

Illness perception of adolescents with well-controlled type 1 diabetes

D Jonker
24474665

Mini-dissertation submitted in partial fulfillment of the requirements for the degree *Magister Artium* in *Applied Positive Psychology* at the Vaal Triangle Campus of the North-West University

Supervisor: Dr E. Deacon
Co-supervisor: Prof. E. van Rensburg

May 2017

Table of contents

Acknowledgements	iii
Summary	v
Opsomming	vii
Preface	ix
Declaration from student	x
Proof of language editing	xi
CHAPTER 1: INTRODUCTION AND RATIONALE	
1.1 Introduction	1
1.2 Contextualisation	1
1.3 Problem statement and orientation	2
1.4 Literature review	4
1.5 Research questions	16
1.6 Research paradigm	16
1.7 Research design	17
1.8 Participants and context	18
Table 1 Characteristics of the nine participants	20
1.9 Data generation	21
1.10 Data analysis	22
Table 2 The 15-point checklist of criteria when doing thematic analyses (Braun & Clarke, 2006)	25
1.11 Trustworthiness	25
1.12 Ethical considerations	29
1.13 Incentives and therapeutic benefit	30
1.14 Conclusion	30
1.15 Reference list	32

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

CHAPTER 2: INTENDED JOURNAL AND AUTHOR GUIDELINES

2.1	Manuscript format and structure	51
2.2	Manuscript: Illness perception of adolescents with well-controlled type 1 diabetes mellitus	63

CHAPTER 3: CRITICAL REFLECTION

3.1	Introduction	87
3.2	Research aims of the study	87
3.3	Conclusion on the findings	87
3.4	Limitations of the study	92
3.5	Recommendations for further research	93
3.6	Reflexivity of the researcher	96
3.7	Complete reference list	98

ADDENDUM

A.	Ethical Approval Certificate: Overarching project	118
B.	Ethical Approval Certificate: Current study	119
C.	Informed consent form for legal guardians of adolescents	120
D.	Informed assent form for adolescents	129
E.	Interview agenda: English version	138
F.	Interview agenda: Afrikaans version	139
G.	Thematic analysis summary: Illness perception of adolescents with well-controlled type 1 diabetes mellitus	140
H.	Thematic analysis summary: How this illness perceptions contributes to the effective-management of participants' diabetes	141
I.	Illustrations: Positive feedback	142

Acknowledgements

My affectionate appreciation to my study leader, **Dr Elmari Deacon**, the heart behind this project. Thank you for including me on this project which you hold so dearly. It was a mind-altering experience. With your kindness and compassion you set the benchmark as an excellent mentor.

I would like to convey my sincere appreciation to **Prof Esmé van Rensburg** for embarking with me on yet another journey in completing my second dissertation. Your guidance and supervision has been absolutely invaluable.

It has been my pleasure to work with my fellow research team members **Christiaan Bekker**, **Marietjie Willemse** and **Werner Ravyse** with a sincere appreciation for **Bea Mulder**. The final result is but a small element of the equation. Thank you for sharing in this exhilarating journey.

I am grateful to the administrative and logistical assistance provided by research assistants, **sister Hester Davel** and **Deidre Maritz**, at the CDE in Houghton and Parktown respectively. In particular sincere thanks to **Prof David Segal** for his continuous support and making his practices available for the study.

My sincerest thanks to **the participants** for partaking in this research study.

Thank you to **Michelle Coetzee** for always painstakingly pouring over compositions and helping me to voice something on paper that I can be proud of.

Thank you, **Cheralee Lubbe**, for your insight and creative portrayal of the study's findings. It takes true talent to convey testimonies of various individuals using only illustrations.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

My parents, **David and Portia Jonker**, you have been an ever present beacon of encouragement and support. Not only did you teach me the importance of perseverance, but without you the past seven years of studies would have been impossible. My gratitude is inexpressible.

Johannes Muller, thank you for always selflessly encouraging me to pursue my interests. And when deadlines seemed unattainable, your support was (in Chris Mann's words) like "sunflowers in a waterless world".

Melissa van der Vyver, you are always available to provide advice and solutions. I am privileged to know you.

My special appreciation also goes to **Bredenkamp van der Merwe**, for being my daily sounding board. Your positivity, willingness to help and continuous technical support is sincerely appreciated.

Summary

Type 1 diabetes mellitus is one of the most prevalent chronic diseases among adolescents. In addition, adherence to the strict diabetes regimen usually deteriorates during adolescence. As adolescents endeavour to make sense of their illness, they develop beliefs that will guide and influence their illness management. These illness perceptions have been shown to be associated with adherence to treatment and metabolic control in patients living with type 1 diabetes mellitus. However, there is a dearth of research exploring the relationships between illness perceptions and diabetes outcomes among adolescents in South Africa. This study has two objectives – firstly to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and, secondly, to explore how this illness perception helps the adolescent to manage their diabetes.

A qualitative approach was adopted for this study and purposive sampling was done to select the participants. The population sample consisted of adolescents between the ages of 12 and 18 years with controlled type 1 diabetes mellitus who were attending the Centre for Diabetes and Endocrinology (CDE) in Parktown, Johannesburg. Data was generated during the course of semi-structured interviews. A thematic analysis using an inductive (data driven) approach was applied. The research was conducted in accordance with Lincoln and Guba's (1985) criteria for establishing trustworthiness, namely credibility, confirmability, dependability and transferability.

Four dominant themes regarding the illness perceptions of the participants were identified. Theme one, *living with diabetes becomes a way of life*, highlights that the participants perceived their type 1 diabetes mellitus to be an integral part of their being and a permanent relationship to acknowledge, not oppose. Theme two, *managing diabetes leads to being different*, indicates how the participants perceived themselves as being distinctive because they had to observe a strict regimen to which people without type 1 diabetes mellitus did not have to

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

adhere. The participants *acknowledged that type 1 diabetes mellitus could have potential negative health consequences* (theme three), especially when it is sub-optimally managed, but *type 1 diabetes mellitus is perceived to be manageable* (theme four), albeit by means of a strict management regimen.

To explore how these illness perceptions contribute to the effective-management of participants' type 1 diabetes mellitus, three themes were identified. By integrating it as a way of life and acknowledging potential negative health consequences, the participants understood and accepted that they had a duty to *procure adequate knowledge* (theme five) about the management of their diabetes. The participants *embraced accountability to comply with obligatory management protocol* (theme six): it is either right or wrong and non-negotiable. Discipline, maturity and accountability were regarded as fundamental to adhering to this strict protocol. Lastly, the majority of the participants recognised that *acceptance of their lot/fate* (theme seven) enabled them to manage their diabetes well.

In conclusion, this study provides new information about the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus in South Africa, as well as insight into how these perceptions aid effective management. The findings will be of use to diabetes-related healthcare experts who can constructively use the conclusions of this study to look beyond just the treatment regimen, and apply and develop these underlying perceptions of patients with type 1 diabetes mellitus to improve their diabetes management.

KEY WORDS: Type 1 diabetes mellitus; diabetes management; adolescents; illness perception; qualitative methods; positive psychology.

Opsomming

Type 1 diabetes mellitus is een van die algemeenste chroniese siektes van adolessente. Nakoming van 'n streng diabetes behandelingsprogram verswak gewoonlik tydens adolessensie. Wanneer tieners probeer om betekenis te vind in hul siekte, ontwikkel hulle oortuigings en persepsies wat die wyse waarop hulle die siekte bestuur, beïnvloed. Navorsing rakende die verhouding tussen siekte-persepsies en diabetes kontrole by tieners is beperk en ontbreek in Suid-Afrika. Hierdie studie het twee doelwitte - eerstens om die siekte-persepsie van adolessente met goed-beheerde tipe 1 diabetes mellitus na te vors en tweedens om te verken hoe dié siekte-persepsie hulle help met die bestuur van hul diabetes.

Hierdie studie het 'n kwalitatiewe navorsingsbenadering gevolg. Doelgerigte steekproeftrekking is gedoen met die kies van die deelnemers. Die navorsing is gerig op adolessente tussen die ouderdomme van 12 en 18 jaar met goed gekontroleerde tipe 1 diabetes mellitus wat die Sentrum vir Diabetes en Endokrinologie (CDE) in Parktown, Johannesburg besoek. Data is tydens semi-gestruktureerde onderhoude gegeneer. 'n Tematiese analise is met behulp van 'n induktiewe (data-gedrewe) benadering toegepas. Lincoln en Guba (1985) se kriteria om vertroubaarheid te verseker, naamlik geloofwaardigheid, bevestigbaarheid, geldigheid en oordraagbaarheid, is geïmplementeer.

Vier dominante temas rakende die siekte-persepsies van die deelnemers is geïdentifiseer. Tema een, naamlik *om te lewe met diabetes is 'n lewenswyse*, het aangedui dat die deelnemers hul tipe 1 diabetes mellitus as 'n integrale deel van hul wese sien, 'n permanente verhouding wat identifiseer wie hulle is. Uit tema twee het geblyk dat die *deelnemers hulself as anders sien*, want hulle volg 'n streng behandelingsprotokol wat mense sonder tipe 1 diabetes mellitus nie hoef te volg nie. Die deelnemers *erken dat tipe 1 diabetes mellitus potensiële negatiewe gevolge vir die gesondheid kan inhou* (tema drie), veral waneer diabetes nie optimaal bestuur word nie,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

maar tog word *tipe 1 diabetes mellitus* beskou as *hanteerbaar en bestuurbaar* (tema vier), ongeag die streng behandelingsprotokol.

Om te verken hoe hierdie siekte-persepsies bydra tot die effektiewe bestuur van tipe 1 diabetes mellitus, is drie temas geïdentifiseer. Deur die integrasie van die diabetes in hul bestaan en dit as 'n manier van lewe te hanteer, tesame met die erkenning dat tipe 1 diabetes mellitus potensiële negatiewe gevolge vir die gesondheid kan inhou, aanvaar die deelnemers dat hulle 'n plig het om *voldoende kennis oor die bestuur van hul diabetes in te win* (tema vyf). Verder erken die deelnemers *aanspreeklikheid om te voldoen aan verpligte behandelingsprotokol* (tema ses): dit is óf reg of verkeerd - ononderhandelbaar. Dissipline en verantwoordelikheid word beskou as fundamenteel belangrik vir die sukses van hierdie streng protokol. Laastens, die meerderheid van die deelnemers erken dat die *aanvaarding van hul noodlot* (tema sewe) bydra tot die goeie bestuur van hul diabetes.

Hierdie studie verskaf nuwe inligting aangaande die siekte-persepsies van adolessente met goed gekontroleerde tipe 1 diabetes mellitus in Suid-Afrika en bied insig oor hoe hierdie persepsies help met effektiewe siektebestuur. Die bevindinge kan aangewend word deur mediese personeel betrokke by diabetes behandelingsprogramme, nie net vir verkryging van beter kontrole nie, maar ook om die onderliggende siekte-persepsies van hul pasiënte te bestuur.

SLEUTELWOORDE: Tipe 1 diabetes mellitus; diabetesbestuur; adolessente; siekte-persepsie; kwalitatiewe metodes; positiewe sielkunde.

Preface

- This dissertation is in article format, complying with the requirements of rules A.5.4.2.7 as determined by the North-West University.
- The article will be submitted for possible publication in the Journal of Diabetes Research and Clinical Practice.
- The essence of the paper comprises of three sections. Section I reflects on the contextualisation and motivation regarding the research topic with a description of the research process leading up to the manuscript. In section II the guidelines used by the author, as required by the abovementioned journal, are outlined and then the article is presented according to these guidelines. Section III presents a conclusion and critical reflection by the researcher on the current study.
- To present the dissertation as a unit, the page numbering is consecutive, starting from the introduction and proceeding to the references.
- The referencing and editorial style of this dissertation is consistent with the guidelines as stipulated in the Publication Manual (6th edition) of the American Psychological Association (APA). The article will be constructed according to the guidelines of the Journal of Diabetes Research and Clinical Practice.
- The dissertation was submitted to Turn-it-in and it was reported that the dissertation is considered as to be satisfactory.
- Dr E. Deacon (supervisor) and Prof. E. van Rensburg (co-supervisor) assisted with the analysis and interpretation of results and were involved in the peer review of the article. They are deemed as co-authors of the article comprising this dissertation.
- The co-authors have provided consent for the submission of this article for examination purposes for a MA Positive Psychology degree.

Declaration from student

I, Deborah Jonker, declare that this dissertation hereby submitted by me for the degree Magister Artium in Positive Psychology at the North-West University is my own individual work, although I give credit to the contributions my two supervisors bestowed. Best efforts were made to acknowledge and cite the various materials and opinions from the academia used in its preparation and to paraphrase these materials. Furthermore, I declare that this dissertation has not previously been submitted for assessment at any other institution.

A handwritten signature in black ink, appearing to read 'D. Jonker', is written above a horizontal line.

Ms. D. Jonker

Proof of language editing

DR MICHELLE COETZEE

(D.Phil.Theology – St Augustine’s College, 2014)

AUTHORISED LANGUAGE PRACTITIONER

(English)

45A Collins St, Brixton, 2092, RSA • Tel+27 (0)11-830-0794 • Cell +27 (0)79-516-8067 • coetzee.michelle71@gmail.com

08-11- 2015

Dear Deborah Jonker

Language editing

This is to confirm that I edited your master’s dissertation, *Illness perception of adolescents with well-controlled type 1 diabetes*, and that I indicated the necessary grammatical corrections.

Although I took all reasonable precautions to ensure that all grammatical and stylistic corrections are indicated, you remain responsible for the final product. Therefore, please check these suggested corrections before applying them and, if possible, again perform a spell check after you have implemented them, in order to eliminate typing errors.

Please contact me if there are any queries or if I can be of further assistance.

Yours sincerely

A handwritten signature in black ink, consisting of a large, stylized initial 'M' followed by the name 'Coetzee' in a cursive script.

Michelle Coetzee

Illness perception of adolescents with well-controlled type 1 diabetes

CHAPTER 1: INTRODUCTION AND RATIONALE

1.1 Introduction

This study comprises an exploration of the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and how this acuity facilitates managing their diabetes. Since this research is part of an overarching project, the first part of section one of this report will contain a brief overview of the context of the larger project. Secondly, the problem statement and orientation of the current study are defined. Thirdly, the relevant literature explored to accomplish this study will be discussed. Fourthly, a rationale of the research model guiding the study's methodology is outlined. To conclude this section, the ethical considerations and therapeutic benefit relevant to this study are stipulated.

1.2 Contextualisation

This study was conducted as part of an ethically approved larger research project. The principal project is titled: Psycho-social variables in adjusting to diabetes management in adolescents and young adults (NWU-HS-2015-0111). The objective of the project is to investigate the psycho-social variables affecting adolescents and young adults' diabetes management, and to develop relevant interventions accordingly to facilitate optimal psychological wellbeing through developmental stadia. The primary objectives of the principal project are:

- a. To identify the psycho-social variables influencing the diabetes management of well-controlled (as measured by their HbA1C levels) adolescents and young adults with type 1 diabetes mellitus – a qualitative study;

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- b. To investigate the association between the psycho-social variables, their diabetes management and the psychological wellbeing of adolescents and young adults;
- c. To develop and assess appropriate interventions to modify psycho-social variables influencing the diabetes management of adolescents and young adults, thus optimizing their psychological wellbeing.

The outcome of the current study contributed to the first objective identified in the principle project.

1.3 Problem statement and orientation

Type 1 diabetes mellitus is recognised as one of the most psychologically and socially demanding chronic diseases (Compas, Jaser, Dunn, & Rodriguez, 2012; Hagger et al., 2016; Reynolds & Helgeson, 2011; Schabert, Browne, Mosely, & Speight, 2013). Inadequate compliance with diabetes management increases the risk of long-term complications and contributes to the economic burden on the health sector (Azevedo & Alla, 2008; Chevreur, Berg Brigham, & Bouché, 2014; Kalk, Raal, & Joffe, 2010). Poor diabetes management has been associated with coping difficulties (Hapunda, Abubakar, van de Vijver, & Pouwer, 2015), psycho-social and psychological disorders such as depression and anxiety (Buchberger et al., 2016; Herzer & Hood, 2010), and has an impact on psychological wellbeing. Patients differ significantly in their perceptions of and attitudes toward the disease and these outlooks can complicate disease management (Anderson, Fitzgerald, Gorenflo, & Oh, 1993; Broadbent, Petrie, Main, & Weinman, 2006). A better understanding of patients' perceptions is therefore desirable to guide interventions to improve diabetes management (Peyrot et al., 2004; Weinman & Petrie, 1997).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

The incidence of type 1 diabetes mellitus is increasing globally at a rate of 2-5% per year – an issue of serious concern for developed and developing countries (Reddy, Ganie, & Pillay, 2013; Tumbo & Kadima, 2013), with 79,000 children worldwide estimated to develop type 1 diabetes mellitus annually (Patterson et al., 2014). Unfortunately there are no published data on its prevalence in South Africa (Reddy et al., 2013).

While type 1 diabetes mellitus can be diagnosed at any stage of life, it typically emerges at or near puberty (Tuomilehto, 2013). It is one of the most frequent chronic illnesses among adolescents (Borus & Laffel, 2010). Adolescence heralds a critical interval in diabetes management (Fortenberry et al., 2014). Adolescents living with type 1 diabetes mellitus are expected to accept more responsibility for their diabetes (Wiebe et al., 2014) which can be exceptionally challenging for adolescents (Comeaux & Jaser, 2010; Griva, Myers, & Newman, 2000) being faced with multifaceted developmental changes (Inagaki & Hatano, 2006). As such, various studies have pointed out that adherence to the strict diabetes treatment regimen usually declines during this transition phase (Borus & Laffel, 2010; Bryden et al., 2001; Hilliard, Wu, Rausch, Dolan, & Hood, 2013; King, Berg, Butner, Butler, & Wiebe, 2014).

While the normative transitions of this developmental period inhibit certain adolescents' adherence to treatment responsibilities (Peters & Laffel, 2011), other individuals succeed in complying with optimal diabetes management (Hilliard et al., 2013). Differences in behaviour might be driven by individual variations in illness perceptions and these mindsets might affect disease management. As adolescents attempt to make sense of their illness, they develop illness perceptions that guide their illness management (Leventhal et al., 1997) and these illness perceptions are associated with psychological and illness-related outcomes (Hagger & Orbell, 2003). Illness perceptions are characterised by an array of beliefs about an illness (Leventhal et al., 1997; Petrie, Jago, & Devcich, 2007), acquired through physical experiences, exposure to

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

medical interventions, and by interpretation of information from social and factual sources (Leventhal et al., 1997). These perceptions are believed to direct their illness management, even if they are medically flawed (Hagger & Orbell, 2003; Leventhal et al., 1997). Very little research has been done on the effect of illness perceptions acquired during periods of rapid developmental change such as adolescence (Fortenberry et al., 2014).

Since an ever-increasing number of people are being affected by type 1 diabetes mellitus worldwide, it is important to identify effective interventions to improve diabetes management in this population (Abualula, Jacobsen, Milligan, Rodan, & Conn, 2016). Changing patients' perceptions and attitudes has been shown to improve management outcomes for various diseases (Broadbent et al., 2006). Extensive literature about adults with diabetes has linked illness perceptions to adherence and psycho-social adjustment (Broadbent, Donkin, & Stroh, 2011; Hagger & Orbell, 2003). However, owing to inconsistencies in the literature, the nature of the relationship between illness perceptions and diabetes outcomes among adolescents remains unclear. This study has two objectives. Firstly, to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and, secondly, to explore how this illness perception helps the adolescent to manage their diabetes.

1.4 Literature review

A thorough literature review related to the topic was done to critically evaluate the existing knowledge base and to determine any identified gaps in current research. The literature review was conducted according to the following procedure:

- An electronic literature review search by using EbscoHost and Health databases, which include the following: CHINAL with full text; Academic Search Premier and PsycInfo.
- An internet search on Google Scholar.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Recall of secondary sources mentioned in academic articles found in the electronic data searches.

The following key words were used: Type 1 diabetes mellitus; diabetes management; adolescents; illness perception; qualitative methods; positive psychology.

1.4.1 Positive psychology framework

Positive psychology is a relatively new scientific sub-discipline in psychology (Compton & Hoffman, 2013). By definition, it relates to the scientific study of factors that enable individuals and the wider community to function optimally (Compton & Hoffman, 2013; Hefferon & Boniwell, 2011). Since the emphasis of positive psychology is on assessing wellbeing, it is not unexpected that the focus of most of the research thus far has been on healthy populations. However, this emphasis is shifting and positive psychology is being progressively more directed at healthcare scenarios (Macaskill, 2016).

The prevalence of children with chronic illnesses surviving into adulthood increased dramatically during the last 30 years as a result of progress in healthcare (Berry, Bloom, Foley, & Palfrey, 2010; Sharma, O'Hare, Antonelli, & Sawicki, 2014). Research should thus aim to investigate how patients living with a chronic illness can be assisted to maintain physical and subsequently psychological wellbeing. Positive psychology has presented a particularly useful framework in which to identify the required factors essential for successful disease management (Macaskill, 2016).

Psychological and physical wellbeing are closely related to each other (Boehm & Kubzansky, 2012; Steptoe, Deaton, & Stone, 2015), especially among youths with type 1 diabetes mellitus (Pires-Yfantouda & Evangelini, 2012). Poor diabetes management by adolescents with type 1 diabetes mellitus has been associated with psychological turmoil (Ashraff, Siddiqui,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

& Carline, 2013). Psychological disorders such as depression and anxiety surface in approximately 30% to 32% of youth with type 1 diabetes mellitus, a rate that is two to three times higher than their peers without type 1 diabetes mellitus (Buchberger et al., 2016; de Wit & Snoek, 2011; Snoek & Skinner, 2006). Both of the above mentioned mood disorders have been correlated with poorer self-management and glycaemic control in adolescents with type 1 diabetes mellitus (Bernstein, Stockwell, Gallagher, Rosenthal, & Soren, 2013; Helgeson, Siminerio, Escobar, & Becker, 2009; Herzer & Hood, 2010; Johnson, Eiser, Young, Brierley, & Heller, 2013) and subsequently a poorer quality of life.

According to Law, Kelly, Huey, and Summerbell (2002), adolescents' beliefs regarding their type 1 diabetes mellitus play an important part in their psychological wellbeing. A positive psychology perspective was adopted for this study in the form of exploring the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and how it aids them in managing their diabetes, in contrast to concentrating on areas in need of improvement.

1.4.2 Type 1 diabetes mellitus

The incidence of type 1 diabetes mellitus is increasing globally, which is an issue of serious concern for countries worldwide (Tumbo & Kadima, 2013). Diabetes does not only impose a considerable economic burden on the health sector of countries (Kirigia, Sambo, Sambo, & Barry, 2009), but also on individuals living with type 1 diabetes mellitus and their families (Wodrich, Hasan, & Parent, 2011).

Type 1 diabetes mellitus is one of the most predominant chronic paediatric diseases, affecting an estimated 1.7 per 100 children and adolescents worldwide (Wodrich et al., 2011). Type 1 diabetes mellitus, previously also identified as insulin dependent diabetes or juvenile onset diabetes, is characterised by an abnormality in the synthesis or secretion of insulin (lack of

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

insulin), reducing the ability of an individual to regulate the level of glucose in the bloodstream, with subsequent chronic hyperglycaemia and disorders of carbohydrate, fat and protein metabolism (Kaul, Tarr, Ahmad, Kohner, & Chibber, 2012; Sherwood, 2010). This is considered to be an autoimmune process, with the depletion of pancreatic beta-cells resulting in absolute dependence on insulin treatment for survival (Chiang, Kirkman, Laffel, & Peters, 2014). The cause of type 1 diabetes mellitus remains unclear. There is clear evidence of a genetic predisposition (gene on chromosome six), but the evidence also indicates that certain viruses might be responsible for triggering this chronic illness (Kaul et al., 2012; Patterson et al., 2014; Sherwood, 2010).

