 5 Caucasian, 1 'more than one race'	which covered six different topics (such as disease specific information, leadership, communication and relationship building skills, and topics around privacy and confidentiality, -The training encouraged skill based and experiential learning **Additional training for peer support volunteers**: -a two-hour booster session, 2 months after the initial training was offered to review information and to discuss difficulties they may have faced as peer support volunteers		sessions (p=0.02). ***Note:*** *-the study included additional findings such as for the peer support volunteers but has not been included here as outside the scope of this systematic review*

Table 5: *Characteristics of Sattoe et al., (2013) study.*

Full title: Sattoe, J.N.T., Jedeloo, S., & Van Staa, A. (2013). Effective peer-to-peer support for young people with end-stage renal disease: a mixed methods evaluation of Camp COOL. *BMC Nephrology, 14*(1), 279-292.

Conducted in the Netherlands

Design	Participants	Description of Intervention	Pre-post measures used	Results
>Mixed method research design: 2-phase study (*only parts of phase 2 included here in aliment with this review*) 1x Intervention group (one to one & group) ***Note:*** *-full study not included here as outside of the scope of this systematic review. Full study includes, observations, interviews and questionnaire measures whilst also including outcomes and experiences of people in addition to the peer support receivers*	**Peer support receivers:** -14 young people **Gender:** -7 male and 7 females **Age:** -mean age of 17.1 and a SD of 1.1 **Age range:** -16 to 18 years of age (for the whole study, including phase1) **Diagnosis**: -end stage renal disease **Treatment modality:** -pre-dialysis (x1), haemodialysis (x1), kidney transplantation (x7) & other (x5 - which was not defined) **Peer support volunteers:** -18 individuals	**Duration of intervention:** -1-week Camp which took place twice. Once in 2011 and once in 2012 **Intervention**: -one to one peer support via peer support pairs in addition to attending group activities with all peer support volunteers and receivers **Details of one-to-one peer support intervention:** -the role of the peer support volunteer to be a role model for the peer support receiver, to encourage the receiver during activities and help to get used to the camp	**Duration between pre- and post-evaluation data:** -not specifically stated **Self-management and social participation measures:** -included general self-efficacy (10-item scale), disease related self-efficacy (16-item scale), health related quality of life (36-item scale), Social participation (Rotterdam Transition Profile covering seven life areas) **Camp evaluation measure:** -including influence of living with the condition (10-item scale), value of peer-	**Statistical tests used:** -Wilcoxon Signed Ranks Test **Main findings:** -statistically significant difference was found in peer support receivers after the intervention in two areas with an increase after the intervention on general self-efficacy ($p<0.05$) and social inclusion ($p<0.05$) **Other:** -the study included additional findings such as for the peer support volunteers but has not been included here as outside the scope of this systematic review

	Gender: -10 male and 8 females **Age:** -mean age of 20.7 and a SD of 2 **Age range:** -18 to 25 years of age (for the whole study, including phase1) **Diagnosis**: -end stage renal disease **Treatment modality:** -pre-dialysis (x1), haemodialysis (x5), kidney transplantation (x11) & other (x1 - which was not defined) **Study withdrawal**: -in total 38 peer support volunteers & receivers were recruited. Out of the total 16% (6 individuals withdraw from the study)	**Program elements of group activities:** -to support build general competencies rather than being focused on disease per se **Training for peer support volunteers:** -received some coaching during the two days before the start of the camp **Additional support for peer support volunteers:** -having daily meetings to discuss any enquiries	to-peer support (2-item scale) and an overall liking score for the camp.	

3.3 Findings of the review

Design

Out of the four articles, three were quantitative research studies and one used a mixed method approach. Both Milani et al., (2017) and Perry et al., (2005) were randomised control trails. Milani et al., (2017) used a block randomisation method to allocate participants into intervention and control groups, whereas Perry et al., (2005) method of randomisation involved using random lots to allocate participants into one of the two intervention groups or the control group. St. Clair Russell et al., (2017) used a single-arm, quasi-experiment study design, whilst Sattoe et al., (2013) applied a mixed methods approach. All four studies used pre-post measures in the form of questionnaires. In addition to the questionnaires, Sattoe et al., (2013) used semi-structured interviews and observations to evaluate the effectiveness of their peer support intervention. In addition to collecting data from peer support receivers, Sattoe et al., (2013) also explored the perception of the peer support intervention from peer support volunteers, referrers, and staff members. Focusing on the aspects of Sattoe et al., (2013) study that involved the analysis of data from non-peer support receivers was considered outside the scope of this review and will therefore not be reported on here. St. Clair Russell et al., (2017) outcome measures on peer support volunteers were also not included due to the same reason.

