Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis

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Mini-Dissertation submitted in partial fulfilment of the requirements for the degree Master of Arts in Counselling Psychology at the

North-West University

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Summary

Type 1 diabetes mellitus (T1D) is one of the most prevalent common chronic conditions in adolescence. The management of T1D hampers successful navigation into adolescence as many diabetes-related tasks impede on it, which results in negative illness perception of T1D. These illness perceptions have been shown to be associated with long-term beliefs held by adolescents about T1D, by means of which their emotional responses that influence their management of T1D could be predicted. Limited research, mostly quantitative in nature, has been conducted on the illness perception of T1D. However, lacunae remain in research on the illness perception of uncontrolled T1D. This study had two objectives – firstly to explore the illness perception among adolescents with uncontrolled T1D and, secondly, to explore how these illness perceptions contribute to diabetes management.

This study utilised a qualitative approach. Non-random purposeful sampling was utilised to select participants. The population sample consisted of adolescents with uncontrolled T1D between the ages of 12-18 years (HbA1c level of 7.5% or above), who attended the Centre for Diabetes and Endocrinology (henceforth CDE) in Parktown, Johannesburg, South Africa. Semi-structured interviews were utilised to gather raw data. Results were analysed using thematic analysis as described by Braun and Clarke (2006, 2013), while four criteria for establishing trustworthiness as held by Lincoln and Guba (1985) was used, including credibility, transferability, dependability, and confirmability.

Moreover, four dominant themes were generated based on the raw data gathered during these interviews namely that (1) management of T1D is challenging, (2) perception of T1D is negative, (3) management of T1D is motivated by fear, and (4) living with T1D leads to a sense of being different. The themes were illustrated by using appropriate verbatim extracts from interview responses of the eight participants.

The findings indicated that T1D was perceived as challenging to manage resulting in internalisation of the failures around it. Ultimately, it led to the perception that T1D was negative. The adolescents were largely motivated to manage their T1D through fear elicited by threat messages. Additionally, they felt that due to dietary restrictions they were different from their peers, resulting in their engagement in a variety of activities and risky behaviours to prove that they were “normal”.

The generalisability of this study is limited since non-random purposive sampling was employed. This demographic variability limits the scope of the study. This does not, however, limit the potential transferability of the study to other settings as qualitative research does not focus on statistics but rather revealing the depth of a phenomena within a specific context. Despite these limitations, the present study adds to the body of knowledge contained in literature on adolescents who have found adhering to diabetes care plans challenging. It lays the foundation for future research into what differentiates well-controlled and uncontrolled T1D, which may ultimately lead to effective intervention strategies to assist people living with T1D to be able to manage their T1D successfully.

KEY WORDS: Illness perception, adolescents, Type 1 diabetes, uncontrolled diabetes, diabetes management, South Africa, thematic analysis.

Preface

- This research paper is presented in article format thereby complying with rule A.4.4.2. of the North-West University.
- The article will be submitted for possible publication in the *Journal of Psychology in Africa* (*JPA*) and will thus be compiled according to their guidelines and house style.
- The referencing and editorial style of this research paper are in line with guidelines in the *Publication Manual of the American Psychological Association* (APA) (6th edition).
- As this research paper is compiled as a unit, the page numbering was set in a consecutive manner, beginning from the introduction and ending with the references.
- Prof. E. Deacon (supervisor) assisted with the analysis and interpretation of results.
- Prof. E. Deacon (supervisor) and Prof. E. van Rensburg (co-supervisor) were involved in the peer review of the article. They, along with Prof. Segal, are deemed co-authors of the article comprising this dissertation.
- The co-authors provided consent for the submission of this article for examination purposes towards fulfilment of requirements for a Master of Arts in Counselling Psychology.
- The research paper was submitted to Turn-it-in. The report concluded that the research paper was within the acceptable range.
- The research paper was edited and proofread by Cum Laude Language Practitioners.

Declaration from the student

I, Schvaughn Lesage, declare that this research paper submitted for assessment for the degree Master of Arts in Counselling Psychology at the North-West University is my own unaided work except where I have explicitly indicated otherwise. However, I give credit to the contributions by my supervisor and co-supervisor. I have followed the required conventions in referencing the thoughts and ideas of others as well as paraphrasing these materials. Furthermore, I declare that this research paper has not previously been submitted for assessment at any other institution.

Signature:  Date: 31 October 2019

Schvaughn Lesage

Permission letter form supervisors

Permission is hereby granted for the submission by the first author, S. Lesage, of the mini-dissertation for examination purposes, towards partial fulfilment of the requirements for the degree Magister Artium in Counselling Psychology at the Potchefstroom campus of the North-West university:

Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis

The roles of the co-authors were as follows: Prof E. Deacon and Prof E. van Rensburg acted as supervisor and so-supervisor respectively. Prof E. Deacon and Prof E. van Rensburg assisted with the conception, design, data generation and peer review of this study.

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DECLARATION OF LANGUAGE EDITING

I, Christina Maria Etrecia Terblanche, hereby declare that I edited the research proposal titled:

Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis

for **SS Lesage** for the purpose of submission as a postgraduate research proposal. Changes were indicated in track changes and implementation was left to the author.

Regards,

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Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis

Section 1: Introduction and rationale

1.1 Introduction

This research paper explores the illness perception among adolescents with uncontrolled type 1 diabetes (henceforth T1D) and how this perception contributes to the management of T1D. The first section of this research paper will outline a brief overview of the present study's problem statement and orientation. The second focuses on relevant literature to provide a foundation for the research and identify lacunae in the current body of knowledge. The third explores research objectives. Subsequently, the research design and method will be expounded and finally ethical considerations relevant to this study will be discussed.

1.2 Problem statement

This study forms part of a group of diabetes research studies exploring psycho-social variables in adjusting to diabetes management among adolescents and young adults. It will explore the illness perception among adolescents with uncontrolled T1D.

T1D is a metabolic disease resulting from "a cellular-mediated autoimmune destruction of the β-cells of the pancreas" (American Diabetes Association, 2013, p. 67) and is measured by quantifying glycated haemoglobin (HbA1C). Diagnosis of T1D peaks in mid-adolescence (Centres for Disease Control and Management [CDC], 2014).

Diabetes is the second most common chronic illness, second to asthma, in adolescence (Borus & Laffel, 2010). As such approximately 1 in 400 under 20-year-olds in the United States have T1D (Liese, 2006). The International Diabetes Federation (IDF, 2015) estimates that people diagnosed with diabetes account for approximately 12% of the global health expenditure. There are approximately 20 million people living with diabetes in the African continent, a number that is expected to double within the next two decades, with over 2.6 million of this number residing in South Africa (IDF, 2015).

There is currently no cure for T1D, but it can be managed through diabetes care plans, which include insulin therapy, regular blood glucose monitoring, staying physically active, and dietary monitoring (CDC, 2007). The long-term impact of diabetes on an adolescent's entire functioning is enormous. Living with diabetes has a significant social impact placing physical, financial, and emotional burdens on the entire family as well as influencing the adolescent's effective participation in school, extramural activities such as sport, and socialisation with peers and friends (Scholes et al., 2013). If we thus consider the health expenditure and social impact of the disease, diabetes is a burden on the economy and society, making effective management of diabetes a priority.

According to Borus and Laffel (2010), good diabetes care has clearly been established, yet many adolescents face difficulties with controlling their T1D. In fact, according to Hougaard and Mortensen (1997), one-third of children (under 18 years old) with T1D suffer from controlled T1D and the T1D exchange (as cited in Juvenile Diabetes Research Foundation, 2015) found that in the United States fewer than a third of people have controlled T1D. Thus, exploring why T1D remains uncontrolled despite the establishment of clear diabetes care plans is necessary.

Griva et al. (2007) found that a patient's illness perception of diabetes could be used to predict physiological and behavioural outcomes related to self-management. Broadbent et al. (2011) defined illness perception as the cognitive belief systems people held about their condition. According to the IDF (2015) self-management education is essential in preventing secondary complications related to diabetes, thereby enabling the reduction of costs in diabetes care. Interventions aimed at promoting and enhancing effective self-management are therefore vital to the management of diabetes and its associated complications and costs worldwide. Although research has been conducted on the management of diabetes, there appears to be an apparent lacuna in literature on the illness perception of uncontrolled T1D, especially in South African. Exploring the illness perception among adolescents with uncontrolled T1D in South Africa will assist in obtaining a clear understanding of T1D. Therefore, this study aims to explore the illness perception among adolescents with uncontrolled T1D by applying two research questions. First, what is the illness perception among adolescents with uncontrolled T1D? Second, how do these illness perceptions influence diabetes management?

1.3 Literature review

A literature review on related research will follow below to explore the existing body of knowledge. The following topics will be explored, namely: diabetes management, T1D in adolescence, and illness perception.

1.3.1 Diabetes management

The "ideal standard" of T1D management involves maintaining blood glucose levels as near to normal as possible and as early as possible with the aim of delaying complications (Anderson et al., 2007). The "ideal standard" involves adherence to a prescribed treatment course for diabetes resulting in the consistent maintenance of HbA1C levels of 7.5% or below (Scholes et al., 2013). However, maintaining this HbA1C "level target" is difficult for adolescents (Anderson et al., 2007). Among other factors, it is affected by the cognitive and emotional state of a person (Lustman et al., 2000).

The psychological impact is aggravated by repetitive, painful needle pricks, which are required for blood glucose checks and medication administration. Additionally, Gee et al. (2007) highlight that negative emotions such as shame and embarrassment are prevalent among those living with diabetes. It follows that adolescents with T1D experience higher rates of psychological distress such as depression (nearly two times that of non-diabetics) (see Hood et al., 2006) and eating disorders (see Colton et al., 2015) that are associated with poorer controlled HbA1C levels as confirmed by these two studies.

Meeting the demands of T1D is complex but vital, as failure to do so can lead to complications such as kidney failure, blindness, amputation, strokes heart disease, and even death (CDC, 2014). Peyrot (2008) reported that according to health professionals, adherence rates of diabetes is around 50%. A longitudinal study by Gill et al. (2005) in Soweto, South Africa, found that their cohort had continuing poor HbA1C control during the 20-year follow ups, with a mortality rate of 33%. Comparative findings in the United States (Nishimura et al., 2001), Cuba (Collado-Mesa et al., 1997) and Ethiopia (Lester, 1992) showed a 7.9%, 16%, and 37% mortality rate. Makombo (2016) reported that South Africa had 91.7 diabetes related deaths per 100 000 people in 2014, which is substantially higher than any other country listed. This highlights the continuing struggle with the management of T1D in Africa and South Africa in particular.

Ultimately, good versus bad management is predicated on standards/ targets that are usually externally imposed (Watts et al., 2010). Adolescents with T1D constantly face daily struggles when these targets of management and particularly self-management are not met, which again confirms the need for a better understanding of adolescents' experiences of living with T1D.

1.3.2 T1D in adolescence

Adolescence is a developmental phase between childhood and adulthood occurring between the ages of 10 to 19, incorporating biological (such as hormonal) and psychological changes (World Health Organisation, n.d.). Role renegotiation (Scholes et al., 2013), independence and autonomy (Fiese & Everhart, 2006), and the development of a personal identity (Silverstein et al., 2005) are major developmental tasks for adolescents transcending into adulthood. This age group has been identified by the researcher for use in this research as it approximately corresponds to the onset of puberty and legal independence (Dahl, 2004). Historically, this typically spans from 12 to 18 years of age, which roughly corresponds to the time from pubertal onset, that is, with a view to specific hormonal changes, to guardian independence and is the legal definition of "adulthood" in many countries.

These changes and how adolescents experience them are further complicated by a diagnosis of a chronic condition such as T1D (see Scholes et al., 2013). Scholes et al. (2013) highlight that adolescents' experiences of T1D can be categorised into four areas namely: 1) experiences of parents, 2) self-management, 3) attitudes/ beliefs, and 4) peers.

First, experiences of parenting: adolescence marks a period where management declines as they are searching for more independence and autonomy (Fiese & Everhart, 2006), which is aggravated by the difficulty parents experience in maintaining a balance between remaining interested on the one hand and controlling of behaviours on the other (Marshall et al., 2009). Due to the typical onset and nature of T1D, parental support is important. This is of further significance among adolescents where renegotiation of roles and responsibilities occur, as they are expected to become increasingly responsible for their own health and self-care and move towards self-management of their condition. Leonard et al. (2005) found that adolescents with uncontrolled T1D had more negative views than adolescents with controlled T1D regarding parental reminders leading to higher rates of parent-

adolescent conflict and lower use of this supportive resource. This conflict is associated with higher HbA1C levels (Sander et al., 2010), while positive, supportive parent-adolescent relationships are associated with lower HbA1C levels (Fiese & Everhart, 2006). Findings by Berg et al. (2008) and Leonard et al. (2005) confirm this, indicating that parent-adolescent relationships are a predictor for successful management.

Second, experiences of self-management: Hanna and Decker (2010) found that the assuming of responsibility for self-care was crucial to successful management. Adolescents generally experienced difficulty in coping with their self-care (Hanna & Decker, 2010) and greater difficulties coping with their diabetes (Novo Nordisk, 2011), since the majority demonstrated low emotional coping abilities (Peyrot, 2008). This is a logical progression as, without self-care, the self-management of and coping with diabetes will be hindered.

Third, adolescents' beliefs and attitudes: adolescents perceive diabetes as a difficult and demanding condition (Davidson et al., 2004), while adolescents with uncontrolled T1D avoid caring behaviour for their condition (Scholes et al., 2013). Additionally, adolescents believe they are invulnerable, adopting risky behaviours, as they do not fear future complications, preferring to live in the here and now (Guthrie et al., 2003), all of which further complicates their self-management of chronic conditions.

Lastly, the experience of peers: peer relationships are important in adolescence (Freeman & Brown, 2001), and have the potential to influence adolescents with T1D by either supporting or impeding their self-care behaviours (Hanna & Decker, 2010). Marshall et al. (2009) found that adolescents and parents perceive themselves as different where T1D occurs, which culminates in a pursuit for the "normal". Additionally, management regimens are intrusive and occur multiple times a day, such as blood glucose monitoring, which disrupt their day-to-day activities. This may heighten adolescents' concerns about being different from their peers, and result in focusing attention and effort on appearing "normal;" they may go to extremes to fit in (Marshall et al., 2009), avoiding being othered. Despite the fear of being othered, Scholes et al. (2013) indicated that friends and peers were still perceived as supportive.

Adolescents' experiences around T1D as related to parents, self-management, attitudes/ beliefs, and peers are not only influenced by, but in their turn also influence, their developmental tasks. Additionally, Tripathy (2012) found that adult lifestyles are based on their childhood and adolescence, and according to Lawson et al. (2008) perception, beliefs, and habits regarding diabetes are formed during this period. Thus, research into this developmental phase is important when it comes to understanding T1D management. As Schur et al. (1999) further emphasise, by understanding adolescents' perceptions around illness perception they can be better supported. Therefore, illness perception plays a role in the management of T1D.