Diagnosis of type 1 diabetes mellitus was previously based on (1) elevated fasting blood glucose (higher than 7mmol/L); (2) any blood glucose of 11.1mmol/L or more; (3) symptoms of hyperglycaemia; or (4) an abnormal two-hour glucose-tolerance test (Silverstein et al., 2005). In 2010, the American Diabetes Association revised its policy for diagnosis and incorporated glycated haemoglobin (HbA1C) levels. This is a test that measures the average blood glucose levels over three consecutive months. If glycaemic control is effective, the HbA1C result should be below 7% (Sharma & Singal, 2015). Furthermore, it is recommended that HbA1C be brought to lower than 7.0% in order to prevent the development and progression of chronic diabetic complications (Hinzman, Schlaeger, & Tran, 2012).

Good adherence and glycaemic control in particular is associated with a decreased risk of various complications and comorbidities (Borus & Laffel, 2010; Roze et al., 2015) responsible for morbidity and high mortality rates among individuals living with type 1 diabetes mellitus (Wadén et al., 2009). Diabetes-related complications have a significant cost impact on medical expenditure (Borus & Laffel, 2010), related mainly to hospitalisation (Franciosi et al., 2013). Individuals with suboptimal metabolic control face the threat of developing chronic

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

complications such as cardiovascular diseases, lower-extremity amputation, blindness and end-stage renal disease, as well as acute complications [ketoacidosis (DKA)] and severe hypoglycaemia (Lung, Clarke, Hayes, Stevens, & Farmer, 2013). Unfortunately most people living with diabetes do not manage it effectively (maintaining a life-long HbA1C of 7% or below), subsequently intensifying their probability of developing complications (Datye, Moore, Russel, & Jaser, 2015).

1.4.3 Diabetes treatment regimen

Adherence signifies the extent to which a person's behaviour parallels medical health advice (Modi et al., 2012). Individuals diagnosed with type 1 diabetes mellitus must take responsibility for the regulation of their blood glucose levels, and this is normally achieved only by adhering to an intricate, multifaceted treatment regimen (Silverstein et al., 2005; Skinner, John, & Hampson, 2000).

Goals for the management of type 1 diabetes mellitus involve accomplishing optimal glycaemic control, avoiding acute complications, and reducing the risk of long-term microvascular and macrovascular complications (Cooke & Plotnick, 2008). To achieve these goals, the essential components of diabetes management are a combination of frequent blood glucose monitoring (BGM), calculating insulin requirements, administering insulin and/or glucose as needed, medication administration, careful attention to diet and the monitoring of exercise levels (Silverstein et al., 2005; Skinner et al., 2000; Tully, Aronow, Mackey, & Streisand, 2016). The responsibility for adhering to these obligations is carried by adolescents and their families, and involves nearly every aspect of their daily lives (Gandhi, Vu, Eshtehardi, Wasserman, & Hilliard, 2015).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Blood glucose monitoring (BGM) is one of the most imperative elements of diabetes management (Cooke & Plotnick, 2008; Rewers et al., 2009). By observing glucose levels, BGM helps individuals to establish their immediate and daily insulin requirements, direct their insulin adjustments and reduce fluctuations in glucose levels, identify and manage hypoglycaemia and hyperglycaemia, and adjust insulin levels to nutrition and physical activity levels (Rewers et al., 2009; Ziegler et al., 2011). The American Diabetes Association (2009) recommends BGM at least three times daily. According to the Clinical Practice Consensus Guidelines published by the International Society for Paediatric and Adolescent Diabetes, BGM is recommended at a frequency that will optimise each child's diabetes control, usually four to six times a day, taking into account the accessibility of equipment and type of insulin regimen (Rewers et al., 2009).

The objective of insulin therapy is to simulate the natural pattern of insulin secretion by the pancreas as closely as possible by maintaining the blood glucose level within a narrow range (Jain, 2014). Insulin is administered subcutaneously, using either insulin syringes with needles, pens or insulin pumps (Seth & Maheshwari, 2013). The recommended sites are the anterolateral thigh, anterior and lateral abdominal wall, posterior aspect of the upper arms and superolateral aspects of the buttocks. Site rotation, i.e., following a regular pattern of using different sites and also different areas within the same site, is necessary. Insulin pens are available in both disposable and reusable varieties (Jain, 2014). Insulin pumps have various practical benefits, including the delivery of insulin by means of a more natural approach by programming the delivery of multiple basal rates over 24 hours, as well as painless administration of additional boluses, which cover between-meal snacks (Jain, 2014; Seth & Maheshwari, 2013). However, this method is costly (Kalweit, Briers, & Olorunju, 2015).

Research done by Beraki and colleagues (2014) indicated that physical activity helped to accomplish optimal glycaemic control and to prevent long-term cardiovascular complications,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

while concurrently improving psychological health. Since adolescents living with type 1 diabetes mellitus are subject to double the risk of developing cardiovascular disease during their lifetime compared with those individuals living without type 1 diabetes mellitus (Miculis, De Campos, & da Silva Boguszweski, 2015) exercise can be regarded as an essential subcategory of effective diabetes management (Tully et al., 2016). Furthermore, studies confirm small but significant benefits of exercise in reducing depression, anxiety and psychological distress in youth not living with type 1 diabetes mellitus (Ahn & Fedewa, 2011; Larun, Nordheim, Ekeland, Hagen, & Heian, 2006). The psychological benefits of exercise can be considered especially valuable for adolescents living with type 1 diabetes mellitus (Tully et al., 2016) due to the considerably increased prevalence of depression and anxiety in this population, and the indisputable connection between depressive and anxiety symptoms and poorer glycaemic control (Bernstein et al., 2013; Johnson et al., 2013).

Although the evidence confirms that adolescents with type 1 diabetes mellitus benefit from exercise (Miculis et al., 2015; Quirk, Blake, Tennyson, Randell, & Glazebrook, 2014) the specific extent and intensity of the physical activity needed to achieve a significant benefit remains unclear (Tully et al., 2016). The particular types of exercise (for example aerobic, strength and/or endurance) most beneficial to adolescents living with type 1 diabetes mellitus health are also not clearly established. Research has also emphasised that exercise is often lacking in adolescents living with type 1 diabetes mellitus (Miculis et al., 2015). One possible explanation could be the fear of enhanced risk for either hypoglycaemia or hyperglycaemia. Specifically, the direct impact of exercise on potential hypoglycaemic and hyperglycaemic episodes among youth with type 1 diabetes mellitus is of great concern to many caregivers (Tully et al., 2016).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Diet regulation is a vital element of the treatment protocol for all individuals living with type 1 diabetes mellitus (Silverstein et al., 2005). Nutrition therapy comprises attempts to educate the patient and the family about the impact of food on blood glucose, about the relationship between food and exercise and insulin to prevent hypo- and hyperglycaemia, and how to implement the food plan in a variety of situations (Chiang et al., 2014). Committed dietary adherence improves glycaemic control among adolescents with type 1 diabetes mellitus, but adolescents might find it challenging to adhere to a strict diet in the long term (Mehta et al., 2008).

A systematic review done by Bell and colleagues (2013) supported the evidence that carbohydrate counting, a nutritional regimen of choice, might be an effective method to help individuals living with type 1 diabetes mellitus to adhere to restricted diets. Carbohydrate counting implies an awareness of foods that contain carbohydrate and their effect on blood glucose levels, and counting the number of 15g carbohydrate exchanges or grams of carbohydrate eaten. An insulin versus carbohydrate ratio is used to calculate the bolus insulin dose needed (Gillespie, Kulkarni, & Daly, 1998). However, the efficiency of this therapy method might ultimately be restricted by either compliance or the inability of individuals to accurately assess the carbohydrate content (Bell, Barclay, Petocz, Colagiuri, & Brand-Miller, 2013; Gabriel, Albuquerque, Consoli, Menezes, & Reis, 2016). The literature indicates that there are well established methods for teaching adults this therapy (Smart et al., 2010; Spiegel et al., 2012), yet training methods for adolescents in carbohydrate counting is limited (Gabriel et al., 2016). Adolescents are experiencing a chapter in their lives in which they are in search of independence, increased activity without supervision and diet flexibility. Also, some caregivers work away from home and cannot supervise adolescents living with type 1 diabetes mellitus

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

during their daily activities, making carbohydrate counting difficult to implement during this transitional phase (Chaney et al., 2012; Wylie-Rosett, Aebbersold, Conlon, & Ostrovsky, 2012).

Impediments to optimal treatment adherence are universal and include demands on time and attention, miscommunication or bewilderment about what to do (for example among family members and healthcare providers), financial restraints, inadequate adult involvement or monitoring of the adolescent's self-management, and emotional or behavioural barriers (Datye et al., 2015; Patton, 2015). It is essential to establish realistic and individualised goals for each child. It is also vital to remember that good physician-patient rapport, counselling and education of the child and the family, psycho-social support and multidisciplinary team effort remain the most crucial pillars of optimal management of type 1 diabetes mellitus in children (Jain, 2014).

Adherence to diabetes regimens often continues to be challenging for patients of all ages, but especially during the difficult interval of adolescence (Borus & Laffel, 2010; Hagger et al., 2016). Adherence and glycaemic control usually deteriorates across adolescence, even when the importance of a strict diabetes treatment regimen has been explained (King et al., 2013), with just 40% of adolescents accomplishing their treatment targets (Hilliard et al., 2013).

Living with type 1 diabetes mellitus, while being concurrently faced with multifaceted developmental changes, can be remarkably difficult for adolescents (Borus & Laffel, 2010; Comeaux & Jaser, 2010; Compas et al., 2012). The strict daily regimen amplifies adolescents' experiences of physical, emotional and social distress (Cheung, Young Cureton, & Canham, 2006), especially because it involves several distinct tasks in order to be considered effective (Coffen, 2009). Adolescents living with type 1 diabetes mellitus face the challenge of having to successfully incorporate diabetes management into their lives while already battling with significant hormonal, psycho-social, academic and interpersonal challenges associated with the developmental phase of adolescence (Husted, Esbensen, Hommel, Thorsteinsson, & Zoffmann,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

2014; Winocour, 2014). The capacity of the adolescents living with diabetes to establish personal identity and autonomy is inevitably complicated by the constant pressure to monitor and manage their blood glucose levels independently (Silverstein et al., 2005; Spear & Kulbok, 2004). Most adolescents with type 1 diabetes mellitus also experience being seen as different from their peers as a barrier to authenticating their own personality. These challenges are often the motives for which adolescents delay blood glucose monitoring, omit insulin injections at the required times, and follow unreliable diabetes meal plans and physical exercise routines (Hood, Peterson, Rohan, & Drotar, 2009).

While the challenges of this developmental period cause certain adolescents to adhere poorly to treatment responsibilities (Peters & Laffel, 2011), other individuals successfully adhere to optimal diabetes management (Hilliard et al., 2013). Differences in behaviour might be driven by individual variations in illness perceptions. Regarding adolescents with type 1 diabetes mellitus, it is submitted that learnt childhood beliefs and habits relating to their diabetes management will continue during adulthood. The appropriate self-management of diabetes during adolescence is therefore considered to be the basis for the future management of diabetes (Bandura, 2004; Borus & Laffel, 2010; Schilling, Grey, & Knafl, 2002).

1.4.4 Illness perception

There is accumulative confirmation that individuals' beliefs about diabetes can be correlated with self-management behaviours and clinical outcomes such as glycaemic control (Broadbent et al., 2011; Griva et al., 2002; Mc Sharry, Moss-Morris, & Kendrick, 2011). This set of cognitive beliefs can be defined as illness perceptions (Leventhal et al., 1997). They originate mainly from three sources: (1) existing knowledge of the illness acquired from external sources; (2) information from authoritative respected sources (for example the physician); and (3) appraisal of personal experiences of the illness and its symptoms (Hagger & Orbell, 2003).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Studies regarding the illness perceptions of individuals living with diabetes have been approached mainly from a particular theoretical framework related to the process of self-regulation, namely Leventhal's Common Sense Model (CSM) (Leventhal et al., 1997). The CSM postulates that, in a perceived health threat, individuals endeavour to understand and make sense of their illness by constructing their own illness perceptions regarding their illness (Leventhal et al., 1997; Petrie & Weinman, 2012). These perceptions originate as soon as patients experience their initial symptoms, and are adapted to disease progression when new symptoms manifest and in reaction to treatment outcomes (Leventhal et al., 1997). The process of recapturing normal health starts with the belief that one is affected by an illness and that this illness necessitates some changes in behaviour if one is to return to the pre-illness baseline (Safo, Batchelder, Peyser, & Litwin, 2015). Thus, this model is premised on the theory that an individual's illness perception is the primary stimulus urging him/her to engage in disease-modifying behaviours such as obtaining treatment and complying with medication regimens (McAndrew et al., 2008).

The theory suggests that the CSM integrates five cognitive domains, namely: (1) the understanding and meaning of the illness (identity); (2) how long it will last (timeline); (3) its causes; (4) its consequences; and (5) whether it can be cured or controlled (Leventhal et al., 1997; Petrie et al., 2007; Petrie & Weinman, 2012). The illness identity domain informs the individuals' concepts about the categorisation and character of their condition (i.e. associated symptoms) and the connections between these. The timeline domain reflects their perception of the expected duration of their illness, whereas the causal dimension includes the individuals' view of the probable cause or causes of the illness. The consequences domain indicates their beliefs about the gravity of the illness and the expected impact on their physical, social and psychological performance. The cure or controlled domain signifies the extent to which the patients believe their condition can be cured or managed (Fortenberry et al., 2014; Petrie et al.,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

2007). Although these areas are different and separate in the sense that they can diversely influence the individual's ability to deal with the illness and its outcomes, they are not necessarily unconnected. There might be very explicit links between these domains that guide the management of an illness (Leventhal et al., 1997). The CSM model is a parallel-processing model whereby individuals typically create cognitive and emotional representations of their illness. Thus an illness representation might not only include the cognitive response to the symptoms and illness mentioned above, but also involve emotional facets that might be important determinants of outcomes (Moss-Morris, Weinman, Petrie, & Buick, 2002).

This process of forming illness perceptions consists of three phases. According to the theory, situational stimuli (such as symptoms) produce both cognitive and emotional responses to the illness (Broadbent et al., 2006). In the first phase the individual attempts to fathom his/her illness by comparing the current illness experience to pre-existing archetypes of illness encounters. Secondly, these perceptions direct the individual to implement a coping mechanism to manage the illness. These include tactics aimed at dealing with the stressor, as perceived by the person, and an approach to handle its emotional consequences. During the final phase the individual evaluate the efficacy of the coping mechanisms to determine further actions. If the outcomes are as anticipated, the individual will continue with the coping mechanism, but if the outcome appears to be detrimental, the individual will change the strategy (Broadbent et al., 2006; Witteman, Bolks, & Hutschemaekers, 2011).

During adolescence, illness perceptions might change as adolescents mature in their cognitive and socio-emotional insight and awareness (Smetana, Campione-Barr, & Metzger, 2006). Olsen, Berg, and Wiebe (2008) conducted a cross-sectional study confirming that illness perceptions might vary across age span – older adolescents exhibit a more developed insight into their chronic illness than do younger adolescents and they tend to recognise the value of their HbA1c

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

levels better (Patiño-Fernández et al., 2010). Adolescents are expected to take more responsibility for independently managing their diabetes (Wiebe et al., 2014), determining their perceptions and exercising control over the illness. However, data on the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus in South Africa are limited. Furthermore, interventions explicitly directed to assess changes in illness perceptions to improve adherence amongst adolescents with type 1 diabetes mellitus is limited. Two research objectives were thus formulated to serve as basis for the current study - firstly, to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and, secondly, to explore how this illness perception helps the adolescent to manage their diabetes.

1.5 Research questions

Based on the background information given, the following research questions were formulated:

- What are the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus?
- How do these contribute to the effective-management of their diabetes?

1.6 Research paradigm

Paradigmatic conjectures underpin the study, guide the researcher's point of view and provide a frame of reference for categorising observations and analysis (Grix, 2002). Science is not a value-free enterprise (Sarantakos, 2013), and it is essential that researchers acknowledge their ontological and epistemological suppositions. Ontology is a system of belief regarding the basis of reality and thus what things, if any, have authenticity or whether reality is the invention

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

of one's mind. Epistemology, flowing from ontology, is concerned with how this reality is denoted or perceived (Grix, 2002; Sarantakos, 2013).

This study was conducted within the framework of a relativism ontological position, taking an interpretivist epistemological stance. Relativism ontology advocates the transactional and subjective stance that multiple and relative realities exist and, as such, deny that only one true reality can be recognised (Guba & Lincoln, 1994; Howitt, 2010; Snape & Spencer, 2003). An interpretivist epistemology, in turn, holds that social reality is co-constructed by individuals who interact and make meaning of their world in an active way. The researcher and participants are inter-reliant and actively collaborating. The interpretivist researcher enters the field with some sort of prior perception of the research agenda but presumes that this is inadequate due to the multifaceted and unpredictable nature of what is recognised as reality. The researcher remains receptive to new knowledge throughout the study and allows it to progress with the help of the participants. As such, the researcher acts as a co-constructor of realities (Guba & Lincoln, 1994; Snape & Spencer, 2003).

1.7 Research design

A qualitative research approach was adopted for the current study. Qualitative research is exploratory and is designed to elicit an in-depth understanding of underlying human behaviour and the motives regulating such behaviour (Bless, Higson-Smith, & Kagee, 2006). The aim of qualitative research is to obtain a detailed and holistic insight into a specific phenomenon from the viewpoint of the person under study (Janesick, 2000; Ritchie, 2009; Snape & Spencer, 2003). It was appropriate to use a qualitative approach in the current study because it enabled the researcher to uncover the perceptions of adolescents with well-controlled type 1 diabetes mellitus, a phenomenon about which little is known.

1.8 Participants and context

Purposive sampling, a non-probability sampling method, was used to select the participants. Non-probability sampling amplifies existing knowledge regarding the phenomenon (Uprichard, 2013) and is valid and relevant for limited in-depth studies (Ritchie, Lewis, & Elam, 2009). With purposive sampling the selection preference is based on the judgement of the researcher, subject to the quality of information available to expand the appreciation of a phenomenon (Bless et al., 2006; Coolican, 2014).

The current research involved a population sample consisting of adolescents between the ages of 12 and 18 years with well-controlled type 1 diabetes mellitus, who were attending the Centre for Diabetes and Endocrinology (CDE) in Houghton and Parktown, Johannesburg. The CDE, a private multi-specialist centre, commenced its Diabetes Management Programme (DMP) in 1994. The DMP has displayed superior clinical results; five-year outcome data showed a 40% overall reduction in the hospital admission rates for diagnoses relating to type 1 diabetes mellitus. Furthermore, five-year HbA1c levels showed a drop from 9.2% to 7.7% for patients with type 1 diabetes mellitus (Distiller, Brown, Joffe, & Kramer, 2010).

The inclusion criteria of the study were as follows:

- Participants must be accomplished and willing to participate in an interview in either English or Afrikaans.
- Participants are required to be within the 12-18-year age group.
- It is essential that participants must have been diagnosed with type 1 diabetes mellitus more than 12 months previously to avoid any impact of continuous adjustment of treatment on the trustworthiness of data obtained.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Participants should be patients at the CDE in Houghton or Parktown, Johannesburg, specializing in paediatric diabetes, to minimise treatment variables.
- Participants need to have an HbA1C of 8% or less during the preceding 12 months for diabetes management to be considered effective. (It is specified in the literature that for type 1 diabetes mellitus to be regarded as managed effectively, the HbA1C result should be below 7%. However it was recommended by Prof D Segal (personal communication, February 21, 2016), a paediatric endocrinologist, that an HbA1C of 8% is still considered to be satisfactory.)

The exclusion criteria of the principal study were as follows:

- Individuals who are currently undergoing psychotherapy were excluded as a precautionary measure, so as not to interfere with the therapy process.
- Individuals suffering from another chronic medical condition that could impact diabetes management were excluded from the study.

Extremely large sample sizes in qualitative research handicap extracting rich data (Onwuegbuzie & Leech, 2007). In a qualitative framework, samples for qualitative research tend to be small (Ritchie et al., 2009) and the appropriate sample size for these studies is one that adequately answers the research question (Marshall, 1996). Polkinghorne (2005) recommends between five and 25 participants when conducting interviews with individuals who have experienced the same phenomena. Crouch and McKenzie (2006) propose that less than 20 participants in a qualitative study enables a researcher to establish and support a close relationship, and thus an open exchange of information, diminishing possible prejudice and validity risks that might emerge when conducting qualitative research. There is a point of diminishing return – when including additional participants will not necessarily lead to new

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

information or themes and, as such, data saturation occurs (Ritchie et al., 2009). Saturation often occurs within the first 12 interviews in homogeneous groups (Guest, Bunce, & Johnson, 2006).

To ascertain whether data saturation had been reached, the current researcher transcribed and thematically analysed the data that had been obtained from each participant and documented it immediately after each individual's interview (Ellis, 2016). See attached Table 1 for the demographic information of the nine participants.

Table 1

Characteristics of the nine participants

Participant ID	Sex	Ethnicity	Home language	Age	Diagnosed from (age)
A1	Male	Caucasian	English	16	12
A2	Female	Caucasian	English	12	11
A3	Female	Caucasian	English	15	5
A4	Male	Caucasian	Afrikaans	16	11
A5	Male	Caucasian	Afrikaans	12	5
A6	Male	Caucasian	Afrikaans	12	9
A7	Female	Asian	English	12	11
A8	Male	Caucasian	English	12	11
A9	Female	Caucasian	English	18	12

1.9 Data generation

Data was generated during the course of semi-structured interviews. The aim of qualitative interviews is to acquire rich descriptive data revealing the participant's own account of his/her experiences. The co-researcher (the participant) is allocated time and space to convey his/her opinion on an allocated topic without being influenced by the researcher or the conversation (DiCicco-Bloom & Crabtree, 2006; Nieuwenhuis, 2007). Semi-structured interviews are extensively used as an interviewing method for qualitative research (DiCicco-Bloom & Crabtree, 2006). They entail using a set of pre-determined open-ended questions; other questions often then emerge from the dialogue between the interviewer and interviewee, allowing for the exploration of additional information and the clarifying of answers (Nieuwenhuis, 2007).

Data collection was done from October 2015 to August 2016 and involved nine semi-structured interviews. Data saturation had been reached after seven interviews but two more interviews were conducted to confirm that no new data was likely to emerge. The interviews were conducted at the site at which the participants normally received their treatment (CDE Parktown). The researcher scheduled the interview sessions to coincide with the participants' regular visits to the CDE. Occasionally, on the request of the parents, the interview was held at the participant's house in the Johannesburg area, South Africa, because it was regarded as least inconvenient. The interviews were conducted by three experienced and trained interviewers who were participating in the overarching project. Three interviews were done in Afrikaans and six in English. The three interviewers were fully bilingual and could therefore do the Afrikaans as well as the English interviews.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

For the purposes of the principal project, an interview agenda consisting of two sections with a total of seven questions, which focused on various research questions regarding diabetes management in adolescents with well-controlled type 1 diabetes mellitus, was developed to guide each interview. For the English interview agenda please refer to Addendum E and for the Afrikaans version please see Addendum F. It was decided, for the current study to obtain, transcribe and analyse the dataset obtained from all seven questions from each individual interview.

