

Young adult women's meaning making of living with Type 1 Diabetes

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PREFACE

- This mini-dissertation was written in article format in accordance with rule A4.4.2 of the North-West University.
- The editorial and referencing style of Sections I and III of this mini-dissertation is in accordance with the guidelines described and defined within the Publication Manual (6th edition) of the American Psychological Association (APA) style guide.
- The article in Section II of this mini-dissertation, titled "Young adult women's meaning making of living with type 1 diabetes", will be submitted for possible publication in the journal *Health & Psychology*.
- The author guidelines of *Health & Psychology*, provided in Section II of this mini-dissertation, stipulate adherence to the American Psychological Association (APA) editorial and referencing style.
- Prof. E. Deacon (supervisor) and Prof. E. van Rensburg (co-supervisor) are the co-authors of the article "Young adult women's meaning making of living with type 1 diabetes" in Section II of this mini-dissertation.
- The co-authors have provided consent for the submission of this article for examination purposes in partial fulfilment for a master's degree in Counselling Psychology.
- The page numbering in this mini-dissertation is consecutive, starting from the introduction.
- For publication purposes, the referencing in this mini-dissertation is restarted in every section.
- This dissertation was language edited by Dr. L. Hoffman.
- This mini-dissertation received a Turn-it-in report within accepted norms.

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To all the participants, thank you for your time and for sharing your journey with diabetes with me. You are so insightful, and I admire your strength.

DECLARATION STATEMENT

DECLARATION STATEMENT

I, Sylvia Kruger, declare that *Young adult women's meaning making of living with Type 1 Diabetes*, a mini-dissertation submitted in partial fulfilment of the requirements for the degree Magister Artium in Counselling 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.



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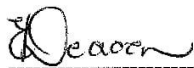
LETTER OF PERMISSION

LETTER OF PERMISSION

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

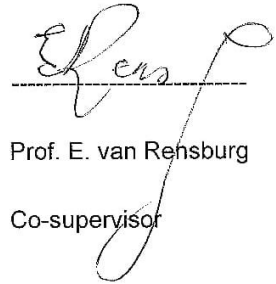
Young adult women's meaning making of living with Type 1 Diabetes'

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



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PROOF OF LANGUAGE EDITING

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DECLARATION

To whom it may concern

I hereby confirm that I have proofread and edited the language of the following dissertation, including the references.

Title of dissertation

Young adult women's meaning making of living with Type 1 Diabetes

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Lariza Hoffman

Kroonstad

5 August 2019

SUMMARY

Young adult women's meaning making of living with Type 1 Diabetes

Diabetes is described as an always-present disease and an ongoing process of adjustment. Diabetes has an impact on the emotional, psychological and social functioning of the young adult. According to the International Diabetes Federation (2008), diabetes is the fourth leading cause of death in developed countries. Managing type 1 diabetes, especially during young adulthood, is considered to be a complex process. The majority of research on diabetes in young adults is based on the reports of healthcare professionals and parents speaking on behalf of the person with diabetes, while the young adult has no 'voice'. Type 1 diabetes is primarily researched as a medical condition, and an examination of the subjective experience thereof is neglected. In spite of improvements in the treatment of type 1 diabetes, many young people do not achieve optimal outcomes.

The experiences of diagnosed young women have scarcely been investigated. It is thus argued that there is a need for a more personal focus, exploring the meaning making of young women with type 1 diabetes. The study focused on the experiences of women to keep the sample homogeneous.

The aim of this study was to explore young women's meaning making of living with type 1 diabetes, with the hope of informing clinical practice and improving support to people with diabetes. A qualitative research approach with an interpretative phenomenological analysis method was adopted. The research question of this study was: How do young adult women between the ages of 18 and 25 make meaning of living with type 1 diabetes?

A non-random, purposive sample was utilised, and the final sample consisted of six young women between the ages of 18 and 25, diagnosed with type 1 diabetes and attending the Centre for Diabetes and Endocrinology in Parktown. The meaning-making process was explored by means of in-depth, semi-structured interviews. The interviews were audio recorded and transcribed. The transcripts were analysed using interpretative

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phenomenological analysis, focusing on identifiable themes. The results of the analysis are considered in light of existing literature on meaning making, specifically Park and Folkman's (1997) meaning-making model.

From the findings, the following themes were identified: (1) the process of reappraising a life with diabetes; (2) the development of diabetes as a lifestyle; and (3) meanings made. The study demonstrates the importance of meaning making in living with type 1 diabetes. Recommendations in this study include the inclusion of a holistic approach in diabetes care.

Keywords: type 1 diabetes, meaning making, young adults, women, qualitative research, interpretative phenomenological analysis

OPSOMMING

Jong volwasse vroue se betekenismaking van 'n lewe met tipe 1 diabetes

Diabetes word beskryf as 'n altyd teenwoordige siekte en 'n deurlopende proses van aanpassing. Diabetes het 'n impak op die sielkundige, emosionele en sosiale funksionering van die jong volwassene. Volgens die Internasionale Diabetes Federasie (2008) is diabetes die vierde hooforsaak van sterftes in ontwikkelde lande. Die bestuur van tipe 1 diabetes, veral tydens die jong volwasse jare, is 'n komplekse proses. Die meeste navorsing oor diabetes in jongmense is gebaseer op die verslae van ouers en gesondheidswerkers wat namens die persoon met diabetes praat, terwyl die jong, ontluikende volwassene geen 'stem' het nie. Tipe 1 diabetes word hoofsaaklik as mediese toestand nagevors, terwyl ondersoek na die subjektiewe ervaring afgeskeep word. Ten spyte van verbeterings in die behandeling van tipe 1 diabetes, bereik baie jongmense nie optimale uitkomst in hierdie verband nie.

Weinig ondersoek is gedoen na die ervarings van gediagnoseerde jong vroue en daar word aangevoer dat daar 'n behoefte is aan 'n meer persoonlike fokus wat die betekenismaking van jong vroue met tipe 1 diabetes ondersoek. Die studie het gefokus op die ervarings van jong vroue ten einde die steekproef homogeen te hou.

Die doel van hierdie studie was om jong vroue se betekenismaking van die lewe met tipe 1 diabetes te verken, met die hoop om die kliniese praktyk in te lig en ondersteuning aan mense met diabetes te verbeter. 'n Kwalitatiewe navorsingsbenadering met 'n interpretatiewe fenomenologiese ontledingsmetode is aangeneem. Die navorsingsvraag van hierdie studie was: Hoe maak jong volwasse vroue tussen die ouderdomme 18 en 25 betekenis van die lewe met tipe 1 diabetes?

'n Nie-ewekansige, doelgerigte steekproef is gebruik en die finale steekproef het bestaan uit ses jong vroue tussen die ouderdomme van 18 en 25, gediagnoseer met tipe 1 diabetes en wat die Sentrum vir Diabetes en Endokrinologie in Parktown besoek. Die betekenismakingsproses is ondersoek deur middel van deurtastende onderhoude. Die

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onderhoude was per oudioband opgeneem en getranskribeer. Die transkripsies is ontleed met behulp van interpretatiewe fenomenologiese ontleding, met die fokus op identifiseerbare temas. Die resultate van die ontleding word beskou in die lig van bestaande literatuur oor betekenismaking, meer spesifiek Park en Folkman (1997) se model van betekenismaking.

Vanuit die bevindinge is die volgende temas geïdentifiseer: (1) die proses om 'n lewe met diabetes te heroorweeg; (2) die ontwikkeling van diabetes as 'n lewenstyl; en (3) betekenis gemaak. Hierdie studie toon die belangrikheid van betekenismaking in 'n lewe met tipe 1 diabetes. Aanbevelings in hierdie studie sluit die insluiting van 'n holistiese benadering in diabetisversorging in.

Sleuteltermes: tipe 1 diabetes, betekenismaking, jong volwassenes, vroue, kwalitatiewe navorsing, interpretatiewe fenomenologiese ontleding

Section I: Introduction and Rationale

1.1 Structure of the Research

This mini-dissertation comprises three sections. Section I (current section) is the problem statement, literature review and methodology. Section II contains the article. The last section, Section III, is a critical reflection by the researcher on her study, together with an overview of the contributions and wider applications of the study.

1.2 Introduction

The first part of Section I of this mini-dissertation outlines the problem statement and orientation of the current study. This is followed by a literature review, in which the following concepts are discussed: type 1 diabetes; self-management of diabetes; young adults living with diabetes; meaning; and previous research conducted. A literature review related to the topic was done to critically evaluate the existing knowledge about type 1 diabetes and to identify gaps within current research. EbscoHost and health databases, including CHINAL, Academic Search Premier, and PsychInfo were used to conduct the literature review. The researcher also conducted an internet search on Google Scholar. The following keywords were used: *diabetes; type 1 diabetes; young adults; emerging adults; meaning; meaning making; sense making; self-management; qualitative research; and interpretative phenomenological analysis.*

Lastly, the research methodology employed in this study is described in detail with reference to the paradigm, research design, research aims, research question, participants, data analysis; and quality in qualitative research. This section is concluded with the ethical considerations relevant to the study.

1.3 Problem Statement and Orientation

Viewing diabetes as a strictly medical phenomenon denies the full impact type 1 diabetes has on the lives of people with diabetes (Cruz, 2014) as diabetes affects, and is affected by, every part of normal life. The psychological, emotional, and social functioning of

the young adult is affected by type 1 diabetes (Daneman, Frank, & Perlman, 2002) and has an impact on the meaning in life that the person experiences (Segal, 2016).

Diabetes is known as a 'silent killer' (Tattersall, 2009, p. 185), with the worldwide prevalence of type 1 diabetes increasing (International Diabetes Federation, 2017). The International Diabetes Federation (2008) indicates that diabetes is the fourth leading cause of death in developed countries and the leading cause of death among woman in South Africa (Statistics South Africa, 2016). However, type 1 diabetes is a physiological condition that requires intensive daily self-management to decrease the risk of complications (Carel & Levy-Marchel, 2008) that can lead to decreased quality and length of life (Funnel & Anderson, 2004).

Type 1 diabetes is primarily researched as a medical condition, and an examination of the subjective experience thereof is neglected (Cruz, 2014). Although the practical aspects of type 1 diabetes self-management have received increased attention in recent years, it is necessary to improve the understanding of the experiences of emerging adults as they make sense of their medical condition. Type 1 diabetes is described as an 'always-present disease' and an ongoing process of adjustment (Stuckey & Tisdell, 2010, p. 43). Managing type 1 diabetes, especially during late adolescence and young adulthood, is a complex process that adds additional challenges to development (Robinson, 2015). Young adults with type 1 diabetes experience competing life demands and a decrease in parental involvement in diabetes care. As a result, adherence to treatment and glycaemic control may decline (Garvey et al., 2016).

The experiences of diagnosed young woman have scarcely been investigated (Foster, 2009). Most research on diabetes in young people is based on the reports of parents and healthcare professionals speaking on behalf of the person with diabetes (Foster, 2009), while young emerging adults have largely been excluded from research. Further exploration of the

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experience of diabetes self-management during the transitional stage between adolescence and early adulthood is therefore needed (Willemse, 2018).

Focusing only on women is motivated by studies indicating gender differences in the management of type 1 diabetes (Kay, Davies, Gamsu, & Jarman, 2009). Rubin and Peyrot (1999) report that health-related quality of life is better among men with type 1 diabetes than among women. Women, in general, have poorer glucose control, resulting in more complications (Kay et al., 2009), and they report more feelings of anxiety and depression related to diabetes and poor glycaemic control (La Greca, Swales, Klemp, Madigan, & Skyler, 1995; Larsen, 2016). Women with type 1 diabetes therefore display a higher risk of diabetes-related complications than men (Kay et al., 2009; La Greca et al., 1995). This study therefore focused on the experiences of young women with type 1 diabetes in an attempt to narrow the gap and to inform effective, gendered treatment plans.

Meaning making is an important aspect of adjusting to stressful life events (Park, 2013), such as being diagnosed and living with type 1 diabetes. In the context of this study, meaning refers to comprehension and sense making (Steger, Oishi, & Kashdan, 2009). Diabetes can cause young adult women to lose their sense of meaning by being exposed to the stressful process of managing diabetes (Willemse, 2018). The meaning-making process is an important aspect of adjusting to living with diabetes and can result in a new, normal way of living with the disease (Willemse, 2018).

The focus of the study was therefore on exploring how young adult women with type 1 diabetes make meaning of living with diabetes. To contextualise the study, a discussion of type 1 diabetes will focus, firstly, on the definition of type 1 diabetes, the management thereof, the implications for young adult women living with type 1 diabetes, and lastly, the importance of meaning within the context of type 1 diabetes.

1.4 Type 1 Diabetes

There are two types of diabetes, namely type 1 diabetes and type 2 diabetes (Daneman et al., 2002; World Health Organisation, 2016). Type 1 diabetes is a chronic autoimmune disease where not enough insulin is produced in the body (Daneman et al., 2002). Type 1 diabetes is a lifelong medical condition (Holt & Hanley, 2012). It is usually diagnosed during or near puberty but can emerge at any stage of life (Tuomilehto, 2013). The insulin-producing beta cells in the pancreas are attacked and destroyed by the immune system, and as a result, the pancreas ceases to produce the hormone insulin (Holt & Kumar, 2012). Insulin is essential for converting glucose into energy. Without sufficient insulin, glucose builds up in the blood and instead of using the glucose, the body turns to breaking down fat reserves for energy. This leads to high blood sugar and can cause the chemical imbalance of ketoacidosis, which can be life-threatening. Type 2 diabetes is also known as 'non-insulin-dependent diabetes', which mostly develops during middle age (Van der Merwe, 2015). Type 2 diabetes is a metabolic disorder and is primarily characterised by high blood glucose (Centre for Diabetes and Endocrinology, 2018). It is often, but not always, associated with obesity, which can cause insulin resistance and increased glucose levels. People diagnosed with type 2 diabetes can often initially manage the medical condition through a healthy lifestyle but will later require oral medication or insulin injections (International Diabetes Federation, 2017).

In this study, the focus was on type 1 diabetes. Type 1 diabetes is most commonly diagnosed in children and adolescents (World Health Organisation, 2016) and represents about 5 to 10% of people living with diabetes (Holt & Hanley, 2012). Before the invention of the treatment, insulin, in 1921, type 1 diabetes was considered a death sentence (Holt & Kumar, 2012). Exogenous insulin, in the form of multiple daily injections or an insulin pump, is essential to keep sugar levels within normal limits and, ultimately, to sustain life (World Health Organisation, 2016). In 2016, 25 225 South Africans died from diabetes (Statistics South Africa, 2016).

1.5 A Brief History of Diabetes

Symptoms of diabetes have been recorded from as early as 400 BC. These symptoms were recognised as a deadly and devastating disease. Although the symptoms were recognised, physicians were powerless to treat the disease. The term 'diabetes' comes from the Greek word for 'to run through' (Ali, 2011; Jacek, Anil, Parini, & Leonid, 2010). In 1776, when Matthew Dobson discovered that the sweet taste of urine from people with diabetes was due to sugar in the urine, the word 'mellitus', meaning honey, was added to the name of the disease (Jacek et al., 2010). Diabetes mellitus thus means 'the passing through of honey-sweet urine' (Tripathy, 2012). An early method of diagnosis was to pour urine on the ground, and if ants moved to the urine, diabetes was confirmed (Daneman et al., 2002).

In 1788, Thomas Cawley found a link between diabetes and the pancreas (Jacek et al., 2010). In 1848, a urine glucose test was developed to measure glucose in urine and to diagnose diabetes. During this time, the prognosis was extremely poor, as no treatment was available (Daneman et al., 2002). Low-calorie diets prolonged the lives of people with diabetes but left them fragile and near starvation. Until 1921, diabetes was considered a death sentence, and most people with the illness would die due to diabetic ketoacidosis (Holt & Hanley, 2012).

The causes of type 1 diabetes are not yet well understood. It is hypothesised that genes and environmental factors contribute to the destruction of beta cells in the pancreas (Holt & Hanley, 2012; World Health Organisation, 2016). Before a diagnosis of diabetes, most people have a short illness along with the 'classic triad of thirst', consisting of excessive thirst, excessive urination, and weight loss. Fatigue, urinary tract infection, dehydration, drowsiness, blurred vision, and diabetic ketoacidosis can also occur (Holt & Hanley, 2012).

The discovery of insulin in 1921 by Frederick Banting and Charles Best dramatically changed the outlook for people with diabetes. 'With insulin the stone was rolled away, and diabetes became a matter of the quality of life, not the speed of death' (Bliss, 1982, p. 248).

Diabetes was no longer a fatal disease, as a treatment had been discovered. However, insulin is not a cure. The hormone, insulin, can be used as a treatment for diabetes, and high blood sugar levels can drop to normal levels (Jacek et al., 2010). Despite great advances in diabetes care, diabetes remains a multifaceted, complex disease, affecting all aspects of daily life (Daneman et al., 2002).

1.6 Management of Type 1 Diabetes

Diabetes requires intensive management, responsibility and behavioural control (Daneman et al., 2002). It is recognised as one of the most 'emotionally and behaviourally challenging and demanding chronic illnesses' (Brown, 2014, p. 133). Effective self-management of type 1 diabetes can reduce the risk of developing complications such as cardiovascular disease, nerve damage, kidney failure, and vision loss (Carel & Levy-Marchel, 2008; World Health Organisation, 2016). Self-management is defined as the measures individuals can take to cope with their chronic disease in collaboration with their healthcare team (Funnell & Anderson, 2004). Successful self-management requires the acquisition of particular skills and behaviours that assist individuals with managing their medical condition physically and psychologically (Daneman et al., 2002). It includes strict glycaemic control, insulin injections or insulin pump therapy, and following a specific diet. As blood glucose levels can deviate, people with diabetes have to self-monitor their glucose levels regularly and adjust their insulin usage accordingly (Dhada, Blackbeard, & Adams, 2014). For example, under-dosing or omitting insulin can lead to hyperglycaemia (abnormally high blood glucose levels) and result in diabetic ketoacidosis. When diabetic ketoacidosis is present, the body will break down fat reserves and produce ketones. Hypoglycaemia (abnormally low blood glucose levels) can be caused by excess insulin, exercise, or under-eating. Hypoglycaemia can lead to shakiness, sweating, and in severe cases, to a coma (Daneman et al., 2002; International Diabetes Federation, 2017; National Institute for Health and Care Excellence, 2016).

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A successful self-management plan involves people with type 1 diabetes being in control of and responsible for the daily self-management of diabetes. In addition, a successful self-management plan usually fits the individual's goals, lifestyle, and the medical condition of diabetes (Funnel & Anderson, 2004; Holt & Hanley, 2012). Diabetes can be objectively measured by HbA1C (glycosylated haemoglobin), which gives an indication of diabetes management over approximately three months. The International Diabetes Federation (2011) and the International Society for Paediatric and Adolescent Diabetes (DiMeglio et al., 2018) consider an HbA1C of 7.5% or below as well controlled for young adults.

Viewing diabetes as a strictly medical phenomenon denies the full impact diabetes has on the lives of people with diabetes (Cruz, 2014). The medical model does not adequately inform regarding the realities of living with a chronic condition where individuals have to take responsibility for their health on a daily basis (Wolpert, 2001). Moreover, the traditional medical model proposes a self-management plan that is designed to fit diabetes to the person with diabetes and is not adjusted to fit the individual's goals, culture, and lifestyle (Funnel & Anderson, 2004). Furthermore, this model is criticised for describing the endpoint or desirable state, but not taking the process of adjustment to diabetes into account (Foster, 2009). A collaborative model is viewed as a more effective way to manage chronic conditions. In this model, the individual as a whole becomes the focus, rather than just the person's diabetes (Funnel & Anderson, 2004). To meet the ever-changing and complex demands of living with diabetes, a diabetes care team, consisting of a doctor, diabetes educator, dietitian, podiatrist, and social worker or psychologist, is recommended (American Diabetes Association, 2016; Daneman et al., 2002). The American Diabetes Association (2016) suggests a patient-centred approach, where the patient is actively involved in and committed to the management of diabetes. As most diabetes care occurs at home, successful self-management requires the acquisition of specific skills and behaviours that assist individuals to manage their medical condition physically and psychologically (Daneman et al., 2002). Therefore self-management

includes optimising well-being and preventing complications by maintaining tight glucose control (Rasmussen, Ward, Jenkins, King, & Dunning, 2011).

The well-being of the person with type 1 diabetes largely depends on successful self-management (Abualula, Jacobsen, Milligan, Rodan, & Conn, 2016; Daneman et al., 2002). Within the context of diabetes, coping with diabetes and managing diabetes have major impacts on the individual's life, affecting both the physical and psychological well-being of the person (Abualula et al., 2016). Stress levels, coping abilities, and adjustment influence the self-management potential of a person with diabetes and, consequently, his or her quality of life. It is crucial for healthcare professionals to have an understanding of the social, cognitive, and emotional factors to best assist young adults with the self-management of type 1 diabetes (Rasmussen et al., 2011).

Successful diabetes management is influenced by the individual's understanding of diabetes, making meaning of life events, social support, motivation, coping, and problem solving (Alea & Bluck, 2013; Schiotz, Bogelund, Almdal, Jensen, & Willaing, 2011).

