

# Meaning in life and psychological well-being of parents of children living with diabetes

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**REMARKS**

The reader is reminded of the following:

- The references and style followed in Chapter 1 and Chapter 3 of this mini-dissertation are according to the Publication Manual (6<sup>th</sup> edition) of the American Psychological Association (APA). This practice is in line with the requirements for the programme Master of Arts in Positive Psychology of the North-West University Vaal Triangle Campus.
- The references and style followed in Chapter 2 of this mini-dissertation are according to the Diabetes Care Instructions for Authors.
- The mini-dissertation is submitted in the form of a research article.

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### DECLARATION

I hereby declare that “Meaning in life and psychological well-being of parents of children living with diabetes” is my own work, that it has not been submitted for any degree or examination at any other institution of higher learning and that all references have, to the best of my knowledge, been correctly reported. It is being submitted for the degree Master of Arts at the North-West University.

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Signature: 

### SUMMARY

#### **Meaning in life and psychological well-being of parents of children living with diabetes**

The figures regarding children living with type 1 diabetes show that the condition is increasing at an alarming rate – approximately 1 in 400 children are diagnosed with the condition (American Academy of Pediatrics, 2015). The parents of children diagnosed with this chronic condition not only face normal developmental challenges in raising their children, but also face the added burden and stress related to an intensive diabetes management regimen. Even though the management of the condition is taxing, there are those that get it right in order to live with well-controlled diabetes. The purpose of the study was to explore the influence of diabetes management behaviours on the parental experience of meaning in life and the psychological well-being of parents of children living with well-controlled diabetes.

To better understand the phenomenon, this multiple case study design study used a qualitative interpretivist approach and a purposive sample of nine parents of children (children aged 8 to 18 years) living with well-controlled diabetes. Semi-structured interviews were conducted and were transcribed verbatim. Thematic coding and analysis of the verbatim interview transcripts delivered four major themes: (1) the positive and negative impact of diabetes management behaviours on parental well-being; (2) positive beliefs about diabetes management; (3) parental-specific diabetes management behaviours and (4) positive relationships with friends, family, the medical team and social media.

Although the article refers to parents collectively, all nine participants were Caucasian mothers, whose children receive their diabetes treatment at the CDE, Parktown. No fathers participated and future studies would benefit from greater paternal involvement.

The influence of diabetes management behaviours on the parental experience of meaning in life and psychological well-being can clearly be seen in the review of existing literature and in

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the empirical results of this study. The empirical results suggest that parents with children with well-controlled diabetes experience meaning in life, despite the various challenges they face while managing the condition. These challenges start the day the child is diagnosed and it is the continuous daily management behaviours that have an impact on the parents' meaning making process. For parents in general, raising children can be just as stressful as it is wonderful. For the parents of children living with diabetes, the impact of the condition and the management thereof is almost tangible and adds extra stress and demands to all areas of life. However, according to the results of this study, parents do experience meaning in life and an increase in psychological well-being while caring for their child living with a chronic condition. These findings emphasise the need for individualised interventions aimed towards enhancing and sustaining parental meaning in life and psychological well-being over time and through different life stages.

*Keywords:* meaning in life, psychological well-being, well-controlled diabetes, diabetes management behaviours, parents, children.

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## CHAPTER 1 INTRODUCTION

### 1.1 Introduction

The purpose of this chapter is to provide the reader with an overview of this mini-dissertation. The main objective was to understand how diabetes management behaviours influenced the meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes. After this introduction, the problem statement is discussed along with existing literature on the different constructs (meaning in life, psychological well-being, well-controlled diabetes, diabetes management behaviours, parents and children) relevant to this study. The preceding constructs are conceptualised before the discussion concerning the main research questions and objectives. The research methodology employed in this study is described in detail, with special reference to the paradigm, design, the participants, the research procedure, data analysis as well as the trustworthiness and credibility of this study. The ethical considerations for this study are identified and explained. An outline of the chapter division for this mini-dissertation along with a summary concludes this chapter.

### 1.2 Problem statement

A total of 387 million people has been diagnosed with diabetes worldwide and this number is estimated to increase to 642 million people by 2040 (International Diabetes Foundation [IDF], 2014; IDF, 2015). Of the 387 million people, it is believed that 22 million people are diagnosed with diabetes in Africa, of which 2.7 million are reportedly living in South Africa (IDF, 2014). While type 1 diabetes is less common, the rate of newly diagnosed children increases by approximately 3% per year (IDF, 2015). In 2015, for the first year ever, statistics showed that there were more than 542,000 children living with type 1 diabetes worldwide (IDF, 2015), which according to other sources indicate that approximately 1 in every 400 children have been

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diagnosed with diabetes (American Academy of Pediatrics, 2015; Couch et al., 2008; Haller, Atkinson, & Schatz, 2005). No valid and reliable statistics are available for children in South Africa, but Prof David Segal, paediatric endocrinologist, estimates that 6000 children under the age of 14 are currently diagnosed each year (Rice, n.d.).

The management of diabetes impacts the parents of the diagnosed children on a physical, emotional and social level (Hansen, Weissbrod, Schwartz, & Taylor, 2012; Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011) and also influences their meaning in life as well as their psychological well-being. In order to adjust to living with diabetes, the American Diabetes Association (ADA) recommended that topics such as the personal meaning of diabetes, social situations and support should be addressed in the developmental stages of adolescents (Chiang, Kirkman, Laffel, & Peters, 2014).

As part of a larger project investigating the psycho-social variables in adjusting to diabetes management in adolescents and young adults, this study aims to better understand diabetes management behaviours and the effect it has on the meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes.

### **1.2.1 Diabetes.**

People that are diagnosed with what is commonly known as diabetes, or diabetes mellitus in medical terms, experience a glucose imbalance or defects in insulin secretion or insulin action, or a combination of the two (ADA, 2010; Centres for Disease Control and Prevention [CDC], 2014; Guariguata et al., 2013; Jerant, Von Friederichs-Fitzwater, & Moore, 2005; Van der Merwe, 2015). There are two types of diabetes, namely, type 1 and type 2. For the purpose of this study, the focus will be on type 1 diabetes. Type 1 diabetes, previously known as insulin dependent diabetes mellitus or juvenile-onset diabetes, develops when the beta-cells that produce insulin are

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destroyed resulting in the pancreas not producing any, or enough insulin, thus, creating the need for lifelong dependence on exogenous insulin (CDC, 2014; Chiang et al., 2014; Van der Merwe, 2015). Type 2 diabetes, also known as non-insulin-dependent diabetes mellitus or adult-onset diabetes, develops during middle age (CDC, 2014; Van der Merwe, 2015).

### **1.2.2 Diabetes management.**

Even though diabetes is a chronic, life-long condition that needs daily management, people that manage their blood glucose levels effectively, can live normal, active and high-quality lives with few, if any, restrictions (Van der Merwe, 2015). The various management behaviours required for managing diabetes effectively involves regular blood glucose testing, taking medication (oral or insulin injections), restricting food choices and regular exercise (CDC, 2014; Silverstein et al., 2005; Van der Merwe, 2015). Distiller (2004) suggests that under the guidance of health care practitioners some of the adverse health related issues can be minimised if diabetes is well-controlled.

The management of diabetes can be measured objectively by the HbA1c (glycosylated haemoglobin) result, which is a measure of average blood glucose concentration over approximately 3 months (Van der Merwe, 2015). The CDE guidelines stipulate specific treatment targets of between 7.0% and 8.5% for children aged 6 to 16 years (CDE, 2015). In collaboration with local medical experts, based upon ADA (2012) and guidelines recommended by Rewers, Pjhoker, Donaghue, Hanas, Swift, and Klingensmith (2009), a lifetime HbA1c level of  $\leq 8.0\%$  was accepted as an indication of well-controlled diabetes for children between the ages of 12 – 18 years. It is, however, evident from research as early as the 1970s (DiMatteo, 2004; Dunbar-Jacob & Mortimer-Stephens, 2001; Stone et al., 2013; Walker & Usher, 2003) that people who live with diabetes do not manage it well, resulting in further health complications.

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Research has indicated the common long-term physical effects of diabetes as nephropathy (kidney damage or failure), retinopathy (partial loss of vision), neuropathy (weakness and numbness in peripheral nerves), dyslipidaemia (abnormal number of triglycerides, cholesterol and/or fat phospholipids in the blood), hypertension, heart disease, stroke or premature death (ADA, 2010; CDC, 2014; Silverstein et al., 2005).

Living with diabetes also affects people's psycho-social functioning (Hörsten, Norberg, & Lundman, 2002). Different psychological experiences of people living with diabetes have been documented (Nicolucci et al., 2013; Watts, O'Hara, & Trigg, 2010) and these experiences are related to the role of stress and anxiety as a product of the diabetes management regimen (Lustman, Carney, & Amado, 1981; Turkat, 1982). These elevated stress levels precipitate hypoglycaemic attacks and children living with type 1 diabetes might find it very difficult to control their blood sugar levels (Van der Merwe, 2015).

Delamater, de Wit, McDarby, Malik, and Acerini (2014) report that a collaborative relationship between the parent and child living with diabetes, could lead to improved emotional functioning as well as better treatment adherence. The improved emotional functioning and treatment adherence happens because parents and children now share the responsibility of diabetes management (Delamater et al., 2014).

This study wanted to explore how parents of children with well-controlled diabetes make sense of their child living with diabetes and what their psychological well-being looks like. This helped the researcher make recommendations for those parents that don't manage or help their child manage their diabetes well. Parents of children with poorly controlled diabetes can benefit and learn from those that get it right. For this reason, the researcher wished to explore the effect that diabetes management behaviours had on parents and their experienced meaning in life and psychological well-being.

### **1.2.3 Parenthood.**

Parenthood is not a decision that is taken lightly and for some parents it involves weighing up the benefits or drawbacks concerning life satisfaction, fulfilling personal needs, continuing the family line, expenses and other possible lifestyle changes (Louw & Louw, 2009). As parenting can be a rewarding and exciting experience, the parents of children living with diabetes face different challenges due to the lifestyle changes that need to be made.

The management of their child's diabetes impacts parents on a physical, emotional and social level. Parents are faced with the challenge that they must learn to balance all the different diabetes management behaviours in order for them to manage their child's chronic condition, as well as to provide a healthy environment for the rest of the family (Lewin et al., 2006; Wysocki et al., 2000). According to Hansen et al. (2012) parents of children diagnosed with type 1 diabetes, reported elevated levels of paediatric parenting stress, depression, anxiety and sleep problems.

Studies have highlighted the emotional reactions that parents have when they discover that their child has diabetes. In most cases, shock, sorrow, frustration, guilt, blame, insecurity and anxiety were present as part of the parents' initial reactions to their child's diagnosis (Haugstvedt et al., 2011). Parents report that the criticality of the condition at diagnosis, the all-pervading nature of the condition and the expectation of having to manage their child's condition all cause stress (Hatton, Canam, Thorne, & Hughes, 1995).

Delamater et al. (2014) reported on recent studies, which indicated that 33.5% of mothers gave an account of having felt distress at diagnosis, with 19% of mothers reporting distress between 1 to 4 years after diagnosis. More significantly, one third of mothers reported a higher incidence of psychological adjustment problems and experienced significant clinical depression

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in the first year after their child had been diagnosed with diabetes (Delamater et al., 2014). In some cases, severe distress, stemming from the lack of confidence in managing a new treatment regimen associated with their child's hypoglycaemia as well as greater responsibility, was experienced by parents (Hansen et al., 2012).

Not only can the management of the child's condition have an impact on a parent's psychological functioning, but parents report that frequent hospitalisation and visits to the doctors and/or emergency rooms had a negative impact on their work performance as well as their physical health (Hansen et al., 2012; Mullins et al., 2007).