1.3.3 Illness perception

Illness perception refers to the cognitive belief systems people have about their condition (Griva et al., 2007) or, more simply put, "lay" beliefs people have about their condition (Singh, 2011).

Leventhal's Illness Representations Model (also known as Leventhal's Common Sense Model) is useful towards clarifying how experiences, perceptions, and the impact of living with T1D influences adolescents' interpretations and responses to the condition (Leventhal et al., 2011). Illness representations integrate with existing schemata enabling sense-making of symptoms, thus guiding coping actions (Meyer et al., 1985). The individual first forms an illness representation, then they adopt new behaviours to cope with the illness, and only then do they evaluate the effectiveness of these behaviours (Singh, 2011). Beliefs about illnesses can be divided into five dimensions (Leventhal et al., 2011). First, identity, which is the label given to the illness and the associated symptoms. Second, cause, which refers to the individual's ideas about the cause of the illness based on personal experiences and opinions of others. Third, timeline, that is, the belief in the acute- versus chronic nature of the illness, in other words, beliefs about how long it will last. Fourth, consequences: these are the perceived consequences and impact of the illness, which become more realistic over time. Lastly, controllability, which refers to the beliefs surrounding curability and control of the illness (Leventhal et al., 2011).

Scholes et al. (2013) conducted a study comparing the illness perception of controlled and uncontrolled T1D in adolescent, and found that their perception of the condition and related factors differed. In line with Leventhal's model, Scholes et al. (2013) found that the uncontrolled T1D group

felt that there would be a cure for diabetes, while the controlled group did not. This belief in the acute nature of their condition influenced their self-care attitudes and behaviours negatively (Scholes et al., 2013). The uncontrolled group refused to take responsibility for their diagnosis and had greater difficulty adopting self-care regimens, indicating a low level of controllability. Additionally, adolescents with uncontrolled T1D found their diagnosis more traumatic than their controlled T1D counterparts (Scholes et al., 2013): 56% of young adults perceived communication from healthcare professionals regarding their diagnosis and treatment as insufficient (Peyrot et al., 2005).

Adolescents with T1D frequently experience messages from parents and healthcare professionals around the threats posed by the disease that occur during diagnosis and diabetes care feedback as negative, leading to lower belief in treatment effectiveness (see Lawson et al., 2010 and Scholes et al., 2013). Leventhal (1970) found that if these threat messages were accompanied by clearly defined instructions for self-management, changes in attitude would occur and positive actions would follow. Further, Lawson et al. (2008) highlighted that these adolescents' perception remained consistent over time: how health threats are communicated and, indeed, how they are perceived are better predictors of illness perception than personality factors. Although limited research has been undertaken to explore the illness perceptions of T1D, the majority has been quantitative in nature, thereby leaving a lacuna in the body of knowledge around illness perceptions of in the case of uncontrolled T1D. The present project therefore proposes to build on the research mentioned above by further exploring illness perception among adolescents living with uncontrolled diabetes, and how these perceptions contribute to their diabetes management.

1.4 Research objective

The objectives of this research are therefore as follows:

- To explore the illness perception among adolescents with uncontrolled T1D.
- To explore how these illness perceptions contributes to diabetes management.

1.5 Research design and method

These research objectives were central to the selection of the proposed research design and methods. The present section expounds this by focusing on the following: research design, research sample and participants, research procedure, data generation, inclusion and exclusion criteria, data analysis and interpretation techniques, and trustworthiness.

1.5.1 Research design

A qualitative research approach will be used. Qualitative research is the study of phenomena in their natural settings, with the aim of interpreting these phenomena according to how people understand them (Denzin & Lincoln, 2000). According to Nieuwenhuis and Smit (2012), a strength of the qualitative research approach is that it allows for selected topics to be studied in-depth and in rich detail. Further, qualitative research is holistic, allowing for the phenomena studied to be explored concomitant with the way in which they unfold as interrelated wholes in the real world (Durrheim, 2012).

The social constructivist framework will be utilised. According to Lock and Strong (2012), it is a broad framework that investigates how language is used to create meaning in social interactions. These interactions shape thoughts and behaviours through a shared language bound within a specific context and time (Lock & Strong, 2012). Therefore, multiple realities can exist as people create and define their own identities and perceptions within their context, which can be understood through language. Adopting an approach and framework based on these important recognitions will provide greater in-depth understanding of illness perception among adolescents who are not maintaining an HbA1C level of 7.5% or below.

1.5.2 Research sample and participants

Individual semi-structured interviews will be conducted on a one-on-one basis at the Centres for Diabetes and Endocrinology in Johannesburg with adolescents between the ages of 12-18 who suffer from uncontrolled T1D. A South African sample will be used to investigate illness perception among adolescents with uncontrolled T1D. The sample will be chosen, because literature suggests that perception, beliefs, and habits regarding diabetes are formed during childhood and adolescence (see

Lawson et al., 2008; Tripathy, 2012). This developmental stage is, therefore, the foundation for diabetes management in adulthood.

The research will comprise of approximately 15 to 20 interviews of participants or until data saturation has been reached. According to Richie et al. (2009) a small sample size is appropriate for qualitative research, because data saturation occurs and thus no new and/ or relevant information will be obtained from including more participants. Furthermore, they argue that, due to the nature of qualitative data, a wealth of information is obtained from each participant; therefore, a small sample size is sufficient. Additionally, in qualitative research, sample sizes that are too large handicap the extraction of rich data (Onwuegbuzie & Leech, 2007).

1.5.3 Research procedure

Data will be collected from participants who attend the Centres for Diabetes and Endocrinology (CDE) in Johannesburg. Recruitment of prospective research participants will take place in accordance with the following recruitment process:

- **Step 1:** Permission to conduct research at the CDE and recruit participants will be gained by meeting with CDE management.
- **Step 2:** Various means of inviting prospective participants to take part was employed, including an information leaflet given to prospective participants by their physicians, an SMS from the physician introducing the project to prospective participants, and advertisements on relevant Facebook groups. In these invitations, prospective participants will be provided with a contact e-mail address of the project co-ordinator. Once prospective participants contact the research team, more information will be given, including that it will be voluntary process and that they could thus withdraw from the study if they were to change their mind as well as inclusion- and exclusion criteria and participants' responsibilities should they choose to participate.
- **Step 3:** After receiving additional information, prospective participants who remain interested in taking part in the research project will be contacted by Prof. Deacon, as project co-ordinator, who will then contact the legal guardians of the interested adolescents telephonically or via e-

mail. A telephonic screening will take place to ensure that participants will qualify to take part in the study.

  - If they meet the criteria, the legal guardians will be informed of the eligibility of the prospective participant and will be asked if they would like to meet the researcher before or after the scheduled appointment discussed in the email. They will be informed that the meeting will take approximately one hour to obtain parental permission, adolescent consent, and for data collection to take place. After the screening a date for the interview will be set and parental permission- and adolescent-informed consent forms will be sent to the prospective participants to examine before meeting for the interview. Those without e-mail addresses will be accommodated by meeting them two days before the scheduled appointment at the physician's office to hand them their informed consent forms.
  - If they do not meet the criteria, they will be informed that they do not qualify to participate and will be given the reasons. However, they will be told that they will still qualify to receive updates of the progress of the research project should they prefer this.

- **Step 4:** On the day of the agreed meeting the researcher will meet the prospective participant and their legal guardian to discuss the relevant information again. Once they agree to participate, written informed parental permission- and adolescent consent will be obtained by an independent person at the aforementioned facilities. Another staff member at these facilities will sign as the witness and the researcher will also sign the parental permission- and adolescent consent forms. At this point, data generation will take place.

1.5.4 Data generation

Data will be generated through the use of a semi-structured interview schedule. This method is often used in qualitative research (DiCicco-Bloom & Crabtree, 2006). The interviews follow a key set of questions but allow the researcher to probe and explore issues as they arise, thus providing the prospect of a deeper understanding of the phenomenon in question (Nieuwenhuis & Smit, 2012). An interview agenda will guide each interview. The interview will take approximately one hour and will

be audio recorded with the permission of the participants. The recording of interviews will enable the researcher to focus on the discussion of the interview instead of trying to make accurate notes during the discussion (Niewenhuis, 2007). A non-random purposive sampling method will be utilised, as random sampling is not possible due to the nature of the research topic and objectives.

1.5.5 Inclusion and exclusion criteria

To be included in the research, prospective participants will have to be fluent in English or Afrikaans as, otherwise, the use of interpreters may compromise the trustworthiness of the collected data. Prospective participants will have to be in the age range of 12-18 years so as to meet the developmental criteria for adolescence. They must attend the CDE, as treatment variables may compromise the trustworthiness of the collected data. The HbA1C levels of prospective participants will have to have been above 7.5% over the preceding 12 months so that T1D will be considered uncontrolled and the diagnosis will have to have been made at least 12 months prior to participation. Guthrie et al. (2003) found that this is the timeframe for adjustment to the diagnosis of diabetes.

Prospective participants who will be receiving psychotherapy at that stage will be excluded to ensure that the research process does not interfere with the therapeutic process. Further exclusion criteria include ruling out prospective participants suffering from another chronic medical condition requiring management, as the management of another condition may interfere with diabetes management.

1.5.6 Data analysis and interpretation techniques

Braun and Clarke (2006, 2013) gives a thematic analysis to be utilised in the present project, as it allows for the collection of rich and detailed data by identifying, analysing, and reporting themes from within the data. This is achieved by minimising, organising, and describing the data in detail. The following six phases, summarised below, as described by Braun and Clarke (2006, 2013) will be followed to analyse the data:

1. Familiarisation of the data. This step involves the immersion of the researcher into the data to become familiar with the content. This will start by transcribing the audio recordings and,

subsequently, by continually reviewing the transcripts to ensure accuracy and familiarity with the data, while searching for possible meanings and patterns.

2. Initial coding generation. During this phase, the data will be organised into meaningful groups and assigned initial codes. This process will be repeated ensuring the accuracy of the process and coding.
3. Theme searching. The codes identified in phase 2 will then be sorted into potential themes and subthemes.
4. Theme reviewing. Identified themes and subthemes are reviewed and refined. The individual themes will then be reviewed for validity and are assessed to ensure that they reflect the meaning of the data set.
5. Defining and naming the emerging themes. The essence of each theme will be identified and then the theme will be assigned a name.
6. Report writing. This phase comprises of the final analysis and write-up, which includes the selection of appropriate extracts for each theme. The write-up will take the form of a research article.

To ensure accuracy during data analysis and interpretation, a research colleague with experience in qualitative research will independently co-code the raw data. If there are any significant discrepancies, a third coder will be utilised to resolve the discrepancy. Additionally, regular meetings with the research supervisor will be held and discussions with a panel of experts (including professionals from the field of psychology, endocrinology and diabetes support) will be conducted throughout the project to obtain alternative views and check possible researcher bias. This will increase the trustworthiness of the data, as discussed in the following section.

1.5.7 Trustworthiness

The methodological soundness and adequacy of research can be indicated by trustworthiness (Holloway & Wheeler, 2002). Lincoln and Guba (1985) put forward four criteria that qualitative researchers should consider to establish the trustworthiness of their research.

1. Credibility, that is, the consistency of the findings (Lincoln & Guba, 1985). According to Lincoln and Guba (1985) credibility can be attained by ensuring peer debriefing, that is, informal discussions with a research colleague to uncover and examine potential biases and test hypotheses as well as member checking, that is, preliminary findings will be summarised and sent to participants via e- mail or a hard copy for those without e-mail access to allow participants to review the preliminary findings and provide feedback if desired.
2. Transferability refers to the applicability/ fittingness of findings to another context (Lincoln & Guba, 1985). Morrow (2005) states that qualitative research cannot be generalised, at least not in the conventional sense, due to the small sample size and lack of statistical analysis. However, Denscombe (1998) argues that, despite the uniqueness of each case, it remains an example of a larger group, thus allowing for the possibility of transferability. Giving a thick description of the research methodology will allow the study to be replicated as it will give other researchers the opportunity to compare contexts and interpret the results and conclusions correctly (Aguinis & Solarino, 2019).
3. Dependability is the conduction of research in a consistent manner, so that findings can be repeated by other researchers (Morrow, 2005). However, Marshall and Rossman (1999) question the ability of qualitative research to be repeated because, as they argue, the "social world is always being constructed" (p. 194). But they continue to say that despite this dependability such repetition is still important, as it allows future researchers to review their procedures and even reanalyse the data. According to Lincoln and Guba (1985), dependability is achieved by describing the details of the procedures used in the research, which will done be in the present case by conducting an audit trial including comprehensive field notes relating significant events observed as well as questions that may arise during data gathering.
4. Confirmability acknowledges that research is never truly objective but aims to represent findings shaped from the data/ respondents' responses and not merely the researcher's biases or interests (Morrow, 2005). According to Lincoln and Guba (1985), this can be achieved through researcher reflexivity and triangulation. A reflexive journal will therefore be utilised in the present study to store ideas and check for researcher bias, while triangulation will

concomitantly be conducted by collecting data from observations, audio recordings of the interviews, and literature reviews that will refine the themes.

1.6 Ethical considerations

The following ethical considerations relevant to this study will be explored to ensure the integrity of this study, namely: vulnerable populations, informed consent, and confidentiality.

1.6.1 Vulnerable populations

The challenges faced here are two-fold, as the participants are under the age of 18 and have been diagnosed with T1D mellitus, therefore putting them at risk. As the researcher will be working with this population, unique ethical challenges must be taken into consideration. This includes possible increased stress levels brought about by discussing the sensitive topic of diabetes. Therefore, the researcher will be following these guidelines: obtaining written parental permission from the guardians of the prospective participants and adolescent consent from the prospective participants themselves. Any intrusions and/ or disruptions to the participant's daily lives will be minimised as far as possible. Additionally, the rights of the participants will be upheld throughout the study by ensuring confidentiality and voluntary participation, which includes the right to withdraw from the research project at any time until data analysis commences. Participants will receive a certificate of appreciation to thank them for their participation.

Due to the nature of diabetes, participants may become fatigued or may experience an unexpected fluctuation in their blood glucose levels during an interview. Given this possibility, open dialogue will be maintained between the researcher and participants to ensure that they feel comfortable about informing the researcher of possible concerns regarding blood glucose levels. Additionally, to minimise this concern, participants will be given a break during the interview and will receive a light carbohydrate snack and bottle of water to consume if necessary. Should any participant become distressed during the research process, he or she will be referred to Mrs Flynn, a registered clinical psychologist at the CDE in Houghton, Johannesburg, who has agreed to provide one free debriefing session. Additionally, the researcher is a registered student-counselling psychologist and has experience

in conducting interviews regarding sensitive topics in addition to working with individuals who may be/ become distressed. In her turn, the present researcher has completed a course in basic research ethics entitled "The Basics of Health Research Ethics" at North-West University further enhancing her ethical sensitivity.