All four studies used pre-post questionnaires to evaluate the effectiveness of the peer support interventions. Two of the four studies, Perry et al., (2005) and St. Clair Russell et al., (2017), used psychosocial health questionnaires, with St. Clair Russell et al., (2017) using a physiological health indicator measure. St. Clair Russell et al., (2017) also used a one-item Health Related Quality of Life (HRQoL) questionnaire, similar to Sattoe et al., (2013) who used a 37-item HRQoL questionnaire. In addition to the HRQoL questionnaire, Sattoe et al., (2013) used questionnaires measuring participants self-efficacy and social participation, along with a self-developed questionnaire evaluating the study's intervention. Milani et al., (2017) used a 15-item self-transcendence scale to measure the effectiveness of their peer support intervention.

Three of the four studies received ethical approval with St. Clair Russell et al., (2017) having been considered and deemed exempt by their Institutional Review Board. Three of the four studies, with the exception of Milani et al., (2017), mentioned explicitly that participants were provided with an explanation on the importance of confidentiality.

Although Milani et al., (2017) did not mention informing the participants of confidentiality, they did state that participants were presented with consent forms, which were signed by participants.

Sample

Participants

In total, 294 participants (including peer support receivers and participants from control groups or other intervention groups) were involved across the studies, with the genders of the participants across the studies totalling to 136 males and 158 females. The mean age across the studies was 41.2 years. It is noteworthy to add that one of the studies, Sattoe et al., (2013), explored a peer support programme for young adults that are yet to transition from paediatric renal care onto adult renal care. Sattoe et al., (2013) participants had the lowest mean age across the studies with a mean age of 17 years, this is likely to have affected the overall mean from all four studies. All except one study provided the standard deviation (SD) of the mean ages. The intervention groups of both St. Clair Russell et al., (2017) and Milani et al., (2017) reported a respective SD of 12.85 and 13.29. Sattoe et al., (2013) reported the lowest SD at 1.1 from the mean age. Although Perry's et al., (2005) did not report the SD from the mean age of the participants they did, along with Sattoe et al., (2013), provide the age range of participants. The two studies combined reported an age range of between 16 years to 83 years of age. The other two studies did not include an age range for their participants.

All four articles stated that the patients they included in their intervention studies had previously been diagnosed with ESRD with most of them receiving haemodialysis treatment. Milani et al., (2017) and St. Clair Russell et al., (2017) clearly stated in their text that the peer support receivers they had recruited were receiving haemodialysis treatment. Participants in the Perry et al., (2005) study were noted as being dialysis patients. Sattoe et al., (2013) stated that they had recruited from a wider range of patients with ESRD, including people that were pre-dialysis, had received a kidney transplantation or were receiving haemodialysis treatment. They also included a category of *other* which was not defined.

Sample size

The sample size across the four reviewed studies ranged from 14 participants (Sattoe et al., 2003) to 203 participants (Perry et al., 2005). Perry et al., (2005) had a far greater sample size than any other study in this review. With the exception of Perry et al., (2005), the combined overall sample size of the other three studies were 91. The withdrawal rates for the studies differed greatly, from a 6.5% drop-out rate in the St. Clair Russell et al., (2017) study to Perry et al., (2005) 27.5%. The combined reasons given for participants withdrawal across the studies included, 25 individuals discontinuing their participation due to changes in their clinical status (e.g. death or hospital admission), 14 participants reported changes in their renal replacement therapy (RRT) (e.g. change in treatment modality and location), six participants voluntarily withdrew or did not engage with the sessions, and the data of four participants were excluded due to data collection issues. St. Clair Russell et al., (2017) did not provide an explanation for their withdrawal rates.

Description of peer interventions

Three out of the four studies used peer support volunteers in their intervention. Perry et al., (2005), St. Clair Russell et al., (2005) and Sattoe et al., (2013) described the provision of training or coaching to their peer support volunteers for the purpose of their studies. Both Perry et al., (2005) and St. Clair Russell et al., (2005) delivered a training programme to their peer support volunteers that involved different aspects, including enhancing communication skills, experiential learning and role-playing. Sattoe et al., (2013) explicitly state that peer support volunteers were not provided with additional training but did receive some coaching before the start of their programme. Milani et al., (2017) was the only study that had no specific pairing of peer support volunteers and receivers, with participating renal patients supporting each other in a peer support group setting.