Being diagnosed with a chronic condition is a life-changing event, which not only affects the person diagnosed, but also affects the parents and their siblings. Diabetes is initially managed by the parents and the management thereof eventually becomes the responsibility of the child. Parents play an invaluable role in reassuring their child that their diagnosis is manageable, helping with testing and insulin tasks, renegotiating roles and preventing and intervening in family conflict relating to diabetes management (Chiang et al., 2014).

Studies from a positive psychology approach have not yet explored the impact of a child's diabetes management regimen on the meaning in life or psychological well-being that the parents experience. Understanding how parents think about this condition and how they make sense of their child living with diabetes could eventually result in enhanced quality of life as well as improved health outcomes for the entire family (Koetsenruijter et al., 2014). Since this study aims to explore the meaning in life and psychological well-being within the positive psychology paradigm, it is necessary to conceptualise positive psychology as well as meaning in life, meaning-making and psychological well-being.

### **1.2.4 Positive psychology.**

Positive psychology as sub-discipline of psychology developed years after traditional psychology, which was based on the medical model focused on illness and pain. “Positive psychology endeavours to enhance the quality of life by focusing on strengths and already existing resources, enriching life and promoting optimal functioning” (Wissing, 2014, p. 5). In order to understand how meaning in life and psychological well-being was conceptualised, it is necessary to look at the traditions regarding well-being.

Deci and Ryan (2008) indicated that the study of well-being generally falls within either the hedonic or eudaimonic tradition. Hedonic well-being includes concepts such as life satisfaction and affect. A positive evaluation of one’s own life combined with the experience of positive affect is universally seen as a significant component for a good life (Hervas & Vazquez, 2013). Eudaimonic well-being refers to optimal psychological functioning, personal growth and sense of autonomy (Baumgardner & Crothers, 2010; Hervas & Vazquez, 2013).

The central feature of human life is the pursuit of meaning and that people make their own meaning by seeking and creating their own understanding of the broader purposes in life (Baumgardner & Crothers, 2010). The study of meaning in life relates strongly to the eudaimonic tradition as studies concerning those living with diabetes, often comment on their quality of life (Jelsness-Jorgensen, Ribu, Bernklev, & Moum, 2010; Wright, 2013).

When stressful events challenge a person’s global meaning system, “meaning-making” efforts are made to reintegrate the appraisal to an individual’s global meaning system. Meaning-making has been described as “the process of restoration of meaning...” (Wissing, 2014, p. 154). An outcome of this meaning-making process is successful adjustment and a meaningful life which acts as a buffer against personal distress, which relates forward to enhancing physical,

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psychological and mental well-being of people (Park & George, 2013; Wissing, 2014). Jim and Andersen (2007) found that meaning mediates the relationship between social and physical functioning and related stress in cancer survivors. Furthermore, research has found that people who believe that their lives have meaning, appear to experience wellness in many aspects (Bonebright, Clay, & Ankenmann, 2000), including better self-related health and health-related quality of life (Scheier et al., 2006).

Existing literature suggests that psychological well-being is an outcome of having meaning in life (Kobau, Snizek, Zack, Lucas, & Burns, 2010; Steger, Kashdan, & Oishi, 2008). In contrast, experiencing life as meaningless has been correlated with a lack of psychological well-being and various other concepts such as anxiety, stress, burnout and depression (De Klerk, Boshoff, & Van Wyk, 2009).

Baumgardner and Crothers (2010) describe psychological well-being as positive psychological and social functioning. The psychological well-being of a person can be affected by different factors, and Bradley and Gamsu (1994) referred to the initial diagnosis of the chronic condition, coping with the condition and the various complications as having major effects on people's lives. As previously discussed, the diabetes management regimen required of the parents of a child living with diabetes can be very difficult. Marshall, Carter, Rose, and Brotherton (2009) reported that understanding how parents and children create meaning and how this meaning influences them, could impact on their perceptions of diabetes. Meaning in life and psychological well-being are thus interrelated and the discussion will also reflect how both concepts appear to be present in the parents of children living with well-controlled diabetes.

Diabetes is a life-long condition that has a significant impact on diagnosed children – as well as their parents, siblings and extended family. Research relating to type 1 diabetes primarily has a quantitative approach, but is conducted from a medical point of view with extensive reflection

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on global concerns about the illness, how to monitor and control treatment (Marshall et al., 2009), comparing the types of diabetes (Eppens et al., 2006) as well as looking at personality and diabetes control (Vollrath, Landolt, Gnehm, Laimbacher, & Sennhauser, 2007). Most of these studies have been questionnaire based with very few rigorous qualitative methods. While these questionnaire-based studies add valuable insight into the lives of people living with diabetes, no significant study has been undertaken in South Africa, which considers how parents live and make sense of their child's diabetes or the influence it has on their experience of meaning in life or their psychological well-being. Seen from a positive psychological perspective and using the parents of children living with well-controlled diabetes, this study used an integrated approach, incorporating hedonic, eudaimonic and social well-being (Baumgardner & Crothers, 2010; Hervas & Vazquez, 2013) in order to better understand the meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes.

The following research questions were formulated in light of the research problem discussed above: (a) How do diabetes management behaviours influence the experience of meaning in life of parents of children living with well-controlled diabetes? and (b) How do diabetes management behaviours influence the experience of psychological well-being of parents of children living with well-controlled diabetes?

### **1.3 Research objectives**

The research objectives were divided into general objectives and specific objectives.

#### **1.3.1 General objectives.**

The research study aimed to explore the influence of diabetes management behaviours on the meaning in life and psychological well-being experienced by parents of children, aged 8 to 18 years, living with well-controlled diabetes.

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### **1.3.2 Specific objectives.**

The specific objectives for this study were:

- To conceptualise well-controlled diabetes, diabetes management behaviours, meaning in life and psychological well-being from existing literature.
- To determine the influence of diabetes management behaviours on the experience of meaning in life of parents of children living with well-controlled diabetes.
- To determine the influence of diabetes management behaviours on the experience of psychological well-being of parents of children living with well-controlled diabetes.

### **1.4 Research method**

This study will consist of a literature review and an empirical study.

#### **1.4.1 Phase 1: Literature review.**

The first phase comprised a literature review regarding concepts such as meaning in life, psychological well-being, well-controlled diabetes, diabetes management behaviours, parents and children. The following resources aided the researcher in conducting the literature review:

- Journal articles
- Internet search engines such as EBSCOHOST, Google Scholar, etc.
- Electronic journals and articles
- Textbooks
- Other master's dissertations and PhD theses.

### **1.4.2 Phase 2: Empirical study.**

The empirical study consists of the research paradigm and design, the participants, the research procedure, the data analysis as well as the trustworthiness and credibility of the study.

#### **1.4.2.1 *Research paradigm.***

This study was conducted from an interpretivist research paradigm. “Interpretive studies generally attempt to understand phenomena through the meanings that people assign to them.” (Nieuwenhuis, 2007a, p. 59). Creswell (2009) states that these meanings and interpretations people assign to phenomena can’t be separated from their background, history or experiences. In this case, how parents make sense of the diagnosis and management of their child’s condition, will evolve and change over time to form a new reality.

#### **1.4.2.2 *Research design.***

The aim of the research design is to provide a plan of how the research will be conducted, who the participants are and how they were recruited as well as what information the researcher would like to obtain from the participants. Hofstee (2006) describes the research design as a theoretical outline of the method that is used by the researcher in order to draw reliable and well-grounded conclusions.

This study followed a qualitative multiple case study design. Qualitative research aims to understand the subjective meaning people attach to life and the experiences and perceptions of individuals (Fouché & Schurink, 2011), while employing a case study design can be defined as “the in-depth study of instances of a phenomenon in its natural context and from the perspective of the participants involved in the phenomenon” (Gall, Borg, & Gall, 1996, p. 545). In this study, the multiple case study design was used to produce detailed descriptions of diabetes and

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the effect thereof on parental experience of meaning in life and psychological well-being, as well as to relate these experiences to literature on the phenomenon.

### **1.4.2.3 Participants.**

The participants for this study were parents of children, aged 8 to 18 years, living with well-controlled diabetes and were recruited from the CDE, Parktown, specialising in paediatric diabetes. The average age of the children were 12 years and the average time since diagnosis was approximately 5 years. Six of these children were males, and 3 of them were female. However, certain inclusion and exclusion criteria had to be met in accordance with the purposive convenience sampling strategy used for this study (Struwig & Stead, 2001).

The inclusion criteria for the study were as follows: (1) participants should be a parent of a child aged 8 to 18 years who lives with well-controlled diabetes; (2) the participant's child had to have been diagnosed with diabetes more than 12 months ago; (3) the participants had to be able to speak Afrikaans or English; (4) participants children must have well-controlled diabetes (HbA1c result of  $\leq 8.0\%$ ) for at least 12 months and; (5) participants should be taking their child to the CDE, Parktown for their medical treatment.

The following exclusion criteria applied to this study: (1) participants were excluded if their child suffered from any other medical condition that might have interfered with the diabetes management regimen of the child and (2) participants who received psychotherapy.

### **1.4.2.4 Research procedure.**

The research study formed part of a larger project investigating the psycho-social variables in adjusting to diabetes management in adolescents and young adults.

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After a stakeholder meeting was held with the multi-disciplinary team of experts (consisting of endocrinologists, dieticians, diabetes educators, psychologists, support staff and nurses) the researcher gained permission to conduct research at the CDE Parktown. The practice ensured their full support during this time.

Potential participants received an information leaflet at the CDE during their visit, explaining the purpose of the larger study. Potential participants could then fill in their contact details and leave it with the receptionist, which the researcher received either from the receptionist via email or by means of personal collection at the CDE. An advertisement was placed on the “Youth with Diabetes” Facebook page, in the Diabetes Lifestyle Magazine and the SA Journal of Diabetes inviting potential participants to contact an independent person. Lastly, SMSs were sent to invite possible participants to reply to the email address provided in the SMS if they would want to partake in the study. This was done by the automated SMS system that the CDE uses to remind patients of their upcoming visits or appointments.

The principal researcher of the larger project then contacted the interested parties to answer any questions (via telephone if a number was given or via email if only an email address was given). The principal researcher oversaw all communication between the researcher, the participants and multi-disciplinary team. The principal researcher conducted no interviews in order to ensure consistency, validity and reliability of the screening process, future communication or feedback to participants and the multi-disciplinary team. Once again, the invitation to partake was extended to the possible participants, and if they agreed once more, the principal researcher contacted them telephonically to screen them according to a set of pre-determined criteria.

Once the participant was successfully screened, the researcher determined whether or not the potential participant qualified for the study. When a participant qualified, the researcher

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ascertained when their next scheduled appointment would be and if they would consent to be interviewed. The informed consent forms were sent to the participants for their perusal before their next appointment (see appendix A).

The researcher subsequently met with each eligible participant at the CDE together with the independent person obtaining the consent. The independent person, who was affiliated with the CDE but was not part of the medical or research team, volunteered to assist the research team in writing. This person was tasked with reviewing the study and informed consent process with each participant. Participants were informed that all information obtained from this study would be used exclusively for research purposes and that they were free to withdraw at any time. Parents consented to partake in the study and gave their permission to the person obtaining the consent to review their child's medical records to determine their average HbA1c during the 12 months before the interview.

Individual semi-structured interviews of approximately 45 minutes each were conducted with each participant using the pre-determined interview protocol. Struwig and Stead (2001) suggested that semi-structured interviews consist of questions already constructed in such a way so as to elicit certain reactions or responses from the participants in order to capture the relevant data during the interview (Foxcroft & Roodt, 2009). Greeff (2011) however, suggested that the process is flexible and that the researcher might also use probing to elicit elaboration on the answer to the original question asked.

