

Diabetes management behaviours of young adults towards psychological well-being

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DECLARATION

I, MARIETJIE WILLEMSE hereby declare that DIABETES MANAGEMENT BEHAVIOURS OF YOUNG ADULTS TOWARDS PSYCHOLOGICAL WELL-BEING, is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

The article format was chosen for this study. The researcher, Marietjie Willemse conducted the research and wrote the articles. Dr E. Deacon acted as promoter. Three articles have been written, and will be submitted for publication in various academic journals.

ARTICLE ONE: Life stories: Young adult's experiences of adjusting to diabetes management
(Health Psychology)

ARTICLE TWO: Understanding young adult's meaning making in adjusting to diabetes management: Multi-methods approach
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ARTICLE THREE: Diabetes management behaviours and meaning-making: The young adult's sense making process of living with type 1 diabetes
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This certificate serves to confirm that the PhD Thesis with the title, ***DIABETES MANAGEMENT BEHAVIOURS OF YOUNG ADULTS TOWARDS PSYCHOLOGICAL WELL-BEING***, has undergone a professional language and reference edit. It is important to note that all content in the thesis, including argumentation, remains the responsibility of the client and the supervisor. The onus rests on the client to work through the proposed changes after the edit has been completed, and either accept or reject the proposed changes.



Natasha Ravyse

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“A million words would not bring you back,

I know because I’ve tried.

Neither would a million tears,

I know because I’ve cried”.

SUMMARY

Significant numbers of young adults living with type 1 diabetes experience diminished psychological well-being due to non-adherence to the strict diabetes self-management care plan required. This study explored psychosocial variables underpinning psychological well-being for young adults living with well-controlled type 1 diabetes in the greater Gauteng province, South Africa. The role of the psychosocial variables such as a personal model of diabetes, meaning, and social support were explored in an attempt to better understand these variables and the relationship thereof towards psychological well-being within blood glucose levels (HbA1c) that were reported to be within the near-normal range.

A multi-methods research methodology was applied from a predominantly qualitative paradigm. The life stories of eight young adults, living with well-controlled type 1 diabetes, were explored in order to gather qualitative data on the psychosocial variables influencing their diabetes management behaviours and psychological well-being. Thereafter, semi-structured interviews were conducted with six young adults living with well-controlled type 1 diabetes, to determine the relationships between the previously identified psychosocial variables and diabetes management behaviours. The aim was to develop an in-depth understanding of how and why these psychosocial variables shape diabetes management behaviours, as well as the mechanisms that are used to make sense of living with type 1 diabetes.

Quantitative data was also analysed to supplement the understanding of the relationships between the psychosocial variables and the young adult's diabetes management behaviours. The quantitative data was obtained from validated, psychometrically sound instruments, measuring diabetes management (DSMP-SR), psychological well-being (PHI), the personal model of diabetes (IPQ-R), meaning (MLQ) and social support (M-DSSQ).

Finally, a case study of a young adult living with well-controlled type 1 diabetes was explored in order to assess the validity of previous findings relating to the psychosocial variables as well as the relationships thereof towards the diabetes management behaviours and psychological well-being of the individual. Ultimately, the study aimed to put forth a meaning-making framework that would encapsulate the meaning-making process for young adults living with type 1 diabetes.

The psychosocial variables influencing diabetes management behaviours were conceptualised and situated in context, allowing for the psychological well-being of young adults living with type 1 diabetes, to be viewed in an integrated way. Emergent themes were, firstly, the experiences of developing an autonomous identity while living with the challenges of managing type 1 diabetes; secondly, the emotional distress that the young adults experienced mainly due to practises linked to the restrictive meal plan and the overall loss of their dreams and aspirations they held for their future; and finally, the diabetes management activities as well as social support that they experience as very personal, frustrating, and challenging, resulting in this diabetes journey to be experienced as incredibly lonesome. Despite young adults experiencing emotional distress, they still managed to uphold near-normal blood glucose levels, which made it necessary to explore the proposed meaning-making framework for these young adults. The outcome of such a meaning-making process was seen in the creation of a new, normal way of living with type 1 diabetes. A new way of living that left room for diabetes self-care, taking responsibility for self-care, and the deliberate use of coping- or meaning-making efforts. Moreover, this research highlighted the cognitive complexity of diabetes management behaviours that need to take place on a daily basis in order to manage the condition effectively.

Keywords: diabetes management behaviours, young adults, psychological well-being, personal model, meaning, social support, case study, multi-methods research

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CHAPTER 1: DIABETES MANAGEMENT BEHAVIOURS OF YOUNG ADULTS TOWARDS PSYCHOLOGICAL WELL- BEING

Preface to chapter 1

The objective of this chapter was to provide an overall orientation to the research on which this thesis was based. The research aim was to form an all-encompassing understanding of the experience of psychosocial variables (identified as a personal model of diabetes, meaning and social support) shaping diabetes management behaviours and psychological well-being of young adults living with well-controlled type 1 diabetes.

Following a general introduction to the study, an exposition of all the relevant psychosocial variables were provided as well as an overview of existing literature on the research topic. Finally, the research problem was discussed, which served as a prelude to outline the main research questions and objectives that guided the study. The remainder of the chapter was devoted to a discussion on the research methodology and research design that were followed during the course of the study, along with an overview of ethical matters relevant to the study. The researcher's position in relation to the research study was also presented. The chapter concluded with an outline of the thesis and a short summary.

1.1 Introduction

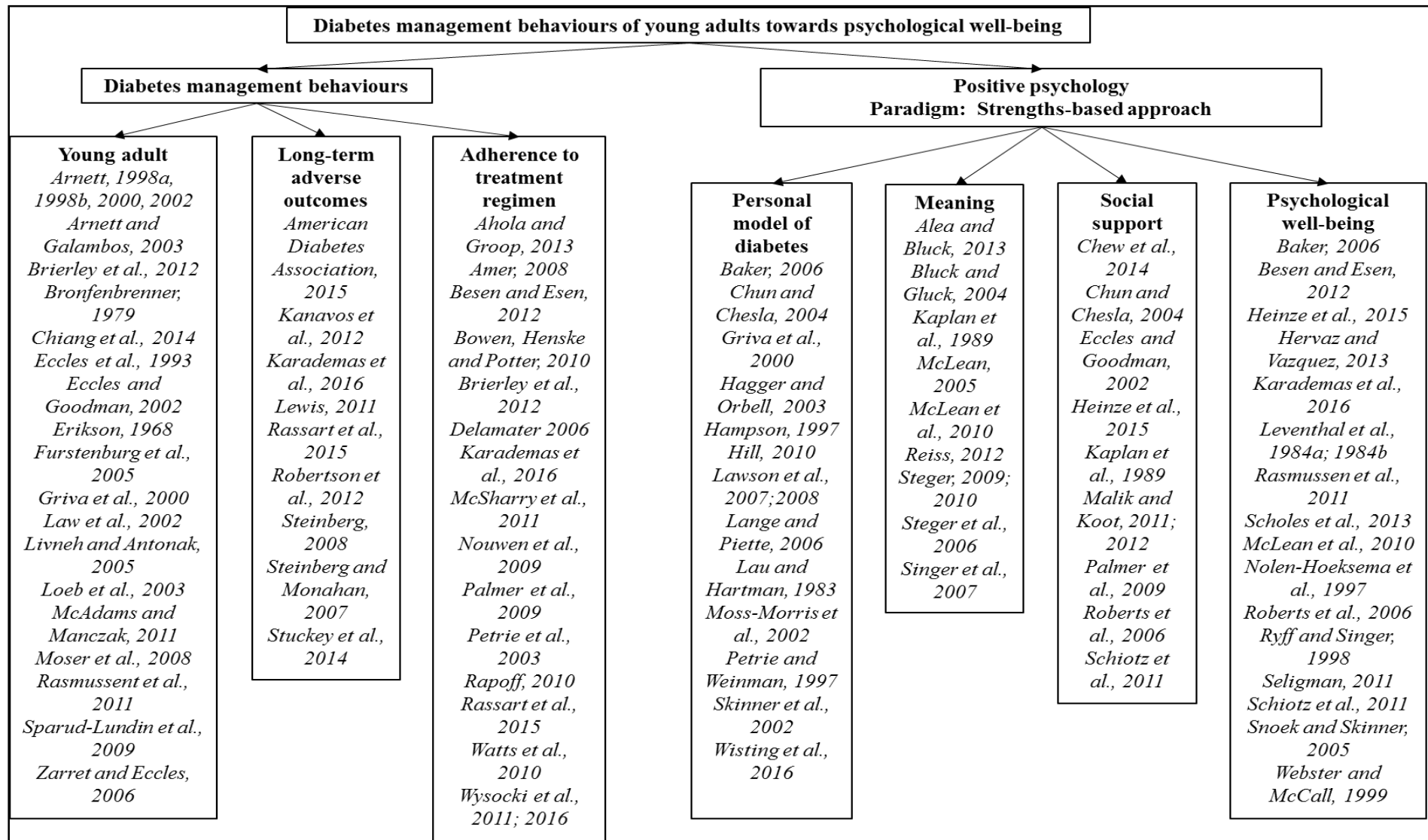
The potential for people living with a chronic condition to be their best selves and enjoy psychological well-being is a topic that has held the interest of researchers for many years (Heinze, Kruger, Reischl, Cupal, & Zimmerman, 2015). In 1989, the St Vincent Declaration was released under the aegis of the World Health Organization (WHO) and the International Diabetes Federation (IDF). The declaration put forward general standards for the health care of people living with diabetes. Significantly, this set of general diabetes care standards provided a platform for the development and evaluation of diabetes care programs, with the central goal of improving the health experience for people living with diabetes. Perhaps most importantly, these “gold standards” of the St Vincent Declaration Action Program became the model to which people living with type 1 diabetes compared their expectations in terms of quality and quantity (Gagliardino, Hera, & Siri, 2001). This diabetes-care-action-plan stimulated initiatives towards improving the experiences of people living with type 1 diabetes (Barcelo, & Vovides, 2001).

In order to improve people’s experiences of living with diabetes, it is essential to understand what living with diabetes entails. Diabetes requires self-management behaviours that are taxing on the person living with type 1 diabetes, and these management behaviours will, in the long run, determine the person’s success in living a meaningful, near-normal life and experiencing psychological well-being (Rasmussen, Ward, Jenkins, King, & Dunning, 2011; Scholes et al., 2013). Although representatives of health departments and patients’ organisations agreed on general standards for diabetes care (The St Vincent Declaration, 1989), it became clear that some individuals effectively live with type 1 diabetes, and as a result, live a near-normal life, while others (with the same access to resources such as medical professionals) outwardly failed to manage the condition effectively (Amer, 2008; Bowen, Henske, & Potter, 2010; Gagliardino, Hera, & Siri, 2001; Karademas et al., 2016; Nouwen, Law, Hussain, McGovern, & Napier, 2009; Rassart et al., 2015). The aforesaid stimulated the question as to why certain individuals

are successful at managing the condition and others not. According to available literature, the answer could lie in the experiences of psychosocial variables associated with a chronic condition such as diabetes (Rassart et al., 2015; Scholes et al, 2013). These psychosocial variables comprise of, but are not limited to: (1) the personal model of diabetes, created by the individual; (2) making meaning of life events; and (3) social support experienced by the person living with type 1 diabetes (Alea, & Bluck, 2013; Hampson, 1997; Lange, & Piette, 2006; Schiotz, Bogelund, Almdal, Jensen, & Willaing, 2011; Skinner, Hampson, & Fife-Schaw, 2002). Prominent literature that guided the research study in the fields of both diabetes management and positive psychology are illustrated in figure 1.

The researcher purposefully investigated the literature on psychological well-being, diabetes management behaviour, and adherence to the type 1 diabetes care plan of young adults with type1 diabetes. The psychosocial variables that emerged from the literature were the personal model of type 1 diabetes, making meaning, and social support. The aforementioned variables are discussed extensively in what follows.

FIGURE 1: PROMINENT LITERATURE



Metaphorically speaking, positive psychology is all about the nature and structure of well-being. From literature, it is clear that the domain of mental health care previously focused on treating or preventing mental health illnesses or complaints. Slowly, the shift towards enhancing positive aspects of mental health occurred (Barry, & Jenkins, 2007; Keyes, 2007; Seligman, & Csikszentmihalyi, 2000; World Health Organization WHO, 2005). A wide array of definitions exist (Dodge, Daly, Huyton, & Sanders, 2012) and basically each one refers to both subjective well-being (hedonic) and psychological well-being (eudaimonic) aspects.

Subjective well-being builds on a hedonic framework in which people's levels of happiness and satisfaction with life are central (Diener, 1984; Diener, & Lucas, 1999) and a balance between positive and negative emotions are found (Diener, 1984). The hedonic, or pleasurable part of human functioning, is every so often supplemented by a eudaimonic or deeper perception of wellness (Ryan, & Deci, 2001). Researchers in positive psychology introduced the concept *psychological well-being* with the intention to develop theory-based indicators of positive human functioning including components such as meaning, a true sense of the self, living one's potential, and lasting relatedness with others (Ryan, & Deci, 2001; Ryff, & Singer, 1996; Tamir, & Gross, 2011).

Due to the variety of definitions that conceptualise psychological well-being in literature, it is important to be precise in the definition of psychological well-being to be used in this study. For the purpose of this study, psychological well-being is conceptualised according to Ryff's definition (Ryff, 1989) that psychological well-being is a process of self-realisation. This process of self-realisation consist of six dimensions: (1) autonomy; (2) environmental mastery; (3) personal growth; (4) positive relations with others; (5) purpose in life; and (6) self-acceptance. Through recent studies done by Ryff (2014) it became evident that high levels of psychological well-being not only serve as a protective factor against mental illnesses, but that it is strongly related to positive physical health and well-being (Keyes, Dhingra, & Simoes, 2010; Lamers,

Westerhof, Glas, & Bohlmeijer, 2015; Ryff, 2013; Wood, & Joseph, 2016). In relation to this growing evidence of positive outcomes of psychological well-being, this study aimed to provide valuable learning as to whether or not psychological well-being of young adults with type 1 diabetes can be improved upon.

The focus of this study is the particular developmental age group, namely the young adult. Young adulthood is a stage where the individual is increasingly challenged by complexity and heterogeneity in society (Zarrett, & Eccles, 2006), resulting in a period often experienced with distress due to contemporary choices and challenges that are faced nowadays (Furstenberg, Rumbaunt, & Settersten, 2005; Rasmussen et al., 2011). After completing high school, young adults soon discover that establishing a personal identity is challenging, as decisions concerning location, social matters, work concerns, and educational questions need to be made in a demanding and complex environment (Chiang, Kirkman, Laffel, & Peters, 2014). Various researchers, however, argued that the most important developmental task young adults need to master, is self-management. Self-management entails assuming responsibility for themselves as well as for all the decisions they make (Arnett, 1998a, 1998b, 2000; Arnett, & Galambos, 2003; Bronfenbrenner, 1979; Eccles et al., 1993; Erikson, 1968; McAdams, & Manczak, 2011; Rasmussen et al., 2011). Some researchers also classified self-management under the overarching theme of autonomy, the cornerstone of a person's self-management processes (Griva, Myers, & Newman, 2000; Livneh, & Antonak, 2005; Loeb, Penrod, Falkenstein, Gueldner, & Poon, 2003; Moser, van der Bruggen, Spreeuwenberg, & Widdershoven, 2008).

The young adult's psychological well-being is said to be influenced by the manner in which they cope with the abovementioned challenges (Law, Kelly, Huey, & Summerbell, 2002). Research highlighted that the psychosocial and cognitive resources of the young adult, as well as the availability of social support, determined the successful management of the challenges created throughout the journey towards adulthood (Eccles, & Goodman, 2002; Eccles et al.,

2003; Sparud-Lundin, Öhrn, & Danielson, 2009) and their experiences of psychological well-being (Wood, & Joseph, 2016).

However, for the young adult living with type 1 diabetes, the journey towards adulthood is slightly more engaging as this individual not only needs to adapt to all the developmental challenges and stage-generated changes, but also needs to deal with purposeful diabetes-related challenges (Sparud-Lundin et al., 2009). Diabetes-related challenges include: (1) the initial diagnosis, which can be experienced as traumatic; (2) commencing with the diabetes care plan, which must be followed very meticulously; (3) attending diabetes-specific educational sessions that allow for the successful integration of diabetes into the lifestyle of the individual; and finally, (4) the reality of developing diabetes-related complications (Chiang et al., 2014; Rasmussen et al., 2011; Sparud-Lundin et al., 2009). In addition, young adults with type 1 diabetes reported higher levels of emotional distress, hormonal changes, and autonomy challenges as compared to their age group without type 1 diabetes (Scholes et al., 2013) and that could negatively influence their diabetes management behaviours.

There is little doubt that type 1 diabetes can be a tough condition to live with, not to mention the impact on the quality of life that can be great. The young adults living with type 1 diabetes face endless demands and challenges in order to achieve glycaemic control targets as recommended by medical professionals (Brierley, Eiser, Johnson, Young, & Heller, 2012; Kovacs et al., 1990). The cost of not achieving the targeted glycaemic control levels could be severe. For example, the American Diabetes Association (2015) reported: (1) hypertension (71% used prescription medications to lower blood pressure); (2) dyslipidaemia (65% reported greater cholesterol levels and used medication to lower levels); (3) heart attack rates (hospitalisation rates were 1.8 times higher than for non-diabetics); (4) amputations (60% underwent non-traumatic lower-limb amputations); and (5) obesity (85.2% reported to be obese)

as common diabetes-related complications and co-morbid conditions in young adults with type 1 diabetes for the period 2011 – 2014.

