

Experiences of adolescents with Type 1 Diabetes Mellitus on treatment adherence

L van der Westhuizen

23278285

Dissertation submitted in fulfilment of the requirements for the degree *Masters of Arts* in Psychology at the Potchefstroom Campus of the North-West University

Supervisor: Dr W de Klerk

Co-Supervisor: Ms C Kahl

Assistant Supervisor: Dr R Pretorius

November 2014

CONTENTS

Acknowledgements	iii
Summary	iv
Opsomming	vii
Preface	x
Permission Letter from Supervisors	xi
Section 1: Introduction (orientation and problem statement)	1
Section 2: Article: Experiences of adolescents with Type 1 Diabetes Mellitus	
on treatment adherence	28
2.1 Guidelines for authors: <i>Journal of Social Sciences and Medicine</i>	29
2.2 Manuscript: Experiences of adolescents with Type 1 Diabetes Mellitus	
on treatment adherence	42
Section 3: Critical reflection	78
Complete Reference List	84
Addendum	98

Acknowledgements

All the glory to **God my Heavenly Father**, this study would not have been possible without Your grace and love.

Herewith I would like to thank the following people for your contribution, support and leadership to make this study possible:

- **Dr. Werner de Klerk**, my study leader, for your proficient leadership, precision, motivation and support. Without your help completion of this study would not have been possible.
- To my co-study leaders **Ms. Carlien Kahl** and **Dr. Ronel Pretorius** for your valuable contributions.
- **Dr. Jacobus van Dyk** and **personnel** for your willingness to help with my study – I will be forever grateful for the opportunity. Dr. Van Dyk you will always be an inspiration.
- To the **participants** and **their parents** in my study. Thank you for your willingness to share your experiences and the time and effort you put in that made it all possible.
- My **mother, parents-in-law** and **family** for your on-going support, motivation and faith to help me completing my study.
- My **husband, Jandre**, thank you for your unconditional love – I am a better person because of you.
- To my **father**, you still inspire me to become the best at what I do and to never give up. I miss you every day.
- To my three precious **children, Christiaan, Adriaan** en **Leah**. Thank you for you love – you are my everything!
- To my **friends** and **colleagues** – thank you for your support and understanding.

SUMMARY

Experiences of adolescents with Type 1 Diabetes Mellitus on treatment adherence

Keywords: Adolescents, Type 1 Diabetes Mellitus, treatment regimen, psychological well-being, physical well-being.

Type I Diabetes Mellitus (T1DM) is a major health problem and a burden for affected young individuals, as well as for society. It is among the most prevalent paediatric disorders, affecting an estimated 1.7 per 100 children and adolescents. Given the complexity of diabetes treatment regimens, it is not surprising that children, adolescents, and their families often have difficulty adhering to these regimens. Studies have found that the overall adherence rate among children and adolescents with diabetes is about 50%. It has also been found that adherence to T1DM often tends to decrease when the adolescent begins to assume most of the responsibility for managing the disease and the parents' role starts to decline.

However, literature indicates that adolescent patients' adherence is poor and an important strategy to improving their metabolic control is to increase self-care. The most common age of onset for T1DM is between 10-14 years. The adolescent population is highly neglected in current research on diabetes, because the focus tends to favour children and not adolescents. It is widely recognised that glycaemic control in adolescents is complex, challenging and dependent on interconnected relationships between numerous inputs at individual, family, community and health service levels. Optimal care of adolescents with diabetes has not been subjected to rigorous scientific studies, and research results related to optimal glycaemic control are conflicting.

Development and continuous evaluation of best practices pertaining to diabetes mellitus remains one of the major objectives of diabetes care, possibly allowing a delay in and/or prevention of later complications. Research indicates that adolescence is the one age group where there has been no discernible improvement in health over the last 20 years. A great number of research studies on the subject of diabetes are done globally, but less literature, especially in the South African context, can be found that focuses on and explain the experiences of adolescents with T1DM with regard to their treatment adherence.

This qualitative study explored the experiences of adolescents with T1DM. A purposive sample (n=7) of young adolescents between the ages of 13 and 15 willingly participated in the research study to explore and describe their experiences with managing their treatment regimen. In-depth interviews were conducted to collect rich descriptive data, followed by participants' verbal reflections once a week for the duration of a month. After the in-depth interviews and weekly reflections, the researcher held a focus group interview with all the participants. Transcribed data were analysed by means of thematic analysis from which themes and subthemes were derived. The participants expressed both positive and negative emotions associated with their diabetes; they experienced a lack of understanding by significant others because of a lack of knowledge, interest or support regarding their diabetes; they mentioned that they continually need age-appropriate support and parental involvement, even though they manage diabetes through their own processes; and lastly, participants struggled with a fear of friends' and peers' perceptions.

From the findings it is clear that in order to cope, the adolescents need not only medical treatment and education about diabetes (T1DM), but emotional support, supervision and repeated reinforcement to achieve effective self-management. The basic suggestion is that diabetes care

for children and young people should include routine assessment of the psychological and social pressures on the adolescent and the family so that strategies can be put in place to give support and education as needed and as appropriate. The researcher also recommends that school personnel must be educated about diabetes so that they can understand the changing medical and psychosocial needs of the adolescent and can help him/her to participate fully in all the available work, sport, and leisure activities. Models of legislation and training programmes for school staff specifically addressing the needs of children with diabetes in school have been developed in a number of countries such as Greece, Germany, Italy, Poland, Spain, Sweden, the UK and the USA. These programmes should be considered as an example to other countries. These best practices can serve as a foundation for national improvement.

OPSOMMING

Ervaringe van adolossente met Tipe 1 Diabetes Mellitus ten opsigte van nakoming van
behandeling

Sleutelwoorde: Adolossente, Tipe 1 Diabetes Mellitus, behandelingsregimen, sielkundige
welstand, fisiese welstand.

Tipe 1 Diabetes Mellitus (T1DM) is 'n groot gesondheidsprobleem en 'n las vir
geaffekteerde individue en vir die samelewing. Dit is een van die mees algemene pediatriese
siektes en beïnvloed 'n geskatte 1.7 per 100 kinders en adolossente. Gegewe die kompleksiteit
van diabetes behandelingsregimens, is dit nie verrassend dat kinders, adolossente en hulle
gesinne dikwels sukkel om by hierdie regimens te hou nie. Studies het gevind dat die oorhoofse
nakomingsyfer onder kinders en adolossente met diabetes sowat 50% is. Daar is ook bevind dat
nakoming van die behandeling van T1DM dikwels afneem sodra die adolossent die meeste van
die verantwoordelikheid vir die bestuur van die siekte begin dra en die ouers se rol begin afneem.

Die literatuur dui egter aan dat adolossente se nakoming sleg is, en 'n belangrike strategie
vir die verbetering van hulle metaboliese beheer is om selfsorg te bevorder. Die algemeenste
ouderdom vir die aanvang van T1DM is tussen 10-14 jaar. Die adolossente bevolking word baie
afgeskeep in huidige navorsing oor diabetes, want die fokus neig na kinders, en nie adolossente
nie. Dit word oraloor erken dat glisemiese beheer in adolossente kompleks en uitdagend is en
afhang van insette op 'n individuele, gesins-, gemeenskaps- en gesondheidsorgvlak. Hierdie
verskillende insette staan in 'n onderlinge verhouding. Optimale sorg van adolossente met
diabetes is nog nie onderwerp aan nougesette wetenskaplike studie nie, en navorsingsresultate
met betrekking tot optimale glisemiese beheer is teenstrydig.

Die ontwikkeling en voortgesette evaluering van beste praktyke met betrekking tot diabetes mellitus bly een van die hoofdoelwitte van diabetessorg. Sodoende kan latere komplikasies uitgestel en/of voorkom word. Navorsing dui aan dat adolessente die enigste ouderdomsgroep is waar daar geen waarneembare verbetering in gesondheid was oor die laaste 20 jaar nie. Daar word wêreldwyd 'n groot hoeveelheid navorsing gedoen oor die onderwerp van diabetes, maar min literatuur is te vinde wat fokus op en die ervaringe van adolessente met T1DM of wat hulle behandelingsregimen verduidelik, veral in die Suid-Afrikaanse konteks.

Hierdie kwalitatiewe studie ondersoek die ervaringe van adolessente met T1DM. 'n Doelgerigte steekproef (n=7) van adolessente tussen die ouderdomme van 13 en 15 het vrywilliglik deelgeneem aan die navorsingstudie om hulle ervaring rakende die bestuur van hulle behandelingsregimen te ondersoek en te beskryf. In-diepte onderhoude is gevoer om ryk beskrywende data in te samel, gevolg deur deelnemers se verbale besinning een maal per week vir die duur van 'n maand. Na die in-diepte onderhoude en weeklikse besinning, het die navorser 'n fokusgroep-onderhoud met al die deelnemers gevoer. Getranskribeerde data is geanaliseer deur middel van tematiese analise, waaruit temas en subtemas afgelei is. Die deelnemers het beide positiewe en negatiewe emosies oor hulle diabetes uitgedruk. Hulle ervaar 'n gebrek aan begrip, belangstelling en ondersteuning met betrekking tot hulle diabetes by geliefdes weens 'n gebrek aan kennis. Hulle noem dat hulle gedurig ouderdomsgepaste ondersteuning en oerbetrokkenheid nodig het, selfs al bestuur hulle die diabetes deur hulle eie prosesse, en laastens sukkel deelnemers met vrees rondom die persepsies van vriende en hulle portuurgroep.

Dit is duidelik uit die bevindinge dat adolessente nie net mediese behandeling en onderrig oor diabetes (T1DM) nodig het om dit suksesvol te hanteer nie, maar ook emosionele ondersteuning, toesig en herhaalde versterking sodat hulle effektiewe selfbestuur kan bereik. Die

basiese voorstel is dat diabetessorg vir kinders en jongmense roetine-assessering van sielkundige en sosiale druk op die adolessent en die gesin moet insluit om sodoende strategieë in plek te sit om steun en onderrig te gee soos nodig en soos gepas. Die navorser stel ook voor dat skoolpersoneel opgelei moet word oor diabetes sodat hulle die veranderende mediese en sielkundige behoeftes van die adolessent kan verstaan en hom/haar kan help om ten volle in die beskikbare werks-, sport- en ontspanningsaktiwiteite deel te neem. Modelle van wetgewing en opleidingsprogramme vir skoolpersoneel wat spesifiek die behoeftes van kinders met diabetes in skole aanspreek is al ontwikkel in lande soos Griekeland, Duitsland, Italië, Pole, Spanje, Swede, die Verenigde Koninkryk en die VSA. Sodanige programme moet in ag geneem word as voorbeelde vir ander lande. Hierdie beste praktyke kan dien as die fondasie vir nasionale verbetering.

PREFACE

- This dissertation is in article format as described in rules A 4.4.2.3 and A 5.4.2.1 of the North-West University.
- The article will be submitted for possible publication in the Journal of Social Science and Medicine.
- The referencing and editorial style of this dissertation are in keeping with the guidelines as set out in the Publication Manual (6th edition) of the American Psychological Association (APA). The article is compiled according to the guidelines of the journal in which the article will be submitted.
- In order to present the dissertation as a unit, the page numbering is consecutive, starting from introduction and proceeding to the references.
- Dr Werner de Klerk, Ms Carlien Kahl and Dr Ronel Pretorius, co-authors of the article included in this dissertation, have provided consent for the submission of this article for examination purposes in fulfilment of the requirements for a Masters of Arts degree in Psychology.
- This dissertation was language edited by Cum Laude Language Practitioners (CC).
- The in-depth interviews, weekly reflections and focus group were conducted in Afrikaans. Please see Addendum for Afrikaans translation to English.
- The dissertation was submitted to Turn-it-in and the report found that the dissertation is within the norms of acceptability.

LETTER OF CONSENT

Permission is hereby granted for submission by the first author, L. van der Westhuizen, of the following article for examination purposes towards obtaining a Masters of Arts degree in Psychology:

Experiences of adolescents with Type 1 Diabetes Mellitus on treatment adherence.

The role of the co-authors was as follows: Dr Werner de Klerk, Ms Carlien Kahl and Dr Ronel Pretorius acted as supervisor and co-supervisors respectively. Dr Werner de Klerk and Ms Carlien Kahl assisted with the coding and re-coding of the qualitative research data. Dr Werner de Klerk, Ms Carlien Kahl and Dr Ronel Pretorius peer reviewed this article.



Dr Werner de Klerk

Supervisor

SECTION 1: INTRODUCTION

Introduction

This section of the dissertation offers an in-depth literature review on Type 1 Diabetes Mellitus (T1DM: with a specific focus on adolescents with T1DM and their adherence) to ensure that the reader gains a comprehensive understanding of this phenomenon. The following topics are discussed shortly: the definition of diabetes; adherence; T1DM in adolescents; complications of T1DM; T1DM adolescents and the role of their peers; T1DM and psychological well-being; T1DM challenges in school; T1DM and the effect on the family; T1DM and age and gender. In addition, the section offers a problem statement, the aim of the study and the structure of the research.

Literature Review

Definition of T1DM

Type 1 Diabetes Mellitus (T1DM) is a major public health problem and a burden for affected young individuals, as well as for society (Wodrich, Hasan, & Parent, 2011). It is among the most prevalent paediatric disorders, affecting an estimated 1.7 per 100 children and adolescents worldwide (Wodrich et al., 2011). T1DM is defined worldwide as a lifelong metabolic disorder brought about by the failure of the human pancreas to produce insulin (Holker, 2008). Insulin is a hormone that regulates carbohydrate and fat metabolism, allowing life-sustaining energy in the form of glucose to enter body cells (Children's Diabetes Foundation at Denver, 2007, as cited in Holker, 2008).

Adherence

Living with T1DM includes pricking a finger approximately two times a day to monitor blood glucose levels and the subsequent injection of insulin. Dosages are calculated based on the child's blood glucose level, food intake and physical activity (Silverstein, et al., 2005). Children and adolescents with T1DM must comply with a treatment regimen to maintain glycaemic control (Lewin, et al., 2006). Glycaemic control is the ability to sustain blood glucose levels within near-normal ranges (Liles & Juhnke, 2008). Optimal glycaemic control is the most difficult to establish and maintain during the early adolescent period because of the normal insulin resistance that occurs during puberty (Holker, 2008; Leonard, Garwick, & Adwan, 2005; Weibe, et al., 2005; Wysocki & Greco, 2006).

Given the complexity of diabetes treatment regimens, it is not surprising that children, adolescents, and their families often have difficulty adhering to them (Delamater, 2006). Family factors, and particularly parental behaviours, have been shown to be important for treatment compliance and glycaemic control in children and adolescents (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). The complexity of treatment in T1DM places great demands on the caregivers of children and adolescents with diabetes, particularly their mothers, who are responsible for most of the treatment management (Kovacs et al., 1985). Better metabolic control is seen among adolescents who have higher levels of parental involvement and lower levels of family conflict (Grey et al., 1998).

Studies have found that the overall adherence rate among children and adolescents with diabetes is about 50% (Stewart, Emslie, Klein, Haus, & White, 2005). It has also been found that adherence to T1DM often tends to decrease when the adolescent begins to assume most of the responsibility for managing their disease, while the parents' role declines (Weibe et al. 2005).

In fact, one study from Scotland showed that of 89 adolescent patients, 28% were using less insulin than prescribed (Fleming, Carter, & Warren, 2002). Adolescent patients' adherence are notoriously poor and an important strategy to improve their metabolic control is to increase their self-care (Stewart et al., 2005). It has become clear that this transition of care is often problematic.

T1DM in Adolescents

Adolescence encompasses a period of life during which physical, psychological and sociological maturity and independence are intermingled and when chronic illness and disability pose additional challenges for the individual and his/her family (Coleman, Kloep, & Kloep, 2007). A major task for families who deal with diabetes involves reorganisation within the family to renegotiate and redistribute responsibilities and obligations so that there is interdependence between the adolescent and parents with respect to diabetes (Anderson et al., 1997).

According to Viner and Barker (2005), adolescence is probably the most turbulent, challenging, stressful and uncertain of all phases in life, both for teenagers and for their parents, teachers and health professionals. The American Diabetes Association (2007) estimates that three quarters of all cases of T1DM are diagnosed in people younger than 18 years of age. The most common age of onset for T1DM is between 10-14 years (Faulkner, 2003). The adolescent population is highly neglected in current research regarding diabetes (Skinner, Channon, Howells, & McEvilly, 2000). According to Viner and Barker (2005), the focus tends to favour children and adults, and not adolescents. Adolescence is the transitional phase of development between childhood and adulthood that incorporates the biological and psychosocial changes of puberty (Coleman et al., 2007).

It is widely recognised that glycaemic control in adolescents is complex, challenging and dependent on interconnecting relationships where there is input at individual, family, community and health service levels (Cooper & Geyer, 2007). While contending with peer influences, school life and developing autonomy, adolescents with T1DM have the added task of developing independence in self-management of diabetes (Spencer, Cooper, & Milton, 2012).

Within this age group, adolescents with a disability or chronic disease have been referred to as ‘the forgotten tribe’ as their needs are often missed in the transition from paediatric to adult services (Viner & Barker, 2005). They have gained the reputation for being difficult and less rewarding to manage than younger children and mature adults (Viner & Barker, 2005).

The impact of chronic illness can be considerable and are amplified by the challenges of the child-adult transition. Even apparently minor illnesses can have a significant impact, resulting in isolation, stigmatisation and handicap (Skinner et al., 2000). The transition from child to adult poses unique challenges to the individual with diabetes, their family, and the diabetes care team (Skinner et al., 2000). Optimal care of adolescents with diabetes has not been subjected to rigorous scientific studies, and research results on optimal glycaemic control are conflicting. The development and continuous evaluation of best practice in diabetes mellitus remains one of the major objectives in diabetes care, possibly allowing a delay in and/or prevention of later complications (Lind, Oden, Fahlen, & Eliasson, 2009).

Complications of T1DM

There are two potentially fatal complications associated with T1DM. The first is diabetic ketoacidosis (DKA), which is a result of dangerously high blood sugar levels, usually resulting from too little insulin or severe physical stress or infection (Holker, 2008). DKA continues to be an important cause of morbidity and mortality in patients with T1DM (Krentz, 2004). All

episodes are, at least theoretically, avoidable, since administration of sufficient doses of insulin should avert major metabolic decompensation (Krentz, 2004). The second is hypoglycaemia, which can result from too much insulin, too much exercise or too little food (Dunning, 2009). This dangerously low blood sugar can lead to coma and seizures (Leonard, Jang, Savik, Plumbo, & Christensen, 2002). Hyperglycaemia refers to an elevated blood glucose level due to an insulin deficiency (Dunning, 2009). The cause of hyperglycaemia should be sought and corrected to avoid the development of DKA. Hyperglycaemia and DKA are often referred to as short-term complications of diabetes (Dunning, 2009). Infection is the most common cause of hyperglycaemia.

According to the Children's Diabetes Foundation (as cited in Holker, 2008) T1DM is the sixth leading cause of mortality in adults and children worldwide with approximately 200 000 deaths annually. The mortality rate of a person with T1DM increases dramatically after 15 years of affliction with the disease, and according to Law (2002), it is the second most common chronic childhood illness after asthma. In Africa, the 2012 figures show that the number of people living with Type I and II diabetes is 14.7 million, and it is expected to increase by approximately 90% (Diabetes Statistics, 2012). At least 78% of people living with Type I and II diabetes in Africa are undiagnosed (Diabetes Statistics, 2012). According to the International Diabetes Federation (IDF) the estimated number of people with diabetes in South Africa is approximately 840 000 (Sweetlifemag, 2011).

Many concerns about long-term health arise in adolescence (Coleman et al., 2007). As young people assume responsibility for their own health, they can become harder to reach with traditional health services (Coleman et al., 2007). Healthy, motivated and well-educated young people are needed to keep our society vibrant, flourishing and productive (Copp, 2005).

Viner and Barker (2005) in their article “Young people’s health: The need for action” point out that adolescence is the one age group where there has been no discernible improvement in health over the last 20 years. As these authors argue, this has to be set in the context of a situation where the prevalence of diseases in children and adolescents such as asthma and diabetes is on the increase (Coleman et al., 2007).