The suggested questions that were posed to all nine participants in this study were: (1) Can you tell me about your experience in terms of managing (the child's name) diabetes?; (2) How did your life change after (the child's name) was diagnosed with diabetes?; (3) How do you manage (the child's name) diabetes?; (4) How does your understanding of diabetes influence how you manage it?; (5) How does managing diabetes impact your daily life?; (6) How does

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support from family and friends influence how you manage (the child's name) diabetes?; (7)

How do you make sense of (the child's name) living with diabetes?; (8) How does managing (the child's name) diabetes influence your meaning in life? and; (9) How does managing (the child's name) diabetes influence your well-being? The interviews were conducted in a comfortable and private room at the CDE. When the interviews were completed, participants received a certificate of recognition for their participation.

### **1.4.2.5 Data analysis.**

Qualitative data analysis comprises of examining and interpreting the data obtained through the interview process. All the interviews were audio recorded and concurrently transcribed and the quality verified. Data analysis of the obtained data followed to assess whether or not more data still needed to be collected or if data saturation had been achieved (Creswell, 2014; Greeff, 2011).

The research was data-driven and inductive data analysis was used to explore and make sense of the data generated, looking for patterns within the data and working towards developing a theory to explain those patterns. Inductive data analysis refers to researchers having an open mind without expecting or having preconceived ideas about what will be found. The aim of this type of approach is to formulate new theory (Gabriel, 2013). Collaborating with participants interactively, gives them a chance to shape the themes that emerge from the data (Blackstone, 2012; Creswell, 2009).

Thematic data analysis was identified as the intended method of analysing the data (Braun & Clarke, 2006). Thematic data analysis can be described as a process of identifying, analysing and reporting on findings within data. According to Braun and Clarke (2006) this method of data analysis allows the researcher to be flexible in the way in which the rich and descriptive

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detail from the interviews are analysed and “linked by a common theme or idea allowing you to index the text into categories” (Gibbs, 2014, para. 1). Braun and Clarke (2006) suggested six phases of thematic analysis:

- Familiarising yourself with the data – Data needs to be transcribed by reading and re-reading the data while making notes on initial ideas. This is a key phase of data analysis within an interpretive qualitative methodology since meanings are created (Bird, 2005).
- Generating initial codes – Coding of interesting parts of the transcribed data should be done throughout the whole data set, while collating data that might be relevant to each code. These codes identify and organise a feature of raw data that could be assessed in a meaningful way regarding the phenomenon (Braun & Clarke, 2006).
- Searching for themes – After these codes have been collated, possible themes should be identified by gathering all relevant data for the potential theme. The list of identified codes is sorted into groups that may be combined to form overarching themes for the study (Braun & Clarke, 2006).
- Reviewing the themes – Themes need to be checked to see if they work for the coded extracts and later the same should be done on the whole data set as this should present the researcher with a thematic map of the analysis. Two levels of analysis are important during this phase. Level one involves reviewing the coded data extracts. This means that each extract needs to be read and considered to see if it forms a coherent pattern. If it does, the researcher can move to the second level. Level two suggests the same process but for the entire data set. Here, the validity of the theme is examined in relation to the entire data set as well as concluding whether the evident themes reflect the meaning of the entire data set (Braun & Clarke, 2006).
- Defining and naming the themes – Analysis should be an on-going process to refine each theme, and resultantly, the story that the findings report on will also become more

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refined. Themes will be clearly named and defined. Here, the essence of each theme needs to be extracted to see which aspect of the data each theme captures (Braun & Clarke, 2006).

- Producing the report – The researcher should extract a selection of vivid and compelling extracts, while reflecting on them and relating it back to the research questions and literature. Once this has been done, the report will be written to tell the story of the data in a way that convinces the reader of the validity and merit of your analysis (Braun & Clarke, 2006).

The transcripts were uploaded to ATLAS.ti version 7 software using participant numbers to ensure confidentiality of the data. As part of this process, both the researcher and co-coder (someone on the research team with subject knowledge) individually read and re-read transcripts, while in some instances, also listening to the audio files again. Discussions between the researcher and co-coder took place and coding was finalised. The emerging themes were summarised in a table, along with a description and relevant quotes from the transcripts, illustrating each subtheme (see appendix B).

### ***1.4.2.6 Trustworthiness and credibility.***

Trustworthiness is defined as “... the acid test of your data analysis, findings and conclusions.” (Nieuwenhuis, 2007b, p. 113). The following were used to enhance the trustworthiness of the study:

- Research diary – process notes were taken during the data collection and analysis phase so that others could see why the researcher created certain codes, themes and interpretations of data. All notes that were made during this process were kept and stored as part of the data.

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- Transcription of data – the researcher read the transcripts several times and listened to the audio files again to get a broad idea of the data. Each transcript was subsequently read in detail to understand the experience of each participant. The researcher was increasingly immersed in the data, and line-by-line, the researcher started coding the data. Gibbs (2014) explains that intensive reading needs to take place so that the researcher will be able to identify all the relevant ideas from the transcripts.
- Co-coding of data – the participants were informed that the researcher was working within a larger research team and that data were to be co-coded and analysed by another researcher on the team. Through this process, higher inter- and intra-coder reliability was established. Inter-coder reliability refers to consistency among coders when seeking agreement on codes and themes, whereas intra-coder reliability refers to consistency within a single coder during the course of data analysis (Creswell, 2014).
- Stakeholder and member checking – the credibility of findings was enhanced by allowing the participants and others with special interest in the study to comment or assess the findings, interpretations and conclusions (Carlson, 2010; Creswell, 2014; Nieuwenhuis, 2007b). The trustworthiness of this study was enhanced through consultations with the panel of experts (supervisor, research team, endocrinologist, dieticians, diabetes educators, support staff, diabetes educators, nurses). Member checking is an opportunity for participants to check aspects of the interpretation of the data they provided (Carlson, 2010). It is a way to find out if the researcher understood participants' responses correctly and to see whether the analysis corresponds to participants' experiences shared during the data generation process.
- Avoiding generalisation – the researcher guarded against generalising findings of this study to the entire diabetes population. Qualitative research rather tries to give the audience an understanding from the participants' perspective. By keeping the

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participant's experiences, attitudes and behaviours in mind, the researcher wanted to collect data that could be transferable to another population, rather than becoming generalisable to the entire population.

### **1.5 Ethical considerations**

Based on the approval by the Humanities and Health Research Ethics Committee (HHREC) of the North-West University Vaal Triangle Campus, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) approved this study with reference number: NWU-HS-2016-0048 (see appendix C).

Booth, Colomb, and Williams (2008) explain that research focused on the best interest of others is also in the researchers' best interest. Therefore, the golden rule when conducting research is that of sound ethical conduct, balancing beneficence (doing well) with non-maleficence (do no harm) and acting in the best interest of the individual or group (Gravetter & Forzano, 2009; Hill, 2009; Mouton, 2011).

Ethical aspects related to research discussed by Mauthner, Mauthner, Birch, Jessop, and Miller (2005), include voluntary participation, anonymity and confidentiality and they are discussed hereafter:

#### **1.5.1 Doing most good.**

As diabetes could potentially be a sensitive topic to discuss, and could increase stress levels for some of the participants, care was taken as to not infringe on their rights. Opportunities for debriefing by a qualified professional were available to all participants that took part in the study.

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Since this study will be one of the first phases of the larger project, care was taken to ensure that no false hope was created and that tokens of recognition for partaking in the study were only given to encourage long-term commitment to the larger project.

### **1.5.2 Independent informed consent.**

Voluntary participation was promoted by the independent person obtaining the informed consent. Participants were asked to give their informed consent once the research project and objectives had been explained to them and after they had the chance to ask questions to help them make their decision on whether to participate or not. Informed consent (which also offered an explanation concerning the process of the interviews) was signed by the participant, denoting an agreement between the researcher and the participant. The participants were also informed about their right to refuse participation or withdraw at any time during the research process (Foxcroft & Roodt, 2009; Gravetter & Forzano, 2009; Mouton, 2011; Struwig & Stead, 2001). Withdrawing from the study did not affect the participant in any way.

Participants also consented that the HbA1c results of their children be made available to the researcher as it was central to the study. These results, however, were obtained from the participants' child's medical record at the CDE and no blood samples were handled by the researcher. Although the diagnosed child's HbA1c score formed part of the inclusion criteria for this study, the participants were not judged on a personal basis based on this score.

### **1.5.3 Privacy, confidentiality and anonymity.**

All the interviews were conducted in a safe and comfortable room at the CDE. None of the doctors or support staff of the CDE could hear the interviews being conducted and in addition, had no access to the raw data after the interviews.

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The participants were aware that the interviews were being recorded and gave their consent. The recorded information was treated confidentially, meaning that it was copied to a password-protected computer for transcription and data analysis purposes. Once transcription and data analysis was completed, the recorded interviews were deleted from the recorders and were uploaded to a password-protected cloud storage for back-up purposes. Only the researcher and co-coder had access to the transcribed data during the data analysis phase of the study.

Although participants needed to be identifiable for the larger project, the research team ensured the participants' optimal anonymity. To assist with this, informed consent letters were not stored with the transcribed data and no one besides the research team had access to personal contact details of participants (which were also stored in a locked cupboard in the researchers' office, separate from a copy of the participants' details). To help ensure optimal anonymity and confidentiality, no identifiable information was mentioned when the findings were reported.

### **1.6 Chapter division**

The chapters in this mini-dissertation are presented as follows:

Chapter 1: Introduction

Chapter 2: Research article: Meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes

Chapter 3: Conclusion, limitations and recommendations

### **1.7 Chapter summary**

This chapter outlined the various challenges of parents of children living with well-controlled diabetes in order to highlight the importance and purpose of this study. A detailed literature review was conducted to explain the constructs that were to be researched. The constructs included in this study are: meaning in life, psychological well-being, well-controlled diabetes, diabetes management behaviours, parents and children. Research questions were formulated and from these questions, the objectives for this study were clearly stated. The research paradigm and design was defined and the nature of the participants and the procedure of data collection and analysis were also described in detail. Ethical considerations were addressed and an outline of the chapter division for this mini-dissertation concluded this chapter.

The next chapter presents the Diabetes Care Instructions for Authors as well as the research article. In the research article, a short overview of recent literature was given, followed by the research design and methods that were employed for data generation. The results are subsequently discussed and conclusions related to practice and future research were drawn.

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## CHAPTER 2 RESEARCH ARTICLE

### 2.1 Diabetes Care - Instructions for authors

#### Manuscripts categories

**Original Articles.** Original Articles should be arranged in the following order: title page, structured abstract, introduction (no heading), “Research Design and Methods,” “Results,” “Conclusions,” “Acknowledgments,” “References,” tables, and figure legends.

A **structured abstract** is required for all Original Articles. Abstracts for an Original Article should not exceed 250 words. The abstract must be self-contained and clear without reference to the text and should be written for a general journal readership. The abstract format should include four sections: “Objective” (the purpose or hypothesis of study), “Research Design and Methods” (the basic design, setting, number of participants and selection criteria, treatment or intervention, and methods of assessment), “Results” (significant data found), and “Conclusions” (the validity, limitations, and clinical applicability of the study and its results).

The **Conclusions** section should discuss the findings of the study in the context of past research concerning the topic of the article, in particular highlighting how these findings add new information. Also, this section should, where possible, assess the possible clinical relevance of the findings avoiding any claim or terminology of superiority, especially when statistically significant but quantitatively modest differences are found. The **word count limit** for Original Articles is 4,000 words, excluding words in tables, table legends, figure legends, title page, acknowledgments, and references. In addition, an original article is limited to a combination of 4 tables and figures. **References** are limited to 40 citations. A conflict-of-interest statement for all authors must be included in the Acknowledgments section of the main document, which should follow the main text and precede the references. If there are no relevant conflicts of interest to disclose, authors should indicate as such in the Acknowledgments section.