The interviews were recorded, with the written, informed assent of the participants and consent from a caregiver. The voice recordings were saved in a digital format on a password-protected computer at the North-West University Vaal Triangle campus, but the recordings were deleted from the original recording device. The reason for recording the interviews was to guarantee that the researcher secured access to the rich data provided by the meeting. Recording interviews allows the researcher to focus on the discussion during the interview, rather than being concerned about making accurate notes (Nieuwenhuis, 2007).

1.10 Data analyses

The unprocessed primary data (digital voice-recordings) from the individual interviews were transcribed by the members of the research team. All hard copies of the interviews were transcribed verbatim, after which the hard copies were shredded. Transcribed copies were available in an electronic format and were also stored on a password-protected computer at the North-West University's Vaal Triangle Campus. Heritage (1998) emphasises the value to be gained from transcribing. Transcribing can give access to numerous interpretations of the text, augmenting the quality of interaction. It can accentuate ideas that might otherwise have been disregarded during the interview process. The relationship between the researcher and

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

participants can also be reviewed through the transcripts. It furthermore allows the interview to be re-visited as often as necessary.

The researcher analysed the data using thematic data analysis. This technique is an extensively used method when analysing qualitative data in the social sciences domain (Braun & Clarke, 2006; Roulston, 2001). Thematic analysis is used for identifying and examining themes within data and then integrating the themes into meaningful accounts of the quintessence of the phenomenon. A theme portrays something significant about the data in relation to the research question, and signifies some level of patterned response or meaning within the data set (Braun & Clarke, 2006). The themes that were generated from the qualitative data will be used to compare theory; theory will not be adopted as the framework of the analysis in order to stay true to the inductive nature of qualitative data analysis. The datasets were coded using the software ATLAS.ti, a computer assisted qualitative data analysis software. The use of such a programme is strongly recommended, because it accelerates the process of analysis by giving the researcher access to coded text quotations in a highly penetrating format. This, in turn, facilitates analysis, allowing the researcher to concentrate on conceptual issues, without having to worry about saving and recovering information (Attride-Stirling, 2001). The researcher analysed the data using Braun and Clarke's (2006) six phases of thematic data analysis, as described in the following paragraph.

During phase one the researcher read through each transcript repeatedly to get acquainted with the data. In addition, she wrote down original thoughts, and highlighted and made notes of preliminary significances as they emerged. In phase two, the researcher systematically went through each transcript again to identify initial codes relating to the research question. Subsequently, in phase three, these initial codes were categorised into potential themes, with

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

pertinent coded data extracts assembled within the themes. Phase four involved the refinement of the themes in relation to the coded data extracts and the entire data set. The validity of the themes was assessed in terms of the dataset. A list of all the themes was made, grouping relevant ones together. Phase five entailed defining, refining and naming themes. This was done to obtain an enhanced appreciation of the essence of each theme. Following the researcher's data analysis, the data were analysed by an independent co-coder (using the same process) to enhance rigour. Both the researcher and co-coder have training in qualitative analyses. The researcher, co-coder and the supervisor then discussed the findings of the qualitative data analysis and reached consensus regarding the main themes emanating from the data and their final organisation. Phase six consisted of constructing a research report (section II), in which the theme-based evidence within the data (i.e. data extracts), as well as the interpretation and discussion of the qualitative findings of the study, were elucidated (Braun & Clarke, 2006).

Braun and her colleague's (2006) approach to thematic analysis were applicable to the current study because the authors acknowledged the current study's aspiration to integrate the experiences of the individual participants and the significance they attribute to them. The benefit of using thematic analysis is that the researcher can appraise the data and attain codes based on intuition, reflection and experience (Fereday & Muir-Cochrane, 2006). Braun and Clarke (2006) suggest that this method is valuable in qualitative research because of its adaptability in application and method. After completion of the thematic analysis for this study, a criteria list consisting of 15 items (Table 2) was used as checklist for good thematic analysis (Braun & Clarke, 2006).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Table 2

A 15-point checklist of criteria when doing thematic analyses (Braun & Clarke, 2006)

Procedure	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate degree of detail and the transcripts have been checked against the data for accuracy.
Coding	2	Each data item has been given equal consideration during the coding process.
	3	A thorough and comprehensive coding process has been done.
	4	All relevant extracts for each theme have been assembled.
	5	Themes have been checked against each other and the original dataset.
	6	Themes are internally rational, consistent and characteristic.
	Analysis	7
8		Analysis and data match each other – the extracts illuminate the analytical claims.
9		Analysis conveys a convincing and well-organised account of the data and the topic.
10		A good balance between analytic narrative and illustrative extracts is offered.
General	11	Adequate time has been allotted to complete all phases of the analysis comprehensively.
Written report	12	The postulation about, specific approach to and thematic analysis are distinctly clarified.
	13	The described method and reported analysis are reliable.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is actively involved in the research process.

1.11 Trustworthiness

The trustworthiness of research refers to its soundness and is a measure of ethical, high quality research (Merriam, 2009). Lincoln and Guba (1985) proposed four criteria that should be considered by qualitative researchers in pursuit of a trustworthy study, namely credibility, transferability, confirmability and dependability.

1.11.1 Credibility

Credibility refers to confidence in the truth of the findings (Creswell, 2009). This involves establishing that the results of the research are authentic from the perspective of the

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

participants, researcher and readers of the research (Janesick, 2000). To ensure credibility, the researcher has employed the following measures:

- The researcher did a thorough literature review to gain as much understanding as possible about the research topic.
- The use of gatekeepers at the CDE ensured that the participants who were recruited were able to make meaningful contributions to the current study, thereby contributing to the integrity of the research.
- Credibility was further enhanced through the use of clarification during the interviews (member checking level 1).
- The interviews were audiotaped and were transcribed verbatim to ensure the accuracy of the data and to exclude misunderstandings.
- A co-coder analysed the data and compared this analysis with that compiled by the researcher. Furthermore, the researcher's supervisor and a panel of medical experts peer-reviewed the thematic analysis and findings to incorporate analyst triangulation. It was declared that the research is dependable (Denzin & Lincoln, 2005).
- Credibility was also augmented by the heterogeneity of the sample, which allowed for the exploration of a vast range of participants' illness perceptions and how it aids in managing diabetes well.

1.11.2 Transferability

This refers to the applicability of the data and the degree to which it could be applied to different contexts (Tobin & Begley, 2004). In short, transferability means that when the research report is read, the narrative should be able to satisfy readers that they might have encountered the same scenario in different circumstances, guiding them to strongly associate with the situation

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

that is being described (Creswell, 2009; Malterud, 2001). To ensure transferability, the researcher has employed the following measures:

- A dense description of the research context, methodology and procedures was provided, contributing to transferability in that good contextualisation occurred.
- In this study participants' illness perceptions and how they helped them to manage diabetes well were described using verbatim quotations to ensure that enough detail was available to allow for transferability.
- The aim was to provide an understanding of the perceptions, not to generalise; therefore the transferability of the results is the onus of the user of the findings.

1.11.3 Confirmability

Confirmability is to ensure neutrality, guaranteeing freedom from bias during the research process (Creswell, 2009; Tobin & Begley, 2004). Confirmability in this study was affected in the following ways:

- The researchers wrote field notes on the same day of every interview.
- Throughout the study the researcher was vigilant with respect to her own prejudices, assumptions and beliefs, and endeavoured to be open-minded so that the data could speak for itself.
- The researcher and the co-coder did data analysis independently and agreed on categories and themes in an organised meeting to confirm their findings. This process was also documented.
- Peer review was done by eliciting inputs from the study supervisor, independent reviewers and experts/stakeholders in the diabetes research field.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Sufficient participant quotations are provided and therefore the findings are deemed credible because they are grounded in data rather than in assumptions.
- Neutrality was achieved when credibility and transferability were achieved.

1.11.4 Dependability

This relates to the consistency of the data and, according to Creswell (2009), it concerns whether the findings of the inquiry can be reproduced with the same participants and in a similar context. To achieve dependability, the following measures were taken into account:

- The research question was stated clearly and the features of the study design were congruent with it.
- All the data were documented and kept safely on password-protected computers or locked cupboards at the North-West University's Vaal Triangle Campus. Interview materials, transcriptions, data analysis and interpretations, and any other material relevant to the study will be made available and accessible to any other researcher for the purpose of conducting an audit trail.
- Data analysis was done using Braun and Clarke's (2006) six phases approach and the co-coder adopted the same approach to conduct analysis on her own.
- Consensus discussions were held with an independent coder and the researcher's supervisor.

Based on the applications discussed above, the findings of this qualitative study can be regarded as trustworthy.

1.12 Ethical considerations

Ethical approval was granted for the principal project (NWU-HS-2015-0111) (see attached addendum A). Based on approval by the Humanities and Health Research Ethics Committee (HHREC), the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) evaluated the ethical merits and granted permission for the current study as well (NWU-HS-2016-0066) (see attached addendum B). The crucial objective of research ethics is to safeguard the welfare of research participants by valuing their rights, needs and principles (Bless et al., 2006).

The sample of the current study belongs to a physically and potentially psychologically vulnerable population. Their vulnerability stems from their diagnosis (type 1 diabetes mellitus), as well as their age (still minors). Arrangements were in place to obtain independent, informed written consent and assent from the legal guardian of each participant, as well as from the participants themselves (see attached Addendum C and D). Care was taken to protect the participants' rights to confidentiality and autonomy and to guarantee and respect their decision to withdraw from the process at any stage if they felt so inclined.

Confidentiality was safeguarded, given that only the researchers had access to the obtained data. The anonymity of each participant was accomplished by providing each participant with a participant code. This code was indicated on both the consent and assent forms of the participants prior to the separate storage of these forms, to ensure that no link could be made between the participants' findings and their identities. Opportunities for debriefing by qualified professionals were made available to all the participants.

1.13 Incentives and therapeutic benefit

The offering of incentives or compensation to participants was a standard practice of the ethically approved overarching research project. The participants received a bottle of still water, a low carbohydrate snack and an information leaflet on diabetes management before or after the completion of the interview. Each participant also received a certificate acknowledging his or her participation and expressing the research team's gratitude for the participant's contribution to the overarching research project. Due to the fact that the larger project will be conducted over several phases, every participant will receive a sticker for his or her participation during each phase. The participants can attach each phase's sticker to their certificate of acknowledgement. The current study contributed to phase 1 of the larger project; thus each of the participants received a sticker after completion of the interview. It is anticipated that both the information leaflet, as well as the certificate, will assist and motivate participants with regard to the management of their diabetes. It may serve as a validation that they are part of a unique, special group and their opinions are important.

After member checking, each participant received an illustration (see attached Addendum I) showing a summary of the current study's findings, as well as positive individual feedback regarding his or her illness perception and how it assisted him/her to manage his/her diabetes well.

1.14 Conclusion

In the first section of this dissertation, the researcher provided a contextualisation of the overarching research project and identified the anticipated contribution of this study. In addition, the motivation for conducting this study was outlined. An overview of the research topic was provided by means of a thorough literature review pertaining to the illness perception of

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

adolescents with well-controlled type 1 diabetes mellitus. The research objectives and methods used to conduct this study were detailed. Lastly, the ethical considerations and potential therapeutic benefit for adolescents partaking in this research were outlined.

The next section will comprise the author guidelines of the Journal of Diabetes Research and Clinical Practice. The article, titled 'Illness perception of adolescents with well-controlled type 1 diabetes' will be submitted to this journal for publication.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

References

Abualula, N. A., Jacobsen, K. H., Milligan, R. A., Rodan, M. F., & Conn, V. S. (2016).

Evaluating diabetes educational interventions with a skill development component in adolescents with type 1 diabetes: a systematic review focusing on quality of life. *The Diabetes Educator*, *42*(5), 515-528. doi:10.1177/0145721716658356

Ahn, S., & Fedewa, A. L. (2011). A meta-analysis of the relationship between children's physical activity and mental health. *Journal of Pediatric Psychology*, *36*(4), 385-397. doi:10.1093/jpepsy/jsq107

American Diabetes Association. (2009). Standards of medical care in diabetes. *Diabetes Care*, *32*(1), 13–61. doi:10.2337/dc09-S013

American Diabetes Association. (2010). Diagnosis and classification of diabetes mellitus. *Diabetes Care*, *33*(1), 62-69. doi:10.2337/dc10-S062

Anderson, R. M., Fitzgerald, J. T., Gorenflo, D. W., & Oh, M. S. (1993). A comparison of the diabetes-related attitudes of health care professionals and patients. *Patient Education and Counseling*, *21*, 41-50.

Ashraff, S., Siddiqui, M. A., & Carline, T. E. (2013). The psychosocial impact of diabetes in adolescents: a review. *Oman Medical Journal*, *28*(3), 159-162. doi:10.5001/omj.2013.46

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, *1*(3), 385- 405.

Azevedo, M., & Alla, S. (2008). Diabetes in Sub-Saharan Africa: Kenya, Mali, Mozambique,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Nigeria, South Africa and Zambia. *International Journal of Diabetes in Developing Countries*, 28(4), 101–108. doi:10.4103/0973-3930.45268

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, 31(2), 143-164. doi:10.1177/1090198104263660

Bell, K. J., Barclay, A. W., Petocz, P., Colagiuri, S., & Brand-Miller, J. C. (2013). Efficacy of carbohydrate counting in type 1 diabetes: a systematic review and meta-analysis. *Lancet*, 2(2), 133–140. doi:10.1016/S2213-8587(13)70144-x

Beraki, Å., Magnuson, A., Särnblad, S., Åman, J., & Samuelsson, U. (2014). Increase in physical activity is associated with lower HbA1c levels in children and adolescents with type 1 diabetes: results from a cross-sectional study based on the Swedish pediatric diabetes quality registry (SWEDIABKIDS). *Diabetes Research and Clinical Practice*, 105(1), 119-125.

Bernstein, C. M., Stockwell, M. S., Gallagher, M. P., Rosenthal, S. L., & Soren, K. (2013). Mental health issues in adolescents and young adults with type 1 diabetes: prevalence and impact on glycemic control. *Clinical Pediatrics*, 52(1), 10–15.
doi:10.1177/0009922812459950

Berry, J. G., Bloom, S., Foley, S., & Palfrey, J. S. (2010). Health inequity in children and youth with chronic health conditions. *Pediatrics*, 126(3), 111-119.
doi:10.1542/peds.2010-1466D

Bless, C., Higson-Smith, C., & Kagee, A. (2006). *Fundamentals of social research methods: An African perspective*. Cape Town, SA: Juta.

Boehm, J. K., & Kubzansky, L. D. (2012). The heart's content: the association between

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- positive psychological well-being and cardiovascular health. *Psychological Bulletin*, 138(4), 655– 691. doi:10.1037/a0027448
- Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current Opinion in Pediatrics*, 22(4), 405–411. doi:10.1097/MOP.0b013e32833a46a7
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77 – 101.
- Broadbent, E., Donkin, L., & Stroh, J. C. (2011). Illness and treatment perceptions are associated with adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care*, 34(2), 338–340. doi:10.2337/dc10-1779
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60, 631– 637.
doi:10.1016/j.jpsychores.2005.10.020
- Bryden, K. S., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care*, 24, 1536–1540.
- Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: a systematic review and meta-analysis. *Psychoneuroendocrinology*, 70, 70-84.
doi:10.1016/j.psyneuen.2016.04.019

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Chaney, D., Coates, V., Shevlin, M., Carson, D., McDougall, A., & Long, A. (2012).

Diabetes education: what do adolescents want? *Journal of Clinical Nursing*, *21*(1-2), 216-223. doi:10.1111/j.1365-2702.2010.03692.x

Cheung, R., Young Cureton, V., & Canham, D. L. (2006). Quality of life in adolescents with type 1 diabetes who participate in diabetes camp. *The Journal of School Nursing*, *22*(1), 53-58.

Chevreur, K., Berg Brigham, K., & Bouché, C. (2014). The burden and treatment of diabetes in France. *Globalization and Health*, *10*(1), 6-14. doi:10.1186/1744-8603-10-6

Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 diabetes through the lifespan: a position statement of the American Diabetes Association. *Diabetes Care*, *37*(7), 2034-2054. doi:10.2337/dc14-1140

Coffen, R. D. (2009). The 600-step program for type 1 diabetes selfmanagement in youth: the magnitude of the self-management task. *Postgraduate Medicine*, *121*(5), 119– 139. doi:10.3810/pgm.2009.09.2059

Comeaux, S. J., & Jaser, S. S. (2010). Autonomy and insulin in adolescents with type 1 diabetes. *Paediatric Diabetes*, *11*(7), 498-504. doi:10.1111/j.1399- 5448.2009.00625.x

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, *8*, 455–480. doi:10.1146/annurev-clinpsy-032511-143108

Compton, W. C., & Hoffman, E. (2013). *Positive psychology – The science of happiness and flourishing* (2nd ed.). Belmont, CA: Wadsworth.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Cooke, D. W., & Plotnick, L. (2008). Type 1 diabetes mellitus in pediatrics. *Pediatrics in Review*, 29(11), 374-384. doi:10.1542/pir.29-11-374
- Coolican, H. (2014). *Research methods and statistics in psychology* (6th ed.). New York, NY: Psychology Press.
- Creswell, J. (2009). *Research design: Qualitative, quantitative and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview based qualitative research. *Social Science Information*, 45(4), 483-499.
- Datye, K. A., Moore, D. J., Russell, W. E., & Jaser, S. S. (2015). A review of adolescent adherence in type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. *Current Diabetes Reports*, 15(8), 621-638. doi:10.1007/s11892-015-0621-6
- de Wit, M., & Snoek, F. J. (2011). Depressive symptoms and unmet psychological needs of Dutch youth with type 1 diabetes: results of a web-survey. *Pediatric Diabetes*, 12, 172-176. doi:10.1111/j.1399-5448.2010.00673.x
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks, CA: Sage.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40, 314-321. doi:10.1111/j.1365-2929.2006.02418
- Distiller, L. A., Brown, M. A., Joffe, B. I., & Kramer, B. D. (2010). Striving for the

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- impossible dream: a community-based multi-practice collaborative model of diabetes management. *Diabetic Medicine*, 27(2), 197-202. doi:10.1111/j.1464-5491.2009.02907.x
- Ellis, P. (2016). *Understanding research for nursing students* (3rd ed.). Thousand Oaks, CA: Sage.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 1-11.
- Fortenberry, K. T., Berg, C. A., King, P. S., Stump, T., Butler, J. M., Pham, P. K., & Wiebe, D. (2014). Longitudinal trajectories of illness perceptions among adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 39(7), 687–696. doi:10.1093/jpepsy/jsu043
- Franciosi, M., Lucisano, G., Amoretti, R., Capani, F., Bruttomesso, D., Di Bartolo, P., ... Nicolucci, A. (2013). Costs of treatment and complications of adult type 1 diabetes. *Nutrition, metabolism, and cardiovascular diseases*, 23(7), 606–611.
- Gabriel, B. D., Albuquerque, C. T., Consoli, M. L. D., Menezes, P. A. F. C., & Reis, J. S. (2016). Training adolescents with type 1 diabetes to carbohydrate counting without parents' help. *Revista de Nutrição*, 29(1), 77-84.
- Gandhi, K., Vu, B. K., Eshtehardi, S. S., Wasserman, R. M., & Hilliard, M. E. (2015). Adherence in adolescents with type 1 diabetes: strategies and considerations for assessment in research and practice. *Diabetes management (London, England)*, 5(6), 485–498. doi:10.2217/dmt.15.41
- Gillespie, S. J., Kulkarni, K. D., & Daly, A. E. (1998). Using carbohydrate counting in diabetes clinical practice. *Journal of the American Dietetic Association*, 98(8), 897-905.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology & Health, 15*(6), 733-750. doi:10.1080/08870440008405578

Grix, J. (2002). Introducing students to the generic terminology of social research. *Politics, 22*(3), 175-186.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the Common-Sense Model of illness representations. *Psychology & Health, 18*(2), 141-184.
doi:10.1080/088704403100081321

Hagger, V., Trawley, S., Hendrieckx, C., Browne, J. L., Cameron, F., Pouwer, F., ... Speight, J. (2016). Diabetes MILES Youth-Australia: methods and sample characteristics of a national survey of the psychological aspects of living with type 1 diabetes in Australian youth and their parents. *BMC Psychology, 4*(1), 42-55. doi:10.1186/s40359-016-0149-9

Hapunda, G., Abubakar, A., van de Vijver, F., & Pouwer, F. (2015). Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC Endocrine Disorders, 15*, 20-39.
doi:10.1186/s12902-015-0013-6

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Hefferon, K., & Boniwell, I. (2011). *Positive psychology: Theory, research and applications*.

Berkshire, UK: McGraw-Hill.

Helgeson, V. S., Siminerio, L., Escobar, O., & Becker, D. (2009). Predictors of metabolic control among adolescents with diabetes: a 4-year longitudinal study. *Journal of Pediatric Psychology, 34*(3), 254–270. doi:10.1093/jpepsy/jsn079

Herzer, M., & Hood, K. K. (2010). Anxiety symptoms in adolescents with type 1 diabetes: Association with blood glucose monitoring and glycemic control. *Journal of Pediatric Psychology, 35*(4), 415–425. doi:10.1093/jpepsy/jsp063

Hilliard, M. E., Wu, Y. P., Rausch, J., Dolan, L. M., & Hood, K. K. (2013). Predictors of deteriorations in diabetes management and control in adolescents with type 1 diabetes. *Journal of Adolescent Health, 52*(1), 28–34. doi:10.1016/j.jadohealth.2012.05.009

Hinzmann, R., Schlaeger, C., & Tran, C. T. (2010). What do we need beyond hemoglobin A1c to get the complete picture of glycemia in people with diabetes? *International Journal of Medical Sciences, 9*(8), 665-681. doi:10.7150/ijms.4520

Hood, K. K., Peterson, C. M., Rohan, J. M., & Drotar, D. (2010). Association between adherence and glycemic control in pediatric type 1 diabetes: a meta-analysis. *Pediatrics, 124*, 1171-1179

Howitt, D. (2010). *Introduction to qualitative methods in Psychology*. Essex, UK: Pearson.

Husted, G. R., Esbensen, B. A., Hommel, E., Thorsteinsson, B., & Zoffmann, V. (2014). Adolescents developing life skills for managing type 1 diabetes: a qualitative, realistic evaluation of a guided self-determination-youth intervention. *Journal of Advanced Nursing, 70*(11), 2634–2650. doi:10.1111/jan.12413

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Inagaki, K., & Hatano, G. (2006). Young children's conception of the biological world.