Additionally, young adults living with type 1 diabetes reported decreased psychological well-being due to strained coping with the changed life routines, the diabetes related challenges, and additional distress experienced (Karademas et al., 2016; Rassart et al., 2015; Robertson, Stanley, Cully, & Naik, 2012; Stuckey et al., 2014). Poor psychological functioning imposes wide-scale distress such as serious interfering with daily management, poor medical outcomes, and associated feelings that the condition burdens their family tremendously. The largest global study on psychosocial variables and behavioural barriers influencing diabetes and diabetes care (The Diabetes Attitudes, Wishes and Needs (DAWN), 2001) reported that the majority of people living with diabetes experienced psychological problems (65.6% - 69.9%) and that only a small minority received psychological treatment (3.3%) (International Diabetes Federation, 2004; Skovlund, & Peyrot, 2005). Psychological complications such as anger, which usually reflects deeper emotions such as guilt and fear of the unknown, depression, and eating disorders were reported to be twice that of a comparison group during a study by Anderson et al. (2001). Crucial then, helping the person with type 1 diabetes to achieve better diabetes control, depends not only on trying to decrease the incidence and prevalence of acute and/or chronic complications, but also on improving a young person's psychological well-being and perception of life quality (Debono, & Cachia, 2007).

Various factors (such as motivation, coping, and problem solving) affect diabetes self-management behaviours (Ahola, & Groop, 2013). With the current study, the focus was on the personal model of diabetes created by the young adult who is living with type 1 diabetes, as well as meaning and social support as influencing factors towards diabetes management and psychological well-being.

The young adult living with type 1 diabetes' personal model refers to the individual's personal beliefs, emotions, and experiences of their specific condition or illness (Hampson, 1997). As such, the personal model is a representation of the condition with regards to symptoms, perceived treatment effectiveness, consequences, and emotional responses to possible short and long term complications (Lawson, Bundy, & Harvey, 2008). Hampson (1997) argued that the personal model serves to process all illness-related incoming information and subsequently guide illness-related behaviour. Lange and Piette (2006) found that although people living with type 1 diabetes had medically consistent views of the condition, the difference in their diabetes management behaviours could independently be explained by the variations in the personal model created of type 1 diabetes.

Kaplan, Greenfield and Ware (1989) highlighted that by acknowledging the fears and concerns of young adults living with type 1 diabetes, these individuals not only felt respected but were more likely to respond positively to changes in their diabetes treatment plan. In order to create the desired platform of acknowledgement to the fears of these young adults, it was critically important to form an understanding of how the young adult with type 1 diabetes ascribed meaning to the condition. Furthermore, there was a need to study how changes in the diabetes treatment plan (e.g. meal plans) influenced the management behaviours as well as the psychological well-being of the young adult living with type 1 diabetes (Campbell et al., 2001; Ovsted, Johansson, Odeberg, & Rastam, 2000). Changes in the diabetes treatment plan should be made incrementally in order to allow for young adults to integrate such changes into their daily routine (Kaplan, Greenfield, & Ware, 1989). All diabetes treatment plan changes should be framed from the perspective of the young adult and presented as a means to achieve higher levels of autonomy, freedom, and psychological well-being in their lives, not merely a means to better glycaemic control.

The young adults must recognise the diabetes treatment plan changes as important and meaningful towards a future in which they are primarily responsible for their own diabetes care (Reiss, 2012). Steger's (2009) definition of meaning in life posits that meaning involves two components (presence of meaning and search for meaning) and the researcher was particularly interested to measure those components within the young adults living with type 1 diabetes. Meaning in life has emerged as one of many variables that could potentially be linked to psychological well-being (Gubitosi-Klug, 2016; Ryff, & Singer, 1998; Seligman, 2011). It was for this reason that the Meaning in Life Questionnaire (MLQ) as a measurement instrument was used in this study.

Research found that the psychological well-being of individuals living with type 1 diabetes are influenced by the level of psychological support they received (Heinze et al., 2015; Schiotz et al., 2011). Researchers claimed that effective self-management behaviours, in order to achieve optimal control of type 1 diabetes, could only be reached when un-wavering psychological support was experienced (Chew, Shariff-Ghazali, & Fernandez, 2014; Heinze et al., 2015). The Modified Diabetes Social Support Questionnaire (M-DSSQ) was included in this study because of meaningful relations found between self-care management, psychological well-being and HbA1c (Malik, & Koot, 2012) and those were the variables that the researcher were interested in. A study done in 2012 by Malik and Koot reported significant correlations between social support, self-care management, and self-reported diabetes treatment plan adherence. That study also showed a relationship between social support and positive well-being. Further research has demonstrated an interplay between the individual's personal model created of a condition, health behaviours, clinical outcomes, and psychological well-being (Baker, 2006; Besen, & Esen, 2012; Chun, & Chesla, 2004; Hagger, & Orbell, 2003; Karademas et al., 2016; Leventhal, Zimmerman, & Guttman, 1984; Rassart et al., 2015; Snoek, & Skinner, 2005; Watts, O'Hara, & Trigg, 2010; Wisting et al., 2016).

Hence, this thesis evolved with the aim of understanding the experiences of a personal model of type 1 diabetes, meaning and meaning-making, as well as social support, in terms of how these factors shape the diabetes management behaviours of young adults towards psychological well-being. Specific emphasis was given to the psychosocial variables within the contemporary context, as that informed a holistic representation of diabetes management behaviours of young adults. In addition, increased knowledge of the mechanisms influencing the diabetes management behaviours of young adults may enhance treatment adherence and psychological well-being, without unintended negative consequences to the young adults living with type 1 diabetes (Brierley et al., 2012). This concludes the discussion of the theoretical variables embedded in this research study of diabetes management behaviours of young adults towards psychological well-being. The rationale for this study as well as the research questions, which governed this study, are discussed next.

1.2 Rationale and research questions

It is a well-known fact that the adolescent lifestyle is associated with risk-taking behaviours, peer influence, and poor communication (Lewis, 2011). Scholars and researchers therefore focused their research on adolescents, their perceptions, experiences and challenges that may hinder effective diabetes management (Lewis, 2011; Palmer et al., 2009; Steinberg, 2008; Steinberg, & Monahan, 2007). As details regarding the young adult living with diabetes' perceptions, experiences and challenges were mainly absent in the literature (Lewis, 2011), this study aimed at understanding the influences on and experiences of the diabetes management behaviours of young adults with type 1 diabetes. In addition, this study formed part of a larger project investigating the adjustment of diabetes management behaviours through different life stages along with developing research-initiated interventions to increase diabetes management behaviours and psychological well-being of people living with diabetes.

Additionally, this research was important due to the need identified by various diabetes care providers to do more than just presenting individuals with a strict diabetes treatment plan. The goal of all diabetes care providers is to make a constructive difference to the young adult's adherence to the prescribed diabetes treatment plan. In light of Rapoff's (2010) report on the non-adherence rate among young adults being as high as 93%, it clearly demonstrates the importance of understanding what the experience of the psychosocial variables that shape diabetes management behaviours is (World Health Organization, 2003). In accordance with the outcomes of the DAWN-study, the method of improving the adherence and overall diabetes management and the focus of all interventions or action plans should be the person behind the diabetes (Skovlund, & Peyrot, 2005). A well-designed, patient-centered and research informed program would ultimately address the psychosocial and behavioural barriers experienced by young adults living with type 1 diabetes. Yet, before any patient-centered program could be designed, answers should be found to how individual young adults manage the condition and how they experience guiding principles. Another answer that should inform the design of any intervention would be why the individual decides to manage the condition in a specific manner; this will also include the individual's purpose and reasons for managing type 1 diabetes (Sinek, 2009). A well-designed program may result in improved adherence to the meticulous diabetes treatment plan and a positive outcome of glycaemic control levels (HbA1c) within the near normal range of <8% (Besen, & Esen, 2012; Brierley et al., 2012; Mc Sharry, Moss-Morris, & Kendrick, 2011; Patient, 2015; Rassart et al., 2015; Watts et al., 2010).

The health community regards diabetes as the pandemic of the current age (Wild, Roglic, Green, Sicree, & King, 2004). Michael Brown, from the Centre for Diabetes and Endocrinology, recently remarked that the number of newly diagnosed cases are "hitting the steep upswing of an exponential climb heavenwards" (Diabetes Lifestyle, 2014, p. 1). The NDEP (National Diabetes Educational Program: USA) released statistics indicating that about

208 000 young people under 20 years of age suffer from diagnosed diabetes in the USA (Centers for Disease Control and Prevention, 2014). But, according to statistics, Africa will bear the biggest brunt of this lifestyle disease as it is spreading at a rapid pace. A 109% rise in the prevalence of diabetes in Africa was reported in 2013 (IDF, 2014). The World Health Organisation (WHO) and the International Diabetes Federation (IDF) estimated that the figure in Africa will double over the next 25 years to approximately 13.6 million diagnosed cases (IDF, 2014; Otterman et al., 2014). In South Africa, diabetes is even more prevalent with an estimate of 3.5 million people living with diabetes and of this, 5 - 10% are presumed to be type 1 diabetes (Distiller, 2012; IDF, 2015; Otterman et al., 2014). According to Piotie (2013), these figures are likely to increase significantly, as the African societies adopt the Western lifestyle as a result of rapid urbanisation. This study came in to being as an attempt to raise awareness of the condition as well as to advocate the possibility of living a near-normal life once the condition is managed effectively.

As was previously mentioned, effective management of diabetes entails that a prescribed diabetes care plan should be followed and the outcome thereof should be a glycaemic control level (HbA1c) within the near normal range of <8% (Besen, & Esen, 2012; Brierley et al., 2012; Mc Sharry, Moss-Morris, & Kendrick, 2011; Patient, 2015; Rassart et al., 2015; Watts et al., 2010). Although diabetes is generally described as one of the major world health problems (Skovlund, & Peyrot, 2005), very little research is available that addresses this condition from a positive point of view. As a consequence, this study investigated diabetes management behaviours from a positive standpoint and involved only individuals that managed to control their condition effectively, hence the low number of participants.

In response to the gaps identified in literature, this study was carried out by following a multi-methods research methodology in order to explore the management behaviours from the perspective of young adults living with well-controlled type 1 diabetes. Multi-methods research

can be defined as a process for generating, analysing, and “mixing” both qualitative and quantitative information at some stage of the research process, with the purpose of gathering meaningful data and understanding the research phenomenon more in-depth (Creswell, & Garrett, 2008).

Taking into account the research problem discussed above, this study sought to answer the following overarching research question: **How do the personal model, ascribing meaning to and social support, shape diabetes management behaviours of young adults towards psychological well-being?** The primary research question gave rise to the following three, sub-questions:

- ❖ How can the psychosocial variables and diabetes management be conceptualised in the context of young adults living with type 1 diabetes?
- ❖ What kind of interactions exist between the personal model of diabetes, making meaning of the condition, social support received and diabetes management behaviours of young adults living with type 1 diabetes?
- ❖ How can the proposed model of the young adult’s experiences of making sense of living with type 1 diabetes be applied to a single case study?

1.3 Methodology overview

The different methods used for producing data necessary for this study are introduced and discussed in detail in this section as there are limits to the extent to which it can be discussed in the articles, which make up the body of this thesis.

This study made use of the established multi-methods research methodology (Creswell, 2014; McMillan, & Schumacher, 2006) to investigate the diabetes management behaviours of young adults towards psychological well-being. In line with the multi-methods research practice, both qualitative and quantitative research methods were utilised to answer the research

questions (Creswell, 2003; Creswell, & Garrett, 2008). It is generally accepted that by employing both methods in a single study such as this one, quantitative results are placed into a rich and descriptive human context which allows for better conceptualisation of the psychosocial variables related not only the diabetes management behaviours, but also the psychological well-being of young adults living with well-controlled type 1 diabetes (Trochim, & Donnelly, 2008).

A sequential collection of data was undertaken to ensure that multiple facets of the diabetes management behaviours were to be revealed and understood (Baxter, & Jack, 2008). For that reason, this study was conducted from a predominantly qualitative paradigm, whilst supplementing this approach with quantitative data as necessary, in order to assess the critical psychosocial variables associated with diabetes management behaviours and psychological well-being of young adults living with type 1 diabetes (Creswell, 2003).

In order to reach the first objective of conceptualising psychosocial variables in diabetes management, this study commenced with exploring qualitative data in the form of autobiographical narratives written by young adults living with well-controlled diabetes. These life stories may serve as an inspiration to other people (living with diabetes) that control is possible and that any person can live a near-normal life with diabetes. The second objective in this study was achieved by conducting interviews with other young adults living with well-controlled type 1 diabetes and analysing their responses. The qualitative data from the semi-structured interviews were then supplemented with quantitative data from self-reported questionnaires that the participants completed. Finally, the last objective in this study was achieved by reporting on a case study of a young adult successfully living with the challenges of managing type 1 diabetes in such a fashion that it continues to be well-controlled. The aforementioned explained the overall qualitative and quantitative (QUAL → QUANT) approach followed throughout the greatest part of this study (Onwuegbuzie, & Leech, 2005; Palinkas et al., 2011).

This study employed both the qualitative and quantitative (QUAL ➔ QUANT) research approach to form a clear understanding of the interactions between the different psychosocial variables shaping the diabetes management behaviours of young adults living with well-controlled, type 1 diabetes. In so doing, this study not only attempted to advance the social sciences on diabetes management behaviour, but also to overcome the limitations of mono-method research (Onwuegbuzie, & Leech, 2005; Tashakkori, & Teddlie, 2003). Thus, in order to achieve the overall purpose of the study, that was, to investigate how the personal model, meaning ascribed and social support shape diabetes management behaviours of young adults towards psychological well-being, neither research tradition could be viewed as independent of the other. Both research traditions were essential so as to understand the psychological well-being of young adults living with well-controlled type 1 diabetes (Babbie, & Mouton, 2001; Johnson, & Onwuegbuzie, 2004; Onwuegbuzie, & Leech, 2005; Struwig, & Stead, 2001).

This research initially drew on a deductive approach while analysing the autobiographical narratives, or life stories, of young adults living well with type 1 diabetes. Deductive research is a basic form of reasoning that starts out with a general statement, or hypothesis, and examines the possibilities to reach a specific, logical conclusion (Creswell, 2014). The aim was to identify possible psychosocial variables shaping the diabetes management behaviours of young adults. As the research progressed, it became evident that much more was being revealed in the data than initially anticipated. Based on the richness of the data being analysed, there was scope to diverge from a deductive to an inductive approach.

Inductive reasoning makes broad generalisations from specific observations (Creswell, 2014). During the analysis of the life stories written by the young adults living well with type 1 diabetes, possible psychosocial variables were identified that could shape diabetes management behaviours as well as psychological well-being. To explore the general application of such variables, more data was deemed necessary. Interviews were conducted with consenting young adults living with

well-controlled type 1 diabetes. A number of these participants also completed questionnaires that were used to supplement the data generated through the interviews.

In this study, there was a constant interplay between inductive reasoning (based on observations) and deductive reasoning (based on theory). This process of constant interplay is defined as an iterative process (Tracy, 2010). An iterative process was used to bring the desired decision or result closer to discovery with each repetition. In other words, the desired result was to identify, analyse and understand the psychosocial variables influencing the diabetes management behaviours of young adults living with well-controlled type 1 diabetes. The desired result was arrived at by repeating rounds or cycles of analysis (Business Dictionary, 2016).

This study addressed the potential inaccuracy of a single method by means of using concurrent triangulation of findings to confirm, cross-verify and endorse the consistency of findings (Creswell, 2014; Gibbs, 2014; Trochim, & Donnelly, 2008). Triangulation as applied in this study intensified and widened the understanding of not only the complexity, but also the experiences of young adults' diabetes management behaviours as it was studied from more than one perspective (Bamberger, 2012; Kennedy, 2009).

Rather than just viewing triangulation as a method for ensuring trustworthiness, this study used different types of triangulation in order to ensure a robust, comprehensive and well-developed description and interpretation of data (Cohen, 2006). The first type is called method triangulation. Method triangulation was done to ensure consistency of the findings that were generated by the interviews (qualitative data). The questionnaires that were completed (quantitative data) served as a method to corroborate the qualitative findings. At some point, the data from the different collection methods (pertaining to social support) diverged and that provided great interest, creating the need for in-depth investigation into social support and accounting for diverse experiences as reported by young adults living with well-controlled type 1 diabetes.

Another type of triangulation used in this study is known as analyst triangulation. Analyst triangulation was predominantly used in association with the thematic analysis process. The findings from the thematic analysis were reviewed by a co-coder (a competent researcher knowledgeable about the project) as well as by a panel of medical experts, inclusive of a clinical psychologist. The goal of this type of triangulation was not to seek consensus as such, but to reduce possible researcher blind spots in the interpretation of the data by drawing attention to multiple ways of interpretation of the same data (Cohen, 2006).

All research in the social sciences represents an attempt to provide truthful claims about human beings and the context in which they live and evolve (Biesta, & Burbules, 2003; Creswell, 2014; Johnson, & Onwuegbuzie, 2004). The general goal of this multi-methods study is to understand the nature of the diabetes management-reality with a depth and richness from the perspective of the young adult living that reality (Creswell, 2014; Tashakkori, & Teddlie, 1998, 2003). This study answered to both the aforementioned as it was an attempt to provide deeper understanding of the psychosocial variables shaping diabetes management behaviours as well as the psychological well-being of young adults living with well-controlled type 1 diabetes.

Scholars in the field of psychology have been sceptical about engaging in this relatively new research paradigm (Bishop, 2015; Creswell, 2014; Mertens, 2011; Tashakkori, & Creswell, 2007; Tashakkori, & Teddlie, 1998, 2003) as most researchers tend to have a strong focus on empirical research that informs theory, and use a formal writing style with impersonal passive voice as well as technical terminology (Tashakkori, & Teddlie, 1998). Throughout this study, a formal writing style was used as that is the preferred reporting style for the different academic journals targeted for publishing the articles.