### **Manuscript format and style**

Articles must be in clear and understandable English. Non-native English authors are encouraged to seek the assistance of an English-proficient colleague, or a communications agency, such as American Journal Experts, to help improve the clarity and readability of a paper before it is submitted to the journal.

**Title Page.** All submissions, regardless of article type, require a title page. The title page should include the following: full title; a short running title (less than 47 characters and spaces combined); the first name, middle initial, last name, and highest academic degree of each author; each author's affiliation (in English) during the time the study was conducted; contact information of the corresponding author (name, current address, telephone number, fax number, and e-mail address); and the word count and number of tables and figures.

If two authors have equal authorship, it may be noted by \* under the author list.

**Main Document.** The main document file includes the title page, abstract, main text, acknowledgements, figure legends, references, and tables, in that order. Please do not use headers, footers, or endnotes in your paper. The Main Document should be in Word document format (not as a PDF). This will allow our Editorial Office to verify word count and our production staff to convert your paper (if accepted) into an article.

**Text Composition.** Articles should be written in clear, concise English following the recommendations for scientific writing found in *Scientific Style and Format*, the Council of Science Editors (CSE) style manual (7th ed., 2006, Reston, VA, Council of Science Editors). All accepted manuscripts will be edited according to the CSE style manual and *The Chicago Manual of Style* (16th ed., 2010, Chicago, IL, The University of Chicago Press) by ADA professional publications staff. The authors are responsible for all statements made in their articles or editorials, including any editing changes made by staff. Proof pages will be sent to the

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corresponding author and should be read carefully. The designations *type 1 diabetes* and *type 2 diabetes* should be used when referring to the two major forms of diabetes. Abbreviations for diabetes, such as T2D for *type 2 diabetes*, should not be used. The term *diabetic* should not be used as a noun. All manuscripts should be double-spaced, in Arial or Times New Roman 12-point font, and saved as a .doc, .txt, or .rtf file. In addition, please do not "lock" or "page protect" your document, and avoid using footnote and endnote functions.

**Abbreviations and Units.** Abbreviations should be used only when necessary, e.g., for long chemical names (HEPES), procedures (ELISA), or terms used throughout the article. See the list of abbreviations that need not be defined; all others must be defined at first use. Abbreviate units of measure only when used with numbers. HbA1c values should be dually reported as “% (mmol/mol).” Please use the NGSP’s hba1c converter at <http://www.ngsp.org/convert1.asp> to calculate hba1c values as both % and mmol/mol.

**Font.** Text, including title and author names, should be in 12-point Arial or Times New Roman. Please avoid using boldface font. Text in tables should be no smaller than 10-point font.

**Margins.** Margins should be 1" at the top and bottom and 1" on the left and right sides.

**Acknowledgments.** The acknowledgments are located after the main text and before the reference list. Acknowledgments should contain the author contributions paragraph, brief statements of assistance, the guarantor’s name (person[s] taking responsibility for the contents of the article), funding/financial support, conflict of interest statement, and reference to prior publication of the study in abstract form, where applicable.

**References.** Please place the reference list after the main text and acknowledgments (if applicable). Original Articles are limited to 40 references. Reference numbers in the text should appear in chronological order in normal type and in parentheses [e.g., “In the study by Norton et

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al. (23)...”]. Please do not use the footnote or endnote function to cite studies or create a reference list. A reference manager must have the ability to customize the display of references. All authors must be listed by first initials and last name in each reference, and please provide inclusive page numbers. Journal titles should be abbreviated according to the National Library of Medicine’s List of Journals Indexed for Medline; for unlisted journals, please provide complete journal titles. Material in press may be cited, but copies of such material may be requested. Authors are responsible for the accuracy of the references.

**Tables.** Each table should be inserted on a separate page at the end of the document with the table number, title, and legend indicated. Table legends should be inserted below the table and should not be included inside the table. Tables should be created using Word and the "Insert Table" command. Please use Arial or Times New Roman font, no smaller than 10-point. Tables with internal divisions are not allowed (Tables 1A and B) and should be submitted as individual tables (Tables 1 and 2). Please avoid using shading within a table.

**2.2 Research article: Meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes**

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Meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes

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Word count: 4282 (without abstract and acknowledgments)

Tables: 1

### **Abstract**

**Objective:** Figures regarding children living with type 1 diabetes show that the condition is increasing at an alarming rate, with approximately 1 in 400 children living the condition (1). Parents of children living with this chronic condition not only face normal developmental challenges in raising their children, but also the added burden and stress related to an intensive diabetes management regimen. The purpose of the study was to explore the influence of diabetes management behaviours on the parental experience of meaning in life and psychological well-being.

**Research Design and Methods:** A multiple case study design was used in this qualitative interpretivist study. A purposive sample of nine parents of children, aged 8 to 18 years, living with well-controlled diabetes participated (n=9).

**Results:** Thematic analysis of the verbatim interview transcripts delivered four major themes: [1] the positive and negative impact of diabetes management behaviours on parental well-being; [2] positive beliefs about diabetes management; [3] parental-specific diabetes management behaviours and; [4] positive relationships with friends, family, the medical team and social media.

**Conclusions:** Although parenting a child living with diabetes can be challenging, parents of children with well-controlled diabetes experience meaning in life and psychological well-being. The limitations of the study are that only nine Caucasian mothers took part. Stakeholder meetings were held and member-checking was done to ensure the validity and reliability of this study.

**Keywords:** meaning in life, psychological well-being, well-controlled diabetes, diabetes management behaviours, parents, children.

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Diabetes is a chronic condition that has a significant impact on children living with it, as well as their parents, siblings and extended family. A global increase in children diagnosed with diabetes every year has been noted (2). In 2015, for the first year ever, statistics showed that there were more than 542,000 children living with type 1 diabetes worldwide (3).

Even though diabetes is a chronic life-long condition that needs daily management, effective blood glucose level management results in individuals being able to live normal, active and high-quality lives with few, if any, restrictions (4). The various management behaviours required for managing diabetes effectively involves regular blood glucose testing, taking medication, restricting food choices and regular exercise (4, 5, 6). The management of diabetes can be objectively measured by the HbA1c (glycosylated haemoglobin) result which is a measure of average blood glucose concentration over approximately 3 months (4). In collaboration with local medical experts and based upon American Diabetes Association (ADA) guidelines (7), a lifetime HbA1c level of  $\leq 8.0\% = 64 \text{ mmol/mol}$  was accepted as an indication of well-controlled diabetes for the purposes of this study.

The parents' role as caregiver and manager of the intensive diabetes management regimen required to manage the condition effectively, is a continuously changing process (6). Children are not able to make lifestyle choices or completely adhere to the treatment regimen without the input or care of their parents. For most children, their parents, more specifically their mothers, are the earliest and probably the most crucial source of support in order for them to manage their diabetes (8, 9). Parents play an invaluable role in reassuring their child that their condition is manageable, helping with testing and insulin tasks, renegotiating roles and preventing and intervening in family conflict relating to diabetes management (10). Having a collaborative relationship with your child living with diabetes could lead to improved emotional functioning as well as better treatment adherence (11).

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Parents are faced with the challenge that they must learn to balance their child's chronic condition with providing a healthy environment for the rest of the family (12, 13). Resultantly, parents of children living with type 1 diabetes reported elevated levels of paediatric parenting stress, depression, anxiety and sleep problems (14). A recent study indicated that 33.5% of mothers reported distress at diagnosis, with 19% of mothers expressing distress between 1 to 4 years after diagnosis. One third of mothers reported a higher incidence of psychological adjustment problems with clinically significant depression in the first year after their child was diagnosed with diabetes (11).

Whereas traditional psychology was based on the medical model of illness and pain, positive psychology as sub-discipline "endeavours to enhance the quality of life by focusing on strengths and already existing resources, enriching life and promoting optimal functioning" (15). As meaning in life and psychological well-being are intertwined, it is sometimes difficult to draw a proper distinction between the two. The researcher will conceptualise meaning in life, meaning-making and psychological well-being for clarity.

Literature suggests that an outcome of having meaning in life, is psychological well-being (16, 17). In contrast, experiencing life as meaningless has been correlated with a lack of psychological well-being and various other concepts such as anxiety, stress, burnout and depression (18).

Even though meaning and purpose are sometimes used interchangeably, literature suggests that meaning is superordinate, consisting of two dimensions, namely: comprehension (understanding your life and how one fits into the world) and purpose (overarching long-term aspirations and the motivations towards those goals) (19).

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When stressful events challenge a person's meaning in life, efforts are made to reintegrate the appraisal to an individual's meaning system. People thus create meaning in a process called meaning-making, which is explained as "the process of restoration of meaning..." (15).

Understanding how parents and children create meaning and how this meaning influences them, could impact on their psychological well-being and their perceptions of diabetes (20).

From positive psychology literature, psychological well-being has been linked to both the hedonic and eudaimonic traditions, with well-being referring to optimal psychological and social functioning, personal growth and a sense of autonomy (21, 22, 23). The physical, psychological and mental well-being of people can be increased when life is experienced as meaningful as this provides a buffer against personal distress (15, 24).

Studies relating to type 1 diabetes primarily have a quantitative approach and are conducted from a medical point of view with extensive reflection on global concerns about the illness, and how to monitor and control treatment (20, 25, 26). While there are qualitative studies about the parental perceptions of children living with diabetes which contribute to knowledge (27, 28, 29), no significant study has been undertaken from a qualitative, positive psychological perspective in South Africa. To address this limitation, this study aimed at exploring the influence of diabetes management behaviours on the meaning in life and psychological well-being experienced by parents of children living with well-controlled versus poorly controlled diabetes.

### **Research design and methods**

The researcher chose a multiple case study design while using a qualitative interpretivist approach to elucidate the impact of diabetes management behaviours on parents of children living with well-controlled diabetes. A purposive sample of nine parents (n=9) of children living with well-controlled diabetes participated in this study. The average age of the participants'

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children was 12, with an average HbA1c level of 7.2 % (55 mmol/mol). The average time since the diagnosis was approximately 5 years. Six of these children were males, and 3 of them were female.

Parents were included if they were (a) the parent of a child aged 8 to 18 years; (b) their child was living with well-controlled diabetes ( $\text{HbA1c} \leq 8.0\%$  [64 mmol/mol maintained over the previous 12 months]); (c) received the diabetes diagnosis more than 12 months ago; (d) were fluent in English or Afrikaans and; (e) received their diabetes care at the CDE, Parktown, Johannesburg, South Africa. Potential participants were excluded if: (a) their child suffered from any other medical condition that might have interfered with the diabetes management regimen and (b) if they were receiving psychotherapy.

Participants received either an information leaflet or saw advertisements placed on the “Youth with Diabetes” Facebook page, in the Diabetes Lifestyle Magazine or the SA Journal of Diabetes. Potential participants could then contact the researcher for more information and screening purposes.

Once the screening process was complete, qualifying participants were invited to, at their next scheduled visit at the CDE, have a 45-minute semi-structured interview conducted with them. Informed consent was obtained by an independent person before the interview started. Interviews were conducted in a comfortable and private room at the CDE. When the interviews were completed, participants received a certificate of recognition for their participation.