Current Directions in Psychological Science, 15(4), 177-181. doi:10.1111/j.1467-8721.2006.00431.x

Jain, V. (2014). Management of type 1 diabetes in children and adolescents. *The Indian*

Journal of Pediatrics, 81(2), 170–177. doi:10.1007/s12098-013-1196-3

Janesick, V. J. (2000). The choreography of qualitative research design. In N. K. Denzin, &

Y. S. Lincoln (Eds.). *Handbook of Qualitative Research* (pp. 379 – 399). London, UK: Sage.

Johnson, B., Eiser, C., Young, V., Brierley, S., & Heller, S. (2013). Prevalence of depression

among young people with type 1 diabetes: a systematic review. *Diabetic Medicine*, 30(2), 199-208. doi:10.1111/j.1464-5491.2012.03721.x

Kalk, W. J., Raal, F. J., & Joffe, B. I. (2010). The prevalence and incidence of and risk

factors for micro-albuminuria among urban Africans with type 1 diabetes in South Africa: an inter-ethnic study. *International Journal of Diabetes Mellitus*, 2(3), 148–153. doi:10.1016/j.ijdm.2010.10.003

Kalweit, K. L., Briers, N., & Olorunju, S. (2015). The success of various management

techniques used in South African children with type 1 diabetes mellitus. *The South African Medical Journal*, 105(5), 400-404. doi:10.7196/samj.9334

Kaul, K., Tarr, J. M., Ahmad, S. I., Kohner, E. M., & Chibber, R. (2012). Introduction to

diabetes mellitus. *Advances in Experimental Medicine and Biology*, 771, 1-10.

King, P. S., Berg, C. A., Butner, J., Butler, J. M., & Wiebe, D. J. (2014). Longitudinal

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- trajectories of parental involvement in type 1 diabetes and adolescents' adherence. *Journal of Health Psychology*, 33(5), 424-432. doi:10.1037/a0032804
- Kirigia, J. M., Sambo, H. B., Sambo, L. G., & Barry, S. P. (2009). Economic burden of diabetes mellitus in the WHO African region. *BMC International Health and Human Rights*, 9(6), 1- 12. doi:10.1186/1472-698X-9-6
- Larun, L., Nordheim, L. V., Ekeland, E., Hagen, K. B., & Heian, F. (2006). Exercise in prevention and treatment of anxiety and depression among children and young people. *The Cochrane Database of Systematic Reviews*, 19(3), CD004691. doi:10.1002/14651858.CD004691.pub2
- Law, G. U., Kelly, T. P., Huey, D. D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: do illness representations play a regulatory role? *Journal of Adolescent Health*, 31(4), 381-385.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L., & Robitaille, C. (1997). Illness perceptions: Theoretical foundations. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 19-45). Amsterdam, Netherlands: Harwood Academic.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lung, T. W., Clarke, P. M., Hayes, A. J., Stevens, R. J., & Farmer, A. (2013). Simulating lifetime outcomes associated with complications for people with type 1 diabetes. *Pharmacoeconomics*, 31(6), 509-518. doi:10.1007/s40273-013-0047-4
- Macaskill, A. (2016). Review of positive psychology applications in clinical medical populations. *Healthcare*, 4, 66-75. doi:10.3390/healthcare4030066.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet*, 358, 483-488.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*, 13(6), 522-525.
- McAndrew, L. M., Musumeci-Szabo, T. J., Moral, P. A., Vileikyte, L., Burns, E., Halm, E. A., ... Leventhal, H. (2008). Using the common sense model to design interventions for the prevention and management of chronic illness threats: from description to process. *British Journal of Health Psychology*, 13, 195–204. doi:10.1348/135910708X295604
- Mc Sharry, J., Moss-Morris, R., & Kendrick, T. (2011). Illness perceptions and glycaemic control in diabetes: a systematic review with meta-analysis. *Diabetic Medicine*, 28(11), 1300-1310. doi:10.1111/j.1464-5491.2011.03298.x
- Mehta, S. N., Volkening, L. K., Anderson, B. J., Nansel, T., Weissberg-Benchell, J., Wysocki, T., & Laffel, L. M. (2008). Dietary behaviors predict glycemic control in youth with type 1 diabetes. *Diabetes Care*, 31(7), 1318-1320. doi:10.2337/dc07-2435
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation* (2nd ed.). San Francisco, CA: Jossey-Bass.
- Miculis, C. P., De Campos, W., & da Silva Boguszewski, M. C. (2015). Correlation between glycemic control and physical activity level in adolescents and children with type 1 diabetes. *Journal of Physical Activity and Health*, 12(2), 232-237. doi:10.1123/jpah.2013-0024
- Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., ...Drotar, D. (2012). Pediatric self-management: a framework for research, practice, and policy. *Pediatrics*, 129(2), 473-485. doi:10.1542/peds.2011-1635

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Moss-Morris, R., Weinman, J., Petrie, K. J., & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health, 17*(1), 1-16.
doi:10.1080/08870440290001494
- Nieuwenhuis, J. (2007). Qualitative research design and data gathering techniques. In K. Maree (Eds.), *First steps in research* (pp. 81 – 93). Pretoria, SA: Van Schaik.
- Olsen, B., Berg, C. A., & Wiebe, D. J. (2008). Dissimilarity in mother and adolescent illness representations of type 1 diabetes and negative emotional adjustment. *Psychology and Health, 23*(1), 113-129. doi:10.1080/08870440701437343
- Onwuegbuzie, A. J., & Leech, N. L. (2007). Sampling designs in qualitative research: making the sampling process more public. *The Qualitative Report, 12*(2), 238-254.
- Patiño-Fernández, A. M., Delamater, A. M., Applegate, E. B., Brady, E., Eidson, M., Nemery, R., ... Richton, S. (2010). Neurocognitive functioning in preschool-age children with type 1 diabetes mellitus. *Pediatric Diabetes, 11*, 424–430. doi:10.1111/j.1399-5448.2009.00618.x
- Patterson, C., Guariguata, L., Dahlquist, G., Soltész, G., Ogle, G., & Silink, M. (2014). Diabetes in the young – a global view and worldwide estimates of numbers of children with type 1 diabetes. *Diabetes Research and Clinical Practice, 103*(2), 161-175.
doi:10.1016/j.diabres.2013.11.005
- Patton, S. R. (2015). Adherence to glycemic monitoring in diabetes. *The Journal of Diabetes Science and Technology, 9*(3), 668-675. doi:10.1177/1932296814567709
- Peters, A., & Laffel, L. (2011). Diabetes care for emerging adults: recommendations for

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- transition from pediatric to adult diabetes care systems. *Diabetes Care*, *34*(11), 2477-2485. doi:10.2337/dc11-1723
- Petrie, K. J., Jago, L. A., & Devcich, D. A. (2007). The role of illness perceptions in patients with medical conditions. *Current Opinion in Psychiatry*, *20*, 163–167.
- Petrie, K. J., & Weinman, J. (2012). Patients' perceptions of their illness: the dynamo of volition in health care. *Current Directions in Psychological Science*, *21*(1), 60–65. doi:10.1177/0963721411429456
- Peyrot, M., Rubin, R. R., Lauritzen, T., Snoek, F. J., Matthews, D. R., & Skovlund, S. E. (2004). Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) study. *Diabetic Medicine*, *22*, 1379–1385.
- Pires-Yfantouda, R., & Evangeliki, M. (2012). The role of psychosocial factors in wellbeing and self-care in young adults with type 1 diabetes. *International Journal of Diabetes Research*, *1*(1), 1-6. doi:10.5923/j.diabetes.20120101.01
- Polkinghorne, D. E. (2005). Language and meaning: data collection in qualitative research. *Journal of Counseling Psychology*, *52*(2), 137–145.
- Quirk, H., Blake, H., Tennyson, R., Randell, T. L., & Glazebrook, C. (2014). Physical activity interventions in children and young people with type 1 diabetes mellitus: a systematic review with meta-analysis. *Diabetic Medicine*, *1*(10), 1163-1173. doi:10.1111/dme.12531
- Reddy, Y., Ganie, Y., & Pillay, K. (2013). Characteristics of children presenting with newly

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

diagnosed type 1 diabetes. *The South African Journal of Child Health*, 7(2), 46-48.

doi:10.7196/SAJCH.500

Rewers, M., Pihoker, C., Donaghue, K., Hanas, R., Swift, P., & Klingensmith, G. J. (2009).

Assessment and monitoring of glycemic control in children and adolescents with

diabetes. *Pediatric Diabetes*, 10(12), 71–81. doi:10.1111/j.1399-5448.2009.00582.x

Reynolds, K. A., & Helgeson, V. S. (2011). Children with diabetes compared to peers:

depressed? distressed? *Journal of the Society of Behavioral Medicine*, 42(1), 29–41.

doi:10.1007/s12160-011-9262-4

Ritchie, J. (2009). The applications of qualitative methods to social research. In J. Ritchie &

J. Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp.26 – 34). London, UK: Sage.

Ritchie, J., Lewis, J., & Elam, G. (2009). Designing and selecting samples. In J. Ritchie & J.

Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp.77 – 85). London, UK: Sage.

Roulston, K. (2001). Data analysis and ‘theorizing as ideology’. *Qualitative Research*, 1(3),

279-302.

Roze, S., Saunders, R., Brandt, A. S., de Portu, S., Papo, N. L., & Jendle, J. (2015). Health-

economic analysis of real-time continuous glucose monitoring in people with type 1

diabetes. *Diabetic Medicine*, 32(5), 618-626. doi:10.1111/dme.12661

Safo, S. A., Batchelder, A., Peyser, D., & Litwin, A. H. (2015). The common sense model

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

applied to hepatitis C: a qualitative analysis of the impact of disease comparison and witnessed death on hepatitis C illness perception. *Harm Reduction Journal*, 12, 20-28.
doi:10.1186/s12954-015-0054-1

Sarantakos, S. (2013). *Social research*. London, UK: Palgrave Macmillan.

Schabert, J., Browne, J. L., Mosely, K., & Speight, J. (2013). Social stigma in diabetes. A framework to understand a growing problem for an increasing epidemic. *Patient*, 6(1), 1–10. doi:10.1007/s40271-012-0001-0

Schilling, L. S., Grey, M., & Knafl, K. A. (2002). The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis. *The Australian Journal of Advanced Nursing*, 37(1), 87-99.

Seth, A., & Maheshwari, A. (2013). Common endocrine problems in children (hypothyroidism and type 1 diabetes mellitus). *The Indian Journal of Pediatrics*, 80(8), 681–687. doi:10.1007/s12098-013-1101-0

Sharma, N., O'Hare, K., Antonelli, R. C., & Sawicki, G. S. (2014). Transition care: future directions in education, health policy, and outcomes research. *Academic Pediatrics*, 14(2), 120-127. doi:10.1016/j.acap.2013.11.007

Sharma, B. D., & Singal, P. (2015). The utility and pitfalls of the currently used measures of glycaemia in the diagnosis and management of diabetes mellitus. *Journal, Indian Academy of Clinical Medicine*, 16(3-4), 227-235.

Sherwood, L. (2010). *Human Physiology : From cells to systems* (7th ed.). Belmont, CA: Brooks/Cole.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., ... Clark, N. (2005). Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care*, 28(1), 186–212.
- Skinner, C. T., John, M., & Hampson, S. E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. *Journal of Pediatric Psychology*, 25(4), 257-267.
- Smart, C. E., Ross, K., Edge, J. A., King, B. R., McElduff, P., & Collins, C. E. (2010). Can children with type 1 diabetes and their caregivers estimate the carbohydrate content of meals and snacks? *Diabetic Medicine*, 27(3), 348-353. doi:10.1111/j.1464-5491.2010.02945.x
- Smetana, J. G., Campione-Barr, N., & Metzger, A. (2006). Adolescent development in interpersonal and societal contexts. *Annual Review of Psychology*, 57, 255-284. doi:10.1146/annurev.psych.57.102904.190124
- Snape, D., & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp. 1 – 23). London, UK: Sage.
- Snoek, F. J., & Skinner, C. T. (2006). Psychological aspects of diabetes management. *Medicine*, 34(2), 61 – 62.
- Spear, H. J., & Kulbok, P. (2004). Autonomy and adolescence: a concept analysis. *Public Health Nursing*, 21(2), 144–152. doi:10.1111/j.0737-1209.2004.021208.x
- Spiegel, G., Bortsov, A., Bishop, F. K., Owen, D., Klingensmith, G. J., Mayer-Davis, E. J., &

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Maahs, D. M. (2012). Randomized nutrition education intervention to improve carbohydrate counting in adolescents with type 1 diabetes study: is more intensive education needed? *Journal of the Academy of Nutrition and Dietetics*, *112*(11), 1736-1746. doi:10.1016/j.jand.2012.06.001
- Steptoe, A., Deaton, A., & Stone, A. A. (2015). Subjective wellbeing, health, and ageing. *Lancet*, *385*(9968), 640–648. doi:10.1016/S0140-6736(13)61489-0
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388– 396.
- Tully, C., Aronow, L., Mackey, E., & Streisand, R. (2016). Physical activity in youth with type 1 diabetes: a review. *Current Diabetes Reports*, *16*(9), 85-93. doi:10.1007/s11892-016-0779-6
- Tumbo, J. M., & Kadima, F. N. (2013). Screening of long-term complications and glycaemic control of patients with diabetes attending Rustenburg Provincial Hospital in North West Province, South Africa. *African Journal of Primary Health Care & Family Medicine*, *5*(1), 375– 380. doi:10.4102/phcfm.v5i1.375
- Tuomilehto, J. (2013). The emerging global epidemic of type 1 diabetes. *Current Diabetes Reports*, *13*(6), 795-804. doi:10.1007/s11892-013-0433-5
- Uprichard, E. (2013). Sampling: bridging probability and non-probability designs. *International Journal of Social Research Methodology*, *16*(1), 1 – 11.
- Wadén, J., Forsblom, C., Thorn, L. M., Saraheimo, M., Rosengård-Bärlund, M., Heikkilä, O.,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- ... Groop, P.-H. (2009). Adult stature and diabetes complications in patients with type 1 diabetes: the FinnDiane Study and the Diabetes Control and Complications Trial. *Diabetes*, 58(8), 1914–1920. doi:10.2337/db08-1767
- Weinman, J., & Petrie, K. J. (1997). Illness perception: a new paradigm for psychosomatics? *Journal of Psychosomatic Research*, 42(2), 113-116.
- Wiebe, D. J., Man Chow, C., Palmer, D. L., Butner, J., Butler, J. M., Osborn, P., & Berg, C. A. (2014). Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence. *Journal of Pediatric Psychology*, 39(5), 532–541. doi:10.1093/jpepsy/jsu006
- Winocour, P. H. (2014). Care of adolescents and young adults with diabetes – much more than transitional care: a personal view. *Clinical Medicine Journal of the Royal College of Physicians*, 14(3), 274-278. doi:10.7861/clinmedicine.14-3-274
- Witteaman, C., Bolks, L., & Hutschemaekers, G. (2011). Development of the illness perception questionnaire mental health. *Journal of Mental Health*, 20(2), 115–125. doi:10.3109/09638237.2010.507685
- Wodrich, D. L., Hasan, K., & Parent, K. B. (2011). Type 1 diabetes mellitus and school: a review. *Pediatric Diabetes*, 12(1), 63-70. doi:10.1111/j.1399-5448.2010.00654.x
- Wylie-Rosett, J., Aebersold, K., Conlon, B., & Ostrovsky, N. W. (2012). Medical nutrition therapy for youth with type 1 diabetes mellitus: more than carbohydrate counting. *Journal of the Academy of Nutrition Dietetics*, 112(11), 1724-1727.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Ziegler, R., Heidtmann, B., Hilgard, D., Hofer, S., Rosenbauer, J., & Holl, R. (2011).

Frequency of SMBG correlates with HbA1c and acute complications in children and adolescents with type 1 diabetes. *Pediatric Diabetes*, 12(1), 11–17. doi:10.1111/j.1399-5448.2010.00650.x

CHAPTER 2: INTENDED JOURNAL AND AUTHOR GUIDELINES

2.1 Manuscript format and structure

Journal Principles

All manuscripts submitted to *Diabetes Research and Clinical Practice* should report original research not previously published or being considered for publication elsewhere, make explicit any conflict of interest, identify sources of funding and generally be of a high ethical standard.

Submission of a manuscript to this journal gives the publisher the right to publish that paper if it is accepted. Manuscripts may be edited to improve clarity and expression. Submission of a paper to *Diabetes Research and Clinical Practice* is understood to imply that it has not previously been published and that it is not being considered for publication elsewhere.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details. Ensure that the following items are present:

1. One author has been designated as the corresponding author with contact details:

- E-mail address
- Full postal address

2. All necessary files have been uploaded:

Manuscript:

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)

Supplemental files (where applicable)

3. Further considerations

- Manuscript has been 'spell checked' and 'grammar checked'
- All references mentioned in the Reference List are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- Relevant declarations of interest have been made
- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop.

Patients and Study Participants

Studies on patients or volunteers require ethics committee approval and informed consent which should be documented in your paper.

Patients have a right to privacy. Therefore identifying information, including patient's photographs, pedigree, images, names, initials, or hospital numbers, should not be included in the submissions unless the information is essential for scientific purposes and written informed consent has been obtained for publication in print and electronic form from the patient (or parent, guardian or next of kin). If such consent is made subject to any conditions, Elsevier must be made aware of all such conditions. Written consents must be provided to the journal on request.

Even where consent has been given, identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve. For example, masking the eye region in

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note.

Submission

Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

Abbreviations

Abbreviations should be avoided in most cases or at least fully defined on first use. Clinical research values and units should be in Système International (SI) form. Kilocalories should be used rather than kilojoules. The term 'diabetic' should be avoided. Preferred terminology is, for example, 'person with diabetes' or 'in the group without diabetes'. The terms 'Type 1' and 'Type 2 diabetes mellitus' should be used.

HbA1c Values

Author should report glycated haemoglobin (HbA1c) measurement in derived NGSP units (%; to one decimal point) in addition to IFCC (International Federation of Clinical Chemistry) units (mmol/mol; no decimal point). NGSP units should be listed first followed by IFCC units in parentheses. The abbreviation for haemoglobin A1c / glycated haemoglobin - should be HbA1c, not the American version of A1C.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Article structure

Subdivision - numbered sections

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Essential title page information

- Title. Concise and informative. Titles are often used in information-retrieval systems.

Avoid abbreviations and formulae where possible.

- Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

- Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.

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

Structured Abstract: Original Research Articles

An abstract of no more than 250 words should be structured as per following:

- Aims: Reflects the purpose of the study (the hypothesis that is being tested);

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- **Methods:** The setting for the study, the subjects (number and type), the treatment or intervention, and the type(s) of statistical analysis used;
- **Results:** The outcome(s) of the study and, if appropriate, its/their statistical significance;
- **Conclusions:** The significance of the results.

Abstracts for other articles (Commentaries and Reviews) should be written as a single paragraph not to exceed 200 words.

Highlights

Highlights are a short collection of bullet points that convey the core findings of the article. Highlights are optional and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view example Highlights on our information site.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Acknowledgements

All contributors who do not meet the criteria for authorship as defined above should be listed in an acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements: Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa]. It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding. If no funding has been provided for the research, please include the following sentence: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Illustration services

Elsevier's WebShop offers Illustration Services to authors preparing to submit a manuscript but concerned about the quality of the images accompanying their article. Elsevier's expert illustrators can produce scientific, technical and medical-style images, as well as a full range of charts, tables and graphs. Image 'polishing' is also available, where our illustrators take your image(s) and improve them to a professional standard. Please visit the website to find out more.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

References

Citation in text

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

Reference links

Increased discoverability of research and high quality peer review are ensured by online links to the sources cited. In order to allow us to create links to abstracting and indexing services, such as Scopus, CrossRef and PubMed, please ensure that data provided in the references are correct. Please note that incorrect surnames, journal/book titles, publication year and pagination

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

may prevent link creation. When copying references, please be careful as they may already contain errors. Use of the DOI is encouraged.

A DOI can be used to cite and link to electronic articles where an article is in-press and full citation details are not yet known, but the article is available online. A DOI is guaranteed never to change, so you can use it as a permanent link to any electronic article. An example of a citation using DOI for an article not yet in an issue is: VanDecar J.C., Russo R.M., James D.E., Ambeh W.B., Franke M. (2003). Aseismic continuation of the Lesser Antilles slab beneath northeastern Venezuela. *Journal of Geophysical Research*, <http://dx.doi.org/10.1029/2001JB000884i>. Please note the format of such citations should be in the same style as all other references in the paper.

Web references

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

Reference management software

Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley and Zotero, as well as EndNote. Using the word processor plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Users of Mendeley Desktop can easily install the reference style for this journal by clicking the following link: <http://open.mendeley.com/use-citation-style/diabetes-research-and-clinical-practice>. When preparing your manuscript, you will then be able to select this style using the Mendeley plug-ins for Microsoft Word or LibreOffice.

Reference formatting

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

Reference style

Text: Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.

List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

Examples:

Reference to a journal publication:

[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. *J Sci Commun* 2010;163:51–9.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Reference to a book:

[2] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.

Reference to a chapter in an edited book:

[3] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2009, p. 281–304.

Reference to a website:

[4] Cancer Research UK. Cancer statistics reports for the UK, <http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/>; 2003 [accessed 13.03.03].

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34) (see also Samples of Formatted References).

Authorship

The Corresponding Author must submit a completed Author Consent Form to DRCP with their manuscript. All authors must sign the Author Consent Form.

All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

2.2 Manuscript:

Illness perception of adolescents with well-controlled type 1 diabetes mellitus

D. Jonker¹, E. Deacon¹, E. Van Rensburg²

¹Optentia Research Focus Area

North-West University

Vaal Triangle Campus

Vanderbijlpark

South Africa

²School of Psychosocial Behavioural Sciences

North-West University

Potchefstroom Campus

Potchefstroom

South Africa

Correspondence concerning this article should be addressed to Elmari Deacon, Optentia Research Focus Area, PO Box 1174, North-West University, Vanderbijlpark, 1900, South Africa (e-mail: elmari.deacon@nwu.ac.za).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Structured Abstract

Aims:

We explored the perceptions adolescents with well-controlled type 1 diabetes mellitus have of their illness and how this aids in managing diabetes.

Participants and methods

A qualitative approach with semi-structured interviews was adopted. Nine adolescents with well-controlled type 1 diabetes mellitus (mean age= 14; SD= 2.37) were purposively selected to participate in the study. Data were analysed thematically.

Results

Most of the participants perceived their type 1 diabetes mellitus to be an integral part of their beings and a relationship to acknowledge, not oppose. The participants perceived themselves to be distinctive because they had to observe a strict regime. They had accepted that type 1 diabetes mellitus could have negative health consequences. Regardless of the strict management regimen, type 1 diabetes mellitus was perceived as manageable. The participants understood that they had a responsibility to acquire adequate knowledge about the management of their diabetes. The majority of them accepted that they should adhere to a strict diabetes treatment regimen. Discipline and responsibility were perceived as vital for effective diabetes management. They acknowledged that acceptance of their illness helped them to manage their diabetes well.

Conclusions

The key finding was that juvenile's perceptions of their type 1 diabetes mellitus contributed to its management. The findings will benefit diabetes-related healthcare experts, who can constructively use the conclusions to look beyond just the treatment regimen to develop any such underlying perceptions among patients with type 1 diabetes mellitus in order to improve their diabetes management.

Keywords

Type 1 diabetes mellitus; diabetes management; adolescents; illness perception; qualitative methods; positive psychology.

1. Introduction

Type 1 diabetes mellitus, one of the most emotionally and behaviourally challenging chronic diseases [1,2], usually presents during childhood, with 79,000 children worldwide estimated to develop type 1 diabetes mellitus annually [3]. Individuals diagnosed with type 1 diabetes mellitus must adhere to a complex, multicomponent treatment regimen [4], which can be challenging, especially during adolescence [1,5]. This is a critical transition period in diabetes management, when adolescents should accept more responsibility for their diabetes management [5] but are also endeavouring to establish autonomy during a time of physiological transformation [5-6]. Research has indicated that adherence to the strict diabetes treatment regimen usually deteriorates during adolescence [7-8].