In summary, the multi-methods research design was an appropriate method to address the research questions in this study. By utilizing this research method, it was possible to use the words and phrases of participants to add meaning to numbers and numbers were again used to

add precision to the words and phrases of individuals. Therefore, this research design was the most suitable to add insight and in-depth understanding into the diabetes management behaviours and psychological well-being of young adults living with well-controlled type 1 diabetes.

1.4 Research sample

Sampling is the process of selecting individuals from a population of interest (Trochim, & Donnelly, 2008). The researcher used nonprobability, purposive sampling for the selection of the research participants. Nonprobability, purposive sampling elicit criticism as it is considered not to be the most accurate and rigorous method of sampling (Cresswell, 2014; Trochim, & Donnelly, 2008). However, for this research it was not theoretically sensible to use random sampling as the researcher was only interested to explore the diabetes management behaviours of young adults living with well-controlled type 1 diabetes ($HbA1c < 8\%$).

The inclusion criteria were: (1) participants had to be patients from the Centre for Diabetes and Endocrinology (CDE) in Houghton or Parktown; (2) participants had to be living with well-controlled diabetes for the last 12 months; (3) they had to be literate in English in order to conduct the interview and/or complete the questionnaires; (4) they had to be between the ages of 18 – 25; and (5) diagnosed with type 1 diabetes for at least more than 12 months. The exclusion criteria comprised: (1) young adults living with type 1 diabetes that were receiving psychotherapy; and (2) young adults with type 1 diabetes that suffer from other chronic illnesses. The total participant group, and the life story narrators, comprised of 11 females and five males, all having been diagnosed with type 1 diabetes for a period exceeding 12 months. Purposive sampling was used to continue recruitment of participants until data saturation occurred. Descriptive statistics indicated that the overall mean age was 21 years.

1.5 Research design and measures

A visual picture or design map of the research study is presented in figure 2.

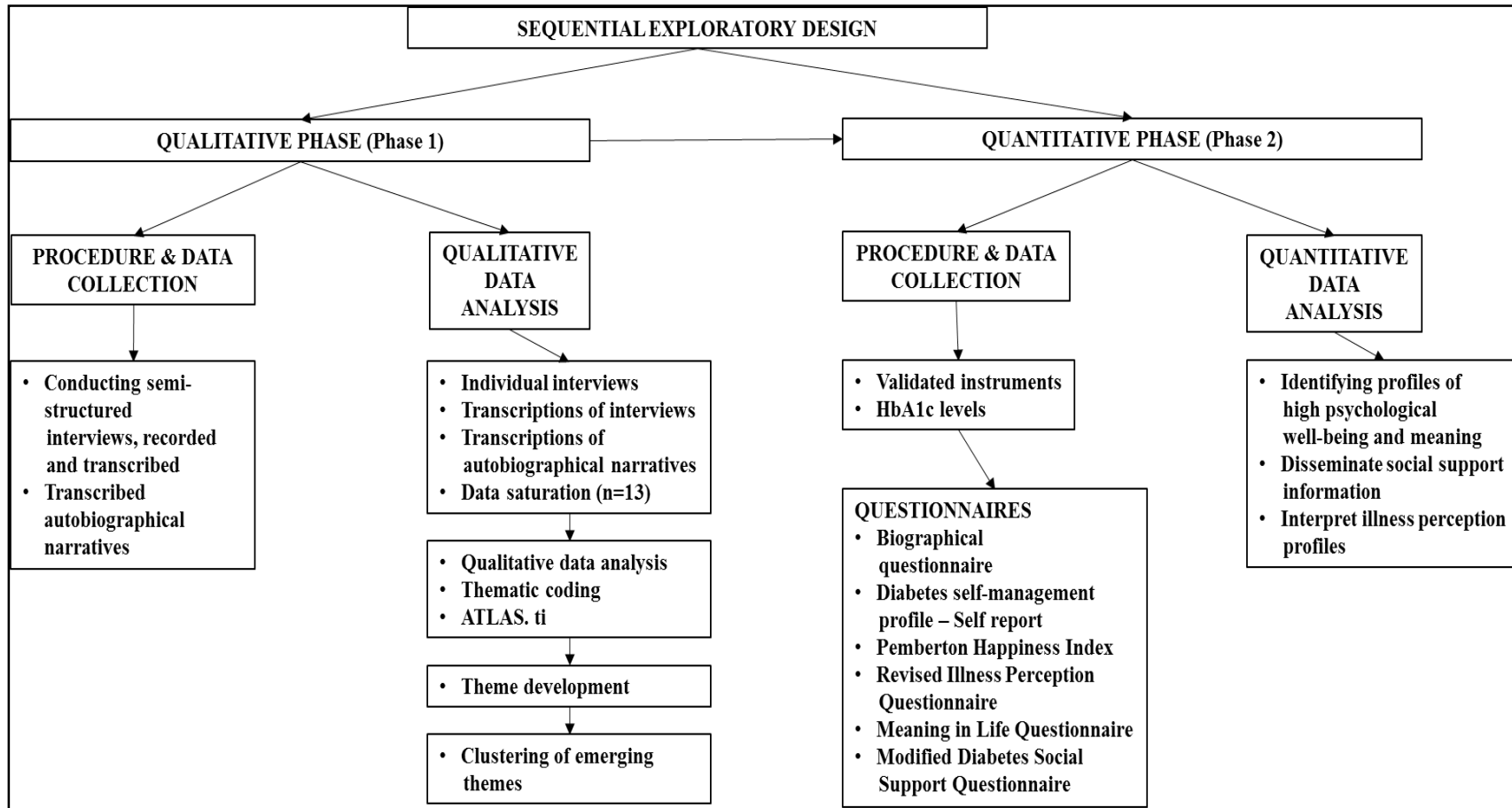


FIGURE 2: DESIGN MAP OF THE RESEARCH STUDY

For the purpose of this study, a multiple case study design was applied, in which each participant was conceptualized as a “case”. Miles and Huberman (1994) explain that a case is, “a phenomenon of some sort occurring in a bounded context” (p. 25). The case study design placed the researcher in the everyday context of the young adult living with well-controlled type 1 diabetes. Data on the diabetes management behaviours of these young adults were objectively recorded and formed the basis for creating a deeper understanding of the psychosocial variables shaping not only the diabetes management behaviours, but also the psychological well-being of the young adult living with type 1 diabetes (Baxter, & Rideout, 2006; Stake, 2005; Trochim, & Donnelly, 2008; Yin, 2009). A multiple case study was used with the aim of offering a broader perspective on the topic and capitalised on variation of experiences and contextual factors between cases. During the data generating process, the meaning of contextual factors, such as the influence of living apart from family and friends, were explored and substantiated by means of quantitative data (Stake, 1995; Yin, 2003).

The life stories of young adults living well with type 1 diabetes ($n = 8$) were studied in order to identify and enhance understanding of the psychosocial variables shaping the diabetes management behaviours of these individuals. This initial step allowed for emergent themes to be identified.

After that, more qualitative data were generated with the purpose of developing an in-depth understanding of the emergent themes. This data were generated through interviews that offered participants the opportunity to reflect on their diabetes management behaviours, as well as their process of making sense of living with type 1 diabetes.

The literature study, as well as the qualitative work done in the prelude phase, informed the selection of research-specific instruments in which aspects of the young adult living with diabetes’ reality were recorded and investigated by the use of numerical data (Bless, & Higson-Smith, 2000; Ivankova, Creswell, & Clark, 2007). The instruments were used to supplement

qualitative data and to assist in answering the research questions (Pallant, 2010). The selected, psychometrically sound instruments assessed the diabetes management behaviours as well as the psychosocial variables (personal model, meaning and social support), identified through the thematic analysis of young adults living well with type 1 diabetes.

The benefit of using self-report questionnaires was that it allowed for the participant to share information in a non-threatening and safe environment. The use of questionnaires provided a relatively quick and efficient way of generating data about the participants and verifying findings that arose from the qualitative phase of the study (Creswell, 2014; Trochim, & Donnelly, 2008). Biographical details of the participants were obtained by using a purposive biographical questionnaire constructed especially for this study. The assessment instruments are discussed in the following section.

Overview of the questionnaires used in this study:

- ❖ *A biographical questionnaire* was developed for this study and included socio-demographic questions as well as questions related to participants' experience of diabetes. Variables included in the biographical questionnaire were gender, age, and highest qualification, the influence of socio-economic status on diabetes management, family structure and family involvement, as well as the time since diagnoses.
- ❖ *The Diabetes Self-Management Profile – Self Report (DSMP-SR)* of Wysocki, Buckloh, Antal, Lochrie and Taylor (2011): The DSMP-SR was adapted from the initial diabetes self-management profile. Separate forms were constructed for patients on flexible (insulin pump or 'basal-bolus' insulin-injection regimens with use of carbohydrate counting) or conventional (fixed dose insulin injection regimens without use of carbohydrate counting) diabetes care plans (Wysocki et al., 2011). The DSMP-SR is a 24-item self-report instrument (not divided into subscales) that quantifies diabetes self-care management behaviours over the preceding 3 months. The question format changed throughout the

instrument and the participant only needed to indicate the most applicable answer.

Examples of some items are: (1) *If you think you are having a low blood sugar, how often do you check your blood sugar before treating?*; (2) *In the past 3 months, before you ate more than usual, did you make any insulin changes?*; (3) *In the past 3 months, if you had two blood sugar results above 13 in a row, how often did you do a ketone test?* The DSMP-SR reported sound reliability indices for the total scale, with a Cronbach alpha coefficient of 0.82. In research done by Wysocki et al. (2012) significant correlations with HbA1c results were reported ($r = -0.35$, $p < 0.001$). In that study it was argued that higher scores on the DSMP-SR were associated with lower HbA1c levels, increased quality of life and less family conflict being experienced (Wysocki et al., 2012).

- ❖ *The Pemberton Happiness Index (PHI)* of Hervas and Vazquez (2013): The PHI was developed as an integrative, quantitative measure of psychological well-being. This measure produced a combined index of an individual's well-being that was the sum of different subscales. Subscales include 11 items related to different domains of remembered well-being (general, meaning, psychological well-being, and social well-being) and 10 items related to experienced well-being (i.e. positive and negative emotional events that have possibly taken place the day before) on a 10-point Likert scale from 0 (*fully disagree*) to 10 (*fully agree*). Examples of items resorting under the domain of remembered well-being are: (1) *I am very satisfied with my life*; (2) *I enjoy a lot of little things every day*; (3) *I have a lot of bad moments in my daily life*. Experienced well-being items are: (1) *Something I did made me proud*; (2) *I gave myself a treat*; (3) *I was bored for a lot of the time*. The PHI reported sound reliability indices for the total scale, with a Cronbach alpha coefficient of 0.82.-0.83 (Hervas, & Vazquez, 2013).

Hervas and Vazquez (2013) argued that this instrument monitors changes in an individual's well-being. For the purposes of this study, it was decided to use this index

because most other measures (e.g. Satisfaction With Life Scale) only tap into some aspects of well-being. On the contrary, the PHI scale measures aspects such as psychological, social, and experienced well-being, which were the aspects of interest in this study.

- ❖ *The Revised Illness Perception Questionnaire (IPQ-R)* of Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick (2002): The IPQ-R stemmed from research done in the early 1960s, and formed the basis on which Leventhal, Nerenz and Steele (1984) based the self-regulatory model. The self-regulatory model describes the response process when an individual perceived a health threat or illness. According to this model, the individual living with type 1 diabetes forms a representation of diabetes, then adopts behaviours to cope with the challenges of living with the condition. Furthermore, the model also judges the efficacy of the such coping behaviours.

The IPQ-R is a 70-item, self-report instrument, which identifies the five subscales within the representation of an illness. These subscales are: (1) *identity* – the category that describes 14 different symptoms associated with the illness; (2) *consequences* – the expected long and short term outcome of the illness; (3) *causes* – ideas on how the illness was contracted or what caused the illness; (4) *timeline* – beliefs on how long the illness will last; and (5) *cure and control* – beliefs on whether or not they can recover from or control the illness (Leventhal et al., 1984; Lau, & Hartman, 1983). For the *identity* subscale, the participants related to symptoms mentioned and had to decide whether or not they have experienced those symptoms and if they perceived those symptoms to be related to their illness. The participants respond by either circling “yes” or “no” to each question. Examples of symptoms are: (1) *pain*; (2) *sore throat*; (3) *fatigue*; and (4) *sleep difficulties*. All responses to the other four subscales of the questionnaire used a 5-point Likert scale, ranging from 1(*strongly disagree*) to 5 (*strongly agree*). Examples of items are: (1) *My diabetes will last a short time*; (2) *My treatment can control my diabetes*; (3) *I do not*

understand my diabetes; (4) I get depressed when I think about my diabetes; and (5) My diabetes may have been caused by chance or bad luck. The IPQ-R reported generally good psychometric properties (Moss-Morris et al., 2002). The Cronbach alpha coefficient reported sound reliability indices of 0.75 - 0.89 for the IPQ-R complete scale. The five dimensions that form the illness perception were the same dimensions used when describing the individual's personal model of an illness. For this study, the preferred term to use was the personal model to describe illness perceptions. For that reason, personal models of young adults living with diabetes were measured in this study.

For the benefit of this study, the IPQ-R measure was used, as previous research has reported this questionnaire to be associated with clinical outcomes (HbA1c) and behaviour (Foster et al., 2006; Griva, Myers, & Newman, 2000; Hill, 2010). Moreover, ongoing research demonstrated not only the importance of an individual's personal model of an illness (Petrie, & Weinman, 1997), but improved self-regulation or self-care management was reported after changing the individual's illness perception (Petrie, Broadbent, & Meechan, 2003).

- ❖ *The Meaning in Life Questionnaire (MLQ)* of Steger, Frazier, Oishi and Kaler (2006): The MLQ was originally developed to measure life meaning in a therapy context, mainly with American college students. This instrument consists of 10 items on a 7-point Likert scale ranging from 1 (*absolutely untrue*) to 7 (*absolutely true*). The MLQ is divided into two subscales, namely (1) *presence* (how meaningful one considers his/her life to be); and (2) *search* (a desire to discover new or more meaning in one's life). Items on the *presence* subscale are concerned with the degree to which the individual feels that his/her life already has some source of meaning, such as: (1) *I understand my life's meaning*; and (2) *My life has a clear sense of purpose*. The *search* subscale examines the extent to which an individual is searching for meaning in his/her life, such as: (1) *I am always looking to find*

my life's purpose; and (2) *I am searching for meaning in my life*). Steger (2010) reported that there were no formal cut-off scores to determine what constitutes a high score or a low score on the MLQ.

- ❖ *The Modified Diabetes Social Support Questionnaire (M-DSSQ)* of Malik and Koot (2011): Data on social support was gathered with the M-DSSQ, which includes two subsections, namely, support from family (58 items) and support from friends (28 items) on a 5-point Likert scale ranging from 0 (*Never*) to 5 (*At least once a day*). Participants also completed a subscale on how he/she feels about the support behaviour mentioned in each item; this is also on a 5-point Likert scale ranging from -1 (*Unhelpful or not supportive*) to 3 (*Very supportive*). The family support subscale consists of five subscales, namely: (1) *guidance and supervision*; (2) *encouragement of self-care and exercise*; (3) *support in critical situations*; (4) *nourishment*; and (5) *emotional support*. The friends support subscale consists of five subscales, namely: (1) *guidance and encouragement*; (2) *help in critical situations*; (3) *nourishment*; (4) *empathy*; and (5) *help in exercise*. Examples of items are as follows: (1) *Give you insulin*; (2) *Nag you until you do your testing*; (3) *Do the grocery shopping for your meals*; (4) *Remind you to exercise*; and (5) *Give you things to read on diabetes care*. Both the M-DSSQ-family and M-DSSQ-friends reported good psychometric properties and Cronbach alpha coefficient reported sound reliability indices of 0.76-0.92 (Malik, & Koot, 2011, 2012).

1.6 Research process

The quality of this study depends on rich data being obtained and analysed (Tracy, 2010). An overview of the research process, inclusive of the recruiting process, the screening questions used, and the data analysis methods are reviewed in the following section. Addressing these

topics in this section, provides for clarity as brief explanations are included in the separate articles.

Before participants were recruited, ethical clearance was obtained (NWU-HS-2015-0156). Professionals at the CDE were contacted and a meeting took place informing them of the study and to gain permission to involve the center and their expertise in this study. Other stakeholders of the CDE, such as the diabetes educators, dieticians, and nurses were also met and informed regarding the aim of the research in order to gain their support. Continuous collaboration with this multi-disciplinary team of diabetes experts, both from the fields of medicine and psychology, took place throughout the study. Thereafter, potential participants were recruited from the CDE in Houghton and Parktown, Johannesburg, Gauteng Province in South Africa. The CDE is an outpatient endocrinology clinic that renders overarching diabetes care to people from all backgrounds and areas. In order to minimize treatment variables, the CDE were the only point of access.

A set of pre-determined criteria was developed in order to enable the researcher to answer the research questions of this study. As a result, purposive homogeneous sampling was used because of the small sample size involved and the specific characteristics that needed to be present in each participant (De Vos, Strydom, Fouché, & Delport, 2005; Struwig, & Stead, 2001; Trochim, & Donnelly, 2008). This type of sampling involves selecting participants based on specific similar characteristic(s). Such criteria allows for a “more closely defined group for whom the research questions will have personal significance” (Fife-Schaw, Smith, Hammand, & Breakwell, 2006, p. 329).

Potential participants were invited to take part in the study by means of an information leaflet handed to them at the CDE, during their normal scheduled visit. This leaflet provided information pertaining to the larger project and the aim of this particular study. The potential participants were invited to fill out their contact details to enable one of the research team

members to contact them. The medical practitioner (or receptionist) then forwarded the contact details to the research team *via* scanning and emailing, or by hand delivery. An advertisement was posted on the “Youth with Diabetes” Facebook page. The purpose was not only to invite potential participants, but to announce the research *via* a different medium that is more appealing to the young adults. This advertisement was also printed in the Diabetes Lifestyle Magazine and the SA Journal of Diabetes. Through this advertisement, prospective participants were invited to make contact with the professionals at the CDE, who then forwarded the contact details to the research team for screening purposes. The final avenue of recruitment was through the CDE’s automated SMS system, where potential participants replied to the CDE by means of an e-mail, stating their interest in the project. This automated SMS system is used by the CDE to remind patients of their scheduled appointments with the medical professionals, thus ensuring no intrusion into the privacy of the potential participants by the researcher.