The unique health and social care needs of young people are driven directly by the developmental nature of adolescence (Viner, 2005). Problems as diverse as exploratory behaviours, sexuality, adaptation to chronic conditions, violence, accidents and mental health problems are directly related to the interplay between biological, psychological and social elements of adolescent development, and the interface of this development with peers, family and the wider community (Viner, 2005). Health care providers view the adolescent with diabetes as being especially difficult to manage. In the past, physicians had hoped that educating them on the complications associated with poor glucose control would help to foster the required knowledge and encourage better self-care (Law, 2002; Urbach et al., 2005). While there is evidence that shows an adolescent’s knowledge, skills and responsibility grow as they mature (Wysocki & Greco, 2006), it is often not soon enough to prevent lasting negative effects. These negative effects can include both developmental and physical complications that emerge later in life (DuPasquier-Fediavsky, Chawalow, The PEDIAB Collaborative Group, & Tubiana-Rufi, 2004, as cited in Holker, 2008)

One important difference between the age groups is that adolescents do not see health in abstract terms (Coleman et al., 2007). For adolescents, health is mostly about the here and the now, and their needs have to do with having the best information, and also having the skills to manage the situations in which they find themselves (Kalnins, McQueen, Backett, & Currie,

1992). Health for adolescents is best seen as a trade-off between knowing what is good for you and dealing with pressure from peers and family (Coleman et al., 2007). Hendry and Reid (2001) found that having the basic skills to 'get along with others' is seen by young people as an essential component of a sense of health and well-being. Well-being here refers to the ability to understand ourselves and other people, and in particular to be aware of, understand, and use information about the emotional states of ourselves and others with competence (Weare, 2004).

Most young people approach the many challenges of the adolescent transition by tackling them one at a time. If these developmental tasks are exacerbated by added complications due to a chronic illness, coping becomes more difficult (Coleman et al., 2007). Some conditions such as acne, eating disorders and scoliosis (lateral curvature of the spine) have their origins in adolescence and together with already established chronic health problems, they present more complications that interact with the adolescent's transition towards adulthood (Coleman et al., 2007). Kidney disease, for example, is aggravated by poorly controlled insulin-dependent diabetes, whose peak incidence occurs in early adolescence (12-14 years: Coleman & Hendry, 1999).

T1DM Adolescents and the Role of their Peers

According to Coleman et al. (2007) having to take medication throughout the day often draws unwanted attention, together with features of the disease that cannot easily be disguised. These are some of the reasons often cited by young people for poor adherence or compliance with regular treatment or the avoidance of situations likely to provoke symptoms and adverse comments from their peers (Coleman et al., 2007). Social isolation of young people with chronic diseases is common and many may have very little contact with their peers outside their own family and during school holidays (Coleman et al., 2007). Young people feel unattractive

because of the physical manifestations of their chronic ill health and the fact that their transition through puberty may be delayed (Coleman et al., 2007). Peer pressure and the need to be accepted as one of the crowd are other influences that are particularly strong in girls and young women (Coleman et al., 2007). The psychological repercussions of the painful, demanding, restricting and relentless therapeutic regime of T1DM on behaviours, self-esteem, sibling and peer relationships and family dynamics present untold challenges for parents and health caregivers (Coleman et al., 2007).

Because of the significant effect T1DM has on the above-mentioned relationships, Bonnici (as cited in Flynn, 2009) points out that to address these matters, a profound change is urgently required in the attitude of doctors, nurse educators and dieticians, as well as the children's parents. Communication skills, effective child behaviour management, psychological support, and crisis intervention approaches have to be learnt and sensitively applied throughout the course of the child's development to reduce family dysfunction, non-compliant behaviours, and difficulty with school performance and to promote psychosocial adjustment (Flynn, 2009).

An adolescent's world does not typically revolve around their home. They are constantly busy with school work, activities and friends (Gleitman, Reisberg, & Gross, 2007). Erikson states that it is a time during which the adolescent's life shifts with respect to their social life (cited in Gleitman et al., 2007). It would be unusual for these activities to not have an effect on the adolescent diabetes treatment regimen. It is a time in their lives that the adolescent is looking for increased acceptance from their peers and increased independence from their parents (Wysocki & Greco, 2006).

Greco, Shroff-Pendley, McDonell, and Reeves (2001) show that as adolescents increase their independence from their parents, they tend to rely on their peers for support and

behavioural norms. These peers are more likely to provide companionship and emotional support in relation to their diabetes than their parents do at this stage in their life. Shroff-Pendley et al. (2002) found that adolescents may share more disease related information with their peers and perceive their friends as offering support for their diabetes.

However, it seems that this support is not equal for all parts of diabetes management. The areas where adolescents believed their friends were more supportive were in the areas of blood glucose testing, exercise and emotions (La Greca, 1990). Adolescents found supportiveness for insulin injections and meals to be much less than the previously mentioned areas (La Greca, 1990). The study of La Greca also shows that the fact that they have diabetes renders adolescents as “different” (La Greca, 1990). These comments show the very powerful effect diabetes can have on the adolescents’ psychological well-being. Psychological well-being seems to be multidimensional with regard to facets of self-involvement (e.g. cognitions, behaviour, and affect), and the areas of life in which these facets display themselves (interpersonal and intrapersonal, social and contextual: Keyes, 2006; Walker, 1999). Therefore the predominant concept of health is a psychological one (Blaxter, 1987).

T1DM and Psychological Well-being

Psychological and physical well-being is well established as being interdependent (Bradley, Gamsu, & Psychological Well-Being Group of the WHO/IDF St Vincent Declaration Action Programme for Diabetes, 1994). According to Bradley et al. (1994, p. 510), “this interdependence is especially apparent in adults and children with diabetes”. Diagnoses of diabetes, coping with diabetes and its complications have major effects on people’s lives, effecting physical as well as psychological well-being (Bradley et al., 1994). According to Law, Kelly, Huey and Summerbell (2002) adolescents’ beliefs regarding their illness, T1DM, and their

related self-management behaviours, are both important contributors to psychological well-being. In a study conducted by Northan, Lin, Finch, Werther, and Cameron (2010), results indicated that T1DM participants reported higher levels of psychiatric morbidity since diagnoses.

Psychological maladjustments in individuals with T1DM is particularly concerning because it is associated with poor metabolic control (Hood et al., 2006; Northam et al., 2010), which in turn increases the risk of diabetes complications (Northam et al., 2010). In a longitudinal study conducted by Northam, Matthews, Anderson, Cameron and Werther (2005), ten years after the onset of diabetes, 37 % of adolescents met the criteria for DSM-IV psychiatric diagnoses. An American study among 144 diabetic adolescents showed that 56 % admits missing meals and snacks (Weissberg-Benchell et al., 1995).

During the early stage of the T1DM adolescent's development, declines are frequently seen with regard to adherence and metabolic control, as well as the psychological well-being of the adolescent (Weibe et al., 2005). Therefore research indicates the importance of parents in adolescents' adherence to diabetes treatment (Allan, Tennen, McGrade, Affleck, & Ratzan, 1983; Anderson, et al., 1997; Weibe et al., 2005).

It must be stressed that childhood diabetes management "happens largely within a social context" (Wysocki & Greco, 2006, p. 117). Therefore, how others behave towards the child or adolescent diabetic can greatly impact how they choose to care for themselves. It has been found that an important factor in diabetes dietary self-care and psychological well-being is how the adolescent views the illness (Law, 2002). Adolescents with diabetes have been found to be less involved in health-compromising behaviour than adolescents and young adults in general (Law, 2002). Teenagers with diabetes may express lower life satisfaction and health perception compared with their peers without diabetes (Lange, Jackson, & Deeb, 2009).

In a study of adolescents with T1DM, it was found that there was a correlation between low glycated hemoglobin (HbA1C) levels and adolescent-rated quality of life (Lange et al., 2009). This emphasises the importance of glycaemic control on both physical and psychological health.

T1DM Challenges in School

For children and young people with diabetes, life in school presents problems on two different levels. The first and fundamental issue is that, as with all young people, they have the right to education and to participate fully in all the experiences of adolescence (Lange et al., 2009). They should not suffer discrimination because of their diabetes, and should not be made to feel different or awkward because of it (Anderson, 2007).

The second problem is establishing the practical means to enable these young people to play a full part in school life by managing their diabetes on a practical level (Lange et al., 2009). The vast majority of countries do not have legislation that mandates school personnel to provide diabetes support in emergencies such as hypoglycaemia. In a large number of countries, support for children with diabetes remains the responsibility of the child and parents (Lange et al., 2009). A survey conducted in Spain showed that only 9 % of children with diabetes inject insulin at school and only 56 % test their blood sugar, suggesting sub-optimal diabetes control due to a lack of support in school (Amillategui, Calle, Alvarez, Cardiel, & Barrio, 2007).

The school functioning of children and adolescents with diabetes is also impaired by frequent absence from school (Yu, Kail, Hagen, & Wolters, 2000) and by the fact that poorly controlled diabetes is associated with subtle neuropsychological deficits that may reduce academic achievement (Northam et al., 2001). More recent diabetes studies suggest that students with T1DM risk missing twice as many school days as healthy peers and siblings (Wodrich et al.,

2011). Some patients appear to attend school regularly, but nonetheless miss out on classroom instruction because of their diabetes (e.g. they leave to eat snacks, perform serum glucose checks, and inject insulin: Wagner, Heapy, James, & Abbot, 2006). Besides school attendance, a study conducted with Arkansas teachers found that only 12 % could correctly recognise the symptoms of low blood sugar when presented with items in a multiple-choice test format (Gormanous, Hunt, Hope, & Gerald, 2002). While Wagner et al. (2006) found that 42 % of parents said that school personnel lacked instruction in ‘routine, non-emergent diabetes care’. The same study found that 22 (8%) students themselves reported difficulty with school personnel because of issues such as attributing all their school problems to diabetes, calling attention to diabetes in class, and dispensing inaccurate diabetes information to classmates (Wagner et al., 2006).

T1DM and the Effect on the Family

The diagnosis of T1DM in a child often and understandably causes an emotional reaction in parents (Butwicka, Zalepa, Fendler, Szadkowska, & Mlynarski, 2013). The complex responsibilities involved in managing T1DM such as serum glucose checks, adjusting insulin doses, exercising regularly, and managing episodes of hypoglycaemia are demanding (Kaugars, Kichler, & Alemzadeh, 2011).

Parents have to change their role from taking full responsibility towards a gradual transition into cooperative care with the adolescent. This is based on evidence that parental support and involvement throughout adolescence is associated with better outcomes (Anderson et al., 1997; White, Kolman, & Wexler, 1984). The nature of the responsibilities of each family member may vary as families work towards interdependence (Anderson, Ho, & Laffel, 1999). However, the adolescent and parent may be in similar or different stages of readiness to make the

necessary changes of assuming, relinquishing, or collaborating on various diabetes-related responsibilities throughout the developmental trajectory (Kaugars et al., 2011). As adolescents grow older, parents' roles may change from them taking less direct responsibility for accomplishing regimen tasks to assuming more supervision or monitoring (Kaugars et al., 2011). Wysocki and Greco (2006) found that the parents did not take into account the adolescents' cognitive maturity when making decisions to relinquish care to the adolescent.

Wysocki and Greco (2006) also note that the adolescents did not often accept these responsibilities. While increased autonomy may be an important developmental task in adolescence (Weinger, O'Donnell, & Ritholz, 2001), early adolescence is a time of difficulty adjusting to the responsibility of self-care related to their diabetes (Dashiff, McCaleb, & Cull, 2006). Weinger, et al. (2001) found that adolescents believed there are times when their parents lose sight of the fact that they are people and not just diabetics. Coleman et al. (2007) suggests that both points of view of the adults and the young people have merit, and that health will always be a complex, multifaceted concept.

Parents may differ in how they perceive their roles and responsibilities for their adolescent's diabetic care. Mothers and adolescents were not found to differ in their views as to what the adolescent is responsible for in terms of the adolescent's responsibility for diabetes management, but there were differences in what the adolescent viewed as the mother's responsibilities and what they viewed as the father's responsibilities (Leonard et al., 2005). Law (2002) found adolescents and their mothers can either differ, or they can agree on their beliefs about diabetic management. Better adherence was observed when mothers worked collaboratively with their adolescents rather than being controlling (Wysocki & Greco, 2006). Interestingly, Law (2002) found fathers of diabetic adolescents were less involved in

communicating with their adolescents than were fathers of non-diabetic adolescents. Leonard et al. (2005) found during their interviews with adolescent diabetics that some teens did not think their fathers understood diabetes or how to help them in a crisis.

Adolescents with diabetes do not necessarily believe that their parents' continued control and involvement is a lower degree of care. It may make them feel safe and protected and, in turn, promote psychosocial health and well-being (Grauce, Wentzel-Larson, Hanestad, & Sovik, 2005). Law (2002) found that when the parents and adolescent negotiate the degree of responsibility in each of the four areas of diabetes self-management (blood glucose testing, insulin administration, diet and exercise), this allows for greater autonomy to increase with age.

According to Coleman et al. (2007) the adolescent may not acquiesce to this situation of mutual dependency and may experience a need to establish independence by deliberately failing to comply with the recommended therapeutic regime or treatment adherence. Coleman et al. (2007) also hypothesise that this may be associated with the adolescent's need to rebel against traditional norms and controls, or it may be related to the decrease in parental involvement. Growing up involves the adolescent in a variety of learning experiences, experimentation and testing the boundaries of rules and accepted social practices (Coleman et al., 2007). A desire to take part in risk taking is normal in the transition to adulthood (Kloep & Hendry, 1999). However, potentially unhealthy behaviours compound existing chronic health problems such as diabetes (Coleman et al., 2007). The most serious cases of non-compliance tend to emerge during middle adolescence or the ages of 17-19 years (Wysocki & Greco, 2006), with the average age being 14.8 years. Readmission to hospital for serious complications of non-adherence, such as DKA and hypoglycaemia was more likely to be seen when the adolescents were between 14-15 years (Hanna & Guthrie, 2003).

T1DM Age and Gender

Problems with adolescents who do not adhere to their treatment regimens are nothing new. Adherence to treatment of diabetes mellitus is a major concern, as failure to maintain regular treatment can have serious immediate and long-term consequences for the health of the affected individual (Holker, 2008). Older adolescents are at risk for various behavioural and health outcomes that may be prevented if they adjust to their illness earlier in adolescence (Leonard et al., 2005). Adolescents with T1DM may experience variability in their diabetes and metabolic control due to hormonal or psychological factors.

There are certain characteristics that have been found to have be predictive of a patient's blood glucose levels. Age and gender are two of these characteristics (Urbach et al., 2005). Gender also plays a role in treatment adherence, as boys and girls do not always view matters in their lives in the same way (Graziano et al., 2011). This is no different with the adolescent diabetic. The study of Graziano et al. (2011) found a significant gender difference in the link between self-regulation and diabetes treatment management as no associations were found for girls. Past studies within the child development and developmental psychopathology domains have documented boys as having significantly greater self-regulation deficits compared to girls (Card, Stucky Sawalani, & Little, 2008; Matthews, Ponitz, & Morrison, 2009). Girls tend to demand more from themselves and take greater responsibility for failure (Weibe et al., 2005). They also seem to believe their self-worth to be more contingent on pleasing others more than boys do (Weibe et al., 2005).

In another study 0,3% of girls and 1,4% of boys with T1DM reported skipping insulin in the past year in an effort to lose weight or keep from gaining weight; furthermore, 7,4% of girls and 1,4% of boys with diabetes reported taking less insulin than recommended as a means of

weight control over the past year (Ackard et al., 2008). Weibe and colleagues (2005) also indicated in their study that females view their mothers as more controlling. This may be damaging to their self-esteem, with a resulting decrease in quality of life (Weibe et al., 2005). The study of Dashiff et al. (2006) showed that girls were more collaborative in their care and placed a greater emphasis on diet to control their diabetes than boys did. The boys, on the other hand, were more likely to perform their diabetes care in private and participate in sports to help control their diabetes as well as to promote their masculinity (Dashiff et al., 2006). Another study showed mothers were more likely to be involved in helping their sons with their diabetes, while the girls were expected to be more independent, which made them reluctant to ask for help (Dashiff et al., 2006).

Problem Statement

The psychological burden associated with concerns over treatment, responsibility, and lack of support may result in emotional problems among caregivers (Buckloh et al., 2008). Although changing emotions are a normal phenomenon for all ages, mood changes have the potential to make the blood glucose levels unstable in adolescents with diabetes (Buckloh et al., 2008). The body reacts to emotional trauma or even emotional excitement by triggering chemical reactions that make the blood glucose rise (Flynn, 2009). Adolescents with diabetes may face a variety of psychosocial challenges, leading to diabetes-specific emotional distress (Flynn, 2009). Adolescents following a treatment regimen for T1DM are at increased risk for anxiety and depressive symptoms, poor coping and problem solving skills, poor regimen adherence and family conflict (Weissberg-Benchell & Antisdel-Lomaglio, 2011).

An important factor in diabetes dietary self-care and psychological well-being is strongly related to how the adolescent views their illness (Law, 2002). It is therefore important to find

out what might promote diabetes management and help what might help the adolescent adapt to their disease (Shroff-Pendley et al., 2002). Young people who are going through a challenging and sometimes turbulent period of their lives and who carry the additional burden of a chronic illness require and deserve a knowledgeable and sympathetic health care team if they are to be afforded the best chance of lifelong health. Parents and carers also need to be supported through this period so that they can assist young people to negotiate the transition to responsible adult independence.

An awareness of the issues facing young people is an absolute requirement in order to ensure that they can successfully manage their own medical problems and understand the contribution they themselves need to make to maintain physical and mental health. Listening to young people themselves and understanding their perceptions can be both helpful for them and instructive and rewarding for those charged with their care. The principles of empathy, understanding and honesty are no different from those necessary for dealing with persons of any age or level of competence (Coleman et al., 2007).

Therefore, improving the management of the illness by finding out the experiences of adolescents regarding their treatment regimen is imperative in helping adolescents understand and cope with their emotions and improve their care and quality of life. The research question that accordingly guides this research study is:

What are adolescents' experiences of treatment adherence with Type 1 Diabetes Mellitus?

Aim of the Study

The aim of this qualitative research study is to explore and describe the experiences of adolescents regarding treatment adherence related to T1DM, using a phenomenological research

design as the theoretical framework of this study. According to Plug, Louw, Gouws and Meyer (2009) phenomenology serves the purpose of capturing and describing the lived experiences of participants.

Structure of the Research

This section, Section A, presented a literature review to establish the background and basis of this study. The following section, Section B, presents the article to be submitted to the Journal of Social Science & Medicine for possible publication. The article addresses the methodology and findings and offers a discussion of the study. The final section, Section C, includes the researcher's critical reflections and the contribution of the study on adolescents' experiences of T1DM and their treatment adherence.

References

- Ackard, D. M., Vik, N., Neumark-Sztainer, D., Schmitz, K. H., Hannah, P., & Jacobs, D. R. Jnr. (2008). Disordered eating and body dissatisfaction in adolescents with type 1 diabetes and a population-based comparison sample: Comparative prevalence and clinical implications. *Pediatric Diabetes, 9*, 312-319.
- Allan, D. A., Tennen, H., McGrade, B. J., Affleck, G., & Ratzan, S. (1983). Parent and child perceptions of the management of juvenile diabetes. *Journal of Paediatric Psychology, 8*, 129-141.
- American Diabetes Association. (2007). *All about diabetes*. Retrieved October 31, 2007 from <http://www.Diabetes.org/about-diabets.jsp>
- Amillategui, B., Calle, J. R., Alvarez, M. A., Cardiel, M. A., & Barrio, R. (2007). Identifying the special needs of children with type 1 diabetes in the school setting. An overview of parents' perception. *Diabetic Medicine, 24*, 1073-1079.
- Anderson, B. (2007). Diabetes in children: Psychosocial aspects. In the global burden of youth diabetes: Perspectives and potential. A charter paper. *Pediatric Diabetes, 8*, 26-31.
- Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatric Nursing, 130*, 257-265.
- Anderson, B., Ho, J., & Laffel, L. M. (1999). An office-based intervention to maintain parent-adolescent teamwork in diabetes management. Impact on parent involvement, family conflict, and subsequent glycemic control. *Diabetes Care, 713-723*.