Effective therapy modules exist, but their essential components include balancing insulin dosing with frequent blood glucose monitoring (BGM), attention to diet and complying with an exercise programme [5,9]. Successful implementation of and consistent adherence to an intricate and demanding treatment regimen presents a challenge to even the most motivated adolescent [9]. A considerable amount of research has been done on adolescents living with type 1 diabetes mellitus and concomitant poor treatment outcomes. Inadequate compliance has been strongly linked to an increased risk of microvascular complications (retinopathy and nephropathy) [10]. Furthermore, poor management has been associated with psychological disorders, including anxiety [11] and depression [12]. The barriers to effective disease management among adolescents with type 1 diabetes mellitus include a phase of psychological turmoil and peer

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

pressure, a lack of knowledge and understanding of treatment regimens and potential health complications, fatigue from adhering to a protocol and experiencing physical changes with greater insulin resistance during puberty [9,13,14]. Yet, while adolescents often adhere poorly to treatment regimens, some succeed in complying with the required protocol [7]. Psycho-social factors reported to be associated with good metabolic control (HbA1c levels) include coping strategies [15] and illness perceptions [16].

This study is an exploration of the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus – and how this enables them to successfully manage their diabetes. As adolescents endeavour to make sense of their illness, they develop beliefs that will guide and influence their management thereof [17]. Illness perceptions are defined as a collection of beliefs about an illness [18-19] acquired through experiencing or being subjected to an ailment and by personal interpretation of information gathered [20]. Chronically ill patients' philosophies about their illnesses prognosticate self-care behaviour, shape illness-related outcomes [21] and have been shown to be independently associated with adherence to treatment and metabolic control in patients living with type 1 diabetes mellitus [16,20].

Research exploring the relationship between illness perceptions and diabetes outcomes among adolescents has been limited in South Africa. Furthermore, previous studies have yielded contradictory results [22,23]. Owing to the dearth of qualitative research concerning illness perceptions among adolescents and the identified gap in current diabetes research, this study has two objectives – firstly, to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and, secondly, to explore how this illness perception helps them to manage their diabetes.

2. Participants and methods

2.1. Rationale for a qualitative design

There has recently been a significant increase in quantitative research into illness perception, especially since the development of validated psychometric instruments to measure this construct. These instruments include the Illness Perception Questionnaire (IPQ) [24], the revised version of the IPQ (IPQ-R) [25] and the Brief Illness Perception Questionnaire (B-IPQ) [26]. However, the researcher deems this research to be the first of its nature to explore the above objectives in a South African context. Therefore a qualitative approach was used in order to acquire in-depth information regarding adolescents' illness perceptions and how they help them to manage their diabetes, a study which would not be achievable applying the quantitative approach. This methodology provides a compelling and effective method to explore new avenues by using flexible, open-ended approaches that allow participants to introduce and discuss the issues they perceive to be significant [27].

2.2. Recruitment and sampling

This is a sub-study of a larger research project investigating the psycho-social variables affecting the diabetes management of adolescents and young adults with a view to developing relevant interventions to facilitate optimal psychological wellbeing through developmental stadia. The gatekeeper was the Centre for Diabetes and Endocrinology (CDE) in Houghton and Parktown, Gauteng province region of South Africa. Prospective participants were informed by the CDE of the background to the study and the voluntary nature of participation. Purposive sampling was done to select participants who conformed to the sampling criteria, namely that they had to be aged 12 – 18 years and had been diagnosed with type 1 diabetes mellitus more than 12 months previously. The latter was to avoid any impact of continuous adjustment of treatment on the

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

trustworthiness of data obtained. The participants had to be enrolled as a patients of the abovementioned CDE to minimise treatment variables and to have an HbA1C (glycated haemoglobin) of 8% or less during the preceding 12 months for diabetes management to be considered satisfactory (as recommended by Prof D Segal, a paediatric endocrinologist). The researchers excluded individuals who were currently undergoing psychotherapy as a precautionary measure so as not to interfere with the therapy process. Individuals suffering from another chronic medical condition that could impact diabetes management were also excluded from the study.

The final sample consisted of five male and four female adolescents of between the ages of 12 and 18 years ($M=14$, $SD=2.37$). All nine participants were recruited from the CDE in Parktown, Johannesburg. Three participants were Afrikaans speaking and six were English speaking. The median age at diagnosis was 9.7 years, ranging from five to 12 years. The average HbA1c levels of the participants was 7.2% (44mmol/mol; $SD=0.68$).

2.3. Ethical considerations

Several measures were implemented to verify the ethicality of this research. Before the study was conducted, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) granted ethical approval for this study (NWU-HS-2016-0066). The participants comprised a physically and potentially psychological vulnerable set of individuals due to their diagnosis (type 1 diabetes mellitus) and their age (minors). The researcher was fully cognisant of the sensitive and emotional nature of the exploratory inquiry, and the rights and prerequisites of the individual were therefore considered at all times. Interviews proceeded once the researchers had obtained independent informed consent from both the parents and participants. The latter were guaranteed confidentiality and anonymity and, as such, no statement would be used in a

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

way that would identify any specific participant. Each participant received a summary of the findings, as well as positive individual feedback regarding their illness perceptions and how they aided in managing their diabetes well.

2.4. Data generation

Open-ended semi-structured interviews were conducted between October 2015 and August 2016 by three interviewers from differing psychology backgrounds who participated in the overarching project and who had been trained in this technique. Recruitment and data collection ceased when ongoing analysis of the data confirmed that no new information or insight was forthcoming. Data saturation was reached after seven interviews but two more interviews were conducted to ensure that no new data emerged.

The interviews were conducted at the site at which the participants normally received their treatment (CDE Parktown). The researchers scheduled the interview sessions to coincide with the participants' regular visits to the CDE. Occasionally, on the request of the parents, an interview was also conducted at the participant's home in the Johannesburg area, South Africa. Three interviews were done in Afrikaans and six in English. The three interviewers were fully bilingual. With the participants' consent, the interviews were audio-recorded and lasted an average of 45 minutes. An interview agenda was adhered to, ensuring consistency across the interviews. Due to the limited amount of previous research conducted in South Africa with adolescents with well-controlled type 1 diabetes mellitus, the content of the interview agenda was directed by the overarching research project's aims, corresponding to reflection done by the research team and in cognisance of the project's investigative purpose. Interviewers also wrote notes and reflections on the day of the interviews.

2.5. Data analysis

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

All the audio recordings were transcribed verbatim by the interviewers. The research team checked each transcript against the recordings for accuracy.

Thematic analysis using an inductive (data driven) approach was used to analyse the data.

Thematic analysis is a method of identifying, analysing and reporting patterns or themes within data [28]. Inductive reasoning was then applied as an open-ended exploration to identify categories and themes in the data [28]. The transcripts were imported into Atlas.ti, a qualitative data management software application, to facilitate data coding. Data were analysed following the six steps described by Braun and Clark [28], namely immersion in data to become familiar with its breadth, developing initial codes, searching for themes, reviewing themes, naming and defining themes and, finally, reporting the outcomes. A co-coder also independently analysed the data, divergent findings were discussed and consensus was reached in discussions with the study supervisor and a panel of medical experts. Thus this qualitative study drew on the concept of investigator triangulation by sharing data collection and data analysis between researchers drawn from various disciplinary backgrounds (research psychology, clinical psychology and general practice in the health psychology domain), again increasing the trustworthiness of the analysis.

To encourage high quality research, this study was subjected to Lincoln and Guba's [29] criteria for establishing trustworthiness, namely credibility, confirmability, dependability and transferability. Credibility was accomplished by the use of the gatekeepers at the CDE. They ensured that the participants who were recruited were able to make meaningful contributions to the current study. Sufficient participant quotations are provided to support the findings (see results section), which are deemed credible because they are grounded in data rather than in assumptions or conjectures, thus also establishing confirmability. To achieve dependability, two researchers deciphered the data individually and independently, after which a consensus was

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

achieved regarding the reliability of the research and its saturation. Good contextualisation included a rich description of the methodology, context and research process, contributing to transferability. However transferability might be limited, mainly due to the qualitative nature of the small, variation-limited sample.

3. Findings

Thematic analyses of the participants' responses to the first research question (What are the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus?) yielded four dominant themes, namely (1) living with diabetes becomes a way of life, (2) managing diabetes leads to being different, (3) acknowledgement of potential negative health consequences and (4) recognising diabetes as manageable. The motive themes are illustrated by verbatim examples from the nine participants, ranging from participant A1- A9.

3.1. Theme 1: Living with diabetes becomes a way of life

The majority of the participants recognised that type 1 diabetes mellitus was an integral part of their daily lives, as reported by participants A1 and A3 respectively: *"It's a way of life. What else?"* and *"can't really be ashamed of something that's part of me"*.

However, it was evident from the data that this perception was shaped over time. The participants described their association with diabetes management as difficult at first, mainly due to limited knowledge and lack of experience. As time progressed, they acquired an understanding of how to manage their diabetes. With a better understanding, well-controlled management became a habit. A1 and A5 explained: *"You brush your teeth in the morning. You have to bath. It's the same thing as that"* (A1) and *"it's just routine action [...] you automatically do"* (A5). As such, the identity and management of type 1 diabetes mellitus could not be separated from the individual, since as it had become a routine component of his or her

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

daily life. There was no concord between the participants themselves, especially among the younger adolescents, regarding the label they attached to type 1 diabetes mellitus, with some reporting: “*condition*” (A1, A3), “*illness*” (A5) or “*disease*” (A3). Yet, diabetes and its management were perceived not just as sheer habit, but an integral part of self, “*something that’s in you*” (A2), a life-long connection to be embraced, not to be fought.

3.2. Theme 2: Managing diabetes leads to being different

The majority of the participants perceived themselves as being different because they had to adhere to a strict regimen, unlike people without type 1 diabetes mellitus, as illustrated by participant A5: “*I am not similar to other people who have a normal pancreas. Other children can eat whenever they want. I must first prepare myself*”.

This perception is supported by the participants’ experiences of various situations in which they were treated differently from their peers and the wider community due to their diabetes management methods. Some participants mentioned that one way of coping with this “being different” is denial. “*I just wanna pretend that I’m normal. Like pretend it’s not there*” (A1). However, it was evident from both the interviews and the inclusion sample criterion of well-controlled type 1 diabetes mellitus that these participants were actively involved in managing their diabetes, not indicating avoidance behaviour. Yet sometimes they wanted to experience being ‘normal’ and conform to ordinary conventional behaviour, for example in social settings regarding their diet restrictions, even though they acknowledged the negative health consequences (theme 3) and the implications (for example high blood sugar) of indulging in a typical ‘normal’ adolescent lifestyle.

3.3. Theme 3: Acknowledgement of potential negative health consequences

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

The participants uniformly acknowledge that type 1 diabetes mellitus could have negative health consequences, as described by participant A8: *“You know what it does to people. You know what it has done to people. You know that it can do it very likely to you”*.

The participants understood that uncontrolled type 1 diabetes mellitus could cause serious damage to the human body. For example, consequences that were reported included: *“into coma”* (A6), *“complications are like your eyesight, your circulation in your feet”* (A3), *“losing weight”* (A9), and admitting that such damage could have fatal consequences, as stated by participant A1: *“if I don’t manage it properly it could kill me in the end”*.

More specifically, the participants realised that these negative outcomes went hand in hand with poor diabetes management. *“You don’t want the trouble that comes with diabetes not managed well”* (A8). However, in some participants this perception elicited fear. *“If it’s high I then get a bit of a fright. Then I give insulin because [...] I don’t wanna compromise my future”* (A3). *“It makes you scared. It makes you feel what could happen so it keeps you in line”* (A8). The illness perception of adolescents living with type 1 diabetes mellitus regarding possible negative health consequences are interlinked with theme 5 and 6. Nonetheless, the knowledge of the complications that might arise due to poor management enabled the participants to appreciate the benefit of managing their diabetes well.

3.4 Theme 4: Diabetes is manageable

Despite the strict treatment regimen, the majority of the participants perceived type 1 diabetes mellitus to be manageable. This perception was regarded as a most positive aspect of diabetes when compared to, for example *“much better like say a cancer patient”* (A3). Consequently, some even perceived themselves to be fortunate because diabetes, however inescapable, was manageable. The participants also perceived managing diabetes well as being beneficial for the

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

future in terms of avoiding negative health consequences (theme 3) and, for some participants, buying time for a future cure, as noted by participant A7: *“if I control it now maybe if a cure comes out and then I can do it, but if I don’t, I can’t use that cure because maybe one limb of mine will be gone”*.

The data indicated that this illness perception might have developed over time as the participants began to perceive, acknowledge and accept that it was part of their lives (theme 1), and as they gained adequate knowledge about how to manage their diabetes (theme 5) and were empowered by hands-on experience. Although type 1 diabetes mellitus was perceived as manageable, some participants acknowledge that crisis situations were inevitable, such as participant A3: *“You gonna get highs and you gonna get lows”*. Yet, due to the fact that diabetes was perceived as manageable, some of the participants experienced guilt if they failed to manage it well, especially in view of the fact that diabetes calls for strict management (theme 6). *“I always think it’s my fault that it’s high. Maybe I have eaten something or I haven’t injected enough”* (A2).

The above illness perceptions were further thematically explored to determine how they contributed to the effective management of the participants’ diabetes (research question 2). Three dominant themes emerged, namely (1) procurement of adequate knowledge, (2) embracing accountability by complying with obligatory management protocol and (3) acceptance of lot/fate.

3.5. Theme 5: Procurement of adequate knowledge

The most prominent repetitive theme in the dataset was the imperative procurement of adequate knowledge. By incorporating it as a way of life (theme 1) and having come to the conclusion that type 1 diabetes mellitus is manageable (theme 4), the participants understood and acknowledged that they had a duty to acquire adequate knowledge of the management of their diabetes.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Furthermore, the participants perceived acquiring such knowledge as a vital obligation, as reported by participant A8: *“Without knowledge you’re pretty much dead”*.

In addition, knowledge of the complications (theme 3) that poor management might generate helped the participants to appreciate the benefit of managing their diabetes well. This procurement of adequate knowledge thus empowered the participants living with type 1 diabetes mellitus to not only manage their diabetes well, but to proceed with self-confidence.

3.6. Theme 6: Embracing accountability to comply with obligatory management protocol

By understanding the beliefs of the participants, which includes that, although type 1 diabetes mellitus is manageable (theme 4), poor management of type 1 diabetes mellitus could generate negative health consequences (theme 3) that should be avoided, it was evident that these philosophies helped, in a specific way, to promote rigorous adherence to their management. The majority of the participants perceived that they had to adhere to a strict protocol: it was either right or wrong, as illustrated by participant A1: *“It’s not grey areas. It’s only black and white”*.

Also, the majority of the participants specifically regarded the diet they had to observe as essential and obligatory, as noted by participant A5: *“to only eat the appropriate food”*.

Furthermore, the majority of the participants perceived this management approach to be non-negotiable, as reported by A9: *“I just have to manage it properly”*. This theme clearly links with theme 5, namely admitting that adequate knowledge is essential.

In general, discipline, maturity and responsibility are perceived to be vital if one is to comply with the obligatory management protocol, as illustrated by participant A1 and A4 respectively: *“Don’t try and make excuses and be lazy[...] I would recommend to them to take care of it [type 1 diabetes mellitus], ’cause it’s taking care of your health”* and *“Nobody else can decide for you*

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

when to eat this or that or when to inject [...]. You yourself must decide how you are going to do it". Becoming more disciplined, responsible and mature will have a positive impact on them as individuals and on their health in the future. Participant A8 reported: *"it's a win-win situation, because I'm more grown up and ready for everything [...] it will help me in the future"*. By embracing accountability to comply with obligatory management protocol, the participants integrated the management of their disease into the nucleus of their daily being (theme 1).

3.7. Theme 7: Acceptance of lot/fate

The participants acknowledged that acceptance of their illness helped them to manage their diabetes well, as explained by participant A3: *"ok, this is something I have; this is something I am going to have to live with, so I might as well just get used to it and make the best of it"*.

With the majority of the participants, it was evident that this perception was also shaped over time. Initially it was not easy to come to this conclusion, but as time progressed they gained insight and a better appreciation of how to manage their condition, and they succeeded in incorporating its management into their daily lives (theme 1). The acknowledgement that they were indeed different but their ability to come to terms with it (*"No point in me whining and complaining, feel bad like why people gonna look at me funny. It's just no point"*, A1) also helped them to accept their disease. As time passed, the participants accepted that *"it is what it is, you can't change it"* (A3) and *"I'm gonna live with it"* (A2). Furthermore, they recognised that diabetes and the management thereof held negative as well as positive consequences, as explained by participant A3: *"It's like everything in your life [...] it's got its ups and downs"*. Subsequently, by accepting responsibility (theme 6) *"it's on you to make yourself better"* (A9) and that their fate is in their own hands will provide them with a future, as reported by participant A7: *"I understand that if maybe there's no cure it will be for [...] with me for the rest of my life. So if I learn now, I won't struggle later"*.

4. Discussion

The merit and contribution of this study is that it is considered by the researchers to be the first South African exploratory study of illness perception among adolescents with well-controlled type 1 diabetes mellitus. In addition, the findings illustrate how illness perceptions can create a positive framework that aids the management of type 1 diabetes mellitus.

Research concerning the barriers to effective disease management among adolescents with type 1 diabetes mellitus yielded contradictory results. Barriers to management include psychological turmoil, peer pressure and lack of knowledge about treatment regimens and potential health complications [9,13,14]. However, the findings of this study illustrate that adolescents with well-controlled type 1 diabetes mellitus can develop positive illness perceptions and even embrace the disease as a positive experience. The participants were empowered by managing their diabetes well and thus gained confidence about the future. Although the perception of being different can be disturbing and problematic for adolescents, the participants had accepted the fact that, due to their diagnosis and treatment regimen, they were dissimilar to their peers. The findings highlighted the fact that the participants understood and accepted that they had a duty to acquire sufficient knowledge regarding the management of their diabetes, and acknowledged that potential negative outcomes went hand in hand with poor diabetes management.

The first goal of this study was to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus. One theoretical model that has been widely applied in diabetes research is the Common-Sense Model (CSM) of illness representations [17]. This model submits that, in response to an illness, people create their own cognitive illness representation about their condition and its treatment, entailing five dimensions namely (1) perceived cause, (2) consequences (beliefs about effects and impact), (3) control/cure (beliefs about curability and controllability), (4) timeline (course and duration) and (5) identity ascribed

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

to illness [17-19]. Although an inductive approach was adopted for this study, the findings signified both similarities and differences between these broad dimensions. Research has emphasised that illness perception dimensions of identity, consequences and control are significantly correlated with well-controlled type 1 diabetes mellitus across studies [22]. For example in Griva et al.'s [30] study of adolescents and young adults (15–25 years of age) with type 1 diabetes mellitus, 30% of the variances in HbA1c was attributed to these three dimensions. Notwithstanding methodological differences, the outcomes of the present study appear to correlate with other studies.

The findings of this study support the identity domain specified in the CSM. Although there is perplexity among the participants regarding the identity of type 1 diabetes mellitus (is it an illness, disease or condition?), a distinctive conclusion manifested, namely that well-controlled adolescents view it as a way of life. They identify their diabetes as an integral part of their existence and a permanent relationship to acknowledge rather than to oppose. This quality has thus far not been identified or explained in diabetes research. The findings of this study also support the consequences and control domains of the abovementioned model. The adolescents seldom reacted to the desire to pretend that they were “normal”. They were supported by the (fear-inducing) knowledge that negative health outcomes went hand in hand with poor diabetes management, making an obligatory management protocol compulsory. The perceived severity of bad outcomes motivated them toward greater adherence. This acceptance of consequences is supported by a study done by Gaston and colleagues [31], in which better blood glucose monitoring was associated with acknowledging the danger of uncontrolled diabetes.

The findings of this study also highlighted variances among the cause and timeline dimensions of the CSM. There was no evidence of distinct beliefs regarding the cause dimension among these participants. Previous research has underlined that patients who believe that their diabetes

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

is variable and unpredictable (timeline dimension) might show little motivation to reduce their blood sugar levels and sustain good control [21]. By contrast, the findings indicate that although some participants acknowledge that crisis situations were inevitable, they still perceived type 1 diabetes mellitus to be manageable and thus strove to maintain good adherence. Although previous research has established that questions concerning long-term outcome beliefs are not valuable because the large majority of patients consider their diabetes to be a chronic condition with no known cure [32], the timeline beliefs between the participants in this study varied. Although some of them believed that there was no cure and had accepted their lot, other participants seemed to be optimistic – they had accepted their fate, but they also believed that controlling diabetes well was a way of buying time while awaiting a potential cure. This contradicts previous research, which stressed that waiting for a potential cure was associated with poorer glycaemic control [33].

The second objective of this study was to explore how this illness perception helps adolescents to manage their diabetes. Disease can be described as a catastrophe affecting the very existence of an individual with consequential psycho-social outcomes [34]. It is conceivable, taking the adolescence developmental phase into account, that especially adolescents living with type 1 diabetes mellitus might experience difficulty in coming to terms with the idea of living with a disease. Some of the participants were found to acknowledge the actuality of their illness and even succeeded in identifying some long-term positive consequences of their chronic illness, which in return encouraged effective management. This acceptance was formed over time, without a clear specific timeframe or end point. Taking the demographic information of the participants into account, the average disease duration had been 4.2 years. However, it was evident from the data that, as time progressed, insight into and appreciation of how to manage diabetes were developed, which in return helped to facilitate acceptance. Furthermore, by

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

accepting living with diabetes as a way of life, the participants also recognised and acknowledged that they had a responsibility to acquire adequate knowledge about the management of their diabetes. This is strongly supported by other studies that showed that a lack of knowledge was associated with poorer treatment adherence. By empowering adolescents from the onset of the disease with more knowledge of how to manage their diabetes, we might help individuals to come to terms with it much sooner.

The main limitation of the study is the restricted generalizability of the findings due to limited demographic variation and a small sample size. The majority of the participants were from an urban, socio-economically moderate income bracket, able to afford a medical aid and thus to access treatment via the private health sector. Within the South African context many patients living with type 1 diabetes mellitus are dependent on the public health sector to receive their diabetes treatment due to socio-economic factors. As such, attention should be given to the transferability of our findings. Furthermore, the inclusion criteria sample was purposely aimed at adolescents between the ages of 12 and 18, yet the study did not synchronise the distribution between the age span – the majority of the participants were age 12. This aspect might have limited the study in terms of obtaining more prolific data. Notwithstanding these limitations, the current study sheds light, from a new perspective, on patients who successfully adhere to treatment and lays the foundation for future innovative research that focuses on positive approaches and mindsets to be nurtured and encouraged, rather than only on what contributes to poor management outcomes.

In conclusion, this study provides new information about the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus in South Africa, as well as insight into how these perceptions aid effective management. The findings will be of use for diabetes-related healthcare experts who can constructively use the conclusions to look beyond just the treatment regimen

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

and change these underlying perceptions of patients with type 1 diabetes mellitus in order to improve their diabetes management. However, it is recommended that future research should focus on understanding the practical implications of illness perceptions of diabetes management when developing interventions aimed at the re-construction of the illness perception of other patients living with diabetes or other chronic diseases.

Conflict of interest

There are no conflicts of interest.

Acknowledgements

We would like to convey our sincere appreciation to the participants and their parents for granting us their valuable time to participate in this study. We would also like to express our gratitude to the research assistants, sisters Hester Davel and Deidre Maritz, at the CDE in Houghton and Parktown for their administrative and logistical assistance. In particular, sincere thanks to Prof David Segal for his continuous support and making his practices available for the study. This research did not receive any financial support by way of a public grant or from commercial funding agencies or non-profit sectors.