The research project’s principal researcher was identified to make contact with the interested potential participants. The project’s principal researcher did not conduct any interviews and, as a result, any possible influence on the results was prevented. All communication relevant to the study was, therefore, also handled by the project’s principal researcher. This strategy ensured both consistency and quality of screening, maintenance of good relationships with participants, and provision of feedback throughout to all participants and professionals at the CDE. Within a week after receiving contact details of potential participants, the project’s principal researcher contacted the potential participant. This initial contact was made either telephonically (if a contact number was provided) or *via* e-mail. The aim of this contact was to provide more information and answer possible questions from the potential participants. The invitation to partake in the study was once again offered and potential participants were requested to respond.

After a positive response was received, further contact was made in order to screen the potential participants according to a set of pre-determined questions. The screening questions were as follows: (1) *How old are you?*; (2) *When were you diagnosed (with diabetes)?*; (3) *Are you a patient at the CDE Houghton or Parktown?*; (4) *Are you willing to be interviewed in English or Afrikaans?*; (5) *Do you suffer from any other chronic illness? What and how does this impact your diabetes management?*; (6) *Are you currently receiving psychotherapy?*; and (7) *Have you been involved in any other diabetes related research over the past two years? When and what did it entail?* Based on the answers to the screening questions, a participant qualified to take part in the study or did not qualify to take part in the study. On provision that the participant qualified, arrangements were made to meet at the CDE during their next scheduled appointment so as to obtain informed consent and generate data (interview and/or completion of questionnaires).

Research participants received the consent form prior to the scheduled meeting for their perusal. Informed consent was obtained by an independent person that was not part of the medical or research team. This identified, independent person was affiliated with the CDE and was well-informed of the process and responsibilities pertaining to this role. This person had to indicate, in writing, willingness to assist the researcher in obtaining the consent from participants.

Written, informed consent were obtained prior to gathering data from the participants. Semi-structured, conversation-style interviews ($n = 7$) were audio-recorded. The interviews were conducted after the participant's scheduled appointment with the medical professionals and in a private venue at the CDE. Interviews lasted about 45 minutes and were structured around five general leitmotifs as identified from the life stories and the literature study on psychosocial variables influencing the diabetes management behaviours of young adults living with well-controlled type 1 diabetes. These leitmotifs included: (1) personal perceptions on diabetes

management behaviours and the influence thereof on the lives of people living with type 1 diabetes; (2) experiences of support from family and friends with regard to the diabetes management behaviours; (3) views on how the young adult makes meaning of managing this condition; and (4) the experience of psychological well-being in the midst of managing diabetes. Participants completing questionnaires ($n = 7$) had the choice to complete the instruments at the CDE or they could take it home and submit the completed questionnaires during their following visit to the CDE.

1.7 Data analysis

Data analysis was done through following an explorative method. This method implied that interviewing, transcribing of interviews, and analysis of data with the intention to identify data saturation, took place simultaneously (Creswell, 1994; Rasmussen et al., 2011). The transcripts were then entered in ATLAS.ti™ software (Version 7). A common and anonymous format was used and transcripts were read several times to allow for a global overview of the data but also read in detail to understand the content as well as the detail (Costa, Breda, Pinho, Bakas, & Durao, 2016). The researcher became completely immersed in the data. A line-by-line examination was done before coding took place.

Thematic content analysis was applied to identify common themes or ideas within the data (Braun, & Clarke, 2006; Gibbs, 2014; Trochim, & Donnelly, 2008). Thematic content analysis is a widely used method of analysis in qualitative research where the text is viewed in an analytical way, which changes the mere descriptive focus of qualitative data analysis (Gibbs, 2014). Braun and Clarke (2006) argue that thematic content analysis is a foundational method of analysis that is also uncomplicated to use and allows for flexibility in reporting data in a rich, detailed way (Braun, & Clarke, 2006; Gibbs, 2014).

In this study, the coding followed a spiral process, from the initial coding (exploring of meaning embedded in data) to a stage where code-categories were grouped into themes. To

minimize the influence of researcher biases, the transcriptions were initially independently read and re-read by the researcher and a co-coder. Both researcher and co-coder created analytic memos reflecting initial thoughts while reading the transcriptions. Subsequently, discussions took place between the researcher, co-coder and a subject expert, and each section of text was described, which resulted in emerging themes being clustered together. A summary table of the specific themes was compiled together with applicable quotations from the transcripts, illustrating each theme.

Measuring instruments were scored by hand as the data set was too small to be meaningfully analysed with a statistical program. Hence, the results of the scoring were transferred to an excel spreadsheet to ease interpretation of the data. Data was interpreted and the questions which could not be statistically interpreted, were thematically analysed. Biographical information was categorised into quantitative categories to ease interpretation as well as generalisation. The qualitative and quantitative data complement each other in that the quantitative data were used to support or refute the findings from the qualitative data. This study used the prevalence of qualitative data, as this type of data open up the study to show important interconnected complexities that shape diabetes management behaviours (Cresswell, 1994). Findings from the exploratory, qualitative, phase were then corroborated by the explanatory quantitative phase, and a representation was generated to illustrate the interactions of all the psychosocial variables shaping the diabetes management behaviours of young adults living with well-controlled type 1 diabetes. To summarize, this study began with the qualitative stage first because the complex diabetes management behaviours of young adults has not been explored much in the literature, and then the quantitative stage followed in which the emergent themes were used to verify or refute the findings.

1.8 Rigor

Continuously, throughout this study, utmost care was taken to ensure rigorous research was done. During the qualitative stage, the evidence-based guidelines for rigor in multi-methods research by Onwuegbuzie and Corrigan (2014) was followed. These guidelines included: (1) *the research formulation stage* – it was clearly stipulated in both the conducting and reporting how the different research components interacted with each other; (2) *the research planning stage* – the sampling design and overall research design have been comprehensively accounted for; (3) *the research implementation stage* – the data collection, data analysis, data legitimisation, and interpretation generated by the researcher fit the data well; and (4) *the research dissemination stage* – during the course of the study, member-checking was done on the findings in order to ensure credibility of findings, and sensitivity was communicated pertaining to the participant's realities and the negotiated realities.

Creswell's (2009) concurrent triangulation strategy to improve the trustworthiness of the research findings was referred to during this study. By using qualitative and quantitative data to answer the same questions, a secondary function, namely "convergence" was achieved (Palinkas et al., 2011). Convergent validity, a subtype of construct validity, is defined as the degree to which measures of constructs that theoretically should be related, are in fact related or similar (Creswell, 2014; Onwuegbuzie, & Leech, 2005; Trochim, & Donnelly, 2008). In the same way, through mixing qualitative and quantitative data, the aim of the study was reached in that a deeper understanding of the diabetes management behaviours and psychological well-being of young adults living with type 1 diabetes were formed (Nieuwnhuis, 2007). No effort was overseen to ensure trustworthiness in the qualitative data, as can be seen in the outline below.

1.8.1 Credibility.

Credibility means the data are true or believable (Babbie, & Mouton, 2001). To achieve credibility the following strategies were used: (1) All the time necessary was taken in doing the research and the participants were never rushed. Answers that were unclear, were probed in order to clarify parts that were unclear. The coded interviews as well as all other information were used to draw conclusions (Babbie, & Mouton, 2001; Creswell, 2009; Leedy, & Ormrod, 2005; Mertens, 2009). (2) Regular discussions took place between the researcher, the co-coder, medical experts and the project leader regarding the findings. This served as a form of feedback to ensure trustworthiness (Babbie, & Mouton, 2001; Creswell, 2009; Guba, & Lincoln, 1989; Mertens, 2009). (3) Findings and conclusions were taken back to the participants in order to ensure that responses had been understood correctly. In the case of any uncertainty, the participants were asked to explain their responses in order for the data to be altered accordingly (Babbie, & Mouton, 2001, p. 277; Leedy, & Ormrod, 2005, p. 100; Mertens, 2009, p. 195).

1.8.2 Transferability.

According to Babbie and Mouton (2001) “transferability refers to the extent to which the findings can be applied in other context or with other respondents” (p. 277). This study included 15 participants of a homogeneous group and as much detail as possible were given to describe the setting in which the study took place. This will allow the reader to independently judge the transferability of the study (Babbie, & Mouton, 2001; Mertens, 2009). Demographic detail about participants were also given (see section 1.4). In addition, purposive sampling was used as only well-controlled young adults living with type 1 diabetes who are registered at the CDE were included (Babbie, & Mouton, 2001). Other researchers using the same sampling criteria (purposive sampling) should get similar results, which makes this study transferable.

1.8.3 Dependability.

Babbie and Mouton (2001) argue that dependability cannot be demonstrated without credibility, therefore, if the study is credible, it should also be dependable. Dependability means that if the research should be repeated with the same participants in the same setting the results should be similar (Babbie, & Mouton, 2001). For that reason, the study was logical and well-documented (Guba, & Lincoln, 1989).

1.8.4 Confirmability.

This is one of the major categories of rigor and equals objectivity (Mertens, 2009). Confirmability represents the degree to which the findings of the study focus on the results and not on the biases of the researcher (Babbie, & Mouton, 2001). During the study, continuous checking between the researcher and the project leader took place to ensure that no biased interpretation of the data was reported. Feedback from participants were also obtained to make sure the interpretation of what they had said was correct. This gave the participants the opportunity to confirm (or refute) the findings.

1.9 Ethical considerations

All ethical principles were adhered to while conducting this project. Ethical approval was obtained from the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University for this research project (NWU-HS-2015-0156). Participation was voluntary, with the option to withdraw at any stage. It was highlighted that withdrawal would not negatively affect the participant in any way. Participants completed an informed consent document that confirmed the voluntary and anonymous nature of the content of their interviews prior to conducting the interviews or completion of the questionnaires. All information was treated confidentially, although participants needed to be identifiable to enable

follow-up studies. A unique, identifiable number was allocated to each participant, and it was paired with the abbreviation YA when referred to in-text. Steps were further taken throughout the research process to maintain the partial anonymity of the participants by ensuring that only researchers working on this project conducted each of the interviews and that all of the documentation completed by the participants were securely guarded in a secure location to ensure confidentiality. Electronic data was password protected. Extra care was taken to ensure that no false hope was created and tokens of appreciation were considered carefully.

The participants belonged to a vulnerable group (being diagnosed with diabetes) and as such, needed to be treated with sensitivity. As diabetes could potentially be a sensitive topic to discuss, and could increase stress levels for some of the participants, precaution was taken not to infringe on their rights, not to disclose information and to uphold their right to withdraw from the process. Opportunities for debriefing by qualified professionals were made available to all participants and referral to psychological services was also available.

Although the HbA1c results of all the participants were central to this research project, the results were obtained from the file of the patient at the CDE; thus no blood samples were handled during this study. The participants were not judged in any way based on their HbA1c result, although discussions were sparked pertaining to how well (or not) the participant managed the particular diabetes treatment plan. Data on the duration of their diabetes, HbA1c concentrations and insulin diabetes care plan were retrieved from the participant's medical records at the CDE after informed consent was obtained from the participant.

Data was only accessed by the researcher involved in this project. Although the researcher worked closely with the personnel at the CDE, no member of the CDE had access to the data. Finally, no one suffered any pain or harm of any kind throughout the research process.

1.10 Thesis at a glance: Report outline, chapter divisions and article presentation

This study developed into a series of three research articles together with introduction and conclusion chapters. Each article necessitated its own purpose, method, data analysis and findings and is presented in a separate chapter. The article approach might give the impression that each research problem was dealt with separately. However, findings were viewed holistically and interrelated, and are present in all articles. The article approach allowed for easier and more effective dissemination of findings.

So far, this chapter has introduced the overarching methodology, research design, data analysis, and the research process. The remainder of this section is then used to provide an overview of the different articles within this study. The research question informing each article, methodology, data analysis, and the main findings are outlined as each related to the various articles presented in this thesis.

Articles were submitted for review to the different journals indicated. Therefore, the articles presented in this thesis were written as to comply with the style as required by the particular journal. Articles have not been standardised into the “sandwich format” as might be the case for other studies (Gustavii, 2014). Table 1 offers the article overview, which describes the title, the research question, method, type of data used, main findings and conclusions, as well as explaining the link to subsequent research and articles.

TABLE 1: ARTICLE OVERVIEW

Diabetes management behaviours of young adults towards psychological well-being			
Chapter Title	Research question	Method	Summary of findings
Article 1 Life stories: Young adult's experiences of adjusting to diabetes management.	<i>How can the psychosocial variables and diabetes management be conceptualised in the context of young adults living with type 1 diabetes?</i>	A qualitative design with thematic analysis was used to identify psychosocial variables from life stories of young adults living with well-controlled type 1 diabetes. General themes emanated after data was thematically analysed with the assistance of ATLAS.ti™, the computer software program.	Condensed themes that emerged included the challenging experiences of identity development, the emotional experiences towards diabetes management behaviours and social support while adjusting to living with type 1 diabetes. The article highlighted the need to form an in depth understanding of the themes identified and to understand how these themes relate to the meaning-making process that young adults use to make sense of their lives with well-controlled type 1 diabetes.
Article 2 Understanding young adult's meaning-making in adjusting to diabetes management behaviour: Multi-methods approach.	<i>What kind of interactions exist between the personal model of diabetes, making meaning of the condition, social support received and diabetes management behaviours of young adults living with type 1 diabetes?</i>	A multi-methods design, including both semi-structured interviews (qualitative data) and questionnaires (quantitative data) was used. Thematic analysis of interview data and hand scoring of questionnaire responses developed a representation of the psychological well-being of young adults living well with type 1 diabetes.	The distinctive themes identified to influence the meaning-making process of the young adults were related to the challenges pertaining to developing of an own identity, the experiences of emotional distress as a result of the diabetes treatment plan, diabetes management behaviours and frustrations related to social support.

			A need arose that the envisaged meaning-making framework that young adults employ to make sense of their diabetes management behaviours, should be studied in depth by applying it to a selected case study.
Article 3 Diabetes management behaviours and meaning-making: The young adult's sense making process of living with type 1 diabetes.	<i>How can the proposed model of the young adult's experiences of making sense of living with type 1 diabetes be applied to a single case study?</i>	A case study, using a multi-methods design, including a semi-structured interview (qualitative data) and a questionnaire (quantitative data) was used. Thematic analysis of interview data and hand scoring of the questionnaire responses were used to create an understanding of the young adult's meaning-making of living with diabetes within the meaning-making framework (Park, 2010)	The driving forces behind the diabetes management behaviours vary significantly and is largely dependent on the discrepancies that derived between the global meaning and the situational meanings that the individual experiences. Living well with controlled type 1 diabetes was no guarantee that higher levels of psychological well-being would be experienced.

In summary, the three articles presented a collective progression apprised from the findings. This study contributed to the generation of theory on diabetes management behaviour as well as the understanding of psychosocial variables related to diabetes management behaviours, the meaning-making process, and psychological well-being for young adults living with well-controlled type 1 diabetes. Each article presented in this thesis begins with a short preface that clarifies the context of that particular article and links the previous article to the current one. By doing this, the thesis storyline is apparent to the reader. The articles follow a general article format.

1.11 Chapter summary

This chapter outlined the challenges faced by young adults living with well-controlled type 1 diabetes, in establishing positive diabetes management behaviours that influence their psychological well-being. These challenges were used to explain the rationale for this research study as well as the contribution to the diabetes management theory and practice. The thinking that informed the direction of the study was discussed.

In summary, psychosocial variables that appeared relevant to the diabetes management behaviours and psychological well-being of young adults were identified. The data was collected through a purposive design that involved drawing the sample with a specific, predefined group in mind. This design was appropriate as it reflected the participants living with well-controlled type 1 diabetes in terms of the characteristics relevant to the study. A thematic analysis of life stories ($n = 8$) and semi-structured interviews ($n = 6$) were conducted in order to determine the validity of the identified variables. Themes were formulated to express the variables that showed relevance to the diabetes management behaviours of young adults living with well-controlled type 1 diabetes. These emergent themes were triangulated with questionnaires ($n = 6$) tapping into relevant variables identified through the research

questions. Once data collection and analyses were completed, the findings were compared to existing knowledge pertaining to the diabetes management behaviours of young adults and the influence thereof on their psychological well-being. A more comprehensive literature review was undertaken once the focus of the study, and more particular, the focus of every article, was determined. The literature review for each particular article resides within that article.

The overarching research methodology, design, process, including the criteria for recruitment of participants for this study, was explained in this chapter. Biographic dissemination of participants were presented. The multi-methods research approach was highlighted as well as the process of data analysis. Possible ethical matters pertaining to this research study were addressed in this chapter. This chapter is, therefore, fundamental for the presentation of the articles in chapters 2 - 4 of this thesis.

The next chapter presents a comprehensive literature review for the purpose of generating understanding of the psychosocial variables shaping the diabetes management behaviours of young adults living with well-controlled type 1 diabetes towards adjusting to diabetes. The research question gave rise to the analysis of life stories and resulted in emergent themes that are discussed in more detail.

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CHAPTER 2: LIFE STORIES: YOUNG ADULT'S EXPERIENCES OF ADJUSTING TO DIABETES MANAGEMENT

Preface to chapter 2

This chapter functions as the gateway chapter for all subsequent chapters in that it conceptualises the psychosocial variables applicable to the study. Furthermore, this chapter highlights existing literature, particularly focusing on the developmental stage related tasks and challenges that young adults face, forming an important basis for the entire study. Article one (as contained in this chapter) embodies the experiences of young adults adjusting to diabetes management. The variables that shape diabetes management behaviours are identified in addition to conceptualising how and why these variables shape diabetes management behaviours of young adults living with well-controlled type 1 diabetes.