1.7 Young Adults Living with Type 1 Diabetes

The self-management of type 1 diabetes changes throughout life, along with age and physical and psychological development (Swift, 2004). With every new developmental phase, a different aspect of living with diabetes needs to be integrated into daily life (Segal, 2010). Following a developmental approach across the lifespan, it is assumed that the self-management of diabetes requires a transition from dependent care to self-care (Segal, 2015). A study conducted by Rasmussen et al. (2011) indicates that being diagnosed is a significant transition for people with diabetes, because it requires a restructuring of the lives of both the people with diabetes and their families. This study indicates that people with diabetes constantly adjust their management of diabetes according to life transitions, for example entering the workforce or leaving home. From a psychological perspective, research indicates that people with diabetes are twice as much at risk of developing depression. This is due to

the stress of living with a chronic condition, feeling 'different', and living with the fear of developing diabetes-related complications (Buchberger et al., 2016; Young & Unachukwa, 2012).

Self-management is related to age and the cognitive maturity required to cope with self-management (Karlsson, Arman, & Wikblad, 2008). For example, Erikson (1982) states that adolescence is a period in which the childhood position of dependence changes to increased autonomy. During this period, a decline in parental involvement takes place. Piaget focused on cognitive development of the developing stages in a person's life (Louw & Louw, 2007). During the formal-operation stage, an important milestone is the acquisition of abstract reasoning, which allows the young person to begin to understand the implications and self-management of type 1 diabetes (Daneman et al., 2002). It is suggested that during the formal-operational stage, the young individual reflects more on experiences and considers future possibilities.

Building on Erikson's psychosocial theory, Arnett (2000) proposes that young adulthood, ranging from 18 to 25 years of age, is known as 'emerging adulthood'. Emerging adulthood represents a transition from adolescence to young adulthood, developing from a state of dependence to full independence. This phase is characterised by life transitions, such as leaving high school, entering a tertiary institution, or moving out of the parental home (Lindell, Campione-Barr, & Killore, 2017). Arnett (2000) suggests that during the transitional phase, young adults usually take on increased responsibility and develop self-awareness, even though they may not always feel like adults. Both developmental and social factors, such as identity exploration, employment, moving out of the parental home, and the influence of peers, may have an impact on the successful self-management of type 1 diabetes (Lee, 2013). A further problem is that during this uncertain phase, many young people engage in high-risk behaviour, such as smoking and drinking, and are more susceptible to the negative influence of peers. Both developmental and social factors can act as barriers to the successful self-

management of type 1 diabetes (Lee, 2013). As a result, during emerging adulthood, glycaemic control tends to deteriorate (Chiang, Kirkman, Laffel, & Peters, 2014). In addition to this developmental phase, differences exist in the management and experiences of type 1 diabetes between men and women (Kay et al., 2009). Rubin and Peyrot (1999) report that health-related quality of life is better among men with type 1 diabetes than among women. In general, women have poorer glucose control, resulting in more complications (Kay et al., 2009).

Several studies (e.g., Chew, Khoo, & Chia, 2015; Pyatak et al., 2017; Vaccaro, Exebio, Zarini, & Huffman, 2014) have found that support from peers and family can have a positive impact on living with diabetes and adherence to treatment. During young adulthood, creating a personal meaning of diabetes is an important task for young adults living with diabetes (Chiang et al., 2014).

1.8 Meaning and Meaning Making

In recent years, research on meaning in life has increased, especially in the context of positive psychology (Wissing, 2014). The construct of meaning has been given a variety of definitions. Frankl (1964) views the primary motivational force of human beings to be the 'will to meaning' (p. 99). According to Frankl (1964), challenges add a deeper meaning to life. When a challenge acquires meaning, it is no longer viewed as unbearable, but becomes both a challenge and a goal in life. This theory assumes that all people have an inherent drive to discover personal meaning. Central to Frankl's (1964) theory is the idea that humans are free to choose and are responsible for the choices they make. Frankl (1964) states that meaning is unique and subjective to each individual. Life has meaning under all circumstances, and meaning is what guides our behaviour (Frankl, 1964). According to Frankl (1964), the search for meaning empowers humans to make sense of life events and move forward. It is implied, in the light of Frankl's theory, that people living with diabetes can decide how they will respond to living with diabetes, which will play a role in the outcomes of their treatment (Segal, 2016).

In agreement with Frankl (1964), Wong (2012) developed a meaning management model, in which acceptance stands central. Wong (2012) hypothesised that in order to experience meaning in life, one needs to accept life's challenges. In the context of this study, it is thus hypothesised that in order to experience meaning in life, women have to accept that diabetes will be a part of their lives.

Park and Folkman (1997) proposed a meaning-making model. This model postulates that individuals have a global meaning system or cognitive framework that assists them in interpreting experiences and motivating their behaviour. Global meaning refers to the individuals' view and general orientating system about the world and themselves (Park, 2013). Being diagnosed with a chronic condition can violate important global beliefs, for example the fairness and predictability of the world and one's sense of personal control (Jim & Jacobsen, 2008). Situational meaning is the meaning of a specific situation and consists of the initial appraisals of the situation (Park, 2013), for example being diagnosed with type 1 diabetes. Steger et al. (2009) describe purpose and comprehension as the basic components informing meaning. Purpose refers to that which is significant to the individual and to his or her experiencing life as meaningful.

When people face a stressful situation, such as the diagnosis of diabetes, they appraise the situation and ascribe meaning to it. According to the meaning-making model, distress will be experienced if there is a disagreement between the appraised meaning of the situation and the individual's global meaning (Park & Folkman, 1997). Discrepancies between global and situational meaning can be reduced by, for example, employing emotion-focused coping strategies. However, in a situation with low control, such as serious medical conditions, meaning making is often the most adaptive way to reduce discrepancies, as opposed to, for example, avoidance (Park, Folkman, & Bostrom, 2001).

Park (2013) proposes that the meaning-making model can be a useful theoretical framework for understanding phenomena and their interrelations within the field of health

psychology. The meaning-making model suggests that the degree to which a chronic condition is perceived as different from global beliefs will determine the extent to which the condition is experienced as distressing (Park, 2013). Meaning is present when an individual believes that an event makes personal sense and fits his or her pre-existing beliefs (Hicks & King, 2009). The model posits that efforts at meaning making are necessary for adjusting to serious medical conditions by helping individuals either assimilate the condition into their global beliefs before the condition or change their global meaning to accommodate the condition. A change in global meaning could include an adjustment of values, beliefs and cognitions (Lepore, 2001). Park (2013) advocates that the meaning-making model identifies the elements that should be examined in future research to better understand central processes of health and adjustment to chronic illness and to inform more effective interventions in order to promote health and well-being. In the current study, there was a focus on the meaning making of young adult women living with type 1 diabetes. According to the meaning-making model, efforts at meaning making are necessary to adjust to living with diabetes.

1.9 Review of Studies on Diabetes and Meaning

In line with research on meaning in life, an interest has developed in understanding the role of meaning in individuals' efforts to deal with serious life events, especially chronic conditions (Roussi & Avdi, 2008). Steger et al. (2009) found that the presence of meaning is strongly associated with well-being. Sharpe and Curran (2006) indicate that the search for meaning may facilitate adjustment to a chronic condition. They describe a search for meaning as involving two components, namely (i) finding order by incorporating the event (i.e., chronic conditions) into pre-existing beliefs; and (ii) finding a purpose by searching for goals that make life purposeful in spite of the chronic condition (Sharpe & Curran, 2006). The authors argue that a change in the appraisal of the event is needed and meaningfulness will occur when the new event is integrated into the individual's life. The construction of meaning is described as central to the experience of living with a chronic condition (Roussi & Avdi, 2008). The American

Diabetes Association (as cited in Chiang et al., 2014) recommends that during young adulthood, the topic of the personal meaning of diabetes should be addressed in order to adjust to living with diabetes. Willemse (2018) recommends that healthcare practitioners should assist young adults with exploring the meaning-making process and identifying goals and dreams that would provide the motivation required to adjust to and take responsibility for self-managing diabetes.

However, research on type 1 diabetes has been criticised for an over-reliance on quantitative research, to the exclusion of qualitative investigations. Paper-and-pencil methods, mostly completed by the parents and relevant healthcare professionals, have been extensively used to explore the experience of living with type 1 diabetes (Wallander, Thompson, & Alriksson-Schmidt, 2003). Consequently, the people who are directly affected by type 1 diabetes are not involved in voicing their own experiences (Foster, 2009; Gomes et al., 2018). A key limitation of this kind of research is that the measures are not sensitive enough to capture the quality and detail of experiences (Willig, 2013). Therefore an interpretative phenomenological analysis technique (IPA), which explores experiences and meanings (Smith, Flowers, & Larkin, 2009), is applicable to the topic. Furthermore, few studies have focused on women, in particular young adult women with type 1 diabetes (Foster, 2009).

In order to address the identified gap in research, increased attention has been paid to qualitative research regarding people experiencing type 1 diabetes. Carroll and Marrero (2006) used focus groups to investigate how diabetes influences adolescents' perceptions of quality of life. The authors concluded that type 1 diabetes can have an impact on the transition to independence.

Taken together, the literature indicates that people with a chronic condition, such as type 1 diabetes, find meaning in the context of their experience of the chronic condition. According to Cruz (2014), diabetes is a complex medical condition, and a gap exists in the knowledge of type 1 diabetes as a physical, medical condition and the lived experience of

people with type 1 diabetes. The meaning attributed to having type 1 diabetes is a neglected but essential component of managing diabetes, as the foundation of type 1 diabetes management begins with the individual's understanding and interpretation of diabetes (Anderson, 2006).

1.10 Aim of the Research

The study aims to explore in depth how young adult women make meaning of living with type 1 diabetes.

1.11 Research Question

The research question of the study was:

How do young adult women between the ages of 18 and 25 make meaning of living with type 1 diabetes?

1.12 Paradigm Perspective

The theoretical and paradigmatic point of departure makes the assumptions that are inherent in a study apparent (Willig, 2013). In the study, various young adult women described their subjective experiences of making meaning of living with type 1 diabetes. The researcher believes that multiple interpretations of the experiences of living with type 1 diabetes exist. Consequently, the researcher's point of departure is interpretivist. In this regard, although all of the participants are diagnosed with type 1 diabetes, a diversity of interpretations of their individual experiences of type 1 diabetes exists.

In the study, the experience of making meaning of type 1 diabetes was viewed from a phenomenological perspective and, more specifically, interpretative phenomenology. The IPA approach is concerned with the manner in which people derive meaning through their experiences. Within this approach, it is assumed that multiple realities exist for every person and that individuals construct meaning from their personal experience rooted in their reality (Smith et al., 2009). The IPA approach has the advantage of providing for an in-depth investigation of making meaning of type 1 diabetes. It suggests that experiences can be

understood by examining the meaning people ascribe to experiences (Smith et al., 2009). The framework for conducting the research was based on interpretative phenomenology, with a focus on how the participants experienced the meaning of living with type 1 diabetes.

The theoretical assumptions of interpretative phenomenology have an impact on methodological choices, which will be discussed in the next section. Phenomenology is both a philosophical approach to understanding the world and a way of gathering information (Smith et al., 2009). The analysis technique of IPA will be used. IPA assumes that participants can experience the same objective condition, in this case type 1 diabetes, in different ways (Willig, 2013). The interpretative aspect of IPA positions meaning making within experiences as central (Smith et al., 2009) and therefore fits within the researcher's epistemological position.

This study provides insight into young adult women's meaning making of diabetes. The researcher believes that this study has the potential to improve clinical practice by gaining a better understanding of how young people can be assisted to make meaning of living with diabetes. For example, the knowledge acquired from this study can enhance the understanding of how people make meaning of diabetes, which could potentially allow for more successful type 1 diabetes treatment regimes. The study promotes an emphasis on experience in order to gain a richer and more in-depth understanding of the phenomenon. This could potentially guide clinical practice and focus attention on how young women with type 1 diabetes can best be supported.

1.13 Research Methodology

1.13.1 Research approach and design.

The study entailed an analysis of existing literature and an empirical study. As implied in the research question, the study is a qualitative exploration of the meaning making of young adult women living with type 1 diabetes. Qualitative research is concerned with meaning and how people make sense of their experiences (Willig, 2013). The qualitative method of IPA was used to explore how young adult women make meaning of living with diabetes. This is

particularly useful in an in-depth investigation of experience, because it captures the 'quality and texture of individual experiences' (Willig, 2013, p. 9). Within this approach, the meaning making of the participant becomes central when the taken-for-granted or 'normal' is breached. A change in health represents such a breach and can lead the person to attend closely to the impact of such a health change on the sense of self (Smith et al., 2009). IPA is one of the most widely used qualitative methods in health psychology (Smith, 2011b). IPA is especially used where the topic under investigation is of existential importance and the issues are affectively laden (Smith et al., 2009). Thus IPA was viewed as a suitable method to investigate the meaning-making process of living with type 1 diabetes.

IPA is committed to exploring how 'people make sense of their major life experiences' (Smith et al., 2009, p. 1), and in this study, specifically to making meaning of living with a chronic medical condition. In the context of the study, IPA required the researcher's interpretation of young women's subjective meaning of living with type 1 diabetes (Smith et al., 2009). IPA allows for the description and understanding of the meaning-making process of individuals. Within IPA the interpretation of the researcher is viewed as an important aspect in understanding the meaning-making process. It can be classified as an idiographic approach. IPA views human beings as sense-making creatures; thus the accounts of participants will reflect their attempts to make sense of their experiences (Smith et al., 2009). IPA is especially useful for understanding the experience of health and illness, where participants are actively engaged in making sense of unexpected and significant things that happen to them (Smith, 2018).

1.13.2 Research context.

The study was conducted at the Centre for Diabetes and Endocrinology, Parktown, Johannesburg, South Africa. The research context is an urban suburb, characterised by a high socio-economic standard.

1.13.3 Participants.

IPA is concerned with understanding experiences in detail; as such, a small sample size was used. Three to six participants are considered a reasonable sample size for a student project using IPA (Smith et al., 2009), depending on when data saturation is reached. Therefore, three to six women participants between the ages of 18 and 25, diagnosed with type 1 diabetes for at least one year were recruited using purposive sampling. The number of participants depended on the number of participants who met the inclusion criteria and were willing to participate in the study.

Francis et al. (2010) state that if no new themes emerge in the last three interviews, data saturation has been reached. Data saturation is not considered a requirement of IPA research (Smith et al., 2009). However, it was viewed as beneficial to continue with data analysis until data saturation was reached and no new themes emerged.

Purposive sampling maximises the understanding of the phenomenon by selecting participants that are 'information rich' (Patton, 2002, p. 230) and for whom the research question will be relevant (Smith et al., 2009).

The inclusion criteria of the study were as follows:

- Based on Arnett's (2000) theory of emerging adulthood, young women between the ages of 18 and 25 were included in this study. The participants had to be between the ages of 18 and 25 years, thus being classified under the emerging adulthood or young adulthood developmental group.
- The participants had to be female. The sample comprised only female participants as IPA literature recommends obtaining a homogenous sample (cf. Smith et al., 2009). As such, only female participants were recruited in order to make the results of such a small study meaningful. The use of three to six participants made it possible to identify commonalities, differences, and contradictions in the participants' experiences of the same phenomenon – type 1 diabetes. In addition, as has previously been outlined,

differences exist in the management and experiences of type 1 diabetes between male and female individuals (Kay et al., 2009; Rubin & Peyrot, 1999).

- Only participants who could communicate well in English or Afrikaans were recruited, as proficiency in expressive language and the language of the researcher is an important part of qualitative research (cf. Willig, 2013). This decision was made as there was a concern that the richness and meaning of language might get lost in translation. IPA literature (cf. Smith et al., 2009) recommends that one language should be used within a single study in order to capture the quality and texture of the data.
- The participants had to be diagnosed with type 1 diabetes for at least one year. The inclusion criterion of a minimum of one year's experience omitted participants recently diagnosed with type 1 diabetes who might still be grieving over the diagnosis and might not yet have experienced the full extent of the complications of living with type 1 diabetes (Cruz, 2014). When an experience is part of a person's life for a long period of time, it becomes more likely that a person can reflect on the meaning of the experience (Roussi & Avdi, 2008; Smith et al., 2009).
- The participants had to be patients at the Centre for Diabetes and Endocrinology, Parktown, in order to minimise treatment variables, in line with IPA literature (cf. Smith et al., 2009). The Centre for Diabetes and Endocrinology is a private multi-specialist centre that provides overarching diabetes care to people from all backgrounds and across South Africa.

The exclusion criteria of the study were as follows:

- Individuals undergoing psychotherapy at the time of the research were excluded. This exclusion criterion was decided on as a precautionary measure in order to avoid interference with the therapy process.
- Individuals with another chronic condition were excluded to ensure homogeneity, as another chronic condition could have an impact on the management of diabetes.

- Individuals who were friends of or familiar with the researcher were excluded.

Table 1

Characteristics of the Non-random Purposive Sample Utilised in the Study

Pseudonym	Age	Time since diagnosis	Employment status
Jenny	25	15 years	Dietitian
Sarah	21	12 years	Education student
Hope	22	8 years	Bookkeeper
Carlia	21	1 year	Small business owner
Karen	25	16 years	Intern medical doctor
Nina	25	15 years	Law student

1.13.4 Research procedure.

The researcher obtained permission to conduct the study from the relevant parties – Optentia Research Entity, the Centre for Diabetes and Endocrinology, and the Health Research Ethics Committee of the North-West University (see Annexures A and B).

Potential participants were invited to take part in the study by means of an information leaflet at the Centre for Diabetes and Endocrinology, Parktown on their normal visit there. Prof. David Segal acted as the gatekeeper and mediator and distributed the leaflet. The leaflet included information on the project and an invitation for participants to provide their contact details to be contacted by the research team. It was emphasised that participation was entirely voluntary. Prof. Segal also informed the participants that he was not part of the data collection or analysis and that they were under no obligation to participate in the study.

Prof. Segal also stated that participation or non-participation was independent of the care received at the Centre for Diabetes and Endocrinology. After completion of the form, Prof. Segal forwarded the information to Prof. Elmarie Deacon (principle researcher). Prof. Deacon was responsible for making the first contact (via email or a telephone call) with potential

participants and doing the screening of all of the participants. No interviews were conducted by Prof. Deacon, as such, any possible influence on the results of the study was prevented. All communication relevant to the study was handled by Prof. Deacon, ensuring both consistency and quality of screening.

The potential participants were screened according to a set of pre-determined questions. The screening questions were as follows: (1) How old are you? (2) When were you diagnosed (with diabetes)? (3) Are you a patient at the Centre for Diabetes and Endocrinology, Parktown? (4) Are you willing to be interviewed in English or Afrikaans? (5) Are you diagnosed with any other chronic medical conditions? What and how does this impact your diabetes management? (6) Are you currently receiving psychotherapy?

Based on the answers to the screening questions, a participant either qualified or did not qualify to take part in the study. Potential participants who did not qualify were thanked for their time and were given the option of receiving the findings of the study after publication.

A meeting was then arranged with the participants who qualified and indicated that they would like to participate. At this meeting, informed consent was obtained by an independent person. The independent person had received training on informed consent and had previously been part of administering informed consent for research studies. The person was not a part of the research or medical team. Potential participants were given the informed consent documentation at least two weeks prior to data collection to ensure that they made an informed choice (Annexure C). The participants had the opportunity to ask questions about the study to Prof. Deacon (as indicated on the Participant Information Leaflet and Informed Consent Form). The participants also had the option to sign the informed consent form on the same day as the interview, ensuring that they would only have to come to the Centre for Diabetes and Endocrinology once.

As stated earlier, the interviews took place at the Centre for Diabetes and Endocrinology. Data were collected from the semi-structured interviews. After the data had

been collected, the interviews were transcribed, analysed and interpreted using the steps as outlined in IPA literature (cf. Smith et al., 2009). The data were then written up. The participants will receive feedback on the research findings.

1.13.5 Data collection.

Consistent with interpretative phenomenology, data were collected through the use of semi-structured interviews (cf. Smith et al., 2009; Smith, 2011a). Semi-structured interviews were carried out with participants and was audio-taped and later transcribed. This facilitated a more informal conversation, allowing participants to share their experiences in their own words (cf. Smith et al., 2009). The topic of study was viewed as potentially sensitive in nature for some participants. As such, semi-structured interviews with open-ended questions were viewed as a suitable data collection technique, providing some prompts but allowing participants to freely elaborate on their experiences (cf. Willig, 2013).

Open-ended and non-directive questions (Annexure D) were asked as these encouraged participants to share their individual experiences of meaning making of type 1 diabetes. When phrasing the questions, leading questions were avoided, and care was taken to avoid making assumptions about the participants' experiences (see 1.14 Measures to Enhance the Quality of Qualitative Research).

An interview schedule was compiled in line with the research question and aim. In addition, the interview schedule helped to avoid difficulties with the phrasing of sensitive questions and to provide starting points for answering the research question. The interview schedule was developed based on relevant IPA literature and discussions with the research supervisors. However, the schedule was used in a flexible manner to allow the researcher to modify questions and ask probing questions during interaction with the participants to gain a deeper understanding of the participants' responses (cf. Smith et al., 2009).

The interviews took place at the Centre for Diabetes and Endocrinology, as the participants were familiar with the setting and, consequently, they likely felt more comfortable

to describe their experiences in a familiar setting. The participants were informed that a psychologist was available for debriefing if required, which would be free of charge. All of the interviews were transcribed.

The interviews were conducted by the researcher herself. The researcher had obtained the necessary academic training regarding interviewing in her honours psychology research module (SLK 764: Research Methodology). The researcher conducted herself in a professional manner, as she is bound to do by the Health Professions Council of South Africa board, where she is currently registered as a master's student in Counselling Psychology. The researcher completed the relevant ethical modules (TRREE online training programme). The researcher worked under the supervision of her study leader, Prof. Deacon, who holds a master's degree in Clinical Psychology and her co-supervisor, Prof. Van Rensburg, who holds a master's degree in Counselling Psychology.

