Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes

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Dissertation submitted in *partial* fulfilment of the requirements for the degree *Magister Artium* in *Clinical Psychology* at the Potchefstroom Campus of the North-West University

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Co-supervisor: Dr E Deacon

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It all starts here ™

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Dedication

God the Almighty

‘For I know the plans I have for you’, declares the Lord, ‘plans to prosper you and not to harm you, plans to give you hope and a future.’ – Jeremiah 29:11

Declaration statement

I, Beatrice Mulder, declare that *Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes*, a mini-dissertation submitted in partial fulfilment of the requirements for the degree *Magister Artium* in *Clinical Psychology* at the Potchefstroom Campus of the North-West University, was completed according to the Copyright Act, No 98 of 1978 of the Republic of South Africa. All literary and academic material and sources, consulted during the writing and compilation of this mini-dissertation have been acknowledged and referenced according to the American Psychological Association's Publication manual (6th edition). No single or comprehensive unit of this mini-dissertation has been plagiarised from another author or institution and remains the intellectual property of the corresponding author, namely myself.

Furthermore I certify that submission of this mini-dissertation is exclusively for examination purposes at the Potchefstroom Campus of the North-West University and has not been submitted for any other purposes to any third party.

....

Beatrice Mulder

Summary

Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes

Type 1 diabetes is regarded as the most common serious endocrinological disorder among adolescents worldwide. Despite suggested annual increases in diagnoses of the disease among children globally, the prevalence thereof among adolescents in South Africa remains unknown. The peak onset period of type 1 diabetes has been identified as puberty. This is due to the fact that the associated insulin resistance leaves adolescents particularly vulnerable to developing this disorder. Being diagnosed with type 1 diabetes not only confronts adolescents with the inevitability of compromised physical wellbeing, but also necessitates immense cognitive, emotional and social adjustment. Moreover, the adolescent has to learn to deal with an intricate and burdensome diabetes management regimen in order to maintain average glycated haemoglobin levels within near normal ranges, prevent the development of serious acute and chronic diabetes-related complications, and uphold a satisfactory quality of life.

The aim of this study was to explore and subsequently formulate a condensed description of the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes. A qualitative research approach with a phenomenological research design was adopted and the study was informed by the theoretical framework of social constructionism. A non-random purposive sampling method was utilised and the final sample consisted of eight adolescents with well-controlled type 1 diabetes. Data was generated by means of in-depth interviews that were audio-recorded and transcribed. A condensed description of the participants' experiences of the physical, psychological and

social aspects of diabetes management was subsequently developed by means of thematic analysis.

The findings of this study are that diabetes management had an immense physical, psychological and social impact on the participants. Physically, the execution of a diabetes management regimen was initially experienced as onerous, necessitating the acquisition of knowledge and experience, leading to mastery and adjustment. Mastery of and adjustment to the diabetes management regimen seemed to gradually ease the difficulty. The maintenance of a strict nutritional programme nevertheless remained challenging. Psychologically, diabetes management was primarily associated with dealing with externalised and internalised negative emotions, while perceptions of the self as being different were common. Socially, others' reactions to the participants following a diabetes management regimen were suggested to be influenced by social ignorance or cognisance of type 1 diabetes management. Social ignorance was associated with paying unwanted attention to the participants' management of their type 1 diabetes, while social cognisance was associated with support of their attempt to follow a diabetes management regimen.

This study demonstrates how adolescents' perceptions and subsequent experiences of diabetes management are personally and socially constructed through social dialogue, are historically grounded and foundational to subsequent behaviours. Additionally, the need for further research aimed at the development of interventions to assist adolescents with well-controlled type 1 diabetes to cope with the challenging nature of diabetes management, as well as the enhancement of social awareness of type 1 diabetes management, are emphasised.

KEYWORDS: Type 1 diabetes, well-controlled type 1 diabetes, diabetes management, adolescence, phenomenology, social constructionist theory

Opsomming

Diabetesbestuur: Die geleefde ervarings van adolessente met goedbeheerde tipe 1-diabetes

Tipe 1-diabetes word wêreldwyd as die mees algemene ernstige endokriene siekte onder adolessente beskou. Ten spyte van aanduidings dat al hoe meer gevalle van hierdie siekte jaarliks wêreldwyd by kinders gediagnoseer word, is die voorkoms daarvan onder adolessente in Suid-Afrika onbekend. Puberteit word beskou as die vernaamste aanvangstyd van tipe 1-diabetes. Dit is omdat die gepaardgaande insulienweerstandigheid adolessente besonder kwesbaar maak om hierdie siekte te ontwikkel. Die diagnose van tipe 1-diabetes plaas adolessente nie net voor die onafwendbare werklikheid van gekompromitteerde fisieke welstand nie, maar behels enorme kognitiewe, emosionele en sosiale aanpassings. Daarbenewens moet die adolessent 'n komplekse en veeleisende diabetesbestuursregimen leer hanteer. Gemiddelde geglikosileerde hemoglobienvlakke moet binne normale reikwydtes gehou word, om ernstige akute en kroniese diabetesverwante komplikasies te voorkom en 'n bevredigende lewenskwaliteit te handhaaf.

Die doel van hierdie studie was om die geleefde ervarings van diabetesbestuur onder 'n groep adolessente met goedbeheerde tipe 1-diabetes te ondersoek en 'n kompakte beskrywing op te stel. 'n Kwalitatiewe navorsingsbenadering met 'n fenomenologiese navorsingsontwerp is toegepas en die studie is op die teoretiese raamwerk van sosiale konstruktivisme gegrond. 'n Nie-ewekansige doelgerigte steekproefmetode is gebruik en die finale monster het uit agt adolessente met goedbeheerde tipe 1-diabetes bestaan. Data is versamel deur middel van diepgaande onderhoude, waarvan klankopnames gemaak is. Die klankopnames is getranskribeer. 'n Verkorte beskrywing van die deelnemers se ervarings van die fisieke, psigologiese, en sosiale aspekte van diabetesbestuur is uiteindelik deur middel van tematiese analise ontwikkel.

Die bevindinge van hierdie studie is dat die bestuur van diabetes ’n enorme fisieke, psigologiese en sosiale impak op die deelnemers gehad het. Prakties gesproke is die toepassing van ’n diabetesbestuursplan aanvanklik as moeilik ervaar. Dit het die opdoen van kennis en ervaring genoodsaak en uiteindelik tot aanpassing en bemeestering gelei. Dit wil voorkom asof bemeestering van en aanpassing by diabetesbestuur geleidelik die moeilikheidsgraad draagliker gemaak het. Volharding met ’n streng voedingsprogram het nietemin ’n uitdaging gebly. Psigologies is diabetesbestuur hoofsaaklik geassosieer met die hantering van geëksternaliseerde en geïnternaliseerde negatiewe emosies, terwyl persepsies van die self as anders algemeen voorgekom het. Op sosiale vlak is ander se reaksies teenoor die deelnemers se nakoming van ’n diabetesbestuursplan waarskynlik deur sosiale onkunde of kennis van tipe 1-diabetesbestuur beïnvloed. Sosiale onkunde is geassosieer met ongewenste aandag aan deelnemers se bestuur van hul tipe 1-diabetes, terwyl sosiale bewustheid gepaard gegaan het met ondersteuning van hul pogings om ’n diabetesbestuursplan te volg.

Hierdie studie toon hoe adolessente se persepsies en daaropvolgende ervarings van diabetesbestuur sosiaal en persoonlik deur middel van sosiale dialoog gevorm word, histories gegrond is en die onderbou van latere gedrag is. Verder beklemtoon dit die behoefte aan verdere navorsing met die oog op die ontwikkeling van intervensies om adolessente met goedbeheerde tipe 1-diabetes by te staan met die uitdagings van diabetesbestuur, sowel as om sosiale bewusmaking van tipe 1-diabetesbestuur te bevorder.

SLEUTELWOORDE: Tipe 1-diabetes, goedbeheerde tipe 1-diabetes, diabetesbestuur, adolessente, fenomenologie, sosiale-konstruktivismeteorie

Preface

- This mini-dissertation was written in article format in accordance with rules A4.4.2 of the North-West University.
- The article in Section II of this mini-dissertation, titled: *Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes* will be submitted for possible publication in the *Health SA Gesondheid – Journal of Interdisciplinary Health Sciences.*
- The editorial and referencing style of Sections I and III of this mini-dissertation is in strict accordance with the guidelines described and defined within the Publication Manual (6th edition) of the American Psychological Association (APA) style guide.
- The author guidelines of the *Health SA Gesondheid – Journal of Interdisciplinary Health Sciences,* described in section 2.1 of this mini-dissertation, stipulates adherence to the APA editorial and referencing style as set forth in the Publication Manual (6th edition) of the American Psychological Association. However, the author guidelines of the *Health SA Gesondheid – Journal of Interdisciplinary Health Sciences,* described in section 2.1 of this mini-dissertation, also stipulates the division of article structures into subdivision numbered sections, which contradicts the APA editorial and referencing style as set forth in the Publication Manual (6th edition) of the American Psychological Association. In order to comply with the author guidelines of the *Health SA Gesondheid – Journal of Interdisciplinary Health Sciences,* described in section 2.1 of this mini-dissertation, Section II of this dissertation was written mainly according to the APA editorial and referencing style as set forth in the Publication Manual (6th edition) of the American Psychological Association, but numbering of the article subdivisions was exceptional.

- The page numbering in this mini-dissertation is consecutive, starting from the introduction.
- Prof E van Rensburg and Dr E Deacon, the co-authors of the article: *Diabetes management: The lived experiences of diabetes management among adolescents with well-controlled type 1 diabetes* in Section II of this mini-dissertation, granted their consent for submission of the said article for examination purposes in partial fulfilment of the requirements of a MA degree in Clinical Psychology.
- While the literature suggests that adolescents living with type 1 diabetes should maintain an average glycated haemoglobin level of approximately 7% or less over a period of three months for type 1 diabetes to be considered to be well controlled, Prof D.G. Segal, a specialist endocrinologist and a gatekeeper of this study, suggested that participants with glycated haemoglobin levels of 8% or lower had well-controlled type 1 diabetes and would thus be eligible for participation in the current study (personal communication, February 21, 2016).
- In-depth phenomenological interviews that were conducted in Afrikaans were translated into English for publication purposes.
- The language editing of this mini-dissertation was done by Dr M Coetzee.
- The language editing of the *'Opsomming'* was done by Mrs H van der Walt.
- The numbering of the tables is restarted in Section II
- For publication purposes the referencing in this mini-dissertation is restarted in every section.
- This mini-dissertation received a Turn-it-in report within accepted norms.

Letter of permission

Permission is hereby granted for the submission by the first author, B. Mulder, of the following mini-dissertation for examination purposes, towards partial fulfilment of the requirements for the degree Magister Artium in Clinical Psychology at the Potchefstroom campus of the North-West University:

Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes

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

Prof E van Rensburg

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11-14-2016

Dear Beatrice Mulder

Language editing

This is to confirm that I edited your master's dissertation, *Diabetes management: The lived experiences 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

Michelle Coetzee

Bewys van taalversorging

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Deur BEATRICE MULDER

- Is nagegaan vir taalkorrektheid en spelling.
- Is nagegaan vir konsekwent en korrekte mediese terminologie.

Die opsomming se inhoud en struktuur is onveranderd gelaat (aard van akademiese inhoud en beredenering in die vakgebied, struktuur van onderafdelings en opskrifte, ordening en balans van inhoud, verwysingstyl).

HESTER VAN DER WALT

Lid: Suid-Afrikaanse Vertalersinstituut
Life member: Professional Editors' Guild

Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes

SECTION 1: INTRODUCTION AND RATIONALE

1.1 Introduction

In this study the lived experience of managing diabetes is explored among a group of adolescents with well-controlled type 1 diabetes.

In the first section of this mini-dissertation, a general introduction to and the rationale for this study are provided. First the problem statement and orientation of this study are outlined. This is followed by the literature review, in which notable findings regarding diabetes mellitus are outlined, with a specific focus on type 1 diabetes mellitus, its etymological origin, aetiology, etiopathogenetic categories, pathophysiology, symptoms, diagnostic criteria and complications. The management of diabetes (with a specific focus on type 1 diabetes among adolescents) and the experience of living with and managing a chronic illness, specifically among adolescents, are also explored. The meaning and applicability of phenomenology, phenomenological qualitative research and social constructionism, which are the paradigms that inform the basis of this study, are explained. The research question for this study is stipulated and the research methodology is described.

1.2 Problem statement and orientation

Type 1 diabetes is estimated to affect approximately 542 000 children aged 14 years and younger globally (International Diabetes Federation, 2015). Moreover, the International Diabetes Federation (2015) suggests that the abovementioned worldwide prevalence of childhood type 1 diabetes is rapidly increasing. With nearly 86 000 children aged 14 years and younger being diagnosed with this endocrine disorder worldwide every year, the global

prevalence of childhood type 1 diabetes is considered to be growing at a rapid rate (International Diabetes Federation, 2015).

However, international statistical indicators pertaining exclusively to the prevalence of type 1 diabetes during the developmental phases of early, middle and late adolescence are exceptionally scarce. Statistics that are available are predominantly region specific. Within the South African context, the national prevalence of type 1 diabetes among adolescents is unknown (Dhada, Blackbeard, & Adams, 2014).

Despite the lack of exact statistics regarding its prevalence in the adolescent population, type 1 diabetes is considered to be the most common serious endocrine disorder among adolescents (Patterson et al., 2014). The pubertal occurrence of endocrine-associated and developmentally typical insulin resistance leaves adolescents particularly vulnerable to the development of type 1 diabetes (Craig et al., 2014; Leonard, Garwick, & Adwan, 2005). The occurrence of type 1 diabetes among adolescents is therefore said to be at its peak during the process of sexual maturation in adolescence (Jayakumar, 2013). Adolescents with type 1 diabetes are also particularly vulnerable to the development of diabetes-related renal, ophthalmic, neurological and vascular-related health complications secondary to poor diabetes management (Buck, 2016; Mlynarczyk, 2013). In order to prevent these complications, adolescents have to engage in demanding and intricate diabetes management regimens (Beaser, 2010; Coffen, 2009).

1.2.1 Diabetes mellitus

The etymological origin of the terms ‘diabetes’ and ‘mellitus’ stem from the ancient Greek and Latin languages respectively (Ali, 2011; Zajac, Shrestha, Patel, & Poretsky, 2010). In approximately 250BC, a physician used the Greek term ‘diabetes’, meaning ‘to pass through’, to describe the clinically significant phenomenon of polyuria among afflicted

humans (Zajac et al., 2010). During the 16th century the Scottish physician William Cullen went on to join the term ‘diabetes’ to the Latin term ‘mellitus’, meaning ‘honey’, to describe the sweet taste of urine passed by certain individuals with polyuria (Tripathy, 2012a). At the time it was not known to medical science that the seemingly isolated phenomenon of sweet-tasting urine was merely a single symptom of a multi-faceted endocrine disorder. However, the term ‘diabetes mellitus’, meaning ‘the passing through of honey-sweet urine’, continues to refer to what is now known as a chronic metabolic disorder comprising several distinct metabolic abnormalities (Tripathy, 2012b). The complex and multiple metabolic abnormalities that constitute diabetes suggest an underlying aetiology of a heterogeneous nature (Craig et al., 2014). The underlying aetiology of diabetes is related to the heterogenic causes of pathophysiological beta cell secretion and/or the working of the hormone insulin within the pancreas (Jones & Persaud, 2010). Deficient secretion and/or pathological functioning of insulin determine the onset and course of diabetes (Craig et al., 2014). The aetiology of insulin deficiency and/or pathological functioning thereof is of utmost importance because it classifies diabetes into distinct and broad etiopathogenetic types of the disease (Beaser, 2010; Craig et al., 2014). The majority of diabetes cases are classified as either type 1 or type 2 diabetes. However, other forms of diabetes that are secondary to genetic defects, genetic syndromes, diseases of the exocrine pancreas, endocrinopathies, drugs, chemicals, infections, gestation and uncommon forms of immune-mediated diabetes are also classified and prevalent (Turner & Wass, 2009). The focus of this study required that the participants be adolescents with well-controlled type 1 diabetes.