This article focuses purposely on identifying the variables that contribute to the young adults' effective management of type 1 diabetes in the midst of developmental stage challenges. Emergent themes are predominantly related to identity development and emotional experiences of young adults in adjusting to diabetes management. The experience of social support is recognised to play an important role in shaping the diabetes management behaviours of young adults living with well-controlled type 1 diabetes. This article conclude with suggestions for future research and possible exploration of other findings emerging from the data. The meaning-making process of young adults living with type 1 diabetes, in

particular, need further investigation as a means to assist medical professionals in working effectively with this specific age group.

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Book Chapter

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Abstract

Objective: This study aims to identify and conceptualise the psychosocial variables shaping diabetes management behaviours of young adults living with well-controlled type 1 diabetes.

Method: A qualitative, explorative design was followed. Life stories of eight young adults, ages 18 - 25 years, with well-controlled type 1 diabetes were analysed through thematic analysis. Data were coded using ATLAS.ti™. Through an iterative process, major themes emerged from the data.

Results: The apparent themes pertain to the experiences of identity development challenges, emotional experiences towards diabetes management, and social support that influenced the diabetes management behaviours of young adults living with type 1 diabetes.

Conclusions: Living with type 1 diabetes as a young adult is identified as a challenging experience. This is in relation to their developmental stage, emotional aspects, and their experience of social support as a valuable management tool. The need to experience a normal life currently, as well as in the future, is the most significant contributor to effective management behaviour. Feelings of distress are primarily related to unmet expectations and a lack of appropriate support. The conclusion, that a reasonable balance should be found between effective self-management and knowing why self-management is important, reflects significance.

Keywords: young adults, diabetes management behaviours, psychological well-being, psychosocial variables

LIFE STORIES: YOUNG ADULT'S EXPERIENCES OF ADJUSTING TO DIABETES MANAGEMENT

Diabetes is a chronic condition that affects people of all ages and ethnic groups. According to relevant data, only a small percentage of people living with diabetes attain the current treatment targets, and the consequences of poor diabetes management are dire (CDE, 2016; IDF, 2015). Researchers were impelled to explore different avenues to create a better understanding of diabetes and the measures that can be taken to improve the self-management of diabetes (Ahola, & Groop, 2013; Brierley et al., 2012; Kovacs et al., 1990).

There are limited data on the exact numbers for people living with type 1 diabetes. Globally, type 1 diabetes is increasing at such a pace that it is estimated that half a million people live with type 1 diabetes (IDF, 2015). The prevalence of diabetes in South Africa is estimated at 8.7 % of the population and of this, 5 - 10% is presumed to be type 1 diabetes (IDF, 2015). This postulates an increase of 155% from statistics recorded in 2010 (Statistics South Africa, 2015). At best, these are estimates on the number of people living with diabetes in South Africa, but this are data based on the glycaemic control self-reported by the people living with diabetes (CDE, 2016).

Bryden and colleagues (2001) revealed a sobering perspective that young adults living with diabetes are a forgotten group and their unique needs are not addressed by either the paediatric- or adult- medicine fraternity. During this stage, young adults are fully aware of the distancing challenges and struggles of adolescence, and start feeling responsible for themselves, however, close ties with parents and family are still acknowledged (Munsey, 2009). In this age group, there is also a lack of focus on how to treat not only the condition, but the individual living with the condition (Pickup, Holloway, & Samsi, 2015).

Researchers, such as Arnett (2000), argue that this “feeling in between” time is the age of: (1) identity exploration, when young people decide what they want; (2) instability, where frequent moves or repeated residence changes take place; (3) self-focus, where the young people experience freedom from the parent- and society-directed constraints; and (4) feeling in between adulthood (with wide-ranging responsibilities) and adolescence (with very few responsibilities).

Some of the unique challenges, for young adults with type 1 diabetes, that must be navigated throughout their journey into becoming independent and responsible adults include financial responsibilities, changes in health care and access to medical care, relationships, job seeking and studying, and finally, integrating diabetes with a new, demanding lifestyle and assuming increasing responsibility for their diabetes self-management (Arnett, 2000; Berg, & Sparud-Lundin, 2009; Chaing, Kirkman, Laffel, & Peters, 2014; Monaghan, Helgeson, & Wiebe, 2015; Munsey, 2009; Rasmussen et al., 2011). These challenges result in a lack of routine and shifting priorities that may result in dropping diabetes related behaviours lower on the list of priorities, which are important for maintaining stable diabetes care.

Traditionally, much has been published about the importance of accepting the diabetes diagnosis and adhering to the recommended diabetes treatment plan. Though goal orientated, individualised diabetes self-management behaviours and the psychological well-being of young adults are largely under-reported. Shifting demands and resources, as well as the shift in focus, requires a reprioritization and necessitates the need to find a new meaning and/or motivation that would result in the behaviours that are required to maintain good diabetes care (Munsey, 2009).

Little is known about which psychosocial variables play a role in shaping the self-management of type 1 diabetes. Consequently, how diabetes management behaviours fit in with the young adults’ inconsistent schedules or time frames is just as unclear. Even the

reasons why some individuals cope well with type 1 diabetes, while others struggle to effectively manage their condition, are still elusive (Munsey, 2009). Through studying the real-time experiences of young adults who successfully manage their diabetes, this study aims to offer evidence that certain motivators, and certain meaning-making processes, motivate good diabetes care.

The effective management of type 1 diabetes depends largely on adherence to the diabetes care plan. This care plan does not refer to the one dictated by the physician, but is rather a self-created plan consisting of a compilation of behaviours that together are known to result in or be associated with good diabetes control. Non-adherence to the diabetes care plan is well documented in existing literature, and in view of that, adherence is implied to be challenging, especially for the young adult transitioning from adolescence (DiMatteo, 2004; Kravitz et al., 1993). The non-adherence rate among young adults is reported at a staggering 93% (Rapoff, 2010). This figure unambiguously demonstrates the importance of understanding the young adult's drive concerning adoption, adherence to and persistence with diabetes management behaviours. Further, improving adherence positively affects the HbA1c levels and in the long run, the individual's understanding of why adherence and self-management are important, will be enhanced (Borus, & Laffel, 2010). There is a call for renewed examination of different paths that may encourage adherence in young adults living with type 1 diabetes (Arnett, 2000; Holmes-Walker, Llewellyn, & Farrell, 2007; Luyckz et al., 2009).

The objective of this study is to identify and conceptualise the psychosocial variables shaping the adoption, adherence to and persistence with diabetes management behaviours in a sample of young adults living with well-controlled type 1 diabetes. Hence, the current article explores the perceptions and experiences of young adults living with well-controlled type 1 diabetes, using qualitative analysis of the young adult's narratives.

Method

This study followed an exploratory, descriptive, and qualitative research design. Ethical approval was obtained from the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2015-0156). The qualitative approach was used to understand young adults' subjective experiences (Fossey, Harvey, McDermott, & Davidson, 2002) of managing type 1 diabetes in an attempt to answer the relevant research question: *how can psychosocial variables and diabetes management be conceptualised in the context of young adults living with type 1 diabetes?*

Data collection

Creswell and Plano Clark (2007) raised the argument that the diabetes reality is subjective, with multiple perspectives of thought. In view of that, this study brought together different perspectives of thought through the analyses of diverse life stories of young adults, all living with well-controlled type 1 diabetes. The Centre for Diabetes and Endocrinology (CDE) is a large, well-managed care organisation that specifically tends to individuals with diabetes. The CDE's official magazine, *Diabetes Lifestyle*, publishes life stories, written by individuals adeptly living with diabetes, in part to celebrate successes as well as to explore challenges when managing diabetes. Thematic analyses was conducted on eight of the published life stories of young adults living with well-controlled type 1 diabetes in South Africa.

The life stories were selected according to pre-determined inclusion criteria, which firstly, addresses an operational definition for well-controlled HbA1c of <8% (64 mmol/mol). The researcher acknowledges that international diabetes bodies, and the Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) recommend that adults

should have a target HbA1c of <7% (53 mmol/mol) to be considered well-controlled. This study, however, was not restricted by a single time point but included young adults achieving and maintaining an HbA1c <8% for longer than a year; arguably a more valid measure of adoption and maintenance of effective diabetes behaviours. Secondly, this study made use of individuals living with well-controlled type 1 diabetes whose respective ages range from 18 years to 25 years, constituting young adults.

Of the eight life stories selected, five were written by women (62.5%) and three were written by men (37.5%). The racial composition of the narrators reflects four (50%) European narrators, three (40%) African narrators, and one (10%) Cape Malayan narrator. At the time of sharing their respective life stories, three (40%) were single and five (63%) were married. The objectives for the analysis were to: (1) identify the psychosocial variables affecting their living with type 1 diabetes; and (2) understand how and why these experiences shape their diabetes management behaviours.

Data analysis

The presented life stories were read thoroughly and a thematic analysis was conducted according to the guidelines published by Saldana (2013) as well as Braun and Clarke (2006). Thematic analysis is a method of identifying and reporting patterns in qualitative data. Thematic analysis as a methodology offered the researcher the advantage of learning how participants dealt with specific situations in specific contexts in great detail (Larkin, Watts & Clifton, 2006; Smith, Flowers & Larkin, 2009). This detail can reveal links and possibly discrepancies within the participants' processes of sense making of certain experiences. The transcripts were entered in ATLAS.ti™ software (Version 7). The analysis process was iterative in nature, which implies that the analysis was guided by the research objectives and

by reading and interpreting the narrative data (Brink, van der Walt, & Van Rensburg, 2006; Saldana, 2013).

Although the thematic analysis allowed for detailed analysis of the data (Nystedt, Hogberg, & Lundman, 2008), insight into the psychosocial variables in diabetes management and adherence to a diabetes care plan were only gained after re-investigating the narratives for that specific data. Verification of the emergent themes was empirical as well as technical. Thus, triangulation of the data was possible by comparing the extracted themes to various literature on diabetes and diabetes management behaviours (Constas, 1992; Tashakkori, & Teddlie, 1998, 2003).

Rigor

Throughout this study, utmost care was taken to ensure rigorous research was conducted. To enhance credibility, the researcher engaged in active and sustained reflection during data interpretation to ensure quality, and to highlight the complexity of the young adults' experiences. The dependability of the analysis and interpretations was established by comprehensively describing the research methods used in data gathering. Dependability was furthermore enhanced in the precise and comprehensive reporting of the data. Appropriate and clear documentation would allow other researchers to follow the investigative process and reach similar conclusions given the researcher's data, perspective and situation (Creswell, 2009; Marshall, & Rossman, 1995; Onwuegbuzie, & Corrigan, 2014).

Findings

With the purpose of exploring the adjustment to diabetes and the understanding of the young adult context, the unique developmental challenges of this age group served as a guideline for the thematic content analysis in order to answer the research question. In this study, as with others it was found that (e.g. Monaghan, Helgeson, & Wiebe, 2015), identity development challenges were strong forces for young adults living with type 1 diabetes since it was *“a challenge, trying to fit in with your peers and knowing that you are different”* (YA4, male, 25 years of age, European, married). Every young adult strived to reach an outcome that not only reflected a blood glucose level of near-normal, but also gave them the sense of living a normal life *“with a diabetes twist”* (YA6, male, 23 years of age, African, single). Living a normal life was possible, as YA5 (male, 20 years of age, European, single) explained that, *“sometimes I even forget I have diabetes”*.

From the data, it was clear that diabetes was managed in a very personal way, *“I learned to listen to my body”* (YA4, male, 25 years of age, European, married). Once the young adults trusted their own abilities to make the correct diabetes management decisions, they felt empowered and motivated to adopt and maintain the right management decisions, *“I started digging deeper into my soul to search for the same kind of strength to enable me to live with diabetes”* (YA11, female, 25 years of age, African, married). Diabetes management was only then accepted as part of the everyday routine. This statement also spoke to the meaning-making process that motivate the search for and implemented certain behaviours that, through trial and error has been proven to be successful.

Young adults found that managing diabetes could be a very lonesome task, as YA4 (male, 25 years of age, European, married) said, *“It’s such an individual thing”* and *“you are very alone in a lot of circumstances, very alone”* (YA6, male, 23 years of age, African,

single). All the young adults came to the conclusion that managing type 1 diabetes demanded accelerated self-reliance, *“I will get the maths wrong and perhaps over count my carb intake, it’s really bad and no-one but you must fix it”* (YA4, male, 25 years of age, European, married).

It was evident that the young adults longed for a subjective experience of normality, only to find such an experience of normality to be distressing or not attainable, needing a re-representation such as creating a new normal. This recreation of normal was not without its challenges as was expressed by YA11 (female, 25 years of age, African, married), *“I can say from my own experience that it is not easy, challenging to say the least”*. Then, YA6 (male, 23 years of age, African, single) added, *“it was an obstacle I had to conquer daily”*. The young adults experienced diabetes management as being a never-ending challenge, since they reported that the maintenance and execution of diabetes management behaviours as being challenging. Furthermore, the young adults particularly mentioned the frustration of adapting to the required lifestyle, *“I was frustrated about everything that needs changing”* (YA5, male, 20 years of age, European, single) and *“I would be so frustrated because I needed my husband to share in the same food choices I was now making”* (YA11, female, 25 years of age, African, married).

Part of developing one’s own identity as a young adult, was the ability to make decisions about diets and food choices, *“I had to sort out my blood glucose levels so I would have enough energy to tackle everything”* (YA5, male, 20 years of age, European, single). All of the young adults experienced the dietary restrictions as frustrating, *“I needed to tackle a major issue, my eating habits, accepting healthy meals was not a simple task”* (YA8, female, 24 years of age, Cape Malayan, married) and *“the idea of being told what to eat and when, did not sit well with me at all”* (YA7, female, 25 years of age, African, married).

On the other hand, four of the young adults acknowledged that the challenges and frustrations that were coupled with the restrictive diet led them to “*stray from the limitations of my diet*” (YA9, female, 24 years of age, European, married). The consequence of not following a healthy, diabetes friendly eating plan eventually led them to experience negative consequences as YA10 (female, 23 years of age, European, single) explained, “*my terrible lack of control lead to severe episodes of diabetic ketoacidosis and a doctor telling me that if I didn’t start looking after myself I would die*”. These negative experiences and consequences in time, became part of their learning process to live successfully with diabetes and was experienced as “*quite a motivating factor in my life*” (YA4, male, 25 years of age, European, married), and “*a wakeup call*” (YA5, male, 20 years of age, European, single).

The initial diagnosis of diabetes precipitated the realization that the young adults were prevented from achieving their dreams and aspirations, “*my dream to pursue a career in aviation was lost when I lost my medical certificate as a pilot*” (YA10, female, 23 years of age, European, single). YA6 (male, 23 years of age, African, single) stated, “*I was told to retire*”, and “*was robbed of performing at my peak in the ring*” (YA6, male, 23 years of age, African, single).

In spite of stating that learning to live with diabetes management was challenging, the question that required answering was, why were some young adults successful at self-management when literature (e.g. DiMatteo, 2004; Kravitz et al., 1993; Rapoff, 2010) argued that young adults were well-known for their non-adherence behaviours? The answer to that question was hidden within the reasons or motivations that every individual shared in wanting to be successful at managing their diabetes. Seven of the young adults professed that it was possible to successfully manage life with diabetes, as YA10 (female, 23 years of age, European, single) expressed, “*remember that you can live a perfectly normal life and accomplish anything*”.

Nevertheless, through all the challenges and frustrations the young adults endured, all of them agreed that *“diabetes is a manageable situation, one to be overcome”* (YA6, male, 23 years of age, African, single). YA8 (female, 24 years of age, Cape Malayan, married) said, *“abandon self-pity and take control of your life with diabetes”*. YA5 (male, 20 years of age, European, single) stated that *“I was determined to be the boss of diabetes and not be working for the man [diabetes]”*. They all concluded with the idea that, *“you will be just fine”* (YA10, female, 23 years of age, European, single).

Instead of initially being frustrated about food and identity challenges, the young adults found individual motivation towards effective management *“so began my journey of finding the correct treatment for me”* (YA 11, female, 25 years of age, African, married). The effective management of diabetes was a personal process, *“I learned to listen to my body”* (YA4, male, 25 years of age, European, married) and a strategy *“to balance the complexity of diabetes with my independence”* (YA9, female, 24 years of age, European, married). Every individual’s diabetes management strategy included prominent management behaviours, but the focus mostly remained on mastering the eating plan, *“I had to look after myself holistically and learn all about testing, eating and injecting”* (YA11, female, 25 years of age, African, married) and *“learn more about carb counting and insulin correction factors”* (YA6, male, 23 years of age, African, single). Five of the young adults explicitly referred to the importance of following an exercise schedule as part of maintaining the near-normal blood glucose levels, as YA8 (female, 24 years of age, Cape Malayan, married) remarked, *“find a fun exercise programme and go with it”*.

Findings of this study, as with others (Monaghan, Helgeson, & Wiebe, 2015), it was found that when the young adults received positive feedback of a blood glucose level within near-normal range, the motivation factor or reason for managing the diabetes, grew stronger and more energy was available to continue with their management strategy. Hence, all the

young adults typically commented that living with diabetes was difficult at the beginning, but eventually it became easier. With learned experience, the study subjects reported that their perceptions of being different, not fitting in with their peers, and being deprived of typical 'young adult food' slowly subsided and they reported to be well adjusted and content young adults, *"now I know who I am, and I'm OK with saying no to pizza and beer"* (YA5, male, 20 years of age, European, single).