References

- [1] Compas BE, Jaser SS, Dunn M J, Rodriguez EM. Coping with chronic illness in childhood and adolescence. *Annu Rev Clin Psychol* 2012; 8:455– 80. doi:10.1146/annurev-clinpsy-032511143108.
- [2] Hagger V, Trawley S, Hendrieckx C, Browne JL, Cameron F, Pouwer F, et al. Diabetes MILES Youth-Australia: methods and sample characteristics of a national survey of the psychological aspects of living with type 1 diabetes in Australian youth and their parents. *BMC Psychology* 2016;4(1):42. doi:10.1186/s40359-016-0149-9.
- [3] Patterson C, Guariguata L, Dahlquist G, Soltész, G, Ogle G, Silink M. Diabetes in the young - a global view and worldwide estimates of numbers of children with type 1 diabetes. *Diabetes Res Clin Pract* 2014;103(2):161-75. doi:10.1016/j.diabres.2013.11.005.
- [4] Gonzalez JS, Tanenbaum ML, Commissariat PV. Psychosocial factors in medication adherence and diabetes self-management: Implications for research and practice. *Am Psychol* 2016;71(7):539-51.
- [5] Hunter CM. Understanding diabetes and the role of psychology in its prevention and treatment. *Am Psychol* 2016;71(7):515-25. doi:10.1037/a0040344.
- [6] Wiebe DJ, Chow CM, Palmer DL, Butner J, Butler JM, Osborn P, Berg CA. Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence. *J Pediatr Psychol* 2014;39(5):532-41. doi:10.1093/jpepsy/jsu006.
- [7] Hilliard ME, Wu YP, Rausch J, Dolan LM, Hood KK. Predictors of deteriorations in diabetes management and control in adolescents with type 1 diabetes. *J Adolesc Health* 2013;52(1):28-34. doi:10.1016/j.jadohealth.2012.05.009.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- [8] King PS, Berg CA, Butner J, Butler JM, Wiebe DJ. Longitudinal trajectories of parental involvement in type 1 diabetes and adolescents' adherence. *Health Psychol* 2014;33(5):424-32. doi:10.1037/a0032804.
- [9] Borus JS, Laffel L. Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Curr Opin Pediatr* 2010;22(4):405–11. doi:10.1097/MOP.0b013e32833a46a7.
- [10] Lung TW, Clarke PM, Hayes AJ, Stevens RJ, Farmer A. Simulating lifetime outcomes associated with complications for people with type 1 diabetes. *Pharmacoeconomics* 2013;31(6):509-18. doi:10.1007/s40273-013-0047-4.
- [11] Herzer M, Hood KK. Anxiety symptoms in adolescents with type 1 diabetes: Association with blood glucose monitoring and glycemic control. *J Pediatr Psychol* 2010;35(4):415-25. doi:10.1093/jpepsy/jsp063.
- [12] Buchberger B, Huppertz H, Krabbe L, Lux B, Mattivi JT, Siafarikas A. Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology* 2016;70:70-84. doi:10.1016/j.psyneuen.2016.04.019.
- [13] Datye KA, Moore DJ, Russell WE, Jaser SS. A Review of adolescent adherence in type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. *Curr Diab Rep* 2015;15(8):621. doi:10.1007/s11892-015-0621-6.
- [14] Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics* 2005;115(6):1562-8.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- [15] Graue M, Wentzel-Larsen T, Bru E, Hanestad BR, Søvik O. The coping styles of adolescents with type 1 diabetes are associated with degree of metabolic control. *Diabetes Care* 2004;27(6):1313–7. doi: 10.2337/diacare.27.6.1313.
- [16] Broadbent E, Donkin L, Stroh JC. Illness and treatment perceptions are associated with adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care* 2011;34(2):338–40. doi: 10.2337/dc10-1779.
- [17] Leventhal H, Benyamini Y, Brownlee S, Diefenbach M, Leventhal E, Patrick-Miller L, Robitaille C. Illness perceptions: Theoretical foundations. In: Petrie KJ, Weinman J, editors. *Perceptions of health and illness: Current research and applications*, Amsterdam: Harwood Academic Publishers; 1997, p.19-45.
- [18] Petrie KJ, Jago LA, Devcich DA. The role of illness perceptions in patients with medical conditions. *Current Opinion in Psychiatry* 2007;20:163–7.
- [19] Petrie KJ, Weinman J. Patients' perceptions of their illness: The dynamo of volition in health care. *Current Directions in Psychological Science* 2012;21(1):60–5. doi:10.1177/0963721411429456.
- [20] Hagger MS, Orbell S. A Meta-Analytic Review of the Common-Sense Model of Illness Representations. *Psychology & Health* 2003;18(2):141-84.
- [21] Mc Sharry J, Morris-Morris R, Kendrick T. Illness perceptions and glycaemic control in diabetes: a systematic review with meta-analysis. *Diabet Med* 2011;28(11):1300-10. doi:10.1111/j.1464-5491.2011.03298.x.
- [22] Fortenberry KT, Berg CA, King PS, Stump T, Butler JM, Pham PK, Wiebe DJ. Longitudinal trajectories of illness perceptions among adolescents with type 1

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

diabetes. *Journal of Pediatric Psychology* 2014;39(7):687–96.

- [23] Wisting L, Bang L, Natvig H, Skrivarhaug T, Dahl-Jørgensen K, Lask B, Rø Ø. Metabolic control and illness perceptions in adolescents with type 1 diabetes. *J Diabetes Res* 2016;2016:3486094. doi: 10.1155/2016/3486094.
- [24] Petrie KJ, Moss-Morris R, Horne R. The Illness Perception Questionnaire: A new method for assessing cognitive representation of illness. *Psychology & Health* 1996;11:431-8.
- [25] Moss-Morris R, Weinman J, Petrie KJ, Buick D. The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health* 2002;17(1):1-16.
- [26] Broadbent E, Petrie KJ, Main J, Weinman J. The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research* 2006;60:631-7.
- [27] Ritchie J. The applications of qualitative methods to social research. In: Ritchie J, Lewis J. editors. *Qualitative research practice. A guide for social science students and researchers*: London: SAGE; 2009, p.26 – 34.
- [28] Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3:77-101.
- [29] Lincoln YS, Guba EA. *Naturalistic Inquiry*. Beverly Hills, CA: Sage; 1985.
- [30] Griva K, Myers LB, Newman S. Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology & Health* 2000;15(6):733–750.
- [31] Gaston AM, Cottrell DJ, Fullen T. An examination of how adolescent-

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

caregiver dyad illness representations relate to adolescents' reported diabetes self-management. *Child: Care, Health and Development* 2012;38:513–519.

[32] Pujilestari CU, Ng N, Hakimi M, Eriksson M. “It is not possible for me to have diabetes”– community perceptions on diabetes and its risk factors in rural Purworejo district, Central Java, Indonesia, *Glob J Health Sci.* 2014;6(5): 204–218.

[33] Scholes C, Mandleco B, Roper S, Dearing K, Dyches T, Freeborn D. A qualitative study of young people's perspectives of living with type 1 diabetes: do perceptions vary by levels of metabolic control? *J Adv Nurs* 2013;69(6):1235-47. doi: 10.1111/j.1365-2648.2012.06111.x.

[34] Lewko J, Polityńska B, Kochanowicz J, Zarzycki W, Okruszko A, Sierakowska M, et al. Quality of life and its relationship to the degree of illness acceptance in patients with diabetes and peripheral diabetic neuropathy. *Advances in Medical Sciences* 2007;52(1): 1-3.

CHAPTER 3: CRITICAL REFLECTION

3.1 Introduction

In this final appraisal it is evaluated whether the research objectives outlined for the research study have been met. The researcher's conclusions on the current study's qualitative findings are presented according to the themes that emerged during the data analysis. The limitations of this research are addressed and recommendations for future research are made. To conclude this section, the researcher offers a short reflection on the process of completing this dissertation.

3.2 Research aims of the study

The aims of this study were twofold:

- Firstly, to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus;
- Secondly, to explore how this illness perception helps the adolescent to manage their diabetes.

3.3 Conclusion on the findings

The contribution of this study is that, to the best of the researcher's knowledge, this is the first South African study to explore illness perception among adolescents with well-controlled type 1 diabetes mellitus and how it helps them to manage their diabetes. In conclusion, based on the empirical results (qualitative findings), the researcher can declare that the aims of the study were achieved. The illness perceptions of adolescents with well-controlled type 1 diabetes

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

mellitus were explored and this study contributed towards understanding how these illness perceptions contributed to managing their diabetes.

Nine semi-structured interviews were conducted to confirm data saturation, although it had been reached after seven interviews. Based on the information provided during the nine interviews, four dominant themes related to the illness perceptions of the participants with well-controlled type 1 diabetes mellitus were identified. These themes are addressed in sections 3.3.1 – 3.3.4 below.

3.3.1 Theme 1: Living with diabetes becomes a way of life

Most of the participants perceived their type 1 diabetes mellitus to be an integral part of their existence and a permanent relationship to acknowledge, not oppose. This illness perception was formed over time. Initially the participants experienced diabetes management to be challenging and associated with negative emotions. Over time they acquired insight and knowledge on how to manage their diabetes. Supported by a better perception, the management of their diabetes advanced to a daily routine. The identity they ascribed to type 1 diabetes mellitus (for example, whether it was viewed as an illness, condition or disease) was inconsistent in the data; however, it was evident that the identity of type 1 diabetes mellitus was inherently connected to the individual, such that they viewed it as ‘their diabetes’. As such, the identity and management of type 1 diabetes mellitus could not be disconnected from the individual, since it had become not only a regular component of their daily lives, but had been assimilated into their selves.

3.3.2 Theme 2: Managing diabetes leads to being different

The participants uniformly perceived themselves as being distinctive because they had to observe a strict regimen that people without type 1 diabetes mellitus did not have to follow.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Some of the participants stated that they wished they could just pretend that they were “normal” (without the burden of managing type 1 diabetes mellitus). However, throughout the interviews the participants seldom reacted to this with denial behaviour. Although this perception of being different can be disturbing and difficult for adolescents at times, they had accepted the fact (theme six) that, due to their diagnosis and treatment regimen, they were dissimilar to their peers. That does not mean, however, that they never felt like acting and experiencing being ‘normal’, to imitate ordinary conventional behaviour, even though they acknowledged the negative health consequences (theme three) and the implications (for example high blood sugar) of a typical ‘normal’ adolescent’s lifestyle.

3.3.3 Theme 3: Acknowledgement of potential negative health consequences

The participants accepted that type 1 diabetes mellitus could have negative health consequences. They recognised that uncontrolled type 1 diabetes mellitus could cause serious harm to the human body and that such damage could eventually have fatal consequences. More specifically, they understood that these negative consequences went hand in hand with poor diabetes management. However, in some instances this perception produced fear. This illness perception is linked with theme five because adequate knowledge about the consequences of poor management enabled the participants to appreciate the benefit of managing their diabetes well.

3.3.4 Theme 4: Diabetes is manageable

Most of the participants perceived type 1 diabetes mellitus to be manageable, albeit only by following a strict management regimen. This belief was regarded as a positive feature of type 1 diabetes mellitus, such that some of the participants even regarded themselves to be privileged because type 1 diabetes mellitus, however inevitable challenging episodes might be, was

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

manageable. In addition, some participants saw managing type 1 diabetes mellitus well in the present, thus preventing negative health consequences (theme three), as beneficial to their future health, buying time for an awaited cure or new therapy. It is evident from the data that this illness perception might also have developed over time as the participants started to recognise and accept that it was part of their lives (theme one), while they were empowered by adequate knowledge and hands-on experience regarding how to manage their diabetes (theme five). Although type 1 diabetes mellitus was perceived to be manageable, some of participants accepted that crisis situations could be expected. Some of the participants experienced guilt if they failed to achieve good control, especially in view of the fact that diabetes calls for strict management, and their ‘it is either right or wrong’ approach (theme seven).

A summary of the themes concerning the first research question (incorporating a description of the themes with inclusion criteria and examples from the data) is presented in Addendum G.

To further explore how these illness perceptions contribute to the effective management of participants’ diabetes, three themes were identified, which will be discussed in sections 3.3.5 – 3.3.7 below.

3.3.5 Theme 5: Procurement of adequate knowledge

The most prominent repetitive theme in the dataset is the essential acquisition of adequate knowledge. By integrating it as a way of life (theme one), the participants understood and accepted that they had a duty to acquire sufficient knowledge about the management of their type 1 diabetes mellitus. Furthermore, they regarded the acquiring of adequate knowledge about how to manage their type 1 diabetes mellitus (theme four) as a fundamental responsibility. In addition, the knowledge of the complications (theme three) poor management might generate

helped them to value the benefit of managing their diabetes well and empowered them with confidence and self-reliance.

3.3.6 Theme 6: Embracing accountability to comply with obligatory management protocol

The participants generally acknowledged that although type 1 diabetes mellitus was manageable (theme four), if managed poorly it could have serious negative health consequences (theme three) that should be avoided. It was apparent that these philosophies assisted in a specific way to encourage rigorous adherence to their management regimes. The majority of the participants believed that they should adhere to a strict protocol, a conviction grounded in the belief that this code of behaviour must be embraced as a way of life (theme one). Also, the majority of the participants viewed the diet they had to respect as vital and mandatory. Furthermore, the majority of the participants regarded this management approach as non-negotiable. It is not exactly clear from the data where this perception of a compulsory right or wrong, non-negotiable approach derived from. However, this theme was clearly linked with theme five, namely that adequate knowledge is essential to doing what is needed.

In general discipline, maturity and accountability are regarded as fundamental for effective diabetes management. By acknowledging the potential negative health consequences of diabetes (theme three), especially when managed poorly, the participants accepted that they had to be self-controlled and accountable. In addition, type 1 diabetes mellitus was perceived as manageable (theme four), although it required the necessary qualities to manage it well. Some participants even regarded this as a benefit of diabetes. Becoming more disciplined, accountable and mature would have a positive influence on them as individuals and on their health in the future.

3.3.7 Theme 7: Acceptance of lot/fate

The majority of the participants recognised that acceptance of their illness enabled them to manage it well. Most of them highlighted the fact that this perception was shaped gradually. Over time they obtained understanding and a better appreciation of how to cope with their diabetes and they succeeded in integrating the management of type 1 diabetes mellitus into their daily lives (theme one). They recognised that they were indeed different from their peers but were able to come to terms with it, a process that made it possible for them to accept their disease. The participants acknowledged their fate as unavoidable.

Furthermore, they had recognised that diabetes and the management thereof included negative as well as positive outcomes. Consequently, it rested on the individual to take responsibility for his/her life, to acknowledge that their fate was in their own hands by managing their diabetes well and thus providing themselves with a future.

A summary of the themes concerning the second research question (incorporating a description of the themes with inclusion criteria and examples from the data) is presented in Addendum H.

3.4 Limitations of the study

The limitations of the current study will be stipulated, in relation to both the literature review and methodological issues.

3.4.1 Limitations of the literature review

Limited literature could be found concerning the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus in South Africa. However, this did not have any impact on the study's findings. This identified deficiency in available research-related information about

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

illness perception among adolescents with type 1 diabetes mellitus in South Africa considerably re-emphasised the need for conducting the current study.

3.4.2 Limitations due to methodological issues

The fact that the study is of an exploratory nature with limited demographic variation and a small sample size might limit the general applicability of findings to the population of adolescents with well-controlled type 1 diabetes mellitus in South Africa. The current study, however, illuminates the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and thus enables one to identify future research topics. Furthermore, while the inclusion criterion for participation in this study was that participants had to be adolescents between the ages of 12 and 18, the study did not regulate the distribution of the age span, seeing as the majority of the participants are age 12. Cross-sectional research indicates that illness perceptions might differ with age and that older adolescents have a more advanced understanding of their chronic illness (Olsen et al., 2008). This aspect might have limited the study in terms of obtaining richer data. Although the research aims were met, another limitation of this study was the application of only one method of data generation. More than one method of data generation might have led to more in-depth information and ensured triangulation. The adolescents who participated in this study were predominately white from an urban, socio-economically moderate income bracket, able to afford a medical aid and thus to receive treatment via the private health sector. Within the South African context many adolescents from other racial groups and socio-economic classes are dependent on the public health sector for their diabetes treatment.

3.5 Recommendations for further research

In light of the limitations of the current study presented above, recommendations for future research include the following:

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

1. Future research should entail an expansion of the demographic variation and treatment venues, and take account of larger samples from various regions and settings, from urban and rural areas, to explore whether the findings of the current study can be generalised in the South African context.
2. Given the variability in diabetes control that occurs across the turbulent time span of adolescence, the researcher anticipates evolution in the illness perceptions of adolescents. It is suggested that future studies should comprise an investigation of how adolescents' perceptions of their well-controlled type 1 diabetes mellitus develop across time and how diabetes-related outcomes are longitudinally associated (Fortenberry et al., 2014).
3. As far as the researcher knows, little research has been done to validate psychometric instruments to measure illness perception in the South African context. The researcher proposes that future research should be directed at validating such instruments and/or to adapt versions, seeing as these instruments are subject to limitations. As such, these instruments should be complemented by including other techniques of eliciting and identifying illness perceptions within a specific group (French & Weinman, 2008).
4. It is suggested that diabetes educators assess the illness perceptions of adolescents with type 1 diabetes mellitus using a validated illness perception questionnaire to appraise and consider the various components of patients' illness perceptions. In addition, diabetes educators should bear in mind the variations in illness perceptions across the age span of adolescence, especially when providing training and education for adolescents diagnosed with type 1 diabetes mellitus,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

because this might contribute to improved diabetes management (Fortenberry et al., 2014).

5. It is recommended that more extended research be done regarding the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus to highlight the practical application of the theoretical knowledge concerning this topic. By understanding the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus, interventions aimed at the reconstruction of the illness perception of those living with diabetes can be investigated in the future.
6. Furthermore, developing clinical interventions to address cognitive or behavioural features linked to perceptions regarding diabetes regimen could improve diabetes adherence (Fortenberry et al., 2014). Also the illness perceptions might be connected with or linked to numerous other challenges during adolescence, including acquiring greater competencies in diabetes numeracy (e.g. insulin dosing) (Mulvaney, Lilley, Cavanaugh, Pittel, & Rothman, 2013) and improving socio-emotional aptitudes (Fortenberry et al., 2014).
7. The findings illustrate how illness perceptions might create a positive framework that facilitates the management of a chronic illness. This is supported by the review done by Yi-Frazier, Hilliard, Cochrane, and Hood (2012) demonstrating clear evidence of the impact of a positive psychological framework on the daily management and health outcomes of people with diabetes. It is recommended that research regarding people living with type 1 diabetes mellitus should equally focus on the positive aspects (Jaser, Patel, Rothman, Choi, & Whittemore, 2014) as opposed to focusing only the areas that need improvement. Clinicians and

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

researchers should appreciate the availability of measurements of wellness (Vázquez, Hervás, Rahona, & Gómez, 2009) and specifically focus on identifying positive areas in addition to addressing deficits during diabetes adherence interventions.

3.6 Reflexivity of the researcher

The merit of this dissertation was in the learning experience itself, embracing knowledge acquired in the field of health and positive psychology, personal development and a demonstration of the new skills acquired.

Due to my academic BSc Human Life Science background, I was familiar with the physiological aspects and the necessity of a strict treatment regimen for type 1 diabetes mellitus. However, conducting this study was a mind-altering experience in which I, as a researcher, could broaden my understanding of this topic beyond the biological insights. The participants shared with me how they made sense of their reality of living with type 1 diabetes mellitus and the concomitant emotions and challenges it brought about. Recently, my own father was diagnosed with type 2 diabetes mellitus and I personally experienced how the diagnosis evoked turmoil in him. I gained a renewed respect and admiration for adolescents who must take on the challenges of living with type 1 diabetes mellitus while simultaneously going through multifaceted developmental changes. It was clear from the findings how illness perceptions could create a positive framework that facilitated the management of the chronic illness. As a student currently doing her master's degree in positive psychology, it was profoundly insightful to experience how the participants, despite the burden of a chronic illness, could move beyond their disease and its restrictions.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Reflecting on the experiences related to this dissertation, my academic journey was beyond my expectations. I firmly believe that setting goals and accomplishing them contributes toward making positive changes in one's life. This research proved to be an extremely rewarding experience, as well as a valuable apprenticeship. Managing the expected obstacles and unexpected hitches proved to be a gratifying, worthwhile chapter in my academic and personal journey. The end achievement is just a small part of the equation; most of the satisfaction and exhilaration was experienced while enduring the path that led to it. This journey has empowered me in numerous ways. I developed my skills as a qualitative researcher, as a writer for a scholarly publication, as an individual on a journey of personal growth, and gained self-discipline and self-insight in the process. I have acquired competence that is truly mine. Conducting this study was both a great challenge and a wonderful opportunity. I am extremely humbled and grateful for the growth residing in gained competence and for new experiences granted.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Complete reference list

Abualula, N. A., Jacobsen, K. H., Milligan, R. A., Rodan, M. F., & Conn, V. S. (2016).

Evaluating diabetes educational interventions with a skill development component in adolescents with type 1 diabetes: a systematic review focusing on quality of life. *The Diabetes Educator*, *42*(5), 515-528. doi:10.1177/0145721716658356

Ahn, S., & Fedewa, A. L. (2011). A meta-analysis of the relationship between children's physical activity and mental health. *Journal of Pediatric Psychology*, *36*(4), 385-397. doi:10.1093/jpepsy/jsq107

American Diabetes Association. (2009). Standards of medical care in diabetes. *Diabetes Care*, *32*(1), 13–61. doi:10.2337/dc09-S013

American Diabetes Association. (2010). Diagnosis and classification of diabetes mellitus. *Diabetes Care*, *33*(1), 62-69. doi:10.2337/dc10-S062

Anderson, R. M., Fitzgerald, J. T., Gorenflo, D. W., & Oh, M. S. (1993). A comparison of the diabetes-related attitudes of health care professionals and patients. *Patient Education and Counseling*, *21*, 41-50.

Ashraff, S., Siddiqui, M. A., & Carline, T. E. (2013). The psychosocial impact of diabetes in adolescents: a review. *Oman Medical Journal*, *28*(3), 159-162. doi:10.5001/omj.2013.46

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, *1*(3), 385- 405.

Azevedo, M., & Alla, S. (2008). Diabetes in Sub-Saharan Africa: Kenya, Mali, Mozambique,

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Nigeria, South Africa and Zambia. *International Journal of Diabetes in Developing Countries*, 28(4), 101–108. doi:10.4103/0973-3930.45268

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, 31(2), 143-164. doi:10.1177/1090198104263660

Bell, K. J., Barclay, A. W., Petocz, P., Colagiuri, S., & Brand-Miller, J. C. (2013). Efficacy of carbohydrate counting in type 1 diabetes: a systematic review and meta-analysis. *Lancet*, 2(2), 133–140. doi:10.1016/S2213-8587(13)70144-X

Beraki, Å., Magnuson, A., Särnblad, S., Åman, J., & Samuelsson, U. (2014). Increase in physical activity is associated with lower HbA1c levels in children and adolescents with type 1 diabetes: results from a cross-sectional study based on the Swedish pediatric diabetes quality registry (SWEDIABKIDS). *Diabetes Research and Clinical Practice*, 105(1), 119-125.

