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## **Adolescents' views and experiences of living with Type 1 Diabetes.**

### **ABSTRACT**

This literature review aims to explore the perceptions and experiences of adolescents living with Type 1 Diabetes, and its impact on their lives. The prevalence and the number of adolescents living with this condition are rapidly increasing in western societies. Therefore, it is imperative that these adolescents' views and experiences are well researched and understood, so they can receive the optimum support they need. A systematic database search identified studies conducted between 2004 and 2014, from 5 different countries. Most participants in the studies were adolescents between the ages of 13-17, although some studies included participants from 11 to 18 years. Key findings identified were striving for autonomy, parental conflicts, yearning for social acceptance and concerns regarding diabetes education. Psychosocial, management and knowledge of type 1 diabetes were the major themes identified following the thematic analysis. The psychosocial impact of living with type 1 diabetes was significant amongst adolescents. Therefore, they would benefit from more in-depth research on this subject, identifying contemporary and innovative ways to help them cope better with their condition.

### **KEYWORDS:**

Type 1 Diabetes, Adolescents, Teen, Young, Youth, Views, Opinion, Perspective, Experience, Perception.

### **INTRODUCTION & BACKGROUND**

The focus of this literature review is to explore the views of adolescents living with type 1 diabetes (T1DM) and to analyse its effects on their lives. Therefore, the research question is "What are adolescents' views or experiences of living with Type 1 Diabetes?"

Diabetes Mellitus is a chronic, progressive condition which affects people of any age, and significantly impacts their lives. This is usually caused by the inability of the pancreas to produce insulin, the insufficiency of insulin to meet the body's demands or due to the level of insulin resistance where the body cannot efficiently utilise the insulin produced (Department of Health, DH 2001). The World Health Organisation (WHO, 2014) states that T1DM can be characterised by deficient insulin production which will require daily administration of insulin, and the American Diabetes Association (2014, p.14) discusses the complexity of the condition requiring "multifactorial risk reduction strategies".

T1DM requires lifelong management of the condition, with daily finger prick blood tests, insulin injections and strict dietary monitoring. Blood glucose monitoring is imperative, as frequent episodes of hyperglycaemia or hypoglycaemia can be fatal (Hackworth et al, 2013) and poor adherence to treatment regimen could lead to serious complications and possibly early mortality (Deshpande et al., 2008, Garvey et al., 2014).

According to Royal College of Nursing (RCN, 2004) diabetes is the most prevalent metabolic disorder amongst children and young people, and T1DM is one of the most common chronic conditions in the USA and Europe, and its incidence is continuing to rise (Freeborn

et al, 2012). The UK diabetes statistics also predict a rapid increase in diabetes in the coming years, especially T1DM with an estimated 25,000 people living with T1DM under 25 years of age, in the UK (DH, 2007). The International Society for Pediatric and Adolescent Diabetes (2014) estimates, that each year around 79 000 children world-wide are newly diagnosed with diabetes.

DH (2007) acknowledges that UK has the highest number of children with diabetes and lowest number achieving ideal diabetic control, and the UK diabetes service is not always tailored to meet the specific needs of children and adolescents. The measured outcomes for children and young people in the UK show evidence of significant improvement, however when compared to the rest of Europe, it is at a much slower rate indicating that “diabetic control markers in children are significantly worse than in other countries with comparable information” (DH, 2012, p.18).

Reaching adolescence is an important milestone and a crucial transition period between childhood and adulthood. During this period, they go through significant physical and neurological changes along with a phase of emotional development, that they yearn for greater independence, explore new experiences and tend to test boundaries (DH, 2009). Therefore, managing a chronic condition like T1DM whilst undergoing psychosocial and hormonal turbulence of puberty, can be a major challenge for adolescents (Winocour, 2014, Zimmermann et al. 2008) and hence the likelihood of non-adherence to treatment is high during this period (Mlynarczyk, 2013). Therefore, it is imperative to understand the reasons for non-adherence and work collaboratively with adolescents to promote adherence to treatment.