Type 1 diabetes occurs in the wake of an unknown interplay of genetic, environmental and the immune-mediated exhaustion of insulin-producing pancreatic beta cells (Beaser, 2010; Chiang, Kirkman, Laffel, & Peters, 2014; Matthews, 2007; Tripathy, 2012b). Facts regarding the characteristics, nature and mode of interaction among specific genes and

environmental factors that pertain to the destruction of insulin producing beta cells seem to be inconclusive and controversial. Martino et al. (2015) and Patterson et al. (2014) unanimously contend that the particular genetic and environmental aetiology of type 1 diabetes remain unknown and require further research. However, some authors postulate that specific exogenous environmental influences, as well as genetic predispositions, play a pivotal role in the aetiology of type 1 diabetes. Ali (2011), Beaser (2010), Devendra, Liu, and Eisenbarth (2004) suggest that exogenous environmental influences such as certain viruses, dietary content, substances and stressful life events are associated with the pathogenesis of type 1 diabetes. Furthermore, some literary sources argue that certain congenitally predisposed genetic pathologies related to the major histocompatibility complex on chromosome 6 have an influence on the development of type 1 diabetes (Howson, Walker, Clayton, Todd, & the Type 1 Diabetes Genetics Consortium, 2009; Leslie, Ho-Le, & Beyan, 2012; Matthews, 2007). The histocompatibility complex refers to the mechanism by which human leukocyte antigens or cellular protein molecules enable the immune system to differentiate between foreign and autogenic cellular bodies (Tait, 2010). The hereditary pathophysiology of the major histocompatibility complex on chromosome 6 is considered to result in T-cell-immune mediated inability to distinguish between foreign cellular bodies and insulin producing autogenic beta cells within the islets of Langerhans in the pancreas (Ali, 2010; International Diabetes Federation, 2011; Matthews, 2007). Inevitably, insulin producing beta cells are erroneously destroyed and exhausted by the immune system, resulting in a radical insulin deficiency and lifelong dependence on exogenous insulin (Chiang et al., 2014; Matthews, 2007).

The effect of immune-mediated destruction and exhaustion of beta cells becomes evident once approximately 90% of the pancreatic beta cells have been destroyed and certain symptoms characteristic of type 1 diabetes manifest (Craig et al., 2014; Meier, 2016).

Symptoms such as polyuria, polydipsia, polyphagia, blurred vision and weight loss, in association with glycosuria and ketonuria, are characteristic of underlying type 1 diabetes (Das, Raghupathy, & Tripathy, 2012; International Diabetes Federation, 2011). These clinically significant symptoms usually have a sudden onset and warrant thorough routine blood examinations to confirm or discard a possible diagnosis of type 1 diabetes (International Diabetes Federation, 2011).

A diagnosis of this disorder can be made when an individual presents with plasma-glucose levels greater than 11,01mmol per litre at any given interval regardless of prior fasting or consumption of food and beverages. Furthermore, a plasma-glucose level greater than 7,0mmol per litre subsequent to active fasting for at least eight hours is also indicative of possible type 1 diabetes (International Diabetes Federation, 2011). Glycated haemoglobin (HbA1c) percentages, which refer to an individual's average blood-glucose level during a specific period, can also provide an indication of possible type 1 diabetes. An HbA1c level greater than approximately 6.5% is clinically significant and might suggest that a diagnosis of type 1 diabetes should be considered (International Diabetes Federation, 2011). However, The International Federation of Diabetes (2011) contends that no definitive diagnosis of type 1 diabetes should be given subsequent to a single examination of an individual's plasma-glucose levels. Accurate diagnosis of the disorder requires continuous examination of plasma-glucose levels across several intervals (International Diabetes Federation, 2011).

A diagnosis of type 1 diabetes usually precedes a tumultuous and challenging period during which patients and their next of kin grieve the loss of health and attempt to become accustomed to treatment regimens and inevitable lifestyle changes (Anderson & Mansfield, 2010). Furthermore, patients and their next of kin can suffer various physical, psychological, and economic complications and consequences related to a diagnosis of type 1 diabetes

(Altamirano-Bustamante et al., 2008; Scaramuzza & Zuccotti, 2015; Whiting, Unwin, & Roglic, 2010).

The physical complications of type 1 diabetes can be of an acute or chronic nature (Cooppan, Beaser, & Shetty, 2010; Misra, Wasir, & Vikram, 2012). Acute physical complications of type 1 diabetes include physiologically-related diabetic ketoacidosis and hypoglycaemia, along with various macro- and microvascular chronic complications (Cooppan et al., 2010). Diabetic ketoacidosis, or diabetic coma, is an acute and potentially fatal complication of type 1 diabetes that requires emergency medical assistance (Kitabchi & Nyenwe, 2011; Tentolouris & Katsilambros, 2011). Diabetic ketoacidosis is characterised by a state of hyperglycaemia and hyperketosis secondary to complete or partial insulin deficiency, which could stem from insufficient exogenous insulin intake, an infection, virus, surgical procedure, trauma or stress (Misra et al., 2012; Ochola & Venkatesh, 2009). The most common acute physiological complication of type 1 diabetes, however, is hypoglycaemia (Cooppan et al., 2010; Sosenko, 2012). Plasma-glucose levels between 2,9mmol and 3,9mmol per litre indicate the presence of severe to mild hypoglycaemic states (Davis, 2013; Landel-Graham, Yount, & Rudnicki, 2003). Hypoglycaemic states arise due to insufficient cerebral glucose volumes, which inhibit normal neurological functioning. Epinephrine is secreted to compensate for insufficient cerebral glucose concentrations. This underlies the manifestation of several clinically significant symptoms of hypoglycaemia (Landel-Graham et al., 2003). Symptoms such as involuntary neurological tremors, cardiovascular palpitations and nutritional starvation could suggest underlying mild hypoglycaemia, while altered mental activity, seizures and stupor are indicative of severe hypoglycaemia (Cooppan et al., 2010). Both diabetic ketoacidosis and severe hypoglycaemia are therefore possibly life-threatening, acute, physiologically-related physical complications of type 1 diabetes that necessitate adequate and timely intervention. While immediate

symptoms of acute hyperglycaemia and hypoglycaemia can be addressed and treated with timely intervention, often including presentation to emergency services, the adverse impact of recurrent hyperglycaemic states accumulates, with a resultant increased risk of the development of chronic micro- and macrovascular complications (Chawla, 2012). Microvascular complications include diabetic retinopathy, diabetic nephropathy and diabetic neuropathy (Seshiah, 2009). Cardiovascular disease, peripheral vascular disease and cerebrovascular disease can occur as macrovascular complications of type 1 diabetes (Beaser & Johnstone, 2010; Chawla, 2012).

Apart from the potential adverse physiologically-related physical consequences and complications, compromised personal psychological wellbeing is also known to occur among those affected by type 1 diabetes. Llorente and Urrutia (2006) suggest that diabetes is among some of the most emotionally challenging chronic medical illnesses, because several studies report a relationship between the development of various psychiatric disorders and being diagnosed with type 1 diabetes. For example, a population-based cohort study in Sweden found that the probability of developing a comorbid psychiatric disorder within six months of being diagnosed with type 1 diabetes tripled among children with the disorder in comparison to the general population. Furthermore, this study indicated an increased risk of attempted suicide among the children with type 1 diabetes who participated in the study (Butwicka, Frisén, Almqvist, Zethelius, & Lichtenstein, 2015). Mood, anxiety, sexual and eating-related psychiatric disorders specifically also seem to be significantly prevalent among those suffering from type 1 diabetes (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009; Kota, Meher, Jammula, Kota, & Modi, 2012; Lin et al., 2008; Luthra & Misra, 2008). Moreover, the psychological impact of a diagnosis of type 1 diabetes extends beyond diagnosed individual to both their familial-relational and functional units. Symons, Crawford, Isaac, and Thompson (2015) found that a diagnosis of type 1 diabetes forced the families of those

diagnosed to reconsider established household patterns and to cope with an array of negative emotions, as well as familial relational strain associated with their loved one's diagnosis.

Lastly, the various possible physiologically-related physical and psychological complications associated with a diagnosis of type 1 diabetes have tremendous economic consequences for patients, families, and national and international healthcare systems and economies (Josifova & Henrich, 2013). Consultations with specialist healthcare professionals, the acquisition of appropriate treatment utensils and medication, hospitalisation for the treatment of acute or chronic diabetes-related complications, and decreased occupational and educational productivity with increased absenteeism from work or school due to diabetes-related ill-health all carry immense economic costs and strain (Altamirano-Bustamante et al., 2008; American Diabetes Association, 2013; Bishu, Gebregziabher, Dismuke, & Egede, 2015). These diabetes-related economic costs are estimated to add up to an annual total of US$948.54 per South African suffering from diabetes (International Diabetes Federation, 2014).

Amid the abovementioned inevitable physical, psychological and economic consequences associated with a diagnosis of type 1 diabetes, individuals have to commit to a complex and burdensome diabetes management regimen. Commitment to adequate diabetes management is necessary to uphold a satisfactory quality of life and minimise potential debilitating adverse consequences of type 1 diabetes (Beaser, 2010; Coffen, 2009).

1.2.2 Diabetes management

The management of diabetes necessitates a holistic and multi-disciplinary approach with the involvement of specialist physicians such as endocrinologists and psychiatrists, ophthalmologists, gastroenterologists, nephrologists, podiatrists, psychologists, pharmacists, nurses, dieticians, exercise physiologists and social workers (American Diabetes Association,

2016; Anderson & Mansfield, 2010; Bismuth & Laffel, 2010; Dadich, 2007). The American Diabetes Association (2016), moreover, suggests a patient-centred approach in which both primary and allied healthcare professionals, as well as patients and their next of kin, are actively committed to and involved in the management of a patient's diabetes. Diabetes management is considered to be an intricate and challenging task requiring cognitive, emotional, behavioural and social adjustment among those affected (Céspedes-Knadle & Muñoz, 2011; Cramer, 2004; Dashiff, Bartolucci, Wallander, & Abdullatif, 2005; Piette & Kerr, 2006). Furthermore, successful diabetes management is reliant on a sense of personal responsibility for and active involvement in all aspects of the management process in conjunction with an adequate understanding of what this endocrine disorder is (American Diabetes Association, 2016).

The regulation and control of plasma-glucose levels are considered to be the primary foundation of diabetes management (Maahs, West, Lawrence, & Mayer-Davis, 2010). Furthermore, Beaser and Jackson (2010) suggest that diabetes management generally aims to firstly prevent and reduce the risk of developing acute and chronic physical diabetes-related complications and, secondly, to limit the impact of the disorder on the lives of the affected population. Falvo (2013) echoes Beaser and Jacksons' (2010) suggested goals for diabetes management and emphasises the reality that no cure for diabetes mellitus is available at present, but that the conscientious management and control of plasma-glucose concentrations can reduce potential adverse diabetes-related consequences and complications. Effective diabetes management, which results in glycated haemoglobin levels or average plasma-glucose levels that are below 7.5% or 58mmol per litre of blood, is therefore considered to indicate what is referred to as well-controlled type 1 diabetes (International Diabetes Federation, 2011). However, the likelihood of developing potentially adverse diabetes-related complications varies among patients and therefore clinical treatment and management plans

should be uniquely tailored according to the needs of each individual patient (Shaw & Cummings, 2012).

Because the current study involves the exploration of diabetes management among adolescents, it is necessary to examine the literature pertaining to diabetes management and treatment regimens for adolescents living with type 1 diabetes. The rationale and underlying objectives of diabetes management among adolescents pertain to nurturing normal physical and psychological development, the promotion of quality of life, the prevention of adverse diabetes-related complications and the maintenance of average plasma-glucose levels within normal or near normal ranges (Guthrie & Guthrie, 2008; International Diabetes Federation, 2007). The development of a uniquely tailored personalised diabetes management plan rests upon and should be informed by the needs of each individual adolescent living with type 1 diabetes (Sikes & Tamborlane, 2013). A personalised diabetes management plan should include aspects pertaining to diabetes education, medical and pharmacological treatment regimens, and interventions aimed at fostering physical, nutritional and psychological wellbeing (Beaser & Jackson, 2010; Bismuth & Laffel, 2010). The foundation of successful diabetes management is considered to be sufficient knowledge and education about diabetes as an endocrine disorder, the management of dietary nutrition, physical exercise and various medications and the administration thereof, and the monitoring of plasma-glucose concentrations, as well as the prevention and management of diabetes-related complications (Blair, 2010). Blair (2010) postulates that diabetes and diabetes management-related education occurs continuously during a diabetes management regimen. As an integral aspect of a personalised diabetes management plan, education should be developmentally appropriate, pleasurable, concrete and present adolescents with positive reinforcement (Blair, 2010).

The development of a diabetes management regimen that is uniquely tailored to the needs of a specific individual should be preceded by an assessment of the individual's blood-glucose concentrations. In addition to informing decision making regarding the selection of the most suitable management aspects of a specific management regimen, blood-glucose monitoring can also provide insight into the efficacy and suitability of a unique diabetes management regimen for a specific individual. Blood-glucose monitoring can therefore signal the need for regimen adjustment (Hirsch & Edelman, 2005). The monitoring and calculation of the average plasma-glucose level of an adolescent living with type 1 diabetes are usually undertaken by a qualified specialist physician and performed every three to six months. The personal examination and record keeping of blood-glucose volumes should be executed on a daily basis by the adolescent living with type 1 diabetes or a familiar individual who takes responsibility for the adolescent's diabetes management regimen (Hirsch & Edelman, 2005). The frequency of personal blood-glucose monitoring varies between those affected, but commonly occurs prior to food or beverage consumption, following food or beverage consumption and prior to nocturnal sleeping (Hirsch & Edelman, 2005). Medifocus. com Incorporated (2012) proposes the use of a finger stick blood-glucose monitoring test for daily personal evaluations of blood-glucose volumes. During the finger stick test, a pricking needle is utilised to capture a small volume of blood on a test strip prior to being placed within a compact computerised blood-glucose monitor (Medifocus.com Incorporated, 2012). Computerised readings of plasma-glucose levels on a blood-glucose monitor serve to provide a guideline according to which pharmacological dosage interventions can be estimated.

The pharmacological treatment regimen associated with the management of type 1 diabetes among adolescents consists mainly of the administration of exogenous insulin. The International Diabetes Federation (2011) suggests that even though the selected method of insulin administration should be in accordance with the preference of the adolescent and his

or her primary caregivers, it should also be as physiological as possible. Syringe insulin injections or insulin secreting pumps are the prescribed methods of insulin administration for adolescents with type 1 diabetes (Bismuth & Laffel, 2010; International Diabetes Federation, 2011). Careful consideration should be given to both methods and a consensus regarding the most suitable manner of insulin administration should be reached between the adolescent, his or her legal guardian and the treating physician. Syringe administration requires multiple daily injections of insulin with a needle, while insulin secreting pumps administer insulin by means of a needle or catheter placed underneath the skin of the patient (Bismuth & Laffel, 2010; Rodgers, 2008). Whether insulin is administrated via syringe injections or a pump, sufficient compensation for pathophysiological diabetes-related insulin deficiency is achieved (Mazze et al., 2012). Furthermore, insulin administration plays a crucial role in the management of glycated haemoglobin (HbA1c) or average plasma-glucose levels (Cavallerano & Stanton, 2010). In contradiction to the International Diabetes Federation's (2011) suggestion of 7.5%, Beaser (2010) contends that average glycated haemoglobin levels should be 7% or less over a period of three months for diabetes management to be considered effective and type 1 diabetes to be controlled (Beaser, 2010).