Bernstein, C. M., Stockwell, M. S., Gallagher, M. P., Rosenthal, S. L., & Soren, K. (2013). Mental health issues in adolescents and young adults with type 1 diabetes: prevalence and impact on glycemic control. *Clinical Pediatrics*, 52(1), 10–15.
doi:10.1177/0009922812459950

Berry, J. G., Bloom, S., Foley, S., & Palfrey, J. S. (2010). Health inequity in children and youth with chronic health conditions. *Pediatrics*, 126(3), 111-119.
doi:10.1542/peds.2010-1466D

Bless, C., Higson-Smith, C., & Kagee, A. (2006). *Fundamentals of social research methods: An African perspective*. Cape Town, SA: Juta.

Boehm, J. K., & Kubzansky, L. D. (2012). The heart's content: the association between

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- positive psychological well-being and cardiovascular health. *Psychological Bulletin*, 138(4), 655– 691. doi:10.1037/a0027448
- Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current Opinion in Pediatrics*, 22(4), 405–411. doi:10.1097/MOP.0b013e32833a46a7
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77 – 101.
- Broadbent, E., Donkin, L., & Stroh, J. C. (2011). Illness and treatment perceptions are associated with adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care*, 34(2), 338–340. doi:10.2337/dc10-1779
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60, 631– 637.
doi:10.1016/j.jpsychores.2005.10.020
- Bryden, K. S., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care*, 24, 1536–1540.
- Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: a systematic review and meta-analysis. *Psychoneuroendocrinology*, 70, 70-84.
doi:10.1016/j.psyneuen.2016.04.019
- Chaney, D., Coates, V., Shevlin, M., Carson, D., McDougall, A., & Long, A. (2012).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Diabetes education: what do adolescents want? *Journal of Clinical Nursing*, 21(1-2), 216-223. doi:10.1111/j.1365-2702.2010.03692.x
- Cheung, R., Young Cureton, V., & Canham, D. L. (2006). Quality of life in adolescents with type 1 diabetes who participate in diabetes camp. *The Journal of School Nursing*, 22(1), 53-58.
- Chevreur, K., Berg Brigham, K., & Bouché, C. (2014). The burden and treatment of diabetes in France. *Globalization and Health*, 10(1), 6-14. doi:10.1186/1744-8603-10-6
- Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 diabetes through the lifespan: a position statement of the American Diabetes Association. *Diabetes Care*, 37(7), 2034-2054. doi:10.2337/dc14-1140
- Coffen, R. D. (2009). The 600-step program for type 1 diabetes selfmanagement in youth: the magnitude of the self-management task. *Postgraduate Medicine*, 121(5), 119-139. doi:10.3810/pgm.2009.09.2059
- Comeaux, S. J., & Jaser, S. S. (2010). Autonomy and insulin in adolescents with type 1 diabetes. *Paediatric Diabetes*, 11(7), 498-504. doi:10.1111/j.1399-5448.2009.00625.x
- Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, 8, 455-480. doi:10.1146/annurev-clinpsy-032511-143108
- Compton, W. C., & Hoffman, E. (2013). *Positive psychology – The science of happiness and flourishing* (2nd ed.). Belmont, CA: Wadsworth.
- Cooke, D. W., & Plotnick, L. (2008). Type 1 diabetes mellitus in pediatrics. *Pediatrics in*

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Review, 29(11), 374-384. doi:10.1542/pir.29-11-374

Coolican, H. (2014). *Research methods and statistics in psychology* (6th ed.). New York, NY: Psychology Press.

Creswell, J. (2009). *Research design: Qualitative, quantitative and mixed methods approaches*. Thousand Oaks, CA: Sage.

Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview based qualitative research. *Social Science Information*, 45(4), 483-499.

Datye, K. A., Moore, D. J., Russell, W. E., & Jaser, S. S. (2015). A review of adolescent adherence in type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. *Current Diabetes Reports*, 15(8), 621-638. doi:10.1007/s11892-015-0621-6

de Wit, M., & Snoek, F. J. (2011). Depressive symptoms and unmet psychological needs of Dutch youth with type 1 diabetes: results of a web-survey. *Pediatric Diabetes*, 12, 172-176. doi:10.1111/j.1399-5448.2010.00673.x

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks, CA: Sage.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40, 314-321. doi:10.1111/j.1365-2929.2006.02418

Distiller, L. A., Brown, M. A., Joffe, B. I., & Kramer, B. D. (2010). Striving for the impossible dream: a community-based multi-practice collaborative model of diabetes management. *Diabetic Medicine*, 27(2), 197-202. doi:10.1111/j.1464-5491.2009.02907.x

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

Ellis, P. (2016). *Understanding research for nursing students* (3rd ed.). Thousand Oaks, CA: Sage.

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 1-11.

Fortenberry, K. T., Berg, C. A., King, P. S., Stump, T., Butler, J. M., Pham, P. K., & Wiebe, D. (2014). Longitudinal trajectories of illness perceptions among adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 39(7), 687–696. doi:10.1093/jpepsy/jsu043

Franciosi, M., Lucisano, G., Amoretti, R., Capani, F., Bruttomesso, D., Di Bartolo, P., ... Nicolucci, A. (2013). Costs of treatment and complications of adult type 1 diabetes. *Nutrition, metabolism, and cardiovascular diseases*, 23(7), 606–611.

French, D. P., & Weinman, J. (2008). Current issues and new directions in psychology and health: "Assessing illness perceptions: beyond the IPQ". *Psychology and Health*, 23(1), 5–9. doi:10.1080/08870440701616714

Gabriel, B. D., Albuquerque, C. T., Consoli, M. L. D., Menezes, P. A. F. C., & Reis, J. S. (2016). Training adolescents with type 1 diabetes to carbohydrate counting without parents' help. *Revista de Nutrição*, 29(1), 77-84.

Gandhi, K., Vu, B. K., Eshtehardi, S. S., Wasserman, R. M., & Hilliard, M. E. (2015). Adherence in adolescents with type 1 diabetes: strategies and considerations for assessment in research and practice. *Diabetes management (London, England)*, 5(6), 485–498. doi:10.2217/dmt.15.41

Gaston, A. M., Cottrell, D. J., & Fullen, T. (2012). An examination of how adolescent-

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- caregiver dyad illness representations relate to adolescents' reported diabetes self-management. *Child: Care, Health and Development*, 38, 513–519.
- Gillespie, S. J., Kulkarni, K. D., & Daly, A. E. (1998). Using carbohydrate counting in diabetes clinical practice. *Journal of the American Dietetic Association*, 98(8), 897-905.
- Gonzalez, J. S., Tanenbaum, M. L., & Commissariat, P. V. (2016). Psychosocial factors in medication adherence and diabetes self-management: implications for research and practice. *American Psychologist*, 71(7), 539-551.
- Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology & Health*, 15(6), 733-750. doi:10.1080/08870440008405578
- Grix, J. (2002). Introducing students to the generic terminology of social research. *Politics*, 22(3), 175-186.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the Common-Sense Model of illness representations. *Psychology & Health*, 18(2), 141-184.
doi:10.1080/088704403100081321
- Hagger, V., Trawley, S., Hendrieckx, C., Browne, J. L., Cameron, F., Pouver, F., ...

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Speight, J. (2016). Diabetes MILES Youth-Australia: methods and sample characteristics of a national survey of the psychological aspects of living with type 1 diabetes in Australian youth and their parents. *BMC Psychology*, *4*(1), 42-55. doi:10.1186/s40359-016-0149-9
- Hapunda, G., Abubakar, A., van de Vijver, F., & Pouwer, F. (2015). Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC Endocrine Disorders*, *15*, 20-39. doi:10.1186/s12902-015-0013-6
- Hefferon, K., & Boniwell, I. (2011). *Positive psychology: Theory, research and applications*. Berkshire, UK: McGraw-Hill.
- Helgeson, V. S., Siminerio, L., Escobar, O., & Becker, D. (2009). Predictors of metabolic control among adolescents with diabetes: a 4-year longitudinal study. *Journal of Pediatric Psychology*, *34*(3), 254–270. doi:10.1093/jpepsy/jsn079
- Herzer, M., & Hood, K. K. (2010). Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycemic control. *Journal of Pediatric Psychology*, *35*(4), 415–425. doi:10.1093/jpepsy/jsp063
- Hilliard, M. E., Wu, Y. P., Rausch, J., Dolan, L. M., & Hood, K. K. (2013). Predictors of deteriorations in diabetes management and control in adolescents with type 1 diabetes. *Journal of Adolescent Health*, *52*(1), 28–34. doi:10.1016/j.jadohealth.2012.05.009
- Hinzmann, R., Schlaeger, C., & Tran, C. T. (2010). What do we need beyond hemoglobin A1c to get the complete picture of glycemia in people with diabetes? *International Journal of Medical Sciences*, *9*(8), 665-681. doi:10.7150/ijms.4520

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Hood, K. K., Peterson, C. M., Rohan, J. M., & Drotar, D. (2010). Association between adherence and glycemic control in pediatric type 1 diabetes: a meta-analysis. *Pediatrics, 124*, 1171-1179.
- Howitt, D. (2010). *Introduction to qualitative methods in Psychology*. Essex, UK: Pearson.
- Hunter, C. M. (2016). Understanding diabetes and the role of psychology in its prevention and treatment. *American Psychologist, 71*(7), 515-525. doi:10.1037/a0040344
- Husted, G. R., Esbensen, B. A., Hommel, E., Thorsteinsson, B., & Zoffmann, V. (2014). Adolescents developing life skills for managing type 1 diabetes: a qualitative, realistic evaluation of a guided self-determination-youth intervention. *Journal of Advanced Nursing, 70*(11), 2634–2650. doi:10.1111/jan.12413
- Inagaki, K., & Hatano, G. (2006). Young children's conception of the biological world. *Current Directions in Psychological Science, 15*(4), 177-181. doi:10.1111/j.1467-8721.2006.00431.x
- Jain, V. (2014). Management of type 1 diabetes in children and adolescents. *The Indian Journal of Pediatrics, 81*(2), 170–177. doi:10.1007/s12098-013-1196-3
- Janesick, V. J. (2000). The choreography of qualitative research design. In N. K. Denzin, & Y. S. Lincoln (Eds.). *Handbook of Qualitative Research* (pp. 379 – 399). London, UK: Sage.
- Jaser, S, S., Patel, N., Rothman, R. L., Choi, L., & Whittemore, R. (2014). Check It!: A randomized pilot of a positive psychology intervention to improve adherence in adolescents with type 1 diabetes. *Diabetes Educator, 40*(5), 659–667. doi:10.1177/0145721714535990

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Johnson, B., Eiser, C., Young, V., Brierley, S., & Heller, S. (2013). Prevalence of depression among young people with type 1 diabetes: a systematic review. *Diabetic Medicine*, 30(2), 199-208. doi:10.1111/j.1464-5491.2012.03721.x
- Kalk, W. J., Raal, F. J., & Joffe, B. I. (2010). The prevalence and incidence of and risk factors for micro-albuminuria among urban Africans with type 1 diabetes in South Africa: An inter-ethnic study. *International Journal of Diabetes Mellitus*, 2(3), 148–153. doi:10.1016/j.ijdm.2010.10.003
- Kalweit, K. L., Briers, N., & Olorunju, S. (2015). The success of various management techniques used in South African children with type 1 diabetes mellitus. *The South African Medical Journal*, 105(5), 400-404. doi:10.7196/samj.9334
- Kaul, K., Tarr, J. M., Ahmad, S. I., Kohner, E. M., & Chibber, R. (2012). Introduction to diabetes mellitus. *Advances in Experimental Medicine and Biology*, 771, 1-10.
- King, P. S., Berg, C. A., Butner, J., Butler, J. M., & Wiebe, D. J. (2014). Longitudinal trajectories of parental involvement in type 1 diabetes and adolescents' adherence. *Journal of Health Psychology*, 33(5), 424-432. doi:10.1037/a0032804
- Kirigia, J. M., Sambo, H. B., Sambo, L. G., & Barry, S. P. (2009). Economic burden of diabetes mellitus in the WHO African region. *BMC International Health and Human Rights*, 9(6), 1- 12. doi:10.1186/1472-698X-9-6
- Larun, L., Nordheim, L. V., Ekeland, E., Hagen, K. B., & Heian, F. (2006). Exercise in prevention and treatment of anxiety and depression among children and young people. *The Cochrane Database of Systematic Reviews*, 19(3), CD004691. doi:10.1002/14651858.CD004691.pub2

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Law, G. U., Kelly, T. P., Huey, D. D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: do illness representations play a regulatory role? *Journal of Adolescent Health, 31*(4), 381-385.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L., & Robitaille, C. (1997). Illness perceptions: Theoretical foundations. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 19-45). Amsterdam, Netherlands: Harwood Academic.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (2005). Transition planning for youth with special health care needs: results from the national survey of children with special health care needs. *Pediatrics, 115*(6), 1562-1568.
- Lung, T. W., Clarke, P. M., Hayes, A. J., Stevens, R. J., & Farmer, A. (2013). Simulating lifetime outcomes associated with complications for people with type 1 diabetes. *Pharmacoeconomics, 31*(6), 509-518. doi:10.1007/s40273-013-0047-4
- Macaskill, A. (2016). Review of positive psychology applications in clinical medical populations. *Healthcare, 4*, 66-75. doi:10.3390/healthcare4030066
- Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet, 358*, 483-488.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice, 13*(6), 522-525.
- McAndrew, L. M., Musumeci-Szabo, T. J., Moral, P. A., Vileikyte, L., Burns, E., Halm, E.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- A., ... Leventhal, H. (2008). Using the common sense model to design interventions for the prevention and management of chronic illness threats: from description to process. *British Journal of Health Psychology, 13*, 195–204. doi:10.1348/135910708X295604
- Mc Sharry, J., Moss-Morris, R., & Kendrick, T. (2011). Illness perceptions and glycaemic control in diabetes: a systematic review with meta-analysis. *Diabetic Medicine, 28*(11), 1300-1310. doi:10.1111/j.1464-5491.2011.03298.x
- Mehta, S. N., Volkening, L. K., Anderson, B. J., Nansel, T., Weissberg-Benchell, J., Wysocki, T., & Laffel, L. M. (2008). Dietary behaviors predict glycemic control in youth with type 1 diabetes. *Diabetes Care, 31*(7), 1318-1320. doi:10.2337/dc07-2435
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation* (2nd ed.). San Francisco, CA: Jossey-Bass.
- Miculis, C. P., De Campos, W., & da Silva Boguszewski, M. C. (2015). Correlation between glycemic control and physical activity level in adolescents and children with type 1 diabetes. *Journal of Physical Activity and Health, 12*(2), 232-237. doi:10.1123/jpah.2013-0024
- Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., ...Drotar, D. (2012). Pediatric self-management: a framework for research, practice, and policy. *Pediatrics, 129*(2), 473-485. doi:10.1542/peds.2011-1635
- Moss-Morris, R., Weinman, J., Petrie, K. J., & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health, 17*(1), 1-16. doi:10.1080/08870440290001494
- Mulvaney, S. A., Lilley, J. S., Cavanaugh, K. L., Pittel, E. J., & Rothman, R. L. (2013).

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Validation of the diabetes numeracy test with adolescents with type 1 diabetes. *Journal of Health Communication*, 18(7), 795–804. doi:10.1080/10810730.2012.757394
- Nieuwenhuis, J. (2007). Qualitative research design and data gathering techniques. In K. Maree (Eds.), *First steps in research* (pp. 81 – 93). Pretoria, SA: Van Schaik.
- Olsen, B., Berg, C. A., & Wiebe, D. J. (2008). Dissimilarity in mother and adolescent illness representations of type 1 diabetes and negative emotional adjustment. *Psychology and Health*, 23(1), 113-129. doi:10.1080/08870440701437343
- Onwuegbuzie, A. J., & Leech, N. L. (2007). Sampling designs in qualitative research: making the sampling process more public. *The Qualitative Report*, 12(2), 238-254.
- Patiño-Fernández, A. M., Delamater, A. M., Applegate, E. B., Brady, E., Eidson, M., Nemery, R., ... Richton, S. (2010). Neurocognitive functioning in preschool-age children with type 1 diabetes mellitus. *Pediatric Diabetes*, 11, 424–430. doi:10.1111/j.1399-5448.2009.00618.x
- Patterson, C., Guariguata, L., Dahlquist, G., Soltész, G., Ogle, G., & Silink, M. (2014). Diabetes in the young – a global view and worldwide estimates of numbers of children with type 1 diabetes. *Diabetes Research and Clinical Practice*, 103(2), 161-175. doi:10.1016/j.diabres.2013.11.005
- Patton, S. R. (2015). Adherence to glycemic monitoring in diabetes. *The Journal of Diabetes Science and Technology*, 9(3), 668-675. doi:10.1177/1932296814567709
- Peters, A., & Laffel, L. (2011). Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems. *Diabetes Care*, 34(11), 2477-2485. doi:10.2337/dc11-1723

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Petrie, K. J., Jago, L. A., & Devcich, D. A. (2007). The role of illness perceptions in patients with medical conditions. *Current Opinion in Psychiatry*, *20*, 163–167.
- Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: a new method for assessing cognitive representation of illness. *Psychology and Health*, *11*, 431-438.
- Petrie, K. J., & Weinman, J. (2012). Patients' perceptions of their illness: the dynamo of volition in health care. *Current Directions in Psychological Science*, *21*(1), 60–65.
doi:10.1177/0963721411429456
- Peyrot, M., Rubin, R. R., Lauritzen, T., Snoek, F. J., Matthews, D. R., & Skovlund, S. E. (2004). Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) study. *Diabetic Medicine*, *22*, 1379–1385.
- Pires-Yfantouda, R., & Evangelii, M. (2012). The role of psychosocial factors in wellbeing and self-care in young adults with type 1 diabetes. *International Journal of Diabetes Research*, *1*(1), 1-6. doi:10.5923/j.diabetes.20120101.01
- Polkinghorne, D. E. (2005). Language and meaning: data collection in qualitative research. *Journal of Counseling Psychology*, *52*(2), 137–145.
- Quirk, H., Blake, H., Tennyson, R., Randell, T. L., & Glazebrook, C. (2014). Physical activity interventions in children and young people with type 1 diabetes mellitus: a systematic review with meta-analysis. *Diabetic Medicine*, *1*(10), 1163-1173.
doi:10.1111/dme.12531
- Reddy, Y., Ganie, Y., & Pillay, K. (2013). Characteristics of children presenting with newly

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

diagnosed type 1 diabetes. *The South African Journal of Child Health*, 7(2), 46-48.

doi:10.7196/SAJCH.500

Rewers, M., Pihoker, C., Donaghue, K., Hanas, R., Swift, P., & Klingensmith, G. J. (2009).

Assessment and monitoring of glycemic control in children and adolescents with

diabetes. *Pediatric Diabetes*, 10(12), 71–81. doi:10.1111/j.1399-5448.2009.00582.x

Reynolds, K. A., & Helgeson, V. S. (2011). Children with diabetes compared to peers:

depressed? distressed? *Journal of the Society of Behavioral Medicine*, 42(1), 29–41.

doi:10.1007/s12160-011-9262-4

Ritchie, J. (2009). The applications of qualitative methods to social research. In J. Ritchie &

J. Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp.26 – 34). London, UK: Sage.

Ritchie, J., Lewis, J., & Elam, G. (2009). Designing and selecting samples. In J. Ritchie & J.

Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp.77 – 85). London, UK: Sage.

Roulston, K. (2001). Data analysis and ‘theorizing as ideology’. *Qualitative Research*, 1(3),

279-302.

Roze, S., Saunders, R., Brandt, A. S., de Portu, S., Papo, N. L., & Jendle, J. (2015). Health-

economic analysis of real-time continuous glucose monitoring in people with type 1

diabetes. *Diabetic Medicine*, 32(5), 618-626. doi:10.1111/dme.12661

Safo, S. A., Batchelder, A., Peyser, D., & Litwin, A. H. (2015). The common sense model

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

applied to hepatitis C: a qualitative analysis of the impact of disease comparison and witnessed death on hepatitis C illness perception. *Harm Reduction Journal*, 12, 20-28.
doi:10.1186/s12954-015-0054-1

Sarantakos, S. (2013). *Social research*. London, UK: Palgrave Macmillan.

Schabert, J., Browne, J. L., Mosely, K., & Speight, J. (2013). Social stigma in diabetes. A framework to understand a growing problem for an increasing epidemic. *Patient*, 6(1), 1–10. doi:10.1007/s40271-012-0001-0

Schilling, L. S., Grey, M., & Knafl, K. A. (2002). The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis. *The Australian Journal of Advanced Nursing*, 37(1), 87-99.

Seth, A., & Maheshwari, A. (2013). Common endocrine problems in children (hypothyroidism and type 1 diabetes mellitus). *The Indian Journal of Pediatrics*, 80(8), 681–687. doi:10.1007/s12098-013-1101-0

Sharma, N., O'Hare, K., Antonelli, R. C., & Sawicki, G. S. (2014). Transition care: future directions in education, health policy, and outcomes research. *Academic Pediatrics*, 14(2), 120-127. doi:10.1016/j.acap.2013.11.007

Sharma, B. D., & Singal, P. (2015). The utility and pitfalls of the currently used measures of glycaemia in the diagnosis and management of diabetes mellitus. *Journal, Indian Academy of Clinical Medicine*, 16(3-4), 227-235.