1.13.6 Data analysis.

The interview transcripts were analysed using the principles of IPA, as outlined by Smith et al. (2009). These principles are outlined below.

1. Reading and re-reading. The researcher listened to the audio recordings after transcription. Every individual transcript was read and re-read. The initial reading and re-reading were done in order for the researcher to become familiar with the participants' accounts. During this stage, the researcher made notes on her reaction to the text.

2. Initial noting. Step 1 and 2 are linked. While reading and re-reading the transcripts, the researcher made interpretative notes in the left margin. The transcripts were worked through line by line. The notes included a summary of the content of what was said, language usage, and the researcher's reaction to the text. Connections, similarities, and contradictions were included in the notes. Through this process, a growing familiarity with the participant's accounts was ensured.

3. *Developing emergent themes.* During the third stage of analysis, the researcher identified themes within the text and assigned a title to each emerging theme. The themes were recorded chronologically in the right margin. Some psychological terminology was used to label themes.

4. *Searching for the connections across emergent themes.* The themes identified were studied in relation to one another and were clustered together, providing a meaningful structure. These clusters were given labels, creating superordinate themes. During this stage, some of the themes identified were discarded, depending on the research question. The researcher ensured that clusters of themes identified were grounded and reflected in the transcripts. The researcher returned to the transcripts throughout the analysis phase.

5. *Moving to the next case.* Step 1 to 4 was repeated for each participant's transcript. At this stage, each transcript was considered in isolation in order to do justice to the individuality of the participants.

6. *Looking for patterns across cases.* During the final stage of analysis, a summary table was made of the identified themes across all of the transcripts, including quotations and keywords that provided substantiation for each theme. Lastly, the individual transcripts were integrated to form a list of master themes (cf. Smith et al., 2009). The data analysis took place under the supervision of the study leader. The master theme titles were intended to provide a coherent framework to understand the meaning that young adult women attach to type 1 diabetes.

1.13.7 Writing up.

The final report is written in narrative form, as the meanings of type 1 diabetes are discussed. The results of the research are structured around the identified master themes, supported by verbatim extracts from the participants (cf. Smith et al., 2009). For quality purposes, a detailed description of the demographics of the participants, the context, the data collection techniques, and the methods of analysis is included. This is discussed in relation to

existing theories and literature (cf. Willig, 2013). Smith (2011b) indicates that after an IPA analysis has been conducted, it should be related to the literature. The literature can be theory or health psychology theory. In this study, the analysis is discussed in relation to the literature on meaning making.

Care was taken to ensure a distinction between what the participants said and the researcher's interpretation thereof. The identified themes can be utilised as a starting point for future research and to gain a deeper understanding of how young women make meaning of diabetes.

1.14 Measures to Enhance the Quality of Qualitative Research

1.14.1 Reflexivity.

IPA is vulnerable to researcher bias (Willig, 2013), therefore a section on self-reflexivity is included to promote credibility. Reflexivity refers to the idea that a researcher's own beliefs and assumptions may influence the way he or she engages with and makes sense of the data (Willig, 2013). Throughout the research process, attention was given to the researcher's possible influence on the research process and outcomes.

Personal interest led the researcher to ask the research question because the researcher has herself been diagnosed with type 1 diabetes. This lens might be helpful for understanding the topic under investigation but might also distort the data with preconceived ideas. To ensure that the data represented the participants' true accounts, a personal journal was completed throughout the process and the researcher regularly engaged in reflective discussions with her supervisors. This enabled the researcher to be constantly mindful of her own assumptions, emotions, views, and personal biases about the research topic (cf. Willig, 2013). The researcher actively kept the role of researcher and ensured that the data collected supported the interpretations and conclusions made in order to avoid possible bias. Throughout the analysis, the researcher returned to the transcripts to ensure that the data supported the emerging themes and were not influenced by personal biases. A co-coder was

also used. Moreover, following the researcher's data analysis, the research supervisors reviewed the analysis to enhance rigour. The steps taken to ensure the quality of the study are further discussed below.

Yardley (2008) presents four criteria by which the quality of qualitative research can be measured, namely sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

1.14.2 Sensitivity to context.

The sensitivity to context criteria was met in the study through consideration of the relevant literature and the context of the participants when the study was designed. The study demonstrated a sensitivity to the participants' accounts by including a large number of verbatim responses to support identified themes and give the participants a 'voice' in the study. This also provides the opportunity for the reader to verify the interpretations made (Smith et al., 2009; Willig, 2013).

In addition, the themes generated during the analysis are clearly motivated (cf. Willig, 2013). Sensitivity to context (Smith et al., 2009) was ensured by using semi-structured interviews with open-ended questions and allowing the participants to share their experiences. Furthermore, direct quotations from the participants were included to support the arguments.

1.14.3 Commitment and rigour.

Commitment refers to prolonged engagement with the topic and immersion with the data (Yardley, 2008). Commitment was shown in the treatment of the participants during data collection and the care taken in transcribing and analysing the participants' accounts (cf. Smith et al., 2009). Rigour was demonstrated by choosing a methodology and method that complement the aim of the study (cf. Willig, 2013). The researcher selected a homogenous group of participants for whom the research question was relevant. The analysis of the data was conducted thoroughly and systematically, following the steps as outlined by Smith et al. (2009). Verbatim quotes from the transcripts were included to support all interpretations. The

researcher aimed to be transparent throughout this process, detailing the stages of the research process and analysis.

1.14.4 Transparency and coherence.

Sincerity was aimed for through self-reflexivity, honesty, transparency, and data auditing (cf. Tracey, 2010). The analysis process was thoroughly checked by the research supervisors. Regular discussions were held with the supervisors to discuss differences of opinion and reasons for interpreting data in particular ways. This provided for alternative perspectives to be considered and reflecting on how the researcher's own assumptions and biases might influence the data (Foster, 2009; Smith et al., 2009).

1.14.5 Transferability.

Transferability enables others to generalise the transferable knowledge of a study to other contexts (Keating, Eales, & Phillips, 2013). In discussing the results, the researcher stated the extent to which the study might or might not have applicability beyond the context of young women. In addition, the particulars of each participant's experience, the research context, the research process, and findings were described in detail to allow the reader to determine the transferability of the findings to other contexts (cf. Willig, 2013).

1.14.6 Impact and importance.

The researcher believes that the research is relevant and important when the literature is considered. The findings of the study have the potential to contribute to clinical practice and may facilitate a better understanding of how young women with type 1 diabetes make meaning of diabetes.

1.15 Ethical Considerations

'Qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict' (Stake, 2000, p. 447). All relevant ethical considerations were adhered to in the study. Ethical approval was obtained from the Health Research Ethics Committee of the North-West University Potchefstroom Campus (reference

number NWU-00124-18-S1). Scientific approval to conduct the study was obtained from the Optentia Research Focus Area.

In accordance with prescribed ethical procedure, the participants were informed of the nature and aim of the research (cf. Willig, 2013), namely to gain insight into the meaning-making process of living with type 1 diabetes. This was communicated via a participant information sheet.

The participants were informed about the purpose, procedure, potential risks the study holds, and future use of the data before data collection took place. Informed consent forms were signed, and the participants were informed that they had the right to withdraw at any stage during the research (cf. Willig, 2013). It was emphasised that participation or non-participation was independent of the care received at the Centre for Diabetes and Endocrinology. This avoided response bias (e.g., self-presentation of being a 'good diabetic') (Smith et al., 2009). The participants were made aware that the researcher only had access to their name and contact details and did not have access to their medical histories.

The researcher maintained the confidentiality of all of the participants in order to safeguard their privacy. During the study, the audio recordings, transcribed material, and the researcher's reflective journal were kept in electronic format on a password-protected computer to which only the researcher and study leaders had access. The participants were informed that although quotations would be used in the write-up of the research (cf. Smith et al., 2009), all identifying information would be removed from quotations and transcripts, and fictitious names would be used in reporting the results.

Prior to the interview, the participants were informed that the interview could be stopped at any time and that they only had to respond to questions they felt comfortable to answer. The researcher aimed to apply the fundamental qualities required of an IPA researcher throughout the process. In other words, flexibility, open-mindedness, patience, the

willingness to enter into the participants' world and empathy were honoured (cf. Smith et al., 2009).

Participation in the study posed no risk of physical harm to the participants. However, as the content of the interviews could possibly be of a sensitive nature, the participants were given the option to receive a free debriefing session by a psychologist (Rosemary Flynn). Moreover, the researcher acted in a professional and empathetic manner at all times.

1.16 Outline of the Study

This section, Section I, presented a literature review to provide an overview and basis of the study. The next section, Section II, presents the author guidelines for the *Health & Psychology* journal, followed by the article. The article titled 'Young adult women's meaning making of living with Type 1 Diabetes' will be submitted to the abovementioned journal for possible publication. The final section, Section III, includes the researcher's critical reflections on the research and a complete reference list.

REFERENCES

- Abualula, N. A., Jacobsen, K. H., Milligan, R. A., Rodan, M. F., & Conn, V. S. (2016). Evaluating diabetes educational interventions with a skill development component in adolescents with type 1 diabetes: A systematic review focusing on quality of life. *The Diabetes Educator*, 42(5), 515-528. doi:10.1177/0145721716658356
- Alea, N., & Bluck, S. (2013). When does meaning making predict subjective well-being? Examining young and older adults in two cultures. *Memory*, 21(1), 44-63. doi:10.1080/09658211.2012.704927
- Ali, N. (2011). *Diabetes and you: A comprehensive, holistic approach*. Plymouth, UK: Rowman & Littlefield.
- American Diabetes Association. (2016). Foundations of care and comprehensive medical evaluation. *Diabetes Care*, 39(1), 25-35. doi:10.2337/dc16-S006
- Anderson, B. J. (2006). Families and chronic illness research: Targeting transitions and tools. *The Journal of Collaborative Family Healthcare*, 24(3), 332-335. doi:10.1037/1091-7527.24.3.332
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480. doi:10.1037//0003-066X.55.5.469
- Bliss, M. (1982). *The discovery of insulin*. Chicago, IL: University of Chicago.
- Brown, O. (2014). Psychological considerations in the management of diabetes. *South African Journal of Diabetes and Vascular Disease*, 11, 133-136. Retrieved from <http://reference.sabinet.co.za/document/EJC159162>
- Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology*, 70, 70-84. doi:10.1016/j.psyneuen.2016.04.019

- Carel, J. C., & Levy-Marchel, C. (2008). Renal complications of type 1 diabetes. *British Medical Journal*, 336, 677-678. doi:10.1136/bmj.39517.508241.80
- Carroll, A. E., & Marrero, D. G. (2006). The role of significant others in adolescent diabetes: A qualitative study. *Diabetes Educator*, 32(2), 243-252.
doi:10.1177/0145721706286893
- Centre for Diabetes and Endocrinology. (2018). *Type 2 diabetes*. Retrieved from <http://www.cdediabetes.co.za/home/diabetes/type-2-diabetes.html>
- Chew, B. H., Khoo, E. M., & Chia, Y. C. (2015). Social support and glycemic control in adult patients with type 2 diabetes mellitus. *Asia-Pacific Journal of Public Health*, 27(2), 166-173. <https://doi.org/10.1177/1010539511431300>
- Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 diabetes through the life span: A positive statement of the American Diabetes Association. *Diabetes Care*, 37, 2034-2054. doi:10.2337/dc14-1140.
- Cruz, I. I. (2014). *The lived experience of insulin-dependent diabetes among adult Latinos in a primary care clinic in San Antonio* (Unpublished doctoral thesis). University of Iowa, Iowa City, IA. Retrieved from <http://ir.uiowa.edu/cgi/viewcontent.cgi?article=5485&context=etd>
- Daneman, D., Frank, M., & Perlman, K. (2002). *When a child has diabetes*. Toronto: Key Porter.
- Dhada, B., Blackbeard, D., & Adams, G. (2014). Paediatric diabetes with a focus on the adolescent. *South African Journal of Diabetes and Vascular disease*, 11, 108-109. Retrieved from <http://reference.sabinet.co.za/document/EJC159169>
- DiMeglio, L. A., Acerinib, C. A., Codner, C., Craig, M. E., Hofere, S. E., Pillay, K., & Maahsg, D. M. (2018). *Glycemic control targets and glucose monitoring for children and adolescents with type 1 diabetes*. Retrieved from

https://cdn.ymaws.com/www.ispad.org/resource/dynamic/forums/20180403_042359_21137.pdf

Eriksson, E. H. (1982). *The life cycle completed, a review*. New York, NY: Norton.

Foster, E. S. (2009). *Adolescents' experience of 'adjustment' to life with diabetes: An interpretative phenomenological analysis* (Unpublished doctoral thesis). University of Hertfordshire, Hertfordshire, UK. Retrieved from <http://uhra.herts.ac.uk/bitstream/handle/2299/4519/Emily%20Foster%20-%20DClinPsy%20research%20thesis.pdf?sequence=1>

Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health, 25*(10), 1229-1245. doi:10.1080/08870440903194015

Frankl, V. E. (1964). *Man's search for meaning*. London: Hodder and Stoughton.

Funnel, M. M., & Anderson, R. M. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes, 22*, 123-127. Retrieved from <http://clinical.diabetesjournals.org/content/diaclin/22/3/123.full.pdf>

Garvey, K. C., Telo, G. H., Needleman, J. S., Forbes, P., Finkelstein, J. A., & Laffel, L. M. (2016). Health care transitions in young adults with type 1 diabetes: Perspectives of adult endocrinologists in the U.S. *Diabetes Care, 39*, 190-197. doi:10.2337/dc15-1775

Gomes, M. B., Santos, D. C., Pizarro, M. H., Barros, B. S. V., Melo, L. G. N., & Negrato, C. A. (2018). Does knowledge on diabetes management influence glycemic control? A nationwide study in patients with type 1 diabetes in Brazil. *Patient Preference and Adherence, 12*, 53-62. doi:10.2147/PPA.S146268

- Hicks, J. A., & King, L. A. (2009). Meaning in life as a subjective judgement and a lived experience. *Social and Personality Psychology Compass*, 3(4), 317-330.
doi:10.1111/j.1751-9004.2009.00193.x
- Holt, R. I. G., & Hanley, N. A. (2012). *Essential endocrinology and diabetes*. London: John Wiley & Sons.
- Holt, T., & Kumar, S. (2012). Diagnosing diabetes. In T. Holt, & S. Kumar (Eds.), *ABC of diabetes* (pp. 115-138). London: Wiley & Sons.
- International Diabetes Federation. (2008). *Diabetes: One of the most challenging health problems in the 21st century*. Retrieved from <http://www.eatlas.idf.org/index.cfm>
- International Diabetes Federation. (2011). *Global IDF/ISPAD guideline for diabetes in childhood and adolescence*. Retrieved from <https://www.ispad.org/?page=IDFISPAD2011>
- International Diabetes Federation. (2017). *IDF Diabetes Atlas* (8th ed.). Retrieved from <http://diabetesatlas.org/resources/2017-atlas.html>
- Jacek, Z., Anil, S., Parini, P., & Leonid, P. (2010). *Principles of diabetes mellitus*. New York: Springer Science and Business Media.
- Jim, H. S., & Jacobsen, P. B. (2008). Posttraumatic stress and posttraumatic growth in cancer survivorship: A review. *Cancer Journal*, 14, 414-418.
doi:10.1097/PPO.Obo13e31818d8963
- Karlsson, A., Arman, M., & Wikblad, K. (2008). Teenagers with type 1 diabetes – A phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies*, 45, 562-570.
doi:10.1016/j.ijnurstu.2006.08.022
- Kay, C., Davies, J., Gamsu, D., & Jarman, M. (2009). An exploration of the experiences of young women living with type 1 diabetes. *Journal of Health Psychology*, 14(2), 242-250. doi:10.1177/1359105308100208

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

- Keating, N., Eales, J., & Phillips, J. E. (2013). Age-friendly rural communities: Conceptualizing 'best-fit'. *Canadian Journal on Aging, 32*(4), 319-322. doi:10.1017/S07149808130004408
- La Greca, A. M., Swales, T., Klemp, S., Madigan, S., & Skyler, J. (1995). Adolescents with diabetes: Gender differences in psychosocial functioning and glycemic control. *Children's Health Care, 24*(1), 61-78. doi:10.1207/s15326888chc2401_6
- Larsen, P. D. (2016). The illness experience. In P. D. Larsen (Ed.), *Lubkin's chronic illness: Impact and intervention* (9th ed.) (pp. 21-42). Sudbury, MA: Jones and Barlett.
- Lee, Y. A. (2013). Diabetes care for emerging adults: Transitions from pediatric to adult diabetes care systems. *Annals of Pediatric Endocrinology and Metabolism, 18*(3), 106-110. doi:10.6065/apem.2013.18.3.106
- Lepore, S. J. (2001). A social-cognitive processing model of emotional adjustment to cancer. In A. Baum, & B. Anderson (Eds.), *Psychosocial interventions for cancer* (pp. 99-118). Washington, DC: American Psychological Association.
- Lindell, A. K., Campione-Barr, N., & Killore, S. E. (2017). Implications of parent-child relationships for emerging adults' subjective feelings about adulthood. *Journal of Family Psychology, 31*(7), 810-820. doi:10.1037/fam0000328
- Louw, D., & Louw, A. (2007). *Die ontwikkeling van die kind en die adolessent*. Bloemfontein: Psychology Publications.
- National Institute for Health and Care Excellence. (2016). *Diabetes in children and young people (quality standard)*. Retrieved from <https://www.nice.org.uk/>
- Park, C. L. (2013). The meaning making model: A framework for understanding meaning, spirituality, and stress-related growth in health psychology. *The European Health Psychologist, 15*(2), 40-47. doi:10.7213/revistapistispraxis.06.001.DS01
- Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *General Review of Psychology, 1*, 115-144. doi:10.1037/1089-2680.1.2.115

- Park, C. L., Folkman, S., & Bostrom, A. (2001). Appraisals of controllability and coping in caregivers and HIV+ men: Testing the goodness-of-fit hypothesis. *Journal of Consulting and Clinical Psychology*, 69, 481-488. doi:10.1037/0022-006X.69.3.481
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Pyatak, E. A., Sequeira, P. A., Vigen, C. L. P., Weigensberg, M. J., Wood, J. R., Montoya, ... Peters, A. L. (2017). Clinical and psychosocial outcomes of a structured transition program among young adults with type 1 diabetes. *Journal of Adolescent Health*, 60(2), 212-218. doi:10.1016/j.jadohealth.2016.09.004
- Rasmussen, B., Ward, G., Jenkins, A., King, S. J., & Dunning, T. (2011). Young adults' management of T1D during life transitions. *Journal of Clinical Nursing*, 20, 1981-1992. doi:10.1111/j.1365-2702.2010.03657.x
- Robinson, E. (2015). Being diagnosed with type 1 diabetes during adolescence. How do young people develop a healthy understanding of diabetes. *Practical Diabetes*, 32, 339-334. doi:10.1002/pdi.1986
- Roussi, P., & Avdi, E. (2008). Meaning-making and chronic illness: Cognitive and narrative approaches. *Hellenic Journal of Psychology*, 5, 147-178. Retrieved from <http://www.pseve.org/journal/UPLOAD/roussi5b.pdf>
- Rubin, R. R., & Peyrot, M. (1999). Quality of life and diabetes. *Diabetes Metabolism Research and Reviews*, 15, 205-218.
- Schiotz, M. L., Bogelund, M., Almdal, T., Jensen, B. B., & Willaing, I. (2011). Education and psychological aspects social support and self-management behaviour among patients with type 2 diabetes. *Diabetic Medicine*, 29, 654-661. doi: 10.1111/j.1464-5491.2011.03485.x
- Segal, D. (2010). A life with diabetes. *South African Journal of Diabetes*, 3, 13-16.
- Segal, D. (2015). Puberty and diabetes. *Living with Diabetes*, 3, 48-49.