The control groups in the studies by Milani et al., (2017) and Perry et al., (2005) received standard care. The intervention group in Milani et al., (2017) study attended weekly two-hour long peer support groups for a period of eight weeks. Similarly, Perry et al., (2005) peer support intervention consisted of eight meetings between the peer volunteers and the peer receivers, while their second intervention group received printed information on one occasion. Even though there was some flexibility in the frequency and method of the communication between the peer support volunteers and the peer support receivers in Perry et al., (2005) and St. Clair Russell et al., (2017), there was some formulated guidance which needed to be followed. In both studies the peer support volunteers and receivers were required to communicate at least once a week throughout the course of the intervention. Overall, Perry et al., (2005) required a minimum of three face-to-face meetings between the peer support volunteer and peer support receiver. Similarly, St. Claire Russell et al., (2017) requested a minimum of two face-to-face meetings for each peer support pair during the period of the intervention. In addition, St. Clair Russell et al., (2017) offered two events for all patients who were participating in their peer support intervention to attend. The first event was a *kick off mixer* to symbolise the start of the intervention. The mixer provided peer support pairs the opportunity to meet and receive information relevant to the intervention. The second event was a *final celebration mixer* that indicated the end of the intervention. Both Perry et al., (2005) and St. Clair Russell et al., (2017) were the only studies that explicitly stated that participants were free to continue their peer support relationship beyond their final programme meeting. The other two studies did not mention this.

In contrast to the other three studies, Sattoe et al., (2013) intervention took place over a period of a week in a camp for young people with ESRD. Even though each of the peer support receivers were paired with a peer support volunteer information about the frequency of their meetings was not provided, other than that daily camp-based activities were organised for all camp attendees.

Training for peer support provider

Three out of the four studies spoke about training the peer support volunteers which they included in their study. One study, Perry et al., (2005), referred to an intensive clinical service training program that was provided to peer support volunteers in renal care independent to their study. Two of the studies (St. Clair Russell et al., 2017; Sattoe et al., 2013), described the level of training they had offered to their peer supporters. One of the studies (Milani et al., 2017), did not mention peer support training as the peer support intervention they had offered was on a basis of peer support group where everyone was supporting each other in the group setting.

Intervention findings

Overall, all four studies found a statistical significance in the effectiveness of their peer support interventions. The most commonly used statistical analysis across the studies was ANOVA, which was used in three of the four studies. Additional statistical tests used included, logistic regression model, T-tests, Friedman’s test and Wilcoxon signed ranks test. Milani et al., (2017) found that self-transcendence increased in both the peer support intervention group ($p<0.0001$) and the control group ($p=0.006$). There was a significant difference in the post-intervention data between the groups, with the peer support intervention group scoring a greater mean difference (5.46) in the pre-post questionnaire when compared with the control group (0.48). Self-transcendence was also found to increase with age ($p<0.05$), with no other contextual variable found to be statistically significant.

The findings of Perry et al., (2005) stated that the likelihood of completing, or having a desire to complete an Advance Directive (AD), was found to be higher in the peer support intervention group compared with the other two groups, the intervention group (printed material) and the control group. Statistically, there was a significant difference in the level of comfort the participants had in discussing AD in the peer support intervention group compared with the other two groups. In analysing the collected demographic data, Perry et al., (2005) identified that the peer support intervention had a greater influence in the completion of AD for ‘African American’ participants than for ‘white’ participants ($p<0.01$).

Both St. Clair Russell et al., (2017) and Sattoe et al., (2013) evaluated the effectiveness of peer support intervention by comparing participants self-reported HRQoL and self-efficacy. St. Clair Russell et al., (2017) reported a statistically significant improvement in most of the psychosocial variables used. Improvements were found in the peer support receivers’ self-efficacy ($p<0.01$), knowledge ($p<0.01$), perceived social support ($p<0.01$), and dialysis social support ($p<0.01$). However, the only physiological measure that improved significantly through the peer support intervention was the reduction in the number of missed haemodialysis treatments ($p=0.02$). General self-efficacy was also found to be statistically significant ($p<0.05$) in Sattoe et al., (2013) study, however disease-related self-efficacy was not found to be significant. St. Clair Russell et al., (2017) reported a significant difference in peer support receivers’ health-related quality of life ($p<0.01$) by using a one-item scale. Sattoe et al., (2013) however, were not able to find significant difference in their overall 36-item HRQoL measure. Sattoe et al., (2013) only found that the social inclusion domain ($p<0.05$), which was part of the 36-item HRQoL measure, achieved a statistical significance ($p<0.05$) in their peer support receivers.