- Blaxter, M. (1987). Attitudes to health. In B. Cox (Ed.). *The health and lifestyle survey*. London: Health Promotion Research Trust.
- Bradley, C., Gamsu, D. S., & Psychological Well-being Working Group of the WHO/IDF St Vincent Declaration Action Programme for Diabetes. (1994). Guidelines for encouraging psychological well-being. *Diabetic Medicine*, *11*, 510-516.
- Buckloh, L. M., Lochrie, A. S., Antal, H., Milkes, A., Canas, A., Hutchinson, S., & Wysocki, T. (2008). Diabetes complications in youth: Qualitative analysis of parents' perspectives of family learning and knowledge. *Diabetes Care*. *31*, 1516-1520.
- Butwicka, A., Zalepa, A., Fendler, W., Szadkowska, A., & Mlynarski, W. (2013). Maternal depressive symptoms predict acute hospitalization among children with Type 1 diabetes. *Pediatric Diabetes*, *14*, 288-294.
- Card, N., Stucky, B, Sawalani, G., & Little, T. (2008). Direct and indirect aggression during childhood and adolescence: A meta-analytic review of gender differences, intercorrelations, and relations to maladjustment. *Child: Care, Health and Development* *79*, 1185-1229.
- Coleman, J. C., & Hendry, L. B. (1999). *The nature of adolescence*. (3rd ed). Routledge, London.
- Coleman, J., Kloep, L. B., & Kloep, M. (2007). *Adolescence and health*. West Sussex, England: Wiley & Sons, Ltd.
- Cooper, H., & Geyer, R. (2007). *Riding the diabetic rollercoaster: A new approach for health professionals, patients and carers*. Oxon: Radcliffe.
- Copp, A. (2005). An overview of children's health, In C. Horton (Ed.). *Working with children*. London: Society Guardian and Sage publications.

- Dashiff, C., McCaleb, A., & Cull, V. (2006). Self-care of young adolescents with type 1 diabetes. *Journal of Pediatric Nursing, 21*(3), 222-232.
- Delamater, A. M. (2006). Improving patient adherence. *Clinical Diabetes, 24*, 71-77.
- Diabetes Statistics. (2012). Retrieved June 13, 2012 from <http://www.globalbuzz-sa.com/forums>
- Dunning, T. (2009). *Care of people with diabetes – a manual of nursing practice*. West Sussex, Wiley-Blackwell.
- Faulkner, M. (2003). Quality of life for adolescents with type 1 diabetes: Parental and youth perspectives. *Paediatric Nursing, 2*(5), 362-368.
- Fleming, E., Carter, B., & Warren, G. (2002). The transition of adolescents with diabetes from the children's health care service into adult health care service: A review of the literature. *Journal of Clinical Nursing, 11*, 560-567.
- Flynn, R. (2009). *The emotion of children with diabetes*. CDE Publication.
- Gleitman, H., Reisberg, D., & Gross, J. (2007). *Psychology*. (7th ed.). New York: W.W. Norton & Company.
- Gormanous, M., Hunt, A., Hope, J., & Gerald, B. (2002). Lack of knowledge of diabetes among Arkansas public elementary teachers: Implications for dietitians. *Junior Diet Association, 102*, 1136-1138.
- Grauce, M., Wentzel-Larson, T., Hanestad, B. R., & Sovik, O. (2005). Health-related quality of life and metabolic control in adolescents with diabetes: The role of parental care, control and involvement. *Journal of Pediatric Nursing, 20*(5), 373-382.
- Graziano, P. A., Geffken, G. R., Williams, L. B., Lewin, A. B., Duke, E. A., & Silverstein, J. (2011). Gender differences in the relationship between parental report of self-regulation

- skills and adolescents' management of type 1 diabetes. *Journal of Pediatric Diabetes*, 12, 410-418.
- Greco, P., Shroff-Pendley, J., McDonell, K., & Reeves, G. (2001). A peer group intervention for adolescents with type 1 diabetes and their best friends. *Journal of Pediatric Psychology*, 26(8), 485-490.
- Grey, M., Boland, E. A., Davidson, M., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. V. (1998). Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care*, 21(6), 901-908.
- Hanna, K. M., & Guthrie, D. (2003). Adolescents' behavioral autonomy related to diabetes management and adolescent activities/rules. *The Diabetes Educator*, 29(2), 283-291.
- Hendry, L. B., & Reid, L. (2001). Social relationships and health: The meaning of social "connectedness" and how it relates to health concerns for rural Scottish adolescents, *Journal of Adolescence*, 23, 705-719.
- Holker, V. M. (2008). Adolescent diabetic treatment adherence and the impact of parental involvement (Unpublished master's thesis). University of Wyoming.
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkering, L., & Laffel, L. M. (2006). Depressive symptoms in children and adolescents with type 1 diabetes: Association with diabetes-specific characteristics. *Diabetes Care*, 29, 1389-1391.
- Kalnins, I., McQueen, D., Backett, K., & Currie, C. (1992). Children, empowerment and health promotion: Some new directions in research and practice. *Health Promotion International*, 7, 53-59.

- Kaugars, A. S., Kichler, J. C., & Alemzadeh, R. (2011). Assessing readiness to change the balance of responsibility for managing Type 1 Diabetes Mellitus: Adolescent, mother, and father perspectives. *Pediatric Diabetes, 12*, 547-555.
- Keyes, C. L. M. (2006). Mental health in adolescence: Is America's youth flourishing. *American Journal of Orthopsychiatry, 76*(3), 395-402.
- Kloep, M., & Hendry, L. B. (1999). Challenges, risks and coping in adolescence, in D. Messer & S. Miller (Eds.). *Exploring developmental psychology from infancy to adolescence* (pp. 400-416). London, Arnold.
- Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paulauskas, S., & Pollock, M. (1985). Initial psychological responses of parents to the diagnoses of insulin-dependent diabetes mellitus in their children. *Diabetes Care, 8*, 568-575.
- Krentz, A. J. (2004). *Emergencies in Diabetes*. West Sussex, England. Wiley & Sons.
- La Greca, A. M. (1990). Issues in adherence with pediatric regimens. *Journal of Pediatric Psychology, 15*(4), 423-436.
- Lange, K., Jackson, C., & Deeb, L. (2009). Diabetes care in schools – the disturbing facts. *Pediatric Diabetes, 13*, 28-36.
- Law, G. U. (2002). Dissimilarity in adolescent and maternal representations of type 1 diabetes: Exploration of relations to adolescent well-being. *Child: Care, Health and Development, 28*, 369-378.
- Law, G. U., Kelly, T. P., Huey, D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role? *Journal of Adolescent Health, 31*(4), 381-385.

- Leonard, B. J., Garwick, A., & Adwan, J. Z. (2005). Adolescents' perceptions of parental roles and involvement in diabetes management. *Journal of Pediatric Nursing, 20*(6), 405-415.
- Leonard, B. J., Jang, Y., Savik, K., Plumbo, M. A., & Christensen, R. (2002). Psychological factors associated with levels of metabolic control in youth with type 1 diabetes. *Journal of Pediatric Nursing, 17*(1), 28-37.
- Lewin, A. B., Heidgerken, A. D., Geffen, G. R., Williams, L., Storch, E. A., Gelfand, K. M., & Silverstein, J. H. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Paediatric Psychology, 31*, 174-183.
- Liles, R. G., & Juhnke, G. A. (2008). Adolescent diabetic control: Using the Process-Person-Context-Time Model. *Journal of Counselling and Development, 86*, 75-86.
- Lind, M., Oden, A., Fahlen, M., & Eliasson, B. (2009). The true value of HbA1c as a predictor of diabetes complications: Simulations of HbA1c variables. *Plos One, 4*, e4412.
- Matthews, J., Ponitz, C., & Morrison, F. (2009). Early gender differences in self-regulation and academic achievement. *Journal of Educational Psychology, 101*, 689-704.
- Northam, E. A., Anderson, P. J., Jacobs, R., Hughes, M., Warne, G. L., & Werther, G. A. (2001). Neuropsychological profiles of children with type 1 diabetes 6 years after disease onset. *Diabetes Care, 9*, 1541-1546.
- Northam, E. A., Lin, A., Finch, S., Werther, G. A., & Cameron, F. J. (2010). Psychological well-being and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care, 33*(7), 1430-1437.
- Northam, E. A., Matthews, L. K., Anderson, P. J., Cameron, F. J., & Werther, G. A. (2005). Psychiatric morbidity and health outcomes in type 1 diabetes-perspectives from a prospective longitudinal study. *Diabetic Medicine, 22*, 152-157.

- Plug, C., Louw, D. A. P., Gouws, L. A., & Meyer, W. F. (2009). *Verklarende en Vertalende Sielkundewoordeboek* (3de uitgawe). Sandton: Heinemann Voortgesette Onderwys (Edms) Bpk.
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., & Clark, N. (2005). Care of children and adolescents with type 1 diabetes: A statement of the American Diabetes Association. *Diabetes Care*, 28, 186-212.
- Skinner, T. C., Channon, S., S., Howells, L., & McEvelly, A. (2000). Diabetes during adolescence. In F. J. Snoek & T. C. Skinner (Eds). *Psychology in diabetes care* (pp. 25-60). Chichester, UK: Wiley.
- Shroff-Pendley, J., Kasmien, L. J., Miller, D. L., Donze, J., Swenson, C., & Reeves, G. (2002). Peer and family support in children and adolescents with Type 1 Diabetes. *Journal of Pediatric Psychology*, 27(5), 429-438.
- Spencer, J. E., Cooper, H. C., & Milton, B. (2012). The lived experiences of young people (13-16 years) with Type 1 Diabetes Mellitus and their parents – a qualitative phenomenological study. *Diabetic Medicine*, 30, 17-24.
- Stewart, S., Emslie, G. J., Klein, D., Haus, S., & White, P. (2005). Self-care and glycaemic control in adolescents with type 1 diabetes. *Children's Health Care*, 34(3), 239-244.
- Sweetlifemag. (2011). *Diabetes in South Africa the facts*. Retrieved January 25, 2013 from <http://sweetlifemag.co.za/2011/07/diabetes-in-South-Africa-the-facts/>
- Urbach, S. L., La Reanchi, S., Lambert, L., Lapidus, J. A., Daneman, D., & Becker, T. M. (2005). Predictors of glucose control in children and adolescents with Type 1 Diabetes Mellitus. *Pediatric Diabetes*, 6, 69-74.

- Viner, R., & Barker, M. (2005). Young people's health: The need for action. *British Medical Journal*, *330*, 901-903.
- Viner, R. (2005). *The ABC of adolescence*. London. British Medical Journal Books.
- Wagner, J., Heapy, A., James, A., & Abbot, G. (2006). Brief report: Glycemic control, quality of life, and school experience among students with diabetes. *Journal of Pediatric Psychology*, *31*, 764-769.
- Walker, H. J. (1999). Clarifying the affective component of psychological well-being (Unpublished master's dissertation). North-West University, Potchefstroom.
- Weare, K. (2004). *Developing the emotionally literate school*. London: Paul Chapman Publishing.
- Weibe, D. J., Korb, C., Palmer, L., Beveridge, R. M., Upchurch, R., ... Donaldson, D. L. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control and quality of life across adolescence. *Journal of Pediatric Psychology*, *30*(2), 167-178.
- Weinger, K., O'Donnell, K. A., & Ritholz, M. D. (2001). Adolescent views of diabetes related parent conflict and support: A focus group analysis. *Journal of Pediatric Psychology*, *30*(2), 167-178.
- Weissberg-Benchell, J., Glasgow, A. M., Tynan, W. D., Wirtz, P., Turek, J., & Ward, J. (1995). Adolescent diabetes management and mismanagement. *Diabetes Care*, *18*, 77-82.
- Weissberg-Benchell, J., & Antisdel-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: Feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatric Diabetes*, *12*, 341-344.

- White, K., Kolman, M. L., & Wexler, P. (1984). Unstable diabetes and unstable families: A psychosocial evaluation of diabetic children with recurrent ketoacidosis. *Pediatrics*, 73, 749-755.
- Wodrich, D. L., Hasan, K., & Parent, K. B. (2011). Type I Diabetes Mellitus and school: A review. *Pediatric Diabetes*, 12, 63-70.
- Wysocki, T., & Greco, P. (2006). Social support and diabetes management in childhood and adolescence: Influence of parents and friends. *Current Diabetes Reports*, 6, 117-122.
- Yu, S. L., Kail, R., Hagen, J. W., & Wolters, C. A. (2000). Academic and social experiences of children with insulin- dependent diabetes mellitus. *Child Health Care*, 29, 189-208.

SECTION 2: ARTICLE

Experiences of adolescents with Type 1 Diabetes Mellitus on treatment adherence

2.1 Guidelines for authors: *Journal of Social Sciences and Medicine*

Author Guidelines

(Key aspects summarised)

Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health and healthcare from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and the organization of healthcare. We encourage material which is of general interest to an international readership.

Journal Policies

The journal publishes the following types of contribution:

- 1) Peer-reviewed original research articles and critical analytical reviews in any area of social science research relevant to health and healthcare. These papers may be up to 8000 words including abstract, tables, and references as well as the main text. Papers below this limit are preferred.
- 2) Peer-reviewed short reports of findings on topical issues or published articles of between 2000 and 4000 words.
- 3) Submitted or invited commentaries and responses debating, and published alongside, selected articles.

4) Special Issues bringing together collections of papers on a particular theme, and usually guest edited.

Ethics in Publishing

For information on Ethics in publishing and Ethical guidelines for journal publication see <http://www.elsevier.com/publishingethics> and <http://www.elsevier.com/ethicalguidelines>.

Please note that any submission that has data collected from human subjects requires ethics approval. If your manuscript does not include ethics approval, your paper will not be sent out for review.

Conflict of Interest

All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. See also <http://www.elsevier.com/conflictsofinterest>. Further information and an example of a Conflict of Interest form can be found at:

http://help.elsevier.com/app/answers/detail/a_id/286/p/7923.

Submission Declaration and Verification

Submission of an article implies that the work described has not been published previously (except in the form of a conference abstract or as part of a published lecture or thesis for an academic qualification), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written

consent of the copyright-holder. To verify originality, your article may be checked by the originality detection software iThenticate. See also <http://www.elsevier.com/editors/plagdetect>.

Changes to Authorship

This policy concerns the addition, deletion, or rearrangement of author names in the authorship of accepted manuscripts: *Before the accepted manuscript is published in an online issue*: Requests to add or remove an author, or to rearrange the author names, must be sent to the Journal Manager from the corresponding author of the accepted manuscript and must include: (a) the reason the name should be added or removed, or the author names rearranged and (b) written confirmation (e-mail, fax, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed. Requests that are not sent by the corresponding author will be forwarded by the Journal Manager to the corresponding author, who must follow the procedure as described above. Note that: (1) Journal Managers will inform the Journal Editors of any such requests and (2) publication of the accepted manuscript in an online issue is suspended until authorship has been agreed.

After the accepted manuscript is published in an online issue: Any requests to add, delete, or rearrange author names in an article published in an online issue will follow the same policies as noted above and result in a corrigendum.

Copyright

This journal offers authors a choice in publishing their research: Open access and Subscription.

For subscription articles. Upon acceptance of an article, authors will be asked to complete a 'Journal Publishing Agreement' (for more information on this and copyright, see

<http://www.elsevier.com/copyright>). An e-mail will be sent to the corresponding author confirming receipt of the manuscript together with a 'Journal Publishing Agreement' form or a link to the online version of this agreement. Subscribers may reproduce tables of contents or prepare lists of articles including abstracts for internal circulation within their institutions. Permission of the Publisher is required for resale or distribution outside the institution and for all other derivative works, including compilations and translations (please consult <http://www.elsevier.com/permissions>). If excerpts from other copyrighted works are included, the author(s) must obtain written permission from the copyright owners and credit the source(s) in the article. Elsevier has pre-printed forms for use by authors in these cases: please consult <http://www.elsevier.com/permissions>.

For open access articles. Upon acceptance of an article, authors will be asked to complete an 'Exclusive License Agreement' (for more information see <http://www.elsevier.com/OAauthoragreement>). Permitted reuse of open access articles is determined by the author's choice of user license (see <http://www.elsevier.com/openaccesslicenses>).

Retained author rights. As an author you (or your employer or institution) retain certain rights. For more information on author rights for: Subscription articles please see <http://www.elsevier.com/journal-authors/author-rights-and-responsibilities>. Open access articles please see <http://www.elsevier.com/OAauthoragreement>.

Role of the Funding Source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the articles;

and in the decision to submit it for publication. If the funding source(s) had no such involvement then this should be stated. Please see <http://www.elsevier.com/funding>.

Funding Body Agreements and Policies

Elsevier has established agreements and developed policies to allow authors whose articles appear in journals published by Elsevier, to comply with potential manuscript archiving requirements as specified as conditions of their grant awards. To learn more about existing agreements and policies please visit <http://www.elsevier.com/fundingbodies>.

Open Access

This journal offers authors a choice in publishing their research:

AUTHOR INFORMATION PACK 26 Oct 2014 www.elsevier.com/locate/socscimed 6

Open access. Articles are freely available to both subscribers and the wider public with permitted reuse. An open access publication fee is payable by authors or their research funder.

Subscription. Articles are made available to subscribers as well as developing countries and patient groups through our access programs (<http://www.elsevier.com/access>) No open access publication fee. All articles published open access will be immediately and permanently free for everyone to read and download. Permitted reuse is defined by your choice of one of the following Creative Commons user licenses:

Creative Commons Attribution (CC BY): lets others distribute and copy the article, to create extracts, abstracts, and other revised versions, adaptations or derivative works of or from an article (such as a translation), to include in a collective work (such as an anthology), to text or data mine the article, even for commercial purposes, as long as they credit the author(s), do not represent the author as endorsing their adaptation of the article, and do not modify the article in such a way as to damage the author's honor or reputation.

Creative Commons Attribution-NonCommercial-ShareAlike (CC BY-NC-SA): for noncommercial purposes, lets others distribute and copy the article, to create extracts, abstracts and other revised versions, adaptations or derivative works of or from an article (such as a translation), to include in a collective work (such as an anthology), to text and data mine the article, as long as they credit the author(s), do not represent the author as endorsing their adaptation of the article, do not modify the article in such a way as to damage the author's honor or reputation, and license their new adaptations or creations under identical terms (CC BY-NC-SA).

Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND): for noncommercial purposes, lets others distribute and copy the article, and to include in a collective work (such as an anthology), as long as they credit the author(s) and provided they do not alter or modify the article.

To provide open access, this journal has a publication fee which needs to be met by the authors or their research funders for each article published open access. Your publication choice will have no effect on the peer review process or acceptance of submitted articles. The open access publication fee for this journal is \$3000, excluding taxes. Learn more about Elsevier's pricing policy: <http://www.elsevier.com/openaccesspricing>.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (<http://webshop.elsevier.com/languageediting/>) or visit our customer support site

(<http://support.elsevier.com>) for more information.

Submission

Submission to this journal occurs online and you will be guided step by step through the creation and uploading of your files. Please submit your article via <http://ees.elsevier.com/ssm>. The system automatically converts source files to a single PDF file of the article, which is used in the peer-review process. Please note that even though manuscript source files are converted to PDF files at submission for the review process, these source files are needed for further processing after acceptance. All correspondence, including notification of the Editor's decision and requests for revision, takes place by e-mail.

Reviewers

During submission you will be asked if you wish to suggest the names and email addresses of potential reviewers. Note that the editor retains the sole right to decide whether or not the suggested reviewers are used.

Additional Information

Please note author information is entered into the online editorial system (EES) during submission and must *not* be included in the manuscript itself. AUTHOR INFORMATION PACK 26 Oct 2014 www.elsevier.com/locate/socscimed 7 *Social Science & Medicine* does not normally list more than six authors to a paper, and special justification must be provided for doing so. Further information on criteria for authorship can be found in *Social Science & Medicine*, 2007, 64(1), 1-4. Authors should approach the Editors in Chief if they wish to submit companion articles. Information about our peer-review policy can be found [here](#).

Please note that we may suggest accepted papers for legal review if it is deemed necessary.

Preparation

New Submission

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process. As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or layout that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

References

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting Requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions. If your article

includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes. Divide the article into clearly defined sections.

Formatting Requirements. The journal operates a double blind peer review policy. For guidelines on how to prepare your paper to meet these criteria please see the attached guidelines. There are no other strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions. If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes. Divide the article into clearly defined sections.

Essential Cover Page Information

The Cover Page should **only** include the following information:

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible and make clear the article's aim and health relevance.

Author names and affiliations in the correct order. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that telephone and fax numbers (with

country and area code) are provided in addition to the e-mail address and the complete postal address. Contact details must be kept up to date by the corresponding author.

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Any acknowledgements. Include if appropriate. These should be as brief as possible and not appear anywhere else in the paper.

Abstract

An abstract of up to 300 words must be included in the submitted manuscript. An abstract is often presented separately from the article, so it must be able to stand alone. It should state briefly and clearly the purpose and setting of the research, the principal findings and major conclusions, and the paper's contribution to knowledge. For empirical papers the country/countries/locations of the study should be clearly stated, as should the methods and nature of the sample, the dates, and a summary of the findings/conclusion. Please note that excessive statistical details should be avoided, abbreviations/acronyms used only if essential or firmly established, and that the abstract should not be structured into subsections. Any references cited in the abstract must be given in full at the end of the abstract.