The physical exercise component of a diabetes management plan is essential, considering that physical exercise is considered to have a positive effect on plasma-glucose levels, resulting in decreased insulin dosage requirements. Furthermore, overall psychological and physical wellbeing are enhanced, which reduces the risk of developing various diabetes-related physical and mental health illnesses (Bismuth & Laffel, 2010; Pavithran, 2013). The planning of a physical exercise routine for adolescents with type 1 diabetes should, however, be done with care, because hypoglycaemic incidents can occur due to excessive physical activity (Pivovarov, Taplin, & Riddell, 2015).

Factors related to the diet of an adolescent living with type 1diabetes should also be considered, because nutrition is another integral part of diabetes management (Smart, Aslander-van Vliet, & Waldron, 2009). Smart et al. (2009) suggest that aspects pertaining to kilojoules homeostasis, kilojoules intake and nutrient characteristics should aid in informing the development of a nutritional diet for adolescents with type 1 diabetes. A personally tailored nutritional diet for adolescent's with type 1 diabetes should therefore incorporate measurements to ensure maintenance of a healthy body weight, as well as the correct distribution of carbohydrate, sucrose, fibre, fat, protein, vitamin, mineral and antioxidant daily intake. Furthermore, consumption of dietary resources, more specifically the consumption of carbohydrates, requires meticulous consideration, planning and calculation, because the administration of insulin dosages via syringes or insulin secreting pumps is calibrated accordingly. Adolescents living with type 1 diabetes should therefore remain mindful of their intake of especially carbohydrates and master the ability to understand and manage carbohydrate intake and insulin dosage relationships (Bussell, 2015).

Apart from the abovementioned core components of a diabetes management plan for adolescents with type 1 diabetes, additional management components should be incorporated into the management plan should the need arise. These additional management components might include strategies to assist adolescents with type 1 diabetes with renal, gastrointestinal, ophthalmic, podiatric, psychiatric, psychological and/or socio-economic difficulties.

Overall, successful diabetes management depends on both the adolescent's adherence and his or her family's involvement in the management plan (Schneider et al., 2007). However, during the developmental phase of adolescence, a transitional process regarding diabetes management regimens seems to occur. Adolescents living with type 1 diabetes and their parents or primary caregivers tend to renegotiate their roles in the diabetes management regimen. Parents or primary caregivers tend to start fulfilling a more supervisory and

monitoring role, while the adolescent assumes increasing personal responsibility for his or her diabetes management regimen (Dashiff, Hardeman, & Mclain, 2008; Kaugars, Kichler, & Alemzadeh, 2011). Continuous diabetes management support from the family and healthcare professionals, however, remains necessary because beliefs, attitudes and habits pertaining to diabetes management during the developmental phase of adolescence is said to continue during adulthood and forms the foundation for lifelong diabetes management (Bismuth & Laffel, 2010).

1.2.3 Lived experiences of life with and management of a chronic illness

Living with a chronic illness is a unique and personal experience that affects an individual’s entire being (Larsen, 2006). Being diagnosed with and living with a chronic illness can cause an individual to experience feelings of distress, anger, anxiety, isolation, grief, helplessness and depression (Larsen, 2016; Livneh & Antonak, 2005; Martz & Livneh, 2007). Compromised functionality, prognostic uncertainty and monetary losses are also common occurrences in the face of a chronic illness (Livneh & Antonak, 2005). Larsen (2016) defines illness experience as ‘the lived experience of the individual and family with chronic disease’ (p. 21). Furthermore, Larsen (2016) contends that chronically ill individuals’ and their families’ illness experiences include their perceptions and beliefs about the specific chronic illness, as well as their physical, psychological, social and emotional responses to it. Aspects pertaining to an individuals’ age, gender, race, socio-economic status, culture, lifestyle, personality dynamics, cognitions and external support structures all contribute to chronically ill individuals’ personal lived experiences of their illness (Falvo, 2013; Larsen, 2006).

Adolescents are the target population of the current study and therefore a better understanding of the lived experiences of chronic illness and chronic illness management among this specific population is important. The findings of a systematic literature review

conducted by Venning, Eliot, Wilson, and Kettler (2008) were that several distinct themes pertaining to adolescents' experiences of living with a chronic illness seemed evident from the examined literature. Firstly, chronically ill adolescents associated being in their own flesh and personal surroundings with feelings of discomfort. Secondly, chronic illness seemed to make them feel that their normal lives had been disrupted. The study also found that adolescents did not necessarily experience chronic illness as being predominantly negative. Also after a critical review of the literature, Taylor, Gibson, and Franck (2008) concluded that living with a chronic illness significantly impacted adolescents' experiences of interpersonal relationships and school, their perception of normality and the future, their approach to their treatment regimen and their relationships with their healthcare providers. Ferro and Boyle (2013), as well as Cheung, Young Cureton, and Canham (2006), indicate that adolescents with a chronic illness also perceive themselves to be different to their healthy peers.

Within the context of the current study, adolescents have to come to terms with the unique and personal experience of living with and managing chronic type 1 diabetes. Living with this disorder, while simultaneously progressing through the developmental stage of adolescence, can be exceptionally challenging for adolescents (Comeaux & Jaser, 2009). They face the challenge of having to attempt to successfully integrate diabetes and diabetes management into their lives amid developmentally challenging hormonal and psychosocial changes associated with the developmental phase of adolescence (Husted, Esbensen, Hommel, Thorsteinsson, & Zoffmann, 2014; Winocour, 2014). Their development of a sense of personal identity and autonomy are also inevitably complicated by the constant need to monitor and manage their blood-glucose volumes (Silverstein et al., 2005). The combination of daily administration of numerous insulin injections, meticulous blood-glucose assessments, sustained monitoring of exercise programmes and the maintenance of a

restricted eating plan can increase adolescents' experience of physical, emotional and social distress (Cheung et al., 2006). The findings of Coffen (2009) seem to support this; he contends that adherence to a prescribed type 1 diabetes management regimen can leave adolescents feeling intimidated, given the immense magnitude thereof (Coffen, 2009). Coffen (2009) explored the various aspects encompassing a type 1 diabetes management regimen by examining various scientific publications, interviewing healthcare professionals and observing individuals with type 1 diabetes executing distinctive type 1 diabetes management regimen tasks. He found that following a type 1 diabetes management regimen confronts adolescents with extremely demanding and extensive challenges. These include the acquisition of sufficient knowledge regarding type 1 diabetic aetiology, the pharmacological treatment of type 1 diabetes, nutrition, physical exercise, acute type 1 diabetic complications (hypoglycaemia, hyperglycaemia and diabetic ketoacidosis) and chronic type 1 diabetes complications (micro- and macrovascular). Furthermore, adolescents need to be cognisant of and able to manage feelings and experiences of stress and trauma, because these can have a potentially negative influence on their health and the execution of their management regimens. Other challenges include mastering the ability to perform practical tasks such as monitoring plasma-glucose and ketone volumes, as well as administering insulin (Coffen, 2009).

By exploring the lived experiences of diabetes management among a group of children and adolescents with type 1 diabetes, Freeborn, Dyches, Roper, and Mandleco (2013) concluded that frequent blood-glucose monitoring and insulin administration were associated with feelings of discomfort and inconvenience. The study also found that the participants experienced pump administration of insulin as less intricate than syringe insulin administration, while the intricacy of their type 1 diabetes management regimen left them feeling isolated and unique in relation to their peers.

1.3 Research paradigms

1.3.1 Phenomenology and phenomenological research

Phenomenology, regarded as ‘the most fundamental region of philosophy’ (Husserl, 1913, p. 1) and the ‘science of phenomena’ (Husserl, 1913, p. 1), can be defined as a discipline ‘examining and describing lived evidence or phenomena’ (Reeder, 2010, p. 21). Dating back to the 20th century and introduced by German philosopher and mathematician Edmund Husserl, phenomenology is concerned with human consciousness and the unique entities confronting their conscious awareness (Giorgi, 2012). Creswell (2007) postulates that phenomenology can be utilised as a qualitative research method and design because it attempts to encapsulate individual experiences of a specific phenomenon within a condensed description of the universal essence thereof. The philosophical assumptive foundations of phenomenological research as described by Van Manen (as cited in Creswell, 2007) include the notion that phenomenological research is the study of individuals’ lived experiences. These lived experiences are also assumed to occur within an individual’s conscious awareness. Furthermore, Moustakas (as cited in Creswell, 2007), emphasises the assumption that the exploration of lived experiences allows for the creation of a concise account of the absolutely essential aspects of the said experiences, while the formulation of explanations for or analysis of these experiences is rejected. Phenomenological researchers therefore aim to describe the abundant richness of lived experiences (Lock & Strong, 2010). However, lived experiences or phenomena are considered to be highly subjective in nature and thus particularly intricate to explore and synthesise. Additionally, it is impossible for lived experiences or phenomena to provide researchers with unprejudiced accounts of their underlying meanings and consequences. Lived experiences or phenomena can therefore be studied only once they have been adequately articulated by those who experienced them by means of language and dialogue (Lock & Strong, 2010). The use of language and dialogue to

articulate and convey the essence of a lived experience or phenomenon highlights the social nature of humanity. Humans are considered to be socially constructed by their “inherent immersion in a shared experiential world with other people” (Lock & Strong, 2010, p. 5). Lived experiences or phenomena are thus not stumbled upon, manufactured or designed, but instead the result of continuous socio-cultural interchange. The latter implies that an individual’s lived experiences are mediated by the use of language and dialogue within social contexts. Theoretically, social constructionist theory can be applied to possibly explicate and account for the processes during which phenomena are interactively constructed within different social spheres and subsequently articulated as the lived experiences of an individual.

1.3.2 Social constructionism

Social constructionism is a multi-disciplinary theoretical approach underpinned by the ontological assumption that no independent external reality exists (Burr, 2015; Gergen, 2015). Reality is postulated to be entirely subjective and constructed through both an individuals’ perception of reality and the social dialogue inspired by it. Social constructionist theory therefore delineates the processes by which individuals narrate, explicate and account for their realities, experiences and the environments in which they function (Burr, 2015; Gergen, 1985; Raskin, 2002). Gergen (1985) asserts that the social constructionist perspective is characterised by a perception of reality and the environment as a relic of collective interchange. The basic premise of social constructionist theory is therefore the notion that individuals’ comprehension of reality, experience and their environment are socially constructed among themselves and others (Burr, 2015; Schwandt, 2000). However, certain fundamental assumptions underlie individuals’ comprehension of their reality, experiences and environments. Social constructionist theory assumes that individuals’ constructions of their realities, experiences and environments are culturally and historically specific, are

maintained through sustained social processes and imply certain subsequent actions or behaviours (Burr, 2015; Gergen, 1985). Aspects pertaining to an individual's cultural and historical background therefore underlie their contribution to the construction of reality during interactive social processes with other individuals in various contexts. Furthermore, sustained social processes, which occur within the realm of interpersonal relations among individuals or groups, constitute the mechanism by which shared understandings of reality, phenomena and lived experiences are subsequently constructed (Burr, 2015; Gergen, 1985). Shared insight into and understanding of reality, phenomena and lived experiences therefore requires active social interaction within various social domains among different individuals. This notion is supported by Leeds-Hurwitz (2009), as well as Conrad and Barker (2010), who contend that social reality comes into being in the wake of communication and behavioural interchange among different groups of people in different contexts. The result of communication and behavioural interchange among these groups is shared perceptions and beliefs regarding their actions and the environments in which they function (Leeds-Hurwitz, 2009). Social constructionist theory therefore suggests that the lived experience of a specific phenomenon is influenced by cultural and historical influences, maintained through sustained interaction among people and resulting in certain behaviours.

The social construction of illness management is relevant to the current study. Conrad and Barker (2010) argue that society's understanding of a specific illness is formulated through active social human interaction – supporting one of the basic premises of social constructionism. Furthermore, illness experience is also suggested to be socially constructed as individuals 'enact and endow' their illnesses with meaning (Conrad & Barker, 2010, p. 5). According to Conrad and Barker (2010), in-depth individual interviews with individuals living with and managing a chronic illness are an appropriate method to obtain knowledge of the essence of illness-related experiences. Eight adolescents with well-controlled type 1

diabetes were therefore interviewed during this study in order to explore the research question: 'What are the lived experiences of adolescents with well-controlled type 1 diabetes?'

The current study will subsequently utilise a social constructionist theoretical perspective, namely that the lived experience of diabetes management of each individual adolescent participant stems from his or her personally constructed descriptions and explanations of what a management regimen for type 1 diabetes means to them (Gergen, 1985). The nature of how adolescents experience the management of their type 1 diabetes is thus considered to be dependent on their social constructs of this regimen. According to social constructionist theory, the social constructs underlying the participants' experiences of type 1 diabetes management were not present at their birth, but rather came into being by means of an acquired ability to engage in dialogue. Social constructionists would consequently argue that subjective and emotive descriptions of experiencing the management of type 1 diabetes allude to discourse and language related to type 1 diabetes management instead of relativistic and inherent experience. Within the context of social constructionist theory, it is postulated that the participants in the current study would thus have attempted to make sense of their lived experiences of type 1 diabetes management by establishing cognitive representations thereof from their social environment. These representations comprise the mutually-constructed understandings adolescents with type 1 diabetes establish regarding their environment, which subsequently form the foundation of their shared assumptions of their diabetes-related reality (Leeds-Hurwitz, 2009). The construction of an understanding of reality would therefore have occurred among these adolescents by means of active interaction during various unique social processes in an array of different contexts. Furthermore, it is suggested that engaging in social interaction in different social settings would have led participants in this study to construct beliefs about what an appropriate type 1

diabetes management and treatment plan would encompass, along with the required behaviours to execute such a type 1 diabetes management plan (Brown, 1995). From a social constructionism theoretical stance, adolescents living with type 1 diabetes are also able to re-construct their thoughts about type 1 diabetes and its management, which can subsequently adjust their ultimate experience of managing their endocrine disorder (Burr, 1998). The current study is therefore of utmost importance because the social constructionist theoretical underpinning thereof will not only enable the researcher to document the lived experiences of type 1 diabetes management among adolescents with well-controlled type 1 diabetes, but the findings of the study could potentially inform decisions regarding improved clinical practice and diabetes management policies (Brown, 1995). Furthermore less stigmatisation of the population under study can be achieved, given that the study could provide improved insight into chronic illnesses as an experience rather than as a medical condition (Falvo, 2013).

1.4 Contextualisation of this study

This study forms part of a larger overarching research project titled: '*Psycho-social variables in adjusting to diabetes management in adolescents and young adults'*. The larger overarching research project commenced in August 2015 and is ongoing. The current study commenced in March 2016 and was concluded in October 2016.

1.5 Research question

The following research question guided this study:

What are the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes?

Considering that the research question guiding this study is of a qualitative and not a quantitative nature, no prior hypothesis was made.

1.6 Research methodology

The abovementioned research question informed decision making regarding the selection of the most appropriate research methods for execution of this study. The methodology applied in the current study therefore aimed to explore the essence of lived experiences regarding a phenomenon as described by the participants (Creswell, 2009).

1.6.1 Research approach

This study was conducted by means of a qualitative research approach. According to Yin (2015), a qualitative research approach is characterised by certain unique attributes. Firstly, it comprises an exploration of the meaning of individuals' existence within various roles and contexts. Furthermore, its aim is to adequately describe the perspectives of individuals, explicate authentic contextual states, and provide alternative and novel theories of social behaviour. Lastly, Yin (2015) contends that a qualitative approach to research enhances cognisance of the utilisation of various sources of data.

This approach was thus considered appropriate in light of this study's research question, which necessitated an exploration of the lived experiences of individuals.

1.6.2 Research design

A phenomenological research design was considered to be appropriate for this study because it was expected to enable the researcher to describe participants' shared meanings of their lived experiences of managing type 1 diabetes. A composite description of the essence

of the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes was compiled by obtaining data from individuals who have all experienced the same phenomenon (Creswell, 2007).

1.6.3 Research context

This study was conducted at two branches of the Centre for Diabetes and Endocrinology, namely in Houghton and Parktown, Johannesburg, South Africa. The research context, situated within the Gauteng province of South Africa, was an urban suburb characterised by a high socio-economic standard of living.