## **METHOD**

### ***2.1 Databases:***

Databases were accessed via City University Library’s EBSCOhost platform.

### ***2.2 Key words / Search Terms:***

The keywords identified from the research question were ‘adolescents’, ‘experiences’ and ‘Type 1 diabetes’. Synonyms for key words were grouped as ‘search terms’ and searched in the abstracts (AB) of the EBSCOhost advanced search, to ensure only relevant studies appear in the search results.

### ***2.3 Boolean Operators / Truncation:***

The Boolean operator ‘OR’ was used with key words to widen the search. Truncation asterisk was applied to keywords to cover wide search terms such as adolescents, adolescence, teens, teenagers, views, opinions, perspectives, experiences, experiencing, perceptions, diabetes and diabetic.

- **Search term 1 (S1):** adolescenc\* OR teen\* OR young OR youth **(1,761,626 results)**
- **Search Term 2 (S2):** view\* OR opinion\* OR perspective\* OR experienc\* OR perception\* **(5,342,266 results)**
- **Search Term 3 (S3):** diabet\* OR type 1 OR T1DM OR T1D **(1,289, 207 results)**

#### **2.4 Abstracts:**

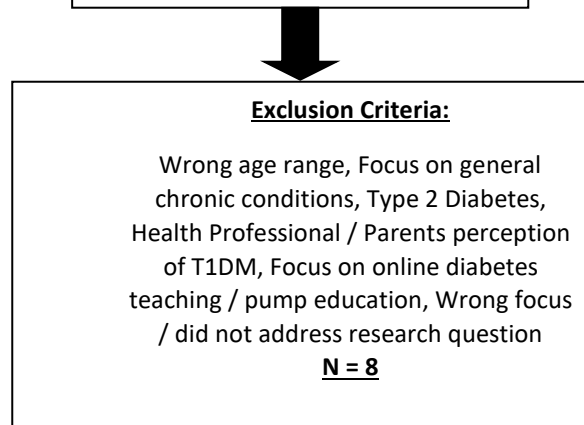
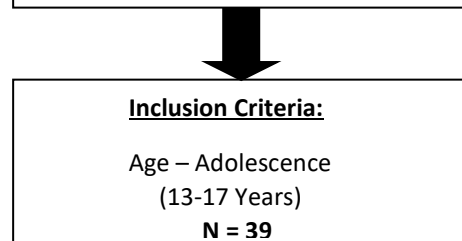
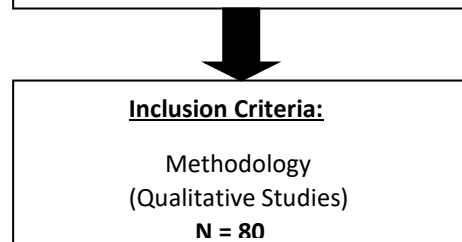
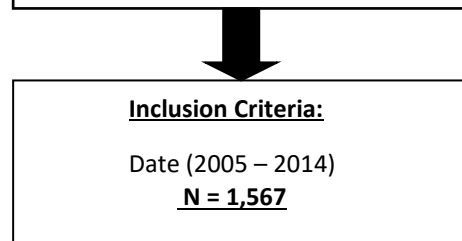
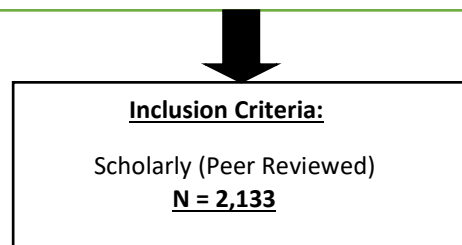
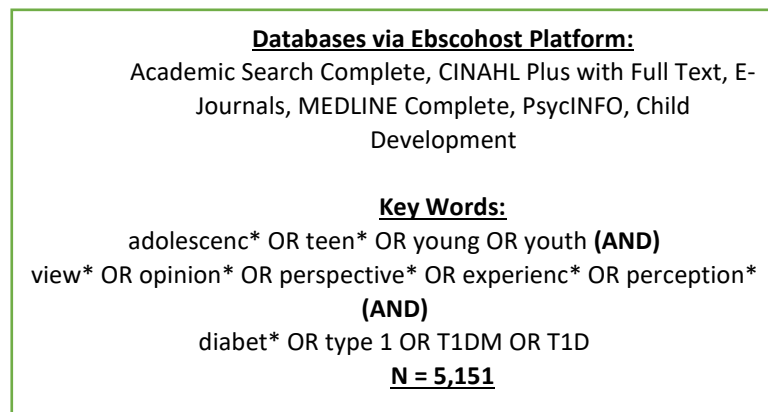
The abstracts of these 39 articles were read to understand the purpose of these studies, and a further 27 articles were excluded.