- Segal, D. (2016). 10 Commandments for better diabetes self-care. *Diabetes Lifestyle*, 2, 34-36.
- Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Sciences and Medicine*, 62, 1153-1166. doi:10.1016/j.socscimed.2005.07.010
- Smith, J. A. (2011a). Evaluating the contribution of interpretative phenomenological analysis, *Health Psychology Review*, 5(1), 9-27. doi:10.1080/17437199.2010.510659
- Smith, J. A. (2011b). Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria. *Health Psychology Review*, 5(1), 55-61. doi:10.1080/17437199.2010.541743
- Smith, J. A. (2018). Yes it is phenomenological: A reply to Max van Manen's critique of interpretative phenomenological analysis. *Qualitative Health Research*, 28, 1995-1958. doi:10.1177/1049732318799577
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory method and research*. London: Sage.
- Stake, R. (2000). Case studies. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 236-247). Thousand Oaks, CA: Sage.
- Statistics South Africa. (2016). *Mortality and causes of death in South Africa, 2016: Findings from death notifications*. Retrieved from <http://www.statssa.gov.za/publications/P03093/P030932016.pdf>
- Steger, C. R., Oishi, S., & Kashdan, T. B. (2009). Meaning in life across the life span: Levels and correlates of meaning in life from emerging adulthood to older adulthood. *The Journal of Positive Psychology*, 4(1), 43-52. doi:10.1080/17439760802303127
- Stuckey, H. L., & Tisdell, E. J. (2010). The role of creative expressions in diabetes: An exploration in the meaning-making process. *Qualitative Health Research*, 20, 42-56. doi:10.1177/1049732309355286

- Swift, P.G.F. (2004). Diabetes in the young: Past present and future. *Practical Diabetes*, 21, 54-60. doi:10.1002/pdi.585
- Tattersall, R. (2009). *Diabetes: The biography*. London: Oxford University Press.
- Tracey, S. J. (2010). Qualitative quality: Eight 'big-tent' criteria for excellent quantitative research. *Qualitative Inquiry*, 16(10), 837-851. doi:10.1177/1077800410383121
- Tripathy, B. B. (2012). Definition, diagnosis and classification. In B. B. Tripathy (Ed.), *RSSDI Textbook of diabetes mellitus* (2nd ed.) (pp. 121-140). New Delhi: Jaypee Brothers Medical Publishers.
- Tuomilehto, J. (2013). The emerging global epidemic of type 1 diabetes. *Current Diabetes Reports*, 13(6), 795-804. doi:10.4102/phcfm.v5il.375
- Vaccaro, J. A., Exebio, J. C., Zarini, G. G., & Huffman, F. G. (2014). The role of family/friend social support in diabetes self-management for minorities with type 2 diabetes. *Journal of Nutrition and Health*, 2(1), 1-9.
- Van der Merwe, A. (2015). *Managing diabetes and related health challenges*. Cape Town: Human & Rousseau.
- Wallander, J. L., Thompson, R. J., & Alriksson-Schmidt, A. (2003). Psychosocial adjustment of children with chronic physical conditions. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology* (pp. 141-158). New York, NY: The Guilford Press.
- Willemse, M. (2018). *Diabetes management behaviours of young adults towards psychological well-being* (Unpublished doctoral thesis). North-West University, Vaal Triangle Campus.
- Willig, C. (2013). *Introducing qualitative research in psychology*. New York, NY: McGraw-Hill.
- Wissing, M. P. (2014). *Towards flourishing: Contextualising positive psychology*. Pretoria: Van Schaik.
- Wolpert, H. A. (2001). Young adults with diabetes. *Diabetes Care*, 24(9), 151-152. doi:10.1186/1472-6823-13-25

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

Wong, P. T. P. (2012). *Acceptance & well-being: A meaning-management perspective*.

Paper presented at the Australian Positive Psychology Conference 2012 in Wollongong.

World Health Organisation. (2016). *Global report on diabetes*. Paris: World Health Organisation Press. Retrieved from

http://apps.who.int/iris/bitstream/10665/204871/1/9789241565257_eng.pdf

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology* (pp. 253-251). London: Sage.

Young, E. E., & Unachukwa, C. N. (2012). Psychological aspects of diabetes mellitus. *African Journal of Diabetic Medicine*, 20(1), 5-7.

**Section II: Article - Young adult women's meaning making of living with Type 1
Diabetes**

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Psychology & Health promotes the study and application of psychological approaches to health and illness. The contents include work on psychological aspects of physical illness, treatment processes and recovery; psychosocial factors in the aetiology of physical illnesses; health attitudes and behaviour, including prevention; the individual healthcare system interface particularly communication and psychologically based interventions. The journal publishes original research, and accepts not only papers describing rigorous empirical work, including meta-analyses, but also those outlining new psychological approaches and interventions in health-related fields.

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2.2 Manuscript

Young adult women's meaning making of living with Type 1 Diabetes

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Young adult women's meaning making of living with Type 1 Diabetes

Objective: Managing type 1 diabetes, especially during young adulthood, is a complex process. Type 1 diabetes is primarily researched as a medical condition, and an examination of the subjective experience thereof is neglected. The study aimed to explore young women's meaning making of living with type 1 diabetes, with the hope of informing clinical practice and improving support to people with diabetes.

Design: Interpretative phenomenological analysis (IPA) enabled the in-depth exploration of participants' personal meaning making of living with type 1 diabetes.

Main outcome measures: Six female participants between the ages of 18 and 25 were recruited from the Centre for Diabetes and Endocrinology, participating in in-depth, semi-structured interviews, lasting approximately 45 minutes. The interviews were audio recorded, transcribed, and analysed using the principles of IPA.

Results: The findings of the IPA analysis are considered against the background of existing literature on meaning making. Three superordinate themes emerged: (1) the process of reappraising a life with diabetes; (2) the development of diabetes as a lifestyle; and (3) meanings made.

Conclusion: The findings of the study indicate that meaning has a significant impact on peoples' adjustment to living with diabetes. It is concluded that optimal care in diabetes services should incorporate a holistic approach.

Keywords: Interpretative phenomenological analysis, meaning-making, qualitative research, type 1 diabetes, women, young adults

Introduction

Diabetes is described as an always-present disease and an ongoing process of adjustment (Stuckey & Tisdell, 2010, p. 43). Diabetes has an impact on the psychological, emotional, and social functioning of the young adult (Daneman, Frank, & Perlman, 2002). The American Diabetes Association (as cited in Chiang, Kirkman, Laffel, & Peters, 2014) recommends that during young adulthood, the topic of the personal meaning of diabetes should be addressed in order to adjust to living with diabetes. Meaning is regarded as a significant aspect of well-being and health (Seligman, 2011; Steger, 2009). Within the context of diabetes, meaning making is associated with more positive adjustment (McLean & Breen, 2009). However, it appears as if little research has been conducted on this topic. To address this gap, the study attempted to gain a rich understanding of young adult women's meaning making of living with type 1 diabetes, with the hope of improving support to young people and to inform clinical practice.

Diabetes is a major health concern, affecting approximately 442 million people worldwide (World Health Organisation, 2016), and this number continues to grow (DiMeglio, Evans-Molina, & Oram, 2018). Type 1 diabetes accounts for 5 to 10% of all people with diabetes (Holt & Hanley, 2012). It is a chronic autoimmune condition caused by the destruction of the insulin-producing beta cells of the pancreas (Atkinson, Eisenbarth, & Michels, 2014). Type 1 diabetes is typically diagnosed in childhood or adolescence. People with type 1 diabetes have an absolute insulin deficiency (Holt & Hanley, 2012).

The discovery of insulin transformed type 1 diabetes from a terminal to a treatable condition (DiMeglio et al., 2018). Exogenous insulin in the form of multiple injections or the use of an insulin pump is required to sustain life. However, insulin is not a cure, and people with type 1 diabetes are required to maintain a strict routine, consisting of healthy eating, glucose monitoring, and engaging in exercise (McCarthy & Grey, 2018; Watts, O'Hara, & Trigg, 2010).

Despite improvements in the treatment of type 1 diabetes, the risk of complications or death remains high (Pastor et al., 2018). Complications include cardiovascular disease, kidney disease, and neuropathy (World Health Organisation, 2016). People with type 1 diabetes can significantly decrease the risks of developing complications by maintaining strict glucose control (National Institute of Clinical and Health Excellence, 2015). Type 1 diabetes requires a high degree of individual self-management behaviour, implying responsibility (Watts et al., 2010). Type 1 diabetes is primarily researched as a medical condition, and an examination of the subjective experience is neglected (Cruz, 2014). Even though the practical aspects of self-management of type 1 diabetes have received increased attention in recent years, it is necessary to improve the understanding of the experiences of emerging adults as they make sense of their medical condition.

It is crucial for diabetes care to be tailored to the individual's developmental stage, as each developmental stage brings about new challenges of living with type 1 diabetes (Garvey, Howard, & Wolpert, 2011). Emerging adulthood is defined as the developmental phase between 18 and 25 years old and refers to the transition from adolescence to young adulthood, when role and identity exploration takes place (Arnett, 2000). In addition, this age group also has to deal with developmental challenges, such as leaving the parental home, forming stable relationships, and searching for a job (Arnett, 2000). Emerging adults with type 1 diabetes are considered a high-risk group in terms of the management of diabetes (McCarthy & Grey, 2018; Pihlaskari, Wiebe, Troxel, & Stewart, 2018). Emerging adulthood is often characterised by developmental challenges and competing priorities (Garvey et al., 2011). Emerging adults experience increased freedom and decreased involvement of parents and must learn to autonomously manage their diabetes (McCarthy & Grey, 2018; Rassart et al., 2016). Less than one third of this population meet the recommendations for diabetes care (Peters & Laffel, 2011). Gender differences in the experience of type 1 diabetes have been documented, with

women experiencing lower well-being, greater distress, and poorer glucose control, which increase the likelihood of complications (Kay, Davies, Gamsu, & Jarman, 2009).

The majority of people with type 1 diabetes experience psychological challenges, including anxiety, stress, depression, burnout, and anger (Delamater et al., 2018; Watts et al., 2010). Hence an important task for researchers is to gain a deeper understanding of the psychological aspects of living with diabetes. As stated by Watts et al. (2010), diabetes cannot be prevented or cured by examining psychological factors; however, diabetes should be regarded as a physical condition with profound psychological effects. Therefore the psychological aspects of diabetes require further investigation, as there is a lack of studies investigating, holistically, the meaning of living with diabetes.

The construct of meaning was greatly influenced by Frankl's (1964) writings of finding meaning in difficult circumstances. Meaning in life is defined as 'the extent to which people comprehend, make sense of, or see significance in their lives, accompanied by the degree to which they perceive themselves to have a purpose, mission or overarching aim in life' (Steger, Oishi, & Kashdan, 2009, p. 43). Park (2013) proposes that the meaning-making model can be a useful theoretical framework for understanding phenomena and their interrelations within the field of health psychology. In accordance with Park and Folkman's (1997) meaning-making model, individuals have a global meaning system that assists them with interpreting experiences. Global meaning refers to an overarching system of personal goals, beliefs and motivation for living that serve as structure to a person's life. Being diagnosed with a chronic condition can violate important global beliefs. Within the framework of the meaning-making model, an individual will experience distress when there is a disagreement between the appraised meaning of the situation and the individual's global meaning (Park, 2013).

Meaning making is central to making sense of stressful life events (Park, 2013), such as being diagnosed with type 1 diabetes. Meaning making is an important aspect of adjusting to life with a chronic condition and can result in a new, normal way of living with diabetes

(Sharpe & Curan, 2006; Willemse, 2018). The majority of studies on diabetes focus on the negative effect of diabetes (Cruz, 2014). However, in more recent research (Buchhorn, Damaiao, Marques, & Pinto, 2007; Hornsten, Sandstrom, & Lundman, 2004), diabetes is viewed from the perspective of empowerment and as a second chance at a healthier life. Studies on meaning making have shown that meaning is crucial to adjusting to a chronic medical condition (Sherman & Simonton, 2012). However, few studies focusing on the meaning-making process of living with diabetes were found. Emerging adults' experiences and meanings made are largely neglected within research, and researchers have been criticised for an over-reliance on quantitative methods (Wallander, Thompson, & Alriksson-Schmidt, 2003). Diabetes is a complex medical condition, and there is a gap in the knowledge of diabetes as a medical condition and the lived experiences of diabetes (Cruz, 2014). Further research focusing on personal experiences and meanings within this developmental group is recommended (Anderson, 2006; Foster, 2009). The present study is therefore an attempt to explore the meaning-making process of emerging adult women living with type 1 diabetes.

Method

Study design

This qualitative study employed an interpretative phenomenological analysis (IPA) design (cf. Smith, Flowers, & Larkin, 2009), which enabled an in-depth analysis of individual accounts. IPA is especially valuable within the field of health psychology (Brocki & Wearden, 2006). This design is useful for exploring subjective experiences in the context of illness and gaining an understanding of how people search for meaning in their lives (Smith et al., 2009).

Participants

Six participants were recruited, representing a homogeneous, purposive sample (cf. Smith et al., 2009). All of the participants attended the same diabetes clinic, namely the Centre for Diabetes and Endocrinology, Parktown, South Africa. The participants were female and aged between 18 and 25, representing emerging adulthood. All of the participants were

diagnosed with type 1 diabetes for at least one year and, at the time of the study, were neither undergoing psychotherapy nor had other chronic medical conditions. The small sample size is typical for an IPA study, as the emphasis is on the in-depth exploration of a shared aspect of a lived experience. Further demographic details are included in Table 1.

Table 1: Demographic features of participants.

Pseudonym	Age	Time since diagnosis	Employment status
Jenny	25	15 years	Dietitian
Sarah	21	12 years	Education student
Hope	22	8 years	Bookkeeper
Carlia	21	1 year	Small business owner
Karen	25	16 years	Intern medical doctor
Nina	25	15 years	Law student

Procedure

Ethical approval was obtained for the study (NWU-00124-18-S1), and informed consent forms were administered. Prospective participants were recruited by means of an information leaflet available at the clinic, requesting possible participants to contact the researchers if they were interested in participating in the study. After giving independent informed consent, the participants were individually interviewed for approximately 45 minutes. All interviews were conducted in a safe environment, familiar to the participants, at the Centre for Diabetes and Endocrinology. The verbatim transcripts were analysed using IPA (cf. Smith et al., 2009), which is described below.

Data collection

A semi-structured interview schedule was developed, following the guidelines described by Smith et al. (2009). In accordance with IPA literature (cf. Smith et al., 2009), the interview schedule was not prescriptive and served as a guide to facilitate the participants'

sharing their experiences, leaving the researcher free to probe further on participant-generated topics. All interviews were audio recorded and transcribed verbatim. Pseudonyms were used to ensure confidentiality and anonymity.

Analysis

IPA posits that the meaning that people ascribe to events stand central (Smith et al., 2009). As such, IPA was deemed well-suited to the current research aim given its focus on individuals who share a common phenomenon. The first author conducted the data analysis and in accordance with IPA guidelines (Smith et al., 2009) a co-coder was employed.

IPA follows a process of considering transcripts individually and then comparing across cases. The method consists of a number of steps. Initially, audio recordings were listened to after transcription. Individual transcripts were read and re-read to become familiar with the data and to obtain a holistic picture of the participant's account. The researcher made initial notes consisting of anything of interest and summaries of ideas. The transcripts were then re-read, and emergent themes were identified. A title was assigned to each theme, with keywords or quotes that captured the essence of the content. The themes identified were studied in relation to one another and clustered together to create a list of superordinate themes. This process was repeated with each individual transcript (cf. Smith et al., 2009).

During the final stage of analysis, a summary table was created containing identified themes across all of the transcripts, including quotations and keywords that provide evidence for each theme. Lastly, the individual transcripts were integrated to form a list of master themes, resulting in a narrative structure of participants' accounts. The researcher returned to the transcripts throughout the analysis phase to ensure that the themes generated were grounded in the data. The research supervisors reviewed the interpretations, and the researcher included verbatim extracts in writing up the study to ensure validity, as suggested by Smith et al. (2009). Also, the researcher kept a reflective journal throughout the study to

ensure that the data represented the participants' true accounts. This enabled the researcher to be constantly mindful of her own assumptions, emotions, views, and personal biases about the research topic.

Results

The participants made meaning of living with diabetes by engaging in three superordinate themes: (1) the process of reappraising a life with diabetes; (2) the development of diabetes as a lifestyle; and (3) meanings made. It was found that the meaning-making processes were not linear, had no specific boundaries, and could occur in parallel. As such, subordinate themes may appear in more than one meaning-making process. The superordinate and subordinate themes are presented in Table 2.

Table 2: Overview of thematic results

Superordinate themes	Subordinate themes
The process of reappraising a life with diabetes	Reaction to the diagnosis Challenges of living with diabetes Incorporating diabetes into identity
The development of diabetes as a lifestyle	The value of support Knowledge Acceptance Self-responsibility
Meanings made	Growth and strengths Opportunities

The process of reappraising a life with diabetes

The first superordinate theme was expressed by all of the participants and represented the process of reappraising a life with diabetes. The process of reappraisal comprises three subordinate themes: reaction to the diagnosis; challenges of living with diabetes; and identity.

Reaction to the diagnosis

The participants responded in unique ways to receiving a diagnosis of diabetes, which varied from shock to initially thinking that diabetes was 'cool'. Making sense of what is happening, asking 'why me?', and seeking answers to that question were common to all of the participants: *'Why did I get this instead of someone else? Which isn't the right way to think of it, but it's that kind of feeling, like being angry about having something but which you can't get rid of'* (Hope).

This discrepancy resulted in emotional distress. In the initial phase of their journey with diabetes, the shock of diagnosis and feeling overwhelmed dominated the participants' minds. Nina recalled feeling scared and uncertain. Karen could recall her diagnosis experience in detail: *'I think I will never ever forget that day, the sequence, how everything happened, ever. I think it's like burnt into your memory – the day that everything changed. So it obviously was a shock.'*

A common response for the young women was an initial lack of understanding of what diabetes was, which contributed to feeling distressed. Hope's account was, *'I really thought it was just testing and injecting yourself.'* Like Hope, Nina and Karen initially did not fully comprehend what diabetes was: *'I think the biggest thing was I had no idea what it was when I first was diagnosed. I had no idea, I'd never heard of it, I never knew what it meant'* (Karen).

The participants found that, psychologically, self-management could have a draining effect, with the implication that type 1 diabetes is not viewed solely as a physical condition but also a psychological condition. After Carla's diagnosis, she described going through a 'dip' and realising that *'it is not so much fun to poke yourself with a needle every day'*. *'Knowing that you are going to have something that's going to be there to the absolute day that you die'* was described by Karen as *'quite a big psychological thing'*. For all of the participants, diabetes involved an emotional struggle. They indicated that emotions could affect stress levels and vice versa. Hope mentioned that *'the physical side is very easy. The emotional side is*

different'. Karen described that she experienced some anxiety related to diabetes and the reality of not being able to manage diabetes perfectly: *'that feeling of knowing you're not getting it right, which is the worst feeling in the world.'* However, she also explained a feeling of accomplishment when diabetes was well controlled, and *'a psychological bummer'* when diabetes was not entirely controlled. Sarah's account relates to Karen's in that she described her diabetes managements as *'test and try'*, implying that perfect control is not possible and diabetes is a constant learning experience.

For Sarah, diabetes was an added extra:

Just having that further stress, that a lot of kids my age didn't have to deal with, having to always be more responsible, always having to be cautious with everything I did, it put a little bit more stress on me than I know a lot of my friends had to deal with. So, I'm slowly ... it just caused me to feel a bit down and feel sorry for myself and so I got depression.

All of the participants had an awareness of psychological challenges associated with diabetes, Carlia stated that *'the physical illness can be an emotional crutch'*. She further explained that diabetes can have psychological side effects. Most of the participants acted on these psychological challenges, for example by attending psychotherapy sessions. Carlia acted by making the decision that she would not be a *'victim'* of diabetes, by handling the physical side of diabetes to prevent psychological complications. The need for healthcare professionals to assist young adults in managing their emotions is highlighted.

Challenges of living with diabetes

Having lived with diabetes for a while, the participants were in a position to get to know diabetes after the diagnosis. This subordinate theme captures an array of challenges that the young women experienced in various areas as a result of living with diabetes. Throughout the transcripts, little reference was made to diabetes being negative or a problem, although some challenges were acknowledged by all of the participants.

The majority of the participants expressed frustration with some people's social ignorance and faulty perception of diabetes. For example, Jenny experienced work-related challenges, where she was treated differently from people without diabetes as a result of others' faulty perception of diabetes. Similarly, Karen, working as an intern medical doctor, explained that she felt frustrated with a senior doctor at the hospital where she worked who did not fully comprehend what a life with diabetes was like. A lack of understanding was not limited to the workplace, and Carlia found that her friends were initially, sympathetic towards her at the time of diagnosis; however, it was soon assumed that she was back to full health as diabetes is an 'invisible' disease. All of the participants expressed a wish for more awareness and understanding of diabetes in the general public.

All of the participants mentioned future concerns, such as possible complications that could result from uncontrolled diabetes, which were feared could be threatening their identity in the future. However, the fear of complications also acted as a motivator and an incentive to aim for good glucose control. The fear of complications was particularly stressful for Sarah: *'Would I be able to afford it one day? Will my children get it? All these other things, but I'm trying to be positive so a lot of unknowns and the finances being difficult.'*

Nina's account captured the reality of living with uncontrolled diabetes:

If you don't control it, it's hard to say it, but if you don't control it, you're dead. If you control it, you can live so long. I also want to be like that old uncle, 115 years old and say, 'Yes, diabetic, everything good and well.'

For Hope, it was important *'to accept that you are not a perfect diabetic'*, but to make the decision to control diabetes as best as possible to avoid *'losing limbs, my eyesight, that kind of stuff'*. Carlia described the reality of complications as a *'wake-up call'* and a motivator for her to have *'quality of life'* by trying her best to manage her diabetes. As has been illustrated above, the participants described an initial difficult experience of diagnosis and initially had a lack of understanding of what the implications of living with type 1 diabetes would be. This

theme reflects a discrepancy and a sense of a change in the direction that the women had thought their lives would go. All of the participants described an array of challenges of living with diabetes. In general, the participants did not dwell on the challenges of diabetes but acknowledged the emotional impact of their physical health. They all viewed diabetes as a chronic condition that was a manageable challenge.

Most of the participants reported feeling '*different*' as a result of living with diabetes, as illustrated by Carlia who felt that living with diabetes placed her in a '*peculiar position*'. She described having lost a sense of normality. She also explained that she had to engage in routines that were different from her peers. For some participants, integrating self-management in a social context proved difficult. All of the participants described that the responsibility of managing diabetes resulted in their having to be more responsible than their peers with some aspects, suggesting a sense of loss of freedom, reinforcing the sense of difference, and adopting a more adult outlook towards life. Sarah's statement summarised this notion: '*I couldn't just go out with my friends, I had to always monitor. So, I became the responsible adult before all my friends did, because of my condition.*'

Jenny described that diabetes was an '*added extra*' within the social context. Hope also stated that since moving in with her boyfriend, she was experiencing challenges regarding food choices. She described the situation:

My parents fed me around my disease, whereas I don't really have the funds to ensure that eat perfectly healthy all the time. Going into the adult world, having to feed yourself, and buying your own food and things like that, is really challenging.