1.6.4 Participants

The participants were selected by means of a non-random purposive sampling method. This method required the participants to meet specific, clearly defined, pre-determined sample inclusion criteria prior to being eligible for participation in the study (Ritchie, Lewis, Elam, Tennant, & Rahim, 2013).

The inclusion criteria for this study were the following:

- The participants had to be able and willing to participate in an interview in either English or Afrikaans.
- They had to be within the developmental period of adolescence (aged between12 and 18 years of age).
- They had to have been diagnosed with type 1 diabetes more than 12 months prior to data collection in order to avoid the impact that ongoing adjustment to the diagnosis might have had on the trustworthiness of the data obtained.

- They had to be patients at the Centre for Diabetes and Endocrinology in Houghton or Parktown, Johannesburg, in order to minimise treatment variables.
- They had to have had an HbA1C of 8% or less (as recommended by Prof D.G. Segal, a specialist paediatric endocrinologist and gatekeeper of this study) during the 12 months preceding the data collection in order for type 1 diabetes management to have been considered effective and the diabetes controlled.

The exclusion criteria stipulated for this study were the following:

- Individuals who were undergoing psychotherapy at the time the study was conducted were excluded because the psychotherapeutic process they were involved in might have had an impact on their lived experiences of type 1 diabetes management.
- Individuals who also suffered from another chronic medical condition were excluded from the study because the lived experience of managing another chronic illness might have had an influence on the lived experience of managing type 1 diabetes.

Adherence to the abovementioned inclusion and exclusion criteria ensured that the selected sample embodied a symbolic representation of the criterion-defined group that was observed during this study (Ritchie et al., 2013). However, one participant's average glycated haemoglobin percentage over the three months preceding data generation was 8.1%. The decision to include this participant in the final sample was made in consultation with Prof D.G. Segal on the basis that this specific participant had had a long history of effective diabetes management. The most recent average glycated haemoglobin percentage was therefore an exceptional occurrence due to unrelated endocrine causes.

Table 1

Characteristics of the non-random purposive sample utilised in this study

Participant no.	Gender	Race	First Language	Current age (years)	Age at time of diagnosis (years)	Mean HbA1C (mmol/l)
A1	Male	Caucasian	Afrikaans	16	11	7.8
A2	Male	Caucasian	Afrikaans	12	5	7.0
A3	Female	Caucasian	English	15	5	6.8
A4	Male	Caucasian	Afrikaans	12	9	7.9
A5	Female	Indian	English	12	11	8.1
A6	Female	Caucasian	English	12	11	6.9
A7	Male	Caucasian	English	12	11	6.3
A8	Female	Caucasian	English	18	12	7.5

1.6.5 Data generation

The data for this study was generated and utilised in conjunction with the previously mentioned larger overarching research study, *Psycho-social variables in adjusting to diabetes management in adolescents and young adults*. Data generated for the purpose of this study *(Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes)* was collected at two branches of the Centre for Diabetes and Endocrinology, namely in Houghton and Parktown, Johannesburg, from March 2016 to August 2016. The data was generated by means of in-depth individual interviews (Creswell, 2007). The aim of these interviews was to elicit accounts of the participants' experiences of type 1 diabetes management, as well as the contexts or situations that had typically influenced or affected their experiences of managing their diabetes (Moustakas, 1994). An interview agenda consisting of two open-ended questions therefore guided each individual in-depth interview (Willig, 2013).

The following two broad and open-ended questions were posed to participants:

- *Can you tell me about your experience in terms of managing your diabetes?*

- *Can you tell me about the contexts or situations that have typically influenced or affected your experience of managing your diabetes?*

The abovementioned broad and open-ended questions assisted in obtaining data that provided a rich description of the participants' lived experiences of diabetes management. Furthermore, the questions allowed the researcher to ask further follow-up open-ended questions to probe for additional information relating to the original answers to the two set questions (Creswell, 2007). Data saturation occurred subsequent to the eighth participant interview.

1.6.6 Data analysis

In an attempt to obtain a rich, detailed and complex account of the dataset generated during this study, a qualitative data analysis method, namely thematic analysis, was conducted (Braun & Clarke, 2006). The dataset utilised during this study was therefore thematically analysed through a recursive process comprising the six phases suggested by Braun and Clarke (2006):

Phase 1: Becoming familiar with the obtained data set

The researcher personally generated the dataset utilised in this study and therefore some degree of insight into the relevant data set already existed prior to the commencement of the data analysis process. Furthermore, the researcher commenced the data analysis process by personally transcribing the audio data obtained from the eight in-depth individual interviews conducted during the data generation process. However, in order to become thoroughly familiar with the depth and breadth of the content of the dataset, repeated reading of the eight data transcripts allowed the researcher to immerse herself in the dataset and

explore possible meanings and patterns. Continuous repeated reading and close studying of the eight data transcripts enabled the researcher to therefore note and delineate possible coding ideas. These preliminary coding ideas were kept in mind and referred to for consideration during subsequent phases of the data analysis process (Braun & Clarke, 2006).

Phase 2: Generation of initial codes

Once the researcher was able to identify preliminary codes from the eight transcribed data scripts, initial codes were generated. This was an integral aspect of the overall data analysis process, because it required the organisation of the data into significant categories (Miles & Huberman, 1994; Tuckett, 2005). The rich content of the dataset guided the generation of codes during a systematic and careful examination of each data item (Braun & Clarke, 2006). This process enabled the researcher to discern interesting data features that could serve as foundational themes occurring across the entire dataset. The researcher took care to ensure that all eight transcribed data scripts within the dataset were coded and collated within each unique code (Braun & Clarke, 2006).

Phase 3: Searching for themes

Braun and Clarke (2006) contend that progression towards analysis of the initial data codes should occur during the third phase of the data analysis process. Analysis of the initial data codes required consideration to be given to the manner in which each unique data code could be synthesised with another to embody overarching themes. The researcher therefore formulated a conglomeration of prospective themes and subthemes.

Phase 4: Reviewing themes

In order to ensure that prospective themes and subthemes adequately reflected the essence and richness of the eight data transcripts, the researcher undertook a process of

refining and reviewing the conglomeration of prospective themes and subthemes formulated during phase three of the data analysis process (Braun & Clarke, 2006). Firstly, a revision of the data extracts that informed the formulation of initial data codes and subsequently constituted the prospective themes was performed to confirm that a coherent pattern existed among them. Seemingly problematic data extracts (and those with some measure of incoherence within their respective data codes and overarching themes) were reconsidered and categorised into more appropriate overarching themes (Braun & Clarke, 2006). Secondly, to ensure the validity of each prospective overarching theme, the researcher also reread the eight data transcripts to verify whether the prospective overarching themes appropriately portrayed the broader content of the entire dataset. Furthermore, according to Braun and Clarke (2006), thematic analysis requires that the coding of data remains a continuous process throughout the entire data analysis process. Data coded during the initial data coding processes were therefore given more appropriate codes and organised among suitable overarching themes at this stage. Phase four of the data analysis process subsequently yielded a comprehensive indication of which themes were evident within the dataset, as well as their relation to one another.

Phase 5: Defining and naming of themes

A conscientious and thorough analysis of each theme was conducted in order to ascertain both their defining qualities and their relation to one another. The analysis of each theme entailed the adequate defining of the theme while also exploring and confirming which facet of the dataset it resembled. The defining of themes made it possible to identify possible subthemes within some of the overarching themes (Braun & Clarke, 2006). Subthemes could thus be utilised within the research report to indicate the organised structure and hierarchy of the essence of the dataset. Upon consideration of the relations existing among the identified themes, the researcher was able to identify any overlapping features among themes and

ensure that clear distinctions were made between them. Themes were also considered in relation to the research question guiding the study to ensure their validity in terms of the study. Lastly, the themes were summarised by means of concisely naming them.

Phase 6: Producing of research report

Following the abovementioned five phases, during which the essential content of the eight data transcripts were coded, thematically organised, refined and verified, the researcher compiled the final research report, titled: *Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes*. Sufficient excerpts from the eight data transcripts were included in the report in order to substantiate the suggested findings of the study (Braun & Clarke, 2006). The research report was written in article format and provides a condensed, logical and coherent account of the dataset used in this study.

1.6.7 Trustworthiness

Efforts to ensure, enhance and maintain the trustworthiness of this study were informed by and executed in accordance with the didactic model for quality in qualitative research developed by Tracy (2010). In terms of this model, the trustworthiness of qualitative research is supported by a worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence (Tracy, 2010).

The in-depth literature review, completed as part of section I of this dissertation, indicated that the explored phenomenon was increasingly prevalent globally, which renders the study relevant, timely and significant. Rich rigour was ensured by basing the study on an appropriate theoretical construct, namely social constructionism, spending six months within the research context, conducting prolonged in-depth phenomenological interviews, personally

transcribing interview audio recordings, performing transcription accuracy audits, analysing data by means of continued thematic analysis and collaboration with an independent co-coder. Sincerity was continuously sought by means of regular supervisory meetings to facilitate researcher reflexivity, avoid research bias and promote transparency of the research process. The credibility of the study lies within the comprehensive description of the research design, approach, data gathering, data analysis and data within this mini-dissertation. Credibility was further enhanced because ambiguities within the data were clarified by means of first-level member checking during the participant interviews. Resonance was achieved by the inclusion of appropriate verbatim data excerpts in the final research report in order to support suggested findings. Planned future presentation of the findings of the study to authoritative entities will hopefully aid in informing the development of refined policies associated with type 1 diabetes and its management within a South African context, which could make a significant contribution to the lives of those affected by type 1 diabetes in South Africa. The trustworthiness of the study was furthermore enhanced because the researcher strictly adhered to universal and national ethical guidelines for research with humans.

Lastly, the study is considered to be trustworthy due to its meaningful coherence in terms of achieving its aims, the adoption of an appropriate research approach and design, and utilisation of sufficient supporting literature (Tracy, 2010).

1.7 Ethical considerations

The estimated ethical risk level of this study was high because the participants were minors who belonged to a physically and potentially psychologically vulnerable group. Consequently, careful consideration of and adherence to national and international ethical guidelines and principles were of paramount importance. Ethical approval of both the larger

overarching research project, '*Psycho-social variables in adjusting to diabetes management in adolescents and young adults'* (NWU-HS-2016-0111) and this study, *'Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes'*, (NWU-HS-2016-0031) was obtained from the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University prior to proceeding with this study **(Please refer to attached addendums B and C respectively)**. Furthermore, this research was completed in strict accordance with the guidelines set forth by the National Health Research Ethics Council, as well as The Code of Ethics of the World Medical Association (International Declaration of Helsinki). Informed, written consent from the parents or legal guardians of all the participants and the informed, written assent of the participants were obtained prior to any data generation **(Please refer to attached addendums D and E respectively)**. Participation in this study was entirely voluntary and the participants' maintained the right to withdraw their participation at any stage. Anonymity and confidentiality were ensured through the allocation of participant codes and restricted access to and the password protection of all data.

The contextual setting of this research study also necessitated adherence to the supreme law of the Republic of South Africa, namely the Constitution of the Republic of South Africa, in order to uphold the rights of all the participants who were included in the non-random purposive sample of this study. Lastly, the provisions of the Children's Act, act 38 of 2005 and the National Health Act, act 61 of 2003 of the Republic of South Africa, were adhered to throughout this research.

1.8 Outline of study

Section I of this mini-dissertation comprises a general introduction to the phenomenon of diabetes mellitus, a sketch of the factors pertaining to the management of

diabetes and lived experiences of the management of a chronic illness, an outline of social constructionist theory, and a description of the research paradigms and methodology used to conduct this study.

Section II specifies the author guidelines for the *Health SA Gesondheid Journal of Interdisciplinary Health Sciences* and includes the article titled: *Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes.*

Section III includes a critical reflection by the researcher on the research and a complete reference list.

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SECTION 2: ARTICLE

Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes

2.1 Guidelines for authors: Health SA Gesondheid - Journal of Interdisciplinary Health Sciences

Description

Health SA Gesondheid - Journal of Interdisciplinary Health Sciences is an open access, peer-reviewed interdisciplinary and inter-professional scholarly journal that aims to promote communication, collaboration and teamwork between professions and disciplines within the health sciences to address problems that cross and affect disciplinary boundaries.

Health SA Gesondheid - Journal of Interdisciplinary Health Sciences publishes original articles on issues related to public health, including implications for practical applications and service delivery that are of concern and relevance to Africa and other developing countries. It facilitates the gathering and critical testing of insights and viewpoints on knowledge from different disciplines involved in health service delivery.

The journal offers the breadth of outlook required to promote health science education, research and professional practice.

Unique features distinguishing this journal:

Health SA Gesondheid - Journal of Interdisciplinary Health Sciences explores issues and posits solutions to current challenges existing in health care from an interdisciplinary perspective within Africa and other developing countries, including but not limited to:

- improvement of health safety and service delivery
- management and measurement of health services
- evaluation and assessment of health care needs
- prevention of ill health and health-affecting behaviours
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The journal has a strong regional focus (South Africa) with abstracts published in English. It offers a nurturing environment for young and novice researchers to showcase their work whilst upholding the standards of health science education, research and professional practice.

Health SA Gesondheid with its interdisciplinary scope attracts interest from a wide audience of scientists and health professionals working in the areas of health care management, health care economics, policy making, nursing, psychology, sociology, ethics and education.

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Introduction

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• References: 40 or less.

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State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results. The introduction should include the following:

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Results should be clear and concise.

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- The article in Section II of this mini-dissertation, titled: *‘Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes’* are written in accordance with the author guidelines of the *Health SA Gesondheid Journal of Interdisciplinary Health Sciences* (please refer to pp. 49-70 of this mini-dissertation). Even though these guidelines stipulate adherence to the editorial and referencing style described in the Publication Manual (6th edition) of the American Psychological Association, numbering of the subsections of the article is required (please refer to p. 59 of this mini-dissertation).
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Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes.

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2.2 MANUSCRIPT

Abstract

Background: Adolescents living with type 1 diabetes are at risk of developing serious acute and chronic diabetes-related physical and psychological complications. Adherence to a challenging diabetes management regimen aimed at maintaining plasma-glucose levels within a near normal range is therefore of cardinal importance.

Aim: To explore and describe the lived experiences of diabetes management among adolescents with well-controlled type 1 diabetes.

Method: A qualitative research approach with a phenomenological research design was adopted. A non-random purposive sampling method informed the selection of eight adolescents living with well-controlled type 1 diabetes who are under the care of a Centre for Diabetes and Endocrinology, either in Houghton or Parktown in Johannesburg, Gauteng Province, South Africa. In-depth phenomenological interviews were conducted and thematically analysed.

Results: The participants indicated that the physical aspects of diabetes management gradually decreases in difficulty, although the maintenance of a nutritional programme associated with effective diabetes management remained challenging. Psychologically, the participants' emotional experiences of diabetes management were characterised by the continued externalisation and internalisation of various negative emotions, while the sense of being dissimilar to others was evident. Socially, individuals who were misinformed about diabetes management were experienced as reacting improperly, while those who were knowledgeable about diabetes management were experienced as being helpful and supportive to maintain their regimens.

Conclusions: The experienced physical, emotional and social impact of diabetes management reported by the participants highlights the need for intervention-based research

to assist adolescents with and promote social awareness of type 1 diabetes management.