#### **2.5 Papers:**

After reading and analysing the 12 articles, another 4 were excluded as they focussed on the wrong age or the parents and HCP's views. Therefore the systematic database search resulted in 8 final articles, for this literature review.

#### **2.6 Critical Appraisal Tool:**

All 8 articles have used qualitative methods for their studies; therefore the Critical Appraisal Skills Programme's (CASP) Qualitative Checklist (CASP, 2014) was used to critically appraise these articles.



## **FINDINGS:**

An article summary table was developed utilising CASP qualitative checklist, and each article was analysed in relation to the following headings:

- Date
  - Country & Discipline
  - Aim of the study
  - Methods
  - Sample size & Gender
  - Ethics & Consent
  - Key Findings
  - Recommendations for practice
  - How does the study answer the research question?
- (Further details could be obtained from the authors)***

The database search resulted in 8 studies from the UK, Australia, Sweden, USA and Iran, between the years 2004 and 2014. All studies used qualitative methods to capture the views and experiences of the participants. Therefore, these studies were analysed using the CASP Qualitative Critical Appraisal Tool. The findings from these studies were grouped together and common themes were identified.

This literature review only focussed on studies within the last 10 years as recommended by Coughlan et al (2013) to understand the contemporary experiences of adolescents with T1DM. All articles have a clear statement of the aims and have justification of research topics.

The criteria by Lincoln and Guba (1985) is considered the 'gold standard' for assessing trustworthiness of qualitative studies based on credibility, dependability, confirmability and transferability (Polit and Beck, 2014). Maslakpak et al's (2010) study from Iran is a detailed, rigorous research; however due to the disparities in the healthcare systems of developing countries, the transferability of the results should be treated with caution.

According to Polit and Beck (2010) ethics committee approval is essential prior to starting any research to ensure standards are upheld during the process (Green and Thorogood, 2009). Studies by Waller et al (2004), Visentin et al (2005), Karlsson et al (2006) Viklund & Wikblad (2009) Maslakpak et al (2010) and Serlachius et al (2011) clearly state that ethical approval was gained prior to conducting their research. But studies by Carroll et al (2007) and Sullivan-Bolyai et al (2014) are ambiguous in their declaration of ethical approval. However Polit and Beck (2010) also acknowledge that due to word limitations, researchers may omit ethical procedure information; therefore critiquing their adherence to ethical guidelines can be impossible.

As a measure of safeguarding the participants and acknowledging their rights, it is crucial to gain informed consent for any research (Polit & Beck, 2014). All studies, except Maslakpak et al (2010) clearly mention gaining informed consent from participants by signing the forms. Goodwin (2006) recognises the difficulties of informed consent, especially in qualitative studies due to the nature of data collection, and the inability to fully inform the participants prior to research. Yet, this can be considered a potential limitation in Maslakpak et al (2010) study.