The young adults found family support to be a lifeline, *"my wife understands the simple maths of living with diabetes 24 hours a day"* (YA4, male, 25 years of age, European, married), *"The never ending support, love and encouragement of my parents were critical"* (YA9, female, 24 years of age, European, married) and *"My twin sister, a solid support structure while on this (diabetes) journey"* (YA7, female, 25 years of age, African, married). Primarily, managing diabetes was easier with the care and assistance of family members.

The young adults expressed that support from friends was what encouraged them and they were grateful for it. They acknowledged that their friends took a personal interest in their diabetes and were, at times, great at noticing diabetes related symptoms. In this regard, YA6 (male, 23 years of age, African, single) explained, *"I have a lot of encouragement from my incredible friends"* and *"members of my band are great at noticing if I am headed for a hypo, and I have thus never had an episode at a gig"* (YA5, male, 20 years of age, European, single) and *"group discussions [with newly found friends] on a monthly basis offer great support"* (YA7, female, 25 years of age, African, married).

The support, advice and guidance received from medical staff were also an important contributor to managing diabetes successfully, *"having a professional team to provide the guidance and support that was required for me to understand and manage my diabetes"* (YA4, male, 25 years of age, European, married). The qualities and attributes of the medical staff played a significant role in reducing possible stress experienced, *"my endocrinologist*

advised me to learn more about carb-counting and insulin correction, for which I am very grateful. The guys at CDE are a helpful bunch and have helped me to understand and manage my diabetes” (YA6, male, 23 years of age, African, single). All the young adults found the medical staff at the CDE as a source of reassurance and comfort that helped to lower anxiety; *“At the Centre (CDE), I’ve made good use of the psychologist – someone to support me in finding the underlying cause of why I’ve made such self-destructive choices in the past”* (YA7, female, 25 years of age, African, married) and *“The quality and level of care provided at the CDE was simply outstanding I was shown resolute, unwavering support throughout my pregnancy, listen to the wonderful people in the medical profession”* (YA8, female, 24 years of age, Cape Malayan, married).

Conclusions, Implications and Limitations

The aim of the study was to conceptualise the psychosocial variables and diabetes management in the context of young adults living with type 1 diabetes. This aim was satisfactorily met through thematic analysis of young adults’ life stories (n = 8) to explore and understand the experience of adopting and maintaining diabetes management behaviours. Themes that emerged pertain to A) Experiences: 1) identity development challenges, 2) emotional experiences towards diabetes management, and 3) social support that influenced the diabetes management behaviours of young adults living with type 1 diabetes. B) Psychosocial variables: 1) the personal model of diabetes, 2) emotional experience of social support and 3) motivators of adherence to diabetes care plans.

Young adults experienced diabetes management as pervasive, permanent, and personal. This experience of being 100 % occupied with the condition is consistent with research by Pundziute-Lycka et al. (2002) that reports how significant the demands of management

behaviours are on young adults. These researchers also argued that due to the strenuous nature of diabetes management, the young adults tend to let adherence fall to the wayside and rather focus their attention on developmental processes related to their age group, such as developing an identity that incorporates diabetes, reconstructing meaningful relationships with significant others in their lives as well as getting married and starting their own families. This study's findings speak against this notion tabled by Pundziute-Lycka et al. (2002). This sample of young adults used exactly that strenuous, challenging nature of the condition as motivation to manage it effectively.

Emotional reactions, such as frustration, being different, and experiences of isolation influence the young adult's personal model of type 1 diabetes (Arnett, 2000; Brassai, Piko, & Steger, 2011; Lustman, Carney, & Amado, 1981; Rasmussen et al., 2011). Mc Sharry et al. (2011) confirmed that negative emotional representations are significantly correlated with higher levels of HbA1c. The present study's results differed from those findings, as all the young adults were well-controlled, with blood glucose levels within the near-normal range.

From this study, it became clear that even negative emotions are normal and can clearly be overcome or could exist congruently with the realization that diabetes behaviours, if adopted and executed, could result in good blood glucose control. Considering that negative emotions were still reported in this study, added to the growing evidence that it is important to address maladaptive perceptions and emotional reactions young adults hold about their diabetes, the discomfort possibly facilitates a change process of adjusting to diabetes management.

The emotions expressed in relation to social support were overall positive in nature, such as being grateful and feeling encouraged to succeed at living well with type 1 diabetes. This is consistent with research that argues that young adults living with diabetes require both family and peer support in order to transform into a diabetic-responsible individual (Wysocki

et al., 1996). As social support is essential for managing type 1 diabetes successfully, diabetes professionals should encourage supportive communication and build relationships that encourage autonomy of the young adult. Opportunities for peer support and social networking should be explored as aids in the young adult's journey to live well with type 1 diabetes.

The objective of promoting the young adult's diabetes management behaviours towards the visualized goal of living a normal life, with well-maintained HbA1c levels within near-normal ranges, requires an approach that incorporates an understanding of the psychosocial ramifications of diabetes within the context of the young adult living with type 1 diabetes. Significant insights emerged as to why young adults want to manage their diabetes in a way that will bring them closer to the envisaged goal (living a normal life) and how one can make sense of living with type 1 diabetes. Most of the young adults were motivated to manage their diabetes effectively just because it was considered challenging to constantly produce near-normal HbA1c levels. Thus, achieving this target was, in itself, a motivating force. Further, the realization that the old normal was no longer attainable, and the desire to create a new normal, was an emotional motivator.

Considering the developmental stage where formation of a personal identity is the main task, it would be advisable that diabetes educators and other medical professionals must strive to understand how and why it is necessary to develop and maintain a healthy relationship where they educate the young adults, as well as encourage the individual to actively participate in setting goals for their own diabetes self-management.

Existing research shows that individuals utilise factors such as complications and glucose control in rating the seriousness of their diabetes (Lange, & Piette, 2006). This exploration, therefore, has important implications for therapeutic intervention and guidance.

Professionals involved with diabetes care and education should consider strategies for

preventing psychological distress through greater, in-depth education, which should promote a sense that diabetes is compatible with a healthy, normal life. Professionals are not only there to provide a sense of security in times when the young adult may be experiencing moments of despair, they must have a clear, deeper understanding of the motivating factors that drives the individual's management behaviours.

The findings draw attention to the importance of the young adult's beliefs as to why diabetes management is important, and this must be a vital discussion point in every professional's encounter with the young adult living with type 1 diabetes. Health care professionals should help young adults to explore the meaning-making process so as to identify goals, dreams or desires that would provide the motivation required to adopt and enact the challenging diabetes behaviours that are known to result in good glycaemic control. Blood glucose targets and control, in and of itself, is neither a predominant motivator nor is the self-stated goal that motivates many of these young adults to succeed in their diabetes journey.

The limitations of this study, such as its small homogenous sample, may underestimate or misrepresent the true nature of the problem. The small sample may limit the transferability of the results. It is important to note that the data collection and analysis were context-specific and the findings reported here may not necessarily be applicable in other contexts. This study's subjects were from mid to high socio-economic groups with access to a capable diabetes multidisciplinary care team. The views of these young adults need to be integrated with those of other young adults in order to inform the development of a comprehensive diabetes management understanding that meets the needs of all young adults living with type 1 diabetes. This asks for the inclusion of quantitative measures as well as routine discussions about empowerment and motivation.

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Chapter 3: Understanding young adult's meaning making in adjusting to diabetes management behaviour: Multi-methods approach

Preface to chapter 3

Findings from the previous chapters on young adult's experiences of adopting and maintaining diabetes management behaviours, prompted questions as to the kind of interactions that exist between the variables and the adopted diabetes management behaviours. This chapter attempts to draw attention to the mechanisms young adults use to construct meaning, while managing type 1 diabetes.

Distinctive themes reported in the previous chapter were: (1) the challenges experienced in developing an identity that included diabetes; (2) the emotional distress that went along with diabetes management behaviours; and (3) the experiences of the diabetes treatment plan and social support in shaping diabetes management behaviours. Previous findings also challenged assumptions of uniformity in the experiences of psychological well-being once HbA1c levels were reported in near-normal ranges. The preceding study drew attention to commonality with work done by Brierley et al. (2012), and argued that successful diabetes management should focus on individual needs and meaningful diabetes management behaviour in order to foster higher levels of treatment adherence. This is further explored and reported on in this chapter.

This chapter aimed to form a greater understanding of the meaning making process while adopting and maintaining diabetes management behaviours. Meaning was also earlier identified as a psychosocial variable affecting diabetes management behaviours. Based on findings, a definition of the meaning-making process is presented, which points to a constant challenging process. This article offers professionals, such as diabetes educators, a glance at how to engage with young adults in a different way that can stimulate readiness to growth, acceptance, and strengthen the learning and empowering process.

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4. The manuscript title should be concise and informative. The title should reflect the content and clearly state the article's aim and health relevance. Avoid abbreviations and formulae.

5. The title page should include the title of the paper, the names of all authors and their affiliations in the correct order and the corresponding author. Authors should make sure that their present/permanent address are correct. The address at which the author actually did the work must be retained as the main, affiliation address.

6. An abstract no longer than 300 words follows the title page on a separate page. The abstract should be able to stand alone and briefly state the purpose and setting of the research, the principal findings and major conclusions. It should also state the paper's contribution to knowledge. Empirical work should state the country/locations of the study. The abstract should not be structured into any subsections. Up to eight keywords or brief phrases after the abstract. The content of the article should clearly be reflected in these keywords. Avoid the use of abbreviations and acronyms.

7. All figures must have a caption. The caption should be a brief title. Text in the illustrations themselves must be kept to a minimum. All symbols and abbreviations should be explained in full.

8. Tables should be submitted as editable text and not as an image. Tables should be numbered consecutively in accordance with their appearance in the text and table notes should be placed below the table body. Data presented in tables should not be duplicated in described results or elsewhere in the article. Avoid the use of vertical rules.

9. Format the reference list using APA style: (a) begin on a new page following the text, (b) double-space, (c) use hanging indent format, (d) italicize the journal name or book title, and (e) list alphabetically by last name of first author. If a reference has a Digital Object Identifier (DOI), it must be included as the last element of the reference.

Journal Article

Kraemer, H.C. (2009). Events per person-time (incidence rate): A misleading statistic? *Statistics in Medicine*, 28, 1028-1039. doi: 10.1002/sim.3525.

Book

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

Book Chapter

Meehl, P.E. (2006). The power of qualitative thinking. In N.G. Walter, L.J. Yonce, W.M. Grove, D. Faust, & M.F. Lenzenweger (Eds.), *A Paul Meehl reader: Essays on the practice of scientific psychology* (pp. 433-444). Mahwah, NJ: Erlbaum.

10. The presentation of qualitative research (or in combination with quantitative methods) should make a compelling case for the fitness of purpose of the study and clearly identify how the study seek to understand social processes or social structures and/or illuminate subjective experiences or meaning.

11. Authors are encouraged to avoid methodological tutorials and cite appropriate references for the methodology. Describe the selection of the sample clearly, justifying the type and size of the sample and any limitations such as non-response, refusal to take part should be discussed.

12. Considerations should be towards the access process, how data were collected and recorded, who collected the data, when the data were collected and how the research was explained to participants.

13. Explain carefully how rigor in the study was strengthened and insured e.g., data analysis protocols (including how coders were trained), audit procedures, and demonstration of data saturation.

14. Describe the data analysis and how it relates to the overall approach or paradigm. The process of analysis should be as transparent as possible. Assurance of analytic rigour should be clearly stated, such as triangulation, inter-rater reliability, member and expert checking and the researcher's own position should clearly be stated.

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Human and animal research studies typically require approval by an institutional research committee that has been established to protect the welfare of human or animal subjects. Details of formal ethical approval should be stated in the main body of the paper. This information should be anonymised in the manuscript and only be given during submission.

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Abstract

Young adults' experiences of adopting and maintaining diabetes management behaviours influence the extent to which they successfully establish their identity, cope with associated emotional distress, and deal with social support, which in turn, influence their sense-making process. In order to understand the interaction between the variables, a multi-methods research approach was applied in a purposive sample (n = 6) of young adults (18 - 25 years) living with well-controlled type 1 diabetes in South Africa. Semi-structured interviews were audio-recorded, transcribed, and thematically analysed. Self-report questionnaires were used to quantify inter-relationships in thematic data.

Diabetes management behaviours were found to be compromised by the young adult's challenges towards establishing an autonomous identity, experiences of emotional distress as well as frustration pertaining to diabetes treatment plans and experience of social support received by family and friends. Seeking a new normal life style incorporating diabetes management behaviours was the most significant contributor to engage in a meaning-making process.

Keywords: young adults, diabetes management behaviours, meaning making, personal model, meaning, social support, multi-methods research

Understanding young adult's meaning making in adjusting to diabetes management behaviour: Multi-methods approach

Introduction

Young adulthood, the years from 18 to 25 are a time of dramatic change, accomplishments, and risk taking (Simpson, 2008). Every young adult faces normal development-stage challenges such as moving out of the parents' home and establishing a sense of autonomy. Among young adults living with type 1 diabetes, these challenges may be compounded by diabetes-related self-management needs (Brown et al., 2009; NICE, 2008).

Considerable research have been done on emphasising the importance of experiencing this development stage in a positive way, as to limit psychological manifestations such as anxiety, increased dependence, passivity and poor self-image (Griva, Myers, & Newman, 2000; Livneh & Antonak, 2005; Loeb, Penrod, Falkenstern, Gueldner, & Poon, 2003; Moser, van der Bruggen, Spreeuwenberg, & Widdershoven, 2008). It is argued that positive experiences during this development stage allow young adults with type 1 diabetes, to spontaneously enter into new diabetes teams, discussions on how to integrate diabetes with a new, "grown-up" lifestyle and how to integrate diabetes into their sense of self or identity (Chiang et al., 2014; Rasmussen et al., 2011; Silverstein et al., 2005). It is also well researched that young adults require support from family, friends, and physicians in order to cope and transit to healthy, productive, and diabetes-responsible individuals, taking self-care seriously (Wysocki, Buckloh, Antal, Lochrie, & Taylor, 1996).

Self-care for the advancement of well-being is a cornerstone in the management of diabetes (American Diabetes Association, 2009; WHO, 2009). Young adults living with type 1 diabetes need to make sound decisions when self-managing their condition. Diabetes management decisions need to be aligned with the recommended diabetes care plan as set out

by physicians. This is a stereotyped view, which neglects patient autonomy and is one of the major reasons that outcomes, such as adherence to the diabetes care plan and HbA1c levels are poor. A treatment plan that is not derived from a shared decision making process is doomed to failure (Segal, 2017). Research confirmed, the most recommended successful approach is one based on shared decision making and respect for patient autonomy, acceptance of the condition (including the ups and downs) and finding an individualised strategy to manage the diabetes adversities (Griva, Myers, & Newman, 2000; Livneh, & Antonak, 2005; Loeb et al., 2003; Moser, Van der Bruggen, Spreeuwenberg, & Widdershoven, 2008).

If young adults living with type 1 diabetes are expected to adhere to the diabetes care plan, they must acquire an understanding of diabetes that is flexible, co-ordinated and interconnected with every other aspect of their lives (Simpson, 2008). Research indicated an association between the young adult's perception of diabetes (identified as the personal model of diabetes), diabetes management behaviours, clinical outcomes (blood glucose levels or HbA1c), and meaning created from life events and psychological well-being (Brassai, Piko, & Steger, 2011; Hagger, & Orbell, 2003; Leventhal, Zimmerman, & Guttman, 1984; Snoek, & Skinner, 2005; Steger, & Park, 2012). Those who studied the psychological well-being of young adults living with type 1 diabetes argued that psychological well-being is corroborated by the level of social support received (Chew, Shariff-Ghazali, & Fernandez, 2014). In addition, adjustment to the demands of type 1 diabetes is argued to be better in those who are open to new information, are engaging, and use critical thinking skills in enhancing their self-efficacy (Abradio-Lanza, Vasquez, & Echverria, 2004). However, less is known about the meaning-making process and whether or not meaning is required for motivation to engage in the behaviours, and perform them to the best of their ability, as often as required.

Before one can elaborate on a meaning-making process, the concept of meaning needs further explaining. For the purpose of this study, meaning was defined as a superordinate term. Research distinguished between experiencing meaning, also called the presence of meaning, and search for meaning (Reker, Peacock, & Wong, 1987; Steger, Frazier, Oishi, & Kaler., 2006). Presence of meaning captures how much participants feel their lives have meaning. This dimension could include components referred to as comprehension and purpose (Steger, 2009; Steger et al., 2006; Steger, & Park, 2012). Comprehension is the ability to make sense of and understand one's life, including the self, the external world, and how one operates within the world (Steger, 2012). The search for meaning indicates how much participants strive to find meaning and understanding in their lives (Steger, Sheline, Merriman, & Kashdan, 2013). Literature is clear on the fact that the search for meaning dimension may also include the comprehension and purpose components as described above (Steger 2012).

Very little is known about young adults living with diabetes's experience of meaning and how it is reflected in their diabetes management behaviours (Schnell, 2009). More research is also needed that explores how perceived successes and failures in managing diabetes, impact the individual's meaning-making process (Schnell, 2009). Proulx and Inzlicht (2012) reported that people will affirm values and other aspects of meaning, such as self-worth, when they encounter challenges of their meaning framework. Such challenges may encourage individuals to affirmations leading to positive actions. But then again, the question remained whether or not affirmations lead to effective diabetes management behaviours.

Incisive research into the occurrence of meaning-making concluded that efforts of meaning-making influenced the meaning made from stressful experiences (Park, Edmondson, Fenster, & Blank, 2008). Young adults experience diabetes management behaviours as

stressful, which makes it harder to adhere to the diabetes treatment plan (American Diabetes Association, 2015). The question arises whether or not this process of managing diabetes infuses meaning into the lives of young adults living with type 1 diabetes. According to researchers, meaning-making or construction of meaning, is found not to be homogeneous and are often an unpredictable process (see American Diabetes Association, 2015; Park, Edmondson, Fenster, & Blank, 2008). In line with this argument, Steger and Park (2012) argued that meaning-making is heterogeneous and the meaning people give to events in their lives motivate the formulation of the meaning-making model. Researchers, moreover, argued that the meaning-making process by itself, can be impartially distressing and is often accompanied by increased anxiety, depression and anger, as well as reduction in overall functioning (Steger, & Park, 2012; Willemse, submitted for review).