Keywords: Type 1 diabetes, well-controlled type 1 diabetes, diabetes management, adolescence, phenomenology, social constructionist theory

Diabetes management: The lived experiences of adolescents with well-controlled type 1 diabetes

1. Introduction

Type 1 diabetes is a chronic endocrine disorder characterised by heterogenic aetiological depletion of pancreatic insulin-secreting beta cells, resulting in permanent dependence on exogenous insulin administration (Chiang, Kirkman, Laffel, & Peters, 2014; Craig et al., 2014; Matthews, 2007; Tripathy, 2012). The peak age of onset of type 1 diabetes is postulated to be during adolescence (Mazze et al., 2012). This developmental phase of the teenage years, characterised by the manifestation of secondary sexual features, is associated with commonly occurring hormonal insulin resistance, which inevitably increases adolescents' vulnerability to developing type 1 diabetes (Colman, 2009; Craig et al., 2014; Leonard, Garwick, & Adwan, 2005). The unexpected emergence of clinically significant symptoms such as excessive urination, thirst and hunger in tandem with visual difficulties and weight loss could be indicative of type 1 diabetes and necessitates timely examination by a medical physician (Das, Raghupathy, & Tripathy, 2012; International Diabetes Federation, 2011). However, a definitive diagnosis of type 1 diabetes should be confirmed by a physician upon repeated observation of an adolescent's plasma-glucose levels over various time intervals (International Diabetes Federation, 2011).

Adolescents diagnosed with type 1 diabetes and their relatives have to come to terms with the new reality of compromised health while simultaneously adjusting to an intricate diabetes management regimen (Anderson & Mansfield, 2010). Individually-customised diabetes management regimens for adolescents are collaboratively developed by a multi-disciplinary team of experts in order to achieve and maintain control of plasma-glucose levels, and prevent diabetes-related acute and chronic complications while also fostering a good quality of life (American Diabetes Association, 2016; Beaser & Jackson, 2010; Maahs,

West, Lawrence, & Mayer-Davis, 2010). A diabetes management regimen for adolescents with type 1 diabetes should also include educational, pharmacological, physical and nutritional interventions to foster their holistic wellbeing (Beaser & Jackson, 2010; Bismuth & Laffel, 2010). Pharmacologically, adolescents have to continuously monitor their blood-glucose volumes to calculate the adequate insulin dosage to be administered via a syringe or an insulin secreting pump (Bismuth & Laffel, 2010). Physical exercise programmes assist with the control of average blood-glucose volumes, while nutritional guidance and mindful consumption of nutritional resources play a significant role in required pharmacological insulin therapy dosage calculations (Bussell, 2015; Smart, Aslander-van Vliet, & Waldron, 2009). Effective diabetes management is evident once individuals succeed in maintaining average glycated haemoglobin, or HbA1C, levels below 7% over a period of three months (Beaser, 2010). Successful diabetes management is dependent on the adolescent's knowledge of type 1 diabetes, as well as his or her sense of personal responsibility for and active involvement in the diabetes management regimen (American Diabetes Association, 2016).

2. Problem statement

The global prevalence of type 1 diabetes among children aged 14 years and younger appears to be rapidly increasing. While 542 000 children are estimated to be affected worldwide, annual global increases of approximately 86 000 new childhood type 1 diabetes cases are reported annually (International Diabetes Federation, 2015).

Despite these global indicators, there is a dearth of specific statistical information regarding the prevalence of type 1 diabetes among adolescents (across the entire developmental span of early, middle and late adolescence), both globally and in South Africa. Nevertheless, Patterson et al. (2014) contends that type 1 diabetes is the most widespread endocrine disorder among adolescents. Moreover, adolescents living with type 1 diabetes are

at risk of developing various potentially fatal and debilitating diabetes-related acute and chronic complications (Mlynarczyk, 2013). The circumvention of these adverse outcomes is subject to cognitive, emotional, behavioural and social adjustment to an intricate and demanding diabetes management regimen (Céspedes-Knadle & Muñoz, 2011; Dashiff, Bartolucci, Wallander, & Abdullatif, 2005; Piette & Kerr, 2006). Having to deal with an intricate and demanding diabetes management regimen during a challenging developmental phase such as adolescence can result in a comprised development of a sense of self and personal autonomy, while increased experiences of physical, emotional and social distress can also occur (Cheung, Young Cureton, & Canham, 2006; Silverstein et al., 2005). Considering the challenging nature of a diabetes management regimen and the suggested impact it can have on adolescents living with type 1 diabetes, the following research question arose: What are the lived experiences of diabetes management among adolescents with well-controlled type 1 diabetes?

3. Central theoretical statement

Social constructionism served as the theoretical framework of this study. The basic premise of social constructionist theory is the notion that an individual's lived experiences of a phenomenon are socially constructed by the self and during social interactions. Furthermore, these lived experiences are assumed to be culturally or historically specific, and maintained through continuous social processes, and result in specific behaviour (Burr, 2015; Gergen, 1985).

4. Research objective

The aim of this study was to explore and develop a composite description of the essence of the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes.

5. Research method and design

The study followed a qualitative research approach with a phenomenological research design to adequately explore and encapsulate the essence of the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes.

5.1 Setting

The study was conducted in the suburbs of Houghton and Parktown in Johannesburg, Gauteng province, South Africa. A high standard of living is associated with these suburbs.

5.2 Population

Adolescents with well-controlled type 1 diabetes, attending a Centre for Diabetes and Endocrinology in Houghton or Parktown in Johannesburg, Gauteng province, South Africa constituted the population of this study.

5.3 Sampling and sample

A non-random, purposive sampling method was used, for which inclusion into the sample was subject to compliance with pre-determined, strictly defined inclusion criteria.

These criteria ensured that the participants constituted an adequate representation of the population under study (Ritchie, Lewis, Elam, Tennant, & Rahim, 2013).

The final sample comprised eight adolescents (n = 8) with well-controlled type 1 diabetes (4 females; 4 males). The distribution of racial representation within the final sample was limited (7 Caucasians; 1 Indian), while the home languages of the participants were either of two of South Africa's 11 official languages (5 English; 3 Afrikaans). The mean current age and age at time of diagnosis with type 1 diabetes of the final sample was 13,63 years (SD = 2,23) and 9,34 years (SD = 2,64) respectively. The final sample's mean glycated haemoglobin percentage was 7,23 (SD = 0,59).

5.4 Inclusion criteria

The participants in this study had to be willing to participate in an interview in English or Afrikaans, be between the ages of 12 and 18 years, diagnosed with type 1 diabetes for at least 12 months, have maintained average glycated haemoglobin or HbA1C levels of 8% or less (as recommended by Prof. D.G. Segal, a specialist paediatric endocrinologist) (personal communication, February 21, 2016) for at least 12 months and under the care of the Centre for Diabetes and Endocrinology, either in Houghton or Parktown, Johannesburg, Gauteng, South Africa.

5.5 Data generation

Data was generated via in-depth individual interviews aimed at obtaining a rich narrative description of the participants' lived experiences of type 1 diabetes management. An agenda with two open-ended questions guided each interview. The participants were asked the following two questions:

"Can you tell me about your experience in terms of managing your diabetes?"
"Can you tell me about the contexts or situations that have typically influenced or affected your experience of managing your diabetes?"

Subsequently, further open-ended probing questions were posed to obtain supplementary information regarding the responses to the two set interview questions (Creswell, 2007). The open-ended nature of the interview agenda facilitated the elicitation of comprehensive data on the participants' lived experiences of diabetes management and on the contexts or situations that typically influenced their experiences (Moustakas, 1994). Audio recordings of the in-depth individual interviews were made.

5.6 Data analysis

The data generated by the interviews was analysed according to the thematic analysis method of Braun and Clarke (2006). This method involves a six-phase recursive data analysis process that facilitates a rich, detailed and complex understanding of the data and the production of a descriptive account of the dataset (Braun & Clarke, 2006). After verbatim transcription of the eight interview audio recordings, the data analysis progressed through the following phases: familiarisation with dataset, generation of initial codes, searching for themes, theme revision, definition and naming of themes, and, lastly, a compilation of the findings (Braun & Clarke, 2006).

6. Trustworthiness

The trustworthiness of this study was established through conscientious application of the eight criteria for quality qualitative research of the pedagogical model of Tracy (2010). A comprehensive literature review that indicated the significance of this study's research scope

met the worthy topic criterion of the model. Rich rigour was achieved by establishing a sound theoretical framework, prolonged immersion in the research context, transcription accuracy audits, and recursive and independent co-coder data analysis procedures. Regular supervisory meetings promoted research transparency, which satisfied the sincerity criterion. Dense descriptions of the research approach, design, sampling, sample, data generation, data analysis and member checking during the interviews enhanced adherence to the credibility criterion. Resonance was achieved by the inclusion of verbatim data segments that illustrated the participants lived experiences, while the potential positive impact of presenting the research findings to authoritative entities could signify the significant contribution of this study. The research was conducted in strict accordance with national and international ethical guidelines and the successful achievement of the research objective, while the application of appropriate research methodology and the scientific literary foundation of the study enhanced its meaningful coherence (Tracy, 2010).

7. Ethical principles

The legal minority age, in conjunction with the physical and potential psychological vulnerability of the sample, increased the ethical risk of this study. National and international policies, guidelines and laws pertaining to research with human subjects were therefore adhered to. These included the Code of Ethics of the World Medical Association (International Declaration of Helsinki), the Constitution of the Republic of South Africa, the Children’s Act, act 38 of 2005 and the National Health Act, act 61 of 2003 of the Republic of South Africa. Moreover, ethical approval of this study was obtained from the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (Ethical clearance number: NWU-HS-2016-0031). The informed written consent of the participants’ legal guardians and the participants’ assent were obtained, while

allocation of participant numbers and the password protection of data safeguarded confidentiality and anonymity.

8. Findings

Six main themes with subthemes emerged during thematic analysis of the data corpus utilised in this study. Verbatim extracts of participant interviews are included in this section to support the reported findings.

Table 1

Summary of themes and subthemes reflecting the lived experiences of diabetes management among adolescents with well-controlled type 1 diabetes

Theme one:	Initial difficulty with diabetes management subsides over time
Subthemes:	Knowledge, experience and mastery of diabetes management Adjustment to diabetes management
Theme two:	Adherence to and maintenance of a nutritional programme are challenging
Subthemes:	Self-discipline is imperative Lack of social consideration and accommodation of nutritional needs
Theme three:	Emotional experiences of diabetes management are predominantly negative
Subthemes:	Externalised frustration, anger and irritation Internalised guilt, stress, anxiety and sadness
Theme four:	Experiencing the self as being different
Theme five:	Social unfamiliarity with diabetes management results in experiences of untoward behaviour
Theme six:	Social cognisance and support positively influence diabetes management experiences
Subthemes:	Knowledge of family members, educators and friends Support from family members, educators and friends

8.1 Initial difficulty with diabetes management subsides over time

The majority of the participants reported that diabetes management was initially difficult. Participants A5 and A6 respectively stated that *'when I first got it, it was hard'* and *'in the beginning it was hard'*. However, over time an experienced gradual decrease in the difficulty of diabetes management was reported. Participant A1 said that it was *'difficult, but easier as time passed'*. Participant A2 echoed this: *'in the first half it was still a bit difficult for me and over the years it has become easier'*.

The participants' shared experiences of a gradually decreasing difficulty of diabetes management appeared to be attributable to certain supplementary experiences:

Knowledge, experience and mastery of diabetes management: Initial difficulties with diabetes management were ascribed to initial insufficient knowledge and experience. Participant A5 shared that *'when I first got it, it was hard and I never knew what to do'* and participant A1 mentioned *'in the beginning you are obviously unfamiliar with everything'*. However, with time the participants acquired increased knowledge of and experience with diabetes management, as reported by participant A1: *'as time pass you actually realise how things work...You understand when you should do what...you learn more as time pass'*. This process of learning about and gaining experience with diabetes management facilitated a sense of mastery, which made diabetes management easier. Participant A5 illustrated this by mentioning that *'it's hard, but once you get the insulin right, then it's kind of not so hard'*.

Adjustment to diabetes management: The essence of this subtheme is captured by participant A5, who reported that *' I'm more used to it...it's kind of getting easier'* and *'once you get like used to it then it's kind of like it doesn't exist to you'*. Moreover, other

participants' experiential accounts show how adjustment to diabetes management made it more routine and less laboured, with subsequent decreased difficulty. Participant A2's statement illustrates this: *'By now it's like an automatic feeling. Like you get up in the morning and you brush your teeth... A normal...action that is just executed by itself...It is easy because now it is like a normal action'*. Participant A3 reported that *'it's kind of like a routine in a sort of a sense, 'cause I'm used to it. So it's like okay, you know you have to eat breakfast, you have to pump with breakfast. Because I've been diabetic for such a long time...it kind of feels more natural like it should be happening...'*

8.2 Theme two: Adherence to and maintenance of a nutritional programme are challenging

The participants indicated that adherence to and maintenance of nutritional programmes were exceptionally challenging. This theme is underpinned by the assumption of personal responsibility for nutritional adherence and others' lack of consideration and accommodation of their nutritional needs in social contexts:

Self-discipline is imperative: Principally, nutritional programmes are experienced as being prescriptive, restrictive and demanding of considerable self-discipline. Participant A1's shared experience reflected this: '*At one stage I really struggled with it...temptation is always there. There is always a sweetie that's lying around somewhere. There is always this and that which looks nice...you are just...going to take the steps to say okay should I or shouldn't I? Should I inject to be able to eat it or should I rather just leave it? You should make the better decision'*. Participant A7 also emphasised this: *'It's hard to not eat the things you are not supposed to.'*

Lack of social consideration and accommodation of nutritional needs: Effective nutritional management proved to be difficult in contexts in which the participants' nutritional needs were not catered for. The experiences of participants A1 and A2 illustrate this: '*...we were actually at a social and they had nothing there, so my father had to bring me something'* and *'...the food especially, because there's never really anything I can eat.'*

8.3 Theme three: Emotional experiences of diabetes management are predominantly negative

The participants' shared emotional experiences of diabetes management indicated an array of negative emotions. Externalised frustration, anger and irritation, as well as internalised guilt, stress, anxiety and sadness were evident:

Externalised frustration, anger and irritation: Diabetes management reportedly provokes feelings of frustration, anger and irritation, which participants externalise toward management tasks, methods and other people. Participants A2 and A8 expressed such feelings towards certain diabetes management tasks: *'I want to eat and then I have to test my blood sugar. Then it is, for example, fifteen. Then I have to wait like ten minutes...then I get rather angry, uncomfortable and I become frustrated'* and *'If I wanted to have lunch and I check before and I was fifteen...then that was really annoying, because then you have to wait'*.

Experiences of diabetes management being intrusive and interruptive were also associated with frustration, as indicated by participant A3: *'I find it frustrating. I'm, like, seriously now? I'm in the middle of something...It puts like a halt and then it frustrates me'*. Feelings of frustration and irritation, associated with the repetitiveness of the diabetes management regimen were voiced by participants A2 and A8: '*That's even more frustrating,*

because instead of sitting in the sea, I should go back every two and a half hours to eat something' and *'I get annoyed... if I'm eating a lot of carbs throughout the day then that's annoying because then I have to inject quite often'*. Additionally, feelings of irritation, anger and resentment toward others who enforce, pry into or are ignorant about diabetes management emerged. Participant A2 recalled feelings of anger within a social context: *'It is a bit irritating...half way through the party an alarm went off on my pump. My battery or my insulin was finished... we had to go home, because we ate things and I had to go sort it out...that spoilt the whole day...I was angry at my mother, because I just want a normal day with all my other friends.'* Participant A6 described feelings of irritation in the face of inquisitiveness – *'everybody keeps asking me the first time they see it...urgh is it sore? And it gets irritating sometimes'*. Resentment towards other people were depicted in participant A8's report that *'I just found it unfair that I had to do it'*.

Internalised guilt, anxiety, stress and sadness: Blaming the self and internalised guilt were apparent in cases in which diabetes management was compromised. Participant A3 stated: *'if I know now I'm feeling sick because I didn't pump insulin for that cupcake I ate or something, then I'd feel guilty...then I'd feel like it's my fault that I'm feeling like this',* while participant A6 reported *'then my sugars are sometimes high and then I always think it's my fault...'*

Feelings of anxiety and stress regarding diabetes management during hypoglycaemic and hyperglycaemic episodes were also mentioned. Participant A1 and A5 respectively divulged that: '*If it's low you stress, you worry. Okay, when am I going to get something to cover my sugar?'* and *'When it goes high then you're not sure what to do then you panic'*.