All adolescents recruited for these studies live with T1DM, therefore the sample was purposefully selected as stated by Carroll et al (2007) utilising a convenience sampling method. Waller et al (2004), Carroll et al (2007) and Sullivan-Bolyai et al (2014) included the adolescent's parents, and Visentin et al (2005) included the HCPs in their samples. The purpose of this literature review was to explore the adolescent's experiences, therefore only the adolescents were considered as 'sample' and only their views were discussed, to keep this literature review concise and focussed.

The sample size of qualitative studies are small, as researchers seek in depth understanding of participant's experiences (Coughlan et al, 2013). Although there is no ideal sample size for qualitative studies, it is good practice to keep sampling until data saturation is achieved (Green and Thorogood, 2009). However, it can seldom be achievable due to financial and time constraints (Coughlan et al, 2013) therefore the sample size of all these studies can be considered satisfactory.

All articles used qualitative methods utilising interviews, focus groups, or a combination of both. Qualitative researches follow an emergent design, which evolves during the process to understand a phenomenon in the participant's context (Polit & Beck, 2014). Hence all the studies have adapted a suitable methodology for their research.

The studies were compared, summarised and the findings were synthesised using thematic analysis which is commonly used for qualitative studies (Coughlan et al, 2013). Recurrent core themes identified were the psycho-social effects T1DM, its management and knowledge.

### ***1. Psycho-social effects of living with T1DM:***

This theme was emphasised across all studies, covering the psychological effects of T1DM and its influence on social network and their daily routine. Studies by Waller et al (2004), Karlsson et al (2006), Maslakpak et al (2010), Serlachius et al (2011) and Sullivan-Bolyai et al (2014) report adolescents living with anxiety, mainly about the blood testing or administering insulin in public or at school and about long term complications of the condition. Others admitted feeling embarrassment or inconvenience in injecting insulin in public. Karlsson et al (2006) referred to the adolescents' experience as 'emotional struggle' and 'psychological burden', reflecting the psychological impact of T1DM. Visentin et al (2005) studied the views of adolescents on transition between diabetic services, and identified anxiety due to lack of psychological preparation for transition to adult services. Adolescents also reported that adult services were less friendly and more formal, thus increasing their anxiety. Similarly adolescents in Sullivan-Bolyai et al (2014) study expressed anxiety due to negative attitudes from the HCPs.



While some adolescents have reported anxiety due to the above reasons, adolescent girls from Iran (Maslakpak et al, 2010) have expressed significant concerns about finding a partner, marriage, pregnancy and possible discrimination in their future career due to T1DM. They also disclosed being more restricted and disadvantaged at home because they are females, feeling insecure and being teased for having diabetes, therefore they tend to keep diabetes as their secret.

Adolescents' desire for socialisation, peer acceptance and normality were highlighted by Karlsson et al (2006), Carroll et al (2007), Viklund and Wikblad (2009), and Serlachius et al (2011). All adolescents reported feeling motivated, secure and inspired to adhere to treatment, when they have social acceptance. In Carroll et al (2007) study, they mentioned seeking validation from peers on their T1DM management strategies. However, Maslakpak et al (2010) identified slightly varied perspective of adolescents. Due to the lack of T1DM awareness in the Iranian community and the fear of being isolated or rejected, disclosure of their condition was a major decision for adolescents and some choose to keep it as their secret. Yet, this study too highlights the longing of adolescents' for their peer's company and acceptance.

## ***2. Management of T1DM:***

This theme discusses adolescents' views on autonomy and parental support, in managing their condition. Studies by Waller et al (2004), Karlsson et al (2006), Viklund and Wikblad (2009) and Serlachius et al (2011) show that most adolescents want to be independent and seek autonomy in their diabetes management. Viklund and Wikblad (2009), Serlachius et al (2011) and Sullivan-Bolyai et al (2014) found that adolescents appreciated the right level of parental involvement, and preferred shared management of diabetes. However, they admitted that too much parental involvement or supervision leads to annoyance, conflicts, humiliation and anger, resulting in demotivation and non-adherence to treatment.