1.6.2 Informed consent

Written permission will be obtained from Professor Segal (Paediatric Endocrinologist at the CDE in Parktown, Johannesburg) and Professor Distiller (Principle Physician, Endocrinologist and Managing Director of the CDE in Houghton, Johannesburg), where a similar research project has been recruiting and continues to recruit prospective participants. The informed consent of prospective participants will follow the guidelines discussed below in section 6.2 under the heading "Recruitment". Each prospective participant will receive a consent form in advance so that he or she will have the opportunity to familiarise himself or herself with its content. Informed consent will be collected by an independent person. Permission for audio recording of interviews will be included in parental permission- and adolescent consent forms. All recordings and transcripts will be handled in the same manner as other data and will be subject to the same procedures and precautions.

1.6.3 Confidentiality

Raw data collected during the research project will be used strictly for the research purposes stated in the parental permission- and adolescent consent form. All data will be kept on a personal password-protected computer for the duration of the research project. Any hard copy data will be kept in a safe and secure, locked cupboard in the researcher's office. Only members of the research team will have access to data collected. Additionally, provision will be made for the safekeeping of collected data so that confidentiality and anonymity can be maintained beyond the individual research project. Anonymity will further be ensured through keeping the names of participants for the proposed research interviews confidential by using a participant code. This code will be allocated to the participant only once all written parental permission- and adolescent consent will have been received. Parental permission- and adolescent consent forms will subsequently be filed away, and only the individual

participant code will be used for all data gathering- / analysing procedures, thereby ensuring confidentiality. The list of participant codes next to consent forms will be stored separately from consent forms. All co-coders will sign confidentiality clauses. Non-pertinent information regarding the present project as well as identifying characteristics and information of the participants will not be disclosed. Permission will be gained to use direct quotes and to make audio recordings. All audio recordings will be identified by means of the individual participant code and will be transcribed verbatim by the researcher. These will then be checked for accuracy according to qualitative methodology guidelines as stipulated by Denzin and Lincoln (2000). Although researchers involved in the present project will liaise with personnel at the CDE (Houghton and Parktown), no member of the CDE or the participant's medical team will have access to the data.

Outline of the study

Chapter 1 of this research comprises of an introduction to the study and rationale for undertaking it. It also describes research design, method, and ethical considerations. Chapter 2 will specify the journal to which the article will be submitted for review, namely the *Journal of Psychology in Africa*, including author guidelines. Additionally, it includes the article entitled "Illness perception among adolescents with uncontrolled T1D mellitus: A thematic analysis". Chapter 3 includes the conclusion to the study, a discussion of its limitations, and recommendations. It concludes with a critical reflection by the researcher and a complete reference list.

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Section 2: Intended journal: Guidelines and article

2.1 Article format and structure

Guidelines for authors: *Journal of Psychology in Africa*

This article will be submitted to the *Journal of Psychology in Africa (JPA)*. It will adhere to *JPA* guidelines, as cited from the journal, below.

JPA provides an inter-disciplinary forum for the dissemination of research findings in the field of Psychology with particular focus on such research from Africa and other related regions. JPA publishes articles such as original research reports, brief reports, analysis reports, research reviews, book reviews, case studies etc. Contributions are encouraged to synthesise local and universal methodologies and applications that contribute to furthering knowledge in applied psychological sciences. The following manuscripts are encouraged:

- Those that combine qualitative and quantitative data;
- Articles that utilise a systematic qualitative or ethnographic approach;
- Articles that are original and utilise a creative methodological approach;
- Articles that address important but overlooked topics;
- Articles that present new theoretical or conceptual idea;
- Articles that present innovative context sensitive applications.

Additionally, articles should show an awareness of the cultural context of the research questions asked, the measures used, the interpretation made, and the results obtained. Finally, the articles should be practical, based on local experience, and applicable to efforts made in the psychological developments in key areas cultural settings in Africa.

Editorial policy

The submission of an article to JPA implies that the material has not previously been published and is not currently being considered for publication anywhere else. Submission of an article will be taken to imply transfer of copyright of the material to the owners, Africa Scholarship Development Enterprize. Contributions are accepted on the understanding that the authors have the authority for publication. Material accepted for publication in this journal may not be reprinted or published without due copyright permissions. The Journal has a policy of anonymous peer review. Articles will be scrutinised and commented on by at least two independent expert referees or consulting editors as well as by an editor. A multi-layered manuscript review process is implemented to result in high quality publications: a peer review and developmental review. The peer review process addresses the primae-face merits of the manuscript's scientific contribution subject to the Editor's discretionary decision. The developmental review by the Editorial office advises the scientific writing presentation qualities of the manuscript. The Editor reserves the right to revise the final draft of the manuscript to conform to editorial requirements.

Publishing ethics

By submitting to the *Journal of Psychology in Africa* for publication review, the authors agree to any originality checks during the peer review and production processes. A manuscript is accepted for publication review on the understanding that it contains nothing that is abusive, defamatory, fraudulent, illegal, libellous, or obscene. During manuscript submission, authors should declare any competing and/or relevant financial interest which might be potential sources of bias or constitute conflict of interest. The author who submits the manuscript accepts responsibility for notifying all co-authors and must provide contact information on the co-authors. The Editor-in-Chief will collaborate with Taylor and Francis using the guidelines of the Committee on Publication Ethics [http://publicationethics.org] in cases of allegations of research errors; authorship complaints; multiple or concurrent (simultaneous) submission; plagiarism complaints; research results misappropriation; reviewer bias; and undisclosed conflicts of interest.

Manuscripts

Articles should be submitted in English. They should conform to the publication guidelines of the latest edition of the American Psychological Association (APA) publication manual of instructions for authors. Articles can be a maximum of 7000 words.

Submission

Manuscripts should be prepared in MSWord, double spaced with wide margins and submitted via email to the Editor-in-Chief, Elias Mpofu. Before submitting a manuscript, authors should peruse and consult a recent issue of the *Journal of Psychology in Africa* for general layout and style.

Manuscript format

All pages must be numbered consecutively, including those containing the references, tables and figures. The typescript of a manuscript should be arranged as follows:

- **Title:** It should be brief, sufficiently informative for retrieval by automatic searching techniques and should contain important keywords. It should preferably not exceed 13 words.
- **Authors and Addresses of authors**: The corresponding author must be indicated. The author's respective addresses where the work was done must be indicated. An e-mail address, telephone number and fax number for the corresponding author must be provided.
- **Abstract:** Articles and abstracts must be in English. Submission of abstracts translated to French, Portuguese and/ or Spanish is encouraged. For data-based contributions, the abstract should be structured as follows:
    - Objective: The primary purpose of the paper;
    - Method: Data source, participants, design, measures, data analysis;
    - Results: Key findings, implications, future directions; and
    - Conclusion: In relation to the research questions and theory development.

    For all other contributions (except editorials, book reviews, and special announcements) the abstract must be a concise statement of the content of the paper. Abstracts must not exceed 150

words. The statement of the abstract should summarise the information presented in the paper but should not include references.

- **Text:** The text should follow the APA guidelines, only one space should follow any punctuation. No spaces should be inserted at the beginning or end of paragraphs. No colour should be used in text. The references should not be aligned using spaces or tabs but rather a hanging indent should be used.
- **Tables and figures:** They should only contain information directly relevant to the content of the paper. Each table and figure must include a full, stand-alone caption, and each must be sequentially mentioned in the text. Tables and figures should be collected together at the end of the manuscript or supplied as separate files. Indicate the correct placement in the text in this form. Figures must conform to the journals style. Pay attention to line thickness, font and figure proportions, considering the journal's printed page size (plan around one column width of 82 mm or two column width of 170 mm). For digital photographs or scanned images, the resolution should be at least 300 dpi for colour or greyscale artwork and a minimum of 600 dpi for black line drawings. These files can be saved (in order of preference) in PSD, PDF or JPEG format. Graphs, charts or maps can be saved in AI, PDF or EPS format. MS Office files (Word, PowerPoint, and Excel) are also acceptable but do not embed Excel graphs or PowerPoint slides in a MS Word document.

Referencing

Referencing style should follow latest edition of the APA manual of instructions for authors.

- **References in text:** References in running text should be quoted as follows: (Louw & Mkize, 2012), or (Louw, 2011), or Louw (2000, 2004a, 2004b). All surnames should be cited the first time the reference occurs, e.g., Louw, Mkize, and Naidoo (2009) or (Louw, Mkize, & Naidoo, 2010). Subsequent citations should use et al., e.g. Louw et al. (2004) or (Louw et al., 2004). "Unpublished observations" and "personal communications" may be cited in the text, but not

in the reference list. Manuscripts submitted but not yet published can be included as references followed by "in press".

- **Reference list:** Full references should be given at the end of the article in alphabetical order, using double spacing. References to journals should include the author's surnames and initials, the full title of the paper, the full name of the journal, the year of publication, the volume number, and inclusive page numbers. Titles of journals must not be abbreviated. For example;
    - **Journal:** Peltzer, K. (2001). Factors at follow-up associated with adherence with adherence with directly observed therapy (DOT) for tuberculosis patients in South Africa. *Journal of Psychology in Africa, 11,* 165–185.
- References to books should include the authors' surnames and initials, the year of publication, full title of the book, the place of publication, and the publisher's name. For example;
    - Book: Gore, A. (2006). An inconvenient truth: T*he planetary emergency of global warming and what we can do about it.* Emmaus, PA: Rodale.
    - *Edited book*: Galley. K. E. (Ed.). (2004). *Global climate change and wildlife in North America.* Bethesda, MD: Wildlife Society.
    - *Chapter in a book*: Cook, D. A., & Wiley, C. Y. (2000). Psychotherapy with members of the African American churches and spiritual traditions. In P. S. Richards & A. E. Bergin (Ed.), *Handbook of psychotherapy and religiosity diversity* (pp 369–396). Washington, DC: American. Psychological Association.

Instructions to authors are available at: https://www.nisc.co.za/products/journals/authors

2.2 Article: Illness perception of adolescents with uncontrolled type 1 diabetes mellitus: A thematic analysis

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Abstract

This study explored the illness perception among adolescents living with uncontrolled type 1 diabetes (T1D) and how these perceptions influenced management of T1D. A qualitative, explorative design with semi-structured interviews was followed. A non-random purposive sampling method was utilised. The illness perception among eight adolescents, ages 12 - 18 years, with uncontrolled T1D were analysed through thematic analysis. Four major themes were generated, namely (1) management of T1D is challenging, (2) perception of T1D is negative, (3) management of T1D is motivated by fear, and (4) living with T1D leads to a sense of being different. Adolescents with uncontrolled T1D believe that T1D is difficult to manage leading to a largely negative perception of the disease. This study contributes to the body of literature on adolescents who have found adhering to management protocols challenging, which may give additional insights into the practical application of such research and assist in designing successful interventions.

Keywords: Illness perception, adolescents, Type 1 diabetes, uncontrolled diabetes, diabetes management, South Africa, thematic analysis.

Introduction

Diabetes is the second most prevalent chronic condition in adolescence (Borus & Laffel, 2010) and the 11th most common cause of disability worldwide (International Diabetes Federation [IDF], 2017). Diagnosis of T1D peaks in adolescence (Centre for Disease Control and Management [CDC], 2014) with over 1.1 million children under the age of 20 living with T1D worldwide (IDF, 2017). T1D occurs as the result of an autoimmune reaction that causes the body's defences to attack insulin-producing pancreatic β cells resulting in a situation where the body produces little or no insulin (Bluestone, Herold, & Eisenbarth, 2010). Insulin is a hormone that regulates blood sugar and is measured by monitoring glycated haemoglobin (HbA1c) levels (Gill, Kukreja, Malhotra, & Chhubrah, 2013).

No cure for diabetes exists; however, it can be managed via a variety of diabetes care plans. Traditionally, T1D management protocols entailed regular blood glucose monitoring to maintain

optimal HbA1c levels of 7.5% or below (Scholes et al., 2013), insulin treatment as well as dietary monitoring and exercise with the aim of preventing future complications (IDF, 2017). It is worth noting, though, that this number fluctuates within the available literature (see CDC, 2014; Rewers et al., 2009), but for the purpose of this paper an HbA1C of 7.5% will be utilised.

Despite the existence of good diabetes care plans (Borus & Laffel, 2010), many adolescents struggle to manage their T1D, as confirmed by the fact that only one third can be considered well-controlled (Hougaard & Mortensen, 1997). A longitudinal study by Gill, Huddle, and Monkoe (2005) found that participants in Soweto, South Africa, continued to experience poor T1D control during a 20 year follow-up study that showed a 33% mortality rate during this time period.

Barriers that prevent adherence to diabetes care plans among adolescents with T1D include lack of parental support and physiological factors (see Marshall, Carter, Rose & Brotherton, 2009; Scholes et al., 2013), demographic factors such as race and age (IDF, 2017), the type of health care support received (see Scholes et al., 2013), attitudes (see Sander, Odell & Hood, 2010), fatigue and peer pressure (see Borus & Laffel, 2010) as well as coping styles (see Lawson, Bundy, Belcher & Harvey, 2010). These are aggravated by the psychological impact of repetitive, painful needle pricks and injections, which are required for blood glucose checks and the administration of medication as well as the difficulties entailed in accomplishing developmental tasks. When T1D is not well managed, it can lead to a variety of complications. These include kidney failure, cardiovascular disease, blindness, amputations, and even death (CDC, 2014; IDF, 2017). It is estimated that in 2017 over 4 million people died of diabetes worldwide (IDF, 2017). Therefore, management plays a vital role in the prevention of complications related to diabetes (IDF, 2017).

Adolescence is a critical transition period for teenagers when it comes to their personal development as well as in diabetes management, as adolescents strive for autonomy, which leads to a need for greater ownership and taking responsibility for such management (Hunter, 2016). As has been mentioned, it is during adolescence that their perception, beliefs, and habits regarding diabetes are formed (Lawson, Bundy, & Harvey, 2008) as they attempt to make sense of their condition (Leventhal et al., 1997). However, these perceptions can change as adolescents gain greater cognitive and socio-emotional insight into their condition (Smetana, Campione-Barr, & Metzger, 2006).

Illness perception is a cognitive belief system that people assume about their condition (Broadbent, Donkin, & Stroh, 2011). Once it has been integrated with existing schemata to enable sense-making of symptoms (see Meyer, Leventhal, & Gutmann, 1985), this guides their management of the condition (Leventhal et al., 1997). Illness representations are first formed by the individual before new behaviours are adopted to cope with the condition and before behavioural effectiveness is evaluated (Singh, 2011).