Keywords

Up to 8 keywords are entered separately into the online editorial system during submission, and should accurately reflect the content of the article. Again abbreviations/acronyms should be used only if essential or firmly established. For empirical

papers the country/countries/locations of the research should be included. The keywords will be used for indexing purposes.

Tables

Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References

Citation in text. Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full at the end of the abstract. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal (see below) and should include a substitution of the publication date with either "Unpublished results" or "Personal communication" Citation of a reference as "in press" implies that the item has been accepted for publication.

Web references. As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Reference style. *Text:* Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the **Publication Manual of the**

American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. *List*: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Examples: Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style*. (4th ed.). New York: Longman, (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.

2.2 Manuscript: Experiences of adolescents with Type 1 Diabetes Mellitus on treatment adherence

Experiences of adolescents with Type 1 Diabetes Mellitus on treatment adherence

Mrs Liezel van der Westhuizen

North-West University (Potchefstroom Campus)

South Africa

Dr Werner de Klerk*

School of Psychosocial Behavioural Sciences

North-West University (Potchefstroom Campus)

South Africa

Ms Carlien Kahl

Optentia Research Programme, Faculty of Humanities

North-West University (Vaal Triangle Campus)

South Africa

Dr Ronel Pretorius

School of Nursing Science

North-West University (Potchefstroom Campus)

South Africa

Corresponding Author: Dr Werner de Klerk

Email: 12998699@nwu.ac.za

Tel: 018 299 1725

Abstract

Psychological and physical well-being is well established as being interdependent, and this interdependence is apparent in children and adults with diabetes. Diabetes Mellitus is widely researched, but there is limited literature on the experiences adolescents have regarding their management regimen in a South African context. This qualitative study explores the experiences of adolescents with Type 1 Diabetes Mellitus (T1DM). A purposive sample (n=7) of young adolescents between the ages of 13 and 15 willingly participated in the research study to explore and describe their experiences with managing their treatment regimen. In-depth interviews were used to collect rich descriptive data, followed by participants offering their verbal reflections once a week for the duration of a month. After the in-depth interviews and weekly reflections, the researcher held a focus group interview with all the participants. Transcribed data were analysed by means of thematic analysis from which themes and subthemes were derived. The participants expressed both positive and negative emotions associated with their diabetes; they experience a lack of understanding from significant others because of a lack of knowledge, interest or support with their diabetes; they mention that they continually need age-appropriate support and parental involvement even though they manage diabetes through their own processes; and lastly, participants struggle with a fear of friends' and peers' perceptions. The study has its limitations due to the limited demographic variation of the qualitative research study and the research findings can therefore not be generalised throughout the population of adolescents with diabetes. From the findings researchers suggest that family education and intervention should be encouraged in collaboration with peers and adolescents with T1DM.

Keywords: Adolescents, Type 1 Diabetes Mellitus, treatment regimen, psychological well-being, physical well-being.

Orientation and Problem Statement

Psychological and physical well-being is well established as being interdependent, as noted by Bradley, Gamsu, and the Psychological Well-being Group of the WHO/IDF St Vincent Declaration Action Programme for Diabetes who stated that (1994, p.510) "this interdependence is especially apparent in adults and children with diabetes". The aim of this study is to explore and describe the experiences of adolescents regarding their treatment adherence of Type 1 Diabetes Mellitus (T1DM), using a phenomenological approach as the theoretical framework of this study.

Diabetes Mellitus (Type 1 and Type 2) is regarded as the most common chronic condition in children and adolescents (Law, 2002). Children with T1DM in a contemporary population based cohort have a threefold higher mortality than the general population, with females at higher risk of diabetes related deaths in relation to males (Law, 2002). The 10-14 year old age group is at greater risk and more than three quarters of deaths in this age group are diabetes related (O'Grady, Delaney, Jones, & Davis, 2013). In Africa, the 2012 figures show that the number of people living with diabetes (Type 1 and Type 2) is 14.7 million, and it is expected to increase by approximately 90% (Diabetes Statistics, 2012). At least 78% of people living with diabetes (Type 1 and Type 2) in Africa are undiagnosed (Diabetes Statistics, 2012), while the International Diabetes Federation (IDF) estimated the number of people with diabetes (Type 1 and Type 2) in South Africa at approximately 840 000 (Sweetlifemag, 2011).

The American Diabetes Association (2007) estimates that three quarters of all cases of T1DM are diagnosed in people under the age of 18 years. The most common age of onset for T1DM is between 10-14 years (Faulkner, 2003). The adolescent population, i.e. the transitional

phase of development between childhood and adulthood, which includes the biological and psychological changes of puberty (Skinner, Channon, Howells, & Mcevilly, 2000), is highly neglected in current research regarding diabetes. Adding to Viner and Barker (2005) the focus tends to favour children and adults, and not adolescents.

T1DM may broadly be defined as a lifelong metabolic disorder brought about by the failure of the human pancreas to produce insulin (Holker, 2008). Insulin is a hormone secreted by the beta cells of the pancreas and which regulates carbohydrate and fat metabolism, allowing life-sustaining energy in the form of glucose to enter the body cells (Children's Diabetes Foundation at Denver, 2007). T1DM requires multiple daily injections of insulin, pricking a finger approximately twice a day to monitor blood glucose levels and adjusting insulin dosages on the basis of the child's blood glucose level, food intake and physical activity (Silverstein et al., 2005). Children and adolescents with T1DM must comply with a treatment regimen to maintain diabetic control (Lewin et al., 2006). Diabetic control is the ability to sustain blood glucose levels within near-normal ranges (Liles & Juhnke, 2008). Optimal glycaemic control is the most difficult to establish and maintain during the early adolescent period because of the normal insulin resistance that occurs during puberty (Holker, 2008; Leonard, Garwick, & Adwan, 2002; Weibe et al., 2005; Wysocki & Greco, 2006).

According to Viner and Barker (2005), adolescence is probably the most turbulent, challenging, stressful and uncertain of all phases in life, both for teenagers and for their parents, teachers and health professionals. The adolescent development phase is characterised by physical growth and normative psychological conflicts and crises that emerge during this phase (Friedman, Connelly, Miller, & Williams, 1998, as cited in Leonard et al., 2002). These authors continue to note that this developmental stage, especially when combined with T1DM, a chronic

illness, poses inherent challenges, which in turn pose additional challenges to the adolescents and their parents, teachers and health care professionals.

Diagnosis of and coping with diabetes and its complications have major effects on people's lives, affecting physical, as well as psychological well-being (Bradley et al., 1994). Adherence to a diabetes regimen is therefore important in keeping blood-sugar levels as close to normal as possible, especially early in the course of the disease, as this helps to prevent or delay the serious long-term complications of T1DM such as blindness, kidney disease, amputations, heart attacks, and stroke (American Diabetes Association, 2007). According to Law, Kelly, Huey and Summerbell (2002) adolescents' beliefs about their illness (diabetes mellitus) and their related self-management behaviours are both important contributors to psychological well-being.

Psychological maladjustments in individuals with T1DM is particularly concerning because it is associated with poor metabolic control (Hood et al., 2006; Northam, Lin, Finch, Werther, & Cameron, 2010), which in turn increases the risk of diabetes complications (Northam et al., 2010). During the early stage of the T1DM adolescent's development, declines are frequently seen with regard to adherence and metabolic control, as well as in the psychological well-being of the adolescent (Weibe et al., 2005).

Therefore, research indicates the importance of parents in adolescents' adherence to diabetes treatment (Allen, Tennen, McGrade, Affleck, & Ratzan, 1983; Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Ingersoll, Orr, Herold, & Golden, 1986; Weibe et al., 2005). Non-adherence is particularly likely when underlying psychological disorders (depression, anxiety, eating disorders) are present, when there is a low level of education in a parent or child, and

when there is a low level of supervision of care by the family (Haughstveldt, Wentzel-Larson, Rokne, & Graue, 2011).

Several studies have identified the impact of diabetes on the family, for example parents' perspectives have been investigated by Boman, Viksten, Kogner, and Samuelsson (2004), Dashiff (1993), Kovacs et al. (1985), Lowes, Gregory and Lynne (2005) and Ray (2003); sibling relationships have been investigated by Adams, Preveler, Stein, and Dunger (1991) and Minagawa (1997); then Gafvels, Lithmer, and Borjeson (1993) studied living with diabetes in relation to gender, duration and complications. Grey et al. (1998) and Hamburg and Inoff (1983) studied the short term effect of coping skills; Hagglof, Fransson, Lernmark, and Thornlund (1994) looked at the psychosocial status of children with diabetes in the first two years after diagnoses; and Hernandez's (1996) study looked at the experience of living with Diabetes Mellitus; whereas research on the specific factors that may play a role in the treatment adherence among adolescents is sparse (Richt, 1992). One study did identify challenges that parents face, such as that they must learn how to balance the many daily requirements of managing their child who has diabetes, while providing a healthy environment for the rest of the family (Lewin et al., 2006).

As noted above with reference to the many studies on the impact of diabetes on the family, few research studies focused on the specific factors that may play a role in treatment adherence among adolescents. Therefore, improving the management of the illness by finding out the experiences of adolescents when it comes to their treatment regimen is imperative in helping adolescents understand and cope with their emotions and to improve their care and quality of life. The following research question emanates from this problem statement: *What are adolescents' experiences of treatment adherence with Type 1 Diabetes Mellitus?*

Central Theoretical Statement

Adolescents who suffer from T1DM can experience challenges with facilitating their adherence to the diabetes treatment regimen as it is interwoven into their everyday lives. It is therefore important to explore and describe the experiences of adolescents with respect to their treatment adherence for T1DM to gain a better understanding of this matter. The phenomenological approach (Moustakas, 1994) allows researchers to view the phenomenon under study from the adolescents' perspectives and is therefore a suitable approach for this study.

Method of Investigation

Research Method

The research study is explorative and descriptive in nature. A qualitative research method (approach) was used. Qualitative research aims to understand the meaning people attach to life and the experiences and perceptions of individuals (Fouché & Schurink, 2011). A qualitative approach was chosen to better describe and understand the experiences of the phenomenon of adolescent adherence to the treatment of T1DM.

Research Design

A phenomenological design is appropriate for exploration of the experiences of adolescents with T1DM related to treatment adherence since, as Plug, Louw, Gouws and Meyer (2009) note; it serves the purpose of capturing and describing experiences as they are lived from the view of the participants themselves. Data were collected from different individuals (adolescents) who have experience in the research phenomenon to get a better understanding of the common and shared experiences (Creswell, 2007).

Participants and Research Context

Purposive sampling (Maree & Petersen, 2007) was used to select adolescents (between the ages 13-18 years), who had been diagnosed with T1DM for at least one year prior to the research. The rationale for choosing participants who had been diagnosed with T1DM for longer than one year is based on early studies conducted by Kovacs et al. (1985), who indicate that in the first year after diagnosis, mild episodes of depression are often experienced, but, thereafter, the person seems to adapt to the disease.

The researcher contacted a paediatric endocrinologist within an independent practice and asked him (as gatekeeper) to approach possible participants on behalf of the researcher to ask whether they would be willing to participate in the study. The sample consisted of seven adolescents (two boys and five girls) between the ages 13-15 that voluntarily participated in the study. The participants come from families from an urban, socio-economically moderate income bracket. They all receive treatment at a private hospital on a monthly basis.

Data Gathering

Firstly, in-depth interviews were used to collect rich descriptive data on a specific area of interest (Greeff, 2011), in this case the adolescents' experiences regarding their adherence to treatment of T1DM. Each participant was asked to describe in their own words their experiences with respect to their treatment regimen of T1DM. Probing (Nieuwenhuis, 2007) were used as the interviews unfolded to gain a deeper understanding of what each participant shared.

Secondly, for the duration of a month following the in-depth interviews, the researcher asked the participants to come once a week for individual verbal reflections on their experiences regarding their treatment adherence. Thirdly, after the in-depth interviews and weekly reflections, the

researcher held a focus group (Nieuwenhuis, 2007) with all the participants. According to Berg (1995, as cited in De Klerk & Nienaber, 2011), the informal group discussion atmosphere of the focus group structure is intended to encourage subjects (participants) to speak freely about their behaviours, attitudes and opinions. All the interviews with the participants were audio-recorded. Consent was obtained from the participants to audio record all the interviews.

Data Analysis

The researcher transcribed the data into written form. Thematic analysis was used to analyse the data as a method for identifying, analysing and reporting themes in the data (Braun & Clarke, 2006). A theme helps the researcher to capture important concepts about the data in relation to the research question, and represents some level of patterned response or meaning in the data through minimising, organising and describing the data set in rich detail (Braun & Clarke, 2006).

The phases that were followed while analysing the data included familiarisation with the data (read and re-read while searching for patterns and meaning), generating initial codes for segments of the descriptions, searching for themes (the different codes were sorted into potential themes and subthemes), reviewing themes, defining and naming themes and finally reporting on the findings (Braun & Clarke, 2006).

Trustworthiness

Trustworthiness is an indication of methodological soundness and adequacy (Holloway & Wheeler, 2002). Trustworthiness for this research study was accomplished by using the strategies as suggested by the article of Krefting (1991). Credibility (truth value) was ensured through prolonged engagement with the participants and reflecting on the data over time.

Transferability (applicability) was ensured through dense description of the selection of participants and the qualitative findings (themes). Dependability (consistency) in this research study was ensured through the stepwise replication of data collection and data analyses, as well as independent coding and recoding of the data by the researcher and co-coder (a registered Research Psychologist) in the data analyses. Finally, confirmability was ensured by researchers who are familiar with qualitative research checking that the data support the analyses and interpretation of the findings.

Ethical Considerations

This study forms part of a research project for which ethical approval was obtained from the Ethics Committee of the North-West University, Potchefstroom Campus (NWU-00060-12-A1). The researcher adhered to the ethical guidelines set out by the North-West University as well as by the Health Professions Council of South Africa (HPCSA: Health Professions Act 56 of 1974). The purpose of ethical research is to protect the rights of the research participants (Durrheim, 2006). Because of the sensitive nature of this study, extra care was taken to ensure that the participants came to no harm. Ethical considerations were taken into account by respecting the rights, needs, values, and desires of all the participants (Creswell, 1994).

Permission was obtained from an independent doctor (paediatric endocrinologist who served as gatekeeper). Assent was obtained from all the participants (adolescents) and consent (signed consent forms) was obtained from the parents to ensure that participation was well-informed and voluntary. Written and verbal consent was obtained by the researcher. The participants were informed that their identity would be protected and that they could withdraw from the research study at any time with no consequences. The in-depth interviews, individual

verbal reflections and focus group were conducted within a safe environment. An appropriate referral source (registered psychologist) for professional help was provided for, should referral be necessary. No participants in this study required referral for professional help. Participants were informed that the North-West University would accept full responsibility for the keeping and safe-guarding of all collected data and that when the findings are published, all identifying information will be omitted.

Findings

Six main themes with subthemes emerged from the data analysis. Appropriate verbatim quotations are provided as validation.

Table 1

Summary of the Themes and Subthemes Portraying Adolescents with T1DM's Experiences of Their Treatment Adherence

Theme 1:	Lack of Understanding by Significant Others on Alignment with Treatment Adherence
Subthemes:	Teachers at school People in general Adolescents (peers)
Theme 2:	Support from Significant Others related to Adherence to Treatment Regimen
Subthemes:	Supporting role of teachers Supporting role of parents Role of friends and peers in supporting T1DM treatment
Theme 3:	T1DM Adolescents' Fears of Friends' and Peers' Perceptions
Theme 4:	Emotional Experiences Related to Treatment Adherence
Subthemes:	Negative emotions curtailing adherence Positive emotions promoting adherence
Theme 5:	Unpleasant Illness Experiences and Learning Curves to Cope with T1DM
Theme 6:	Non-obtrusive and User-friendly Alternative Treatment Options for T1DM

Theme 1: Lack of Understanding by Significant Others on Alignment with Treatment

Adherence

Participants reported a lack of understanding from significant others in different settings, such as their school teachers, people in general, and their peers.

Teachers at school. In this study most participants were treated differently or had to change their treatment regimen because the teachers would not allow them to leave the classroom to follow their treatment or to meet their needs. Participants reported a lack of knowledge among teachers regarding T1DM and its treatment.

One participant shared: “...but some have told me to take it off [insulin pump]. Then I told them I will die if I take it off. I think teachers are so uneducated about diabetes.”

Participants shared experiences with their teachers in the classroom, describing teachers’ attitudes towards requests from the participants to follow their treatment regimen or to support their needs. These participants didn’t receive support or understanding in the classroom, as is illustrated by the following quote:

“Some of them are friendly and some of them are nasty. Like when I ask if I may eat something, they say no, or if I want to go to the bathroom they don’t allow me to go... I eat in secret when the teacher is not looking... In primary school when I wore my bracelet, the teacher told me to take it off because I am not allowed to wear it.”

Another participant shared an experience in class:

“Once in the mathematics class I was not aware that it was vibrating, and it (the sensor) started to ring. The teacher shouted that I should put away my phone. When I told her that it was not my phone and showed her that it was my pump, she just told me to put it away.”

The quote above shows that some teachers do not understand the Medtronic insulin pump's operational function and warning sound and this impacted on this respondent's ability to follow her treatment regimen safely.

A participant shared an experience where the teacher thought she is using her diabetes as an excuse to go the tuck shop at school.

"In high school the teachers don't really understand, they are not interested. My sugar once dropped and when I asked the teacher if I could go to the tuck-shop, she didn't want to let me go, she thought I was lying. I will never lie about diabetes, because if something happens and no-one believes me. After she first asked the entire class, she let me go."

This incident shows that the teacher does not understand that the respondent would not use diabetes as an excuse to walk around. The respondents find it very difficult to ask the teachers to leave the classroom. They do not want to draw any extra attention to themselves and this makes it very difficult for them to be responsible in their treatment adherence.

People in general. In this study most of the participants experience that people in general have no or little knowledge of diabetes and the difference between Type 1 and Type 2 diabetes. Most of the participants shared an experience when people commented that they have diabetes because they ate too much sugar, as the following quotation illustrates: *"I think many people don't really understand diabetes. You ate too much sugar and that is why you got diabetes."* One participant shared an incident when a general practitioner did not identify the Medtronic insulin pump she was wearing:

"I was once at the doctor and he told me to put my little radio away... It was a shock, I was in grade two and I told him it was my pump. I first had to explain everything to him. Oh my word!"

As the quotation illustrates, there is a lack of knowledge regarding T1DM, sometimes even in the medical field. Another example of a lack of knowledge regarding T1DM is illustrated by a participant who shared an experience where a person asked if diabetes was the reason why he is so hyperactive:

“One guy asked if that is why I’m so hyper active... Most people just ask what it is and how it works. Some people think it is Type 2 because you ate too much sugar and then I try to tell them that there are different types that have different factors.”

These quotes again illustrate how uninformed people in general are about diabetes, its causes and how it is treated. The following participant shared the type of comments people make about diabetes in general: *“People have asked me what diabetes is, then I explain it like in our language, then you just come to a point where you say, my pancreas doesn’t work and yours does.”*

Adolescents (peers). In this study participants reported social isolation from their peers because of their lack of knowledge and understanding regarding the illness. Participants shared their experiences of peers as follows: *“I think, when I was small and I found out that I have diabetes, I did not have many friends, because some thought that it is contagious.”* Peers show no support for their illness and isolate them. Some reported that peers thought diabetes makes you sick and weak all the time:

“They think diabetes is like a cold and you are always sick from it. I think that is what they think. Like sometimes I am just tired, because my count is low, then I tire easily, then they ask “is it because you are sick?” Then I have to explain to them that it is just one of my symptoms.”

Another participant shared her frustration with her peers’ lack of knowledge: *“One asked me today how I got diabetes and if it was because I ate too much sugar. Then I want to have a fit.”* One participant shared her frustration regarding the misperception of peers that people with

diabetes normally have a weight problem. *“One guy has asked me why I have diabetes, I am so thin...they will never understand.”*

Theme 2: Support from Significant Others to Adhere to Treatment Regimen

The study found that participants view any support given to the diabetic adolescent in a positive light. These sources of support include support from teachers, parents and peers.