All interviews were audio recorded and subsequently transcribed verbatim. The research was data-driven and inductive data analysis was used to explore and make sense of the data generated, looking for patterns within the data and working towards developing a theory to explain those patterns (30). Collaborating with participants interactively, gave them a chance to

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shape the themes that emerged from the data (31). Thematic analysis (32) was used to identify codes and themes within the transcripts of the participants' interviews. Before the analysis, the researcher compared each transcription to the audio recordings to ensure that interviews were accurately transcribed verbatim. Then, the researcher invented initial coding categories that were organised into a preliminary coding table and subsequently entered into ATLAS.ti version 7. Using these preliminary codes, the researcher became systematically immersed in the data by coding each interview line-by-line to ensure that topics were not overlooked.

The co-coder independently coded a third of the transcripts using the initial coding template in order to validate coding done by the researcher and reviewed all audio recordings to verify that findings were interpreted appropriately and interpreted within context. The researcher and co-coder reviewed the findings and identified four themes.

Once themes were identified, the researcher provided participants with general feedback in the form of a poster. The poster was sent out as part of the member-checking process. Several stakeholder meetings were held with various experts during the data generation and analysis phase to ensure the validity and reliability of the data and how it was interpreted.

### **Results**

Four themes emerged from the qualitative analysis of the participant's interviews. Similarities and differences in how parents talked about each of these themes are described. The four themes are presented and Table 1 summarised the themes and subthemes.

#### **Theme 1: The positive and negative impact of diabetes management behaviours on parental well-being**

Parents reported that the diabetes diagnosis was initially a cause of great concern and **psychological distress**, including anxiety and depression.

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Several parents reflected on the psychological distress that they faced both directly after the diagnosis and later on in their everyday management of the condition. As one parent reflected, *“I was beside myself, I was in tears”* [P2C]. Another parent said *“I actually couldn’t... I couldn’t face it and I knew that I have to face it”* [P2A]. Initially, the shock and fear of what is to come overwhelmed parents and they might not have known what to expect. As time progressed, parents had to deal with the stress of three-monthly doctor visits and HbA1c results. As one parent noted, *“mothers are more nervous before that than going to the gynie every year and that’s big I can tell you”* [P3C].

Along with the psychological distress, most of the parents experienced **social isolation** both directly after the diagnosis and later. *“It can be quite an isolating experience”* [P1A]. When the parents received the diabetes diagnosis, they felt that they were now different to other parents. Since they needed to manage their child’s condition, parents often did not socialise with friends and family. When parents did opt to go out or socialise with friends or family, the hosts were often not mindful enough to cater for the child living with diabetes. One parent reflected and said, *“you literally are at the whim of this disease and it has a huge impact on your exchange with your world...that has an impact when you socialise with family.”* [P1A]. Parents had to make provisions for their own children, which could have been one of the reasons why they would rather have preferred to stay at home.

In contrast to all the negative experiences of the impact of diabetes management, parents also reported **positive impact and change** in their lives. One parent specifically said, *“It’s had a positive impact not a negative impact”* [P2A]. The same parent reflected on how healthy the family has become after the diagnosis and said, *“I think a lot of good has come out of it”* [P2A].

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The experience of psychological distress and social isolation had a negative impact on their psychological well-being. Parents did not have time to prepare themselves as the treatment of the condition started immediately which added stress and anxiety, often causing parents to feel unsure about how they will manage their child's condition. Despite the negative effect reported by parents with regards to diabetes and the impact of the management thereof, parents recognised the positive impact it has had on their lives.

### **Theme 2: Positive beliefs about diabetes management**

Parents of children living with well-controlled diabetes viewed diabetes as a chronic condition that was manageable and required a lifestyle adjustment in order to create a new normal for their child and the rest of the family.

Almost all parents viewed **diabetes as a chronic condition** that is **manageable**. Very little reference was made to “illness, problem, sickness, etc.” One parent said, “*it is not necessarily a death sentence...it feels that way initially and it feels as if you are going through hell and you don't know how you are going to make sense of all these things that are happening*” [P4A].

When parents believed that their child's condition was manageable, it resulted in better treatment adherence and better glycaemic control. This parent reflected that the feeling that it is a death sentence, gets better because “*we respect that if we don't manage it, the personal cost to our son will be profound and to ourselves as a family*” [P1A]. This finding correlates with research. Parents set the stage for their children when it came to management.

Diabetes requires constant management, and parents knew that their **lifestyle needed to be adjusted** and they strived towards finding and adopting management behaviours that worked and fit their individual and family routines. One parent noted, “*it's just actually more a lifestyle*

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*management.” [P2C]. Parents were realistic and saw diabetes management as “a long journey... and it’s changing and we’re up for it changing all the time” [P3C].*

Some participants felt that **normalcy should be redefined** when caring for a child living with diabetes and that they should raise their child to be as normal as possible, not treated any differently. One parent reported, *“finding a new normal is important” [P1A].* Achieving this normalcy is something that parents and their children aspired to, even though the parents knew that their children had to do things that other children need not do in order to manage the diabetes well. Finding what works for them, helped parents feel more in control, making the task of managing their child’s diabetes, seem less daunting. Parents’ perceptions are often linked to better treatment and adherence. When the adolescent’s peers also treated, the child living with diabetes as a normal child, it helped to take away the stigma around diabetes. One parent said that *“they just treat him as a normal adolescent and their behaviour towards him is not in any way hypersensitive or hyper vigilant...that’s important for Al otherwise it just feels [like] a stigma” [P1A].*

### **Theme 3: Parental-specific diabetes management behaviours**

As part of managing their child’s diabetes, parents were more aware of variables that influenced diabetes and carefully planned with these variables in mind. Parents also saw education of themselves, the child and others as an opportunity to not only empower the child to manage their diabetes independently, but also to create awareness of the condition for others in the community.

Parents always had a sense of **awareness** regarding their child’s condition. This awareness was related to being mindful **about how the condition could be managed**. One parent commented that, *“you are much more aware of what you buy to eat” [P3A].* Parents not only became aware

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and changed their eating habits, but in some instances, introduced exercise and new routines.

One parent said that *“he then twice during the week has sport at school and then invariably every afternoon there’s a sport and possibly Saturday...and I find that helps so much with his sugar...I can see the difference when he’s done exercise...”* [P6A].

**Education** informed beliefs about diabetes and the management behaviours. One parent said, *“the more we learn and the more you know, the more empowered you will be to cope”* [P1A].

This in turn helped them to empower their children so that they could take over the management responsibility when they were old enough. If they helped their children take ownership of the condition, they felt a bit more relaxed and content over time. Education also includes contributing to another person’s understanding and knowledge of the condition. One parent commented that to educate others made *“...a world of difference”* [P1C], contributing to parents’ experience of meaning in life. Part of the journey of diabetes management parents embarked on, was that beliefs and the necessary management behaviours for living with well-controlled diabetes, were transferred. One parent noted that *“they wanted me to tell them what they had to do and they would do it...and it was actually exciting for her friends because it was something new for them to learn and she taught them all how to inject her”* [P2A].

Parents saw **planning** as crucial to diabetes management as it alleviated pressure and helped to balance different roles, as one parent said that *“having a plan helps”* [P1A]. Parents made different plans. For some parents, planning consisted of capturing their child’s life on an Excel spreadsheet or spending time weighing and measuring food over weekends to take the load off of them during the week. For others, it might have been to regularly consult with their child to see if the routine was still working or if something else could be done to make their lives and the management of the condition, a bit better.

### **Theme 4: Positive relationships with friends, family, the medical team and social media**

Parents noted the importance of the **medical team**, be it the endocrinologist, the diabetes educators or a nurse in hospital: *“have full trust in them, be open with them, make them your friends. You know your child is coming here every 3 months”* [P2A]. Parents needed to better understand the condition, and at first, the doctor and his medical team, were the only people that could help parents do exactly that. Parents saw the doctors and other staff as being competent, well-trained and knowledgeable. Not only did the doctors provide parents with the necessary information regarding the management of the condition, but they were also the people who parents came to confide in when things were going wrong. One parent reflected by saying *“anything that happened that I didn’t know the answer to I wrote it down and when I first came to David I used to have lists of questions and that was my way of understanding...my way of learning”* [P2A]. Therefore, the medical team helped parents by also offering them the necessary support when they were not at the doctor. The medical team did this by ensuring that parents could always reach them when they had concerns or problems. Another parent reflected on how this made her feel at ease and increased her well-being by saying *“it is important to know that you can contact Dr Segal at any time of day or night if you have a problem, and he or someone in his team will tell you what to do in your crisis situation”* [P3A].

Parents also felt the support of their **family and friends** to be important, especially those who are *“mindful when it comes to social activities”* [P1A]. Parents often visited family and friends that made the necessary provisions for their child. Although some parents felt that their families could be more supportive, they didn’t expect it of them.

Parents also referred to people at **school** as being supportive. Parents reported high levels of anxiety when their children were at school or not under their direct supervision. Parents believed that when the school and the teachers receive training on diabetes and the management thereof,

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that it would give them some peace of mind as their child's glycaemic levels would be monitored and better controlled. Friends at school also added to the parents' peace of mind, *"his friends also know how to use the emergency injection that is in his suitcase if anything should happen"* [P4A]. If the staff and friends at school were well-informed, parents were more at ease which lead to an increase in psychological well-being.

Parents also referred to **social media** as a form of social support. Joining diabetes groups on Facebook gave parents a sense of belonging and it also gave them a platform to express their concern regarding their own child, or to potentially help and contribute to someone else's understanding or management of diabetes. A parent reflected by saying *"it's a safe space to whine and speak about sugar levels and ketones...it's a closed group so no one else can see the stuff and you are not gonna look like a complete fool or people are not gonna judge you"* [P3C]. One parent reflected on her experience of joining a support group on Facebook and stated, *"I look for positives and I am always looking for what we can learn not for the negative stuff"* [P2A]. As social media has become one of the world's fastest growing platforms for people to interact on, parents of children with diabetes join pages on Facebook with the hope of better understanding their child's condition, or to help another parent or person living with diabetes, to better manage their condition.

## Conclusions

The aim of this study was to explore the influence of diabetes management behaviours on the meaning in life and psychological well-being experienced by parents of children living with well-controlled diabetes.

The results indicated that diabetes management behaviours had a positive and negative impact on parental well-being. The negative impact of diabetes management behaviours have been well-

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documented for the person living with the condition, as well as the impact that it could have on the extended family and friends (12, 13). Parents experienced psychological distress, accompanied by social isolation or change. In reaction to the diagnosis and adjusting to diabetes management behaviours, parents also experience stress, depression and anxiety (14, 27). Even though some parents experienced adverse impacts while in the process of managing their child's condition, parents in this study commented on the positive impact and change it has had on them and the rest of the family. Parents had to adjust their lifestyle, routines, schedules and behaviour in order for them to assist their child to manage their condition. Most of these changes assisted parents in their meaning-making process, which lead to increased psychological well-being.

Parents' perceptions about diabetes as a condition, the adjustment process as well as the fact that a new normal had to be defined, all played a valuable role in parents helping their child achieve average blood glucose levels, which were acceptable. From literature, it is suggested that there are four aspects of diabetes management behaviours, e.g. testing, using insulin, restricting food choices and regular exercise (4, 5, 6). However, from the empirical results of this study, the researcher suggests that the management behaviours of diabetes do not only include those four aspects, but also includes an additional three factors, namely, a sense of awareness, education and planning. Empowering their children to manage their diabetes formed part of the parents' meaning-making process and resulted in parents experiencing an increase in meaning in life. The positive impact of positive relationships also helped parents make sense of their child's condition, and made it manageable over time.