4 Discussion

This systematic review presents the limited available evidence suggesting that peer-to-peer support is an effective intervention in the care of renal patients. The studies found that peer support interventions were beneficial in assisting patients with kidney disease in developing self-transcendence (Milani et al., 2017), self-efficacy and different psychosocial elements of quality of life (St. Clair Russell et al., 2017; Sattoe et al., 2013). Peer support interventions were also found to be effective within palliative care and in increasing renal patients' engagement with AD as they enter end of life care (Perry et al., 2005). The key findings of this review capture the benefits of peer support schemes, this supports existing literature on the effectiveness of peer support as an addition to the treatment of chronic illnesses, including kidney disease (Kapron et al., 1997; Hughes et al., 2009).

In accordance with Dennis' (2003) definitive concept of peer support, all four studies demonstrated the essential elements of emotional, informational and appraisal support as being evident throughout their interventions. It is unclear however, whether any of the interventions included instrumental support elements. Dennis (2003) referred to instrumental support as an attribute of peer support but not a defining one, unlike emotional, informational and appraisal support. The interventions discussed in this review therefore are good examples of peer support that include Dennis' (2003) three defining attributes of peer support.

The findings highlighted the various methods used to conduct peer support. The reviewed studies consisted of interventions that used a single method of peer-to-peer contact and interventions that combined several contact methods. One study used a single method of contact, which was within a group setting (Milani et al., 2017), and the remaining three used a combination of between two to five different methods of peer contact. This is in keeping with Green and Boulware (2016) suggestion that peer support is conducive to several formats within a healthcare setting, including face-to-face programmes, group-based interventions, telephony and online peer support (e.g. email, text messages, website-based interventions).

The studies within this review investigated the effectiveness of peer support for renal patients at different stages of their illness and treatment. Sattoe et al., (2013) study of peer support interventions for young people with ESRD at a week-long camp found that peer support receivers reported improved self-efficacy and social inclusion. This youthful population with ESRD tend to live geographically distant from other similar aged patients (Zheng et al., 2010) and experience social isolation and limited social relationships

(Nicholas et al., 2004). Whereas some other studies have used online resources to access this population, Sattoe et al., (2013) intervention that brought this geographically dispersed age group to one setting seems to have been beneficial in connecting patients with otherwise difficult to reach peers. Peer support for this population is particularly important in supporting young people as they transition from paediatric renal care to adult renal care (Harden & Sherston, 2013).

Limitations of this review

There are limitations to this review that are important to discuss. The four studies were conducted in culturally different countries, which would likely differ in the social perception of the illness and the availability and quality of available RRT treatments. Two of the studies were carried out in the United States of America, one was in Iran and one was from the Netherlands. The studies included recruitment from single hospital settings for two of the studies, one study recruited across 21 treatment centres and another study recruited and was based at a retreat camp for young people. As a result, the generalisability of this review's findings may be limited. A further limitation may be that there was a large variation in the sample sizes and the withdrawal rates of the studies. The withdrawal rates ranged between 6.5% to 27.5%, with only three of the four studies providing an explanation for their dropout rates. Despite the limitations of this review, the studies indicate that peer support is highly beneficial to renal patients but that further empirical evidence is required.

Implications for future practice

Peer support is a growing addition to the treatment of renal disease (Wood, 2015). This review highlights the positive regard that peer support receivers held towards the effectiveness of the additional support from individuals that had shared experiences of living with kidney disease. Three of the four studies spoke about the delivery of training to peer support volunteers. Wood (2014) stated that the provision of adequate training of peer support volunteers was crucial for a safe and high-quality peer support service to be achieved. It is worth considering that in the area of service development for healthcare providers that a standardised training programme for peer support volunteers might enhance patients' experience of care received, for both the peer support receiver and the peer support volunteers. Existing literature suggests that there is generally a low referral rate to peer support programmes, with poor clinician engagement noted as a main contributing factor (Wood, 2018). Improving clinician awareness and support for peer support interventions may enable an increase in a currently underutilised addition to treatment that is not only beneficial to participating patients but also cost effective at a time of reduced resources.