It was evident that the experience of distress had altered most of the participants' views about themselves and the world. Sarah explained that when she was younger, she experienced being self-conscious about taking insulin injections and having marks on her body

as a result of that. Nina also recalled feeling tired of injecting and not being able to be as carefree as her peers.

Incorporating diabetes into identity

Despite the challenges reported by the participants with regard to diabetes and the impact of the management thereof, the participants recognised the positive impact diabetes had had on their lives. Over time, diabetes was not viewed as a threat to their identity. It was evident that the participants held positive beliefs about diabetes and had an optimistic outlook, possibly increasing their well-being. Nina and Karen assimilated diabetes into their view of themselves and stated that they were '*proud*' of living with diabetes. For Sarah, reframing her experience into a more positive outlook, facilitated self-discovery – '*diabetes was a way of discovering me*'. Karen also assimilated diabetes into her view of herself:

This is not going to define you, this is not the end of everything. It's simply just something that is going to be in the back of your mind, but it doesn't by any chance mean that you can't do anything as a result, that you are different person as a result, that people should treat you differently.

Nina also reframed diabetes into a more positive light and stated, '*I cannot imagine myself without diabetes*.' She reflected that diabetes was a good part of who she was. Living with diabetes helped Karen look at life differently. Jenny also described how diabetes had altered her outlook on life for the positive. She went on to say, '*[D]iabetes doesn't define me, it is a part of me, but it is not a negative aspect*.' Each participant expressed gratitude. For Sarah and Karen, reflecting on the fact that they had access to medication was sufficient to fill them with gratitude. In this way, appreciating their health was an integral part of each participant's experience of making meaning, and diabetes was not perceived to be a debilitating factor in their lives. The participants re-evaluated what was important to them and reassessed how they viewed diabetes, and over time, diabetes was accommodated into their identity.

Making meaning of diabetes included assimilating the knowledge that diabetes is permanent: *'The realisation that it is not going to go away, it is not the flu, it will not disappear within two weeks'* (Carlia). Jenny's account indicated that assimilating diabetes into one's life is a process: *'It is a long road, it is a manageable disease and it becomes a way of life. Diabetes doesn't define you.'* Carlia had a similar experience and stated that *'time heals all wounds'*. She elaborated and said that perspective was gained over time, and time was needed to make sense of diabetes. For Hope, acceptance of diabetes meant making a decision of *'wanting a life despite diabetes'*, implying that better control was needed. She acknowledged that diabetes was a part of her identity. For Sarah, acceptance meant *'it's not the end of the world, you are going to learn to live with it'*. From the initial diagnosis, it was evident that a shift in the perspective of diabetes had occurred and that the participants had gradually shifted their views of diabetes in a more positive direction, with the realisation that they could still be healthy individuals and that it was possible to integrate diabetes in their lives and goals: *'diabetes definitely doesn't define me, it is a part of me, but it is not a negative aspect'* (Karen). Similarly, Carlia stated that *'diabetes does not influence your core being'*, and the participants reported that they were able to live a normal life, despite diabetes.

The development of diabetes as a lifestyle

An important meaning-making process for the participants was the development of diabetes as a lifestyle. Learning to live with diabetes involved a change in perspective to view diabetes as a way of life, accepting that it was a part of one's life by gaining more knowledge and incorporating self-management behaviours into daily life as well as taking responsibility for one's diabetes. The support of others contributed to the process of making meaning of diabetes.

The value of support

All of the participants described support as being a salient part of their meaning-making process. Within this subordinate theme, many different types of support were prominent –

friends and family, healthcare professionals, and the value of role models. All the participants described their parents as playing a crucial role in their journey with diabetes. The participants who had been diagnosed as children initially relied on their parents in terms of insulin administration, food choices, and accompanying them to the healthcare team. Karen described her parents as '*incredibly supportive*'. She elaborated:

I did the Midmar mile less than six months after my first diagnosis and my mum just said to my dad: 'Ok cool, you will swim with her and you won't let her out of your sight and it's fine.' And I did, you know, I like, I still do a lot of exercise and doing my first marathon, like small things like that ... I went to boarding school, I went on exchange for three months. I think just like mostly because everyone is so supportive and very well educated on everything, so my family is incredible.

The participants also felt that the emotional support of their friends was important. Many of the participants reported that their friends responded in positive ways. Karen and Nina described their boyfriends as important in their support systems. Sarah also found the support of her boyfriend very helpful:

He was just like, 'This is so cool, you know, yes you've got these lumps and bumps but you've had to deal with this for so long, so screw it and just appreciate your body, appreciate that you've got scars that other people don't have, they will never get to have.'

For the majority of the participants, role models were a positive influence in their meaning-making process. Carlia mentioned that her sister was also diagnosed with diabetes, relating to her assistance in her meaning-making process of diabetes. However, she indicated a desire to have more support from other people also living with diabetes. Karen's account demonstrated the significance of relating to others with diabetes: '*I always find that when you*

meet people who have diabetes, they will understand something about you that like 90% of people can't ever understand, which is always quite cool. You always feel connected.'

For Nina, initially being scared of injecting herself, her perspective was changed when an attractive older man with diabetes showed her how he injected, and she recalled making the choice on that day to start injecting herself. She also described a difficult experience relating to a girl who had lost a limb due to diabetes and making the choice, *'I am not going to be like that.'* Jenny's statement encapsulated the essence of this subordinate theme: *'I think it involves a lot of having a good support system, so family, friends, your parents, siblings, obviously, are the most affected. Then having good support from your doctor, your educators, and that sort of thing.'*

The participants had been profoundly affected by healthcare professionals, and the information received from them assisted the participants in appraising the meaning of diabetes and their ability to manage it. All of the participants indicated that healthcare professionals had helped them to develop an understanding of diabetes. For Nina, the support of her endocrinologist was crucial, and she described him as an *'angel'*, implying that he was playing a significant role in her journey with diabetes. Carlia had a similar experience and described the important role that a dietitian had played in her journey. She also referred to her endocrinologist:

I actually remember how the doctor told me when I was diagnosed, 'You are not diabetes, you are Carlia and you have diabetes. How is it going with Carlia? How is it going with diabetes? You are Carlia, before you are diabetes.'

Carlia's meaning-making process is clearly illustrated in the above example, as she internalised the doctor's words and started to develop her own understanding of diabetes. Similarly, Sarah spoke of the importance of regular follow-ups with her doctor to assist her in adjusting her self-management plan, before it was a *'problem'*. Jenny described regular follow-ups to be a facilitator in making meaning of diabetes. She added that getting praise from her

doctor when her management was good acted as a motivator for better self-management. Karen and Sarah also described the value of psychologists who had assisted them in coming to terms with diabetes. An integral part of making meaning of living with diabetes for all of the participants was having a good support system. It can thus be concluded that support facilitates coping with diabetes.

Knowledge

An important part of making meaning of a life with diabetes for the participants was directly related to knowledge. All of the participants viewed knowledge as crucial to making meaning of living with diabetes and viewed knowledge as an opportunity to empower themselves to better manage their diabetes. Jenny described it as follows, *'[K]nowledge is key. Knowing how to manage it.'* The participants reached a point of acceptance where diabetes was incorporated into their identity and they accepted that it was a part of life. What contributed to this acceptance was the practical application of the knowledge gained in their self-management regimen: *'if we know how to manage it, we can prevent the negatives'* (Jenny). When the participants gained more knowledge and started engaging in self-management behaviours, a sense of competence followed: *'that feeling of satisfaction when you know you got it right, I think no matter how old you get it's always gonna be like: "Yes, flip I did well!"'* (Jenny).

In line with this finding, research has linked a sense of competence to well-being (Lacham & Agrigoroaei, 2010). The participants acknowledged that they would live with diabetes forever; however, incorporating diabetes into their daily lives had become a way of life, as Nina suggested: *'Diabetes is a lifestyle, it is not an illness or a death sentence.'*

Acceptance

In contrast to the initial feelings of shock, diabetes had become a normal part of the participants' lives, as Karen stated, *'I accept that I need insulin to survive. It has to be a way of life. There is no other way for me.'* Making meaning of diabetes was an evolving process,

and the meaning was shaped over time. Initially, diabetes was seen as a threat, but later it became a normal part of life and a positive challenge. For all of the participants, a routine helped make diabetes more normal and a way of integrating diabetes into daily life: *'wake up, do your thing, before breakfast do your thing, for lunch, so it is a part of my routine'* (Jenny). The participants viewed diabetes as a chronic condition that was manageable and required lifestyle adjustments in order to create a new normal way of life. For Karen, making meaning involved realising that diabetes was not her fault: *'Something like 34 factors that can affect blood glucose levels, so some days it is just one of those days, so just understanding that it isn't always your fault.'* Similarly, Hope stated, *'... to accept that you are not a perfect diabetic.'* Acceptance was initiated by gaining more knowledge about diabetes.

An important part of making meaning of diabetes was the realisation and acceptance that diabetes cannot be *'perfectly'* managed and that there will be difficult days. Karen described experiencing *'good days and bad days'* while reflecting on her experience with diabetes. Nina experienced a similar struggle and highlighted the fact that diabetes could not always be perfectly managed: *'But as I say, we not only have positives and negatives, but also ups and downs with your sugar.'* Hope explained that the small things of diabetes could be frustrating: *'Just those little things affecting my work, where I have to go to the bathroom all the time. Stuff like that... So the little things start to really add up.'* Jenny captured the essence of living with diabetes: *'Obviously there are days where I feel, "Ag, I have to do it and I have to wait my 30 minutes before eating," and yes there are those days. But 90% of the time it is just a way of life.'*

Self-responsibility

'In order to control and manage it, one needs to accept the fact that one has got this disease. And it is not going away. It is in your hands, no one else can control it for you' (Karen).

The participants had a strong sense of taking ownership of their diabetes and felt responsible for the management thereof, which had implications on their management of diabetes. Jenny's account captured the core of this subordinate theme: *'In order to control and manage it, you need to accept the fact that you have got this disease. And it is not going away. It is in your hands, no one else can control it for you.'* Their sense of ownership grew with age, time, and knowledge. A striving for autonomy, while still receiving support from others, was prevalent. Sarah discussed the value of taking responsibility for her diabetes management, which resulted in her becoming more confident. She explained that, at the same time, her mother's support was still valuable. Jenny's account also demonstrated the significance of responsibility: *'... injections are mine, like I do them. I've always been quite, almost like, possessive over it.'* Nina also stated, *'... it is my body, it is my sugar.'*

Meanings made

It was evident in this study that the participants did not perceive themselves to be victims of diabetes but rather as being empowered by living with diabetes. By re-evaluating their experiences with diabetes, the participants were able to accommodate diabetes into their understanding of themselves and the world and set new health goals for themselves. The meanings made include acknowledging growth and strengths and discovering opportunities. The meanings made led to a reduced perception of diabetes as discrepant from global meaning.

Growth and strengths

Meaning making in the form of positive reappraisal had led to increased growth. The participants reported that, despite the challenges of diabetes, they had been positively changed by the experience, including adopting healthy behaviours, as expressed by Hope. When engaging with the participants' narratives, newly discovered strengths stood out, opening the doors to new ways of looking at diabetes and life. All of the participants named positive consequences of living with diabetes, including confidence, being organised,

improved self-awareness, an appreciation for life and health, and an increased appreciation for the '*small things in life*'. The participants reported an awareness of their inner strength, and Sarah indicated that '*you learn so much more holistically about yourself*' and '*it taught me a lot about me*'. In line with Sarah, Karen stated, '*I think that, obviously, it changes your perspective completely and just kind of like evolves it, like your responsibility, your own health and stuff that's just changed in terms of like how I've matured.*'

Acknowledging growth and strengths was an integral part of each participant's meaning-making journey with diabetes and all of the participants spoke at length about newly discovered strengths.

Opportunities

Illness, according to Louw (1994), becomes an art when the individual is able to view the illness as an exceptional opportunity for personal growth and life purpose. All of the participants demonstrated a considerable amount of optimism. A significant finding was that most of the participants viewed diabetes as an opportunity to reach out and make a contribution to others living with chronic illnesses. Karen and Jenny were in the unique position of working within the medical field. Karen, an intern medical doctor, felt that she had more insight compared to her colleagues – '*I've been there, I've been the patient*'. She was grateful for having the personal experience and felt that it provided her with an advantage. She elaborated by saying that her journey with diabetes was one of the main reasons for wanting to become a doctor. Jenny, a dietitian, described using her personal experience with diabetes in her professional life and stated that working with diabetes was her '*passion*'. She went on to describe a list of activities that she was able to do while living with diabetes: '*For me, I live a completely normal life. There is nothing that I can't do that my friends can do. Well, nothing yet. Like I can go scuba diving, I can climb up a mountain if I want.*'

Carlia regarded her diagnosis as a '*massive blessing*' and stated that she believed that she was healthier at the time of the research than before her diagnosis, viewing diabetes as

an opportunity for better health. Hope also viewed diabetes as an opportunity for a healthier life. Nina, a law student, hoped that one day she could make changes within medical law. She found it valuable to '*give back*' by hosting talks about diabetes and assisting others with diabetes. Sarah also found it meaningful to assist a young boy with living with diabetes. As has been illustrated above, it can be concluded that the participants had meaningful experiences with diabetes, based upon the emergence of new perspectives, discovering strengths, and finding new opportunities.

Discussion

Roussi and Avdi (2008) argue that the construction of meaning is central to the illness experience. The results of the present study demonstrate the significance of meaning making in adjusting to a life with diabetes. The results of this study demonstrate the emergence of three superordinate themes: (1) the process of reappraising a life with diabetes; (2) the development of diabetes as a lifestyle; and (3) meanings made. Together, these themes illustrate the meaning-making process of young adult women living with type 1 diabetes.

An understanding of the findings of this study, supported by existing literature, can be understood from Park and Folkman's (1997) meaning-making model. When facing a difficult situation that challenges the existing view of the world, individuals attempt to integrate this situation into their view of themselves and the world, through a search for meaning (Papadopoulou, Johnston, & Themessl-Huber, 2015; Park, 2010). The results of the current study indicate that initially, the participants experienced a wide range of emotions and challenges in reaction to the diagnosis. Such challenges include some people's social ignorance of diabetes, the experience of feeling different, experiencing days where diabetes is not fully controlled, and concerns regarding the future and complications. Previous research has also revealed emotional distress that occurred when being diagnosed with diabetes (Flynn, 2014). The results of the current study highlight that psychological needs co-exist with physical needs. Being diagnosed with a serious illness can violate important global beliefs,

including one's sense of personal control and goals for the future (Jim & Jacobson, 2008; Park, 2010). Within the current study, a violation of global beliefs was evident in the participants asking 'why me?' and their initial concerns about the future.

Park and Folkman (1997) theorised meaning making as both a process and an outcome. In the current study, all of the participants made meaning in these two ways. Similar to the findings by Park and Folkman (1997), the results of the current study indicate that the acceptance of diabetes played an essential role in the participants' meaning-making process and initiated the process of integrating diabetes into the individuals' lives, goals, and views of the world. Knowledge allowed the young women to manage their condition by integrating self-management as a part of their lives. The participants had to adjust their lifestyle, adopt self-management behaviours, and gain more knowledge about diabetes in order to integrate and accept diabetes as a part of their lives. These behavioural changes assisted in the meaning-making process. This finding is in line with those of a study by Smith et al. (2018), indicating that glucose control was achieved once diabetes was accepted as a part of life. The positive impact of support from others assisted the participants to make meaning of their condition and make it manageable. This is in line with existing literature (e.g. Visagie, Van Rensburg, & Deacon, 2018). The depth of responsibility held by healthcare professionals was highlighted as they played a key role in the participants' appraisal of diabetes.

As outcomes, a reappraisal of diabetes was found, as well as a revision of global beliefs. According to Park and Folkman's (1997) meaning-making model, it is crucial to integrate one's understanding (appraisal) of the condition with one's global meaning to reduce the discrepancy between them. In the current study, meaning making involved attempts to fit the understanding of diabetes together with global meaning to reduce the discrepancy between them. As such, the participants shifted their view of diabetes in a more positive direction over the course of time and reconsidered their view of life. All participants considered diabetes to be manageable and a positive aspect of their lives. Personal growth was reported

by all participants. As time progressed, the participants developed a positive representation of diabetes. This finding is similar to Liamputtong and Suwankhong's (2016) findings on women living with cancer. In the current study, all of the participants reflected on newly found benefits, strengths, growth, and opportunities. Optimism was evident in the study, as the participants could look at their lives with positive prospects, despite living with diabetes. It was indicated that the participants' meaning making was a reframing process through assigning a new meaning to diabetes, resulting in a new view of the self and of life. This is mirrored in research by Park (2010). According to Park and Folkman (1997), meaning making takes place when the reappraised meaning of a situation and the individual's global beliefs are congruent. In the current study, all of the participants viewed diabetes as a part of themselves, and over time, diabetes was not viewed as a factor that would interfere with their future. Making meaning in difficult situations has been shown to increase subjective well-being, gain a better quality of life, and decrease levels of distress (Liamputtong & Suwakhong, 2016; Papadopoulou et al., 2015).

In conclusion, within the current study, the meaning-making process included changes in the appraisal of diabetes as well as changes in global meaning, such as growth and a change in the view of the world. According to Park (2013), meaning making usually involves looking for a more favourable understanding of a situation and the implications thereof. This process may lead to better adjustment. In the current study, the meaning-making process assisted the participants in changing their understanding of diabetes and the implications thereof for their lives and their ability to manage diabetes in a more positive direction. They made meaning in terms of making sense of diabetes but also restored a sense of meaningfulness that was initially threatened by the diagnosis. The significance of meaning making when adjusting to living with type 1 diabetes was evident.

Implications of the findings

There are a number of implications of the study findings. The participating young women all described a wide range of emotions experienced in their journey with diabetes and spoke of the psychological impact of diabetes. The findings of this study call diabetes care to be considered in more holistic terms, whereby the meaning-making process is included. This is in line with the World Health Organisation's (n.d.) definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (para. 1). An awareness of the psychological needs that may be experienced by people living with type 1 diabetes should be fostered among healthcare professionals. The inclusion of screening tools to explore potential psychological challenges and appropriate referrals to psychological services may be beneficial within the context of health care. Healthcare professionals could take a preventative and proactive approach and offer courses or support groups on the psychological impact of diabetes and the meaning-making process in order to meet the psychological needs of people with diabetes. The meaning-making process is related to better psychological adjustment (Park, Edmondson, Fenster, & Blank, 2008). The findings of the current study suggest that by including aspects of meaning making in type 1 diabetes care, it is likely that the quality of life of people with diabetes will be improved.

The American Diabetes Association (2017) recommends that psychosocial care should be integrated into diabetes care and be provided to all people with diabetes, with the goal of optimising health outcomes and health-related quality of life. Within this study, it was highlighted that physical health can have an impact on psychological health and that looking at the individual holistically has potential benefits. Therefore, the inclusion of a psychologist at diabetes clinics in South Africa is recommended. Psychological support could be aimed at assisting people living with type 1 diabetes with integrating diabetes into their lives and developing a healthy meaning of diabetes by assimilating diabetes into their lives, thereby improving the quality of care.

The findings of the study illustrate the importance of recognising that individuals have a separate identity to type 1 diabetes. This is in line with the *Guidelines on Diabetes Care* of the American Diabetes Association (2016): 'In alignment with the position that diabetes does not define people, the word "diabetic" will no longer be used when referring to individuals with diabetes.' Healthcare professionals seemed to play a crucial role in the participants' meaning-making process, and thus healthcare professionals should ensure that they give sufficient support and information in order to assist individuals in developing a healthy understanding of how diabetes will be incorporated into their lives, empowering them in the process.

Parents, friends, and family appeared to play a crucial role in the young women's meaning making of diabetes, and providing education about diabetes to the support structures could further stimulate the process of learning to live with diabetes. Support groups could also prove to be beneficial, as most of the participants indicated a desire to receive support from others.

Limitations and future research

The homogeneity of the sample and the small sample size limit the generalisability of the meaning-making experience to the larger population of individuals living with type 1 diabetes. However, this is typical of an IPA study (Smith et al., 2009), and it should be noted that the current study yielded fundamental insight into the subjective experiences of making meaning of living with diabetes. An examination of the meaning-making process for male individuals would be a useful extension of the current study. Further research could also consider the perspectives of different age groups. Age groups should be examined separately due to different life roles and experiences within each stage of life, specifically regarding meaning making and type 1 diabetes. It is important to note that the participants in the study all attended a specialist centre, and not all people living with diabetes have access to high-quality medical care. Thus, the findings of the study cannot be generalised to other populations. Future research on the topic of meaning making could make use of both

qualitative and quantitative methods as well as an increased sample size. Research on the same topic in rural areas could also provide valuable insight. This might enable a more in-depth exploration of the meaning-making process, and new emergent themes could arise. Within this study there was a difference in the duration of diagnosis. A further limitation is that the time elapsed since diagnosis may play an important role in meaning making (Davis, Nolen-Hoeksema, & Larson, 1998). Studies tracking global and appraised meaning over the course of time are recommended, whereby the process of meaning making could be determined as well as changes in meaning over time. In an effort to further understand the phenomenon of meaning making in the context of diabetes, it would be beneficial to examine its relation to several variables, for example self-management regimen variables.