The study of meaning falls within the existential paradigm with Victor Frankl as one of the founding inspirations of research on meaning in life. Frankl suggested that people have a unique function in life and that is to perceive a sense of meaning and to live a life of purpose (33). Even though an inductive data analysis process was followed to come up with new theory, the

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researchers found that the theory could also be applied deductively to the theory of Frankl. The existential theory, and more specifically the propositions (34), is relevant to the study of meaning in life of parents of children living with well-controlled diabetes. The results are subsequently applied to the propositions:

[1] the capacity for self-awareness relates to parents being aware of their child's condition and the impact on their lives, and resultantly parents wish to create awareness through education so that others too can be more aware and mindful;

[2] freedom and responsibility. Parents felt responsible for the management of their child's diabetes, but through proper planning and execution of successful diabetes management behaviours, parents experienced a sense of freedom and were more relaxed;

[3] creating one's identity and establishing meaningful relationships with others was linked to how parents' internalised the beliefs regarding their child's condition and this contributed to their sense of self and their identity. The condition became something they lived with and it became part of their families' identity. In order to manage the condition, meaningful relationships were formed with the medical team, friends, family and on Facebook;

[4] the search for meaning, purpose, values and goals was reflected in the parent-specific diabetes management behaviours as they educated themselves regarding the condition and the management thereof, creating a sense of meaning and purpose. This they not only did for themselves, but also with the purpose of empowering their children and other in the community;

[5] anxiety as a condition for living and [6] awareness of death and nonbeing was strongly associated to their beliefs about diabetes and diabetes management. From literature and the results of this study it was clear that parents experienced anxiety related to everyday life, and even more so when diabetes-specific problems arose, requiring immediate management.

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Diabetes management behaviours served as a daily reminder to parents that life is short and that in turn motivated parents to manage the condition of their child to the best of their ability.

Although the article refers to parents collectively, all nine participants were Caucasian mothers of children, aged 8 to 18 years, receiving their diabetes treatment at the CDE Parktown, Johannesburg, South Africa. This is a specialist centre and not all children with diabetes have access to a specialist multi-disciplinary care team. No fathers participated and future studies would benefit from greater paternal involvement as well as collecting data from parents of children that are not managing their diabetes well so as to establish factors that could prevent effective management within the South African context.

Conducting parent-centred qualitative research allowed the researcher to explore the experiences of parents regarding the diabetes management behaviours' effect on their meaning in life and psychological well-being. This gave a better understanding of the impact diabetes had on not only the person living with the condition, but on the whole family. Research such as this could potentially help shape individualised interventions aimed towards enhancing and sustaining parental meaning in life and psychological well-being over time and through different life stages.

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**Table 1: Themes and subthemes**

| Themes    | Description                                                                                                    |
|-----------|----------------------------------------------------------------------------------------------------------------|
| Theme 1   | The positive and negative impact of diabetes management behaviours on parental well-being                      |
| Subthemes | Psychological distress, Social isolation, Positive impact and change                                           |
| Theme 2   | Positive beliefs about diabetes management                                                                     |
| Subthemes | Diabetes as a chronic condition that was manageable, Lifestyle adjustment was necessary, Creating a new normal |
| Theme 3   | Parental-specific diabetes management behaviours                                                               |
| Subthemes | Awareness, Education, Planning                                                                                 |
| Theme 4   | Positive relationships with friends, family, the medical team and social media                                 |
| Subthemes | Medical team, Family and friends, School, Social media                                                         |

## CHAPTER 3 CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

### 3.1 Introduction

The purpose of this chapter is to present conclusions, recommendations and limitations based on the empirical results of this study. Conclusions will be drawn from the objectives as set out in Chapter 1. The limitations of the study are described. Finally, recommendations will be made by identifying possibilities for future research.

### 3.2 Conclusions from literature and empirical results

The aim of this study was to explore the influence of diabetes management behaviours on the meaning in life and psychological well-being experienced by parents of children, aged 8 to 18 years, living with well-controlled diabetes. Based on the results of the study, the following conclusions were made:

**The first objective was to conceptualise diabetes, diabetes management behaviours, meaning in life and psychological well-being from literature.**

Based on the literature review, type 1 *diabetes* can be conceptualised as a condition that develops when the beta-cells that produce insulin are destroyed, resulting in the pancreas not producing any, or enough insulin, thus, creating the need for lifelong dependence on exogenous insulin (Centres for Disease Control and Prevention [CDC], 2014; Chiang, Kirkman, Laffel, & Peters, 2014). People living with diabetes experience a glucose imbalance or defects in insulin secretion or insulin action, or a combination of the two (American Diabetes Association [ADA], 2010; CDC, 2014; Guariguata et al., 2013; Jerant, Von Friederichs-Fitzwater, & Moore, 2005).

The concept *diabetes management behaviours* was conceptualised as involving regular blood glucose testing, taking medication (oral or insulin injections), restricting food choices and

## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

regular exercise (CDC, 2014; Silverstein et al., 2005). The management of diabetes can be objectively measured by the HbA1c (glycosylated haemoglobin) result which is a measure of average plasma glucose levels over approximately 3 months. The Centre for Diabetes and Endocrinology (CDE) guidelines stipulate specific treatment targets of between 7.0% and 8.5% for children aged 6 to 16 years (CDE, 2015). In collaboration with local medical experts, based upon ADA (2012) and guidelines recommended by Rewers, Pjhoker, Donaghue, Hanas, Swift, and Klingensmith (2009), a lifetime HbA1c level of  $\leq 8.0\%$  was accepted as an indication of well-controlled diabetes for children between the ages of 12 – 18 years.

Literature on *meaning in life* suggests that an outcome of having meaning, is psychological well-being (Kobau, Snizek, Zack, Lucas, & Burns, 2010; Steger, Kashdan, & Oishi, 2008). Frankl (1963) is commonly cited as one of the founding inspirations of research on meaning in life. Frankl (1963) suggested that people have a unique function in life and that is to perceive a sense of meaning and to live a life of purpose. Even though meaning and purpose is sometimes used interchangeably, Steger (2012) suggests that meaning is superordinate consisting of two dimensions i.e. comprehension (understanding your life and how one fits into the world) and purpose (overarching long-term aspirations and the motivations towards those goals). For this study, the researcher conceptualised meaning in terms of Viktor Frankl's theory of "will to meaning" which can be explained as an inner pull to find meaning in life and to a life of purpose (Frankl, 1963). When stressful events challenge a person's meaning in life, efforts are made to reintegrate the appraisal to individuals' meaning systems, in a process called meaning-making. Meaning-making is explained as "the process of restoration of meaning..." (Wissing, 2014, p. 154). Marshall, Carter, Rose, and Brotherton (2009) reported that understanding how parents and children create meaning and how this meaning influences them, could impact on their perceptions of diabetes.

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From positive psychology literature, *psychological well-being* has been linked to both the hedonic and eudaimonic traditions, with well-being referring to optimal psychological and social functioning, personal growth and a sense of autonomy (Baumgardner & Crothers, 2010; Deci & Ryan, 2008; Hervas & Vazquez, 2013). An outcome of this process is successful adjustment and a meaningful life acts as buffer against personal distress, which relates forward to enhancing physical, psychological and mental well-being of people (Park & George, 2013; Wissing, 2014).

**The second and third objectives were to determine the influence of diabetes management behaviours on the experience of meaning in life and psychological well-being of parents of children living with diabetes.**

These objectives will be discussed as a unit as the literature review illustrated the relatedness of the two concepts.

Thematic analysis delivered four major themes: (1) the positive and negative impact of diabetes management behaviours on parental well-being; (2) positive beliefs about diabetes management; (3) parental-specific diabetes management behaviours; (4) positive relationships with friends, family, the medical team and social media.

In order to experience life as meaningful, the existential theory suggested six propositions: (1) the capacity for self-awareness; (2) freedom and responsibility; (3) creating one's identity and establishing meaningful relationships with others; (4) the search for meaning, purpose, values and goals; (5) anxiety as a condition for living and; (6) awareness of death and nonbeing (Corey, 2009). The results from this study were applied to these propositions and it gave valuable insight as to how parents created and experienced meaning in life.

Understanding how parents made sense of their child's condition and the impact of the daily management behaviours on their experience of meaning in life and psychological well-being

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should help practitioners better understand what parents go through in caring for a child living with well-controlled diabetes. The impact of the diabetes management behaviours were not solely negative, but parents also felt some good has come from it. Parents' perceptions about diabetes as a condition, the adjustment process as well as the fact that a new normal had to be created, all played a valuable role in helping their child achieve average blood glucose levels, that were acceptable. Three additional parent-specific diabetes management behaviours were identified that contributed to the parental experience of meaning in life and psychological well-being. The positive impact of positive relationships and social support also helped parents make sense of their child's condition, and made it manageable over time.

The influence of diabetes management behaviours on the parental experience of meaning in life and psychological well-being could clearly be seen in the above discussion. The empirical results suggested that parents experienced meaning in life, despite the various challenges they faced. These challenges started the day the child was diagnosed and it was the continuous daily management behaviours that had an impact on the parents' meaning-making process. For parents in general, raising children could be just as stressful as it is wonderful. For parents of children living with diabetes, the impact of diabetes and the management thereof is almost tangible and adds extra stress and demands in all areas of life. However, seen from the results, parents did experience meaning in life and an increase in psychological well-being while caring for their child living with a chronic condition.

### **3.3 Limitations**

Although the article refers to parents collectively, all nine participants were Caucasian mothers of children, aged 8 to 18 years, living with well-controlled diabetes and receiving their diabetes treatment at the CDE, Parktown, Johannesburg, South Africa. No fathers participated and future studies would benefit from greater paternal involvement.

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While the small sample size may be appropriate for qualitative research purposes, it is important to indicate that these mothers only represent a very small group of mothers of children living with well-controlled diabetes. This might influence the results and it is recommended in future research that even more mothers are invited to partake in similar studies.

Since these children received their care at the CDE Parktown, it should also be highlighted that the results of this study might vary in other areas of the country. This is a specialist centre and not all children with diabetes have access to a specialist multi-disciplinary care team. These findings thus aren't generalisable to other parts of South Africa or to families in lower socio-economic areas.

### **3.4 Recommendations**

This study provided valuable insight as to how diabetes management behaviours impacts parents' experience of meaning in life as well as the influence thereof on their psychological well-being. Recommendations were made based on the results of the study.

#### **3.4.1 Practical implications.**

Conducting parent-centred qualitative research allowed the researcher to explore the experiences of parents regarding the diabetes management behaviours' effect on their meaning in life and psychological well-being. This gave a better understanding of the impact diabetes had on not only the person living with the condition, but on the whole family. Research such as this could potentially help shape individualised interventions aimed towards enhancing and sustaining parental meaning in life and psychological well-being over time and through different life stages.

### **3.4.2 Future research.**

For future research, it is recommended that the paternal experience of meaning in life and psychological well-being should also be researched as this could be different as compared to that of the maternal experience.

As this was only a study done with nine mothers, some questions arose which could inform future research. These questions include: Do fathers experience the same impact on their meaning in life and psychological well-being as mothers do?; What interventions could help parents on their meaning-making journey?; Do parents of children living with diabetes experience support from organisations where they are employed? and; What could the effect of organisational support be on parental functioning, psychological well-being, engagement and productivity?

As only a small percentage of people adhere to the diabetes management behaviours necessary for effective management, a great deal of future research is necessary to better understand diabetes and the impact of the management behaviours on parents of children that live with diabetes that is not well-controlled. Intervention programmes for these parents and their children should be researched.

A further possibility for future research could be to also include the parents of children that no longer reside at home (e.g. young adults studying or working). This could enhance the understanding of the effect of diabetes on the family even after a child is no longer under direct care or supervision of the parents.

### **3.5 Chapter summary**

In this chapter, conclusions were drawn regarding the objectives as set out in Chapter 1. The limitations of the study were discussed. The recommendations made considered the practical implications as well as the possibilities for future research.