Illness perception has been used to predict physiological and behavioural outcomes in self-management (Griva, Meyers, & Newman, 2007), such as adherence to medication regimes (Kucukarslan, 2012). In their turn, Cosma and Bâban (2017) found that long-term beliefs held by adolescents about T1D predicted their emotional responses. In a study conducted by Scholes et al. (2013), adolescents with uncontrolled T1D found it more challenging than adolescents with controlled T1D to adopt self-care regimens, indicating that they felt that they could not control their T1D. According to Broadbent et al. (2011), the management of a variety of conditions can be improved through changing people's perception of and attitudes towards the condition. Additionally, Schur, Gamsu, and Barley (1999) emphasise that by understanding an adolescent's illness perception the support provided can be given more effectively. Thus, illness perception plays a key role in the management of T1D.

Therefore, this study aims to explore the illness perception among adolescents with uncontrolled T1D. Limited research, mostly quantitative in nature, has been conducted around the illness perception of T1D (see Cosma & Bâban, 2017; Fortenberry et al, 2014; Jonker, Deacon, van Rensburg, & Segal, 2018; Kucukarslan, 2012); however, a lacuna remains in research on the illness perception of uncontrolled T1D, especially from a South African perspective. Exploring the illness perception among adolescents with uncontrolled T1D in South Africa will lead to improved understanding of T1D and thus aid in the management of uncontrolled T1D.

Research objective.

The objectives of this research are as follows:

- To explore the illness perception among adolescents with uncontrolled type 1 diabetes.

- To explore how these illness perceptions contribute to diabetes management.

Methods

Rationale for a qualitative design

This study is explorative in nature. A qualitative research approach was utilised, the study aims to understand an individual's experiences and perception (Fouché & Schurink, 2011), while the approach further allows in-depth study of phenomena (Nieuwenhuis & Smit, 2012). Qualitative research is holistic, allowing for the phenomena examined to be explored as they unfold in the real world as interrelated wholes (Durrheim, 2012). Therefore, this approach does not focus on the generalisability of the findings but rather the extent to which the results are transferable to other settings (Smith, 2018). Thus, this approach is well suited to gaining in-depth understanding of the illness perception of adolescents with uncontrolled T1D.

Participants

The Centre for Diabetes and Endocrinology (henceforth CDE) in Parktown, South Africa, served as the gatekeeper who informed prospective participants about the background to the study and the voluntary nature of participation. Non-random, purposive sampling was utilised to select participants who conformed to the sampling criteria. Eligibility criteria included (a) age between 12–18; (b) a diagnosis of T1D for at least 12 months prior to enrolment, thus to avoid any impact of continuous adjustments in treatment on the trustworthiness of data obtained (Guthrie, Bartsocas, Jarosz-Chabot, & Konstantinova, 2003); (c) an HbA1c level above 7.5% at the time of enrolment; (d) being a CDE patient so as to minimise treatment variables; (e) English- or Afrikaans speaking. Ineligible criteria included (a) suffering from another chronic medical condition that could impact diabetes management; (b) undergoing psychotherapy at the time of the research, as the psychotherapeutic process may alter their illness perception, and as a precautionary measure to avoid interfering with the therapy process.

Prospective participants who were interested in taking part were screened to ensure eligibility and once again explain the study. No participants dropped out after screening. Written informed consent was gathered from the adolescents and parental permission from their legal guardian. Data were

collected from May 2018 to March 2019. The final sample consisted of eight adolescents whose biographical information and pseudonyms are expanded on in table 1 below.

Table 1: **Biographical information and pseudonyms of participants**

Participant's pseudonym	Age	Gender	Age when diagnosed with T1D
Bill	13	M	3
John	14	M	11
Jane	13	F	5
Alice	13	F	5
Sue	13	F	10
Frank	14	M	10
Joy	16	F	9
Claire	12	F	9

The biographic distribution was as follows: female 63%, male 37%, white 75%, and black 25%. The mean age was 13.5 years (range 12 - 16). The mean age of diagnosis was 8 (range 3 - 11). The mean HbA1c levels was 10.5% (range 8 - 14).

Ethical considerations

This study was granted ethical approval by the North-West University's Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities (NWU-HS-2017-0167). As the participants were under the age of 18 and had been diagnosed with T1D, the study was considered to be of medium ethical risk. Therefore, the researchers remained cognisant of the physical- and potentially psychological vulnerabilities of the participants throughout the study. To avoid participant stress, interviews were conducted in a familiar space, a low-carb snack was provided, and free psychological services were offered if needed. The rights of the participants were upheld by ensuring confidentiality

and voluntary participation. Anonymity was ensured by using participant codes and storing consent forms separately from the participant code list. Interviews commenced after independent, written, informed consent were received from all participants and parental permission were received from their legal guardians. The interviews were conducted in English, audio recorded, and transcribed verbatim. Participants received a summary of the findings.

Data generation

Data was collected through an open-ended semi-structured interview schedule. An agenda was utilised to ensure consistency between the interviews. Additional open-ended probing questions were asked to obtain a deeper understanding of the materials. Six interviews were conducted at the CDE, in each case after the participants' routine quarterly endocrinology appointment at this institution. Two participants requested to be interviewed at their homes in Gauteng, South Africa. The interview procedure took on average 45 minutes. The interviews were audio recorded with consent from the participants and parental permission from their legal guardians. The researcher also wrote notes and reflections shortly after the interview.

Data analysis and interpretation techniques

The researcher transcribed the audio recordings verbatim, and each transcript was checked against the recording to ensure accuracy. Thematic analysis as described by Braun and Clarke (2006, 2013) was utilised, as it allows for the collection of rich and detailed data by identifying, analysing, and reporting themes from within the data. This is achieved by minimising, organising, and describing the data in detail. A recursive six-phase process characterises this kind of analysis, as follows: familiarisation of the data, initial code generation, theme searching, theme reviewing, defining and naming of themes, and report writing. To ensure accuracy and reliability during data analysis and interpretation the raw data was co-coded by another researcher. No significant discrepancies were found. No new contributing themes emerged after interview five, that is, data saturation had occurred.

To ensure the trustworthiness of the data, the study utilised the four criteria asserted by Lincoln and Guba (1985), namely credibility, transferability, dependability, and confirmability. Credibility was

attained through peer debriefing, that is, informal discussions with a research colleague to uncover and examine potential biases and test hypotheses was well as member checking, that is, allowing participants to review the preliminary findings. A thick description of the methodology and research process was provided to enhance transferability. Despite this, transferability might be limited due to the small sample size and lack of statistical analysis (see Morrow, 2005). However, Denscombe (1998) argues that despite the uniqueness of each case it remains an example of a larger group, allowing for the possibility of transferability. Dependability was achieved through the co-coding process and by taking comprehensive field notes. Lastly, confirmability was achieved through researcher reflexivity and triangulation. In its turn, triangulation was achieved by collecting data from observations, audio recordings of the interviews, and literature reviews that refined understanding of the themes.

Results

This study aimed to explore the illness perception among adolescents with uncontrolled T1D, and how this perception contributes to their management of the illness. Thematic analyses of the participants' responses yielded four main themes: (1) management of T1D is challenging, (2) perception of T1D is negative, (3) management of T1D is motivated by fear, and (4) living with T1D leads to a sense of being different. These themes are illustrated below by appropriate verbatim extracts from the eight participants.

Theme 1: Management of T1D is challenging

Participants perceived the management of diabetes as challenging, since they struggled to cope with the demands entailed with a view to the successful management of T1D. Managing T1D is seen as difficult, because it needs to be done perfectly. Participants chose to control only part of it, resulting in not managing T1D. Most participants developed an attitude of just having to live with the illness.

The participants felt that **managing T1D was hard and easy.** There seemed to be an ambiguity regarding the participants' experiences of T1D management, where they found it both hard and easy. In discussion of his experiences around managing T1D, Bill said*: "Um, my experience has been hard and easy at the same time. So, some days it will be hard but some days it will be easy".*

Alice said: *"Well it's kinda difficult…I get really emotional so it's kinda hard for me…"* The participants further indicated that managing T1D should be easy but remains just hard. Joy said: *"…it's quite easy, people just make it hard".*

This belief that managing T1D is easy but that is complicated leads to participants blaming themselves for their failure to control T1D perfectly. Frank responded: *"I'm not good at taking my stuff and doing it at the right times, so that's why my sugars aren't at the place that they should be."* There was particular emphasis on feeling pressured to follow diabetes care plans strictly so as to maintain blood glucose at an optimal level. Bill indicated that one should: *"…eat the right things, do the right corrections, always check your sugar".*

Participants felt like their control over T1D was limited, as they could only **control part of it themselves**. Most of them strictly focused on control over their food intake and medication adherence. Alice indicated: *"Um, well there is a little bit of stuff, like I can eat certain stuff and like be on a certain diet …"*. Jane said: *"Mm, I think there is a few things you can do but it is very limited because there is only one thing that can bring your sugar sown and manage your diabetes, which is insulin."*

Since adolescence involves a transitionary stage between childhood and adulthood, it was found that participants generally relied on their family (especially their mother) and friends to assist in controlling T1D; they felt unable to control it themselves or were not ready to do so yet. Jane averred: "*Yeah, my mom's probably a really big part of that, cause she comes to all of the appointments and she knows what to do. She probably knows more than me."* Claire revealed: *"…my best friend, uh she doesn't want me um to even eat um all the cupcake. She doesn't even allow me to hold a cupcake for someone."* Frank confirmed the notions arising from these utterances: "*So, if I take too much spoons [sugar] they actually take my food away from me."* The participants often used "we" when discussing the management of T1D. Jane said: *"Um, well, we do struggle a bit …."* However, this reliance could lead to additional stress, as illustrated by Alice:

> *"Well, I have always worried about like when I get older and then eventually like my parents will like die um and I'm worried about because for my pump we have to put my needle in and my parents always do that because I can't do it…"*

Most of the participants held that they valued and depended on support from their family and friends. Despite this help, they still did not feel like it was an easy task, and often felt that they were not managing T1D well. Sue expressed that managing T1D had been challenging: *"It does become difficult, most of the time I can't handle it. It's difficult because then it's too much to handle for me."*

This apparent struggle of dealing with T1D made some participants feel that they were incapable of managing their T1D, and thus they chose not to. Ultimately, they felt as though they **did not manage their T1D,** as illustrated by Bill: *"I'm bad with my diabetes so I don't really manage it".* Participants found it particularly challenging to manage their T1D at school resulting in failure to do so. Sue indicated the following: *"Taking insulin at school because most of the time I get busy and something that just holds me up that I can't take my insulin."* The challenges of managing T1D also came with an enormous amount of pressure, further inhibiting their resolve to manage it. Joy said: "… *don't do it because it's too much work and it's too much pressure on me".* There was no respite for adolescents with T1D. Since they were overwhelmed by it, they give up on trying to manage it and developed the perception that they just had to live with it – taking on a passive role when it came to managing the illness.

The participants indicated that they **just had to live with it** and thus had to accept their fate of merely living with T1D. Sue said: "*I just have to move on and take care of myself."* Bill indicated the following: *"I just live with it, yeah".* This indicated a resignation to their allotment in life. As John stated: *"... you've got to suck it up, cause it's your life and it's not going anywhere".* Joy reinforced this when she said: *"But yeah, I I like get to live with it…"*

Theme 2: Perception of T1D is negative

Participants expressed negative feelings in response to T1D. When they thought of food constraints that it caused, they felt dejected, and different from others, as they were unable to participate in social activities, which often centred on food matters such as those encountered at birthday parties and family reunions. These negative feelings led to a perception of T1D as negative. As a result, they preferred to avoid thinking about it.

Negative perception of T1D often resulted in feelings of sadness, as became clear when they related experiences of living with T1D. When asked how he experiences T1D, Bill reported: *"Um, it kinda sucks…".* Claire said that it made her *"sad,"* expanding on this to say *"only when I think about it and when there is cake is around."*

Participants also felt that their T1D was holding them back in school, since they had to miss out on activities due to being ill. Jane indicated the following: "… *well sometimes I get a little held back in group activities… So sometimes that's quite frustrating…"* And Frank said: "… *and sometimes it delays me and I get into trouble for that".* It is evident that adolescents with T1D face considerable emotional challenges of a great variety not shared by their peers.

The participants expressed that they **tried not to think about T1D**, as indicated above, since it evoked feelings of sadness and fear. Joy expressed her feelings around this: *"It is quite scary. I'm not used to focusing and talking about it so yeah its quite scary."* This tendency towards avoidance was also illustrated by one of Sue's utterances: *"Well, I don't think too much because then I feel like it's okay, I've accepted that I have, I have diabetes. I just have to move on and take care of myself."*

This tendency towards denial or avoidance included their understanding of T1D, since they did not think about what T1D meant beyond a medical definition. Alice said: *"I actually really don't know because like when I got it my parents just like told me and I was like ok. So, I guess I've just adapted to the word but never really thought about it."* The intrusiveness of T1D made it difficult to avoid, thus participants attempted to limit its influence on their lives where possible.

In this study, **food constraints** were found to be a major factor in participants' perception of T1D as a negative phenomenon that made them feel different, causing much frustration. Bill illustrated this when he said: *"…like kinda hard cause if you have like something nice on the table and you have salad like you have to go for the salad cause don't want my sugar to get high".* The constraint was largely perceived as negative with a view to limiting adolescents' choices regarding not only their diet but also meaningful social interactions. Joy expressed it as follows: *"… it's hard sometimes when my friends going out to parties and stuff. I can't drink that or eat that stuff like that, so sometimes it's hard."* This sentiment often prevented participants from engaging in the normal process of exploring life.

They furthermore regularly engaged in risky food behaviour by consciously eating foods outside of their dietary plans. These experiences were perceived as positive, because they allowed them to feel that they were just like everyone else, resulting in moments of normality. In this respect, Frank said:

"My parents told me not to eat certain foods, my grandparents don't actually care that I have diabetes, so they go wild every time when I go there to eat whatever I want to. Whatever I haven't eaten in a long time. I can just. Have fun, basically."

However, it should be noted that friends would often assist the participants to avoid temptation, as has been discussed under the rubric of the first theme above. For example, Frank indicated that friends would "…*go get another bowl bowl of cereal and then pour the right amount or they pour it for me."*

Theme 3: Management of T1D is motivated by fear

All the participants experienced fear of future medical complications if they did not manage T1D well. Jane said: *"…high blood sugar can be quite worrying, cause I've heard of people getting um DKA and going to hospital and some, some um don't make it."* This fear, however, served as the main motivation to manage their T1D, given that participants directed their fears to ensuring that they would not experience these medical complications. John expressed this inference when he said:

> *"Um, I think when you look at the severity of the long-term effects, I think it kind of is a it's a motivation to manage it better seeing what it can do to you and what a danger it is. I think if I didn't know as much I wouldn't I wouldn't manage it as well but knowing the consequences of unmanaged diabetes it helps me manage quite a bit."*

Participants imparted that they were constantly reminded of medical complications that would arise if they did not manage their diabetes well; as Bill declared:

> *I didn't do my sugar that much my mom says like they will cut off your legs you won't be able to walk you you'll like your body won't last longer. So, the like now I've started doing my sugar because I wanna live my full life and I don't wanna get like cut off or something."*

Despite this, some participants still felt resigned to merely continuing to experience complications, since they felt they were unable to manage their T1D now. Joy expressed this as follows: *"… I know what's going to happen in a few years. I feel fine now, but I know what's coming. So, it's a scary thing", and* continued by saying, *"Yeah, I just don't want to die before my parents my grans because didn't listen when I was a teenager."*

Theme 4: Living with T1D leads to a sense of being different

Adolescence is a period marked by attempts to find a place in society, a sense of belonging, and a personal identity. However, adolescents with T1D must negotiate its successful management, which often leads to them feeling like they are different. These feelings were mitigated through participation in sports. Sport plays an important role in assisting adolescents in finding their role in society, making them feel normal and socially competent.