Despite these limitations, the researcher believes that the study offers valuable information to support the notion that meaning making is important for women living with diabetes and meaning making can be facilitated through the provision of information on diabetes self-management and support from others.

Conclusion

The study investigated the meaning-making process of young adult women living with type 1 diabetes. It helped provide a more in-depth understanding of life with diabetes. The study contributes to the conceptual understanding of meaning making and the experience of living with diabetes among young adult women. It is suggested that people living with diabetes may benefit from the meaning-making process as suggested above.

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Conflict of interest

The first author lives with type 1 diabetes. To avoid bias in the findings of this study, she kept a reflective journal throughout the research process and all themes were supported

by verbatim extracts to ensure that the participants' true accounts were reflected in the data. In addition, a co-coder and regular discussions with the research supervisors were used.

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2.3 Manuscript References

- American Diabetes Association. (2016). Standards of medical care in diabetes. *Diabetes Care*, 39, 54–55. Retrieved from http://care.diabetesjournals.org/content/suppl/2015/12/21/39.Supplement_1.DC2/2016-Standards-of-Care.pdf
- American Diabetes Association. (2017). Lifestyle Management. *Diabetes Care*, 40, 33–43. <https://doi.org/10.2337/dc17-S007>
- Anderson, B. J. (2006). Families and chronic illness research: Targeting transitions and tools. *The Journal of Collaborative Family Healthcare*, 24(3), 332–335. doi:10.1037/1091-7527.24.3.332
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469–480. doi:10.1037//0003-066X.55.5.469
- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *The Lancet*, 383, 69–82. doi:10.1016/S0140-6736(13)60591-7
- Brocki, J., & Wearden, A. (2006). A critical evaluation of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21, 87–108. <https://doi.org/10.1080/14768320500230185>
- Buchhorn, E., Damiao, C., Marques, C., & Pinto, M. (2007). Being transformed by illness: Adolescents' diabetes experience. *Revista Latino-Americano de Enfermagem*, 15(4), 568–574. doi:10.1590/S0104-11692007000400008

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

- Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 diabetes through the life span: A positive statement of the American Diabetes Association. *Diabetes Care*, 37, 2034–2054. doi:10.2337/dc14-1140
- Cruz, I. I. (2014). *The lived experience of insulin-dependent diabetes among adult Latinos in a primary care clinic in San Antonio* (Unpublished doctoral thesis). University of Iowa, Iowa City, IA. Retrieved from <http://ir.uiowa.edu/cgi/viewcontent.cgi?article=5485&context=etd>
- Daneman, D., Frank, M., & Perlman, K. (2002). *When a child has diabetes*. Toronto: Key Porter.
- Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two constructs of meaning. *Journal of Personality and Social Psychology*, 75, 561–574. doi:10.1037/0022-3514.75.2.561
- Delamater, A. M., De Wit, M., McDarby, V., Malik, J. A., Hillard, M. E., Northam, E., & Acerini, C. L. (2018). ISPAD clinical practice consensus guidelines 2018: Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes*, 19, 237–249. doi:10.1111/pedi.12736
- DiMeglio, L. A., Evans-Molina, C., & Oram, R. A. (2018). Type 1 diabetes. *The Lancet*, 391, 2449–2462. doi:10.1016/S0140-6736(18)31320-5
- Flynn, R. (2014). Insulin resistance... The psychological kind: Emotional aspects of injecting insulin. *South African Journal of Diabetes*, 7(3), 17–20.
- Foster, E. S. (2009). *Adolescents' experience of 'adjustment' to life with diabetes: An interpretative phenomenological analysis* (Unpublished doctoral thesis). University of Hertfordshire, Hertfordshire, UK. Retrieved from <http://uhra.herts.ac.uk/bitstream/handle/2299/4519/Emily%20Foster%20-%20DClinPsy%20research%20thesis.pdf?sequence=1>
- Frankl, V. E. (1964). *Man's search for meaning*. London: Hodder and Stoughton.

- Garvey, K. C., Howard, A., & Wolpert, M. D. (2011). Identifying the unique needs of transition care for young adults with type 1 diabetes. *Diabetes Spectrum*, 24(1), 22–24. <https://doi.org/10.2337/diaspect.24.1.22>
- Holt, R. I. G., & Hanley, N. A. (2012). *Essential endocrinology and diabetes*. London: John Wiley & Sons.
- Hornsten, A., Sandstrom, H., & Lundman, B. (2004). Personal understandings of illness among people with type 2 diabetes. *Journal of Advanced Nursing*, 47(2), 174–182. doi:10.1111/j.1365-2648.2004.03076.x
- Jim, H. S., & Jacobsen, P. B. (2008). Posttraumatic stress and posttraumatic growth in cancer survivorship: A review. *Cancer Journal*, 14, 414–419. doi:10.1097/PP).0b013e31818d8963
- Kay, C., Davies, J., Gamsu, D., & Jarman, M. (2009). An exploration of the experiences of young women living with type 1 diabetes. *Journal of Health Psychology*, 14(2), 242–250. doi:10.1177/1359105308100208
- Lacham, M. E., & Agrigoroaei, S. (2010). Promoting functional health in midlife and old age: Long-term protective effects of control beliefs, social support, and physical exercise. *Public Library of Science One*, 5(10), e13297. doi:10.1371/journal.pone.0013297
- Liamputtong, P., & Suwankhong, D. (2016). Living with breast cancer: The experiences and meaning-making among women in Southern Thailand. *European Journal of Cancer Care*, 25, 371–380. doi:10.1111/ecc.12321
- Louw, D. J. (1994). *Illness as crisis and challenge: Guidelines for pastoral care*. Doornfontein: Orion.
- McCarthy, M. M., & Grey, M. (2018). Type 1 diabetes self-management from emerging adulthood through older adulthood. *Diabetes Care*, 41, 1608–1614. <https://doi.org/10.2337/dc17-2597>

- McLean, K., & Breen, A. V. (2009). Processes and content of narrative identity development in adolescence: Gender and well-being. *Developmental Psychology, 45*, 702–710. doi:10.1037/a0015207
- National Institute of Clinical and Health Excellence. (2015). *Type 1 diabetes in adults: Diagnosis and management (NG17)*. Retrieved from <https://www.nice.org.uk/guidance/ng17>
- Papadopoulou, C., Johnston, B., & Themessl-Huber, M. (2015). Decay, transformation, and growth: Meaning-making processes of patients with acute leukemia within the first year after diagnosis or relapse. *Oncology Nursing Forum, 43*(2), 73–81. doi:10.1188/16.ONF.E73-E81
- Park C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology 1*, 115–144. doi:10.1037/1089-2680.1.2.115
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin, 136*, 257–301. doi:10.1037/a0018301
- Park, C. L. (2013). The meaning making model: A framework for understanding meaning, spirituality, and stress-related growth in health psychology, *The European Health Psychologist, 15*(2), 40–47. doi:10.7213/revistapistispraxis.06.001.DS01
- Park, C. L., Edmondson, D., Fenster, J. R., & Blank, T. O. (2008). Meaning making and psychological adjustment following cancer: The mediating roles of growth, life meaning and restored just world beliefs. *Journal of Consulting and Clinical Psychology, 76*, 863–875. doi:10.1037/a0013348
- Pastor, A., O'Brien, C. L., Teng, J., Conn, J., Loh, M., Collins, L., MacIsaac, R. J., & Bonomo, Y. (2018). Experiences of young adults with type 1 diabetes while using alcohol and recreational drugs: An interpretative phenomenological analysis (IPA) of

- semi-structured interviews. *Diabetes Research and Clinical Practice*, 141, 47–55.
doi:10.1016/j.diabres.2018.04.029
- Peters, A., & Laffel, L. Diabetes care for emerging adults: Recommendations for transitions from pediatric to adult diabetes care systems. *Diabetes Care*, 34, 2477–2485.
<https://doi.org/10.2337/dc11-1723>
- Pihlaskari, A. K., Wiebe, D. J., Troxel, N. R., & Stewart, S. M. (2018). Perceived peer support and diabetes management from adolescence into early emerging adulthood. *Health Psychology*, 37(11). <http://dx.doi.org/10.1037/hea000062>
- Rassart, J., Luyckx, K., Oris, L., Eveline, G., Moons, P., & Weets, I. (2016). Coping with type 1 diabetes through emerging adulthood: Longitudinal associations with perceived control and haemoglobin A1c. *Psychology & Health*, 31(5), 622–635.
doi:10.1080/08870446.2016.114753
- Roussi, P., & Avdi, E. (2008). Meaning-making and chronic illness: Cognitive and narrative approaches. *Hellenic Journal of Psychology*, 5, 147–178. Retrieved from <http://www.pseve.org/journal/UPLOAD/roussi5b.pdf>
- Seligman, M. E. P. (2011). *Flourish: A new understanding of happiness and well-being*. London: Nicholas Brealy.
- Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Sciences and Medicine*, 62, 1153–1166. doi:10.1016/j.socscimed.2005.07.010
- Sherman, A. C., & Simonton, S. (2012). Effects of personal meaning among patients in primary and specialized care: Associations with psychosocial and physical outcomes. *Psychology & Health*, 27(4), 475–490. doi:10.1080/08870446.2011.592983
- Smith, D. M., Donnelly, P. J., Howe, J., Mumford, T., Campbell, A., Ruddock, A., Tierney, S., & Wearden, A. (2018). A qualitative interview study of people living with well-controlled type 1 diabetes. *Psychology & Health*, 33(7), 872–887.
doi:10.1080/08870446.2017.1423313

- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory method and research*. London: Sage.
- Steger, C. R., Oishi, S., & Kashdan, T. B. (2009). Meaning in life across the life span: Levels and correlates of meaning in life from emerging adulthood to older adulthood. *The Journal of Positive Psychology*, 4(1), 43–52. doi:10.1080/17439760802303127
- Steger, M. F. (2009). Meaning in life. In S. J. Lopez (Ed.), *Oxford handbook of positive psychology* (2nd ed.) (pp. 679–687). Oxford: Oxford University Press.
- Stuckey, H. L., & Tisdell, E. J. (2010). The role of creative expressions in diabetes: An exploration in the meaning-making process. *Qualitative Health Research*, 20, 42–56. doi:10.1177/1049732309355286
- Visagie, E., Van Rensburg, E., & Deacon, E. (2018). Social support effects on diabetes management by South African emerging adults: A replication and extension study. *Journal of Psychology in Africa*, 28(6), 504–509. doi:10.1080/14330237.2018.1544392
- Wallander, J. L., Thompson, R. J., & Alriksson-Schmidt, A. (2003). Psychosocial adjustment of children with chronic physical conditions. In M. C. Roberts (Ed.), *Handbook of pediatric psychology* (3rd ed.) (pp. 141–158). New York, NY: The Guilford Press.
- Watts, S., O'Hara, L., & Trigg, R. (2010). Living with type 1 diabetes: A by-person qualitative exploration. *Psychology and Health*, 25(4), 491–506. doi:10.1080/08870440802688588
- Willemse, M. (2018). *Diabetes management behaviours of young adults towards psychological well-being* (Unpublished doctoral thesis). North-West University, Vaal Triangle Campus.
- World Health Organisation. (2016). *Global report on diabetes*. Paris: World Health Organisation Press.

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

World Health Organisation. (n.d.). *Frequently asked questions*. Retrieved from <http://www.who.int/suggestions/faq/en/>

Section III: Critical Reflection

3.1 Introduction

This section of the study entails a personal critical reflection by the researcher on her overall experience of this study. The critical reflection on the researcher's experience regarding this qualitative research process includes a discussion of the research topic, the research design, the participants, data collection and analysis, the conclusion of the findings, the significance of the study, the limitations of the study, recommendations, and the researcher's personal reflection on the process.

3.2 Research Topic

The researcher and her supervisors shared a mutual interest in diabetes before the commencement of the study. The researcher consulted literature to identify understudied topics relating to diabetes. It became evident that there is a lack of qualitative research on type 1 diabetes. The American Diabetes Association (cited in Chiang, Kirkman, Laffel, & Peters, 2014) recommends that during young adulthood, the topic of the personal meaning of diabetes should be addressed in order to adjust to living with diabetes. Research (e.g. Park, 2013; Sherman & Simonton, 2012) has shown that meaning is an essential aspect in adjusting to a chronic condition. Research on the topic of meaning has been conducted in the context of other chronic illnesses, such as cancer (Liamputtong & Suwakhong, 2016; Papadopoulou, Johnston, & Themessl-Huber, 2015; Park, Edmondson, Fenster, & Blank, 2008). However, limited studies investigating meaning in the context of diabetes were found. Moreover, a gap between the knowledge of diabetes as a medical condition and the lived experience of diabetes was identified (Cruz, 2014). To address this gap, the current study set out to gain an in-depth understanding of young adult women's meaning making of living with type 1 diabetes.

The aim of the study was to explore the meaning-making process of young adult women between the ages of 18 and 25 living with type 1 diabetes. The formulated research

question was: 'How do young adult women between the ages of 18 and 25 make meaning of living with type 1 diabetes?'

3.3 Research Design

The researcher explored young adult women's personal experiences of meaning making of living with type 1 diabetes. As such, a qualitative research method, namely interpretative phenomenological analysis (IPA), was deemed appropriate for the study. According to Smith, Flowers, and Larkin (2009), IPA enables researchers to gain insight into the meanings and lived experiences of phenomena. IPA is committed to examining how individuals make sense of major life experiences. IPA is based on the premise that humans are 'sense-making creatures' (Smith et al., 2009, p. 9), with the implication that participants' accounts will reflect their attempts to make meaning of their experience. Thus, IPA made it possible to gain an in-depth understanding of young women's meaning-making process.

3.4 Participants

As recommended by IPA literature (cf. Smith et al., 2009), a homogenous, purposive sampling method was utilised, ensuring the selection of participants based on the phenomena they experienced. The participants in the study were six young women between the ages of 18 and 25 years living with type 1 diabetes for at least one year. All of the participants attended the same diabetes clinic – the Centre for Diabetes and Endocrinology in Parktown, Johannesburg. The participants were neither diagnosed with other chronic illnesses nor receiving psychotherapy at the time of the study. This is an acceptable sample size according to IPA literature (cf. Smith et al., 2009) and allowed for a rich account that captured the essence of the participants' lived experiences and could be analysed in depth.

3.5 Data Collection and Analysis

Data were obtained by means of in-depth semi-structured interviews, as recommended by Smith et al. (2009), to obtain an in-depth understanding of the women's meaning-making process of living with diabetes. The researcher spent a large amount of time

creating open-ended questions for the semi-structured interviews that would capture the essence of the participants' life worlds. To accomplish this, relevant literature, previous studies on the topic of meaning, and the research supervisors were consulted. Two interview questions were generated, the first being 'Please tell me more about yourself' and the second 'Tell me about your journey of meaning making in living with diabetes'. The researcher probed further to obtain an in-depth understanding of the participants' accounts. The interviews were audio recorded, transcribed, and analysed using the principles of IPA (cf. Smith et al., 2009). The researcher spent ample time becoming familiar with the participants' accounts. Identifying themes was time consuming, although it came relatively naturally, as there were many repetitive themes in the transcripts. However, organising subthemes proved challenging, as many of the themes overlapped. Given the fact that the researcher has personal experience with diabetes, she remained mindful of possible bias throughout the process. Themes were co-coded by the research supervisor to ensure validity. Subsequently, the results were written in a narrative account, where the researcher's interpretation is presented and is supported by verbatim extracts from the participants' accounts in the form of a research article.

3.6 Conclusion of the Findings

The literature on IPA recommends that results should be considered against relevant literature (Smith et al., 2009). Therefore, the results were considered against the backdrop of literature on meaning, specifically the meaning-making model of Park and Folkman (1997).

The IPA delivered three superordinate themes: (1) the process of reappraising a life with diabetes; (2) the development of diabetes as a lifestyle; and (3) meanings made. The themes that developed from the study contribute to the understanding of the meaning-making process of young adult women living with type 1 diabetes. The first two themes serve as processes of meaning making, and the third theme as an outcome of meanings made. A summary of the themes with verbatim extracts is presented in Annexure E.

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The first theme conveyed the process of reappraising a life with diabetes. The participants reported that initially, diabetes was a shock and they felt overwhelmed, without adequate knowledge of what diabetes was or what it would mean for their lives. This is indicative of a discrepancy between the individuals' appraised meaning of diabetes and the global meaning thereof. This discrepancy led to emotional distress. Having lived with diabetes for a while, the participants experienced various challenges of living with diabetes. They experienced others as having faulty perceptions of what diabetes was. The participants reported feeling different and having lost a sense of normality. All of the participants reflected on the psychological impact of living with diabetes. Concerns regarding the future were evident in the participants' accounts, reflecting a threat to their future goals; however, these acted as a motivating factor to manage their diabetes.

The second theme represents a process of developing diabetes as a lifestyle. For all of the participants, diabetes became a way of life over time. Support from parents, family, friends, and healthcare professionals, as well as relating to others with diabetes, contributed to the participants making meaning of diabetes. The knowledge that healthcare professionals provided was especially valuable, and some participants reflected on the value of psychological services in their meaning-making process. The support and knowledge obtained assisted the participants in viewing diabetes as a manageable condition and integrating diabetes into their lives. All of the participants viewed knowledge as crucial to making meaning of diabetes. Accepting diabetes as a part of one's life involved adopting a self-management regimen, taking self-responsibility for diabetes, and the realisation that diabetes is permanent and a healthy life can still be lived despite diabetes. Acceptance of diabetes was related to the realisation that diabetes cannot be perfectly managed and difficult days will occur. This theme also represented a start in the change of the participants' appraisal of diabetes.

The final theme reflects an outcome of meanings made. All of the participants changed their appraisal of diabetes into a positive representation. They could expand on newly found

strengths, growth, and opportunities they were able to experience as a result of living with diabetes. Diabetes was not viewed as different from their global beliefs but was integrated into their view of themselves and the world.

Throughout the participants' accounts it was evident that initially, diabetes was viewed as a threat to their view of themselves, the world, and their future goals. However, over time, diabetes was integrated into their view of themselves, and the world and no longer viewed as a threat but rather an empowering experience. Fundamentally, the study's findings are grounded in the participants' accounts. As a result, the aim of the study, namely to gain an in-depth understanding of the meaning-making process of young adult women with type 1 diabetes, has been met.

From the findings, it is clear that meaning is an important factor in living with diabetes. The findings of this study gave valuable insight into the meaning-making process of young women living with type 1 diabetes. It was evident that not only medical treatment for diabetes is needed but also a holistic approach, where psychological needs are addressed as well.

3.7 Significance of the Study

Overall, the results of this study are believed to have made a positive contribution to the literature on meaning and diabetes. Understanding how young women make meaning of diabetes adds value to understanding diabetes as a lived experience. The study may also lay the foundation upon which an intervention can be built for people living with diabetes, with the inclusion of the meaning-making process.

In the study, it is indicated that support plays a valuable role in accepting and integrating diabetes into one's life. As such, the study can lay the foundation upon which support groups for people living with diabetes can be created.

3.8 Limitations of the Study

IPA literature recommends the inclusion of a small sample size to obtain an in-depth understanding of phenomena (Smith et al., 2009). Smith et al. (2009) argue that in-depth

interviews are sufficient to establish the nature of shared phenomena. However, the relevance of the findings for the entire population of people living with type 1 diabetes is limited due to the limited demographic variation of the qualitative research study.

Another aspect of the study that should be considered is the participants' socio-economic status. All of the participants in the study attended the same diabetes clinic. The reality in South Africa is that not all people have access to quality medical care. Thus an accurate representation of all groups was not obtained. Therefore the relevance to other young women living with type 1 diabetes and type 2 diabetes is limited.

3.9 Recommendations

In light of the limitations stipulated above, the following recommendations could be made for future research:

- A future possibility for research could be to conduct a longitudinal study that would be able to provide more thorough and rich information with regard to the meaning-making process over time.
- More studies that aim to develop intervention programmes with the process of meaning making in mind are warranted.
- The results and findings of this study should be considered by healthcare professionals when working with people with diabetes.
- Prospective research should include more demographic variation and treatment regimens to explore whether the findings of the current study can be generalised.
- It is advisable that this study is replicated in different age groups and different contexts in order to determine the generalisability of the study.

3.10 Reflection by the Researcher

Reflexivity is a necessary part of qualitative research (Palaganas, Sanchez, Molintas, & Caricativo, 2017; Willig, 2013). The researcher's own values, interests, and assumptions were considered throughout the research process. Throughout the research, I found it

valuable to reflect on the process. Reflectivity was accomplished by keeping a reflective journal and through supervision by my research supervisors.

The experience of this study was valuable and a personal growth experience, not only as someone living with diabetes but especially as an intern psychologist. I was diagnosed with type 1 diabetes in 2005, and psychologically and physically, it initially had a major impact on me. However, over time, diabetes became a way of life. This made me wonder: How do people accept the diagnosis of diabetes and make meaning of their diagnosis? Prior to embarking on the research process, I was aware of my own experiences and ideas about diabetes. However, I approached the interview transcripts with an open mind and ensured that my interpretations were grounded in the data by using verbatim extracts from the transcripts. I found that my supervisors' feedback and suggestions improved my skills as a researcher.

Throughout the study, I aimed to explore the participants' lived experiences in an empathetic manner. While engaging with the participants' accounts, I was particularly struck by the positive way in which the young women spoke about diabetes. I felt privileged that the participants shared their experience with me. At times during the interviews, I was tempted to ask therapeutic questions as an intern psychologist; however, I was mindful of this throughout the study and only used questions from the interview schedule. This research process enabled me to learn more about the meaning-making process of young women living with type 1 diabetes.