Observations of diabetes management by peer groups and perceptions of personal incompetence regarding independent diabetes management were related to experiences of

sadness. Participants A2 and A4's distinctive accounts highlighted this: *'Then I just feel bad. Emotional. Just, like, sad...' ; 'Sometimes I just feel sad that I don't know what to do...'*

8.4 Theme four: Experiencing the self as being different

Feeling different to other individuals was another common theme. This occurred in various contexts and situations. Participant A7 illustrated it with a school holiday experience: *'...you want to be like your friends...you want to eat lots of junk food. You want to do normal things like go to the movies and eat as much popcorn as you like...and you just do it because you feel, 'cause you just want to be normal'*. Participant A3 shared a similar experience of the school environment: '*I have to go outside and drink something or eat something, because you are not allowed to eat and drink in some of the classes, so it's a bit of an exclusion kind of and like you're different'*. Participant A2 demonstrated this theme when relating a school camp experience: *'it was just different...I felt like a baby, because I was the only child whose mother was there'*. Participant A2 also noted *'it's just not pleasant...I'm not like other people whose pancreas works and then I have to do all these other things while other children can just start eating'*.

8.5 Theme five: Social unfamiliarity with diabetes management results in experiences of untoward behaviour

Almost all the participants agreed that diabetes management drew unwanted attention in a wide variety of contexts, such as social, recreational and educational environments. In most cases, others' untoward reactions towards diabetes management behaviours and equipment seemed to stem from ignorance. Participant A1's experience at a social event illustrates this: *'people are like, ah he is injecting himself!...then that part of it being steroids comes again...it's as though people tease you about it, but they don't really know what it is,*

why you do it.' Other individuals also appear to pry when witnessing diabetes management, especially in educational and recreational contexts. Within the school environment, participant A4 shared: *'if there is another child in the bathroom, then I had to explain to him why I do this and that was a nightmare'*, while participant A6 mentioned that *'when I'm on a plane or holiday and the people... always ask me how did you get diabetes?...I don't like telling them about it'*. Participant A6 also recalled: *'when I'm in the movies people walk past... they look at me like I'm crazy, like I'm on steroids or something'*. Furthermore, participant A8 described an incident in a social context: *'If I'm out with my friends...like restaurant managers...they'll come like check up...they walk past like a few times. They check me out...like it's not something sinister or anything'*.

Other's untoward behaviour upon witnessing diabetes management elicits feelings of self-consciousness and discomfort, as is evident from participant A2's accounts: *'then I become a bit shy, because they always want to see and then I show them how'* and *'then everyone stands like this and watches what I do, because for them it is something different. Something interesting, but it's uncomfortable for me'*.

8.6 Theme six: Social cognisance and support positively influence diabetes management experiences

This theme relates to the participants' common experience of the positive impact of family members, educators and close friends who were knowledgeable about and supported their diabetes management.

Knowledge of family members, educators and friends: Family members, educators and close friends being knowledgeable about their diabetes management-related needs appeared to positively influence the participants' experiences of diabetes management

because it empowered these persons to assist the participants with their diabetes management. Participant A2 demonstrated this by referring to a parental figure: *'It helps more, because I cannot inject myself on my bum with the port, so she helps me a lot. She times it and inserts the new insulin and the batteries.'* Participant A8 spoke of an educator and some friends in a similar way: *'My math teacher knows quite a lot about diabetes, 'cause her…son was diabetic…she's my emergency person at school…two of my friends are quite clued up about it...they know how to check my blood sugars…'*

Support from family members, educators and friends: Knowledge of diabetes management not only empowered others to assist the participants, but also seemed to enhance others' support of their diabetes management. Speaking of the experience of parental support, participant A1 and A3 shared respectively: *'at least I know that they worry about me and they are still concerned...'* and '*Like with my mom, she's really supportive and she'll like help me and she will be like okay, I know you are not feeling well'*. Participant A8's description of support from educators synthesised this experience: *'My science teacher asks me how I am like all the time...all of them seem really nice about it. A lot of them if I go low in class, they send someone out with me to go get stuff. They make sure I'm fine...'cause I used to panic a lot when I went low and then a lot of them were very calming and relatively nice when I went low and then understood like what was happening...'* Lastly, participant A7 spoke similarly about an experience of support from friends: '*They do help a lot when I'm feeling low ...they always try and help me...they know when I'm low...they help me excuse myself and get to test my sugar'*.

9. Discussion

The aim of this study was to explore and encapsulate the experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes. The

outcome of this study was a rich and dense description of the shared experiential descriptions of the physical, psychological and social aspects of diabetes management of the population under study. Theoretically, the participants' descriptive accounts might be completely subjective because social constructionist theory ontologically assumes that no independent external reality exists (Gergen, 1985). Epistemologically, in theory the participants' reported lived experiences of diabetes management were thus not imposed on them, but were personally and socially constructed among themselves and others (Burr, 2015; Schwandt, 2000). A condensed description of the participants' accounts was captured, portraying the following:

Physically, the execution of a diabetes management regimen was described as difficult. This concurs with the findings of Grey, Boland, Yu, Sullivan-Bolyai, and Tamborlane (1998). However, the participants in the current study also found that it became increasingly easier due to increased knowledge of, experience with, mastery of and adjustment to diabetes management. The challenging nature of the nutritional aspect of a diabetes management regimen among the participants in the current study was indicated when the participants' described nutritional prescriptions and restrictions, which necessitated self-discipline. These findings affirm similar observations made by Chao et al. (2016) and Lowes et al. (2015). Insufficient social consideration and accommodation of nutritional needs appeared to also contribute to the participants' experienced challenges with respect to nutritional diabetes management. This again supported the study conducted by Chao et al. (2016), whose respondents attributed the challenging nature of nutritional management, in part, to others' undesired persistent interference with and monitoring of their nutritional intake.

The participants in the current study experienced diabetes management to cause externalised and internalised negative emotions. Studies by Lowes et al. (2015) and Van der

Westhuizen, De Klerk, Kahl, and Pretorius (2014) found that participants' diabetes-related negative emotional experiences were the combined result of diagnostic adjustment and treatment management. Chao et al. (2016) indicated that the negative emotional experiences of adolescents living with type 1 diabetes might also pertain exclusively to normal developmental tasks without any relation to a type 1 diabetes diagnosis or the management thereof. Evidently, the kinds of emotions experienced by adolescents with type 1 diabetes across different empirical studies are predominantly similar, although the casual factors associated with these emotions differ.

Participants in the current study associated diabetes management with their sense of self being experienced as personally socially different. This experience is significant, because Huus and Enskär (2007) suggest that feeling socially conformed is of paramount importance to adolescents living with type 1 diabetes. Nevertheless, Commissariat, Kenowitz, Trast, Heptulla, and Gonzalez (2016) comparably found that adolescents experience various aspects of type 1 diabetes, including the management thereof, to compromise their sense of personal normalcy and social relatedness with others. Regardless of the reported experiences of compromised senses of personal and social conformity, the participants in the current study adjusted their diabetes management-associated decisions and behaviours in social contexts in an attempt to avoid compromised management efficacy.

Ultimately, the participants in the current study reported that their experiences of diabetes management were significantly influenced by social relations. They described their diabetes management as being met by both untoward as well as supportive behaviours by others. They found others' untoward behaviour toward their diabetes management to be stigmatising and ostracising, which is notable in light of Van der Westhuizen, De Klerk, Kahl, and Pretorius' (2014) finding that adolescents are fearful of anticipated possible social stigmatisation and ostracisation. Findings from the current study suggest that the participants

experienced others untoward behaviours to stem from diabetes management-related ignorance. Jayarajah (2016) contends that several studies on adolescent type 1 diabetes have emphasised the negative impact of social ignorance on type 1 diabetes treatment adherence among adolescents. However, the sound knowledge and proper support structures of participants in the current study seemed to enhance their treatment adherence in the face of social ignorance. Lastly, the participants in the current study noted that supportive behaviour from others seemed to be underpinned by sufficient knowledge of diabetes management, demonstrating the need for the promotion of social awareness of type 1 diabetes management.

In short, the participants' experiential accounts suggest that diabetes management is literally challenging and demands learning, experience, mastery and adjustment. The psychological challenges of diabetes management primarily include coping with negative emotions and compromised evaluations of the self. Socially, others' behaviours toward diabetes management are dependent on diabetes management-associated knowledge.

10. Conclusion

The adolescents with well-controlled type 1 diabetes who participated in this study, emphasised the physical, psychological and social impact of diabetes management. Participants' reported lived experiences are speculated to be subject to capricious modifications as infinite exposure to and participation in various contextual social dialogues, throughout the remainder of their lives, is inevitable. Nevertheless, the personally and socially constructed interpretations of the realities experienced by the participants in this study articulated with respect to their diabetes management are in significant agreement with previous empirical studies.

11. Limitations of the study

The limited demographic variability of the non-random purposive sample utilised in this study restricted the potential applicability of the findings of this study to the entire population of adolescents living with type 1 diabetes in South Africa.

12. Recommendations

Further research focusing exclusively on early, middle or late adolescence is necessary to ascertain the lived experiences of diabetes management during the specific phases of adolescence. Moreover, research aimed at the development of interventions to help adolescents with well-controlled type 1 diabetes to cope with diabetes management-associated challenges and to promote social awareness of type 1 diabetes management is necessary within the South African context.

Declarations

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2. Conflict of interest: none.

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SECTION 3: CRITICAL REFLECTION

3.1 Introduction

The scope of this study falls within the realm of the social sciences. The primary aim of social research is to enhance understanding of the complexities constituting human nature and behaviour (Rovai, Baker, & Ponton, 2014). In order to establish the contribution of this study to the field of social science, a critical reflection on the core components constituting this study is necessary. Section III of this mini-dissertation therefore provides a brief overview of the conception and aim of this study. This section concludes with an epilogue on the research process, findings, significance, limitations and recommendations.

3.2 Conception of the study

Principally, in order to meaningfully contribute to the field of social science, the researcher had to identify an idiosyncratic socially significant topic that required further exploration in order to enhance existing scientific understanding thereof. An extensive review of the existing literature led to the identification of a rapid annual global increase in the prevalence of the most common paediatric endocrine disorder, namely type 1 diabetes (Patterson et al., 2014). From a social sciences perspective, the latter is problematic given that a diagnosis of type 1 diabetes necessitates adherence to a burdensome and intricate diabetes management regimen to maintain average glycated haemoglobin levels within near normal ranges and prevent the adverse physical, psychological and economic consequences and complications of type 1 diabetes (International Diabetes Federation, 2015). Consequently, diabetes management has to be executed effectively for type 1 diabetes to be rendered well-controlled. The following research question thus arose: '*What are the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes?'*

3.3 Research aim

The aim of this study was to explore and encapsulate the essence of the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes.

3.4 Epilogue

3.4.1 Research process

A qualitative research approach with a phenomenological research design was implemented and a social constructionist theoretical framework was utilised. A non-random purposive sampling method ensured that the selected participants met the pre-determined and clearly defined inclusion criteria for participation in this study (Ritchie, Lewis, Elam, Tennant, & Rahim, 2013).

The final sample consisted of eight (4 female and 4 male; 7 Caucasians and 1 Indian; 4 Afrikaans and 4 English-speaking) adolescents between the ages of 12 and 18 years living with well-controlled type 1 diabetes. In order to limit the effect of continued adjustment to the diagnosis of type 1 diabetes, care was taken to ensure that all the participants were diagnosed at least one year prior to their participation in this study. Furthermore, in an attempt to limit variations among the participants' prescribed diabetes management regimens, all the selected individuals had to attend a Centre for Diabetes and Endocrinology, either in Houghton or Parktown in Johannesburg, for treatment for their type 1 diabetes. Ultimately, even though the literature suggests that type 1 diabetes is well controlled and diabetes management is effective once those living with the disorder achieve average glycated haemoglobin levels of approximately 7% or less for at least three months, the inclusion criteria for this study stipulated that prospective participants had to maintain average glycated

haemoglobin levels of 8% or less over a period of three months. The latter was enforced upon recommendation by the primary gatekeeper of this study, Prof D.G. Segal, a specialist paediatric endocrinologist, who contended that adolescents maintaining average glycated haemoglobin percentages of 8% or less were also effectively controlling their type 1 diabetes (personal communication, February 21, 2016). All but one participant in the final sample had managed to maintain average glycated haemoglobin percentages of 8% or less. The exception was permitted because Prof D.G. Segal maintained that the participant had a history of well-controlled type 1 diabetes, with the most recent average glycated haemoglobin percentage being exceptional. None of the participants had any other chronic illnesses and nor were any of them receiving psychotherapy at the time of this study.

The data for this study was gathered by means of in-depth phenomenological interviews, the aim of which was to elicit the participants' descriptions of their lived experiences of diabetes management. Audio recordings of the interviews were transcribed and thematically analysed according to the thematic analysis method described by Braun and Clarke (2006). After this, a condensed description of the essence of the participants' lived experiences of diabetes management was developed. This condensed description constitutes the empirical findings of this study.

3.4.2 Findings of the study

The findings of this study were encapsulated by six comprehensively descriptive themes and subthemes:

Theme 1: Initial difficulty with diabetes management subsides over time (Subthemes: Knowledge, experience and mastery of diabetes management; Adjustment to diabetes management)

The first main theme denoted the participants' lived experiences of the difficulty of diabetes management. While it was experienced as being difficult initially, most of the participants contended that it gradually became easier as diabetes management became less intricate. The participants attributed this primarily to the attainment of increased knowledge about, experience with and mastery of diabetes management over time. Furthermore, reports of gradual improved adjustment to diabetes management led to a subsequent experience of it becoming more routine and less strenuous, which in return also alleviated the experienced difficulty level thereof.

Theme 2: Adherence to and maintenance of a nutritional programme are challenging (Subthemes: Self-discipline is imperative; Lack of social consideration and accommodation of nutritional needs)

Secondly, the participants' experiential descriptions of diabetes management demonstrated that maintenance of a prescribed nutritional programme was particularly challenging. They found the prescribed nutritional programmes restrictive, prescriptive and demanding, which they experienced as demanding immense self-discipline. The latter seemed to apply specifically to diabetes management in the face of culinary temptations.

Additionally, others' insufficient awareness and mindfulness of the participants' nutritional needs appeared to also contribute to their experience of their nutritional programme as challenging.

Theme 3: Emotional experiences of diabetes management are predominantly negative (Subthemes: Externalised frustration, anger, and irritation; Internalised guilt, stress, anxiety and sadness)

Experiences of predominantly negative emotions associated with diabetes management delineated the third main theme evident within this study. Despite a significant

time lapse since initiation of a diabetes management regimen, most of the participants had continuous experiences of an array of negative emotions in relation to their diabetes management. The externalisation of frustration, anger and irritation, along with the internalisation of guilt, stress, anxiety and sadness, represented the general emotional reaction to diabetes management among the majority of the participants. Externalised feelings of anger, frustration and irritation appeared to be directed essentially towards the diabetes management itself. However, the participants also seemed to externalise these negative emotions towards individuals who played supportive diabetes management roles in their lives, as well as towards those individuals who were not living with type 1 diabetes and who were thus not subject to a diabetes management regimen. Internalisation of guilt, upon subjective evaluation of diabetes management tasks being executed ineffectively, demonstrated how the participants also directed these negative emotions towards the self. Furthermore, the anxiety and stress experienced during emergency incidents such as hyperglycaemic and hypoglycaemic episodes further emphasise this theme. Lastly, internalised feelings of sadness were also reported in the face of perceived personal inability to execute diabetes management tasks and public observation of diabetes management.