The participants perceived themselves as being different because of their T1D care plans. This difference was experienced in a variety of contexts among which the school environment being the most salient. Frank said: *" I was the only one in my age group and stuff like that was quite hard to deal with because knowing that nobody else is going to miss the stuff that I am going to and that there was no one I could ask for help and stuff."* Alice expressed herself around this by saying: *"Like I kind feel like the odd one out since everybody you know does certain stuff and then if my blood sugar is low then I have to sit you know in a corner…"* She continued by indicating the following: *"Sometimes, um I do sometimes feel left out…"* These experiences often left participants feeling isolated and left out.

Such feelings of difference where exacerbated when participants were teased at school due to suffering from T1D. Jane said: *"Lots of people used to make fun of me they said I was a robot because I had my injections and all that and they thought that was like contagious so that they didn't want to play with me…"* To escape the teasing, Jane changed schools, relocating to one with a more inclusive environment, since other adolescents with T1D were present there, allowing her to feel more normal. Other participants indicated that they did not tell their peers about their illness out of fear for

being teased. Bill said: "… *I know if I go tell it to everyone they will like go and say things about me, if they get angry with me. So, I don't tell everyone".*

Some of the participants experienced sport as vital to not only managing their T1D but also when it came to fitting in with their peers. They experienced it as a space where they could feel less different and thus engaged in multiple sporting activities. Bill reinforced this notion when he said: *"Uh, I do swimming, I do swimming, cricket, soccer, uh and hockey…"* Given the range of activities that Bill listed, there appeared to be multiple attempts to be part of their peer group, which would give them a sense of belonging over and above the issues around their illness. Frank expressed it as follows: "*Sports is my way out basically. So, playing sport makes me forget about everything else. Makes me feel normal and..."* The adolescents also use sport to prove that they were capable of activities similar to those without T1D, and thus normal. Joy said: *"I usually tell everyone that because I'm a diabetic it doesn't mean that I'm, I can't do this, I can't do that it's just empowers me to do more. And I'm just like who cares if I have got diabetes…"*

Discussion

This study aimed to explore the illness perception among adolescents with uncontrolled T1D and how this perception contributed to their management of the illness. Consistent with current literature, negative perceptions of T1D were found to be linked with lower metabolic control.

Adolescents viewed managing T1D as challenging, which confirms the findings of Davidson, Penney, Muller, and Grey (2004) that adolescents perceive diabetes as a difficult and demanding condition. According to Hagger and Orbell (2003), illness perception may originate from how an individual evaluates their personal experiences of the condition. In the present study, participants' personal experiences of T1D were not only as challenging as has thus been suggested by these scholars. The moreover struggled to manage their T1D well, exacerbated by the belief that they could only control part of it themselves as well as the immense pressures involved in successful management of the illness. This led to some participants giving up on such management, as they felt that they were not able to manage it perfectly.

Adolescents who perceived enjoying greater control over their condition experienced better adherence to their regimes (see Fortenberry et al., 2014) and better metabolic control (see Harvey & Lawson, 2009). Hanna and Decker (2010) found that assuming responsibility for self-care is crucial to successful management of the illness. This is a logical conclusion as, without self-care, the self-management and coping with T1D would be hindered. However, when the participants were unable to meet their management targets, they internalised their failure, resulting in negative self-talk, which affected how they viewed T1D, themselves, and their capabilities. They were resigned to accepting their fate in life, feeling like they just had to "live with it". This finding is in contrast with a study by Jonker et al. (2018): their participants perceived acceptance of their fate optimistically. Additionally, as adolescents believe they are invulnerable, they tend to adopt risky behaviours preferring to live in the here and now (Guthrie et al., 2003), thus further complicating self-management of the chronic condition.

These risky behaviours were predominantly focused around their strict diets. All the participants discussed the challenges experienced adhering to these. Consider that food consumption is an integral part of socialisation (Fox, 2003), which is inhibited by the demands entailed in keeping to a strict diet the management of T1D necessitates. Their dietary restrictions were viewed as negative, since they limited their social interactions not only making them feel different, but like outsiders. This confirms research by Commissariat, Kenowitz, Trast, Heptulla, and Gonzalez (2016), who found that adolescents experience T1D and its management negatively with a view to impacting their sense of normalcy and social relations. Further, Marshall et al. (2009) found that adolescents living with T1D perceive themselves as different, culminating in the pursuit for "normal". Pursuing social activities such as sport not only made the participants feel less different, but served as a means to prove that they were just as capable as their "normal" peers, as mentioned.

Despite contrasting evidence regarding support from family, friends, and peers support in existing literature, it was found that adolescents rely on support to manage their T1D. Watkins et al. (2000) found that social support predicted well-being. Additionally, many studies indicate that a lack of parental support was associated with uncontrolled T1D (Borus & Laffel, 2010; Sander et al., 2010; Scholes et al., 2013). Parental control is on the other hand associated with better adherence over time (Fortenberry, 2014). However, in this study most of the participants felt supported by their families,

and mothers in particular were found to exert considerable control over management, while the adolescents still suffered from uncontrolled versions of T1D. The present study could not determine and evident reason for this. However, this could be associated with challenges parents experience when they try to strike a balance between holding back and providing support (Spencer, Cooper, & Milton, 2010). This balance is difficult to obtain, since adolescence is marked by higher HbA1c levels along with increased demands for autonomy. Many participants indicated that they wanted to take on more responsibility regarding their T1D management, but where anxious about having the necessary skills and knowledge to successfully manage it.

The participants indicated that they had little knowledge and understanding of T1D beyond the medical world. This slant towards medical understanding suggests that the adolescents have not yet internalised or embraced living with T1D, thus tending not to not experience T1D as part of their personal identity. Additionally, by refusing to think about T1D and how they perceive it, participants limit their ability to accept living with T1D, and perceive it as anything but negative, since they only think about it when they face difficulties. These patterns of avoidance and disengagement are associated with poorer metabolic control (Jaser & White, 2011). They are also linked with problems in social competency (Jaser & White, 2011), which make adolescents who live with T1D vulnerable (Jacobson et al., 1997), because they may not adhere to their management protocols such as injecting insulin when they are with peers (Thomas, Peterson, & Goldstein, 1997), nor disclose their diagnosis out of fear for rejection (Hains, Berlin, Davies, Parton, & Alemzadeh, 2006). The present study confirmed these findings.

As has been indicated, Jonker et al. (2018) found that adolescents embraced living with T1D and were thus able to have positive illness perception about it, and successfully manage it. Similarly, Watkins et al. (2000) found that a better understanding of T1D is associated with fewer negative feelings associated with T1D as well as a more positive attitude towards it. A better understanding of T1D is also associated with improved diet adherence (Watkins et al., 2000). Adolescents can be empowered to manage their T1D better by providing them with continuous health education from the onset of the condition, while limiting threatening messages.

Parents'- and medical attempts to support adolescents by using threat messages, although motivating at times, do not translate into improved management of T1D. The adolescents believe that, due to the difficulties of managing T1D, they would still suffer from T1D-related complications in the future regardless of threats. Ultimately, the threat reminders they receive serve to reinforce their belief that they are incapable of managing their T1D effectively. Lawson et al. (2010) indeed conducted research that indicates that threat messages received are often perceived as negative. Additionally, Edgar and Skinner (2003) found that the perceived impact of T1D and not the perceived threat to health, nor the management of T1D to prevent complications, predicted more positive management outcomes. Ultimately, the use of threat messages to motivate management in adolescents may have a negative impact on illness perception (Edgar & Skinner, 2003; Leventhal et al., 1997). This negative perception is linked with higher HbA1c levels (Wisting et al., 2016). This is a salient point, not least since Lawson et al. (2008) found that these perceptions remain consistent over time, and that the manner in which health threats are communicated, and indeed how they are perceived, is a better predictor of illness perception than personality factors.

Conclusion

This study demonstrated that adolescents with uncontrolled T1D assume the belief that it is difficult to manage, which is internalised as personal failure, leading to largely negative perception of the illness. Ultimately, good versus bad management is predicated upon targets that are usually externally imposed (Watts, O'Hara, & Trigg, 2010). Adolescents internalise failure to meet these targets as a personal flaw, perpetuating the belief that managing T1D is difficult and not in their control. By focusing on T1D management as predicated strictly on diet and medication adherence, we therefore unfortunately lose sight of the individual, while successful management of T1D relies far more than him or her.

This study provides new information about the illness perception among adolescents with uncontrolled T1D in South Africa, as well as insight into how these perceptions affect management. The findings will prompt health care professionals to look beyond dietary and medication adherence, thus to include psychological factors such as illness perception when implementing diabetes care plans and designing interventions. It also lays the foundation for future research around what differentiates

well-controlled and uncontrolled T1D, and may ultimately lead to developing intervention strategies that will assist people living with T1D to manage it successfully.

Limitations of the study

The generalisability of this study is limited due to the use of non-random purposive sampling, which limited demographic variability. This demographic variability may limit the scope of the study but not the transferability of the study. Notwithstanding these limitations, the present study adds to the body of knowledge contained in literature on adolescents who have found adhering to management protocols challenging.

Conflict of interest

There are no conflicts of interest.

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Section 3: Conclusion, limitations, and recommendations

3.1 Introduction

This chapter will present a brief overview of the aim of the present study. It includes a conclusion and discussion of the limitations of the present research as well as recommendations for further research. This chapter will conclude by briefly discussing the researcher's reflexivity around the process of completing the present study.

3.2 Research aims of the study

This study aims to explore the illness perception among adolescents with uncontrolled T1D, by focusing on two research questions.

- First, what is the nature of illness perception among adolescents with uncontrolled type 1 diabetes?
- Second, how do these illness perceptions contribute to diabetes management?

3.3 Conclusion of the findings

This study is the first to explore, with a view to South Africa, the illness perception among adolescents with uncontrolled T1D, and how these illness perceptions contribute to the management of T1D. Eight semi-structured interviews were conducted, although data saturation occurred after the fifth interview. Based on the raw data gathered during these interviews, four dominant themes were identified.

Theme 1: Management of T1D is challenging

The majority of participants found the management of T1D challenging. They struggled to cope with the demands of successful management of T1D, finding it difficult and thus, at times, gave up on managing their T1D. The pressures of trying to manage their T1D perfectly, was overwhelming. This was aggravated by social demands in the school environment, as participants just wanted to fit in, and not have to worry about managing their T1D. When management of T1D was sub-optimal, they started

to internalise this as a personal failure, believing that managing T1D should be easy; but this just made it even harder. They felt they could control only part of their T1D management themselves, such as adhering to medication protocols, leaving them to feel even more like failures. Ultimately, participants felt that they were doomed to live with T1D and the associated complications. Social support received from family, friends, and peers was their only respite, and played a significant role in managing their T1D.

Theme 2: Perception of T1D is negative

The participant's perception of T1D was predominantly negative. They did not embrace living with T1D, and preferred not to think about it. They also reported having little knowledge about T1D beyond a medicalised understanding. By refusing to think about T1D and how they perceived it, participants limited their ability to perceive T1D as anything but negative.

Their strict diet was considered the most challenging aspect among management protocols that they had to adhere to. They felt that their strict diet limited their social interactions making them feel different. At times they tried to achieve brief moments of normality by engaging in risky behaviours with friends and extended family regarding dietary choices.

Theme 3: Management of T1D is motivated by fear

Participants frequently spoke of their fears around future complications. These fears motivated them to manage T1D better, as they did not want to experience these first hand. However, this motivating factor did not translate in better glycaemic control, leading to a belief that they would eventually suffer from T1D related complications regardless of their efforts. This reinforced internalisation of their sense of failure where they saw the struggle as a personal shortcoming instead of viewing it as part of normal challenges adolescents face when learning how to manage T1D. This problem was aggravated by constant reminders from family, friends, peers, and various medical personnel of complications when they did not meet their management goals.

Theme 4: Living with T1D leads to a sense of being different

Participants experienced themselves as different from their friends, family, and peers due to constantly having to manage T1D. This difference was not viewed in a positive light, as they felt that managing T1D hindered their ability to live their lives to the fullest. These experiences made participants feel isolated, especially at school. This was aggravated when they were teased at school because of their diagnosis, making these adolescents hesitant to disclose their diagnosis, thereby limiting a possible extended social support network. Most participants played multiple sports, as it made them feel less different. They also felt that playing sport proved to their friends and peers that they were just as capable as everyone else. This resulted in increased pressure to perform, but if this were not managed well, it would exhaust their limited resources even further.

The findings of this research project embody achieving its aims, namely to explore the illness perception among adolescents with T1D and how it influences management of the illness.

3.4 Limitations of this study

Despite the achievement of the research aim, potential limitations of this study should be considered. First, its generalisability is potentially limited by the use of non-random purposive sampling, which limits demographic variability. This demographic variability may limit the scope of the study but not the transferability of the study. The chosen demographic was used due to recruitment of potential participants taking place at the CDE in Johannesburg. This was done to limit treatment variability between participants. As has been mentioned, the present study only included adolescents between the ages of 12-18 years, who suffered from T1D with HbA1c levels of 7.5% or above. Despite having access to more participants than studies conducted into adolescents with well-controlled T1D, recruitment was challenging. It took over a year to recruit eight participants. This was largely due to the emotional challenges parents faced around their child suffering from uncontrolled T1D. That is, during adolescence parents take a great deal of responsibility for the management of their child's T1D, and when it was not managed well, they might have perceived it as a personal failure. A different research project title may therefore have aided in recruitment.

As mentioned, the transferability of this study was potentially limited by the small sample size of eight participants. However, Denscombe (1998) argues that, despite the uniqueness of each case, a small sample can still enjoy transferability to a larger group. Additionally, as data saturation was reached after the fifth interview, it is unlikely that any new data would have occurred, especially since the additional three interviews yielded no new data. The positionality of the participants may also have limited the transferability of the findings. Six of the eight were white, and the entire group was from an urban area with a moderate to high socio-economic status, as mentioned before. Their socio-economic status afforded them greater access to private treatment facilities such as the CDE in JHB. The majority of people in South Africa, however, are unlikely to have access to these private treatment facilities due to socio-economic factors.