### **3.6 Reflection by the researcher**

One of the main ideas in psychology, is that people need to be studied holistically. For someone to do that, people with all their behaviour, lifestyle choices and actions should be studied. Being aware and mindful when observing people teaches that people do things differently, and that is also true for the way in which people manage their diabetes.

The researcher became interested in the topic when it was introduced in one of the lectures during the course-work component of this degree. The researchers' father was diagnosed three years ago with type 2 diabetes and knowing how burdensome the management regimen can be for someone living with the condition, it became clear that parents of children living with diabetes, could also face various challenges in ensuring that their child's diabetes is managed effectively. Understanding how people manage the condition, make sense after the diagnosis and still experience well-being baffled the researcher. As the researcher became more immersed in various studies undertaken to explain this, it was clear that positive psychology and related constructs could easily be applied to the lives of people living with diabetes. At first the idea was to work with the children themselves, but the researcher decided that it would be good to also give a voice to the parents of the children living with well-controlled diabetes.

Resultantly, the parents of children became the chosen participants for the study. During the data generation period, the researcher came to a deeper understanding as to how parents made sense and experienced well-being. Over time, the researcher became more confident in

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questioning and asking probing questions to elucidate responses from participants. During the concurrent data analysis period, the researcher had the opportunity of learning how ATLAS.ti version 7 works. A workshop was held with all researchers in the larger project to help with better understanding how to code and create various themes. During this process, the researcher was also joined by a co-coder (one of the other researchers in the larger project), and this helped with independent coding and verification of themes extracted from the data. Once data analysis was completed, the researcher made sure to give feedback to the participants in the form of a poster (sent via e-mail for member-checking purposes) and to be attached to notice boards at the CDE Parktown once the study has been finalised.

Throughout the whole research process, the researcher became more aware of his own competencies. As an inexperienced researcher, completing the Master of Arts degree, brought a sense of achievement to the researcher. The researcher still has a lot to learn in the field of positive psychology and related disciplines, but the researcher will pursue his dream of contributing to existing knowledge as well as to help people, communities and organisations.

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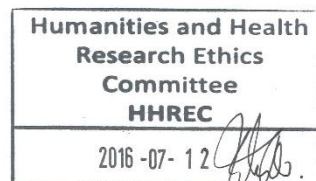
## APPENDIX A



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

PO Box 1174, Vanderbijlpark  
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12 July 2016

### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR PARENTS

**TITLE OF THE RESEARCH PROJECT:** The meaning in life and psychological well-being of parents of children living with diabetes.

**REFERENCE NUMBERS:** NWU-HS-2016-0048

**RESEARCHER:** Mr. Christiaan Bekker

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

**CONTACT NUMBER:** (016) 910 3414

You are being invited to take part in a research project exploring the influence of diabetes management behaviours on the meaning in life and psychological well-being of parents of children living with diabetes. Take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project you do not fully understand. It is very important that you be fully satisfied that you clearly understand what this research is about and how you could be involved.

We want you to be comfortable with the research process and all it entails. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you had initially agreed to take part.

This study has been approved by the **Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2016-**

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

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0048) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health Research Ethics Council. It might be necessary for the research ethics committee members or relevant authorities to inspect the research records to make sure that I (the researcher) am conducting research in an ethical manner.

### What is this research study all about?

- *This study will be conducted at the CDE Houghton or Parktown. The research involves an interview with you. The researcher has been trained to use the method mentioned.*
- *The researcher cannot specifically say how many participants will be involved in the interviews, but predict that approximately twelve to twenty participants will be interviewed.*
- *The objective of this research is to explore the influence of diabetes management behaviours on the meaning in life and psychological well-being you as parent of a child living with diabetes, experience.*
- *The following questions will be asked: How do you make sense of (the child's name) living with diabetes? How does managing (the child's name) diabetes influence your meaning in life? How does managing (the child's name) diabetes influence your well-being?*

### Why have you been invited to participate?

- *You have indicated that you would be interested in taking part in the project. You already received a phone call in which you indicated your interest in the project, followed by an e-mail with this form attached. Also note that the researchers have obtained permission from the CDE Houghton and Parktown to conduct this research.*
- *You are the parent of a child living with diabetes that has also complied with the following inclusion criteria: he/she can speak English or Afrikaans, he/she is between the ages of 8 and 18, was diagnosed more than 12 months ago, is a patient at the CDE Houghton or Parktown and has an HbA1C of 8% or less over the last 12 months.*
- *You will be excluded if your child suffers from any other medical condition that might interfere with the diabetes management regimen or if you are currently receiving psychotherapy.*

### What will your responsibilities be?

- *You will be expected to participate in an interview of which the duration will be approximately 45 minutes. This will take place in a suitable venue at the CDE Houghton or Parktown, before or after your regular appointment with either the diabetes educator or medical practitioner, depending on your preference.*
- *We would also like to include your child's HbA1C results in this study as this will give us an objective measure of how your child's diabetes is managed. The researchers will, however, not be doing the blood test themselves, but will obtain the results from your medical record at the CDE Houghton or Parktown. This will only happen once you have given your written informed consent.*



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### Will you benefit from taking part in this research?

- The direct benefits for you as a participant will probably be the following:
  - While you think about the questions, you may come to a better understanding of diabetes management behaviours, which may positively influence how your child's diabetes is managed.
  - After participation in the interview you will receive an information leaflet on diabetes management which could further assist you in managing your child's diabetes.
  - As part of thanking you for taking part in this study, the researchers will give you a certificate. Because you will be receiving this token of appreciation that is personalised and only meant for parents of children living with diabetes, you may start feeling that you belong to a special group and that your opinions are important.
- The indirect benefit will probably be:
  - The research community, both medical and behavioural sciences, could benefit from a better understanding of the experiences of diabetes management behaviours.
  - The cost of not managing diabetes well could be reduced, resulting in savings for individuals (less hospitalization, medical expenses, less time off from school), the workplace (less days off from work, absenteeism, medical aid expenses, loss of productivity – to name only a few) and the community at large (healthier members that can contribute to improving society).

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

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

| <i>Probable/possible risks/discomforts</i>                                                                                                                                                  | <i>Strategies to minimize risk/discomfort</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Because you may be spending 45 minutes participating in the interview, it is possible that you will become tired.                                                                           | The researcher facilitating the interview will give you a low carb snack with bottled water when the interview starts.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Because the researcher will ask you questions about your child's diabetes management, you will need to think about how you manage their diabetes, and this may make you feel uncomfortable. | Upon completion of the interview, the researcher will ask you 'whether you experienced any psychological distress or discomfort while taking part in the research. If you indicate that you did, a follow-up telephone call (by Dr Deacon) will follow the next day to see if you are still feeling the same way. If not, you will be thanked for your participation and wished well. If you are still distressed, a session will be booked with Rosemary Flynn (a registered clinical psychologist affiliated with the CDE Houghton) for you to discuss your experience and debrief you. These arrangements will be made by the researcher. |

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## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

|                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| The researcher will be using your child's HbA1C results (done every three to six months), which indicates how well their diabetes is managed. The researcher will, however, not be doing these tests himself, but will obtain the results from your child's medical record at the CDE Houghton or Parktown, with your permission.                       | We will not be drawing blood or doing any other tests that need us to hurt your child physically. The researcher will ask your written informed consent to retrieve the information from your child's record at the CDE Houghton or Parktown.                                                                                                                                                                                                                                 |
| In this study the researcher will be asking you how well your child's diabetes is managed, which is also measured by the HbA1C test. Although the researcher will not be talking about this result, you may be concerned that he will judge you based on that result, or think less of you based on how well (or not) you manage your child's diabetes. | Living with diabetes can be difficult and the researcher will treat every person that is willing to share their experience, with respect. The researcher will not discriminate against any person based on how well (or not) they manage their child's diabetes. If at any stage you feel uncomfortable talking about your feelings, please let the researcher know so he can help you identify a psychologist in your region and help you to arrange an appointment for you. |
| Caring for a child living with diabetes, may cause you to feel that you are different from your friends and that you feel you do not belong in the same group as your friends.                                                                                                                                                                          | As part of thanking you for taking part in this study, the researcher will give you a certificate. Receiving this may lead to you feeling that you belong to a special group and that your opinions are important.                                                                                                                                                                                                                                                            |
| Caring for a child living with diabetes might make you worried that people learn about your child's diagnosis and start treating you differently.                                                                                                                                                                                                       | The researcher will meet with you at the place where your child normally receives his/her treatment (CDE Houghton or Parktown), so you can feel comfortable in a safe place familiar to you.                                                                                                                                                                                                                                                                                  |
| As the researcher will be meeting with you at the CDE Houghton or Parktown, you may encounter transport costs to get there. There may also be time taken off from work to take part in this study.                                                                                                                                                      | In order to minimize transport and other costs, the researcher will schedule the sessions to coincide with your child's normal visits to the CDE Houghton or Parktown.                                                                                                                                                                                                                                                                                                        |
| This study is a long-term project (5-10 years). This means that you will be asked to participate several times over the next few years.                                                                                                                                                                                                                 | You will be asked to take part not more than once every two years. You also at any time have the right to no longer participate.                                                                                                                                                                                                                                                                                                                                              |

➤ *However, the benefits (as noted) outweigh the risks.*

### Who will have access to the data?

➤ *Anonymity (that is, how your results will be linked to your identity) will be managed by providing you with a code that will only be used for your information. As this is a*

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## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

*long-term project, this code will be used every time you take part in a phase of the project. This code will be allocated to you once you have given written informed consent. This code will be indicated on the consent form, after which the consent form will be stored in a separate place, away from the data, to ensure that no link can be made between your results and identity.*

- *Confidentiality is the way the researcher ensures that he will protect the information he has concerning you. During the interview, only you and the researcher will be present. The information gathered will be linked to your individual code. The researcher will also make sure that in recording the data, only your code will be used, and references to your name or any other identifiable details will be removed. Reporting of findings will be anonymous by only referring to your participant code.*
- *Only the researcher will have access to the data. Although the researcher works closely with the CDE Houghton or Parktown, 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' office and electronic data will be password protected.*
- *Audio-recorded data will be sent to a transcriber who will sign a confidentiality agreement (i.e., this person will not be allowed to talk to anyone about any aspect of the data). As soon as data has been transcribed it will be deleted from the recorders. The transcripts will be stored on a password-protected computer. All co-coders will sign confidentiality agreements.*
- *As this forms part of a long-term project, data will be stored for a minimum of 10 years.*

### **What will happen to the data?**

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

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

### **Will you be paid/compensated to take part in this study and are there any costs involved?**

No, you will not be paid/compensated to take part in the study, but refreshments will be provided (a bottle of still water and a low-carb snack). The researcher aims to incorporate the interviews to coincide with your child's scheduled visits to the CDE Houghton or Parktown. This means, you do not have to travel additionally for the purpose of participating in the project. Thus, there will be no additional costs involved for you as parent.

### **How will you know about the findings?**

- *As this forms part of a long-term project, participants will receive (preferably via e-mail) an annual progress report, including the main findings thus far, as well as further opportunities for participation. Posters containing the main findings will also be displayed at the CDE Houghton and Parktown.*



## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

- Even though no feedback on your personal interview results will be discussed with you (as the interview in itself will be a discussion of your experiences), the researcher will make telephonic contact with you to ascertain whether the analysis of your interview is a true reflection of what you intended to convey to the researcher.

### Is there anything else you should know or do?

- You can contact Dr Elmarie Deacon at [elmarie.deacon@nwu.ac.za](mailto:elmarie.deacon@nwu.ac.za) or (016 910 3414) if you have any further questions or encounter any problems.
- You can contact the chair of the Humanities and Health Research Ethics Committee, (Prof Tumi Khumalo (016 910 3397 or [Tumi.khumalo@nwu.ac.za](mailto:Tumi.khumalo@nwu.ac.za)) if you have any concerns or complaints that have not been adequately addressed by the researcher. You can also contact the co-chair, Prof Werner Nell (016 910 3427 or [Werner.nell@nwu.ac.za](mailto:Werner.nell@nwu.ac.za)). You can leave a message for Tumi or Werner with Ms Daleen Claasens (016 910 3441).
- You will receive a copy of this information and consent form for your own records.