Theme 4: Experiencing the self as being different

The fourth theme that emerged during thematic analysis of the dataset pertained to a shared experience of diabetes management being associated with experiencing and perceiving the self as being different to other individuals. The majority of the participants divulged experiences within recreational and educational environments and situations in which managing their diabetes left them feeling as though their ability to engage in common activities was limited compared to other individuals. Moreover, diabetes management necessitated exceptional treatment of the participants by significant others, such as teachers, in order to accommodate diabetes management tasks within regulated environments. This

was reported to be associated with the participants’ experience of feeling and perceiving themselves to be different in relation to others. Feeling and perceiving the self to be different to other individuals was described as an unpleasant experience.

Theme 5: Social unfamiliarity with diabetes management results in experiences of untoward behaviour

The penultimate theme pertained to the participants’ experiences of others’ untoward behaviour towards them when witnessing the execution of diabetes management tasks by participants. Occurring within various social, educational and recreational contexts, other individuals’ ignorance regarding type 1 diabetes and the magnitude of what a diabetes management regimen encompassed seemed to result in unfavourable reactions. Consequently, the participants experienced feelings of self-consciousness and discomfort.

Theme 6: Social cognisance and support positively influence diabetes management experiences (Subthemes: Knowledge of family members, educators and friends; Support from family members, educators and friends)

The final theme that emerged related to the participants’ experiences associated with the knowledge of significant others regarding diabetes management, including family members, teachers and close friends. The participants’ accounts demonstrated that significant others’ knowledgeability is related to enhanced ability to assist and support participants in terms of their diabetes management.

Essentially, the findings of this study are based on empirical evidence rather than speculation or theory (Colman, 2009). The researcher therefore declares that the aim of this study, namely to explore and encapsulate the lived experiences of diabetes management among a group of adolescents with well-controlled type 1 diabetes, has been met.

3.4.3 Limitations

Despite the successful achievement of the research aim, some limitations of this study are evident and should be considered:

- This study explored and encapsulated the lived experiences of diabetes management among adolescents with well-controlled type 1 diabetes across the entire developmental phase of adolescence. Subsequently, no empirical conclusions regarding this phenomenon within the distinctive phases of early, middle and late adolescence, can be drawn from this study.
- The final sample utilised in this study represents a limited demographic and socio-economic variability, restricting the applicability of the findings of this study to the entire South African population of adolescents with well-controlled type 1 diabetes.
- The final sample utilised in this study is considered to have been relatively small. However, Polkinghorne (as cited in Creswell, 2007) suggests the inclusion of five to 25 participants when conducting interviews with individuals who have experienced the same phenomena. Due to the fact that data saturation occurred subsequent to conducting and analysing the eighth interview, further interviews with additional participants would have yielded no new data and therefore the sample of eight participants was considered to be sufficient.
- Data generation for the purpose of this study was limited to in-depth phenomenological interviews, which inhibited the researcher’s ability to triangulate the findings of this study. However, Conrad and Barker (2010) postulate that conducting in-depth phenomenological interviews with individuals who have all experienced the same phenomenon is sufficient to establish the nature of shared human experiences of a phenomenon.

3.4.4 Recommendations

This study demonstrates the need for further research to enhance empirical insight into the lived experiences of diabetes management among adolescents with well-controlled type 1 diabetes. The following is recommended:

- Due to anticipated continuous exposure to various social contexts and dialogue, the descriptions of the lived experiences of diabetes management among the sample in this study are likely to change in the future. A follow-up study could be conducted to evaluate how the lived experiences of diabetes management among the sample evolve with time.
- Future studies pertaining to the South African paediatric population living with type 1 diabetes should focus exclusively on the lived experiences of diabetes management within one separate developmental phase of adolescence, that is, either the early, middle or late stage.
- Studies should be done that are aimed at the development of interventions to assist the South African paediatric population living with type 1 diabetes to deal with diabetes management, which could potentially alleviate the challenging nature thereof.
- Increased social cognisance of type 1 diabetes management within the South African context is necessary. Research aimed at the possibility of incorporating educational outcomes associated with type 1 diabetes management into the primary and secondary level education curricula in South Africa could enhance social awareness.
- Additionally, a critical systematic review of existing policies and guidelines governing type 1 diabetes management among the paediatric population in South Africa is necessary. This could provide potential insight into this specific population’s experiences of diabetes management in various contexts and emphasise the need for refined policies to improve said experiences.

3.4.5 Significance of the study

This study is considered to contribute significantly to the field of social sciences, specifically within the South African context:

- This study addressed Van der Westhuizen, De Klerk, Kahl, and Pretorius' (2014), reports of a dearth of empirical insight into the lived experiences of diabetes management in the South African adolescent population and their recommendations for further research to be done on the matter.
- The findings of this study could facilitate dialogue with the National Department of Health of the Republic of South Africa regarding promoting awareness of adolescent type 1 diabetes management within the South African context. Possible refinement of existing contextual policies guiding adolescent diabetes management within South Africa could subsequently be discussed with the said department.

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ADDENDUM A

Proposal approval letter issued by scientific committee

COMPRES Post-graduate Proposal Application

Faculty of Health Sciences

COMPRES – SCIENTIFIC COMMITTEE

RESEARCH PROJECT APPLICATION

SCIENTIFIC APPROVAL OF RESEARCH PROPOSAL

TYPE OF PROPOSAL	A. **Large Project**:	
	B. **Student Research**:	X
	C. **Independent Project**:	

Applicant/s: Beatrice Mulder

Student/Staff no.: 21639728

Degree: **MA Clinical Psychology**

Title: Diabetes management: The lived experiences of adolescents with well controlled type 1 diabetes

It is hereby confirmed that abovementioned proposal has been approved by this committee. The applicant may proceed with title registration and application for ethical approval.

Signature

Designation: Chair COMPRES Scientific Committee

Date of final approval: 11 March 2016

SUBMISSION HISTORY			
25/02/16	First submission	Accepted	Minor changes
08/03/16	Second submission	Accepted	

(Approval Version 1) on page 1

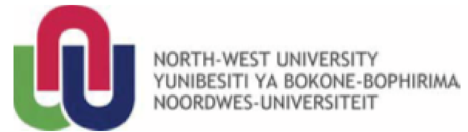
COMPRES Post-graduate Proposal Application

REVIEW PANEL:	
Prof K Botha	Prof M Weyers
Dr W de Klerk	Prof H Grobler
Prof W Roestenburg	Dr M van der Merwe

(Approval Version 1) on page 2

ADDENDUM B

Ethical approval certificate of the overarching larger study



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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:	N	W	U	-	HS	-	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

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:*
  - *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-RERC. 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:*
  - *request access to any information or data at any time during the course or after completion of the project;*
  - *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 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

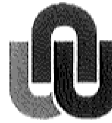
Linda du Plessis

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)

ADDENDUM C

Ethical approval certificate of the current study



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

Institutional Research Ethics Regulatory Committee
Tel: +27 18 299 4849
Email : Ethics@nwu.ac.za

2016-07-04

ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the **Humanities and Health Research Ethics Committee (HHREC)** on **24/06/2016**, 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: **Diabetes management: The lived experiences of adolescents with well controlled type 1 diabetes**

Project Leader/Supervisor: **Dr E Deacon**
Student/ Applicant: **B Mulder**

Ethics number: N W U - HS - 2 0 1 6 - 0 0 3 1
(Institution / Project Number / Year / Status)
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Application Type: N/A
Commencement date: 2016-06-24 **Expiry date**: 2019-06-24 **Risk:** **High**

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.

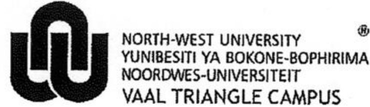
Yours sincerely

Prof LA Du Plessis — Digitally signed by Prof LA Du Plessis Date: 2016.07.05 09:16:46 +02'00'

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

ADDENDUM D

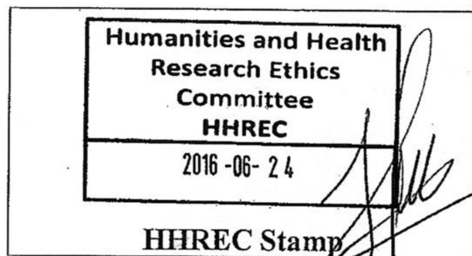
Participant information leaflet and consent form for parents/guardians of adolescents



PO Box 1174, Vanderbijlpark
South Africa, 1900

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

11 April 2016



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

TITLE OF THE RESEARCH PROJECT: Diabetes management: The lived experiences of adolescents with type 1 diabetes.

REFERENCE NUMBERS: NWU-HS-2016-0031

RESEARCHER: Ms. Beatrice Mulder

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 the lived experiences of diabetes management in adolescents.Take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project you do not fully understand. It is very important that you be fully 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, thus this consent letter is written in such a way that in all instances “you” refer to both you and your child. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you had initially agreed to take part.

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

This study has been approved by the **Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2016-0031)** 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. It might be necessary for the research ethics committee members or relevant authorities to inspect the research records to make sure that we (the researchers) are conducting research in an ethical manner.

What is this research study all about?

- *This study will be conducted through the CDE, Houghton and a private medical practice specialising in paediatric diabetes. The research involves an interview with your child. The researcher has been trained to use the methods mentioned.*
- *The researcher cannot specifically say how many participants will be involved in the interviews, but predict that approximately twelve to twenty participants will be interviewed.*
- *The objective of this research is to explore how your child experience the management of type 1 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 to us the information leaflet you completed at your previous visit at the CDE or private medical practice. You already received a phone call in which you indicated your interest in the project, followed by an e-mail with this form attached. Also note that we have obtained permission for the CDE and medical practice to conduct this research.*
- *Your child has also complied with the following inclusion criteria: he/she is willing to conduct the interview in English or Afrikaans, he/she is between ages 12 and 18, was diagnosed more than 12 months ago, is a patient at the CDE, Houghton or medical practice and have 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 sit in (along with their legal guardian) an interview of which the duration will be approximately 45 minutes. This will take place in a suitable venue at the CDE, Houghton or medical practice, before or after your regular appointment with either the diabetes educator or medical practitioner, depending on your preference.*
- *We would also like to include your child's HbA1C results in this study as this will give us an objective measure of how you manage your child's diabetes. We will, however, not be doing the blood test ourselves, but will obtain the results from your medical record at the CDE and medical practice. This will only happen once you have given your written informed consent.*
- *Your child will also be asked to take part in an intervention at a later stage following their interview with the researchers. As we do not have more information on the kinds of activities and your child's responsibilities in the intervention phase yet, a separate*

assent and consent form will be compiled and discussed with you and your child before the intervention starts.

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 think about the questions, he/she may come to a better understanding of diabetes management, which may positively influence how they manage their diabetes.*
  - *After participation in the interview your child will receive an information leaflet on diabetes management which could further assist him/her in managing your child's diabetes well.*
  - *As part of thanking you for taking part in this study, we will give your child a certificate. After their interview with the researcher, your child will receive a sticker to paste on the certificate. Because they will be receiving these tokens of appreciation that are personalised and only meant for those living with diabetes taking part in the study, they may start feeling 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 in a better way.*
  - *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 and possibly improve their diabetes management.*
- *The indirect benefit will probably be:*
  - *The research community, both medical and behavioural sciences, could benefit from a better understanding of the experiences of diabetes management.*
  - *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 – to name only a few) and the community at large (more healthy members that can contribute to improving society).*

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

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

Probable/possible risks/discomforts	***Strategies to minimize risk/discomfort***
Because your child may be spending one hour participating in the interview, it is possible that he/she will become tired.	The researcher facilitating the interview will give your child a 15-minute break with some refreshments (a low carb snack with bottled water) about half way through the interview.
Because the researchers will ask your child questions about their diabetes management, they will need to think about how they manage their diabetes,	The researchers have arranged one psychological debriefing session per participant with Rosemary Flynn (who is affiliated with the CDE).

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

and this may make them feel uncomfortable.	
Although we do not expect that the research process will have an impact on your child's health, having diabetes implies having low and high blood glucose levels unexpectedly and this may happen while your child are busy with the interview.	If your child feel ill at any time during the interview, he/she needs to tell the researcher so that their blood glucose can be tested and the corrected.
We will be using your child's HbA1C results (done every three to six months), which indicates how well they manage their diabetes. We will, however, not be doing these tests ourselves, but will obtain the results from your child's medical record at the CDE and medical practice, with your permission.	We will not be drawing blood or doing any other tests that need us to hurt your child physically. We will ask your written informed consent to retrieve the information from your child's record at the CDE and medical practice.
In this study we will be asking your child how well he/she manages the diabetes, which is also measured by the HbA1C test. Although we will not be talking about this result, your child may be concerned that we will judge him/her based on that result, or think less of them based on how well (or not) they manage their diabetes.	Living with diabetes can be difficult and we will treat every person that is willing to share their experience, with respect. We will not discriminate against any person based on how well (or not) they manage their diabetes. If at any stage you or your child feels uncomfortable talking about your feelings, please let the researchers know so they can help you identify a psychologist in your region and arrange an appointment for you and/or your child.
Living with diabetes may cause your child to feel that he/she is different from their friends and that they feel they do not belong in the same group as their friends.	As part of thanking your child for taking part in this study, we will give your child a certificate. After sharing their experiences with diabetes management with us during the interview, we will give them a sticker to paste on the certificate. Receiving this may lead to them feeling that they belong to a special group and that their opinions are important.
Living with diabetes you or your child may be worried that people learn about your diagnosis and start treating you differently.	We will meet with you and your child at the place where you normally receive your treatment (CDE Houghton, and medical practice), so you and your child can feel comfortable in a safe place familiar to you.
As we will be meeting with you and your child at the CDE and medical practice, you may encounter transport	In order to minimize transport and other costs, we will schedule the sessions with your child's normal visits to the CDE and

costs to get there. There may also be time taken off from work, or time taken off from school to take part in this study.	medical practice. We plan to visit the CDE and medical practice during the afternoons and in school holidays to prevent your child from being away from school unnecessarily.
The researcher will be asking questions concerning your child's diabetes management and things that influence it. If in the discussion that follows your child share other situations where they were harmed or neglected, the researchers will have to share this with the right people to make sure that your child is safe.	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 duty to disclose abuse or harm of a minor. We will ask your child how they want to deal with it and let them know what the different things are that can happen, depending on what happened, who was present and how serious the problem is.
This study is a long-term project (5-10 years). This means that your child will 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 have the right to no longer participate.

- *However, the benefits (as noted) outweigh the risks.*
- *Should we learn, in the course of the research, that someone is harming 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) have given written informed consent, followed by your child's written assent. This code will be indicated on the consent and assent forms, after which the consent and assent forms will be stored in a separate place, away from the data, to ensure that no link can be made between you or your child's results and identity.*
- *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, 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.*
- *Only the researchers will have access to the data. Although we work closely with the CDE Houghton and medical practice, no member of the CDE or medical practice, or your medical team will have access to the data. Data will be kept safe and secure by*

locking hard copies in locked cupboards in the researchers' offices and electronic data will be password protected.

- *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). As soon as data has been transcribed it will be deleted from the recorders. The transcripts will be stored on a password-protected computer. All co-coders will sign confidentiality clauses.*
- *As this is a long-term project, data will be stored for a minimum of 10 years.*

What will happen to the data?

The data from this study will be reported in the following ways: it will be written up in articles and research reports, and presented at conferences. In all of this reporting, you or your child will not be personally identified. This means that the reporting will not include your name or your child's name or details that will help others to know that you or your child had participated (e.g., your address or the name of your child's school).

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 paid/compensated to take part in this study and are there any costs involved?

No, you will not be paid/compensated to take part in the study, but refreshments will be provided (a bottle of still water and a low-carb snack). The researchers aim to incorporate the interviews and/or completion of questionnaires with your scheduled visits to the CDE or medical practice. This means, you do not have to travel additionally for the purpose of participating in the project. Thus there will be no additional costs involved for you as parents.

How will you know about the findings?

- As this is a long-term project, participants and/or parents/care-givers will receive (preferably via e-mail) an annual progress report, including the main findings thus far, as well as further opportunities for participation. Posters will also be displayed at the CDE Houghton and medical practice containingthe main findings.
- Feedback on your child's individual interview will not be given as the interview in itself is a discussion of their experiences.