Finally, the application of only one research method might entail a further limitation. Future studies may benefit from using more than one research method for data generation as well as by employing triangulation.

3.5 Recommendations for further research and practice

This study provides insights into how illness perception among adolescents with uncontrolled T1D in South Africa impact T1D management and how this, in turn, impacts adolescents' psychological well-being. It contributes to the existent body of knowledge contained in literature on adolescents who have found adhering to diabetes care plans challenging. The findings of research such as that of the present study can assist health care professionals in looking beyond dietary and medication adherence, allowing for the inclusion of psychological factors such as illness perception when supporting adolescents and during the implementation of diabetes care plans and around designing interventions. This can be achieved through additional educational programmes that highlight psychological well-being, which will ultimately facilitate the incorporation of T1D into the adolescents' personal identities, allowing them to take greater ownership of the management of T1D as well as the reaching the belief that T1D is compatible with living a normal, healthy life. This incorporation may also be enhanced through open dialogue between the adolescents and their caregivers and/or medical personnel about the adolescent's associated concerns and fears. The dialogue may be more fruitful when the caregivers/

medical personal limit threatening messages to encourage adherence. This openness will also aid in a greater understanding of T1D thereby limiting the intrusive nature of T1D. Additionally, this research highlights the need for adolescents and their caregivers to engage with a dietician in order to find suitable alternatives to restricted food, especially during social gatherings, which will allow for more meaningful social interactions and fewer engagements with risky food behaviour. This may reduce the adolescent's sense of being different and thus ultimately their negative perceptions associated with T1D.

Future research on well-controlled T1D is necessary to improve the understanding of diabetes and the impact these perceptions have on the management of T1D. Intervention programmes for these adolescents should also be researched. In line with this, research can be conducted to further contrast illness perception among adolescents with controlled and uncontrolled T1D, which may give additional insights into the practical application of this research. For future research, it is recommended that additional studies be done regarding the illness perception among adolescents in a variety of contexts and within variable demographics. A further possibility for future research could be to also include the parents of adolescents. This could give greater insight into the illness perception among adolescents, as parents play a vital role in the day to day management of their adolescents' T1D. It would also enhance the understanding of the effect of diabetes on the family. Finally, due to the prevalence of diabetes, future studies could examine the additional practical implications of the present project, such as directing policies and their implementation.

3.6 Researcher reflexivity

As with any other research, acknowledgement of reflexivity around the research process is crucial. It is important to acknowledge that my analysis in this paper was shaped by my subjective experiences and educational background. Therefore, processes such as ensuring trustworthiness are crucial to give credence to the conclusions drawn within the project. Willig (2008) argues that the use of the personal reflections, that is, being aware of how personal subjectivity shaped this research, give credibility to a project such as the present one.

My interest in health psychology and in particular diabetes was sparked by my mother's diagnosis of type 2 diabetes five years ago. Therefore, this research process was extremely rewarding for me as a researcher, mental health practitioner, and on a personal level, as I have experienced first-hand how difficult managing diabetes and the related emotional turmoil can be. My previous research in health psychology provided me with insights not only into the psychological factors of conditions /diseases but also the medical factors that play a role around this. Additionally, due to my previous academic work on diversity (MA Diversity studies), I was familiar with the challenges encompassed by feelings of difference, and how these affect perceptions and motivation.

The most rewarding and challenging part of the research process was the interview process. Participants' willingness to openly discuss their day to day experiences and perceptions of living with T1D was admirable. It was rewarding to give them feedback in the form of posters via email. It also ensured that the data generated were accurate by means of member checking. The interview process was challenging, as recruitment was slow, which led to a period of low motivation. However, the completion of this project has provided me with a valuable learning experience and it has motivated me to pursue my dreams, despite the difficulties entailed in achieving them. Ultimately, I am grateful for the opportunity to continue contributing to an understanding of adolescence and health psychology. I would like to conclude with a quote by Foucault (2004):

> *...if you are not like everybody else, then you are abnormal, if you are abnormal, then you are sick. These three categories, not being like everybody else, not being normal and being sick are in fact very different but have been reduced to the same thing.*

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A. Ethical approval certificate: Current study

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Fax: (018) 299-4910
Web: http://www.nwu.ac.za
Research Ethics Regulatory Committee
Tel: 018 299 4849
Email: Ethics@nwu.ac.za

ETHICS APPROVAL CERTIFICATE OF STUDY

Based on approval by the **Human and Health Research Ethics Committee (HHREC)** on **22-Nov-2017** after being reviewed at the meeting held on **22-Nov-2017**, the North-West University Research Ethics Regulatory Committee (NWU-RERC) hereby approves your study as indicated below. This implies that the NWU-RERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study Title: Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis

Study Leader/Supervisor: DR E DEACON

Student: SCHAVAUGHN SANDRINE LESAGE

Ethics Number:

NWU-HS-2017-0167

Application Type: New Sub-study Application

Commencement Date: 24-Nov-2017 Expiry Date:23-Nov-2020

Medium risk (greater than minimal risk)

Special conditions of the approval (if applicable):

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The study leader (principle investigator) must report in the prescribed format to the NWU-RERC via HHREC:
  - annually (or as otherwise requested) on the progress of the study, and upon completion of the project
  - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
  - Annually a number of projects may be randomly selected for an external audit.
- The approval applies strictly to the proposal as stipulated in the application form. Would any changes to the proposal be deemed necessary during the course of the study, the study leader must apply for approval of these changes at the HHREC. Would there be deviated from the study proposal without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-RERC via HHREC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-RERC and HHREC retains the right to:
  - request access to any information or data at any time during the course or after completion of the study;
  - to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.
  - withdraw or postpone approval if:
    - any unethical principles or practices of the project are revealed or suspected,
    - it becomes apparent that any relevant information was withheld from the HHREC or that information has been false or misrepresented,
    - the required annual report and reporting of adverse events was not done timely and accurately,
    - new institutional rules, national legislation or international conventions deem it necessary.
- HHREC can be contacted for further information or any report templates via Daleen.Claasens@nwu.ac.za or 018 210 3441.

The RERC would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the RERC or HHREC for any further enquiries or requests for assistance.

Yours Sincerely

Prof. Refilwe Phaswana-Mafuya

Chair NWU Research Ethics Regulatory Committee (RERC)

B. Informed consent form for legal guardians of adolescents

NORTH-WEST UNIVERSITY ®
YUNIBESITI YA BOKONE-BOPHIRIMA
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29 November 2017

Humanities and Health Research Ethics Committee
HHREC
2016 -11- 29

C. van Eeden.

PARTICIPANT INFORMATION LEAFLET AND PERMISSION FORM FOR PARENTS/GUARDIANS OF ADOLESCENTS

TITLE OF THE LARGER RESEARCH PROJECT: Psycho-social variables in adjusting to diabetes management in adolescents and young adults (NWU-HS-2015-0111)

TITLE OF SUB-STUDY: Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis (NWU-HS-2017)

RESEARCHER: Ms. Schvaughn Lesage

ADDRESS: North-West University, Vaal Triangle Campus, Hendrick van Eck Blvd

CONTACT NUMBER: (016) 910 3414

Your child is being invited to take part in a research project exploring diabetes management in adolescents and young adults. Within the larger project (*Psycho-social variables in adjusting to diabetes management in adolescents and young adults (NWU-HS-2015-0111)*), a number of sub-studies are conducted, including this sub-study titled *Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis (NWU-HS-2017)*.

We would greatly appreciate your assistance. Please read through the information provided below which will explain the details of this project. You are welcome to ask the researcher any questions about any part of this project that you do not fully understand. It is important

This document is an adapted version of the one used by HREC, Potchefstroom Campus (HREC General WICF Version 2, August 2014).

that you are satisfied that you clearly understand what this research is about and how you could be involved.

As parent/guardian of an adolescent, we as researchers see you as a co-participant. We want you to be comfortable with the research process and all it entails. Your child's participation in this study is completely voluntary. If you allow your child to be part of the study, you may change your mind and withdraw your approval at any time without any consequences. In addition to your permission, your child will also be asked if he or she would like to take part in this project. Your child may decline to participate or may withdraw from participation at any time. Withdrawal or refusal to participate will not affect your child negatively in any way.

The larger study (NWU-HS-2015-0111), as well as this sub-study have been approved by the **Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2017)** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health Research Ethics Council. Please note that the research ethics committee members or relevant authorities may inspect the research records to make sure that the research was done in an ethical manner.

What is this research study all about?

- *This study will be conducted through the CDE in Houghton and Parktown, specialising in paediatric diabetes. The research involves an interview with your child. You are welcome to attend the interview if you and your child prefer it, however it is not allowed to communicate with or assist the child in completing the interview process. The researcher has been trained to use the method mentioned.*
- *The researcher cannot definitely specify how many participants will be involved in the interviews. It is predicted that approximately fifteen to twenty participants will be interviewed.*
- *This research project has two objectives, firstly to explore the illness perception of adolescents with uncontrolled type 1 diabetes and secondly to explore how this illness perception aids in managing diabetes well. In order to achieve these objectives, as well the objectives of the larger study, the following questions will be asked: Can you tell me about your experience in terms of managing your diabetes? How did your life change after being diagnosed with diabetes? How do you manage your diabetes? How does your understanding of diabetes influence how you manage it? How does managing diabetes impact your daily life? How does support from family and friends influence how you manage your diabetes? How do you make sense of living with diabetes?*

Why have you been invited to participate?

- *You have indicated that you and your child would be interested in taking part in the project. Your medical practitioner forwarded us the information leaflet you completed at your previous visit at the CDE, or you have indicated your willingness to participate in replying to an e-mail address. You have already received a screening phone call, followed by an e-mail with this form attached. Also note that we have obtained permission for the CDE (Houghton and Parktown) to conduct this research.*

- *Your child has also complied with the following inclusion criteria: he/she is willing to participate in an interview in either English or Afrikaans, he/she is between ages 12 and 18, was diagnosed with diabetes more than 12 months ago, is a patient at the CDE (Houghton or Parktown) and has an HbA1C of 7.5% or more over the last 12 months.*
- *Your child will be excluded if he/she suffers from any other chronic illness or is currently receiving psychotherapy.*

What will your responsibilities be?

- *Your child will be expected to participate in an interview (accompanied by their legal guardian if they prefer so). The duration of the interview will be approximately 60 minutes. If your child does not wish to answer any of the questions during the interview, he/she may say so and the interviewer will move on to the next question. With your permission, we would also like to audio-record the interview. The interview will take place in a suitable venue at the CDE, before or after your regular appointment with the diabetes educator (depending on preference).*
- *We would also like to include your child's HbA1C results in this study as this will provide us with an objective measure of how your child's diabetes is managed. We will, however, not do the blood test ourselves, but will obtain the results from your medical record at the CDE. This will only happen once you have given your written informed parental permission.*
- *Your child will also be invited to take part in an intervention at a later stage. As we currently do not have more information on the kind of activities or details about your child's responsibilities in the intervention phase, a separate parental permission and adolescent consent form will be compiled and discussed with you and your child before the intervention starts. This intervention will be completely voluntary, and you or your child are free not to take part in the intervention, should you decide so.*

Will you benefit from taking part in this research?

- *The direct benefits for you as a participant will probably be the following:*
  - *While your child is thinking about the questions, he/she may come to a better understanding of diabetes management. This insight may positively influence how your child's diabetes is managed.*
  - *After participation in the interview, your child will receive an information leaflet on diabetes management which could further assist him/her in managing his/her diabetes well.*
  - *As part of thanking your child for taking part in this study, we will give your child a certificate. After the interview with the researcher, your child will receive a sticker to paste on the certificate. Receiving these personalised tokens of appreciation only awarded to those living with diabetes taking part in the study, they may start appreciating that they belong to a special group and that their opinions are important. Receiving the sticker for participation could motivate them to manage their diabetes even better.*
  - *The next phase of this project involves the development of interventions to improve diabetes management and your child will be invited to take part in these interventions as well.*
  - *The immediate therapeutic benefit for your child will be that he/she receives an individualized visual presentation of the themes in their interview,*

This document is an adapted version of the one used by HREC, Potchefstroom Campus (HREC General WICF Version 2, August 2014).

specifically focusing on the strengths showed in the interview. Your child will have the option to receive the feedback in person, or telephonically. This feedback session will also be used to check if the researcher understood your child's comments correctly, and as such will also be audio-recorded.

- *The indirect benefit will probably be:*
  - *The research community, both medical and behavioural sciences, could benefit from a better understanding of the experiences of diabetics.*
  - *The cost of not managing diabetes well could be reduced, resulting in savings for individuals (less hospitalization, medical expenses, less time off from school), the workplace (less days off from work, absenteeism, medical aid expenses, loss of productivity) and the community at large (more healthy members that can contribute to improving society).*

Are there risks involved in your taking part in this research and how will these be managed?

- *The risks in this study, and how these will be managed, are summarised in the table below:*

Probable/possible risks/discomforts	***Strategies to minimize risk/discomfort***
Because your child may be spending approximately 60 minutes participating in the interview, it is possible that he/she can become tired.	The researcher facilitating the interview will give your child a 15-minute break about half way through the interview to enjoy some refreshments (a low carb snack with bottled water).
Because the researchers will ask your child questions about their diabetes management, they will need to think about how they manage their diabetes, and this may make them feel uncomfortable.	Upon completion of the interview, we will ask your child whether he/she experienced any psychological distress or discomfort while taking part in the research. If they indicate that they did, a follow-up telephone call (by Dr Deacon) will follow the next day to see if they are still feeling the same way. If not, they will be thanked for their participation and wished well. If they are still distressed, a session will be booked with Rosemary Flynn (a registered clinical psychologist affiliated with the CDE) for them to discuss their experience and debrief them. These arrangements will be made by the research team.
Although we do not expect that the research process will have an impact on your child's health, having diabetes implies experiencing low and high blood glucose levels unexpectedly and this may happen while your child is busy	If your child feels ill at any time during the interview, he/she needs to inform the researcher. Your child's blood glucose will be tested and then corrected if necessary.

with the interview.	
We will be using your child's HbA1C results (done every three to six months), which indicates how well their diabetes is managed. We will, however, not do these tests ourselves, but will obtain the results from your child's medical record at the CDE with your permission.	We will not be drawing blood or doing any other tests physically hurting your child. We will ask your written informed parental permission to retrieve the information from your child's record at the CDE.
In this study we will be asking your child how well he/she manages the diabetes, which is also measured by the HbA1C test. Although we will not be talking about this result, your child may be concerned that we will judge him/her based on that result, or think less of them based on how well (or not) they manage their diabetes.	Living with diabetes can be difficult and we will treat every person that is willing to share their experience, with respect. We will not discriminate against any person based on how well (or not) they manage their diabetes. If at any stage you or your child feels uncomfortable talking about your feelings, please let the researchers know so they can help you identify a psychologist in your region and arrange an appointment for you and/or your child.
Living with diabetes may cause your child to feel that he/she is different from their friends and that they do not belong in the same group as their friends.	As part of thanking your child for taking part in this study, we will give your child a certificate. After sharing their diabetes management experiences with us during the interview, we will give them a sticker to paste on the certificate. Receiving this may encourage them feeling that they belong to a special group and that their opinions are important.
Living with diabetes you or your child may be worried that people learn about their diagnosis and start treating him/her differently.	We will meet with you and your child at the place where you normally receive your treatment (CDE Houghton or Parktown), ensuring that you and your child feel comfortable in a safe place familiar to you.
As we will be meeting with you and your child at the CDE, you may be worried about transport costs or time taken off from work or school to take part in this study.	In order to minimize transport and other costs, we will schedule the sessions with your child's normal visits to the CDE. We plan to visit the CDE during the afternoons and during school holidays to prevent your child from being away from school unnecessarily.
The researcher will be asking questions concerning your child's diabetes management and things that influence it. If it happens during the discussion that your child share situations where they	We will not be asking for information on the times when your child was harmed or neglected. If this kind of information is shared, we have a legal obligation to report abuse or harm of a minor. We will

were harmed or neglected, the researchers will have to share this information with the right people to make sure that your child is safe.	ask your child how they want to deal with it and inform them about the different things that can be done, depending on the identified event and how serious the problem is.
This study is a long-term project (5-10 years). This means that your child could be asked to participate (in an intervention) several times over the next few years.	Your child will be asked to take part (in an intervention) not more than once every two years. Your child also, at any time, has the right to stop participating.