### Declaration by parent/guardian

By signing below, I ....., parent/guardian of ..... agree to take part in a research study titled: **The meaning in life and psychological well-being of parents of children living with diabetes.**

I declare that:

- I have read and understood this information and consent form and it is written in a language in which I am fluent and with which I feel comfortable.
- I have been afforded the opportunity of posing questions to both the person obtaining consent, as well as the researcher (if this is a different person), and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I understand that what my contribution (what I report/say/write/draw/produce visually) could be reproduced publically and/or quoted, but without reference to my personal identity.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the research before it has been completed, if the researcher feels it is in my best interests, or if I do not follow the research plan, as agreed on.
- I agree to the CDE Houghton or Parktown giving the researcher access to my child's medical records and that the HbA1C results, as reported in these medical records, may be used for this project.

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

.....  
Signature of participant

.....  
Signature of witness

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## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

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

The best way to reach me is:

Name & Surname: \_\_\_\_\_  
Postal Address: \_\_\_\_\_  
Email: \_\_\_\_\_  
Phone Number: \_\_\_\_\_  
Cell Phone Number: \_\_\_\_\_

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

Name & Surname: \_\_\_\_\_  
Phone/ Cell Phone Number /Email: \_\_\_\_\_

### Declaration by person obtaining consent

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

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

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

.....  
Signature of person obtaining consent

.....  
Signature of witness

### Declaration by researcher

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

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

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

.....  
Signature of researcher

.....  
Signature of witness

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APPENDIX B

| Summary data table                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                    |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1: The positive and negative impact of diabetes management behaviours on parental well-being</b><br><i>The management of diabetes brings about change and this impacts parents in different ways</i> |                                                                                                                                                                                                                                                                                                                                                    |
| <b>Psychological distress</b><br><i>Anxiety, denial, depression, lack of sleep and distress experienced in the management of diabetes</i>                                                                     | <i>I think for a very long time the impact I felt was the little sleep that I got (P3A)</i><br><i>It has a day to day impact on your life...your stress levels are higher (P3A)</i><br><i>Well I went into a major depression (P6A)</i><br><i>I wasn't joking about the denial stuff (P3C)</i>                                                     |
| <b>Social isolation</b><br><i>Parents of children living with diabetes feel isolated because of the diagnosis, and sometimes excluded from social gatherings of family and friends</i>                        | <i>It affects us on a social level (P1A)</i><br><i>It changes the way in which you handle your friends (P3A)</i><br><i>It is not nice for the person living with diabetes, but also for the family of that person (P5A)</i>                                                                                                                        |
| <b>Positive impact and change</b><br><i>Diabetes brings about a change in lifestyle, which most parents see as positive</i>                                                                                   | <i>It has had a very positive impact on our lives (P3A)</i><br><i>I think December was a turning point because we started living again...because we relaxed...and understand it will not be the same every day (P2A)</i><br><i>We are on this road with him...even though it is still under construction...it is better than what it was (P4A)</i> |
| <b>Theme 2: Positive beliefs about diabetes management</b><br><i>Various beliefs contribute to the parental experience of meaning and well-being during the management of the condition</i>                   |                                                                                                                                                                                                                                                                                                                                                    |
| <b>Diabetes as a chronic condition that was manageable</b><br><i>Diabetes is a condition that</i>                                                                                                             | <i>We don't classify diabetes as a problem (P3A)</i><br><i>You have it now...just accept it...it is not a death sentence (P1C)</i><br><i>When P2C was diagnosed with diabetes which is completely</i>                                                                                                                                              |

## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

|                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p><i>is life-long but manageable. Parents choose not to label diabetes as a problem, but rather accept it as part of their life.</i></p>                                                                                 | <p><i>manageable and not terminal...I actually felt it was okay (P2C)</i></p>                                                                                                                                                                                                                                                                                                                                                                |
| <p><b>Lifestyle adjustment was necessary</b></p> <p><i>The change and adjustment necessary to manage the condition, is a process and will change over time</i></p>                                                        | <p><i>I understand what's going on now and from that point things changed...I forced myself...I knew I had to get my head around it (P2A)</i></p> <p><i>We are just going to adjust our lifestyle with what happened to us (P3A)</i></p> <p><i>You must adjust to your circumstances and make the best of it (P5)</i></p> <p><i>It's just actually more a lifestyle management (P2C)</i></p>                                                 |
| <p><b>Creating a new normal</b></p> <p><i>Parents believe that their children are normal and they should find a new normal for them as a family</i></p>                                                                   | <p><i>In terms of the adjustment process...finding a new normal is important (P1A)</i></p> <p><i>I decided I am going to make it part of life, she will be a normal person just like anyone else (P3A)</i></p> <p><i>Apart from the stress and injections, ketones and everything...I'm not sure a day is that different from other peoples' (P3C)</i></p> <p><i>It's finding your way of understanding and it will get better (P2A)</i></p> |
| <p><b>Theme 3: Parental-specific diabetes management behaviours</b></p> <p><i>Certain behaviours help parents to make sense of their child's diagnosis</i></p>                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <p><b>Awareness</b></p> <p><i>Being aware and mindful of what they eat and drink. Becoming more motivated and disciplined to lead healthier lives. Also creating awareness within others to lead healthier lives.</i></p> | <p><i>It's just made us more aware around discipline, being a good steward in terms of our health (P1A)</i></p> <p><i>We're so much more healthy in terms of what we drink and what we look at...we look at food differently (P2A)</i></p> <p><i>As a family we became more aware of how we exercise and what we eat (P4A)</i></p>                                                                                                           |

## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

|                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p><b>Education</b></p> <p><i>Education of the self as well as others helps parents make sense and manage their child's condition</i></p>                                                                                                | <p><i>so you live and you learn (P6A)</i></p> <p><i>I like books and I like to do research...we are lucky to live in an era where information is so readily available as compared to years ago (P4A)</i></p> <p><i>I've even taken my glucometer to work and tested all my colleagues (P6A)</i></p>                                                                                                                                                                                                                                             |
| <p><b>Planning</b></p> <p><i>Daily routines and schedules are effected. Proper planning in terms of testing, meals, exercise and other activities helps parents to manage the condition effectively.</i></p>                             | <p><i>everything in my life revolves around sugar now...everything (P6A)</i></p> <p><i>Not just particularly his eating plan, but his day schedule...getting up earlier to plan in the morning (P1C)</i></p> <p><i>So it's...Your planning. And still today with his pump. Have you got the right food for lunch? What time will you be home? Do I need to pack a second lunch? (P2C)</i></p>                                                                                                                                                   |
| <p><b>Theme 4: Positive relationships with friends, family, the medical team and social media</b></p> <p><i>The supportive relationships parents have with various stakeholders helps them while managing their child's diabetes</i></p> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <p><b>Medical team</b></p> <p><i>The specialist physicians, endocrinologists, doctors, diabetes educators and nurses involved in the treatment of the child's condition</i></p>                                                          | <p><i>Positivity from everyone is very important...the support from your medical team (P3A)</i></p> <p><i>You have to invest in the right doctor...we are blessed with a good medical aid and having a good doctor that has the necessary equipment... it makes it manageable (P4A)</i></p> <p><i>Those people really helped me to manage diabetes and I thank them for that (P5A)</i></p> <p><i>I'm very thankful every day for the specialist in my life... who really go over and above their call of duty to help and support (P3C)</i></p> |
| <p><b>Family and friends</b></p> <p><i>The immediate circle of people around the parents of the child living with diabetes</i></p>                                                                                                       | <p><i>when family and friends know... they can be supportive and mindful when it comes to social activities (P1A)</i></p> <p><i>people are very concerned...even people that don't understand it, are concerned when kids have health conditions (P3C)</i></p>                                                                                                                                                                                                                                                                                  |

## MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

|                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                                                                                                                           | <i>My mom and dad try and every now and then they'll go out and buy him some sugar free biscuits (P6A)</i>                                                                                                                                                                                                                                                                                                                                                                     |
| <p><b>School</b></p> <p><i>Teachers and friends at school that help parents feel more at ease</i></p>                                                                                                                     | <p><i>The teacher just keeps an eye to see whether she turns for the correct insulin (P1C)</i></p> <p><i>So her friends help her to inject...that support is huge (P2A)</i></p> <p><i>His friends were also aware and very concerned... his English teacher always used to say that he is going to give her a heart attack... she was always worried (P5A)</i></p>                                                                                                             |
| <p><b>Social media</b></p> <p><i>Facebook is one of the fastest growing platforms where people can interact with one another. Parents also join WhatsApp groups to stay in touch and ask for help when necessary.</i></p> | <p><i>I'll go on to Facebook and there will be someone in America saying please can somebody help (P6A)</i></p> <p><i>I had to message people on WhatsApp to ask for different proteins because my mind just went blank (P1C)</i></p> <p><i>Every two months on my Facebook profile I put the signs and symptoms (P6A)</i></p> <p><i>Social media and mums...they can be irritating but they are daily support...hourly support for you...there if you need them (P3C)</i></p> |

# MEANING AND PSYCHOLOGICAL WELL-BEING OF PARENTS

## APPENDIX C



NORTH-WEST UNIVERSITY  
YUNIBESITHI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT

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Institutional Research Ethics Regulatory Committee

Tel: +27 18 299 4849

Email: [Ethics@nwu.ac.za](mailto:Ethics@nwu.ac.za)

2016-07-11

### ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the Humanities and Health Research Ethics Committee (HHREC) at the meeting held on 10/02/2016, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

|                                                                                                                     |   |   |   |   |    |   |   |   |   |                                |   |   |                     |   |   |        |  |
|---------------------------------------------------------------------------------------------------------------------|---|---|---|---|----|---|---|---|---|--------------------------------|---|---|---------------------|---|---|--------|--|
| <b>Project title:</b> The meaning in life and psychological well-being of parents of children living with diabetes. |   |   |   |   |    |   |   |   |   |                                |   |   |                     |   |   |        |  |
| <b>Project Leader/Supervisor:</b> Dr E Deacon                                                                       |   |   |   |   |    |   |   |   |   |                                |   |   |                     |   |   |        |  |
| <b>Student:</b> Bekker, CI                                                                                          |   |   |   |   |    |   |   |   |   |                                |   |   |                     |   |   |        |  |
| <b>Ethics number:</b>                                                                                               | N | W | U | - | HS | - | 2 | 0 | 1 | 6                              | - | 0 | 0                   | 4 | 8 |        |  |
| Institution                                                                                                         |   |   |   |   |    |   |   |   |   | Project Number                 |   |   | Year                |   |   | Status |  |
| Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation                         |   |   |   |   |    |   |   |   |   |                                |   |   |                     |   |   |        |  |
| <b>Application Type:</b> N/A                                                                                        |   |   |   |   |    |   |   |   |   |                                |   |   |                     |   |   |        |  |
| <b>Commencement date:</b> 2016-07-11                                                                                |   |   |   |   |    |   |   |   |   | <b>Expiry date:</b> 2019-07-11 |   |   | <b>Risk:</b> Medium |   |   |        |  |

#### Special conditions of the approval (if applicable):

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

#### General conditions:

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

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

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

Yours sincerely

Prof LA  
Du Plessis

Digitally signed by  
Prof LA Du Plessis

Date: 2016.07.11  
15:31:14 +02'00'

Prof Linda du Plessis

Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)