The most challenging part of the research process was finding literature on meaning in the context of diabetes. However, this challenge emphasised the gap in the literature and confirmed that the study would make a valuable contribution. My aim with the current research was to answer the question: How do young adult women between the ages of 18 and 25 make meaning of living with type 1 diabetes? It was clear from the findings that this aim was met and an in-depth understanding of the phenomenon was obtained.

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My overall experience during the process of this study has taught me a great deal about the research process. I have developed my skills as a researcher and broadened my world view. I have learnt how to properly plan and to probe and reflect in a sensitive manner. I, as a researcher, was able to broaden my knowledge and understanding of diabetes. Furthermore, through listening to the interviews, I have learnt much about my interview style. Reflecting on this skill and an awareness of asking open-ended questions are things I will continue to be aware of as a psychologist and as a researcher. I envision using all of the knowledge gained in putting forward a strong case for a PhD in the future.

This study challenged me in many ways but was an exceptional learning experience. Reflecting on my experience as a psychology student, my academic journey has been challenging but invaluable. This was a learning experience that expanded my knowledge. I am grateful for the opportunity to conduct research on a topic that I am passionate about. Overall, I feel passionate about my research study. It is my hope that the findings of this study will assist others living with type 1 diabetes.

COMPLETE REFERENCE LIST

- Abualula, N. A., Jacobsen, K. H., Milligan, R. A., Rodan, M. F., & Conn, V. S. (2016). Evaluating diabetes educational interventions with a skill development component in adolescents with type 1 diabetes: A systematic review focusing on quality of life. *The Diabetes Educator*, 42(5), 515-528. doi:10.1177/0145721716658356
- Alea, N., & Bluck, S. (2013). When does meaning making predict subjective well-being? Examining young and older adults in two cultures. *Memory*, 21(1), 44-63. doi:10.1080/09658211.2012.704927
- Ali, N. (2011). *Diabetes and you: A comprehensive, holistic approach*. Plymouth, UK: Rowman & Littlefield.
- American Diabetes Association. (2016). Foundations of care and comprehensive medical evaluation. *Diabetes Care*, 39(1), 25-35. doi:10.2337/dc16-S006
- American Diabetes Association. (2016). Standards of medical care in diabetes. *Diabetes Care*, 39, 54-55. Retrieved from http://care.diabetesjournals.org/content/suppl/2015/12/21/39.Supplement_1.DC2/2016-Standards-of-Care.pdf
- American Diabetes Association. (2017). Lifestyle Management. *Diabetes Care*, 40, 33-43. <https://doi.org/10.2337/dc17-S007>
- Anderson, B. J. (2006). Families and chronic illness research: Targeting transitions and tools. *The Journal of Collaborative Family Healthcare*, 24(3), 332-335. doi:10.1037/1091-7527.24.3.332
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480. doi:10.1037//0003-066X.55.5.469
- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *The Lancet*, 383, 69-82. doi:10.1016/S0140-6736(13)60591-7

- Bliss, M. (1982). *The discovery of insulin*. Chicago, IL: University of Chicago.
- Brocki, J., & Wearden, A. (2006). A critical evaluation of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health, 21*, 87-108.
<https://doi.org/10.1080/14768320500230185>
- Brown, O. (2014). Psychological considerations in the management of diabetes. *South African Journal of Diabetes and Vascular Disease, 11*, 133-136. Retrieved from <http://reference.sabinet.co.za/document/EJC159162>
- Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology, 70*, 70-84.
[doi:10.1016/j.psyneuen.2016.04.019](https://doi.org/10.1016/j.psyneuen.2016.04.019)
- Buchhorn, E., Damiao, C., Marques, C., & Pinto, M. (2007). Being transformed by illness: Adolescents' diabetes experience. *Revista Latino-Americano de Enfermagem, 15*(4), 568-574. [doi:10.1590/S0104-11692007000400008](https://doi.org/10.1590/S0104-11692007000400008)
- Carel, J. C., & Levy-Marchel, C. (2008). Renal complications of type 1 diabetes. *British Medical Journal, 336*, 677-678. [doi:10.1136/bmj.39517.508241.80](https://doi.org/10.1136/bmj.39517.508241.80)
- Carroll, A. E., & Marrero, D. G. (2006). The role of significant others in adolescent diabetes: A qualitative study. *Diabetes Educator, 32*(2), 243-252.
[doi:10.1177/0145721706286893](https://doi.org/10.1177/0145721706286893)
- Centre for Diabetes and Endocrinology. (2018). *Type 2 diabetes*. Retrieved from <http://www.cdediabetes.co.za/home/diabetes/type-2-diabetes.html>
- Chew, B. H., Khoo, E. M., & Chia, Y. C. (2015). Social support and glycemic control in adult patients with type 2 diabetes mellitus. *Asia-Pacific Journal of Public Health, 27*(2), 166-173. <https://doi.org/10.1177/1010539511431300>
- Cruz, I. I. (2014). *The lived experience of insulin-dependent diabetes among adult Latinos in a primary care clinic in San Antonia* (Unpublished doctoral thesis). University of Iowa,

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

- Iowa City, IA. Retrieved from
<http://ir.uiowa.edu/cgi/viewcontent.cgi?article=5485&context=etd>
- Daneman, D., Frank, M., & Perlman, K. (2002). *When a child has diabetes*. Toronto: Key Porter.
- Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two constructs of meaning. *Journal of Personality and Social Psychology*, 75, 561-574. doi:10.1037/0022-3514.75.2.561
- Delamater, A. M., De Wit, M., McDarby, V., Malik, J.A., Hillard, M. E., Northam, E., & Acerini, C. L. (2018). ISPAD clinical practice consensus guidelines 2018: Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes*, 19, 237-249. doi:10.1111/pedi.12736
- Dhada, B., Blackbeard, D., & Adams, G. (2014). Paediatric diabetes with a focus on the adolescent. *SA Journal of Diabetes and Vascular disease*, 11, 108-109. Retrieved from <http://reference.sabinet.co.za/document/EJC159169>
- DiMeglio, L. A., Evans-Molina, C., & Oram, R. A. (2018). Type 1 diabetes. *The Lancet*, 391, 2449-2462. doi:10.1016/S0140-6736(18)31320-5
- DiMeglio, L. A., Acerini, C. A., Codner, C., Craig, M. E., Hofree, S. E., Pillay, K., & Maahs, D. M. (2018). *Glycemic control targets and glucose monitoring for children and adolescents with type 1 diabetes*. Retrieved from https://cdn.ymaws.com/www.ispad.org/resource/dynamic/forums/20180403_042359_21137.pdf
- Eriksson, E. H. (1982). *The life cycle completed, a review*. New York, NY: Norton.
- Flynn, R. (2014). Insulin resistance... The psychological kind: Emotional aspects of injecting insulin. *South African Journal of Diabetes*, 7(3), 17-20.
- Foster, E. S. (2009). *Adolescents' experience of 'adjustment' to life with diabetes: An interpretative phenomenological analysis* (Unpublished doctoral thesis). University of

- Hertfordshire, Hertfordshire, UK. Retrieved from
<http://uhra.herts.ac.uk/bitstream/handle/2299/4519/Emily%20Foster%20-%20DClinPsy%20research%20thesis.pdf?sequence=1>
- Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health, 25*(10), 1229-1245. doi:10.1080/08870440903194015
- Frankl, V. E. (1964). *Man's search for meaning*. London: Hodder and Stoughton.
- Funnel, M. M., & Anderson, R. M. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes, 22*, 123-127. Retrieved from
<http://clinical.diabetesjournals.org/content/diaclin/22/3/123.full.pdf>
- Garvey, K. C., Howard, A., & Wolpert, M. D. (2011). Identifying the unique needs of transition care for young adults with type 1 diabetes. *Diabetes Spectrum, 24*(1), 22-24. <https://doi.org/10.2337/diaspect.24.1.22>
- Garvey, K. C., Telo, G. H., Needleman, J. S., Forbes, P., Finkelstein, J. A., & Laffel, L. M. (2016). Health care transitions in young adults with type 1 diabetes: Perspectives of adult endocrinologists in the U.S. *Diabetes Care, 39*, 190-197. doi:10.2337/dc15-1775
- Gomes, M. B., Santos, D. C., Pizarro, M. H., Barros, B. S. V., Melo, L. G. N., & Negrato, C. A. (2018). Does knowledge on diabetes management influence glycemic control? A nationwide study in patients with type 1 diabetes in Brazil. *Patient Preference and Adherence, 12*, 53-62. doi:10.2147/PPA.S146268
- Hicks, J. A., & King, L. A. (2009). Meaning in life as a subjective judgement and a lived experience. *Social and Personality Psychology Compass, 3*(4), 317-330. doi:10.1111/j.1751-9004.2009.00193.x

- Holt, R. I. G., & Hanley, N. A. (2012). *Essential endocrinology and diabetes*. London: John Wiley & Sons.
- Holt, T., & Kumar, S. (2012). Diagnosing diabetes. In T. Holt, & S. Kumar (Eds.), *ABC of diabetes* (pp. 115-138). London: Wiley & Sons.
- Hornsten, A., Sandstrom, H., & Lundman, B. (2004). Personal understandings of illness among people with type 2 diabetes. *Journal of Advanced Nursing*, 47(2), 174-182. doi: 10.1111/j.1365-2648.2004.03076.x
- International Diabetes Federation. (2008). *Diabetes: One of the most challenging health problems in the 21st Century*. Retrieved from <http://www.eatlas.idf.org/index.cfm>
- International Diabetes Federation. (2011). *Global IDF/ISPAD guideline for diabetes in childhood and adolescence*. Retrieved from <https://www.ispad.org/?page=IDFISPAD2011>
- International Diabetes Federation. (2017). *IDF Diabetes Atlas* (8th ed.). Retrieved from <http://diabetesatlas.org/resources/2017-atlas.html>
- Jacek, Z., Anil, S., Parini, P., & Leonid, P. (2010). *Principles of diabetes mellitus*. New York: Springer Science and Business Media.
- Jim, H. S., & Jacobsen, P. B. (2008). Posttraumatic stress and posttraumatic growth in cancer survivorship: A review. *Cancer Journal*, 14, 414-418. doi: 10.1097/PPO.0bo13e31818d8963
- Karlsson, A., Arman, M., & Wikblad, K. (2008). Teenagers with type 1 diabetes – A phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies*, 45, 562-570. doi:10.1016/j.ijnurstu.2006.08.022
- Kay, C., Davies, J., Gamsu, D., & Jarman, M. (2009). An exploration of the experiences of young women living with type 1 diabetes. *Journal of Health Psychology*, 14(2), 242-250. doi:10.1177/1359105308100208

- Keating, N., Eales, J., & Phillips, J. E. (2013). Age-friendly rural communities: Conceptualizing 'best-fit'. *Canadian Journal on Aging, 32*(4), 319-322. doi:10.1017/S07149808130004408
- La Greca, A. M., Swales, T., Klemp, S., Madigan, S., & Skyler, J. (1995). Adolescents with diabetes: Gender differences in psychosocial functioning and glycemic control. *Children's Health Care, 24*(1), 61-78. doi:10.1207/s15326888chc2401_6
- Lacham, M. E., & Agrigoroaei, S. (2010). Promoting functional health in midlife and old age: Long-term protective effects of control beliefs, social support, and physical exercise. *Public Library of Science One, 5*(10), e13297. doi:10.1371/journal.pone.0013297
- Larsen, P. D. (2016). The illness experience. In P. D. Larsen (Ed.), *Lubkin's chronic illness: Impact and intervention* (9th ed.) (pp. 21-42). Sudbury, MA: Jones and Barlett.
- Lee, Y. A. (2013). Diabetes care for emerging adults: Transitions from pediatric to adult diabetes care systems. *Annals of Pediatric Endocrinology and Metabolism, 18*(3), 106-110. doi:10.6065/apem.2013.18.3.106
- Lepore, S. J. (2001). A social-cognitive processing model of emotional adjustment to cancer. In A. Baum, & B. Anderson (Eds.), *Psychosocial interventions for cancer* (pp. 99-118). Washington, DC: American Psychological Association.
- Liamputtong, P., & Suwankhong, D. (2016). Living with breast cancer: The experiences and meaning-making among women in Southern Thailand. *European Journal of Cancer Care, 25*, 371-380. doi:10.1111/ecc.12321
- Lindell, A. K., Campione-Barr, N., & Killore, S. E. (2017). Implications of parent-child relationships for emerging adults' subjective feelings about adulthood. *Journal of Family Psychology, 31*(7), 810-820. doi:10.1037/fam0000328
- Louw, D. J. (1994). *Illness as crisis and challenge: Guidelines for pastoral care*. Doornfontein: Orion.

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

- Louw, D., & Louw, A. (2007). *Die ontwikkeling van die kind en die adolessent*. Bloemfontein: Psychology Publications.
- McCarthy, M. M., & Grey, M. (2018). Type 1 diabetes self-management from emerging adulthood through older adulthood. *Diabetes Care*, 41, 1608-1614.
<https://doi.org/10.2337/dc17-2597>
- McLean, K., & Breen, A. V. (2009). Processes and content of narrative identity development in adolescence: Gender and well-being. *Developmental Psychology*, 45, 702-710.
[doi:10.1037/a0015207](https://doi.org/10.1037/a0015207)
- National Institute for Health and Care Excellence. (2016). *Diabetes in children and young people (quality standard)*. Retrieved from <https://www.nice.org.uk/>
- National Institute of Clinical and Health Excellence. (2015). *Type 1 diabetes in adults: Diagnosis and management (NG17)*. Retrieved from <https://www.nice.org.uk/guidance/ng17>
- Palaganas, E. C., Sanchez, M. C., Molintas, M. P., & Caricativo, R. D. (2017). Reflexivity in qualitative research: A journey of learning. *The Qualitative Report*, 22(2), 426-438.
Retrieved from <https://nsuworks.nova.edu/tqr/vol22/iss2/5>
- Papadopoulou, C., Johnston, B., & Themessl-Huber, M. (2015). Decay, transformation, and growth: Meaning-making processes of patients with acute leukemia within the first year after diagnosis or relapse. *Oncology Nursing Forum*, 43(2), 73- 81.
[doi:10.1188/16.ONF.E73-E81](https://doi.org/10.1188/16.ONF.E73-E81)
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*, 136, 257-301. [doi:10.1037/a0018301](https://doi.org/10.1037/a0018301)
- Park, C. L. (2013). The meaning making model: A framework for understanding meaning, spirituality, and stress-related growth in health psychology, *The European Health Psychologist*, 15(2), 40-47. [doi:10.7213/revistapistispraxis.06.001.DS01](https://doi.org/10.7213/revistapistispraxis.06.001.DS01)

- Park, C. L., Edmondson, D., Fenster, J. R., & Blank, T. O. (2008). Meaning making and psychological adjustment following cancer: The mediating roles of growth, life meaning and restored just world beliefs. *Journal of Consulting and Clinical Psychology, 76*, 863-875. doi:10.1037/a0013348
- Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *General Review of Psychology, 1*, 115-144. doi:10.1037/1089-2680.1.2.115
- Park, C. L., Folkman, S., & Bostrom, A. (2001). Appraisals of controllability and coping in caregivers and HIV+ men: Testing the goodness-of-fit hypothesis. *Journal of Consulting and Clinical Psychology, 69*, 481-488. doi:10.1037/0022-006X.69.3.481
- Pastor, A., O'Brien, C. L., Teng, J., Conn, J., Loh, M., Collins, L., MacIsaac, R. J., & Bonomo, Y. (2018). Experiences of young adults with type 1 diabetes while using alcohol and recreational drugs: An interpretative phenomenological analysis (IPA) of semi-structured interviews. *Diabetes Research and Clinical Practice, 141*, 47-55. doi:10.1016/j.diabres.2018.04.029
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Peters, A., & Laffel, L. Diabetes care for emerging adults: Recommendations for transitions from pediatric to adult diabetes care systems. *Diabetes Care, 34*, 2477-2485. <https://doi.org/10.2337/dc11-1723>
- Pihlaskari, A. K., Wiebe, D. J., Troxel, N. R., & Stewart, S. M. (2018). Perceived peer support and diabetes management from adolescence into early emerging adulthood. *Health Psychology, 37*(11). <http://dx.doi.org/10.1037/hea000062>
- Pyatak, E. A., Sequeira, P. A., Vigen, C. L. P., Weigensberg, M. J., Wood, J. R., Montoya, ... Peters, A. L. (2017). Clinical and psychosocial outcomes of a structured transition program among young adults with type 1 diabetes. *Journal of Adolescent Health, 60*(2), 212-218. doi:10.1016/j.jadohealth.2016.09.004

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

- Rasmussen, B., Ward, G., Jenkins, A., King, S. J., & Dunning, T. (2011). Young adults' management of T1D during life transitions. *Journal of Clinical Nursing*, 20, 1981-1992. doi:10.1111/j.1365-2702.2010.03657.x
- Rassart, J., Luyckx, K., Oris, L., Eveline, G., Moons, P., & Weets, I. (2016). Coping with type 1 diabetes through emerging adulthood: Longitudinal associations with perceived control and haemoglobin A1c. *Psychology & Health*, 31(5), 622-635. doi:10.1080/08870446.2016.114753
- Robinson, E. (2015). Being diagnosed with type 1 diabetes during adolescence. How do young people develop a healthy understanding of diabetes. *Practical Diabetes*, 32, 339-334. doi:10.1002/pdi.1986
- Roussi, P., & Avdi, E. (2008). Meaning-making and chronic illness: Cognitive and narrative approaches. *Hellenic Journal of Psychology*, 5, 147-178. Retrieved from <http://www.pseve.org/journal/UPLOAD/roussi5b.pdf>
- Rubin, R. R., & Peyrot, M. (1999). Quality of life and diabetes. *Diabetes Metabolism Research and Reviews*, 15, 205-218.
- Schiotz, M. L., Bogelund, M., Almdal, T., Jensen, B. B., & Willaing, I. (2011). Education and psychological aspects social support and self-management behaviour among patients with type 2 diabetes. *Diabetic Medicine*, 29, 654-661. doi:10.1111/j.1464-5491.2011.03485.x
- Segal, D. (2010). A life with diabetes. *South African Journal of Diabetes*, 3, 13-16.
- Segal, D. (2015). Puberty and diabetes. *Living with Diabetes*, 3, 48-49.
- Segal, D. (2016). 10 commandments for better diabetes self-care. *Diabetes Lifestyle*, 2, 34-36.
- Seligman, M. E. P. (2011). *Flourish: A new understanding of happiness and well-being*. London: Nicholas Brealy.

- Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Sciences and Medicine*, 62, 1153-1166. doi:10.1016/j.socscimed.2005.07.010
- Sherman, A. C., & Simonton, S. (2012). Effects of personal meaning among patients in primary and specialized care: Associations with psychosocial and physical outcomes. *Psychology & Health*, 27(4), 475-490. doi:10.1080/08870446.2011.592983
- Smith, D. M., Donnelly, P. J., Howe, J., Mumford, T., Campbell, A., Ruddock, A., ... Wearden, A. (2018). A qualitative interview study of people living with well-controlled type 1 diabetes. *Psychology & Health*, 33(7), 872-887. doi:10.1080/08870446.2017.1423313
- Smith, J. A. (2011a). Evaluating the contribution of interpretative phenomenological analysis, *Health Psychology Review*, 5(1), 9-27. doi:10.1080/17437199.2010.510659
- Smith, J. A. (2011b). Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria. *Health Psychology Review*, 5(1), 55-61. doi:10.1080/17437199.2010.541743
- Smith, J. A. (2018). Yes it is phenomenological: A reply to Max van Manen's critique of interpretative phenomenological analysis. *Qualitative Health Research*, 28, 1995-1958. doi:10.1177/1049732318799577
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory method and research*. London: Sage.
- Stake, R. (2000). Case studies. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 236-247). Thousand Oaks, CA: Sage.
- Statistics South Africa. (2016). *Mortality and causes of death in South Africa, 2016: Findings from death notifications*. Retrieved from <http://www.statssa.gov.za/publications/P03093/P030932016.pdf>

- Steger, C. R., Oishi, S., & Kashdan, T. B. (2009). Meaning in life across the life span: Levels and correlates of meaning in life from emerging adulthood to older adulthood. *The Journal of Positive Psychology, 4*(1), 43-52. doi:10.1080/17439760802303127
- Steger, M. F. (2009). Meaning in life. In S. J. Lopez (Ed.), *Oxford handbook of positive psychology* (2nd ed.) (pp. 679-687). Oxford: Oxford University Press.
- Stuckey, H. L., & Tisdell, E. J. (2010). The role of creative expressions in diabetes: An exploration in the meaning-making process. *Qualitative Health Research, 20*, 42-56. doi: 10.1177/1049732309355286
- Swift, P. G. F. (2004). Diabetes in the young: past present and future. *Practical Diabetes, 21*, 54-60. doi: 10.1002/pdi.585
- Tattersall, R. (2009). *Diabetes: The biography*. London: Oxford University Press.
- Tracey, S. J. (2010). Qualitative quality: Eight 'big-tent' criteria for excellent quantitative research. *Qualitative Inquiry, 16*(10), 837-851. doi:10.1177/1077800410383121
- Tripathy, B. B. (2012). Definition, diagnosis and classification. In B. B. Tripathy (Ed.), *RSSDI Textbook of diabetes mellitus* (2nd ed.) (pp. 121-140). New Delhi: Jaypee Brothers Medical Publishers.
- Tuomilehto, J. (2013). The emerging global epidemic of type 1 diabetes. *Current Diabetes Reports, 13*(6), 795-804. doi:10.4102/phcfm.v5il.375
- Vaccaro, J. A., Exebio, J. C., Zarini, G. G., & Huffman, F. G. (2014). The role of family/friend social support in diabetes self-management for minorities with type 2 diabetes. *Journal of Nutrition and Health, 2*(1), 1-9.
- Van der Merwe, A. (2015). *Managing diabetes and related health challenges*. Cape Town: Human & Rousseau.
- Visagie, E., Van Rensburg, E., & Deacon, E. (2018). Social support effects on diabetes management by South African emerging adults: A replication and extension study.