Role of teachers as support. The participants shared their positive experiences when their teachers supported them with their illness. Positive feedback from teachers seemed to help the adolescents to feel more confident to confide in the teachers about their blood glucose and if they needed help. One adolescent stated that: *“Once I was with the discipline head and I tested my sugar and it was very low, and he asked if he can go and get cookies and tea.”* Another participant noted concerned teachers and shared that: *“And because the teachers know they say I don’t have to ask anymore, because they also become concerned about my count when it is low... The teachers, if I just lay on my arms they ask if I’m okay.”*

This involvement of the educators makes it easy for the participants to adhere to their treatment. They can now take responsibility for their adherence in the classroom without drawing too much attention by asking permission. One adolescent reported: *“The teachers know, most of them. If I tell them I don’t feel good then they say I can quickly have juice or something sweet.”* This confirms that some of the teachers have more knowledge about diabetes which supports the participants.

Role of parents as support. The participants shared their experiences regarding parental involvement in their treatment adherence. Almost all of the participants reported that they rely

on family support with their diabetes, especially nocturnal blood glucose measurements. Family support was reported by participants as in the following example:

“We went to Camp Discovery, it is close-by. For three to four days. My dad went along again... Just to come and test my sugar in the evenings... My dad is actually just there for times when my sugar dips too low, because if it is low in my sleep I won’t know it, I would just sleep.”

Most adolescents require age-appropriate parental involvement in their diabetes management. One participant noted feeling more at ease because his/her parents still tested his/her blood glucose at night, as the quote suggests: *“Especially in the holidays, then my mom will come every two hours during the night to test.”* One participant remarked that she has a tendency to have high blood glucose at night and prefers her mother making corrections.

“My mom still does it, my sugar tends to go up after I am, then she does a correction and then when I get up my sugar is fine... I don’t even know she was there... My dad keeps me up to date, he also reminds me to test. When my sugar drops I tend to be moody, then he’ll quickly ask “what is your sugar?”

One participant noted that she did not feel comfortable going on a school trip if her mother could not be close-by. Most respondents liked to share the responsibility for adhering to their treatment as they were not ready to take full responsibility: *“She (mom) said that she will stay in a resort close-by.... it will actually be better for me if my mommy does it that way. Then I know if something fails, she is not far away.”*

Role of friends and peers in supporting T1DM treatment. Participants regard peers’ acceptance of their illness as very important for adhering to their treatment.

“Three friends with BLS are on the First Aid team, so they know more or less what to do... and then my one friend will tell me I shouldn’t eat the chocolate because my sugar is 10, and then I have other friends who give me sweets in secret of who will always remember to buy a 2l Tab when they buy their juice.”

One participant shared her relationship with her friends and how well they know her diabetes, showing that shared friendships with peers regarding the illness can be very beneficial to the participants, giving them a feeling of acceptance and support:

My friends are nice, if they see me eating they will ask if I've had insulin... My good friends know a lot, they know to test me, they know how my pump works. So I was on holiday with my friends, but then they knew everything, if I don't feel well, they know what to do... my good friends understand what it is. They also know what to do to help me when I don't feel good. With the sensor, when we came the first time, my friend came along so that she can see how it works... When my sugar is low someone will walk with me and get me a coke, they don't mind at all.

Another participant shared how his peers react to this illness: *"When we play cricket during breaks, then they will ask if I'm still okay. My friends know I have an emergency injection in the fridge and the first aid people know how to use it."* This quote suggests that the more involved the participants' friends and peers are with the illness, the easier it is for the participant to adhere to this treatment regimen.

Theme 3: T1DM Adolescents' Fears of Friends' and Peers' Perceptions

Adolescents who participated expressed their fears related to people's perceptions, especially their friends and peers. One participant noted that acceptance from peers is very important: *"One thing that I stress about in relation to my diabetes is if they will accept me. As far as I know I will be the only diabetic in my grade."* This shows that participants fear being isolated and treated differently because of their diabetes. Another participant shared the experience of feeling that diabetes makes him/ her different. *"Sometimes it is a case of feeling different as soon as I take my pump out."* One participant shared his experience of feeling isolated because of the disease, showing that the participants would like to share their

experiences and difficulties with someone that is going through the same (another diabetic adolescent):

“I don’t find diabetes much fun. It makes you feel different, because in my grade 8 group I am the only diabeticI don’t like testing, because you do it in front of friends and then they wonder what it’s all about..... But now all I worry about is that children should not look at me and think that I am different. I also don’t want them to look at me and tell me that I am sick.”

Most of the participants noted that they would like to share their experiences with another diabetic adolescent.

“I don’t like testing anymore; because it wasn’t fun... I didn’t want to feel different, because I saw no-one else doing it. But they wouldn’t do it, because they are not diabetic. And that made me feel as if I am not normal.”

Theme 4: Emotional Experiences Related to Treatment Adherence

It seems that most participants experienced the negative emotions regarding diabetes in the beginning stages. They reported that these negative emotions prevented them from adhering to their treatment regimen, while positive emotions promoted their adherence.

Negative emotions curtailing adherence. In the study the participants mentioned many negative emotions related to their illness, especially in the beginning stages of the illness. The study found that suffering is reduced when adolescents can maintain their own identity – some participants see diabetes as part of them. One participant shared that diabetes goes with much emotional conflict in the beginning stages:

“It takes a while to get over the shock. Then you become angry at life, and angry at God, but then you realise it is not His fault, it is not my parents’ fault, it is not my brother’s fault, and it is nobody’s fault.... I once stumbled upon a blog of the one or the other ‘Diabetes problems’ or something like that, and I realised how many people who have diabetes suffer from depression and how negative they are about it.”

One participant shared many negative feelings that she has felt since having diabetes, such as self-blame, guilt, frustration, sorrow, showing that diabetes causes many emotional reactions: :

“I don’t like testing, because you do it in front of friends and then they wonder what it’s all about... And sometimes I forget to take insulin and then my counts rise and then I feel very guilty... I always feel as if I did something wrong because it is so high... In the beginning I did not want it, I felt that all the time, why did I get it,” what did I do wrong?” Sometimes one feels as if it would have been easier to have someone to talk to who understands... I don’t talk to anyone. It doesn’t help to talk to my mom, because she doesn’t understand. The long term stuff bothers me, like the gangrene and your eyes, so I am trying to get everything under control now so that I don’t have to worry about it”

The following participant noted that she felt she was on a constant emotional rollercoaster:

“I wasn’t very impressed with the clinical scenario that my mother double-checks everything every time, it irritated me. Yesterday my sugar was low, one moment you cry and the next moment you see unicorns... I have my temper tantrums every three months or so, when it becomes too much. I cry through the whole night, and then I am fine again the next morning.”

These statements reveal that the participant’s glucose levels and emotions are connected.

Positive emotions promoting adherence. Some of the participants noted that their diagnosis with diabetes changed them so that they became better people, they have better relationships with their parents and are more in touch with their own identity and emotions. One participant shared how diabetes changed her as a person:

“My diabetes is kind of like a ‘blessing in disguise’, it was hard for me the first few months, but I learned that before I was diagnosed I was completely a different person and since I have been diagnosed I see life with different eyes and it is kind of more positive.”

One participant noted that diabetes made her become more responsible:

“Most of the time I thought it is all my fault, but now that I am older I know that it is not my fault. And that I have to take responsibility for it and for what I have to do.”

Another participant reported that diabetes defines her now as a person: *“It is no longer diabetes to me, it’s just me, and it is who I am.”*

Theme 5: Unpleasant Illness Experiences and Learning Curves to Cope with T1DM

Most participants reported unpleasant experiences because of their diabetes. One participant commented:

“Once I had too much cake and I injected too much and it went very low and in the night I got terrible hypo... I don’t know why I do not wake up, then they feed me banana to get my sugar up. My reflexes are also different then, my mom said once when she said I should bite, she had to throw in the banana otherwise I bite her finger.”

This confirms that if the adolescent is not yet in the transitional phase of taking full responsibility of their illness, the parents help them with the burden of daily treatment tasks.

Another example is the following participant’s experiences:

“When I feel bad in my sleep I don’t wake up, my parents say I cry in my sleep and when I wear my sensor I wake up from the alarm, in my room I always have something to eat when my count is low, such as Coke or Super C’s.”

This participant confirms that every adolescent experiences their illness differently than the next one. Some adolescents wake up and others don’t realise that their sugar count is low when they are asleep.

“The next day on the bus I became so nauseous, and I threw up in front of my whole class. And I’ve had to walk home a few times, because my pump doesn’t work, and then I have to walk back again.”

It is clear that the health care and emotional needs of the adolescent with diabetes can be distinctly different from what other adolescents need, and diabetes sufferers’ peers and educators should be educated to provide them with the necessary help. It is very traumatic to have an

incident like the above participant; most commonly in the company of their peers when they have a strong need to fit in and be accepted outside the family.

“I guess the bad part of it is that you know that everything you eat will have consequences, like I might get a high sugar count because of it. Most people see their plate with food and it is their plate with food, but I see 30, 40, 50, 10. This is how I see my plate with food.”

In this study food was a positive or a negative part of their illness. Diabetes may inhibit some adolescents from exploring life, while others deliberately explore risk-taking behaviour involving their diabetes care. The diabetic adolescent quickly realises the consequences of their actions and have a more realistic perspective of their future.

Lastly, another participant commented:

“It just takes a bit of time to get to know everything and you are scared that you might do something wrong. Like sometimes the needle breaks off and then you have to take a new one. Sometimes the tube comes off and the needle stays behind, then you have to do it all over again.”

Theme 6: Non-obtrusive and User-friendly Alternative Treatment Options for T1DM

Most of the participants in the study reported higher satisfaction with pump therapy compared to the use of injections. Participant shared the potential benefits of the insulin pump compared to using injections:

“I was on the injection for three months and all that I remember about the injections it that my leg is still rock hard, and if you didn’t change the needle, then it hurt and burned and there was blood. And the one time I was tired and sick and we got KFC that evening and I decided ‘not the hell’, I am not going to inject, and I woke during the night with a sugar count of 20. It was still in the beginning, the second week or so, and there was panic at 1 am through the entire house about the injections.....but I have more freedom with the pump. And when I look at what my friends do I can do exactly the same as they can, but on the injections I knew, now I have to sit, now I have to eat, now I have to inject otherwise something will happen. It (the pump) is kind of a little more freedom and more normal.”

The insulin pump gives patients more flexibility and the ability to administer insulin at will and in very small increments. One participant reported many physical complaints regarding the injections:

“It (the pump) is not as painful as the injections. The injections left blue marks on my legs and the pump doesn’t... The thing about the injections that I didn’t like is that there are three different injections. In the morning one, then the Nova rapid during the day and in the evening a green one. The morning one I didn’t like because you have to inject half an hour before you eat and sometimes there wasn’t time.”

Another participant shared that the injection limits privacy because it is difficult to inject without anyone seeing: *“It’s not easy to inject while you are at school, because you cannot go to the bathroom all the time... The pump is much more expensive than the injection, but much better.”* One participant shared that the pump makes you feel a sense of normality again:

“If you treat it correctly you sometimes forget you have it, and it is like a normal life. The sensor makes it easier because you don’t have to test all the time, you can manage it better. It is easier with the pump, because you don’t have to inject all the time, you inject, but not with the injection, it is better.”

Another participant shared that the pump also has liabilities, for example that a patient’s glucose levels are not as precise as with the injections, but they still have more freedom with meals:

“I have had the pump for 8 years. My mother has spoken to the people at the high school expo, there were people there who did diabetes, then my mother asked them things. They said they found that with the injections the counts are much better, because you have to be more precise. But the pump gives me much more freedom to eat what I want. I think the pump is easier.”

Discussion

The research question in this study was: What are adolescents’ experiences of treatment adherence with Type 1 Diabetes Mellitus? In explaining their experiences of their treatment of T1DM, most of the participants mentioned a lack of understanding by significant others (teachers at school, people in general, and peers) regarding alignment with treatment adherence. This concurs with the studies of Hains et al. (2007) and Hains, Davies, Parton and Silverman (2001),

which found that negative attributions of teachers', friends' and peers' reactions have a significant effect on glycaemic control (adherence to treatment).

Literature indicates that diabetes specific legislation governing access to educational programmes in schools for young people with diabetes is largely absent (Lange, Jackson, & Deeb, 2009). According to Olson, Seidler, Goodman, Gaelic and Nordgren (2004), most teachers say that they know relatively little about T1DM. In a study by Wagner, Heapy, James and Abbott (2006) parents indicated that school staff lacked instruction in routine, non-emergent diabetes care. The same study found that the learners themselves reported difficulty with school staff because of issues such as attributing all their school problems to diabetes, calling attention to diabetes in class, and dispensing inaccurate diabetes information to classmates (Wagner et al., 2006). In another study parents experienced problems at their children schools when they informed staff about their children's diabetes and in a small percentage of cases, parents reported that their child was then forced to change schools (Anderson, 2007). A study by Wodrich (2005) offers an empirical indication of the negative consequences attached to uninformed teachers. Wodrich (2005) found that teachers presented with descriptions of T1DM-related fluctuating classroom performance often misattribute these symptoms to psychiatric or learning problems, not diabetes. In this study most participants were treated differently or had to change their treatment regimen because the teachers did not allow them to leave the classroom to attend to their treatment due to lack of knowledge regarding the illness. But findings in this current research study also indicated that significant others (teachers, parents, and peers [friends]) support participants with their treatment regimen.

Research indicates that adolescents with diabetes will most likely talk to school friends and teachers about their diabetes and they would turn to their school friends and teachers if they

need help with managing their diabetes at school (Lange et al., 2009). Research therefore supports the importance of support from friends/peers regarding diabetes (Wodrich et al., 2011). The findings in the current research study indicate how support from friends and peers help the participants to exercise control over their treatment regimen.

The participants furthermore mentioned the importance of the support of their parents in the treatment of T1DM. Previous studies have shown that parents influence the extent to which the illness will affect their children as they prepare them to incorporate lifelong health habits (Anderson et al., 1997; Hanna & Guthrie, 2003). Lack of support influences the way that they treat their illness. When the adolescent is not yet taking full responsibility of his/her illness the parents help him or her with the burden of daily treatment tasks (Weibe et al., 2005). Better outcomes of diabetes are strongly associated with collaborative parent involvement and support throughout adolescence (Anderson et al., 1997; Butwicka, Zalepa, Fendler, Szadkowska, & Mlynarski, 2013). A survey indicated that 60% of parents of children with diabetes have adapted their employment arrangements to accommodate school time needs of their child with diabetes (Bodas, Marin, Amillategui, & Arana, 2008).

The current study also indicates participants' fear of friends and peers' perceptions regarding their T1DM. They fear that they will not be accepted and that they will be isolated and treated differently. This fear of acceptance concurs with the research by Wagner et al. (2006), which indicates that most of the learners in their study reported trouble with other learners because of their diabetes. The fear of social isolation and being treated differently concurs with Coleman, Kloep and Kloep (2007), who state that social isolation of young people with chronic disease is common and many may have very little contact with their peers outside their own family and during school holidays.

The participants mentioned negative and positive emotional experiences relating to their treatment adherence. In this study some of the participants noted that their diagnosis with diabetes changed them so that they became better people, have better relationships with their parents and are more in touch with their own identity and emotions. No literature relating to positive aspects and emotional experiences of diabetes could be found, only the negative effects associated with the disease, for example: the measurement of stress in older children and adolescents with T1DM (Delamater et al., 2013); anxiety and sensitivity in adolescents with T1DM and their parents; the fear for hypoglycaemia and prediction of metabolic control (Messenger, 2006); and diabetes specific emotional distress among adolescents (Weissberg-Benchell et al., 2011) to name only a few.

Lastly, most of the participants mentioned the many potential benefits of the insulin pump, and this concurs with the findings of Slijper et al. (1990) and Low, Massa, Lehman and Olshan's (2005) studies. They found that pump users reported having more control over their lives compared to non-users over 6 months and that they did not have problems with depression, self-esteem or social adjustment and reported little self-consciousness about wearing the pump. Slijper et al. (1990) found that pump users had fewer physical complaints, fewer physical constraints, and better metabolic control than those using injections. The pump also appears to facilitate social interaction because of its flexibility (Low et al., 2005). To a certain extent, the insulin pump that participants use helps to ease the way in which insulin is administered. None the less, participants reported that most teachers did not understand what they use it for and still reprimanded them in class when the pump would beep, and this would interfere with their class performance.

Limitations and Recommendations

One of the limitations of the study is the limited demographic variation of the qualitative research study. As a result of this, the research findings cannot be generalised for the population of adolescents with T1DM in South Africa. The participants come from an urban, socio-economically moderate income bracket, making the findings specific to their living conditions. They all receive treatment at a private hospital on a monthly basis. This study only recruited adolescents who use a Medtronic insulin pump. Thus, the possibility of generalising the findings to a conventionally managed population may be limited.

Though extensive literature on adolescents with T1DM exists, little could be found on the experiences of adolescents regarding their treatment adherence in a South African context. It is recommended that more research be done on the experiences of adolescents with T1DM. It is further recommended that a programme with guidelines for adolescents with T1DM and their parents be developed to support them in coping with their illness.

Conclusion

The aim of the study was to explore and describe the experiences of adolescents with T1DM with respect to treatment adherence. According to Bonnici (as cited in Flynn, 2009) a profound change is urgently required in the attitude of doctors, nurse educators and dieticians, and also the children's parents with regard to T1DM and its treatment regimen. Communication skills, effective child behaviour management, psychological support and crisis intervention approaches have to be learned and sensitively should be applied throughout the course of the child's development to reduce family dysfunction, non-compliant behaviours, and difficulties

with school performance and to promote psychosocial adjustment (Bonnici, as cited in Flynn, 2009).

Adolescence is the transitional phase of development between childhood and adulthood that includes the biological and psychosocial changes of puberty (Court, Cameron, Berg-Kelly, & Swift, 2008). Having access to medical and psychosocial support at this time is essential for these young adults not to lose the medical and emotional investment they, and many others, have made in their health since diagnoses (Kovacs et al., 1985). Diabetes poses unique challenges for the individual, their families and the diabetes care team. According to Hillege (2005) the weekly care of diabetes to keep blood glucose and diabetics HbA1c's in the normal range is very difficult and the risk for burnout is high if expectations are not realistic and practical strategies are not put into place.

How well the body copes with the diabetes is strongly linked to how the adolescent thinks and feels and relates to others (Flynn, 2009). Although changing emotions are normal for all people, in children with diabetes they have the potential to make the blood glucose levels unstable (Flynn, 2009) thus stable emotional relationships are of vital importance.

Clearly, in order to cope, adolescents need not only medical treatment and education about diabetes, but also emotional support from significant others, supervision and repeated reinforcement if they are to achieve effective self-management. The most basic suggestion is that diabetes care for children and adolescents should include routine assessment of the psychological and social pressures on the child and family, so that strategies can be put in place to give support and education as needed and as appropriate.

References

- Adams, R., Preveler, R. C., Stein, A., & Dunger, D. B. (1991). Siblings of children with diabetes involvement, understanding and adaptation. *Diabetic Medicine*, 8, 855-859.
- Allen, D. A., Tennen, H., McGrade, B. J., Affleck, G., & Ratzan, S. (1983). Parent and child perceptions of the management of juvenile diabetes. *Journal of Paediatric Psychology*, 8, 129-141.
- American Diabetes Association. (2007). *All about diabetes*. Retrieved October 31, 2007 from [http://www. Diabetes.org/about-diabetes.jsp](http://www.Diabetes.org/about-diabetes.jsp)
- Amillategui, B., Calle, J. R., Alvorez, M. A., Cardiel, M. A. & Barrio, R. (2007). Identifying the special needs of children with type 1 diabetes in the school setting. An overview of parents' perception. *Diabetes Medicine*, 24, 1073-1079.
- Anderson, B. (2007). Diabetes in children: Psychosocial aspects. In: The global burden of youth diabetes: Perspectives and potential. A charter paper. *Pediatric Diabetes*. 8, 26-31.
- Anderson, B. J., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescence with insulin dependent diabetes mellitus. *Journal of Paediatrics*, 130, 257-265.
- Bodas, P., Marin, M. C., Amillategui, B., & Arana, R. (2008). Diabetes in the school. Perceptions of children and adolescents with type 1 diabetes. *Avances en Diabetologia*, 24(1), 51-55.