Karlsson et al (2006) showed that although most adolescents strived for autonomy, they were hovering between being independent and relying on parental support, leading to confusion and conflicts. Similarly, Waller et al (2004) and Serlachius et al (2011) studies have expressed adolescents' anxieties about becoming autonomous, especially in administering insulin during school times. Maslakpak et al (2010) study, discusses the restriction imposed on adolescents and constantly being reminded that 'they are ill' significantly hinders self-management of T1DM. These findings highlight the adverse psychological impact, poor diabetes management can have on adolescents, leading to negative psychological impact.

Adolescents from Karlsson et al (2006) and Viklund and Wikblad (2009) studies see management of T1DM, from a knowledge based perspective. They believed that in order to self-manage diabetes, they need the cognitive maturity and self-determination. They admitted that lacking the knowledge and complete understanding of diabetes makes them insecure, leading to the belief that their parents have more knowledge about T1DM. Therefore, they express their desire to gain more knowledge, so they can be more independent in managing T1DM.

### **3. Knowledge:**

This theme covers knowledge of adolescents, parents, teachers, peers and community. The major concern expressed across all studies is the lack of knowledge and awareness regarding diabetes, which contributes to psycho-social issues and non-adherence. Waller et al (2004) and Maslakpak et al (2010) studies talk about the challenges adolescents face when teachers lack T1DM knowledge, while Maslakpak et al (2010) elaborate on this further, and explore adolescents views on negative reaction from peers, teachers and community due to lack of knowledge.

Adolescents in Visentin et al (2005) study identified gaps in their knowledge and commented about the lack of formal education review since their diagnosis. Similarly, Serlachius et al (2011) expressed adolescents' desire to clarify doubts, refresh knowledge and to improve self-management skills. They also acknowledged being confused about certain aspects of their treatment, and suggested a more skill-based education system to improve knowledge and to promote autonomy.

## **DISCUSSION**

The three major themes identified were psychosocial, management and knowledge. The impact of T1DM, on the psychosocial wellbeing of the adolescents is a well-researched subject with comprehensive evidence to support these claims. This literature review identified various subthemes of psychosocial effects such as striving for normality, dealing with family conflicts, seeking peer acceptance and the emotional burden of living with diabetes. Studies by Luyckx et al (2008) and Zimmermann et al. (2008) state that adolescence is a testing developmental stage, which can become more challenging if they have a chronic condition like T1DM. Similarly, Winocour (2014, p.274) claim that coping with T1DM through the 'hormonal and psychosocial turbulence of puberty and adolescence' puts added stress on the individual. NICE guidelines (2004) acknowledges the degree of psychosocial impact T1DM can have on the adolescents, and emphasises that the Diabetes Teams should be aware of the greater risk of these individuals developing emotional and behavioural problems. Williams et al (2009) also expressed similar concerns in their studies, stating that adolescents with T1DM are two to three times more likely to experience depression, than adolescents in general. Therefore the NICE guidelines (2004) recommend that these adolescents and their families should have timely access to mental health professionals, to help them deal effectively with their psychological disturbances due to living with T1DM.

Many studies have explored the relationship between the adolescents and parental conflicts due to disparities in their diabetes management styles. Holmbeck (1996) claims that due to various psychological, developmental and social changes during adolescence, conflicts are highly probable as a result of discrepancies in their perception of 'autonomy' between adolescents and their parents. Studies by Herzer (2011), Hilliard et al (2013) and Luyckx et al (2013) have all discussed the various reasons for conflicts and have made explicit correlation

between conflicts and decreased adherence or suboptimal diabetes control. Therefore, there is compelling evidence of decreasing adherence to treatment and deterioration of glycaemic control during adolescence. Hence, this concern should be appropriately addressed and adolescents should be well supported through this developmental stage to adhere to treatment regimen.