- *However, the benefits (as noted) outweigh the risks.*
- *Should we learn, in the course of the research, that someone is harming your child, or that you or your child is intending to harm someone, we then have to tell someone who can help you and/or your child or warn the person you or your child are intending to harm.*

Who will have access to the data?

- *Anonymity (that is, how your results will be linked to your identity) will be managed by providing each participant with a code that will only be used for your information. As this is a long-term project, this code will be used every time your child takes part in a phase of the project. This code will be allocated to your child once you (as the parent/legal guardian) have given written informed parental permission, followed by your child's written consent. Only the signed parental permission and adolescent consent forms will identify you and your child and they will be stored in a cabinet separate from the data.*
- *Confidentiality is the way we ensure that we will protect the information we have concerning you and your child. During the interviews, only you as parent/legal guardian (if preferred), your child and the researcher will be present. The information gathered will be linked to your child's individual code. The researchers will also make sure that in recording the data, only your child's given code will be used, and references to you or your child's name or any other identifiable details will be removed. Reporting of findings will be anonymous by only referring to your child's participant code.*
- *As this is a long-term project, data will be stored for a minimum of 10 years. All documentation will be securely stored in locked rooms and will then be destroyed by shredding it. The electronic data (e.g. datasets) will be stored on a password protected computer and will then be destroyed by deleting it from the computer in question.*
- *Audio-recorded data will be sent to a transcriber who will sign a confidentiality clause (i.e., this person will not be allowed to talk to anyone about any aspect of the data). The data will then be erased from the recorder as soon as it's been transcribed on a password-protected computer. All co-coders will sign confidentiality clauses.*
- *Only the members of the research team will have access to the information your child provide. Although we work closely with the CDE in Houghton and Parktown, no member of the CDE will have access to the data.*

What will happen to the data?

On the completion of the research, the research results may be used for publications in books, journals, and websites or for conference papers or presentations. In such instances, you child's identity will not be revealed. Should we use a quote from your child's interview, we will ensure that the details are changed to make it impossible to identify your child as the source of information.

As this is a long-term study, the data will be re-used by members of this research group, affiliated with the NWU, to determine patterns by doing more analysis on it and comparing it with previous results.

Will you be compensated for taking part in this study and are there any costs involved?

You will not be paid for partaking in the study. However, your child will receive a bottle of still water and a low-carb snack during the course of the interview. There will be no costs involved for you if your child does take part. We will schedule the sessions with your child's normal visits to the CDE.

How will you know about the findings?

- As this is a long-term project, participants and/or parents/legal guardians will receive (preferably via e-mail) an annual progress report, including the main findings thus far, as well as further opportunities for participation. Posters containing the main findings will also be displayed at the CDE in Houghton and Parktown.
- Even though no feedback on your child's personal interview results will be discussed with you or your child, the researcher will make telephonic contact with your child to ascertain whether the analysis of your child's interview is a true reflection of what your child intended to convey to the researcher.

Is there anything else you should know or do?

- You can contact Dr Elmari Deacon at elmari.deacon@nwu.ac.za or (018 299 1728) if you have any further questions or encounter any problems.
- You can contact the chair of the Humanities and Health Research Ethics Committee, Prof Chrizanne van Eeden (016 910 3441 or Chrizanne.VanEeden@nwu.ac.za) if you have any concerns or complaints that have not been adequately addressed by the researcher. You can also contact the co-chair, Dr Marita Heyns (016 910 2581 or Marita.Heyns@nwu.ac.za). You can leave a message for either Chrizanne or Marita with Ms Daleen Claasens (016 910 3441).
- You will receive a copy of this information and parental permission form for your own records.

Declaration by parent/guardian

By signing below, I ……., parent/guardian of ……. agree that my child can take part in a research sub-study titled: **Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis,** provided that they give written adolescent consent, following my parental permission.

I declare that:

- I have read and understood this information and parental permission form and it is written in a language in which I am fluent and with which I feel comfortable.
- I have been afforded the opportunity of posing questions to both the person obtaining parental permission, as well as the researcher (if this is a different person), and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and neither I nor my child has been pressurised to take part.
- I understand that my or my child's contribution (what we report/ say/ write/ draw/ produce visually) could be reproduced publically and/or quoted, but without reference to our personal identity.
- I and my child may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I and my child may be asked to leave the research before it has been completed, if the researcher feels it is in my best interests, or if we do not follow the research plan, as agreed on.
- I agree to the CDE and medical practice giving the researchers access to my child's medical records and that the HbA1C results, as reported in these medical records, may be used for this project.

Signed at (*place*) ..... on (*date*) ..... 20....

....

Signature of participant **Signature of witness**

- You may contact me again ☐ **Yes** ☐ **No**
- I would like a summary of the findings of this research ☐ **Yes** ☐ **No**

The best way to reach me is:

Name & Surname: _____

Postal Address: _____

Email: _____

Phone Number: _____

Cell Phone Number: _____

In case the above details change, please contact the following person who knows me well and who does not live with me and who will help you to contact me:
Name & Surname:

_____

Phone/ Cell Phone Number /Email:

_____

Declaration by person obtaining parental permission

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and spent adequate time answering them.

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- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

....

Signature of person obtaining parental permission **Signature of witness**

Declaration by researcher

I *(name)* ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (place) ..... on (date) ..... 20....

....

Signature of researcher **Signature of witness**

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C. Informed assent form for adolescents

NORTH-WEST UNIVERSITY ®
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
VAAL TRIANGLE CAMPUS

PO Box 1174, Vanderbijlpark
South Africa, 1900

Web: http://www.nwu.ac.za

29 November 2017

Humanities and Health Research Ethics Committee
HHREC
2016 -11- 29

C. van Eeden.

PARTICIPANT INFORMATION LEAFLET AND ADOLESCENTS CONSENT FORM

TITLE OF THE LARGER RESEARCH PROJECT: Psycho-social variables in adjusting to diabetes management in adolescents and young adults (NWU-HS-2015-0111)

TITLE OF SUB-STUDY: Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis (NWU-HS-2017)

RESEARCHER: Ms. Schvaughn Lesage

ADDRESS: North-West University, Vaal Triangle Campus, Hendrick van Eck Blvd

CONTACT NUMBER: (016) 910 3414

You are being invited to take part in a research project exploring diabetes management in adolescents and young adults. Within the larger project (*Psycho-social variables in adjusting to diabetes management in adolescents and young adults (NWU-HS-2015-0111)*), a number of sub-studies are conducted, including this sub-study titled *Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis (NWU-HS-2017)*.

We would greatly appreciate your assistance. Please read the information presented here carefully as this will explain the details of this project. You are welcome to ask the researcher any questions about any part of this project you do not fully understand. It is very important

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that you should feel comfortable taking part in the project, that you clearly understand what this research is about and how you could be involved.

Since you are an adolescent, we, as researchers, also asked your parents to read a similar document and give permission to allow you to take part in the project. Having received their written parental permission, we would appreciate it if you would also agree to take part. Your participation is **entirely voluntary** and you may refuse to be part of this project. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the research at any point, even if you had agreed to take part.

The larger study (NWU-HS-2015-0111), as well as this sub-study (NWU-HS-2017) have been approved by the **Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health Research Ethics Council. Please note that the research ethics committee members or relevant authorities may inspect the research records to make sure that the research was done in an ethical manner.

What is this research study all about?

- *This study will be conducted with the permission of the CDE in Houghton and Parktown. The project will consist of an interview which will require of you to talk to a researcher. Your parents/legal guardian may be present during the interview if you want someone there. The researchers have been trained to use the method mentioned.*
- *The researchers are not at present certain how many participants will be involved in the interviews, but they predict that approximately fifteen to twenty participants will be interviewed.*
- *This research project has two objectives, firstly to explore the illness perception of adolescents with uncontrolled type 1 diabetes and secondly to explore how this illness perception aids in managing diabetes well. In order to achieve these objectives, as well the objectives of the larger study, the following questions will be asked: Can you tell me about your experience in terms of managing your diabetes? How did your life change after being diagnosed with diabetes? How do you manage your diabetes? How does your understanding of diabetes influence how you manage it? How does managing diabetes impact your daily life? How does support from family and friends influence how you manage your diabetes? How do you make sense of living with diabetes?*

Why have you been invited to participate?

- *You and your parents have indicated that you would be interested in taking part in the project. Your medical practitioner forwarded the information leaflet which your parents/legal guardian had completed at your previous visit at the CDE to us, or you have forwarded your e-mail address indicating that you are interested in taking part in the research. Your parents have already received a phone call in which they indicated that they/you will be interested in being part of this project, followed by an e-mail with this form attached. Also note that we have obtained permission from the CDE practice (Houghton and Parktown) to conduct this research.*
- *The reasons why you were selected to take part in this research project are: you are willing to conduct the interview in English or Afrikaans, you are between ages 12 and*

18, were diagnosed with type 1 diabetes more than 12 months ago, you are a patient at the CDE (Houghton or Parktown), and have an HbA1C of 7.5% or more over the last 12 months.

- *You will be excluded if you suffer from any other long-term illness or are currently seeing a psychologist for therapy.*

What will your responsibilities be?

- *If you agree to take part in this study, we will conduct an interview with you. The interview will take about 60 minutes to complete. Your parents/legal guardian is welcome to sit in during the interview at your request. With your permission, we would also like to audio-record the interview. The interview will take place at the CDE, before or after your regular appointment with the diabetes educator (depending on your preference).*
- *We would also like to include your HbA1C results in this study as this will give us an objective measure of how you manage your diabetes. We will, however, not do the blood test ourselves, but will obtain the results from your medical record at the CDE. This will only happen once you have given your written informed consent.*
- *You will also be invited to take part in an intervention at a later stage. Currently we do not have more information on the kind of activities and your responsibilities in the intervention phase. A separate adolescent consent form will be compiled and discussed with you before the intervention starts. This intervention will be completely voluntary, and you are free not to take part in the intervention, should you decide so.*

Will you benefit from taking part in this research?

- *The direct benefits for you as a participant will possibly be the following:*
  - *While you think about the interview questions, you may get a better insight in diabetes management, which may influence the future way you manage your diabetes and how you experience your life.*
  - *After your interview with the researcher, you will receive an information leaflet on diabetes management which could further assist you with managing your diabetes well.*
  - *As part of thanking you for taking part in this study, we will give you a certificate. After your interview with the researcher, we will provide you with a sticker to paste on the certificate. Because you will be receiving these personalised tokens of appreciation only meant for those living with diabetes and who are taking part in the study, you may appreciate that you belong to a special group and that your opinions are important. Participation could motivate you to manage your diabetes even better.*
  - *The next phase of this project involves the development of interventions to improve diabetes management and you will be invited to take part in these interventions. These interventions may possibly improve your diabetes management.*
  - *The immediate therapeutic benefit for you will be that you will receive an individualized visual presentation of the themes in your interview, specifically focusing on the strengths showed in the interview. You will have the option to receive the feedback in person, or telephonically. This feedback session will also be used to check if the researcher understood your comments correctly, and as such will also be audio-recorded.*

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- *The indirect benefit will possibly be:*
  - *The research community, both medical and behavioural sciences, could benefit from a better understanding of the influences of diabetes management on diabetics, and thus develop effective interventions that could possibly improve the management of diabetes.*
  - *The cost of not managing diabetes well could be reduced, resulting in savings for individuals (less hospitalisation, medical expenses, less time off from school), and the community at large (more healthy members that can contribute to improving society).*

Are any risks involved in your taking part in this research and how will these be managed?

- *The risks in this study, and how these will be managed, are summarised in the table below:*

Probable/possible risks/discomforts	***Strategies to minimize risk/discomfort***
Because you will spend about 60 minutes participating in an interview, it is possible that you will become tired.	The researcher doing the interview with you will give you a 15-minute break half way through the interview to have a low carb snack and bottled water).
Because the researchers will ask you questions about your diabetes management, you will need to think about how you manage your diabetes, and this may make you feel uncomfortable/sad.	Upon completion of the interview, we will ask you if you experienced any feelings of emotional discomfort or distress while taking part in the research. If you indicate that you did feel uncomfortable or distressed secondary to participating in the research project, we will call you the next day to see if you are still feeling the same way. If not, we will thank you for your participation in the research project. If you are still distressed, we will arrange one complimentary session with Rosemary Flynn (a registered clinical psychologist) who can help you work through your feelings of discomfort or distress which you experienced whilst participating in the research project.
We will be using your HbA1C results; this will indicate how well you manage your diabetes. We will, however, not be doing these tests ourselves, but obtain the results from your medical record at the CDE with your permission.	We will not be drawing blood or doing any other tests causing you physical discomfort. We will ask your written informed consent to retrieve the information from your record at the CDE.
Although we do not expect that the research process will have an impact on your health, having diabetes implies	If you feel ill at any time during the interview, you need to tell the researcher so that your blood glucose can be tested

possible low and high blood glucose levels unexpectedly and this may happen while you are participating in an interview with the researcher.	and corrected.
In this study we will be asking you how well you manage your diabetes, which is also measured by the HbA1C test. Although we will not be talking about this result, you may be worried that we will judge you based on that result, or think less of you based on how well (or not) you manage your diabetes.	Living with diabetes can be difficult and we will treat every person that is willing to share their experience, with respect. We will not discriminate against any person based on how well (or not) they manage their diabetes. If at any stage you feel uncomfortable talking about your feelings, please let the researchers know so they can help you identify a psychologist in your region and arrange an appointment for you.
Living with diabetes may cause you to feel that you are different from your friends and that you feel you do not belong in the same group as your friends.	As part of thanking you for taking part in this study, we will give you a certificate. Each time you share your experiences with us or take part in another phase of the study, we will give you a sticker to paste on the certificate. Receiving this may help you to appreciate that you belong to a special group and that your opinions are important.
Living with diabetes, you may be worried that people learn about your diagnosis and start treating you differently.	We will meet with you at the place where you normally receive your treatment (CDE Houghton and Parktown), so you can feel comfortable in a safe place you are familiar with.
As we will be meeting with you at the CDE, you may encounter transport costs to get there. There may also be time taken off from school to take part in this study.	In order to minimise transport and other costs, we will schedule the sessions with your normal visits to the CDE. We plan to visit the CDE during the afternoons and in school holidays to prevent you from being away from school unnecessarily.
The researcher will be asking questions about your diabetes management and things that influence it. If in the discussion that follows you share other situations where you were harmed or neglected, the researchers will have to share this with the right people to make sure you are safe.	We will not be asking for information on the times when you were harmed or neglected. If this kind of information is shared, the law expects us to tell the right people to secure your safety. We will ask you how you want to deal with it and inform you about the different thing that can happen, depending on what had happened, who was present and how serious the problem is.