- Boman, K. K., Viksten, J., Kogner, P., & Samuelsson, U. (2004). Serious illness in childhood: the different threats of cancer and diabetes from a parent perspective. *Journal of Paediatrics, 145*, 373-379.
- Bradley, C., Gamsu, D. S., & Psychological Well-being Working Group of the WHO/IDF St Vincent Declaration Action Programme for Diabetes. (1994). Guidelines for encouraging psychological well-being. *Diabetic Medicine, 11*, 510-516. doi: 10.1111/j.1464-5491.1994.tb00316.x
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
- Butwicka, A., Zalepa, A., Fendler, W., Szadkowska, A., & Mlynarski, W. (2013). Maternal depressive symptoms predict acute hospitalization among children with type 1 diabetes. *Pediatric Diabetes, 14*, 288-294.
- Children's Diabetes Foundation at Denver. (2007). *Questions and answers*. Retrieved June 23, 2007, from <http://www.childrensdiabetesfdn.org/educ/whatis.html>.
- Coleman, J., Kloep, L. B., & Kloep, M. (2007). *Adolescence and health*. West Sussex, England: Wiley & Sons, Ltd.
- Court, J. M., Cameron, F. J., Berg-Kelly, K., & Swift, P. G. F. (2008). Diabetes in adolescence. ISPAD Clinical Practice Consensus Guidelines 2006-2007. *Pediatric Diabetes, 9*, 255-262.
- Creswell, J. W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications, Inc.

- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. (2nd. ed.). Thousand Oaks, CA: SAGE publications.
- Dashiff, C. J. (1993). Parents' perceptions of diabetes in adolescent daughters and its impact on the family. *Journal of Pediatric Nursing*, 8, 361-369.
- De Klerk, W., & Nienaber, A. W. (2011). A discussion of a unique collaboration model between schools. *Psychology Research*, 1(3), 170-181.
- Delamater, A.M., Patino-Fernandez, A.M., Smith, K.E., & Bubb, J. (2013). Measurement of diabetes stress in older children and adolescents with Type 1 Diabetes Mellitus. *Pediatric Diabetes*, 14, 50-56.
- Diabetes Statistics. (2012). Retrieved June 13, 2012 from [http:// www.globalbuzz-sa.com/forums](http://www.globalbuzz-sa.com/forums)
- Durrheim, K. (2006). Research design. In M. Terre Blanche, K. Durrheim, & D. Paintor (Eds.), *Research in Practice: Applied Methods for the Social Sciences* (2nd ed., pp. 33-59). Cape Town: University of Cape Town Press.
- Faulkner, M. (2003). Quality of life for adolescents with type 1 diabetes: Parental and youth perspectives. *Paediatric Nursing*, 2(5), 362-368.
- Flynn, R. (2009). *The emotion of children with diabetes*. CDE Publication.
- Fouchè, C. B., & Schurink, W. (2011). Qualitative research designs. In A. S. De Vos, H. Strydom, C. B. Fouche, & C. S. L. Delport (Eds), *Research at Grass Roots: For the social Sciences and human service professions*. (4th ed., pp. 307-327), Pretoria: Van Schaik.

- Gafvels, C., Lithner, F., & Borjeson, B. (1993). Living with diabetes: relationship to gender, duration and complications. A survey in northern Sweden. *Diabetic Medicine*, *10*, 768-773.
- Greeff, M. (2011). Information collection: Interviewing. In A. S. De Vos, H. Strydom, C. B. Fouché, & C. S. L. Delpont (Eds.), *Research at Grass Roots: For the social sciences and human service professions* (4th ed., pp. 341-376), Pretoria: Van Schaik.
- Grey, M., Boland, E. A., Davidson, M., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. V. (1998). Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care*, *21*(6), 901-908.
- Hanna, K. M., & Guthrie, D. (2003). Adolescents' behavioral autonomy related to diabetes management and adolescent activities/rules. *The Diabetes Educator*, *29*(2), 283-291.
- Hagglof, B., Fransson, P., Lernmark, B., & Thernlund, G. (1994). Psychosocial status of children with diabetes in the first 2 years after diagnosis. *Arctic Medical Research* *53*(Suppl. 1), 20-29.
- Hains, A. A., Davies, W. H., Parton, E., & Silverman, A. H. (2001). Brief report: a cognitive Behavioural intervention for distressed adolescents with type 1 diabetes. *Journal of Paediatric Psychology*, *26*, 61-66.
- Hains, A. A., Berlin, K. S., Davies, W. H., Smothers, M. K., Sato, A. F. & Almenzadeh, R. (2007). Attributions of adolescents with type 1 diabetes related to performing self-care around friends and peers: The moderating role of friend support. *Journal of Paediatric Psychology*, *32*, 561-570.

- Hamburg, B. A., & Inoff, G. E. (1983). Coping with predictable crises of diabetes. *Diabetes Care*, 6, 409-416.
- Haugstvedt, A., Wentzel-Larson, T., Rokne, B. & Graue, M. (2011). Perceived family burden and emotional distress: similarities and differences between mothers and fathers of children with type 1 diabetes in a population-based study. *Pediatric Diabetes*, 12, 107-114.
- Hernandez, C. A. (1996). Integration: The experience of living with insulin dependent (type 1) diabetes mellitus. *The Canadian Journal of Nursing Research*, 28, 37-56.
- Hillegge, S. (2005). *The impact of Type 1 Diabetes on the self of adolescence and young adults* (Unpublished manuscript). University of Western Sydney, School of Applied Social and Human Sciences.
- Holker, V. M. (2008). Adolescent diabetic treatment adherence and the impact of parental involvement (Unpublished master's thesis). University of Wyoming.
- Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing*. Oxford: Blackwell.
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkering, L., & Laffel, L. M. (2006). Depressive symptoms in children and adolescents with type 1 diabetes: Association with diabetes-specific characteristics. *Diabetes Care*, 29, 1389-1391.
- Ingersoll, G. M., Orr, D. P., Herrold, A. J., & Golden, M. P. (1986). Cognitive maturity and self-management among adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics*, 108, 620-623.

- Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paul-auskas, S., & Pollock, M. (1985). Initial psychological responses of parents to the diagnoses of insulin-dependent diabetes mellitus in their children. *Diabetes Care*, 8, 568-575.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 55(3), 1-19.
- Lange, K., Jackson, C., & Deeb, L. (2009). Diabetes Care in Schools: The disturbing facts. *Pediatric Diabetes*, 13, 28-36.
- Law, G. U. (2002). Dissimilarity in adolescent and maternal representations of type I diabetes: Exploration of relations to adolescent well-being. *Child: Care, Health and Development*, 28, 369-378.
- Law, G. U., Kelly, T. P., Huey, D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role? *Journal of Adolescent Health*, 31(4), 381-385.
- Leonard, B. J., Garwick, A., & Adwin, J. Z. (2002). Adolescents' perceptions of parental roles and involvement in diabetes management. *Journal of Paediatric Nursing*, 20(2), 405-415.
- Lewin, A. B., Heidgerken, A. D., Geffen, G. R. Williams, L., Storch, E. A., Gelfand, K. M., & Silverstein, J. H. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Paediatric Psychology*, 31, 174-183.
- Liles, R. G., & Juhnke G. A. (2008). Adolescent diabetic control: Using the Process-Person-Context-Time Model. *Journal of Counselling and Development*, 86, 75-86.

- Low, K. G., Massa, L., Lehman, D., & Olshan, J. (2005). Insulin pump use in young adolescents with Type 1 diabetes: A descriptive study. *Pediatric Diabetes*, 6, 22-31.
- Lowes, L., Gregory, J. W., & Lynne, P. (2005). Newly diagnosed childhood diabetes: A psychosocial transition for parents. *Journal of Advanced Nursing*, 50, 253-261.
- Maree, K., & Petersen, J. (2007). Sampling. In K. Maree (Ed.), *First Steps In Research* (pp. 172-180) Pretoria: Van Schaik Publishers.
- Messenger, C.L. (2006). *Anxiety sensitivity in adolescents with Type 1 Diabetes and their parents: Relationship to the fear of hypoglycemia and prediction of metabolic control*. (Unpublished manuscript). Columbian College of Arts and Sciences of the George Washington University.
- Minagawa, M. (1997). Sibling relationships of Japanese children with diabetes. *Journal of Pediatric Nursing*, 12, 311-316.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: SAGE Publications.
- Nieuwenhuis, J. (2007). Qualitative research designs and data gathering techniques. In K. Maree (Ed.), *First steps in research* (pp. 70-92). Pretoria: Van Schaik Publishers.
- Northam, E. A., Lin, A., Finch, S., Werther, G. A., & Cameron, F. J. (2010). Psychological well-being and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care*, 33(7), 1430-1437.

- O'Grady, M. J., Delaney, J., Jones, W., & Davis, E. A. (2013). Standardised mortality is increased three-fold in a population-based sample of children and adolescents with type 1 diabetes. *Pediatric Diabetes, 14*, 13-17.
- Olson, A. L., Seidler, A. B., Goodman, D., Gaelic, S., & Nordgren, R. (2004). School professionals' perceptions of about the impact of chronic illness in the classroom. *Pediatric Adolescent Medicine, 158*, 53-58.
- Plug, C., Louw, D. A. P., Gouws, L. A., & Meyer, W. F. (2009). *Verklarende en Vertalende Sielkundewoordeboek* (3de uitgawe). Sandton: Heinemann Voortgesette Onderwys (Edms) Bpk.
- Richt, B. (1992). *Mellan twa valdar: Om konflikten mallan livets drav och kotorns onskingar: lardomar fran familjer med diabetessjuka barn* (Unpublished manuscript). University of Tema, Linkoping.
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., & Clark, N. (2005). Care of children and adolescents with type I diabetes: A statement of the American Diabetes Association. *Diabetes Care, 28*, 186-212.
- Skinner, T. C., Channon, S., Howells, L., & McEvelly, A. (2000). Diabetes during adolescence. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in Diabetes Care* (pp. 25-60). Chichester, UK: Wiley.
- Slijper, F. M., De Beaufort, C. E., Bruining, G. J., De Visser, J. J., Aarsen, R. S., Kicker, D. A., & Van Stik, R. (1990). Psychological impact of continuous subcutaneous insulin infusion

- pump therapy in non-selected newly diagnosed insulin dependent (type 1) diabetic children: evaluation after two years of therapy. *Diabetes & Metabolism*, 16(4), 273-277.
- Sweetlifemag. (2011). *Diabetes in South Africa the facts*. Retrieved January 25, 2013 from <http://sweetlifemag.co.za/2011/07/diabetes-in-south-Africa-the-facts/>
- Viner, R., & Barker, M. (2005). Young people's health: The need for action. *British Medical Journal*, 330, 901-903.
- Wagner, J., Heapy, A. James, A., & Abbott, G. (2006). Brief report: glycemic control, quality of life, and school experience among students with diabetes. *Journal of Paediatric Psychology*, 31, 764-769.
- Weibe, D. J., Berg, C. A., Korbel, C., Palmer, L., Beveridge, R. M., Upchurch, R., & Donaldson, D. L. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control and quality of life across adolescence. *Journal of Paediatric Psychology*, 30(2), 167-178.
- Wodrich, D. L. (2005). Disclosing information about epilepsy and type 1 diabetes mellitus: the effects on teachers' understanding of classroom behaviour. *School Psychology*, 30, 288-303.
- Wodrick, D. L., Hasan, K., & Parent, K. B. (2011). Type 1 Diabetes Mellitus and school: A review. *Pediatric Diabetes*, 12, 63-70.
- Wysocki, T., & Greco, P. (2006). Social support and diabetes management in childhood and adolescence: Influence of parents and friends. *Current Diabetes Reports*, 6, 117-122.

SECTION 3: CRITICAL REFLECTION

Critical Reflection

Diabetes is known to be the third most common chronic condition in children and adolescents (Law, 2002) and that requires a lifetime of self-care to prevent complications. A significant link has been found between the impact of stress associated with this chronic illness and the transitional phase of late childhood to adolescence (Holker, 2008). The unique health and social care needs of young people are driven directly by the developmental nature of adolescence. Problems as diverse as exploratory behaviours, sexuality, adaptation to chronic conditions, violence, accidents and mental health problems are directly related to the interplay of biological, psychological and social elements of adolescent development, and the interface of this development with peers, family and the wider community (Viner, 2005). Adolescents' health in general has shown little change for the past 40 years, in contrast to the dramatic strides made in the health of children and the elderly (Coleman et al., 2007). Thus it is of great importance to emphasise the management of diabetes within the social context as behaviours towards the children and adolescent with chronic diabetes impact their self-care choices (Wysocki & Greco, 2006). Therefore, others' behaviour towards the child- or the adolescent diabetic can greatly impact how they choose to care for themselves (Wysocki & Greco, 2006).

The psychological well-being of the adolescent is strongly connected to how the adolescent views the illness, and this will then in turn affect adherence. It has been found that diabetes dietary self-care and psychological well-being is strongly related to how the adolescent views his or her illness (Law, 2002). Problems with adolescents with diabetes adhering to their treatment regimen are nothing new (Holker, 2008). Research are very focused on parental involvement with adolescents with T1DM (Delamater, 2006; Holker, 2008; Kaugars, Kichler, &

Alemzadeh: 2011) to name a few, but there is little literature available that discusses the experiences of adolescents with T1DM with regard to their treatment adherence in the South African context.

In order to address the above-mentioned problem, the following question was asked in this research study: “What are the experiences of adolescent with Type 1 Diabetes Mellitus with respect to their treatment adherence?” The aim of the study was therefore to explore and describe the experiences of adolescents with T1DM regarding their treatment adherence. A qualitative research method, more specifically a phenomenological approach, was followed. Purposive sampling (Maree & Petersen, 2007) was used to select adolescents (between 13–18 years) who have been diagnosed with T1DM for at least one year prior to the research. The rationale for choosing respondents who had been diagnosed with T1DM for longer than one year is based on early studies conducted by Kovacs et al. (1985), which indicate that during the first year after diagnosis, patients experienced mild episodes of depression, but thereafter they seemed to adapt to the disease. The sample consisted of seven adolescents (two boys and five girls) between the ages of 13-15 that participated in the study voluntarily. In-depth interviews were used to collect rich descriptive data, whereafter the participants came once a week for a month to share their reflections, and lastly a focus group was held with all the participants. All the interviews with the participants were audio-recorded.

Six main themes with subthemes emerged from the data analysis. First, the participants experienced a lack of understanding by significant others with regard to their treatment adherence. This occurred in different settings, such as their school teachers, people in general, and their peers. Most participants were treated differently or had to change their treatment regimen because the teachers would not allow them to leave the classroom to follow their

treatment, or to meet their needs. The reason they cited was that teachers lack knowledge regarding T1DM and its treatment. Participants also indicated that people in general have no or little knowledge of diabetes and the difference between Type 1 and Type 2 diabetes. Most of the participants shared an experience when people commented that they have diabetes because they ate too much sugar. Participants reported social isolation from their peers because of their lack of knowledge and understanding regarding the illness. Some reported that peers thought diabetes makes you sick and weak all the time.

The second main theme in the study is that any support given to the diabetic adolescent is seen in a positive light. These sources of support include support from teachers, parents and peers. The participants regard support from their teacher regarding their T1DM as a positive experience. Positive feedback from the teachers seems to help the adolescents to feel more confident to confide in the teachers about their blood glucose and if they need help. Some participants shared ideas on parent involvement in their treatment adherence. Almost all of the participants reported that they rely on family support with their diabetes, especially for nocturnal blood glucose measurements. Participants want their peers to accept their illness, and this proves to be very important for treatment adherence.

The third theme that emerged from this research study is the participants' (adolescents) fears of friends' and peers' perceptions regarding their T1DM. The participants indicated that they had a fear of being isolated and being different. They indicated that they have a great need for sharing their experiences with other diabetic adolescents.

Theme four revealed both negative and positive emotional experiences regarding the treatment adherence. The participants shared that diabetes made them deal with many emotional

conflicts since their diagnoses. They reported that these negative emotions prevented them from adhering to their treatment regimen, while positive emotions promoted their adherence. The study showed that suffering is reduced when adolescents can maintain their own identity – some participants see diabetes as part of them. In the last sub-theme of this theme, participants shared that positive emotions changed them into better people. They have better relationships with their parents and are more in touch with their own identity and emotions.

In theme five the participants shared their unpleasant illness experiences and learning curves to cope with T1DM. It became clear in the study that the health care and emotional needs of an adolescent with diabetes is distinctly different than other adolescents and their peers, and the condition may inhibit some adolescents from exploring life, while the others deliberately explore risk-taking behaviour involving their diabetes care. The participants in the study quickly realised the consequences of their actions and have a more realistic perspective of their future.

Lastly, in theme six most of the participants in the study reported high satisfaction with pump therapy compared to the use of injections. Participants shared the potential benefits of the insulin pump compared to using injections.

From the findings it is clear that in order to cope, the adolescents need not only medical treatment and education about diabetes (T1DM), but also emotional support, supervision and repeated reinforcement if they are to achieve effective self-management. The basic suggestion is that diabetes care for children and young people should include routine assessment of the psychological and social pressures on the adolescent and the family so that strategies can be put in place to give support and education as needed and as appropriate. The researcher also recommends that school personnel must be educated on diabetes so that they understand the

changing medical and psychosocial needs of the adolescent and can help him/her to participate fully in all the available work, sport, and leisure activities. Models of legislation and training programmes for school personnel specifically addressing the needs of children with diabetes in schools have been developed in a number of countries such as Greece, Germany, Italy, Poland, Spain, Sweden, the UK and the USA. These programmes should be considered as an example to other countries. These best practices can serve as a foundation for national improvement.

The research findings cannot be generalised for the entire population of adolescents with T1DM in South Africa due to the limited demographic variation of the qualitative research study. The topic of adolescents with T1DM has been researched numerous times. A few studies on the emotional experiences of adolescents with T1DM could be found, but none of the studies found addressed the South African context. This current study therefore contributes new knowledge to the field of adherence in adolescents with T1DM. Further studies and programmes with guidelines regarding the improvement of the lives of adolescents with T1DM and their families are needed, and findings and results can then be compared.

References

- Coleman, J., Kloep, L. B., & Kloep, M. (2007). *Adolescence and health*. West Sussex, England: Wiley & Sons, Ltd.
- Delamater, A. M. (2006). Improving patient adherence. *Clinical Diabetes*, 24, 71-77.
- Holker, V. M. (2008). Adolescent diabetic treatment adherence and the impact of parental Involvement (Unpublished master's thesis). University of Wyoming.
- Kaugars, A. S., Kichler, J. C., & Alemzadeh, R. (2011). Assessing readiness to change the balance of responsibility for managing Type 1 Diabetes Mellitus: Adolescent, mother, and father perspectives. *Pediatric Diabetes*, 12, 547-555.
- Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paul-auskas, S., & Pollock, M. (1985). Initial psychological responses of parents to the diagnoses of insulin-dependent diabetes mellitus in their children. *Diabetes Care*, 8, 568 -575.
- Law, G. U. (2002). Dissimilarity in adolescent and maternal representations of type I diabetes: Exploration of relations to adolescent well-being. *Child: Care, Health and Development*, 28, 369-378.
- Maree, K., & Petersen, J. (2007). Sampling. In K. Maree (Ed.), *First steps in research* (pp. 172-180) Pretoria: Van Schaik Publishers.
- Viner, R. (2005). *The ABC of adolescence*. London. British Medical Journal Books,
- Wysocki, T., & Greco, P. (2006). Social support and diabetes management in childhood and adolescence: Influence of parents and friends. *Current Diabetes Reports*, 6, 117-122.

COMPLETE REFERENCE LIST

References

- Ackard, D. M., Vik, N., Neumark-Sztainer, D., Schmitz, K. H., Hannah, P., & Jacobs, D. R. Jnr. (2008). Disordered eating and body dissatisfaction in adolescents with type 1 diabetes and a population-based comparison sample: Comparative prevalence and clinical implications. *Pediatric Diabetes*, 9, 312-319.
- Adams, R., Preveler, R. C., Stein, A., & Dunger, D. B. (1991). Siblings of children with diabetes involvement, understanding and adaptation. *Diabetic Medicine*, 8, 855-859.
- Allan, D. A., Tennen, H., McGrade, B. J., Affleck, G., & Ratzan, S. (1983). Parent and child perceptions of the management of juvenile diabetes. *Journal of Paediatric Psychology*, 8, 129-141.
- American Diabetes Association. (2007). *All about diabetes*. Retrieved October 31, 2007 from <http://www.Diabetes.org/about-diabets.jsp>
- Amillategui, B., Calle, J. R., Alvarez, M. A., Cardiel, M. A., & Barrio, R. (2007). Identifying the special needs of children with type 1 diabetes in the school setting. An overview of parents' perception. *Diabetic Medicine*, 24, 1073-1079.
- Anderson, B. (2007). Diabetes in children: Psychosocial aspects. In the global burden of youth diabetes: Perspectives and potential. A charter paper. *Pediatric Diabetes*, 8, 26-31.
- Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatric Nursing*, 130, 257-265.