Reflections

Having the chance to conduct this systematic literature review presented a number of challenges that provided opportunities for professional growth. Relatedly, one such challenge was my initial inexperience in conducting systematic literature reviews in its entirety at doctoral level. I did enter this process with some experience of conducting systematic literature reviews in my previous roles as a Research Assistant, however these were in the form of collaborative pieces of work as opposed to working independently as was the case here. As such, I felt it would be useful to build on my knowledge by arranging and attending an additional systematic review workshop offered by City, University of London. The experience from attending the workshop increased the confidence I had in my ability to be solely responsible in delivering a systematic review that could have wider implications.

A further challenge faced was identifying a suitable research area to review that firstly had not recently received a systematic literature review, and secondly met my personal preference of also having the potential to inform my work within the field of renal care. Other topic areas were considered but after conducting a thorough search of the literature they lacked sufficient peer-reviewed articles to continue the review. This was a very time-consuming process that increased a sense of anxiety with regards to additional time pressures. The decision to settle on reviewing the topic of peer support interventions in renal care was very much motivated by there being a small peer support programme facilitated by the department I worked in. Having conducted a search of peer-reviewed articles in this area it was evident that this was a topic that meets the requirements of the doctorate in health psychology.

Through conducting this systematic literature review my personal knowledge and appreciation of peer support programmes has increased markedly. It has resulted in my investigation of the existing peer support scheme at the renal unit where I am employed. Following discussions with senior clinicians, where I have had the opportunity to disseminate the findings of this systematic literature review, it has led to the planning of expanding the opportunities of peer support for renal patients in the department.

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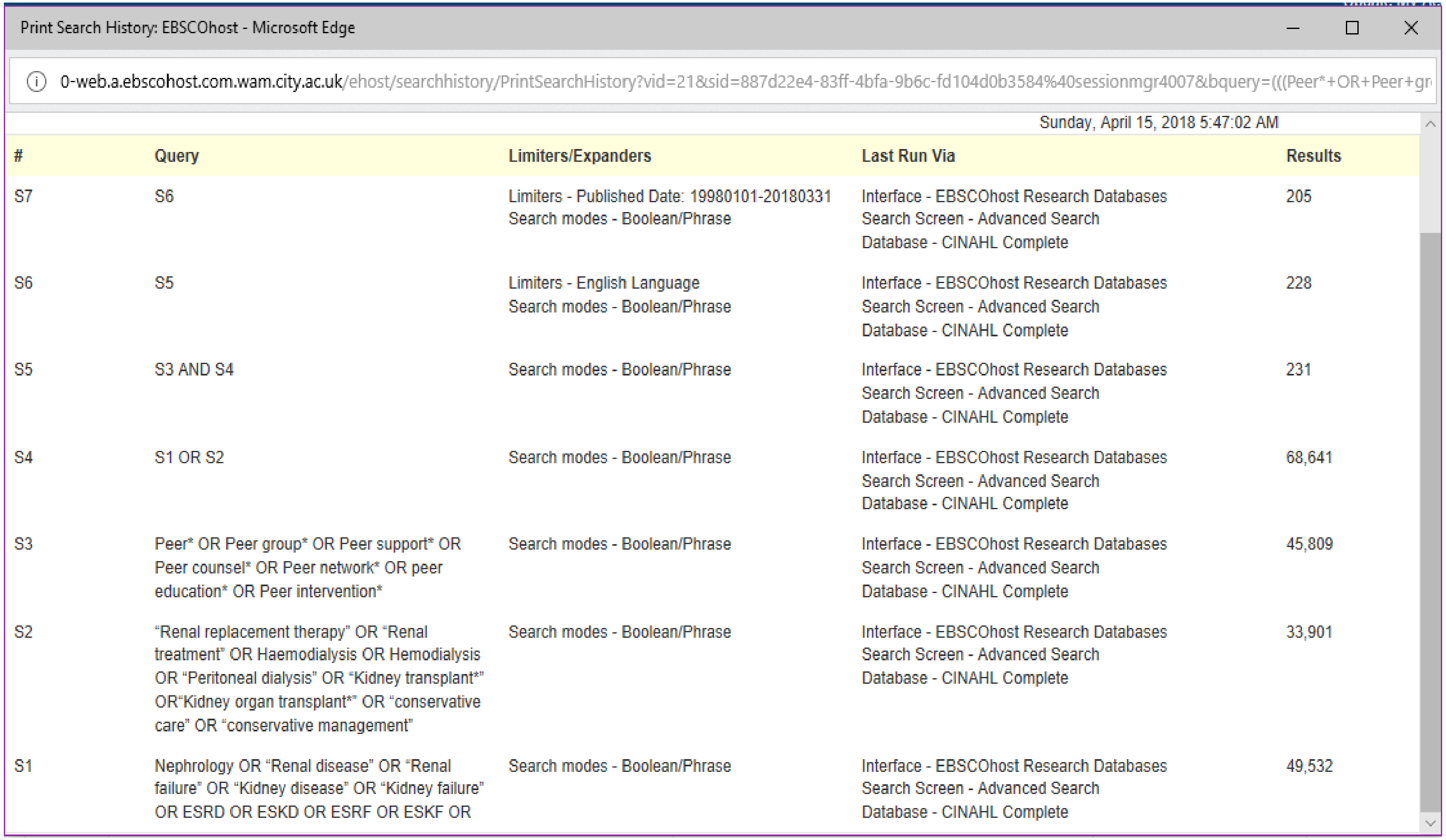
Appendices