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 Linda Theron) at 016 910 3076 or Linda.theron@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 Tumi Khumalo (016 910 3397 or Tumi.khumalo@nwu.ac.za). You can leave a message for either Linda 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 by parent/guardian

By signing below, I ………………………………………………, parent/guardian of ……………………………........ agree that my child can take part in a research study titled: **Diabetes management: The lived experiences of adolescents with 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.
- I understand that what me 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 the 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: ________________________

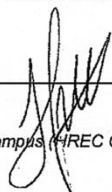
Email: ________________________

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:



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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.

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**

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ADDENDUM E

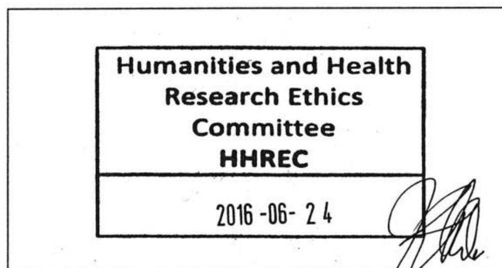
Participant information leaflet and informed assent form for adolescents

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

PO Box 1174, Vanderbijlpark
South Africa, 1900

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

11 April 2016



PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM FOR ADOLESCENTS

TITLE OF THE RESEARCH PROJECT: Diabetes management: The lived experiences of adolescents with well controlled type 1 diabetes.

REFERENCE NUMBERS: NWU-HS-2016-0031

RESEARCHER: Ms. Beatrice Mulder

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 investigating the experiences of diabetes management amongst adolescents. Please read this document carefully as this will explain the details of this project. Please ask us any questions about any part of this project you do not fully understand. It is very important that you should feel happy taking part in the project, that you clearly understand what this research is about and how you could be involved.

Since you are still of a school going age, we, as researchers, also asked your parents to read a similar document and give permission that you can take part in the project. Once they have given us their permission, in writing, we would also like you to decide if you would want to participate in this research project. Remember that participating in this project is entirely up to you and therefore you may say that you do not want 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 end your

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

participation in our research project at any time, even if you have already told us that you wanted to be a part of our project.

This study has been approved by the **Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2016-0031)** and will be conducted in accordance with the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health Research Ethics Council. It might be necessary for the research ethics committee members (the people who are granting us permission to do this project) or relevant authorities to inspect the research records to make sure that we (the researchers) do our research according to certain important ethical rules.

What is this research study all about?

- *This study will be conducted with the permission of the CDE, Houghton and Parktown. As part of this project we would expect of you to talk to one of our researchers as part of an interview. Your parents will be a part of this. We have been trained to do interviews with people.*
- *We cannot specifically say how many people will be involved in the interviews, but we think we will interview more or less twelve to twenty people.*
- *With this research project we would like to come to a better understanding of how you experience the management of type 1 diabetes.*

Why have we invited you to be a part of this research project?

- *You and your parents have told us that you would be interested in taking part in the project. Your doctor sent us the information leaflet, which your parents have completed at your previous visit at the CDE, 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 told us 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 to conduct this research.*
- *The reasons why you were selected to take part in this research project are: you are willing to do an interview with us 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, 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.*

What will your responsibilities be?

- *We would expect you to do an interview with us. The interview will be more or less 45 minutes long. This will take place in a suitable venue at the CDE, before or after your regular appointment with either the diabetes educator or doctor, depending on your preference.*
- *We would also like to include your HbA1C results in this study as this will give us a good idea of how you manage your diabetes. We will, however, not be doing the blood test ourselves, but will get the results from your medical record at the CDE. This will only happen once you have given us permission, in writing, to do so.*
- *You will also be asked to take part in an intervention at a later stage. As we do not have more information on the kinds of activities and your responsibilities in the*

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

intervention phase yet, a separate assent form will be compiled and discussed with you before the intervention starts.

Will you benefit from taking part in this research?

- *The direct benefits for you as a participant will probably be the following:*
  - *While you think about the questions we ask you in the interviews, you may better understand diabetes management, which may positively influence how you manage your diabetes and experience your life.*
  - *After your interview with the researcher you will receive an information leaflet on diabetes management which could further help to assist you to 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 give you a sticker to paste on the certificate. Because you will be receiving these tokens of appreciation that are personalised and only meant for those living with diabetes taking part in the study, you may start feeling that you belong to a special group and that your opinions are important. Receiving the sticker for participation could motivate you to manage your diabetes in a better way.*
  - *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 and possibly improve your diabetes management.*
- *The indirect benefit will probably be:*
  - *The research community, both medical and behavioural sciences, could benefit from a better understanding of the influences of diabetes management, as well as effective interventions that could possibly improve the management of diabetes.*
  - *The cost of not managing diabetes well could be reduced, resulting in savings for individuals (less hospitalisation, medical expenses, less time off from school), and the community at large (more healthy members that can contribute to improving society).*

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

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

Probable/possible risks/discomforts	***Strategies to minimize risk/discomfort***
Because you will spend about one hour 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 with a low carb snack and bottled water) about half way through the interview.
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.	After the interview, we will ask you if you felt any feelings of discomfort or stress while we had the interview with you or thereafter. If you then tell us that doing the interview with us made you feel uncomfortable or stressed, we will call you the next day to hear if you are still

	feeling the same way. If not, we will thank you for your participation in the research project and wish you well. However, if you are still feeling uncomfortable or stressed, we will arrange one free session with Rosemary Flynn (a registered clinical psychologist) who can help you with the feelings of discomfort or stress which you felt due to doing the interview with us.
We will be using your HbA1C results; this will show us how well you manage your diabetes. We will, however, not be doing these tests ourselves, but get the results from your medical record at the CDE with your permission.	We will not be drawing blood or doing any other tests that need us to hurt you physically. We will ask for your permission, in writing, to get 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 having 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.
In this study we will be asking you how well you manage your diabetes, which is also measured by the HbA1C test. Although we will not be talking about this result, you may be worried that we will judge you based on that result, or think less of you based on how well (or not) you manage your diabetes.	Living with diabetes can be difficult and we will treat every person that is willing to share their experience, with respect. We will not discriminate against any person based on how well (or not) they manage their diabetes. If at any stage you feel uncomfortable talking about your feelings, please let the researchers know so they can help you identify a psychologist in your region and arrange an appointment for you.
Living with diabetes may cause you to feel that you are different from your friends and that you feel you do not belong in the same group as your friends.	As part of thanking you for taking part in this study, we will give you a certificate. Each time you share your experiences with us or take part in another phase of the study, we will give you a sticker to paste on the certificate. Receiving this may lead to you feeling that you belong to a special group and that your opinions are important.
Living with diabetes, you may be worried that people learn about your diagnosis and start treating you	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

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differently.	know.
As we will be meeting with you at the CDE, it might cost you money to get there by car, bus, train or otherwise. You might also have to take time off from school to take part in this study.	In order to minimise transport and other costs, we will schedule the sessions with your normal visits to the CDE. We plan to visit the CDE during the afternoons and in school holidays to prevent you from being away from school unnecessarily.
The researcher will be asking questions about your diabetes management and things that influence it. If in the discussion that follows you share other situations where you were harmed or neglected, the researchers will have to share this with the right people to make sure you are safe.	We will not be asking for information on the times when you were harmed or neglected. If this kind of information is shared, the law expects us to tell the right people so you can be safe. We will ask you how you want to deal with it and let you know what the different things are that can happen, depending on what had happened, who was present and how serious the problem is.
This study is a long-term project (5-10 years). This means that you will be asked to participate (by doing an interview and participating in interventions) several times over the next few years.	You will be asked to take part (either participate in an interview or intervention) not more than once every two years. You also, at any time, have the right to no longer participate.

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

Who will have access to the data?

- *Anonymity (that is, how your results will be linked to your identity) will be managed by providing each participant with a code that will only be used for your information. As this is a long-term project, this code will be used every time you take part in a phase of the project. This code will be given to you once you have given us your permission, in writing. 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 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.*
- *Only the researchers will have access to the raw/obtained data. Although we work closely with the CDE, no member of the CDE, or your medical team will have access*

to the data. Data will be kept safe and secure by locking hard copies in locked cupboards in the researchers' offices and electronic data will be password protected.

- *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.*
- *As this is a long-term project, data will be stored for a minimum of 10 years.*

What will happen to the data?

The data from this study will be reported in the following ways: it will be written up in articles and research reports, and presented at conferences. 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.

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

No, you will not be paid for taking part in the study, but a bottle of still water and a low-carb snack will be provided. The researchers aim at conducting the interviews with your scheduled visits to the CDE. This means you do not have to travel additionally for the purpose of participating in the project. Hence there will be no additional costs involved for you or your parents/care-givers.

How will you know about the findings?

- As this is a long-term project, participants and/or parents/care-givers will receive (preferably via e-mail) a yearly progress report setting out the main findings thus far, as well as further opportunities for participation. Posters detailing the main findings will also be displayed at the CDE.
- Once we have worked through the word for word typed out document of your interview with us, we will call you and tell you what we think you were trying to tell us during the interview. By doing this, we want to make sure that we understood you correctly, whilst also giving you the opportunity to then tell us if we misunderstood what you were trying to tell us.

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) at 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 of adolescent

By signing below, I …………………………………..…………,agree to take part in a research study titled: Diabetes management: The lived experiences 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 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 entirely up to me and I have not been pressurised to take part.
- I understand that what my contribution (what I report/say/write/draw/produce visually) could 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 in any way.
- I may be asked to leave the study before it has been completed, if the researcher feels it is in my best interests, or if we do not follow the agreed-upon research plan.
- I agree to the CDE giving the researchers access to my 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:

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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**

Declaration by researcher

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

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

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

....

Signature of researcher **Signature of witness**

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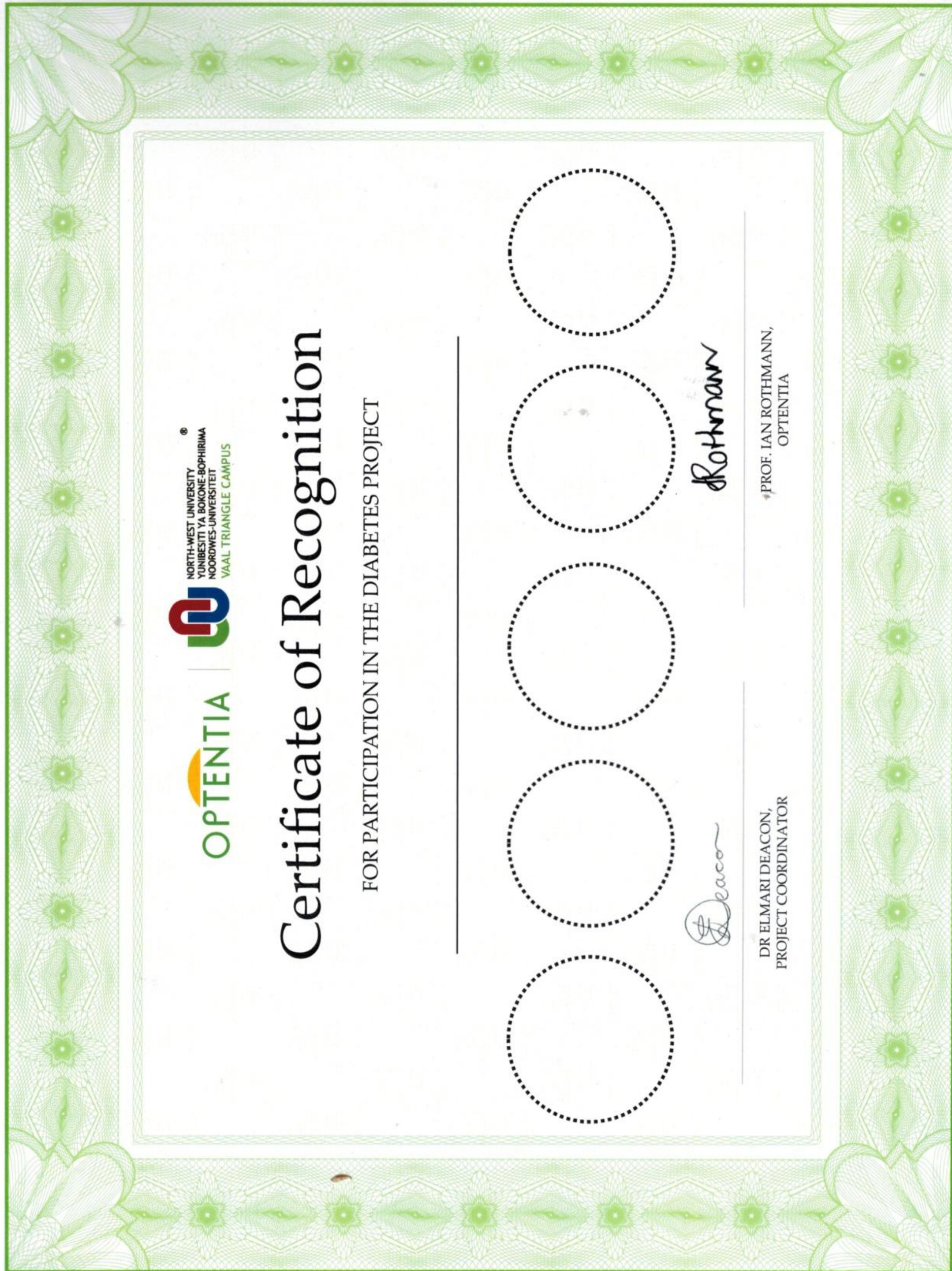
ADDENDUM F

Certificate of recognition of participation issued to participants


OPTENTIA
NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
VAAL TRIANGLE CAMPUS
Certificate of Recognition
FOR PARTICIPATION IN THE DIABETES PROJECT
DR ELMARI DEACON,
PROJECT COORDINATOR
PROF. IAN ROTHMANN,
OPTENTIA

ADDENDUM G

Diabetes management information leaflet for participants

Facing diabetes head on (www.healthline.com)

MANAGING DIABETES IN YOUR EVERYDAY LIFE

Don't get overwhelmed	Remain calm – realize the changes you'll have to make in your life and continue on with what you want to do with your life
Pay attention	Your body is changing, so it's important that you listen to what it's trying to tell you – responses to food, exercise and other factors that can affect your blood sugar level
Get moving	Don't sit around, there's no reason to be lazy – remember that being diagnosed with diabetes doesn't mean you're sentenced to a sedentary lifestyle, exercise becomes that much more important
Enjoy yourself	Be smart about your food choices – after enjoying small indulgences, manage your blood sugar levels and go about your normal routine
Make diabetes part of the routine	Don't let it rule your life – everyday we all wake up, brush our teeth, shower and perform other daily routines, caring for your diabetes should be part of the routine
Have a sense of humor	You must never be ashamed of your diabetes – instead of walking around feeling down, use humor when the subject of diabetes comes up
Face your fears	You have to face the fear of something new – confront your fears head on and live a normal, active life

THE BOTTOM LINE .....

Once you work diabetes management into your routine, there is no excuse for not doing everything else you want to do.

ENJOY LIFE – NO ONE ELSE IS GOING TO DO THAT FOR YOU!

LEARN MORE ABOUT DIABETES:

- **What do you want to know about diabetes?**
  http://www.healthline.com/health/diabetes

- **Living well with diabetes:**
  http://www.besthealthmag.ca › Best You › Diabetes
  www.diabetes.org › Newsroom › Press Releases › 2015
  www.nhs.uk/**Livewell**/**Diabetes**/Pages/**Diabetes**home.aspx
  www.cdc.gov/**diabetes**/ndep/new-beginnings.htm

- **Diet tips for diabetics:**
  www.**diabetes**.org/food-and-fitness/food/what-can-i-eat
  www.helpguide.org/articles/**diet**-weight.../**diabetes-diet**-and-food-tips.ht...
  www.mayoclinic.org/diseases.../**diabetes**/in.../**diabetes-diet**/art-20044295