Management of T1DM was another theme highlighted across most of the studies, with a majority of adolescents expressing a desire for autonomy, while some others preferred a shared responsibility with their parents. Studies by Skinner et al. (2000) and Wysocki et al. (2000) show that parenting styles which involve positive relationships with adolescents, effective communication and promoting independence, results in better glycaemic control in adolescents. Similarly, Luyckx and Seiffge-Krenke (2009) claim that, optimum parental involvement during adolescence, will encourage them to have a good glycaemic control as adults. Although most parents are eager to encourage autonomy in adolescents, they often continue to monitor and participate in the care, due to the difficulty in letting them completely take control of their T1DM management (Wennick et al. 2009, Sparud-Lundin et al. 2010). The Department of Health (DH, 2004) National Service Framework for Children, Young People and Maternity Services (NSF, 2003) state that children reaching adolescence, and yearning for more independence is a testing time for parents, therefore they find it difficult to manage the transition effectively. However, due to all the additional psychological stresses of adolescence, they often tend to see the monitoring of their parents as being controlling or intrusive. Therefore, it is crucial that adolescents are supported and encouraged through this stage to be more responsible for their health, so that they can become independent adults in the future.

Knowledge was another major theme highlighted by most adolescents across the studies. Adolescents showed eagerness to keep their knowledge and skills updated, and expressed concerns of lack of T1DM awareness in the communities and school. RCN (2013) acknowledges the inequalities in meeting the needs of children and adolescents in the school setting, and clearly sets out guidelines that Health Care Professionals and education staff should follow in order to meet the adolescents' needs. The DH (2007) also emphasises the need for individualised care plan for every child and young person with diabetes at school. Similarly, the Department for Education (2015) recognises all of the above concerns and the complexities of managing chronic conditions during school times, and clearly stipulates the roles and responsibilities of the governing bodies, proprietors and management committees in order to consolidate all the support network available, to effectively manage the child's condition at school. Therefore, implementing and adhering to these guidelines rigorously, will increase awareness of diabetes, promote autonomy and compliance to treatment, and outline everyone's responsibilities in providing optimum support to adolescents with T1DM.

## IMPLICATIONS FOR FUTURE PRACTICE

| Practice & Health Care Delivery  | Education  | Research  |
|--|--|---|
| HCPs to acknowledge the psychosocial impact of T1DM on adolescents and treat them holistically, especially focussing on their psychological wellbeing. | Increase T1DM awareness in the community to promote normality and adherence to treatment   | More research to identify ways of helping adolescents to effectively deal psychosocial effects of living with T1DM and to overcome the barriers.                          |
| Effective collaboration between the diabetic nurses, dieticians and the medical team to bridge the gaps in the care of the adolescents                 | Update adolescents' knowledge and skills to promote autonomy.  | More qualitative research to gain an in-depth understanding of the adolescents' concerns, to reduce psychological stress and to improve better coping strategies and QoL. |
| To follow a standardised, sensitive approach during diabetic clinics.  | Parental education to promote independence, reduce conflicts and to improve QoL.   |   |
|  | Teachers to be re-educated / updated on contemporary treatment and training to deal effectively with hyper / hypoglycaemic episodes during school hours. |   |
|  | Replacing traditional training with more contemporary, IT based training to re-educate / update adolescents and community.                               |   |

## **CONCLUSION**

This literature review explored the views and experiences of adolescents with T1DM and addressed the research question. The psychosocial impact of living with T1DM was highlighted across all the studies. The concerns regarding management and knowledge of T1DM, emerged as main themes across most studies. Changes should be made in practice and management, to incorporate more collaborative clinics with adolescents and MDT. Ongoing refresher courses and contemporary advice should be available to adolescents. Training should be available to families, educational staff and community to promote T1DM awareness and treatment regimens. These strategies could address the adolescents' concerns, promote adherence to treatment and ultimately improve their QoL.

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