Appendix 1: Search History for CINAHL database on EBSCO platform



0-web.a.ebscohost.com.wam.city.ac.uk/ehost/searchhistory/PrintSearchHistory?vid=21&sid=887d22e4-83ff-4bfa-9b6c-fd104d0b3584%40sessionmgr4007&bquery=(((Peer*+OR+Peer+gr

Sunday, April 15, 2018 5:47:02 AM

#	Query	Limiters/Expanders	Last Run Via	Results
S7	S6	Limiters - Published Date: 19980101-20180331 Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205
S6	S5	Limiters - English Language Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	228
S5	S3 AND S4	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	231
S4	S1 OR S2	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	68,641
S3	Peer* OR Peer group* OR Peer support* OR Peer counsel* OR Peer network* OR peer education* OR Peer intervention*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	45,809
S2	“Renal replacement therapy” OR “Renal treatment” OR Haemodialysis OR Hemodialysis OR “Peritoneal dialysis” OR “Kidney transplant*” OR“Kidney organ transplant*” OR “conservative care” OR “conservative management”	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	33,901
S1	Nephrology OR “Renal disease” OR “Renal failure” OR “Kidney disease” OR “Kidney failure” OR ESRD OR ESKD OR ESRF OR ESKF OR	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	49,532

Appendix 2: Quality Assessment tool for articles

Paper Ref. No.:		**Researcher Initials:**		**Total Score:**	

Item No.	Quality Assessment Question	Score 0 = (No) 1 = (Partly) 2 = (Yes)
1	Is the aim of the study clearly stated?	
2	Is the overall design of the study appropriate for answering the research question?	
3	Was an intervention used in the study?	
4	Has a clear description of the intervention been provided?	
5	Is there a control group?	
6	Has demographical data of participants been collected and presented?	
7	Has pre-post questionnaires been used?	
8	Does the study use standardised data collection tools? (e.g. questionnaires)	
9	What was the ‘drop-out’ rate of participants in this study? <15% = 2 <30% = 1 >31% = 0	
10	Are the limitations of the study mentioned?	

Appendix 3: Reference of included articles with their overall quality score

Table 6: *Overall quality assessment score of the included articles.*

Article number	**Reference of included articles**	**Overall quality score out of 20**
1	• Milani, M.J., Amiri, P., Vejdani, M., Salehiniya, H., and Malek-khahi, A. (2017). The effect of peer support group on self-transcendence in patients undergoing haemodialysis. *Biomedical Research & Therapy, 4*(3), 1198-1209.	**18 ½**
2	• Perry, J., Swartz, J., Brown, S., Smith D., Kelly, G., and Schwartz, R. (2005). Peer Mentoring: A Culturally Sensitive Approach to End-of-Life Planning for Long-Term Dialysis Patients. *American Journal of Kidney Disease, 46*(1), 111-119.	**17**
3	• St. Clair Russell, J., Thomson, M., Southerland, S., Meyer, K.B., Huff, E.D., and Lynch, J.R. (2017). A Peer-to-Peer Mentoring Program for In-Centre Hemodialysis: A Patient-Centred Quality Improvement Program. *Nephrology Nursing Journal, 44*(6), 481-489.	**16 ½**
4	• Sattoe, J.N.T., Jedeloo, S., and Van Staa, A. (2013). Effective peer-to-peer support for young people with end-stage renal disease: a mixed methods evaluation of Camp COOL. *British Medical Council Nephrology, 14*(1), 279-292.	**16 ½**