Sherwood, L. (2010). *Human Physiology : From cells to systems* (7th ed.). Belmont, CA: Brooks/Cole.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., ... Clark, N. (2005). Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care*, 28(1), 186–212.
- Skinner, C. T., John, M., & Hampson, S. E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. *Journal of Pediatric Psychology*, 25(4), 257-267.
- Smart, C. E., Ross, K., Edge, J. A., King, B. R., McElduff, P., & Collins, C. E. (2010). Can children with type 1 diabetes and their caregivers estimate the carbohydrate content of meals and snacks? *Diabetic Medicine*, 27(3), 348-353. doi:10.1111/j.1464-5491.2010.02945.x
- Smetana, J. G., Campione-Barr, N., & Metzger, A. (2006). Adolescent development in interpersonal and societal contexts. *Annual Review of Psychology*, 57, 255-284. doi:10.1146/annurev.psych.57.102904.190124
- Snape, D., & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp. 1 – 23). London, UK: Sage.
- Snoek, F. J., & Skinner, C. T. (2006). Psychological aspects of diabetes management. *Medicine*, 34(2), 61 – 62.
- Spear, H. J., & Kulbok, P. (2004). Autonomy and adolescence: a concept analysis. *Public Health Nursing*, 21(2), 144–152. doi:10.1111/j.0737-1209.2004.021208.x
- Spiegel, G., Bortsov, A., Bishop, F. K., Owen, D., Klingensmith, G. J., Mayer-Davis, E. J., &

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Maahs, D. M. (2012). Randomized nutrition education intervention to improve carbohydrate counting in adolescents with type 1 diabetes study: is more intensive education needed? *Journal of the Academy of Nutrition and Dietetics*, *112*(11), 1736-1746. doi:10.1016/j.jand.2012.06.001
- Step toe, A., Deaton, A., & Stone, A. A. (2015). Subjective wellbeing, health, and ageing. *Lancet*, *385*(9968), 640–648. doi:10.1016/S0140-6736(13)61489-0
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388– 396.
- Tully, C., Aronow, L., Mackey, E., & Streisand, R. (2016). Physical activity in youth with type 1 diabetes: a review. *Current Diabetes Reports*, *16*(9), 85-93. doi:10.1007/s11892-016-0779-6
- Tumbo, J. M., & Kadima, F. N. (2013). Screening of long-term complications and glycaemic control of patients with diabetes attending Rustenburg Provincial Hospital in North West Province, South Africa. *African Journal of Primary Health Care & Family Medicine*, *5*(1), 375– 380. doi:10.4102/phcfm.v5i1.375
- Tuomilehto, J. (2013). The emerging global epidemic of type 1 diabetes. *Current Diabetes Reports*, *13*(6), 795-804. doi:10.1007/s11892-013-0433-5
- Uprichard, E. (2013). Sampling: bridging probability and non-probability designs. *International Journal of Social Research Methodology*, *16*(1), 1 – 11.
- Vázquez, C., Hervás, G., Rahona, J. J., & Gómez, D. (2009). Psychological well-being and health. Contributions of positive psychology. *Annuary of Clinical and Health Psychology*, *5*, 15-27.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- Wadén, J., Forsblom, C., Thorn, L. M., Saraheimo, M., Rosengård-Bärlund, M., Heikkilä, O., ... Groop, P.-H. (2009). Adult stature and diabetes complications in patients with type 1 diabetes: the FinnDiane Study and the Diabetes Control and Complications Trial. *Diabetes*, 58(8), 1914–1920. doi:10.2337/db08-1767
- Weinman, J., & Petrie, K. J. (1997). Illness perception: a new paradigm for psychosomatics? *Journal of Psychosomatic Research*, 42(2), 113-116.
- Wiebe, D. J., Man Chow, C., Palmer, D. L., Butner, J., Butler, J. M., Osborn, P., & Berg, C. A. (2014). Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence. *Journal of Pediatric Psychology*, 39(5), 532–541. doi:10.1093/jpepsy/jsu006
- Winocour, P. H. (2014). Care of adolescents and young adults with diabetes – much more than transitional care: a personal view. *Clinical Medicine Journal of the Royal College of Physicians*, 14(3), 274-278. doi:10.7861/clinmedicine.14-3-274
- Wisting, L., Bang, L., Natvig, H., Skrivarhaug, T., Dahl-Jørgensen, K., Lask, B., Rø, Ø. (2016). Metabolic control and illness perceptions in adolescents with type 1 diabetes. *Journal of Diabetes Research*, 2016, 1-8. doi:10.1155/2016/3486094
- Witteman, C., Bolks, L., & Hutschemaekers, G. (2011). Development of the illness perception questionnaire mental health. *Journal of Mental Health*, 20(2), 115–125. doi:10.3109/09638237.2010.507685
- Wodrich, D. L., Hasan, K., & Parent, K. B. (2011). Type 1 diabetes mellitus and school: a review. *Pediatric Diabetes*, 12(1), 63-70. doi:10.1111/j.1399-5448.2010.00654.x
- Wylie-Rosett, J., Aebersold, K., Conlon, B., & Ostrovsky, N. W. (2012). Medical nutrition

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

therapy for youth with type 1 diabetes mellitus: more than carbohydrate counting.

Journal of the Academy of Nutrition Dietetics, 112(11), 1724-1727.

Yi-Frazier, J. P., Hilliard, M., Cochrane, K., & Hood, K. K. (2012). The impact of positive psychology on diabetes outcomes: a review. *Psychology*, 3(12), 1116-1124.

doi:10.4236/psych.2012.312A165

Ziegler, R., Heidtmann, B., Hilgard, D., Hofer, S., Rosenbauer, J., & Holl, R. (2011).

Frequency of SMBG correlates with HbA1c and acute complications in children and adolescents with type 1 diabetes. *Pediatric Diabetes*, 12(1), 11–17. doi:10.1111/j.1399-

5448.2010.00650.x

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

ADDENDUM A

Ethical Approval Certificate: Overarching project



Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Institutional Research Ethics Regulatory Committee

Tel +27 18 299 4849
Email Ethics@nwu.ac.za

ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by **Humanities and Health Research Ethics Committee (HHREC)**, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: Psycho-social variables in adjusting to diabetes management in adolescents and young adults																																															
Project Leader: E Deacon																																															
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>H</td><td>S</td><td>-</td><td>2</td><td>0</td><td>1</td><td>5</td><td>-</td><td>0</td><td>1</td><td>1</td><td>1</td></tr><tr><td colspan="3">Institution</td><td colspan="5">Project Number</td><td colspan="3">Year</td><td colspan="3">Status</td></tr><tr><td colspan="16">Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</td></tr></table>	N	W	U	-	H	S	-	2	0	1	5	-	0	1	1	1	Institution			Project Number					Year			Status			Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation															
N	W	U	-	H	S	-	2	0	1	5	-	0	1	1	1																																
Institution			Project Number					Year			Status																																				
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation																																															
Approval date: 2015-08-11	Expiry date: 2018-08-10	Category: N/A																																													

Special conditions of the approval (if any): None

<p>General conditions:</p> <p>While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:</p> <ul style="list-style-type: none">• The project leader (principle investigator) must report in the prescribed format to the NWU-IRERC:<ul style="list-style-type: none">- annually (or as otherwise requested) on the progress 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.• The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-IRERC. Would there be deviated from the project protocol 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-IRERC and new approval received before or on the expiry date.• In the interest of ethical responsibility the NWU-IRERC retains the right to:<ul style="list-style-type: none">- request access to any information or data at any time during the course or after completion of the project;- withdraw or postpone approval if:<ul style="list-style-type: none">- any unethical principles or practices of the project are revealed or suspected,- it becomes apparent that any relevant information was withheld from the NWU-IRERC 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.
--

The IRERC 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 IRERC for any further enquiries or requests for assistance.

Yours sincerely

Linda du Plessis
Digitally signed by Linda du Plessis
DN: cn=Linda du Plessis, o=NWU,
ou=Vaal Triangle Campus,
email=Linda.duplessis@nwu.ac.za,
c=ZA
Date: 2015.08.11 14:25:23 +02'00'

Prof Linda du Plessis
Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

ADDENDUM B

Ethical Approval Certificate: Current study



Private Bag X6001, Potchefstroom,
South Africa, 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Institutional Research Ethics Regulatory Committee

Tel: +27 18 299 4849

Email: Ethics@nwu.ac.za

2016-08-23

ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the **Humanities and Health Research Ethics Committee (HHREC)** on **18/08/2016**, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby **approves** your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: Illness perception of adolescents with well-controlled type 1 diabetes																														
Project Leader/Supervisor: Dr E Deacon																														
Student: D Jonker																														
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>HS</td><td>-</td><td>2</td><td>0</td><td>1</td><td>6</td><td>-</td><td>0</td><td>0</td><td>6</td><td>6</td></tr><tr><td colspan="4">Institution</td><td colspan="4">Project Number</td><td colspan="2">Year</td><td colspan="4">Status</td></tr></table> <small>Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</small>	N	W	U	-	HS	-	2	0	1	6	-	0	0	6	6	Institution				Project Number				Year		Status			
N	W	U	-	HS	-	2	0	1	6	-	0	0	6	6																
Institution				Project Number				Year		Status																				
Application Type: N/A	Risk: > Than Minimal																													
Commencement date: 2016-08-18	Expiry date: 2019-08-18																													

Special conditions of the approval (if applicable):

- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HHREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HHREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

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 project leader (principle investigator) must report in the prescribed format to the NWU-IRERC via HHREC:
 - annually (or as otherwise requested) on the progress of the project, 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 protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the HHREC. Would there be deviated from the project protocol 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-IRERC via HHREC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-IRERC and HHREC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - 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 via Daleen.Claasens@nwu.ac.za or 018 210 3441

The IRERC 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 IRERC or HHREC for any further enquiries or requests for assistance.

Yours sincerely

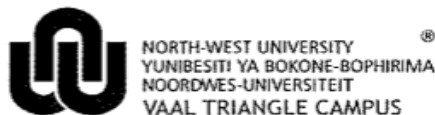
Prof LA Du Plessis
Digitally signed by Prof LA Du Plessis
Date: 2016.08.23
15:36:36 +02'00'

Prof Linda du Plessis

Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)

ADDENDUM C

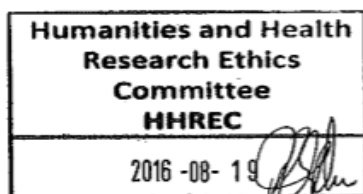
Informed consent form for legal guardians of adolescents



PO Box 1174, Vanderbijlpark
South Africa, 1900

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

18 August 2016



**PARTICIPANT INFORMATION LEAFLET AND CONSENT
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 well-controlled type 1 diabetes (NWU-HS-2016-0066)*

RESEARCHER: Ms. Deborah Jonker

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 well-controlled type 1 diabetes (NWU-HS-2016-0066)*.

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 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

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

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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-2016-0066)** 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 eight to fifteen participants will be interviewed.*
- *This research project has two objectives, firstly to explore the illness perception of adolescents with well-controlled 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 8% or less 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 45 minutes. If your child do 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 consent.*
- *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 assent and 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, 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.*



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- *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:*

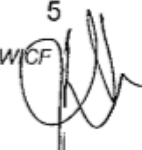
<i>Probable/possible risks/discomforts</i>	<i>Strategies to minimize risk/discomfort</i>
Because your child may be spending more or less 45 minutes participating in the interview, it is possible that he/she can become tired.	The researcher facilitating the interview will give your child a 15-minute break 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 with the interview.	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.
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	We will not be drawing blood or doing any other tests physically hurting your child. We will ask your written informed consent to retrieve the information from your child's record at the CDE.

4

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

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

<p>at the CDE with your permission.</p>	
<p>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.</p>	<p>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.</p>
<p>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.</p>	<p>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.</p>
<p>Living with diabetes you or your child may be worried that people learn about their diagnosis and start treating him/her differently.</p>	<p>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.</p>
<p>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.</p>	<p>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.</p>
<p>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 were harmed or neglected, the researchers will have to share this information with the right people to make sure that your child is safe.</p>	<p>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 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.</p>



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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 consent, followed by your child's written assent. Only the signed consent and assent 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.

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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 (016 910 3414) if you have any further questions or encounter any problems.
- You can contact the chair of the Humanities and Health Research Ethics Committee (Prof Tumi Khumalo) at 016 910 3397 or Tumi.khumalo@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, Prof Werner Nell (016 910 3427 or Werner.Nell@nwu.ac.za). You can leave a message for either Tumi or Werner with Ms Daleen Claasens (016 910 30441).
- You will receive a copy of this information and consent 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 well-controlled type 1 diabetes**, provided that they give written assent, following my consent.

I declare that:

- I have read and understood this information and consent 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 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 neither I nor my child has been pressurised to take part.

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



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- 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 consent

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.



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

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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

.....
Signature of person obtaining consent

.....
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

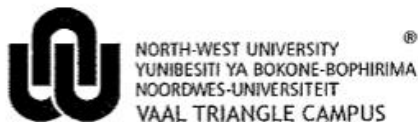


9

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

ADDENDUM D

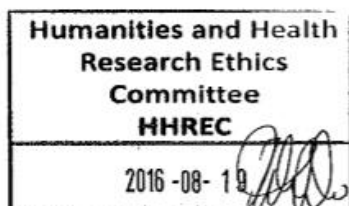
Informed assent form for adolescents



PO Box 1174, Vanderbijlpark
South Africa, 1900

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

18 August 2016



**PARTICIPANT INFORMATION LEAFLET AND ASSENT
FORM FOR 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 well-controlled type 1 diabetes (NWU-HS-2016-0066)

RESEARCHER: Ms. Deborah Jonker

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 well-controlled type 1 diabetes (NWU-HS-2016-0066)*.

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 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 consent we would appreciate it if you would also agree to take part. Your

1

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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-2016-0066) have been approved by the **Humanities and Health Research Ethics Committee (HREC) 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 eight to fifteen participants will be interviewed.*
- *This research project has two objectives, firstly to explore the illness perception of adolescents with well-controlled 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 8% or less 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.*

2

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



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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 45 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 assent 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.*
- *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*

ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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:*

<i>Probable/possible risks/discomforts</i>	<i>Strategies to minimize risk/discomfort</i>
Because you will spend about 45 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 possible low and high blood glucose levels unexpectedly and this may happen while you are participating in an interview with the researcher.	If you feel ill at any time during the interview, you need to tell the researcher so that your blood glucose can be tested and corrected.

4

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



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

<p>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.</p>	<p>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.</p>
<p>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.</p>	<p>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.</p>
<p>Living with diabetes, you may be worried that people learn about your diagnosis and start treating you differently.</p>	<p>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.</p>
<p>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.</p>	<p>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.</p>
<p>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.</p>	<p>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 things that can happen, depending on what had happened, who was present and how serious the problem is.</p>
<p>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</p>	<p>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</p>

5

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



times over the next few years.

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 consent form, after which the 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).

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.



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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 (016 910 3414) if you have any further questions or encounter any problems.
- You can contact the chair of the Humanities Research Ethics committee, Prof Tumi Khumalo (016 910 3397 or Tumi.khumalo@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, Prof Werner Nell (016 910 3427 or Werner.nell@nwu.ac.za). You can leave a message for either Tumi or Tumi with Ms Daleen Claasens (016 910 30441).
- You will receive a copy of this information and 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 well-controlled type 1 diabetes.

I declare that:

- I have read and understood this information and 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.
- 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.

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

7



ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

- 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 assent.


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 assent

.....
Signature of witness

8


ILLNESS PERCEPTION OF ADOLESCENTS WITH TYPE 1 DIABETES

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



9

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

ADDENDUM E

Interview agenda: English version

Interview agenda

- Firstly, the researcher introduced herself to the participant;
- The procedure (including the use of the digital voice recorder) was explained;
- The digital voice recorder was set up and sound quality was tested beforehand;
- It was clearly stated why the researcher would take notes during the interview;
- The participant was reassured of confidentiality and anonymity;
- Voluntary participation and permission to withdrawal at any stage was addressed;
- Questions were addressed if there was any before the interview started.

Table 1

Interview agenda used in the current study

Section A	
Question 1	Can you tell me about your experience in terms of managing your diabetes?
Question 2	Can you tell me about the contexts or situations that have typically influenced or affected your experience of managing your diabetes?
Section B	
Question 3	How did your life change after being diagnosed with diabetes?
Question 4	How do you manage your diabetes?
Question 5	How does your understanding of diabetes influence how you manage it?
Question 6	How does managing diabetes impact your daily life?
Question 7	How does support from family and friends influence how you manage your diabetes?
Question 8	How do you make sense of living with diabetes?

- After the questions were asked, time was provided for participant to add anything should they desire to;
- The participant was thanked for the time and the interview was concluded;
- The process of analysis and sharing of findings were discussed;
- The participant received a certificate with a sticker, an information leaflet on diabetes management, a bottle of still water and a low carbohydrate snack;
- Right after the interview the researcher verified if the recorder operated throughout the interview. Field notes were written on the same day after the interview.

ADDENDUM F

Interview agenda: Afrikaans version

Agenda van Onderhoud

- Die navorser stel haarself bekend aan die deelnemer;
- Die prosedure sowel as die gebruik van 'n digitale bandopnemer word verduidelik;
- 'n Klank kwaliteitstoets is reeds vooraf met die bandopnemer gedoen;
- Die deelnemer word ingelig waarom die navorser notas gaan maak tydens die onderhoud;
- Die deelnemer word weer eens verseker van vertroulikheid en anonimiteit;
- Vrywillige deelname en die reg om ter eniger tyd van die studie te onttrek word beklemtoon;
- Geleentheid word gegun om enige vrae of onsekerhede aan te spreek.

Tabel 1

Agenda van Onderhoud gebruik tydens die studie

Afdeling A	
Vraag 1	Kan jy my vertel van jou ervarings rondom jou diabetes behandeling?
Vraag 2	Kan jy my vertel van situasies wat 'n invloed mag hê op die hantering van jou diabetes?
Afdeling B	
Vraag 3	Hoe het jou lewe verander nadat jy met diabetes gediagnoseer is?
Vraag 4	Hoe bestuur jy jou diabetes?
Vraag 5	Hoe beïnvloed jou begrip van diabetes die wyse waarop jy dit bestuur?
Vraag 6	Hoe beïnvloed diabetesbehandeling jou daaglikse lewe?
Vraag 7	Watter rol speel die ondersteuning van vriende en familie in jou bestuur van jou diabetes?
Vraag 8	Hoe maak jy sin daarvan om met diabetes te lewe?

- Na afloop van die vrae, word die deelnemer geleentheid gegee iets by te voeg indien verkies;
- Die deelnemer word bedank vir die deelname en die onderhoud beëindig;
- Die proses van analise en deel van bevindinge word bespreek met die deelnemer;
- Die deelnemer ontvang 'n sertifikaat met 'n plakker, 'n informasiepamflet oor diabetes, 'n bottel met water en 'n lae GI versnapering;
- Na afloop van die onderhoud word die funksionering van die bandopnemer nagegaan. Notas word voltooi op dieselfde dag van die onderhoud.

ADDENDUM G

Thematic analysis summary: Illness perception of adolescents with well-controlled type 1 diabetes mellitus

Table 1

Summary of the themes portraying adolescents with well-controlled type 1 diabetes mellitus illness perception

Theme	Description	Inclusion criteria	Example from the data
Theme 1: Living with diabetes becomes a way of life	The participants perceive that diabetes is an inevitable part of their daily life. Over time they have gained insight and understanding on how to manage their diabetes and it became a routine component of their daily life. Type 1 diabetes mellitus and its management were perceived as not just sheer habit, but an integral part of self	<ul style="list-style-type: none"> • Perception formed over time • Management force of habit • Identity ascribed to type 1 diabetes mellitus • An integral part of self 	<p>A1: "It's a way of life. What else?"</p> <p>A2: "part of my life"</p> <p>A3: "routine"</p> <p>A4: "You live with it"</p> <p>A5: "routine"</p> <p>A6: "all that I know"</p> <p>A7: "my diabetes"</p> <p>A8: "routine"</p> <p>A9: "such an habit"</p>
Theme 2: Managing diabetes leads to being different	The participants perceive themselves as being different, because they must adhere to a strict regime that people without living with diabetes do not have to adhere to.	<ul style="list-style-type: none"> • Supported by experiences • Denial • Seldom reacted to denial behaviour • Acceptance 	<p>A1: "bit different"</p> <p>A2: "I'm different"</p> <p>A3: "I just wanne pretend I'm normal"</p> <p>A4: "one diabetic out of a whole group of children"</p> <p>A5: "just want a normal day"</p> <p>A6: "plain normal. Now look at me"</p> <p>A7: "they can all have the sweets and I can't"</p> <p>A8: "wanna be normal"</p> <p>A9: "do so much more than most people"</p>
Theme 3: Acknowledgement of potential negative health consequences	The participants perceive that type 1 diabetes mellitus in general can have negative health consequences. It can cause serious health damage to the human body with eventually fatal consequences. More specifically, some participants realised that these negative consequences go hand in hand with poor diabetes management.	<ul style="list-style-type: none"> • Damage body/health • Fatal consequences • Associated with poor diabetes management • Perception can produce fear 	<p>A1: "impact your health"</p> <p>A2: "going into coma"</p> <p>A3: "eyesight"</p> <p>A4: "you know the consequences"</p> <p>A5: "die"</p> <p>A6: "going into coma"</p> <p>A7: "damage a limb"</p> <p>A8: "It makes you feel what could happen so it keeps you in line"</p> <p>A9: "really sick"</p>
Theme 4: Diabetes is manageable	Despite the strict treatment regimen, the participants perceive type 1 diabetes mellitus to be manageable.	<ul style="list-style-type: none"> • Perception formed over time • Regarded as a positive feature • Beneficial for the future • Crisis situations are inevitable • Self-guilt 	<p>A1: "manageable"</p> <p>A2: "Always think it's my fault that it's high"</p> <p>A3: "you gonna get highs and you gonna get lows"</p> <p>A4: "not the most difficult thing to manage"</p> <p>A5: "I manage it"</p> <p>A6: "then it stays down for the rest of the day"</p> <p>A7: "controlled".</p> <p>A8: "I manage it"</p> <p>A9: "kind of my fault cause I could've... should've brought a coke"</p>

ADDENDUM H

Thematic analysis summary: How this illness perception contributes to the effective-management of participants' diabetes

Table 1

Summary of the themes portraying how this illness perception contributes to the effective-management of participants' diabetes

Theme	Description	Inclusion criteria	Example from the data
Theme 5: Procurement of adequate knowledge	By incorporating it as a way of life participants acknowledge that they have a responsibility to gain adequate knowledge on the management of their diabetes. Furthermore, the knowledge about what complications poor management might produce helps the participants to appreciate the benefit of managing their diabetes well.	<ul style="list-style-type: none"> • Interlinked with theme 1 and theme 5. 	<p>A1: "If I need to be improve is just to learn more about it"</p> <p>A3: "I'll just do this to make it better"</p> <p>A7: "if I learn now I won't struggle"</p> <p>A8: "without knowledge you're pretty much dead"</p> <p>A9: "a lot of time is spent thinking about meals or carb counting or exercising"</p>
Theme 6: Embracing accountability to comply with obligatory management protocol	The participants perceive diabetes management to be strict according to specific guidelines: it is either right or wrong. Adhering to this management protocol is perceived as non-negotiable. Also, the majority of the participants specifically perceive their diet to be right or wrong. It is not exactly clear from the data where this perception of right and wrong originated from.	<ul style="list-style-type: none"> • Interlinked with theme 3, 4 and 5. • Discipline, maturity, and responsibility. 	<p>A1: "It's not grey areas. It's only black and white"</p> <p>A2: "you have to do it every day"</p> <p>A5: "to only eat the appropriate food"</p> <p>A6: "I have to inject in a place where it can work"</p> <p>A7: "have to eat properly"</p> <p>A9: "I just have to manage it properly"</p>
Theme 7: Acceptance of lot/fate	The participants acknowledge that acceptance of their illness helps them to manage their diabetes well.	<ul style="list-style-type: none"> • Perception formed over time. • Interlinked with theme 1 and 2. • Negative as well as positive consequences. 	<p>A1: "No point in me whining and complaining"</p> <p>A2: "I'm gonna live with it"</p> <p>A3: "it is what it is, you can't change it"</p> <p>A8: "you don't feel like you want to but you have to"</p> <p>A9: "on you to make yourself better"</p>

ADDENDUM I

Illustrations: Positive feedback



Illness perception of adolescents with well-controlled type 1 diabetes
(NWU-HS-2016-0066)
(D. Jonker)

North West University
NORTH WEST UNIVERSITY
MAGDOONAVILLE CAMPUS
MALL TRAFALGAR CAMPUS

Individuals understand and accept that they have a duty to procure adequate knowledge about the management of their type 1 diabetes. Furthermore, they embrace accountability to comply with obligatory management protocol.

Acceptance of illness facilitates individuals to manage their type 1 diabetes well.

Living with diabetes becomes a way of life, an integral part of individuals' being. A permanent relationship to acknowledge, not to oppose.

Individuals perceive themselves as being distinctive because they have to observe a strict regime that people without living with type 1 diabetes do not have to follow.

Type 1 diabetes can have potential negative health consequences especially when sub-optimally managed, yet it is perceived to be manageable regardless of the strict management regimen.

I perceive diabetes to be manageable and part of my daily routine. I understand the consequences of diabetes: it is for my own future benefit to stand the consequences of diabetes. Although I am not like others, my diabetes is well managed in my own hands. I might as well make the best of it.

Icons in the brain: person, bicycle, medical cross, insulin syringe, magnifying glass, apple.