- Journal of Psychology in Africa*, 28(6), 504-509.
doi:10.1080/14330237.2018.1544392
- Wallerstein, J. L., Thompson, R. J., & Alriksson-Schmidt, A. (2003). Psychosocial adjustment of children with chronic physical conditions. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology* (pp. 141-158). New York, NY: The Guilford Press.
- Watts, S., O'Hara, L., & Trigg, R. (2010). Living with type 1 diabetes: A by-person qualitative exploration. *Psychology and Health*, 25(4), 491-506. doi: 10.1080/08870440802688588
- Willemsse, M. (2018). *Diabetes management behaviours of young adults towards psychological well-being* (Unpublished doctoral thesis). North-West University, Vaal Triangle Campus.
- Willig, C. (2013). *Introducing qualitative research in psychology*. New York, NY: McGraw-Hill.
- Wissing, M. P. (2014). *Towards flourishing: Contextualising positive psychology*. Pretoria: Van Schaik.
- Wolpert, H. A. (2001). Young adults with diabetes. *Diabetes Care*, 24(9), 151-152.
doi:10.1186/1472-6823-13-25
- Wong, P. T. P. (2012). *Acceptance & well-being: A meaning-management perspective*. Paper presented at the Australian Positive Psychology Conference 2012 in Wollongong.
- World Health Organisation. (2016). *Global report on diabetes*. Paris: World Health Organisation Press. Retrieved from http://apps.who.int/iris/bitstream/10665/204871/1/9789241565257_eng.pdf
- World Health Organisation. (n.d.). *Frequently asked questions*. Retrieved from <http://www.who.int/suggestions/faq/en/>
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology* (pp. 253-251). London: Sage.

MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

Young, E. E., & Unachukwa, C. N. (2012). Psychological aspects of diabetes mellitus. *African Journal of Diabetic Medicine*, 20(1), 5-7.

ANNEXURES

Annexure A: Proposal Approval Letter Issued by Scientific Committee



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Ms Sylvia Kruger

[28964713]

23 October 2018

"Young adult women's meaning making of living with Type 1 Diabetes"

Dear Ms Kruger,

This letter serves to confirm that your research proposal has been accepted and approved by the Optentia Research Committee.

The ethics application is referred to the Health Research Ethics Committee (HREC).

Best of luck with your study!

Best Regards,

A handwritten signature in black ink, which appears to read 'Rothmann'.

Prof. S. (Ian) Rothmann

Annexure B: Ethical Approval Letter



Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
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Research Ethics Regulatory Committee
Tel: 018 299-4849
Email: nkosinathi.machine@nwu.ac.za

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the North West University Health Research Ethics Committee (NWU-HREC) on 27/11/2018, the NWU Health Research Ethics Committee hereby approves your study as indicated below. This implies that the North-West University Research Ethics Regulatory Committee (NWU-RERC) grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Young adult women's meaning making of living with Type 1 Diabetes.																														
Study Leader/Supervisor (Principal Investigator)/Researcher: Dr E Deacon																														
Student: S Kruger																														
Ethics number:	<table border="1"> <tr> <td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>1</td><td>2</td><td>4</td><td>-</td><td>1</td><td>8</td><td>-</td><td>A</td><td>1</td> </tr> <tr> <td colspan="3">Institution</td> <td colspan="3">Study Number</td> <td colspan="3">Year</td> <td colspan="3">Status</td> </tr> </table>			N	W	U	-	0	0	1	2	4	-	1	8	-	A	1	Institution			Study Number			Year			Status		
N	W	U	-	0	0	1	2	4	-	1	8	-	A	1																
Institution			Study Number			Year			Status																					
<u>Status:</u> S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation																														
Application Type: Single study																														
Commencement date: 2018/11/27		Risk: Medium																												
Expiry date: 2019/11/30																														
Approval of the study is initially provided for a year, after which continuation of the study is dependent on receipt and review of a six-monthly (or as otherwise stipulated) monitoring report and the concomitant issuing of a letter of continuation.																														

Special in process conditions of the research for approval (if applicable): None

General conditions: <i>While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:</i> • The study leader/supervisor (principle investigator)/researcher must report in the prescribed format to the NWU-HREC: – annually (or as otherwise requested) on the monitoring of the study, whereby a letter of continuation will be provided, and upon completion of the study; and – without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study. • The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the study leader/researcher must apply for approval of these amendments at the NWU-HREC, prior to
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MEANING MAKING OF YOUNG WOMEN WITH TYPE 1 DIABETES

implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.

- *Annually a number of studies may be randomly selected for an external audit.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility the NWU-RERC and NWU-HREC reserves the right to:*
 - *request access to any information or data at any time during the course or after completion of the study;*
 - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;*
 - *withdraw or postpone approval if:*
 - *any unethical principles or practices of the study are revealed or suspected;*
 - *it becomes apparent that any relevant information was withheld from the NWU-HREC or that information has been false or misrepresented;*
 - *submission of the annual (or otherwise stipulated) monitoring report, the required amendments, or reporting of adverse events or incidents was not done in a timely manner and accurately; and / or*
 - *new institutional rules, national legislation or international conventions deem it necessary.*
- *NWU-HREC can be contacted for further information or any report templates via Ethics-HRECApply@nwu.ac.za or 018 299 1206.*

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

Yours sincerely



Digitally signed by Wayne
Towers
Date: 2018.12.04
12:09:04 +02'00'

Prof Wayne Towers
Chair NWU Health Research Ethics Committee

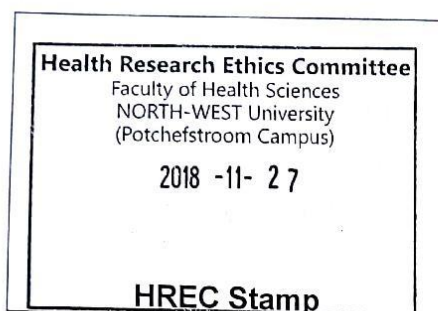
Current details: (22351930) M:\DSS\18533\Monitoring and Reporting Cluster\Ethics\Certificates\Templates\Research Ethics Approval Letters\9.1.5.4.2 HREC Ethical Approval Letter.docm
3 December 2018

File reference: 9.1.5.4.2

Annexure C: Informed Consent Form



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**INFORMED CONSENT DOCUMENTATION FOR YOUNG
ADULT WOMEN WITH TYPE 1 DIABETES**

TITLE OF THE RESEARCH STUDY: Young adult women's meaning making of living with Type 1 Diabetes

ETHICS REFERENCE NUMBERS: NWU-00124-18-S1

PRINCIPAL INVESTIGATOR: Dr. Elmarie Deacon

POST GRADUATE STUDENT: Miss. Sylvia Kruger

ADDRESS: North-West University, Potchefstroom Campus, 11 Hoffman Street

CONTACT NUMBER: 074 908 7794

You are being invited to take part in a **research study** that forms part of a Masters study in Counselling Psychology. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you might be involved. Also, your participation is **entirely voluntary** and you are free to say no 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 do agree to take part now. It is

This study has been approved by Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU-00124-18-S1) and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

What is this research study all about?

- *We plan to explore in depth how young adult women make meaning of living with type 1 diabetes.*
- *This study will be conducted at the CDE in Parktown and will be done by experienced health researchers trained in interviewing. Three to six participants will be included in this study.*

Why have you been invited to participate?

- *You have told us that you would be interested in taking part in the project. Your doctor sent us the information leaflet, which you 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.*
- *You have already received a phone call in which you told us that 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.*
- *You have been invited to be part of this research because you are willing to do an interview with us in English or Afrikaans, you are female, you are between ages 18 and 25, were diagnosed with type 1 diabetes more than 1 year ago and you are a patient at the CDE.*
- *You will unfortunately not be able to take part in this research if you are currently undergoing psychotherapy or if you have another chronic illness.*
- *You will not be able to take part in this research if you are friends or familiar with the researcher.*

What will be expected of you?

- *It is expected that you and the independent person, obtaining consent (Deidre Maritz), sign the consent form in one another's' presence. This will take place in a private room at the CDE. The independent person will again remind you that participation is entirely voluntary and will answer any questions that you might have.*
- *You will receive this document at least two weeks prior to the interview, to ensure that you make an informed choice regarding your participation.*
- *You will be expected to do an interview with us. The interview will be more or less 45 minutes long, with an optional 15 minute break. This interview will be audio recorded. 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.*
- *Before the interview starts, you will be asked if you are still willing to participate and if you have any further questions. You will be informed once again that the interview will be audio recorded and transcribed (this is done in order to prevent*

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any assumptions made by the researcher herself) and upon your permission, the researcher will start the audio-recording.

Will you gain anything from taking part in this research?

The direct benefits for you as participant will probably be the following:

- *After the study is written up, you will be invited to participate in a free, voluntary workshop on meaning-making.*
- *The indirect benefits of the study is for 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.*
- *After your interview with the researcher you will receive an information leaflet, as a token of appreciation, on diabetes management which could further help to assist you to managing your diabetes well.*
- *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 there risks involved in you taking part in this research and what will be done to prevent them?

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

<i>Probable/possible risks/discomforts</i>	<i>Strategies to minimize risk/discomfort</i>
The risks of this study can be estimated as medium. However, there are no foreseen risk of physical harm to you.	The in-depth interview will be conducted in a secure, comfortable and private room at the Centre for Diabetes and Endocrinology. A "do not disturb" sign will also be attached to the door.
Because you will spend about 45 minutes participating in an interview, it is possible that you will become tired.	The researcher doing the interview with you will give you an optional 15-minute break 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.	Upon completion of the interview, we will ask you if you experienced any feelings of emotional discomfort or distress while taking part in the research. If you indicate that you did feel uncomfortable or distressed secondary to participating in the research project, we will call you the next day to see if you are still feeling the same way. If not, we will thank you for your participation in the research project. If you are still distressed, we will arrange one complimentary session with Rosemary Flynn (a

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	registered clinical psychologist) who can help you work through your feelings of discomfort or distress which you experienced whilst participating in the research project.
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.
Living with diabetes, you may be worried that people learn about your diagnosis and start treating you differently.	We will meet with you at the place where you normally receive your treatment (CDE Parktown), so you can feel comfortable in a safe place you 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 during holidays to make it easier for you to attend.

- However, the benefits (as noted) outweigh the risks.
- There are more gains for you in joining this study than there are risks.

How will we protect your confidentiality and who will see your findings?

- Anonymity (that is, how your results will be linked to your identity) of your findings will be protected by providing each participant with a pseudo name that will only be used for your information. Your privacy will be respected by only using a given pseudo name and references to your name or any identifiable details will be removed. Your results will be kept confidential by safely storing all data and by using pseudo names. Only the researchers will be able to look at your findings. Findings will be kept safe by locking hard copies in locked cupboards in the researcher's office and for electronic data it will be password protected. (As soon as data has been transcribed it will be deleted from the recorders.)
- Data will be stored for 10 years. All documentation will be securely stored in locked rooms and will then be destroyed by shredding it. The electronic data (e.g. datasets) will be stored on a password protected computer and will then be destroyed by deleting it from the computer in question.
- 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.
- Reporting of findings will be anonymous by only referring to your pseudo name.

What will happen with the findings or samples?

- *The findings of this study could be used in future studies. 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).*

How will you know about the results of this research?

- *We will give you a summary of the main findings of this research when the research study is completed and written up by means of an email.*
- *You will be informed of any new relevant findings by means of an email.*

Will you be paid to take part in this study and are there any costs for you?

- *No, you will not be paid for taking part in the study. 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.*
- *There will thus be no costs involved for you, if you do take part in this study.*

What is the role of the researcher within this study?

- *The administrative duties will be the responsibility of an independent person. This person will administer and collect your consent form in person as well as sign the informed consent form in your presence. The independent person will also be present when you – as the participant – sign the informed consent form as an undertaking of participation in this study. The signature of a witness will also be required.*
- *The researcher (Miss Sylvia Kruger) will conduct the in-depth interviews. She will take care in providing an empathic and comfortable environment for the participants to share their experiences. The interview time and date will be scheduled according to a time best convenient for both you and the researcher, and will take place in a private room located at the CDE. Before the interview commences, the researcher will confirm your written consent to take part in this study, and ask your permission to audio record the interview. Your clarity and understanding with regard to the aim, purpose and procedure of the research will be discussed. If, at any time during the research process, you as the participant feel the need to withdraw, Miss Sylvia Kruger will - without any prejudice - ensure and confirm your withdrawal. If the containment of a situation is needed, the researcher will do so where after debriefing services will be made available to you (free of charge). The researcher is furthermore responsible for ensuring the confidentiality of the data and will consequently report her anonymous findings within her Masters Research dissertation. This is done in accordance to the procedure of obtaining her Masters' degree in Counselling Psychology, and she will therefore also submit an article about the findings to an accredited scientific journal for possible publication.*
- *The project head (Dr. Elmari Deacon) and co-supervisor (Prof. Esme van Rensburg) will act as study leaders for the research dissertation of Miss Sylvia Kruger in order to ensure the adherence to all ethical aspects within this research study. Dr. Elmari Deacon will oversee that the researcher (Miss Sylvia Kruger), as well as the independent person, act within their specified research roles and*

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will also submit monitoring reports to the HREC referring to the progress of this research study.

Is there anything else that you should know or do?

- You can contact Dr Elmari Deacon at elmari.deacon@nwu.ac.za or (018 299 1728) if you have any further questions or have any problems.
- You can also contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 or carolien.vanzyl@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.
- You will receive a copy of this information and consent form for your own purposes.

Declaration by participant

By signing below, I agree to take part in the research study titled: Young adult women's meaning making of living with type 1 diabetes.

I declare that:

- I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.
- The research was clearly explained to me.
- I have had a chance to ask questions to both the person getting the consent from me, as well as the researcher and all my questions have been answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be handled in a negative way if I do so.
- I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.
- I give consent for my interview to be audio-recorded.

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

.....
Signature of participant

.....
Signature of witness

Declaration by person obtaining consent

I (*name*) declare that:

- I clearly and in detail explained the information in this document to

-
- I did/did not use an interpreter.
 - 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 gave him/her time to discuss it with others if he/she wished to do so.

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

.....
Signature of person obtaining consent

Declaration by researcher

I Sylvia Kruger declare that:

- I explained the information in this document to or I had it explained by who I trained for this purpose.
- I did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

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

.....
Signature of researcher

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25 April 2018
File reference: 9.1.5.6

Annexure D: Interview Schedule

1. Tell me about yourself? (Vertel my meer oor jouself?)

Possible prompts:

- What is your age? (Hoe oud is jy?)
- When were you diagnosed with type 1 diabetes? (Wanneer is jy met tipe 1 diabetes gediagnoseer?)
- How do you manage your diabetes? (Hoe bestuur jy jou diabetes?)

2. Tell me about your journey of meaning making in living with diabetes (Vertel my van jou reis van betekenismaking in die lewe met diabetes)

Possible prompt questions that will be asked are the following:

- What impact does type 1 diabetes have on your life? (Watter impak het tipe 1 diabetes op jou lewe?)
- How do you experience self-managing type 1 diabetes on a daily basis? (Hoe ervaar jy die selfbestuur van tipe 1 diabetes op 'n daaglikse basis?)
- How do you make meaning of living with type 1 diabetes? (Hoe maak jy betekenis van 'n lewe met tipe 1 diabetes?)
- How do you make sense of living with diabetes? (Hoe maak jy sin van 'n lewe met tipe 1 diabetes?)
- How has your meaning of diabetes changed over the course of time? (Hoe het jou betekenis van tipe 1 diabetes oor die verloop van tyd verander?)
- Please tell me more about your experience with diabetes. (Vertel my asseblief meer oor jou ervaring met diabetes.)
- What areas of your life does diabetes affect? (Watter areas van jou lewe word deur diabetes beïnvloed?)
- Is there anything positive about having diabetes? (Is daar enigiets wat positief is van diabetes?)

Annexure E: IPA Summary: Young Adult Women's Meaning Making of Living with Type 1 Diabetes

	Superordinate themes	Subordinate themes	Description	Example from the data
Process	1. The process of reappraising a life with diabetes	Reaction to diagnosis Challenges of living with diabetes Incorporating diabetes in to identity	Participants made meaning of diabetes by engaging in a process of reappraisal. This process can be understood by considering three subordinate themes. Initially participants experienced diabetes as a shock and as discrepant from their global meaning. This discrepancy resulted in distress. Participants experienced several challenges as a result of living with diabetes (for example, social ignorance, possible complications and feeling different). Despite these challenges, over time, diabetes was not viewed as a threat to their identity and diabetes was assimilated into participants' view of themselves.	<u>Reaction to diagnosis</u> Jenny: "still a shock" "why me" Sarah: "further stress" "diabetes is cool" "schlep" Hope: "stress" "difficult" "why me" "Why did I get this..." "emotional side is different" Karen: "never ever forget that day" "I had no idea what it was" "was a shock" Carlia: "shock" "emotionally a difficult time" "why me?" Nina: "why do I have this?" <u>Challenges of living with diabetes</u> Jenny: "complications" Sarah: "further stress" "I couldn't just drink" Hope: "ignorant" "really difficult" Carlia: "not 100% normal" "impacts everything" Karen: "tons of challenges" Nina: "I was shy" "It was rough" "I saw what sugar does to a person" <u>Identity:</u> Jenny: "diabetes doesn't define you" "long road" Sarah: "more special" "not the end of the world" Hope: "part of me" "wanting a life despite diabetes" Carlia: "does not determine your identity" "time heals all wounds" "it's not the flu" "not your core being" Karen: "part of your identity" "not a negative aspect"

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				Nina: "proud of being a diabetic"
Process	2. The development of diabetes as a lifestyle	The value of support Knowledge Working with diabetes/ Acceptance Self-responsibility	A crucial process in making meaning of diabetes was the development of diabetes as a lifestyle. Four subordinate themes are discussed which contributed to this process, namely, the value of support, knowledge, acceptance and self-responsibility. All participants acknowledged the importance of emotional support from family and friends, as well as role models. All participants viewed knowledge as crucial to making meaning of diabetes. Acceptance of diabetes was related to the realisation that diabetes cannot be perfectly managed and that difficult days will occur. Taking responsibility for diabetes management contributed to the process of making meaning of diabetes.	The value of support Jenny: "good support from your doctor" "my family" Sarah: "diabetic community" "collaborate with doctor" Hope: "parents" "boyfriend" "nurses" Carlia: "my sister" "dietitian" Karen: "my parents" "psychologist" "doctor" "I enjoy people with diabetes" Nina: "girl in the wheelchair" "attractive man helped me to inject" "doctor is like an angel" "my mom" Knowledge Jenny: "Knowledge is key" "feeling of satisfaction when you got it right" Sarah: "Knowing how to manage it" Hope: "month course" "made more sense of what I have to do" Carlia: "dietitian explained everything" Karen: "enjoyed learning" "learn, learn, learn" Nina: "know how to control your sugar" Working with diabetes / Acceptance Jenny: "I accept that I need insulin to survive" "manageable disease" "becomes a way of life" "34 factors that can affect your sugar" "part of my routine" "way of life" Sarah: "all a thing of acceptance" "working with it. I'm not working against it" Hope: "have to take care of it"

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				“to accept you are not a perfect diabetic” “you don’t always feel in control” Carlia: “invest everything in healthy eating” “there were times” Karen: “realise it’s not the end” “never complete control” Nina: “I can actually make this work” “ups and downs” <u>Self-responsibility</u> Jenny: “I always injected myself” “in your hands” Sarah: “this is my thing” Hope: “testing and injecting yourself” Carlia: “my healthy, it is not my mom who handles it” “Chose to handle it positively” Karen: “injections are mine” Nina: “decide to look after myself”
Outcome	3. Meanings made	Growth and strengths Opportunities	It was evident that participants did not perceive themselves to be victims of diabetes but rather empowered by living with diabetes. Through re-evaluating the experiences with diabetes, participants were able to accommodate diabetes into their understanding of themselves and the world. As an outcome, meaning were made, including personal growth, the realisation of strengths and new found opportunities.	<u>Growth and strengths</u> Jenny: “as far as diabetes goes for me, it has been positive” “positive impact” “passionate about it” “organized” Sarah: “A bit more special than other people” “growth” “maturity” “confidence” “learn so much more holistically about yourself” Hope: “healthier life” Carlia: “healthier now than before” “opportunity to be healthier” Karen: “grow with it” “grateful” “matured me” “change your perspective” Nina: “I got wiser” “grew a lot” “feel popular” <u>Opportunities</u> Jenny: “presentation for dietitians” “use personal and professional side”

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				"work with diabetes" Sarah: "taught me a lot about me" "grateful for it" Hope: "lets me live a healthier life" "grown up a lot since" Carlia: "massive blessing" Karen: "done a lot" "Midmar mile" "I've been the patient" "more insight" "connected to your patients" Nina: "change medical law"
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