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This study is a long-term project (5-10 years). This means that you will be asked to participate (by doing an interview and participating in interventions) several times over the next few years.	You will be asked to take part (either participate in an interview or intervention) not more than once every two years. You also, at any time, have the right to no longer participate.

- *However, the benefits (as noted) outweigh the risks.*
- *Should we learn, in the course of the research, that someone is harming you, or that you are intending to harm someone, we then have to tell someone who can help you/warn the person you are intending to harm.*

Who will have access to the data?

- *Anonymity (that is, how your results will be linked to your identity) will be managed by providing each participant with a code that will only be used for your information. As this is a long-term project, this code will be used every time you take part in a phase of the project. This code will be given to you once you have given written informed consent. This code will be indicated on the adolescent consent form, after which the adolescent consent forms will be stored in a separate place, away from the data to ensure that no link can be made between your results and identity.*
- *The treatment of confidentiality (that is, we assure you that we will protect the information we have about you) will differ in the different phases of the project. During the interviews, only you, your parents/legal guardian and the researcher will be present. The information gathered will be linked to your individual code. The researchers will also make sure that in recording the data, only your given code will be used, and references to your name or any other identifiable details will be removed. Reporting of findings will be anonymous by only referring to your participant code.*
- *As this is a long-term project, data will be stored for a minimum of 10 years. All documentation will be securely stored in locked rooms and will then be destroyed by shredding it. The electronic data (e.g. datasets) will be stored on a password protected computer and will then be destroyed by deleting it from the computer in question.*
- *Audio-recorded data will be sent to a person who will type it out word for word and this person will sign a confidentiality letter (i.e., this person will not be allowed to talk to anyone about any aspect of the data). As soon as data has been typed, it will be deleted from the recorders. The typed conversations will be stored on a password-protected computer. All the people that will be working with the data will sign confidentiality letters.*
- *Only the members of the research team will have access to the information you provided. Although we work closely with the CDE in Houghton and Parktown, no member of the CDE will have access to the data.*

What will happen to the data?

The research results from this study may be used for publications in books, journals, and websites or for conference papers or presentations. In all of this reporting, you will not be personally identified. This means that the reporting will not include your name or details that will help others to know that you had participated (e.g., your address or the name of your school).

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As this is a long-term study, the data will be re-used by members of this research group working with/at the NWU to determine patterns by doing more analysis on it.

Will you be paid for taking part in this study and are there any costs involved?

You will not be paid for taking part in the study, but you will receive a bottle of still water and a low-carb snack. There will be no costs involved for you or your parents/legal guardian. The researchers will do the interviews with your scheduled visits to the CDE.

How will you know about the findings?

- As this is a long-term project, participants and/or parents/legal guardians will receive (preferably via e-mail) a yearly progress report setting out the main findings thus far, as well as be informed about further opportunities for participation. Posters detailing the main findings will also be displayed at the CDE (Houghton and Parktown).
- Even though no feedback on your own personal interview results will be discussed with you (as the interview in itself will be a discussion of your experiences), the researcher will contact you telephonically to ascertain whether the analysis of your interview is a true reflection of what you intended to convey to the researcher.

Is there anything else you should know or do?

- You can contact Dr Elmari Deacon at elmari.deacon@nwu.ac.za or (018 299 1728) if you have any further questions or encounter any problems.
- You can contact the chair of the Humanities Research Ethics committee, Prof Chrizanne van Eeden (016 910 3441 or Chrizanne.VanEeden@nwu.ac.za) if you have any concerns or complaints that have not been adequately addressed by the researcher. You can also contact the co-chair, Dr Marita Heyns (016 910 2581 or Marita.Heyns@nwu.ac.za). You can leave a message for either Chrizanne or Marita with Ms Daleen Claasens (016 910 3441).
- You will receive a copy of this information and adolescent consent form for your own records.

Declaration of adolescent

By signing below, I .....,agree to take part in a research sub-study titled: Illness perception of adolescents with uncontrolled type 1 diabetes: A thematic analysis.
I declare that:

- I have read and understood this information and adolescent consent form and it is written in a language in which I am fluent and with which I feel comfortable.
- I have been given opportunity to question both the person obtaining consent, as well as the researcher (if this is a different person), and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I understand that my contribution (what I report/say/write/draw/produce visually) can be reproduced publically and/or quoted, but without reference to my personal identity.

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- I may choose to leave the study at any time and will not be penalised or prejudiced against in any way.
- I may be asked to leave the study before it has been completed, if the researcher feels it is in my best interests, or if we do not follow the agreed-upon research plan.
- I agree to the CDE (in Houghton or Parktown) giving the researchers access to my medical records and that the HbA1C results, as reported in these medical records, may be used in this project.

Signed at (*place*) ..... on (*date*) ..... 20....

....
Signature of participant **Signature of witness**

- You may contact me again ☐ **Yes** ☐ **No**
- I would like a summary of the findings of this research ☐ **Yes** ☐ **No**

The best way to reach me is:

Name & Surname: _____
Postal Address: _____
Email: _____
Phone Number: _____
Cell Phone Number: _____

In case the above details change, please contact the following person who knows me well and who does not live with me and who will help you to contact me:
Name & Surname:

_____
Phone/ Cell Phone Number /Email:

_____

Declaration by person obtaining adolescent consent

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time answering them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

....
Signature of person obtaining adolescent consent **Signature of witness**

This document is an adapted version of the one used by HREC, Potchefstroom Campus (HREC General WICF Version 2, August 2014).

Declaration by researcher

I *(name)* ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and spent adequate time answering them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

....

Signature of researcher **Signature of witness**

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D. Interview agenda

Interview agenda

- The researcher started by introducing herself to the participants and their guardians.
- The procedure (including digital recording and note taking) was then explained.
- The digital recording devices where set up and tested before the interview commenced.
- The participant was reassured of confidentiality and anonymity
- The participant was reminded that that their participation is voluntary and thus they can withdraw from the study until data analysis commences.
- Any questions were then answered.

Interview questions in project, with sub-study questions

Section 1

1. Can you tell me about your experience in terms of managing your diabetes?

Section 2

1. How did your life change after being diagnosed with diabetes?

2. How do you manage your diabetes?

3. (a) How do you understand diabetes?

(b) How does your understanding of diabetes influence how you manage it?

4. How does managing diabetes impact your daily life?

5. How does support from family and friends influence how you manage your diabetes?

6. How do you make sense of living with diabetes?

Possible probing questions for sub-study will follow from questions asked in the interview.

1. Tell me about your concerns about future complications of living with diabetes. (Emotional response to future complications).

2. Do you feel there is a lot you can do to manage your diabetes? (Personal control).

- After the interview questions were asked, time was provided for the participant to discuss anything they felt was pertinent to the study.
- The participant was given a certificate with a sticker, an information leaflet on T1D, and a bottle of water and low carbohydrate snack (if not provided during a break in the interview).
- The process of sharing information was discussed.
- The interview was concluded, and the participant was thanked.
- The interviewer then verified that the digital recording devices functioned as expected and the field notes were written.

E. Thematic analysis summary

Theme 1: Management of T1D is challenging	Do not manage it	**Sue:** Taking insulin at school because most of the time I get busy and something that just holds me up that I can't take my insulin." **Claire:** "I do not do it at school…" **Alice:** "…over time I forget how to do it…" **Bill:** "I'm bad with my diabetes so I don't really manage it". **Frank:** "I'm not good at taking my stuff and doing it at the right times, so that's why my sugars aren't at the place that they should be." **Joy:** "… don't do it because it's too much work and it's too much pressure on me".
	Control part of it	**Joy:** "Ugh there is not much I can do…" **John:** "…not all of it can be controlled…" **Alice:** "Um, well there is a little bit of stuff…" **Jane:** "Mm I think there's a few things you can do but it is very limited…" **Sue:** Well, I'm not sure, it depends what I do yeah and my actions. DO I take my insulin in order to control it, Do I not? So If I don't then I can't control because then I control If I take my medicine."
	Hard and easy/ kinda difficult	**Sue:** "It does become difficult, most of the time I can't handle it. It's difficult because then it's too much to handle for me." And " It's not hard or easy for me" **Alice:** "Well it's kinda difficult…I get really emotional so it's kinda hard for me…" **Bill:** "Um, my experience has been hard and easy at the same time. So, some days it will be hard but some days it will be easy". **Joy:** "So, you it's quite easy, people just make it hard". **Frank:** "It was quite difficult for me, I got through it this far."
	Be perfect	**John:** "Yes, you have to be good with that kind of stuff." **Bill:** "…eat the right things, do the right corrections, always check your sugar". **Joy:** "Ah yeah, I have to get a routine to get my blood sugar right." And "Just get it right, get your routine, get stuff right." **Sue:** "What I'm supposed to do and not supposed to do."
	Just have to live with it	**Joy**: "But yeah, I I like get to live with it, so yeah." **Sue**: "I just have to move on and take care of myself." **Bill:** "I just live with it, yeah". **John:** "… you've got to suck it up, cause it's your life and it's not going anywhere". **Frank:** "It's just something I have to just deal with basically."
Theme 2: Motivate to manage by fear		**John:** "Um, I think when you look at the severity of the long term effects, I think it kind of is a it's a motivation to manage it better seeing what it can do to

		you and what a danger it is. I think if I didn't know as much I wouldn't I wouldn't manage it as well but knowing the consequences of unmanaged diabetes it helps me manage quite a bit." **Jane:** "[Pause] Well um, I'm, uh high blood sugar can be quite worrying, cause I've heard of people getting um dka and going to hospital and some, some um don't make it." **Bill:** "I didn't do my sugar that much my mom says like they will cut off your legs you won't be able to walk you you'll like your body won't last longer. So, the like now I've started doing my sugar because I wanna live my full life and I don't wanna get like cut off or something." **Joy:** "… I know what's going to happen in a few years. I feel fine now, but I know what's coming. So, it's a scary thing." Further stating that: "Yeah, I just don't want to die before my parents my grans because didn't listen when I was a teenager. So yeah." **Claire:** "My mom says if um I get cut on my foot it can get infected and then they would have to cut it off." **Sue:** Yeah, because then I'm just like it's fine it's not it's not like I'm sure if it's going to kill me but then if it is then its ok". Further stating that "So I'm just scared of being in a diabetic coma".
Theme 3: Perception of T1D is negative	Negative perception (sad, and bad/ it sucks)	**Bill:** "Um, it kinda sucks…" **Claire:** it makes me "sad" expanding by saying "only when I think about it and when there is cake is around." **Jane:** "… well sometimes I get a little held back in group activities… So sometimes that's quite frustrating…" **Frank:** "… and sometimes it delays me and I get into trouble for that". **Joy:** "So yeah sometimes it sucks". **John:** "…what a danger it is." **Alice:** "I get really emotional" and "I tend to be very sad.
	I don't think about it/ I don't know	**Sue:** "Well, I don't think too much because then I feel like it's okay, I've accepted that I have, I have diabetes. I just have to move on and take care of myself." **Joy:** "It is quite scary. I'm not used to focusing and talking about it so yeah its quite scary." **Alice:** "I actually really don't know because like when I got it my parents just like told me and I was like ok. So, I guess I've just adapted to the word but never really thought about it." **John:** "Um, I don't think anyone's very, very good on understanding it…" **Jane:** "So I don't know where I got it from…" and "… I don't really think about that. So it's not a big thing I worry about." **Frank:** "I don't have an understanding at the moment" and "I don't actually male sense of it."

	Food constraints	**Bill:** "…like kinda hard cause if you have like something nice on the table and you have salad like you have to go for the salad cause don't want my sugar to get high". **Joy:** "… it's hard sometimes when my friends going out to parties and stuff. I can't drink that or eat that stuff like that, so sometimes it's hard." **Frank:** "My parents told me not to eat certain foods, my grandparents don't actually care that I have diabetes, so they go wild every time when I go there to eat whatever I want to. Whatever I haven't eaten in a long time. I can just. Have fun, basically." **John:** "…eating and going out has become a bit more of a challenge." **Alice:** "…and everybody else like you know eats ice cream and stuff …I can't eat the ice cream like I have to just eat my proper lunch and that's it." **Jane:** "…16 hour fasting everyday…" **Claire:** "Eat, don't eat. I mustn't eat carbs." And "…when there is cake around." **Sue:** "It changed the way I eat."
Theme 4: Being different		**Frank:** " I was the only one in my age group and stuff like that was quite hard to deal with because knowing that nobody else is going to miss the stuff that I am going to and that there was no one I could ask for help and stuff." He further stated that: "Sports is my way out basically. So, playing sport makes me forget about everything else. Makes me feel normal and..." **Alice:** "Like I kind feel like the odd one out since everybody you know does certain stuff and then if my blood sugar is low then I have to sit you know in a corner…" and "Sometimes, um I do feel left out…" **Jane:** "Lots of people used to make fun of me they said I was a robot because I had my injections and all that and they thought that was like contagious so that they didn't want to play with me…" **Bill:** "But like it's more complicated for like us diabetics" Further stating that: "… I know if I go tell it to everyone they will like go and say things about me, if they get angry with me. So, I don't tell everyone". **Joy:** "I usually tell everyone that because I'm a diabetic it doesn't mean that I'm, I can't do this, I can't do that it's just empowers me to do more. And I'm just like who cares if I have got diabetes…" **Sue:** "Because then I I've had people who are teasing me that I'm diabetic and…" **John:** "I think sometimes especially what you think people will think if you take an injection during class…"Further indicating that: "Um what I see is it's it's it's very important role in diabetes is doing exercise… Um so I play hockey."

F. Participant feedback summary