- Anderson, B., Ho, J., & Laffel, L. M. (1999). An office-based intervention to maintain parent-adolescent teamwork in diabetes management. Impact on parent involvement, family conflict, and subsequent glycemic control. *Diabetes Care*, 713-723.
- Bodas, P., Marin, M. C., Amillategui, B., & Arana, R. (2008). Diabetes in the school. Perceptions of children and adolescents with type 1 diabetes. *Avances en Diabetologia*, 24(1), 51-55.
- Boman, K. K., Viksten, J., Kogner, P., & Samuelsson, U. (2004). Serious illness in childhood: the different threats of cancer and diabetes from a parent perspective. *Journal of Paediatrics*, 145, 373-379.
- Blaxter, M. (1987). Attitudes to health. In B. Cox (Ed.). *The health and lifestyle survey*. London: Health Promotion Research Trust.
- Bradley, C., Gamsu, D. S., & Psychological Well-being Working Group of the WHO/IDF St Vincent Declaration Action Programme for Diabetes. (1994). Guidelines for encouraging psychological well-being. *Diabetic Medicine*, 11, 510-516.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Buckloh, L. M., Lochrie, A. S., Antal, H., Milkes, A., Canas, A., Hutchinson, S., & Wysocki, T. (2008). Diabetes complications in youth: Qualitative analysis of parents' perspectives of family learning and knowledge. *Diabetes Care*. 31, 1516-1520.
- Butwicka, A., Zalepa, A., Fendler, W., Szadkowska, A., & Mlynarski, W. (2013). Maternal depressive symptoms predict acute hospitalization among children with type 1 diabetes. *Pediatric Diabetes*, 14, 288-294.

- Card, N., Stucky, B, Sawalani, G., & Little, T. (2008). Direct and indirect aggression during childhood and adolescence: A meta-analytic review of gender differences, intercorrelations, and relations to maladjustment. *Child: Care, Health and Development* 79, 1185-1229.
- Children's Diabetes Foundation at Denver. (2007). *Questions and answers*. Retrieved June 23, 2007, from [http://www. childrensdiabetesfdn.org/educ/whatis.html](http://www.childrensdiabetesfdn.org/educ/whatis.html).
- Coleman, J. C., & Hendry, L. B. (1999). *The nature of adolescence*. (3rd ed). Routledge, London.
- Coleman, J., Kloep, L. B., & Kloep, M. (2007). *Adolescence and health*. West Sussex, England: Wiley & Sons, Ltd.
- Court, J. M., Cameron, F. J., Berg-Kelly, K., & Swift, P. G. F. (2008). Diabetes in adolescence. ISPAD Clinical Practice Consensus Guidelines 2006-2007. *Pediatric Diabetes*, 9, 255-262.
- Cooper, H., & Geyer, R. (2007). *Riding the diabetic rollercoaster: A new approach for health professionals, patients and carers*. Oxon: Radcliffe.
- Copp, A. (2005). An overview of children's health, In C. Horton (Ed.). *Working with children*. London: Society Guardian and Sage publications.
- Creswell, J. W. (1994). *Research design: Qualitative and Quantitative approaches*. Thousand Oaks, CA: Sage Publications, Inc.
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. (2nd. ed.). Thousand Oaks, CA: SAGE publications.

- Dashiff, C. J. (1993). Parents' perceptions of diabetes in adolescent daughters and its impact on the family. *Journal of Pediatric Nursing*, 8, 361-369.
- Dashiff, C., McCaleb, A., & Cull, V. (2006). Self-care of young adolescents with type 1 diabetes. *Journal of Pediatric Nursing*, 21(3), 222-232.
- De Klerk, W., & Nienaber, A. W. (2011). A discussion of a unique collaboration model between schools. *Psychology Research*, 1(3), 170-181.
- Delamater, A. M. (2006). Improving patient adherence. *Clinical Diabetes*, 24, 71-77.
- Delamater, A.M., Patino-Fernandez, A.M., Smith, K.E., & Bubb, J. (2013). Measurement of diabetes stress in older children and adolescents with type 1 diabetes mellitus. *Pediatric Diabetes*, 14, 50-56.
- Diabetes Statistics. (2012). Retrieved June 13, 2012 from <http://www.globalbuzz-sa.com/forums>
- Dunning, T. (2009). *Care of people with diabetes – a manual of nursing practice*. West Sussex, Wiley-Blackwell.
- Durrheim, K. (2006). Research Design. In M. Terre Blanche, K. Durrheim, & D. Painter (Eds.), *Research in Practice: Applied Methods for the Social Sciences* (2nd ed., pp. 33-59). Cape Town: University of Cape Town Press.
- Faulkner, M. (2003). Quality of life for adolescents with type 1 diabetes: Parental and youth perspectives. *Paediatric Nursing*, 2(5), 362-368.
- Fleming, E., Carter, B., & Warren, G. (2002). The transition of adolescents with diabetes from the children's health care service into adult health care service: A review of the literature. *Journal of Clinical Nursing*, 11, 560-567.
- Flynn, R. (2009). *The emotion of children with diabetes*. CDE Publication.

- Fouchè, C. B., & Schurink, W. (2011). Qualitative research designs. In A. S. De Vos, H. Strydom, C. B. Fouche, & C. S. L. Delpont (Eds), *Research at Grass Roots: For the social Sciences and human service professions*. (4th ed., pp. 307-327), Pretoria: Van Schaik.
- Gafvels, C., Lithner, F., & Borjeson, B. (1993). Living with diabetes: relationship to gender, duration and complications. A survey in northern Sweden. *Diabetic Medicine*, *10*, 768-773.
- Gleitman, H., Reisberg, D., & Gross, J. (2007). *Psychology*. (7th ed.). New York: W.W. Norton & Company.
- Gormanous, M., Hunt, A., Hope, J., & Gerald, B. (2002). Lack of knowledge of diabetes among Arkansas public elementary teachers: Implications for dieticians. *Junior Diet Association*, *102*, 1136-1138.
- Grauce, M., Wentzel-Larson, T., Hanestad, B. R., & Sovik, O. (2005). Health-related quality of life and metabolic control in adolescents with diabetes: The role of parental care, control and involvement. *Journal of Pediatric Nursing*, *20*(5), 373-382.
- Graziano, P. A., Geffken, G. R., Williams, L. B., Lewin, A. B., Duke, E. A., & Silverstein, J. (2011). Gender differences in the relationship between parental report of self-regulation Skills and adolescents' management of type 1 diabetes. *Journal of Pediatric Diabetes*, *12*, 410-418.
- Greco, P., Shroff-Pendley, J., McDonell, K., & Reeves, G. (2001). A peer group intervention for adolescents with type 1 diabetes and their best friends. *Journal of Pediatric Psychology*, *26*(8), 485-490.

- Greeff, M. (2011). Information collection: Interviewing. In A. S. De Vos, H. Strydom, C. B. Fouché, & C. S. L. Delport (Eds.), *Research at Grass Roots: For the social sciences and human service professions* (4th ed., pp. 341-376), Pretoria: Van Schaik.
- Grey, M., Boland, E. A., Davidson, M., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. V. (1998). Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care*, *21*(6), 901-908.
- Hagglof, B., Fransson, P., Lernmark, B., & Thernlund, G. (1994). Psychosocial status of children with diabetes in the first 2 years after diagnosis. *Arctic Medical Research* *53*(Suppl. 1), 20-29.
- Hains, A. A., Davies, W. H., Parton, E., & Silverman, A. H. (2001). Brief report: A cognitive Behavioural intervention for distressed adolescents with type 1 diabetes. *Journal of Paediatric Psychology*, *26*, 61-66.
- Hains, A. A., Berlin, K. S., Davies, W. H., Smothers, M. K., Sato, A. F., & Almenzadeh, R. (2007). Attributions of adolescents with type 1 diabetes related to performing self care around friends and peers: The moderating role of friend support. *Journal of Paediatric Psychology*, *32*, 561-570.
- Hamburg, B. A., & Inoff, G. E. (1983). Coping with predictable crises of diabetes. *Diabetes Care*, *6*, 409-416.
- Hanna, K. M., & Guthrie, D. (2003). Adolescents' behavioral autonomy related to diabetes management and adolescent activities/rules. *The Diabetes Educator*, *29*(2), 283-291.
- Haugstvedt, A., Wentzel-Larson, T., Rokne, B., & Graue, M. (2011). Perceived family burden and emotional distress: Similarities and differences between mothers and fathers of

- children with type 1 diabetes in a population-based study. *Pediatric Diabetes*, 12, 107-114.
- Hendry, L. B., & Reid, L. (2001). Social relationships and health: The meaning of social “connectedness” and how it relates to health concerns for rural Scottish adolescents, *Journal of Adolescence*, 23, 705-719.
- Hernandez, C. A. (1996). Integration: The experience of living with insulin dependent (type 1) diabetes mellitus. *The Canadian Journal of Nursing Research*, 28, 37-56.
- Hillege, S. (2005). *The impact of Type 1 Diabetes on the self of adolescence and young adults* (Unpublished manuscript). University of Western Sydney, School of Applied Social and Human Sciences.
- Holker, V. M. (2008). Adolescent diabetic treatment adherence and the impact of parental involvement (Unpublished master’s thesis). University of Wyoming.
- Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing*. Oxford: Blackwell.
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkering, L., & Laffel, L. M. (2006). Depressive symptoms in children and adolescents with type 1 diabetes: Association with diabetes-specific characteristics. *Diabetes Care*, 29, 1389-1391.
- Ingersoll, G. M., Orr, D. P., Herrold, A. J., & Golden, M. P. (1986). Cognitive maturity and self-management among adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics*, 108, 620-623.
- Kalnins, I., McQueen, D., Backett, K., & Currie, C. (1992). Children, empowerment and health promotion: Some new directions in research and practice. *Health Promotion International*, 7, 53-59.

- Kaugars, A. S., Kichler, J. C., & Alemzadeh, R. (2011). Assessing readiness to change the balance of responsibility for managing Type 1 Diabetes Mellitus: Adolescent, mother, and father perspectives. *Pediatric Diabetes, 12*, 547-555.
- Keyes, C. L. M. (2006). Mental health in adolescence: Is America's youth flourishing. *American Journal of Orthopsychiatry, 76*(3), 395-402.
- Kloep, M., & Hendry, L. B. (1999). Challenges, risks and coping in adolescence, in D. Messer & S. Miller (Eds.). *Exploring developmental psychology from infancy to adolescence* (pp. 400-416). London, Arnold.
- Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paul-auskas, S., & Pollock, M. (1985). Initial psychologic responses of parents to the diagnoses of insulin-dependent diabetes mellitus in their children. *Diabetes Care, 8*. 568 -575.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy, 55*(3), 1-19.
- Krentz, A. J. (2004). *Emergencies in Diabetes*. West Sussex, England. Wiley & Sons.
- La Greca, A. M. (1990). Issues in adherence with pediatric regimens. *Journal of Pediatric Psychology, 15*(4), 423-436.
- Lange, K., Jackson, C., & Deeb, L. (2009). Diabetes care in schools – the disturbing facts. *Pediatric Diabetes, 13*, 28-36.
- Law, G. U. (2002). Dissimilarity in adolescent and maternal representations of Type 1 Diabetes: Exploration of relations to adolescent well-being. *Child: Care, Health and Development, 28*, 369-378.

- Law, G. U., Kelly, T. P., Huey, D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role? *J Adolescent Health, 31*(4), 381-385.
- Leonard, B. J., Garwick, A., & Adwan, J. Z. (2005). Adolescents' perceptions of parental roles and involvement in diabetes management. *Journal of Pediatric Nursing, 20*(6), 405-415.
- Leonard, B. J., Jang, Y., Savik, K., Plumbo, M. A., & Christensen, R. (2002). Psychological factors associated with levels of metabolic control in youth with type 1 diabetes. *Journal of Pediatric Nursing, 17*(1), 28-37.
- Lewin, A. B., Heidgerken, A. D., Geffen, G. R., Williams, L., Storch, E. A., Gelfand, K. M., & Silverstein, J. H. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Paediatric Psychology, 31*, 174-183.
- Liles, R. G., & Juhnke, G. A. (2008). Adolescent diabetic control: Using the Process-Person-Context-Time Model. *Journal of Counselling and Development, 86*, 75-86.
- Lind, M., Oden, A., Fahlen, M., & Eliasson, B. (2009). The true value of HbA1c as a predictor of diabetes complications: Simulations of HbA1c variables. *Plos One, 4*, e4412.
- Low, K. G., Massa, L., Lehman, D., & Olshan, J. (2005). Insulin pump use in young adolescents with type 1 diabetes: A descriptive study. *Pediatric Diabetes, 6*, 22-31.
- Lowes, L., Gregory, J. W., & Lynne, P. (2005). Newly diagnosed childhood diabetes: A psychosocial transition for parents. *Journal of Advanced Nursing, 50*, 253-261.
- Maree, K., & Petersen, J. (2007). Sampling. In K. Maree (Ed.), *First Steps In Research* (pp. 172-180) Pretoria: Van Schaik Publishers.

- Matthews, J., Ponitz, C., & Morrison, F. (2009). Early gender differences in self-regulation and academic achievement. *Journal of Educational Psychology, 101*, 689-704.
- Messenger, C.L. (2006). *Anxiety sensitivity in adolescents with Type 1 Diabetes and their parents: Relationship to the fear of hypoglycemia and prediction of metabolic control*. (Unpublished manuscript). Columbian College of Arts and Sciences of the George Washington University.
- Minagawa, M. (1997). Sibling relationships of Japanese children with diabetes. *Journal of Pediatric Nursing, 12*, 311-316.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: SAGE Publications.
- Nieuwenhuis, J. (2007). Qualitative research designs and data gathering techniques. In K. Maree (Ed.), *First steps in research* (pp. 70-92). Pretoria: Van Schaik Publishers.
- Northam, E. A., Anderson, P. J., Jacobs, R., Hughes, M., Warne, G. L., & Werther, G. A. (2001). Neuropsychological profiles of children with type 1 diabetes 6 years after disease onset. *Diabetes Care, 9*, 1541-1546.
- Northam, E. A., Lin, A., Finch, S., Werther, G. A., & Cameron, F. J. (2010). Psychological well-being and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care, 33*(7), 1430-1437.
- Northam, E. A., Matthews, L. K., Anderson, P. J., Cameron, F. J., & Werther, G. A. (2005). Psychiatric morbidity and health outcomes in type 1 diabetes-perspectives from a prospective longitudinal study. *Diabetic Medicine, 22*, 152-157.

- O'Grady, M. J., Delaney, J., Jones, W., & Davis, E. A. (2013). Standardised mortality is increased three-fold in a population-based sample of children and adolescents with type 1 diabetes. *Pediatric Diabetes, 14*, 13-17.
- Olson, A. L., Seidler, A. B., Goodman, D., Gaelic, S., & Nordgren, R. (2004). School professionals' perceptions of about the impact of chronic illness in the classroom. *Pediatric Adolescent Medicine, 158*, 53-58.
- Plug, C., Louw, D. A. P., Gouws, L. A., & Meyer, W. F. (2009). *Verklarende en Vertalende Sielkundewoordeboek* (3de uitgawe). Sandton: Heinemann Voortgesette Onderwys (Edms) Bpk.
- Richt, B. (1992). *Mellan twa valdar: Om konflikten mallan livets drav och kotorns onskingar: lardomar fran familjer med diabetessjuka barn* (Unpublished manuscript). University of Tema, Linkoping.
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., & Clark, N. (2005). Care of children and adolescents with type 1 diabetes: A statement of the American Diabetes Association. *Diabetes Care, 28*, 186-212.
- Skinner, T. C., Channon, S., S., Howells, L., & McEvelly, A. (2000). Diabetes during adolescence. In F. J. Snoek & T. C. Skinner (Eds). *Psychology in diabetes care* (pp. 25-60). Chichester, UK: Wiley.
- Shroff-Pendley, J., Kasmien, L. J., Miller, D. L., Donze, J., Swenson, C., & Reeves, G. (2002). Peer and family support in children and adolescents with type 1 diabetes. *Journal of Pediatric Psychology, 27*(5), 429-438.

- Slijper, F. M., De Beaufort, C. E., Bruining, G. J., De Visser, J. J., Aarsen, R. S., Kicker, D. A., & Van Stik, R. (1990). Psychological impact of continuous subcutaneous insulin infusion pump therapy in non-selected newly diagnosed insulin dependent (type 1) diabetic children: evaluation after two years of therapy. *Diabetes & Metabolisme*, 16(4), 273-277.
- Spencer, J. E., Cooper, H. C., & Milton, B. (2012). The lived experiences of young people (13-16 years) with type 1 diabetes mellitus and their parents – a qualitative phenomenological study. *Diabetic Medicine*, 30, 17-24.
- Stewart, S., Emslie, G. J., Klein, D., Haus, S., & White, P. (2005). Self-care and glycaemic control in adolescents with type 1 diabetes. *Children's Health Care*, 34(3), 239-244.
- Sweetlifemag. (2011). *Diabetes in South Africa the facts*. Retrieved January 25, 2013 from <http://sweetlifemag.co.za/2011/07/diabetes-in-South-Africa-the-facts/>
- Urbach, S. L., La Reanchi, S., Lambert, L., Lapidus, J. A., Daneman, D., & Becker, T. M. (2005). Predictors of glucose control in children and adolescents with Type 1 Diabetes Mellitus. *Pediatric Diabetes*, 6, 69-74.
- Viner, R., & Barker, M. (2005). Young people's health: The need for action. *British Medical Journal*, 330, 901-903.
- Viner, R. (2005). *The ABC of adolescence*. London. British Medical Journal Books.
- Wagner, J., Heapy, A., James, A., & Abbot, G. (2006). Brief report: Glycemic control, quality of life, and school experience among students with diabetes. *Journal of Pediatric Psychology*, 31, 764-769.
- Walker, H. J. (1999). Clarifying the affective component of psychological well-being (Unpublished master's dissertation). North-West University, Potchefstroom.
- Weare, K. (2004). *Developing the emotionally literate school*. London: Paul Chapman

Publishing.

- Weibe, D. J., Berg, C. A., Korbel, C., Palmer, L., Beveridge, R. M., Upchurch, R., Donaldson, D. L. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control and quality of life across adolescence. *Journal of Pediatric Psychology, 30*(2), 167-178.
- Weinger, K., O'Donnell, K. A., & Ritholz, M. D. (2001). Adolescent views of diabetes related parent conflict and support: A focus group analysis. *Journal of Pediatric Psychology, 30*(2), 167-178.
- Weissberg-Benchell, J., Glasgow, A. M., Tynan, W. D., Wirtz, P., Turek, J., & Ward, J. (1995). Adolescent diabetes management and mismanagement. *Diabetes Care, 18*, 77-82.
- Weissberg-Benchell, J., & Antisdel-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: Feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatric Diabetes, 12*, 341-344.
- White, K., Kolman, M. L., Wexler, P. (1984). Unstable diabetes and unstable families: A psychosocial evaluation of diabetic children with recurrent ketoacidosis. *Pediatrics, 73*, 749-755.
- Wodrich, D. L. (2005). Disclosing information about epilepsy and type 1 diabetes mellitus: the effects on teachers' understanding of classroom behaviour. *School Psychology, 30*, 288-303.
- Wodrich, D. L., Hasan, K., & Parent, K. B. (2011). Type I Diabetes Mellitus and school: A review. *Pediatric Diabetes, 12*, 63-70.
- Wysocki, T., & Greco, P. (2006). Social support and diabetes management in childhood and adolescence: Influence of parents and friends. *Current Diabetes Reports, 6*, 117-122.

Yu, S. L., Kail, R., Hagen, J. W., & Wolters, C. A. (2000). Academic and social experiences of children with insulin- dependent diabetes mellitus. *Child Health Care*, 29, 189-208.

Addendum

Afrikaans translation to English

Please take note: All quotes were translated by a trained linguist.

Theme 1: Lack of Understanding by Significant Others to align with Treatment Adherence

1.1 Teachers at School

“But some have told me to take it off. Then I tell them I will die if I take it off. I think teachers are so uneducated about diabetes.”

“Maar ander het al gesê ek moet dit afhaal. Dan sê ek vir hulle ek gaan doodgaan as ek dit afhaal. Ek dink onnies is so onopgevoed oor diabetes.”

“Some of them are friendly and some of them are nasty. Like when I ask if I may eat something, they say no, or if I want to go to the bathroom they don’t allow me to go... I eat in secret when the teacher is not looking... In primary school when I wore my bracelet, the teacher told me to take it off because I am not allowed to wear it.”