The meaning-making process for young adults is an ongoing quest to compose their own realities in connection with their need for autonomy, belonging, connection, inclusion, relationships, and intimacy (Baxter Magolda, 2009; Kegan, 1994; Park, 2010a). Meaning-making is the renegotiation of relationships within the context of the young adult's living area. This process of renegotiating relations within context is particularly relevant to young adults living with diabetes as there is no option to undo the diagnosis. Diabetes can cause young people to lose their sense of meaning by direct exposure to the unpredictable, stressful process of managing the condition on a daily basis. These young people are also prematurely exposed to even darker sides of life and humanity, including human vulnerability, which may give rise to a sense of mistrust and a sense of shame (Gray, Maguen, & Litz, 2007; Janoff-Bulman 1989; Willemse, submitted for review).

Given the vital role that meaning-making supposedly plays in the processes of adjusting to diabetes management behaviours, discerning research into this field is essential. Willemse (submitted for review) reported that young adults experienced the following when adopting

and maintaining diabetes management behaviours: (1) identity development was challenging; (2) intense emotional distress went along with diabetes management behaviours; and (3) diverse experiences of the diabetes treatment plan and social support. In the present study, the purpose was to explore and understand the meaning-making process by investigating the mechanisms by which psychosocial variables, such as the personal model that young adults create of diabetes, social support, and diabetes management behaviours fit together in order to delineate and operationalize the meaning making process of young adults living with type 1 diabetes in South Africa.

Materials and methods

Research design

This study employed an overall qualitative, quantitative (QUAL – QUANT) research approach. This approach was embedded within an exploratory, multi-methods design. A critical realism framework with concurrent triangulation approach was chosen to form a deeper understanding of the meaning making process employed by young adults living with type 1 diabetes (Creswell, 2014; Mertens, 2009). In adopting a critical realist stance, the contribution of both scientific and objective knowledge are recognized. This implies that an individual's experiences and meanings can coexist and affect behaviours as well as wider social structures (Clark, Lissel, & Davis, 2008; Papadopoulou, Johnston, & Themessl-Huber, 2016).

Research setting

The research was conducted at the Centre for Diabetes and Endocrinology (CDE), in the Gauteng Province, South Africa. Data collection took place between October 2015 and June 2016.

Ethical considerations

Permission to carry out the study was obtained from the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2015-0156). Independent, written, informed consent were received from all participants in this study. Participation was voluntary and interviews were conducted in either Afrikaans or English, audio-recorded, and transcribed verbatim. Questionnaires were only available in English.

Participants

Purposive sampling resulted in 6 young adults participating in this study. Biographic distribution was as follows: four females (67%) and two males (33%). The average HbA1c levels at the time of the study was 7.3% (45 mmol/mol (recommended range 6.3% - 8.0%; 39 mmol/mol – 49 mmol/mol)). The mean age was 21.3 years (range 19 - 25) at the time of the study. The mean time since diagnosis of diabetes was 12 years (range 2 - 22). Out of the six participants, five (83%) were white and one (16%) was of Cape Malay decent. None of the participants reported significant co-morbidity that could have influenced their health beliefs or coping responses.

The following steps – data collection, data analysis, data validation/legitimation, and data interpretation – were interactive and cyclical steps in the multi-methods research process.

Data collection

Participants within the age range of 18 - 25 years, were invited to participate in this study. The screening of individuals took place to ensure they met the inclusion criteria. The inclusion criteria were that participants must have been diagnosed with type 1 diabetes, and experience well-controlled HbA1C levels (<8%, 64 mmol/mol). The researcher acknowledges that international diabetes bodies, and the Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) recommend that adults should have a target HbA1c of <7% (53 mmol/mol) to be considered well-controlled. This study, however, used an HbA1c level that was the average for a year, and since fluctuations in HbA1c do normally occur over a year, this level captured most candidates. Hence, it could be viewed as a valid measure of adoption and maintenance of effective diabetes behaviours. Participants also had to be fluent in English and could not suffer from any other condition that may influence their diabetes management behaviours. All potential participants that were approached, agreed to participate and provided written, informed consent. There were no refusals to participate or any drop-outs once research began.

The qualitative data were collected through face-to-face, semi-structured interviews conducted at the CDE. A flexible interview schedule was compiled, covering the basic contribution themes to be enclosed (Costa, Breda, Pinho, Bakas, & Durao, 2016). Interview questions and or prompts, such as (1) *Explain how your life changed after being diagnosed with diabetes*; (2) *How do you manage your diabetes?*; (3) *How does your understanding of diabetes influence your management of the condition?*; (4) *Explain how social support influence your management behaviour* and (5) *How do you make meaning of your diabetes management behaviours?* were used during the interviews. A brief, verbal summary of the project was given prior to obtaining the written informed consent. Permission to audiotape each interview was obtained individually and was used as the opportunity to establish

positive rapport with the participant. For the purpose of this study, questionnaires covering the psychosocial variables in questions were incorporated. The questionnaires included were:

Biographical questionnaire: Information gathered through this questionnaire included socio-demographic questions such as gender, age, and time since diagnoses. Data on HbA1c concentrations were retrieved from the participant's medical records at the CDE after informed consent was obtained from the participant.

The Diabetes Self-Management Profile – Self report (DSMP-SR) (Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2011): This 24-item self-report instrument (not divided into subscales) quantifies diabetes self-care management behaviours over the preceding three months. The question-format changes throughout the instrument and participants indicate the most applicable answer to each question. Item examples are: (1) *If you think you are having a low blood sugar, how often do you check your blood sugar before treating?*; (2) *In the past 3 months, before you ate more than usual, did you make any insulin changes?*; (3) *In the past 3 months, if you had two blood sugar results above 13 in a row, how often did you do a ketone test?* The DSMP-SR reported a Cronbach alpha coefficient of 0.82 (Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2011, 2012).

The Pemberton Happiness Index (PHI) (Hervas, & Vazquez, 2013): The PHI produces a combined index of an individual's well-being that is the sum of different subscales. Subscales include 11 items on remembered well-being (general, meaning, psychological well-being, and social well-being) and 10 items on experienced well-being (i.e. positive and negative emotional events that have possibly taken place the day before). Each item is rated on a 10-point Likert scale from 0 (fully disagree) to 10 (fully agree). Examples of items on remembered well-being are: (1) *I am very satisfied with my life*; (2) *I enjoy a lot of little things every day*; and (3) *I have a lot of bad moments in my daily life*. Experienced well-being items are: (1) *Something I did made me proud*; (2) *I gave myself a treat*; and (3) *I*

was bored for a lot of the time. The PHI reported a Cronbach alpha coefficient of 0.82-0.83 (Hervas, & Vazquez, 2013).

The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002):

This 70-item, self-report instrument identifies the five subscales within the representation of an illness. These subscales are: (1) identity – describes 14 symptoms associated with the illness. Participants decide whether or not they have experienced those symptoms and if they perceived those symptoms to be related to their illness. The participants respond by either circling “yes” or “no” to each question. Examples of symptoms are; pain; sore throat; fatigue and sleep difficulties; (2) consequences – the expected long and short term outcome of the illness; (3) causes – ideas on how the illness was contracted or what caused the illness; (4) timeline – beliefs concerning how long the illness will last; and (5) cure and control – beliefs on whether or not the individual can recover from or manage the condition (Lau, & Hartman, 1983; Leventhal, Nerenz, & Steele, 1984). Responses to the other four subscales are on a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Examples of items are: (1) *My diabetes will last a short time*; (2) *My treatment can control my diabetes*; (3) *I do not understand my diabetes*; (4) *I get depressed when I think about my diabetes*; and (5) *My diabetes may have been caused by chance or bad luck*. The IPQ-R reported a Cronbach alpha coefficient of 0.75-0.89 for the IPQ-R complete scale (Moss-Morris et al., 2002).

The Meaning in Life Questionnaire (MLQ) (Steger, Frazier, Oishi, & Kaler, 2006):

This instrument consists of 10 items on a 7-point Likert scale ranging from 1 (absolutely untrue) to 7 (absolutely true). It is divided into two subscales, namely: (1) presence of meaning; and (2) search for meaning. Items on the presence of meaning subscale are concerned with the degree to which the individual feels that his/her life already has some source of meaning (e.g. (1) *I understand my life's meaning*; and (2) *My life has a clear sense*

of purpose). The search for meaning subscale examines the extent to which an individual is searching for meaning in his/her life (e.g. (1) *I am always looking to find my life's purpose*; and (2) *I am searching for meaning in my life*). Steger (2010) reported that there were no formal cut-off scores to determine what constitutes a high score or a low score on the MLQ.

The Modified Diabetes Social Support Questionnaire (M-DSSQ) (Malik, & Koot, 2011): This instrument includes two subsections, namely, support from family (58 items) and support from friends (28 items) on a 5-point Likert scale ranging from 0 (*never*) to 5 (*at least once a day*). Participants also complete a subscale on how he/she feels about the support behaviour mentioned in each item, also on a 5-point Likert scale ranging from 1 (*unhelpful or not supportive*) to 3 (*very supportive*). The family support subscale consists of five subscales, namely, (1) guidance and supervision; (2) encouragement of self-care and exercise; (3) support in critical situations; (4) nourishment; and (5) emotional support. The friends-support subscale consists of five subscales, namely, (1) guidance and encouragement; (2) help in critical situations; (3) nourishment; (4) empathy; and (5) help in exercise. Examples of items are: (1) *Give you insulin*; (2) *Nag you until you do your testing*; (3) *Do the grocery shopping for your meals*; (4) *Remind you to exercise*; and (5) *Give you things to read on diabetes care*. Both the M-DSSQ-family and M-DSSQ-friends reported Cronbach alpha coefficients of 0.76-0.92 (Malik, & Koot, 2011, 2012).

Data analysis

For the purpose of this study, the qualitative and quantitative data were combined and data integration took place. A coherent whole, i.e. meta-inference, (Tashakkori, & Teddlie, 2003) was formed (Leech, & Onwuegbuzie, 2010).

Every interview was read thoroughly, transcribed, and a thematic analysis was conducted according to guidelines published by Braun and Clarke (2006, 2014). The transcripts were

entered in ATLAS.ti™ software (Version 7) and the analysis was iterative throughout, allowing for the emergence of patterns in the data (Braun, Clarke, & Rance, 2014; Leedy, & Ormrod, 2005). Patterns in the interviews were coded, compared and contrasted between and within interview transcripts, using constant comparative methods (Corbin, & Strauss, 1988). Interview codes were organised into themes reflecting the research question. No new contributing themes emerged after interview 3, therefore, data saturation had taken place.

All transcripts were coded by the researcher and a co-coder, an independent third party with outstanding subject knowledge, as well as a panel of experts in the field of diabetes. This ensured reliability of the study (Braun, & Clarke, 2006; Braun, Clarke, & Rance, 2014). Emergent contributions were compared and discussed between coders at regular meetings until consensus on key issues was reached. A qualitative data analysis software package (ATLAS ti™ version 7), was used to facilitate data coding and ease the retrieval of data.

For the purpose of this study, the questionnaires were hand-scored by the researcher. The results of the quantitative data were used to verify and enhance findings emerging from the qualitative data. Integration of the qualitative data with the quantitative data took place during the interpretation phase of the study (Creswell, 2014).

Rigor

Throughout this study, attention was given to ensure rigorous research was done. During the qualitative stage, the evidence-based guidelines for rigor in multi-methods research by Onwuegbuzie and Corrigan (2014) was followed. These guidelines included: (1) the research formulation stage – it was clearly stipulated in both the conduct and reporting how the different research components interacted with each other; (2) the research planning stage – the sampling design and overall research design have been comprehensively accounted for;

(3) the research implementation stage – the data collection, data analysis, data legitimisation, and interpretation generated by the researcher fit the data well; and (4) the research dissemination stage – during the course of the study, discussions with knowledgeable colleagues were conducted in order to ensure credibility of findings, and sensitivity was communicated pertaining to the participant's realities and the negotiated realities. Regardless of the specific tool or research method used, the key was to provide the reader with a clear audit trail, as well as well-considered and justified rationales for the decisions made throughout the research process (Lavelle, Vuk, & Barber, 2013).

Furthermore, trustworthiness of the research findings were improved by using Creswell's (2014) concurrent triangulation strategy. Through mixing qualitative and quantitative data, the aim of the study was achieved in that a deeper understanding of the meaning-making process in adjusting to diabetes management behaviours of young adults living with type 1 diabetes were formed (Nieuwenhuis, 2007).

Results

This study was conducted to gain a better understanding of young adult's meaning-making process of adjusting to diabetes management behaviours by examining mechanisms, which emanated from a study done by Willemse (submitted for review). The significant shaping of diabetes management behaviours via the personal model of diabetes, meaning, and social support crystallised through the participants' recollection of experiences and perceptions. Relevant vignettes from interviews and questionnaires were offered to support the concepts. Statement pieces used by participants that preferred to be interviewed in Afrikaans, were translated into English for the purpose of this discussion.

Participants reported experiences that centered on the age-appropriate challenges of establishing their own identity, autonomy, and effective self-management. Participants' personal identity was not equal to the condition, YA2 (male, 19 years of age, European, 6 years since diagnosis) said, "*I am not just diabetes*". Participants were very aware of the impact that living with diabetes had on their lives, especially regarding their autonomy and self-management as YA6 (male, 24 years of age, European, 10 years since diagnosis) realized, "*I had to take responsibility for myself*". In this study, as with others (Monaghan, Helgeson, & Wiebe, 2015) it was found that young adults were navigating various challenges on their path towards adulthood including assuming increased responsibility for their diabetes self-management.

The participants in this study maintained an average HbA1c level of 7.3% (45 mmol/mol), which could be categorised in the near-normal range for blood glucose levels. Achieving these levels were seen as part of their responsibility as, "*that is where it's supposed to be*" (YA3, female, 19 years of age, Cape Malayan, 6 years since diagnosis). Achieving blood glucose levels within the near normal range also filled them with a sense of pride as YA1 (female, 20 years of age, European, 2 years since diagnosis) commented, "*you are feeling pretty proud when your HbA1c is under seven*". Feelings of control and personal mastery over the diabetes care plan, as well as correct interpretation of their diabetes symptoms indicated enhanced self-management behaviours, according to the study done by Keogh et al. (2011). Thus, identity was influenced through diabetes management behaviours; whenever they interpreted it correctly, it could be seen as positive interaction, which led to feelings of mastery and control. These results corresponded with the IPQ's personal control subscale where 60% of the participants indicated that they believed in their own ability to manage the condition and take responsibility for their self-management behaviours, as YA6 (male, 24 years of age, European, 10 years since diagnosis) said, "*the more I understand it*

[diabetes], the more I can tweak my lifestyle”. This finding was in accordance with findings reported by other researchers (Davies et al., 2008; Hagger, & Orbell, 2003; Keogh et al., 2011; Rassart et al., 2015) who argued that the score on the IPQ-R’s personal control subscale and blood glucose control levels of an individual were significantly positively related.

Participants were clear that diabetes was an unpredictable, lifelong experiment and that they have to take responsibility for the management thereof. Participants experienced the diabetes management behaviours as their new reality and, *“just something I had to do”* (YA3, female, 19 years of age, Cape Malayan, 6 years since diagnosis). In spite of continual progression in the understanding of self-management behaviours, the participants still experienced the unpredictability of the condition, as YA1 (female, 20 years of age, European, 2 years since diagnosis) said, *“no day is the same”* and *“you take it one day at a time”* (YA2, male, 19 years of age, European, 6 years since diagnosis). In research done by Willemse (submitted for review) it was found that young adults experienced diabetes management behaviours as being a never-ending experiment and it was undeniably also experienced as such by participants in this study, *“I think I’m still trying to figure it out”* (YA1, female, 20 years of age, European, 2 years since diagnosis). The quantitative data supported that the participants believed their diabetes to be unpredictable, 60% indicated higher scores on the cyclical and timeline subscales of the IPQ-R. These results were expected as diabetes is a lifelong, unpredictable condition, as was concluded by various previous studies (Davies et al., 2008; French, 2008; Glasgow et al., 1997; Mc Sharry et al., 2011).

Despite maintaining near-normal blood glucose levels, the findings of this study strengthened arguments that young adults were poor at adhering to the diabetes treatment plan, as YA1 (female, 20 years of age, European, 2 years since diagnosis) remarked, *“of course there will be times where I say screw it”*. This inclination to poor adherence was shown by results on the DSMP-SR, where 80% of the participants obtained low scores,

which in turn, were indicative of poor treatment adherence. In addition, all participants scored very low on the IPQ-R's treatment control subscale, which indicated that they believed that their diabetes treatment plan and accompanied self-management behaviours would not control the condition. This could be resultant of a generic diabetes treatment plan that was structured without the incorporation of individual needs and experiences, hence poorer adherence. Previous research concluded that the treatment control subscale gave an indication of the adherence ability of the individual – higher scores on the treatment control subscale would transpire in better adherence and glucose control (Hagger, & Orbell, 2003; Harvey, 2009; Keogh, 2011).

The discrepancy between the participants' beliefs about personal control and treatment control led them to experience internal conflict and emotional distress. The additional responsibility of successfully managing diabetes, contributed to increased negative perceptions of the condition, "*there's no reward, nothing*" (YA1, female, 20 years of age, European, 2 years since diagnosis), and YA2 (male, 19 years of age, European, 6 years since diagnosis) remarked, "*and that's the way you go on*". All participants agreed that, "*it's a full time job, you don't ever stop thinking about it....no break, and no vacation*" (YA 1, female, 20 years of age, European, 2 years since diagnosis). Participant YA6 (male, 24 years of age, European, 10 years since diagnosis) stated "*if I was hungry I'd sometimes just avoid eating because I didn't want to mess up the glucose*" and "*I find myself going what if I am doing something wrong now that I'm gonna look back on and regret?*" (YA1, female, 20 years of age, European, 2 years since diagnosis). In this study, 60% of the participants reported experiencing negative emotions in relation to diabetes management behaviours (according to the IPQ-R emotional representation subscale). The experience of negative emotions were also evident in the PHI scores that indicated 60% of the participants did not experience present-day happiness.