“Van hulle is vriendelik en van hulle is snaaks. Soos as ek vra kan ek iets eet, dan sê hulle nee, of ek badkamer toe wil gaan dan wil hulle nie hê ek moet gaan nie... Ek eet skelm as die juffrou nie kyk nie... in die laerskool toe ek my bandjie gedra het, toe sê die juffrou ek moet dit afhaal, ek mag dit nie dra nie”

“Once in the mathematics class I was not aware that it was vibrating, and it (the sensor) started to ring. The teacher shouted that I should put away my phone. When I told her that it was not my phone and showed her that it was my pump, she just told me to put it away.”

“Eenkeer in die wiskunde klas toe was ek nie bewus hy vibreer nie, toe begin dit (sensor) skree. Toe skree die juffrou dat ek my foon moet bere. Toe ek vir haar sê dit is nie my foon nie, maar wys dit is my pompie toe sê sy net bere dit.”

“In high school the teachers don’t really understand, they are not interested. My sugar once dropped and when I asked the teacher if I could go to the tuckshop, she didn’t want to let me go,

she thought I was lying. I will never lie about diabetes, because if something happens and no-one believes me... After she first asked the entire class, she let me go.”

“In die hoërskool verstaan onderwysers nie eintlik nie, hulle stel nie belang nie. My suiker het geval toe ek die onderwyser vra om snoepie toe te gaan toe wil sy nie, sy het gedink ek jok. Ek sal nooit oor diabetes jok nie, wat as iets gebeur en niemand glo my nie. Nadat sy eers die hele klas gevra het, het sy my laat gaan.”

1.2 People in General

“I think many people don’t really understand diabetes. You ate too much sugar and that is why you got diabetes.”

“Ek dink baie mense verstaan nie diabetes rêrig nie. Jy het te veel suiker geëet en dit is hoekom jy diabetes gekry het.”

“I was once at the doctor and he told me to put my little radio away It was a shock, I was in grade two and I told him it was my pump. I first had to explain everything to him. Oh my word!”

“Ek was eenkeer by die dokter, toe sê hy vir my ek moet my radiotjie weg vat.....Dit was ‘n skok, ek was in graad twee ek en sê toe dit is my pomp. Toe moes ek eers vir hom alles verduidelik. Oh my word!”

“One guy asked if that is why I’m so hyper active... Most people just ask what it is and how it works. Some people think it is type 2 because you ate too much sugar and then I try to tell them that there are different types that have different factors.”

“Een ou het vir my gevra is dit hoekom ek so hyper active is... Maar meeste mense vra maar wat is dit, en hoe werk dit.party mense dink dit is tipe 2 omdat jy te veel suiker geëet het dan probeer ek hulle sê dat daar ander ook is wat ander faktore het.”

“People have asked me what diabetes is, then I explain it like in our language, then you just come to a point where you say, my pancreas doesn’t work and yours does.”

“Daar het al mense gevra wat is diabetes, dan verduidelik ek dit soos in ons taal, dan kom jy tot ‘n punt wat jy net sê, my pankreas werk nie en joune doen.”

1.3 Adolescents (peers)

“I think, when I was small and I found out that I have diabetes, I did not have many friends, because some thought that it is contagious.”

“Ek dink, toe ek klein was en ek uitgevind het ek het diabetes, toe het ek nie baie maatjies gehad nie, want baie het gedink dit is aansteeklik.”

“They think diabetes is like a cold and you are always sick from it. I think that is what they think. Like sometimes I am just tired, because my count is low, then I tire easily, then they ask “is it because you are sick?” Then I have to explain to them that it is just one of my symptoms.”

“Hulle dink diabetes is soos ‘n verkoue en ‘n mens is heeltyd siek daarvan. Ek dink dit is wat hulle dink. Soos partykeer is ek net moeg, want my telling is laag, dan word ek baie vinnig moeg, dan vra sê hulle “is dit omdat jy siek is?” Dan verduidelik ek vir hulle dat dit net een van die simptome is.”

“One asked me today how I got diabetes and if it was because I ate too much sugar. Then I want to have a fit.”

“Een het sommer vandag gevra hoe het ek diabetes gekry en was dit omdat ek te veel suiker geeet het. Dan wil ek sommer ‘n oorval kry.”

One guy has asked me why I have diabetes, I am so thin ... they call it ‘sugar disease’ [suikersiekte], they will never understand.”

“Een outjie het my al gevra dat hoekom het ek diabetes, ek is dan so maer.....hulle noem dit suikersiekte, hulle sal nooit verstaan nie.”

Theme 2: Support from Significant Others to Adhere to Treatment Regimen

2.1 Supporting Role of Teachers

“Once I was with the discipline head and I tested my sugar and it was very low, and he asked if he can go and get cookies and tea.”

“Eenkeer was ek by die dissipline hoof en ek toets toe my suiker en dit is toe baie laag, hy vra toe of hy koekies en tee kan gaan haal.”

“And because the teachers know they say I don’t have to ask anymore, because they also become concerned about my count when it is low ... The teachers, if I just lay on my arms they ask if I’m okay.”

“En omdat die onderwysers weet sê hulle ek hoef nie meer te vra nie, want hulle raak ook bekommerd oor my telling as dit laag is... Die juffrouens as ek net op my arms lê dan vra hulle dadelik of ek okay is.”

“The teachers know, most of them. If I tell them I don’t feel good then they say I can quickly have juice or something sweet.”

“Die onderwysers weet darem, meeste van hulle. As ek vir hulle sê ek voel nie lekker nie dan sal hulle sê ek kan gou ‘n sappie of sweet kry.”

2.2 Supporting Role of Parents

“We went to ‘veldskool’... We went to Camp Discovery, it is close-by. For three to four days. My dad went along again... Just to come and test my sugar in the evenings... My dad is actually just there for times when my sugar dips too low, because if it is low in my sleep I won’t know it, I would just sleep.”

“Gaan op veldskool... Ons gaan Camp Discovery toe, dit is net hier naby. Vir drie tot vier dae. My pa gaan weer saam... Net om my suiker te kom toets in die aand... My pa is eintlik net daar vir my as my suiker laag is, want as dit laag is in my slaap sal ek nie weet nie, ek sal net slaap.”

“Especially in the holidays, then my mom will come every two hours during the night to test.”

“Veral in die vakansies, dan sal my ma elke twee ure in die aand kom toets.”

“My mom still does it, my sugar tends to go up after 1am, then she does a correction and then when I get up my sugar is fine... I don’t even know she was there... My dad keeps me up to date, he also reminds me to test. When my sugar drops I tend to be moody, then he’ll quickly ask “what is your sugar?”.”

“My ma doen dit nogsteeds, my suiker is geneig om so lam op te gaan, dan doen sy ‘n korreksie en dan as ek opstaan is my suiker reg... ek weet nie eers sy was daar nie... My pa hou my gereeld op hoogte, hy herinner ook my om te toets. As my suiker gewoonlik laag is dan is ek misluk, dan sal hy vinnig vra “wat is jou suiker?”.”

“She (mom) said that she will stay in a resort close-by... it will actually be better for me if my mommy does it that way. Then I know if something fails, she is not far away.”

“Sy (ma) het gesê dat sy in ‘n resort daar naby gaan bly... dit sal eintlik beter vir my wees as mamma dit so doen. Dan as ek weet iets flop, dan is sy nie ver nie.”

2.3 Role of Friends and Peers in Supporting T1DM Treatment

“Three friends with BLS are on the First Aid team, so they know more or less what to do. And then my one friend will tell me I shouldn’t eat the chocolate because my sugar is 10, and then I have other friends who give me sweets in secret of who will always remember to buy a 2l Tab when they buy their juice.”

“‘n Vriend, vriendin en ‘n vriendin met BLS is op die noodhulpspan, so hulle weet min of meer wat om te doen. En dan my een vriendin sal sommer vir my sê ek moet nie die sjokolade eet nie, want my suiker is 10, en dan het ek ander vriende wat my skelm sal ‘n sweetie gee of altyd sal onthou om ‘n 2l TAB te koop saam met hulle sap.”

“My friends are nice, if they see me eating they will ask if I’ve had insulin... My good friends know a lot, they know to test me, they know how my pump works. So I was on holiday with my friends, but then they knew everything, if I don’t feel well, they know what to do... my good friends understand what it is. They also know what to do to help me when I don’t feel good. With the sensor, when we came the first time, my friend came along so that she can see how it works... When my sugar is low someone will walk with me and get me a coke, they don’t mind at all.”

“My maatjies is ook oulik as hulle sien ek eet dan vra hulle of ek insulien gekry het... My goeie vriendinne weet baie, hulle weet om my te toets, hulle weet hoe my pompie werk. So ek was saam my vriendinne op vakansie, maar dan weet hulle alles, as ek nie lekker voel nie, dan weet hulle wat om te doen... my goeie vriende verstaan wat dit is. Hulle weet ook hoe om my te help as ek

nie lekker voel nie. Met die sensor, toe ons die eerste keer gekom het, toe kom my maatjie saam sodat sy weet hoe dit werk...As my suiker laag is sal iemand saam my stap en vir my coke kry, hulle gee glad nie om nie.”

“When we play cricket during breaks, then they will ask if I’m still okay. My friends know I have an emergency injection in the fridge and the first aid people know how to use it.”

“As ons nou maar krieket speel pouses, dan sal hulle vra of ek nog reg is. My maatjies weet ek het ‘n noodinspuiting in die yskas en die noodhulmense weet hoe om dit te gebruik.”

Theme 3: T1DM Adolescents’ Fears of Friends’ and Peers’ Perceptions

“One thing that I stress about in relation to my diabetes is if they will accept me. As far as I know I will be the only diabetic in my grade.”

“Een ding waaroor ek net stres is oor my diabetes en of hulle my gaan aanvaar. So ver ek weet gaan ek die enigste diabeet in my graad wee.”

“Sometimes it is a case of someone feeling different as soon as I take my pump out.”

“Dit is soms ‘n geval dat jy anders voel as ek my pompie uithaal.”

“I don’t find diabetes much fun. It makes you feel different, because in my grade 8 group I am the only diabetic ... I don’t like testing, because you do it in front of friends and then they wonder what it’s all about... But now all I worry about is that children should not look at me and think that I am different. I also don’t want them to look at me and tell me that I am sick.”

“Diabetes is nie vir my baie lekker nie. Dit maak jou anders voel, want in my graad 8 groep is ek die enigste diabeet... Dit is ook nie lekker vir my om te toets nie, want jy doen dit voor maatjies en dan wonder hulle waaroor dit gaan.. Maar nou is ek net geworried dat die kinders moet nie na my kyk en dink ek is anders nie. Ek wil ook nie hê hulle moet na my kyk en vir my sê ek is siek nie.”

Theme 4: Emotional Experiences related to Treatment Adherence

4.1 Negative Emotions Curtailing Adherence

“It takes a while to get over the shock. Then you become angry at life, and angry at God, but then you realise it is not His fault, it is not my parents’ fault, it is not my brother’s fault, it is nobody’s fault... I once stumbled upon a blog of the one or the other ‘Diabetes problems’ or something like that, and I realised how many people who have diabetes suffer from depression and how negative they are about it.”

“Dit vat maar ‘n rukkie om oor die skok te kom. Dan word jy kwaad vir die lewe, en kwaad vir God, maar dan kom jy agter dit is nie y skuld nie, dit is nie my ma-hulle se skuld nie, dit is nie my broer se skuld nie, dit is nie enige iemand se skuld nie... Ek het eenkeer op ‘n blog afgekom van een of ander ‘Diabetes problems’ of so iets, ek het agter gekom hoe baie mense wat diabetes het aan depressie ly en hoe negatief hulle daaroor is.”

“I don’t like testing, because you do it in front of friends and then they wonder what it’s all about... And sometimes I forget to take insulin and then my counts rise and then I feel very guilty... I always feel as if I did something wrong because it is so high... In the beginning I did not want it, I felt that all the time, why did I get it, what did I do wrong?... Sometimes one feels as if it would have been easier to have someone to talk to who understands... I don’t talk to anyone. It doesn’t help to talk to my mom, because she doesn’t understand.”

“Dit is ook nie lekker vir my om te toets nie, want jy doen dit voor maatjies en dan wonder hulle waaroor dit gaan... En ek vergeet soms om insulien te kry dan gaan my tellings hoog en dan voel ek baie skuldig... Voel altyd of ek iets verkeerd gedoen het omdat dit so hoog is... Aan die begin wou ek dit nie gehad het nie, ek het heeltyd gevoel, maar hoekom het ek dit gekry, wat het ek verkeerd gedoen... Partykeer voel ‘n mens af dan sou dit makliker gewees het om met iemand te praat wat verstaan... Ek praat nie met iemand nie. Dit help nie ek praat met my ma nie, want sy verstaan nie.”

“I wasn’t very impressed with the clinical scenario that my mother double-checks everything every time, it irritated me... Yesterday my sugar was low, one moment you cry and the next

moment you see unicorns... I have my temper tantrums every three months or so, when it becomes too much. I cry through the whole night, then I am fine again the next morning.”

“Ek was nie baie impress oor die kliniese senario dat my ma elke keer alles dubbele check nie, dit het my geïrriteer... Gister was my suiker baie laag, een oomblik dan huil jy en volgende oomblik sien ek unicorns... Ek kan my ‘temper tantrims’ hê so elke drie maande, dan raak dit bietjie te veel. Ek huil die hele aand deur, en dan is ek weer fine die volgende oggend.”

4.2 Positive Emotions Promoting Adherence

“My diabetes is kind of like a ‘blessing in disguise’, it was hard for me the first few months, but I learned that before I was diagnosed I was completely a different person and since I have been diagnosed I see life with different eyes and it is kind of more positive.”

“My diabetes is half vir my ‘n ‘blessing in disguise’, dit was vir my die eerste paar maande erg, maar ek het geleer dat voor ek gediagnoseer was ek ‘n heeltemal ‘n ander mens en vandat ek gediagnoseer is sien ek die lewe met ander oë en dit is half meer positief.”

“Most of the time I thought it is all my fault, but now that I am older I know that it is not my fault. And that I have to take responsibility for it and for what I have to do.”

“Meeste van die tyd het ek gedink dit is alles my skuld, maar nou dat ek ouer is weet ek dat nie my skuld is nie. En dat ek verantwoordelikheid moet vat daarvoor en wat ek moet doen.”

“It is no longer diabetes to me, it’s just me, it is who I am.”

‘Dis nie meer vir my diabetes nie, dit is net ek, dit is wie ek is.’

Theme 5: Unpleasant Illness Experiences and Learning Curves to Cope with T1DM

“Once I had too much cake and I injected too much and it went very low and in the night I got terrible repo... I don’t know why I woke up, they were feeding me banana to get my sugar up. My reflexes are also different then, my mom said once when she said I should bite, she had to throw in the banana otherwise I bite her finger.”

“Ek het eenkeer te veel koek gehad toe spuit ek te veel toe gaan hy vreeslik laag in die nag toe kry ek een vreeslike repo... ek weet nie hoekom word ek nie wakker nie, dan voer hulle my

piesang om my suiker op te kry. My refleksie is ook anders dan, my ma het gesê eenkeer toe sê sy ek moet hap, dan gooi sy die piesang in anders byt ek haar vinger.”

“When I feel bad in my sleep I don’t wake up, my parents say I cry in my sleep and when I wear my sensor I wake up from the alarm, in my room I always have something to eat when my count is low, such as Coke or Super C’s.”

“As ek baie sleg voel in my slaap dan word ek nie wakker nie, my ma-hulle sê ek huil in my slaap en as ek my sensor dra dan word ek van die alarmpie wakker, in my kamer het ek altyd iets om te eet as my telling laag is, soos coke en Super C’s.”

“And the next day on the bus I became so nauseous, and I threw up in front of my whole class. And I’ve had to walk home a few times, because my pump doesn’t work, and then I have to walk back again.”

“Selfde persoon: En die volgende dag op die bus toe word ek so naar, toe gooi ek op voor my hele klas. En ek moes al paar keer huis toe stap, want dan werk my pompie nie en dan weer terug stap.”

“I guess the bad part of it is that you know that every thing you eat will have consequences, like I might get a high sugar count because of it. Most people see their plate with food and it is their plate with food, but I see 30, 40, 50, 10. This is how I see my plate with food.”

“Die slegte dele daarvan is seker maar die feit dat jy weet dat elke ding wat jy eet gaan konsekwense hê, soos ek gaan dalk hoë suiker kry daarvan. Meeste mense sien sy bord kos en dit is sy bord kos, dan sien jy daar 30, 40, 50, 10. Dit is hoe ek my bord kos sien.”

“It just takes a bit of time to get to know everything and you are scared that you might do something wrong. Like sometimes the needle breaks off and then you have to take a new one. Sometimes the tube comes off and the needle stays behind, then you have to do it all over again.”

“Dit vat net tyd bietjie tyd om alles te leer en jy is bang jy doen dit verkeerd. Soos partykeer breek die naaldjie af en dan moet jy nuwe ene vat. Partykeer dan kom die pypie af en die naald bly agter, dan moet jy heeltemal van vooraf doen.”

Theme 6: Non-obtrusive and User-friendly Alternative Treatment Options for T1DM

“I was on the injection for three months and all that I remember about the injections it that my leg is still rock hard, and if you didn’t change the needle, then it hurt and burned and there was blood. And the one time I was tired and sick and we got KFC that evening and I decided ‘not the hell’, I am not going to inject, and I woke during the night with a sugar count of 20. It was still in the beginning, the second week or so, and there was panic at 1 am through the entire house about the injections.....but I have more freedom with the pump. And when I look at what my friends do I can do exactly the same as they can, but on the injections I knew, now I have to sit, now I have to eat, now I have to inject otherwise something will happen. It (the pump) is kind of a little more freedom and more normal”.

“Ek was op die inspuiting vir drie maande en al wat ek onthou van die inspuiting is, my been is nogsteeds so kliphard, en as jy die naald nie geruil het nie, dan is dit seer en dit brand en daar is bloed. En die een keer ek was moeg en siek toe kry ons KFC die aand toe besluit ek ‘not the hell’, ek gaan nie spuit, toe word ek wakker die aand met suiker van 20. En dit was nog aan die begin, die tweede week of so, toe is daar paniek 1am in die hele huis oor die inspuitings.....maar ek het meer vryheid met die pompie. En as ek kyk wat my vriende aanvang kan ek presies dieselfde doen as hulle, maar op die spuite het ek geweet nou moet ek sit, nou moet ek eet, nou moet ek spuit anders gaan ek iets oorkom. Dit (pompie) is half bietjie meer vryheid en meer normaal.”

It (the pump) is not as painful as “the injections. The injections left blue marks on my legs and the pump doesn’t...The thing about the injections that I didn’t like is that there are three different injections. In the morning one, then the Nova rapid during the day and in the evening a green one. The morning one I didn’t like because you have to inject half an hour before you eat and sometimes there wasn’t time.”

“Dit (pompie) is nie so pynvol soos die inspuitings nie. Die inspuitings het blou kolle op my bene gemaak en die pompie doen nie dit nie... Die ding met die inspuiting wat ek ook nie gelaai het nie, daar is drie verskillende spuite. Die oggend een, dan die Nova rapid deur dag en in die aand so groene. Die oggend ene wat ek nie gelaai het nie is jy moet ‘n halfuur voor jy eet inspuit, en partykeer was daar nie tyd nie.”

“If you treat it correctly you sometimes forget you have it, and it is like a normal life. The sensor makes it easier because you don’t have to test all the time, you can manage it better. It is easier with the pump, because you don’t have to inject all the time, you inject, but not with the injection, it is better.”

“As jy dit reg behandel dan vergeet jy partykeer jy het dit, en dit is soos ‘n normale lewe. Die sensor maak dit makliker omdat jy nie heeltyd hoef te toets nie, jy kan dit beter kontroleer. Dit is makliker met die pompie, want jy hoef nie heeltyd te spuit nie, jy spuit, maar nie met die inspuiting nie, dit is lekkerder.”

“I have had the pump for 8 years. My mother has spoken to the people at the high school expo, there were people there who did diabetes, then my mother asked them things. They said they found that with the injections the counts are much better, because you have to be more precise. But the pump gives me much more freedom to eat what I want. I think the pump is easier.”

“Ek het die pompie al 8 jaar. My ma het al met mense gepraat by die hoërskool se expo, toe was daar mense wat diabetes doen, dan vra my ma hulle. Hulle het toe gesê hulle vind met die inspuitings is die tellings baie mooier, want jy moet baie meer presies wees. Maar die pompie gee my baie meer vryheid om te eet wat ek wil. Ek dink die pompie is makliker.”