The emotional distress influences adherence to the diabetes care plan. This could be summed up by the words of YA4 (female, 24 years of age, European, 22 years since diagnosis), *“even with that [diabetes management] I took chances, experimenting, trying everything and not injecting for it, resulting in me suffering the consequences for always”* and *“it is so frustrating to know your sugar will be jumping around and you can do nothing”* (YA2, male, 19 years of age, European, 6 years since diagnosis) even said, *“the management plan doesn’t work out all the time, kind of frustrating”* (YA3, female, 19 years of age, Cape Malayan, 6 years since diagnosis). Participants especially experienced frustration regarding meal plans and food choices as YA1 (female, 20 years of age, European, 2 years since diagnosis) stated, *“my mom would be like, why did you eat that and I’m like but I was low. Then she’s like, you should tell me first”* and *“healthy food choices were not a simple task”* (YA2, male, 19 years of age, European, 6 years since diagnosis) as well as *“my lifestyle was very healthy but it was still a huge flip, it’s so frustrating, annoying”* (YA1, female, 20 years of age, European, 2 years since diagnosis).

The elevated levels of distress and frustration pertaining to meal plans were further linked to the participant’s experience of support from family and friends, *“but no one understands ...it can get like upsetting”* (YA1, female, 20 years of age, European, 2 years since diagnosis) and *“I was tired and frustrated with my mom constantly taking over”* (YA4, female, 24 years of age, European, 22 years since diagnosis). This was supported by the DSSQ, which indicated that majority of the participants felt frustrated with others trying to control their meal plan adherence. In addition, the qualitative and quantitative results contradicted each other with regard to social support. All participants stated that they needed support, *“obviously you need support”* (YA1, female, 20 years of age, European, 2 years since diagnosis) and *“it definitely helped a lot”* (YA6, male, 24 years of age, European, 10 years since diagnosis), while the results from the DSSQ reflected that 100% of participants

experienced low levels of support from their families and 60% reported low support levels from their friends. These findings contrasted research that found good social support correlated positively with effective diabetes management behaviours, which in turn, resulted in blood glucose levels remaining at near-normal levels (Gallant, 2003; Kaplan, & Hartwell, 1987; Levy, 1983; Rosland et al., 2008; Schiotz et al., 2011).

Participants also experienced emotional distress regarding the consequences of not adhering to the diabetes treatment plan, as YA6 (male, 24 years of age, European, 10 years since diagnosis) said, “*it freaked me out*”, but a quote from YA3 (female, 19 years of age, Cape Malayan, 6 years since diagnosis) was testament of the distress the young adults experience, “*knowing about all the things that can happen if I don’t manage it, is a huge thing*” as well as “*I don’t want to go down that route, but I want to enjoy my life*” (YA4, female, 24 years of age, European, 22 years since diagnosis). According to the IPQ-R’s consequence sub-scale, 80% of the participants experienced emotional distress connected with the consequences of not adhering to the diabetes treatment plan. This study supported work done by DiMatteo (2004), Hagger and Orbell (2003), Kravitz et al. (1993), and Rapoff (2010) who argued that young adults were well-known for their non-adherence behaviours and poor self-management of type 1 diabetes, which will result in serious consequences for the individual.

The following clearly shows the interaction of identity, negative emotions, and meaning. Poorly managed blood glucose levels prevented participants from accomplishing their dreams and aspirations, which led to the experience of disappointment, “*I am competitive and I know I’m not performing to what I can*” (YA1, female, 20 years of age, European, 2 years since diagnosis) and “*I want healthy kids and for that I must manage it a certain way*” (YA3, female, 19 years of age, Cape Malayan, 6 years since diagnosis). This conflict permeated every facet of their lives, to the point where participants actually felt fearful that their

children “*will suffer and that scares me*” (YA3, female, 19 years of age, Cape Malayan, 6 years since diagnosis). By not being able to execute their expectations for the future, participants reported the experience of internal conflict (Willemse, submitted for review) that manifested in experiences of unhappiness and perceived lower quality of life.

Adhering to a diabetes care plan was driven by diverse motivations such as a longing to be like everyone else, “*I want to be the same as everyone else*” (YA6, male, 24 years of age, European, 10 years since diagnosis) and “*all you want is to experience a normal sort of life style*” (YA1, female, 20 years of age, European, 2 years since diagnosis). A ‘new’ normal was sought after by all participants. Yet, the longing for normality came with an emotional package, as YA3 (female, 19 years of age, Cape Malayan, 6 years since diagnosis) said, “*I am like not emotionally strong enough to deal with it (management of diabetes)*”. This longing experienced by the participants was reflected in the MLQ scores where 58% of the participants indicated that they were actively searching to find meaning in their lives. Thus, participants were actively searching to make sense of the world as viewed through the diabetes lens. This search incorporated participants’ desire to find the value and significance of their lives, as well as the purpose of their lives, “*it has become more difficult*” (YA3, female, 19 years of age, Cape Malayan, 6 years since diagnosis). The high search-for-meaning score could also be linked to the participants’ wish for their environment to be structured and predictable amidst the unpredictable nature of diabetes; participants searched to understand their ‘new normal’ with type 1 diabetes.

Conclusion

In this study, diabetes management behaviours were described as experiences that confronted the young adults with considerable adjustment difficulties. This study highlighted

important relations between variables such as the negative emotions that were the result of the identity challenges and restricted food choices. Despite having to adhere to the complex and ever changing diabetes management requirements, the young adults employed different processes to make sense of their world and their diabetes experiences (Park, 2010b).

It could be argued that the relation between the search for meaning and the meaning-making process resulted in the creation of a new normal way of living with type 1 diabetes. Meaning-making involved changing the way of understanding one's own identity. Through the process of developing autonomy and responsibility, the young adults found it difficult to uphold a sense of happiness and psychological well-being. This development process resulted in non-adherence to the prescribed diabetes treatment plan. In addition, the young adults spoke of experiencing their diabetes management behaviours as a never ending experiment of trial-and-error. A constant search for meaning, and more specifically, finding the new sense of comprehension, would increase their sense of meaning in life (Park, 2010a).

The research further suggested that the non-adherence behaviours enhanced internal conflict in the young adults resulting in experiences of emotional distress. As evidenced in the study, the participants made conscious and deliberate efforts to cope with the diabetes management behaviours and the distress associated with following the challenging meal plans. Participants had to cope with frustration provoking incidents of social support by renegotiating relations that added to their experiences of emotional distress. Hence, in these situations, social support were not contributing to successful diabetes management behaviours for the young adults living with type 1 diabetes.

It could be argued that diabetes created a state of difference within the mind of the young adult as the envisaged future plans and ideas now seemed unreachable and effective diabetes management behaviours had to be initiated to find a new state of consistency.

Participants' yearning for living a "normal" life, a life where they do not need to worry about injections and eating plans, were found to be the motivating factor behind their constant efforts to manage the condition effectively, and this process infused their lives with meaning. Through application and adherence to diabetes management behaviours, with the help of trial and error learning, young adults managed to achieve a good level of diabetes control.

Limitations and recommendations

The current study was only able to provide a snapshot of young adults living with type 1 diabetes and the processes used to overcome challenges to accommodate the condition and the accompanying management behaviours. This study consisted primarily of women (n = 4); including more men in additional studies is necessary to better understand meaning-making processes. The small sample may limit the transferability of findings. The majority of citizens in South Africa are African and this study had no representatives from this majority population group. All participants were from a more affluent part in South Africa, reporting near-normal HbA1c; including more people with different backgrounds and HbA1c levels could produce different narratives and, therefore, different findings. The study also did not discriminate between well-controlled and uncontrolled diabetes, which could have important implications for the meaning-making processes employed.

An implication for practice could be that participants needed their autonomy to be preserved through the process of establishing their identity. Young adults want to be included in the decision making process regarding their diabetes management treatment plan. Shared decision making should result in a diabetes treatment plan that meets the goals of both the physician and the individual. Because this is a shared process, the resultant plan should have been carefully constructed so that the individual is able and willing to execute it – i.e. adhere

to it. This is in contrast to compliance where a physician dictates a diabetes treatment plan that the individual has not fully participated in content or design, and therefore, may not be capable or willing to execute it, leading to non-compliance. Interventions are needed that aim to enhance young adults' capability of managing various cognitive and emotional challenges of diabetes and increase their adherence. Further research is warranted to understand the meaning-making processes employed towards psychological well-being of individuals.

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Chapter 4: Diabetes management behaviours and meaning-making: The young adult's sense making process of living with type 1 diabetes

Preface to chapter 4

This chapter explores the meaning making process displayed by young adults living with type 1 diabetes. Notwithstanding the fact that all participants reported well-controlled blood glucose levels, the motivational factors as well as the meaning-making process resulting from the self-management of their diabetes, differs significantly. Brierley et al. (2012) argued that successful diabetes management should focus on the individual's levels of need in order to foster higher levels of treatment adherence.

The subsequent article aimed to put forth a framework that would encapsulate the meaning-making process for young adults living with type 1 diabetes. Hence, this article reported on a case study that explored and created a greater understanding as to how psychosocial variables fit together to establish not only effective diabetes management behaviours, but a meaning-making process that would contribute to the young adult's psychological well-being. This article offers professionals, such as diabetes educators, a glance at how to engage with young adults in a different way and, as such, reinforce the learning and empowering process.

Prepared for submission to the Journal of Behavioral Medicine

Guidelines for authors: *Journal of Behavioral Medicine*

Target journal and guidelines for authors

The third article will be submitted to *Journal of Behavioral Medicine* for publication. This article and reference list has been styled according to this journal's specifications. *Journal of Behavioral Medicine* provides a platform where committed professionals share and promote better patient care by expanding on the needs of all patients living with diabetes. The following is a copy of the guidelines for prospective authors as set out by the journal.

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2. Different types of contributions are accepted for this interdisciplinary journal. Articles devoted to furthering our understanding of physical health and illness through the knowledge and techniques of behavioral science in the following categories: (1) Psychology, (2) Psychiatry, (3) Sociology, (4) Epidemiology and (5) Public health to name but a few.

Types of submissions considered are regular articles, brief reports and letters to the editor..

3. Articles submitted to the *Journal of Behavioral Medicine* should be written according to recommendations of the Publication Manual of the American Psychological Association, 6th Edition (2009). Manuscripts are formatted using letter or A4 page size, 1 Inch (2.54 cm) margins on all sides, Times New Roman 12 point font, and double-spacing for text, tables, figures, and references.

4. The manuscript title should be concise and informative. The title should reflect the content and clearly state the article's aim and health relevance. Avoid abbreviations and formulae.
5. The title page should include the title of the paper, the names of all authors and their affiliations in the correct order and the corresponding author. Authors should make sure that their present/permanent address are correct. The address at which the author actually did the work must be retained as the main, affiliation address. This page should also include the full title as well as a short running title.
6. An abstract no longer than 150 words should be provided. The abstract should be able to stand alone and be concise, without reference citations, and written for a general journal readership. A list of 5-6 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript.
7. List the references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. In a slight departure from APA format, where there are three or more authors, only the first author's name is given in the text, followed by et al. References should include titles of papers and follow APA format in all other respects.
8. The *Journal of Behavioral Medicine* does not impose a strict page limit, however, it is strongly suggested that manuscripts be no more than 25-30 double-spaced pages, including all figures, captions, tables, notes and references.

9. Statement of ethical standards: all work submitted to the *Journal of Behavioral Medicine* must conform to applicable governmental regulations and discipline-appropriate ethical standards. Responsibility for meeting these requirements rests with all authors. Human and animal research studies typically require approval by an institutional research committee that has been established to protect the welfare of human or animal subjects. Details of formal ethical approval should be stated in the main body of the paper. This information should be anonymised in the manuscript and only be given during submission.

10. Submission is a representation that the manuscript has not been published previously and is not currently under consideration for publication elsewhere. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to APA will be required before the manuscript can be accepted for publication.

11. Pre-Submission English-Language Editing: Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English.

12. The *Journal of Behavioral Medicine* is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPEE guidelines on how to deal with potential acts of misconduct. More information at <http://www.springer.com/medicine/journal/10865>.

Abstract

This study aims to explore and develop a conceptual framework that encapsulates the meaning-making process of a young adult living with type 1 diabetes. A case study with multiple embedded units of analysis was applied. Data was collected from a 25 year old participant through a mixed-method approach, consisting of a semi-structured interview and questionnaires. A conceptual model based on the meaning-making model of Park (2010) was used and translated well with the meaning-making model of the young adult. Meaning-making is a dynamic process and findings support this approach. Young adults' diabetes education should highlight the importance of persistence with the diabetes management behaviours and making meaning of diverse life events in order to live successfully with diabetes. Young adults should be empowered to follow a personalised diabetes care plan, which may lead to improvement in diabetes outcomes, meaning made, and psychological well-being.

Key words: young adults, diabetes management behaviours, meaning, meaning-making, case study

Diabetes management behaviours and meaning-making: The young adult's sense making process of living with type 1 diabetes

Psychological well-being and achieving satisfactory medical outcomes involve adoption, adherence to and persistence with diabetes management behaviours (Adams, 2010; Cuff, & Vaneslow, 2004; Wardian, & Sun, 2014; Watts et al., 2010; Young-Hyman et al., 2016). The integration of these complex self-management behaviours is causing distress (Willemse, submitted for review) as young adults navigate through a developmental stage with increased challenges such as financial responsibilities, changes in health care and access to medical care, changing relationships, job seeking, studying, and assuming increasing responsibility for their diabetes self-management (Arnett, 2000; Chaing et al., 2014; Monaghan et al., 2015; Munsey, 2009; Rasmussen et al., 2011; Sparud-Lundin et al., 2009). Prevailing diabetes treatment research support the notion that individual-centered diabetes treatment plans should be respectful of and responsive to individual preferences, needs, and values (Institute of Medicine, 2001; Young-Hyman et al., 2016). Establishing these personalised diabetes care plans require dialogue and interactions that take the context of the young adult into account (Institute of Medicine, 2001).

The utilization of an understanding of health behaviours to modify diabetes care plans includes the understanding of personal meaning-making pathways (Husserl, 1970; Merleau-Ponty, 1967). People can never escape meaning-making and for the young adult with type 1 diabetes, every word spoken, every management behaviour, every habit and every experience informs the creation of meaning (Dahlberg & Dahlberg, 2004; Merleau-Ponty, 1967).

According to Frankl (1946), the primary purpose of life is the quest to find meaning. Meaning is found in every moment of living and focus on future goals enhances purposeful behaviour. Therefore, meaning is the mental representation that allows the human being to

understand experiences (Proulx, & Inzlicht, 2012). Meaning and purpose is sometimes used interchangeably, but Steger (2012) suggests that meaning is superordinate consisting of two dimensions, i. e. presence of meaning that captures how much people perceive their lives to have meaning and purpose and the search for meaning indicates how much a person strives to find meaning and understanding in their lives (Steger, 2009; Steger et al., 2006; Steger et al., 2013; Steger, & Park, 2012).

For the purpose of this study, meaning was thus conceptualised in terms of the above mentioned theory as the presence of meaning and search for meaning (Reker et al., 1987; Steger et al., 2006). Searching for meaning implies the individual is actively searching for explanations, for understanding, or for life to make sense (Steger 2012; Steger et al., 2008). This conceptualisation of meaning allows for the young adult to judge behaviours as significant attributors to their life events in relation to the larger understanding of their world. At its core, meaning allows for a person to make sense of perceptions and experiences by creating expected relationships (Proulx, & Inzlicht, 2012) and processes (Steger, & Park, 2012).

The meaning-making process (figure 3) used in this study postulates that meaning has two core aspects, namely: (1) *Global meaning* – an overarching system of personal beliefs, goals, and motivation for living that serve as structure to a person's life. Global meaning informs the meaning attached to everyday events as well as stressful events. Through global meaning, the individual gains a better understanding of himself and directs all behaviour accordingly (e.g. Steger, 2009; Steger et al., 2006); and (2) *Situational meaning* – the meaning appraised to a specific occurrence or event (Park, 2010; Steger, & Park, 2012). Whenever the appraised meaning is compared to the global meaning, and it is found to be different, stress results (Janoff-Bulman, 1992; Koss, & Figueredo, 2004). So, meaning-making refers to the interaction of global meaning with a specific event in one's life (Steger,

& Park, 2012). People need to have a sense of meaning and any violations of their meaning causes distress (Proulx, & Heine, 2010). This increased anxiety results in lower levels of functioning (Steger, & Park, 2010). The experience of distress initiates the meaning-making process (Park et al., 2012). The meaning-making process incorporates potentially adaptive outcomes or products. Meanings made are end results or changes derived from attempts to reduce discrepancies between appraised and global meaning (Park, 2010; Park, Edmondson, Fenster, & Blank, 2008). According to Park (2010), many different meanings can be made, such as (1) *a sense of “having made sense”* – where the individual would indicate variations in understanding of the event; (2) *acceptance* – coming to terms with the event that has taken place; (3) *causal understanding* – attributions towards understanding the cause of the event; (4) *perceptions of growth* – could be reported as anything from positive life changes, such as improved relationships and coping skills to greater appreciation for life; (5) *changed global beliefs and goals* – these types of changes can result in identifying beliefs and goals that are not attainable and abandoning them or substituting it for alternatives and (6) *sense of meaning in life* – people may experience reduction or increases in their sense of meaning in life.

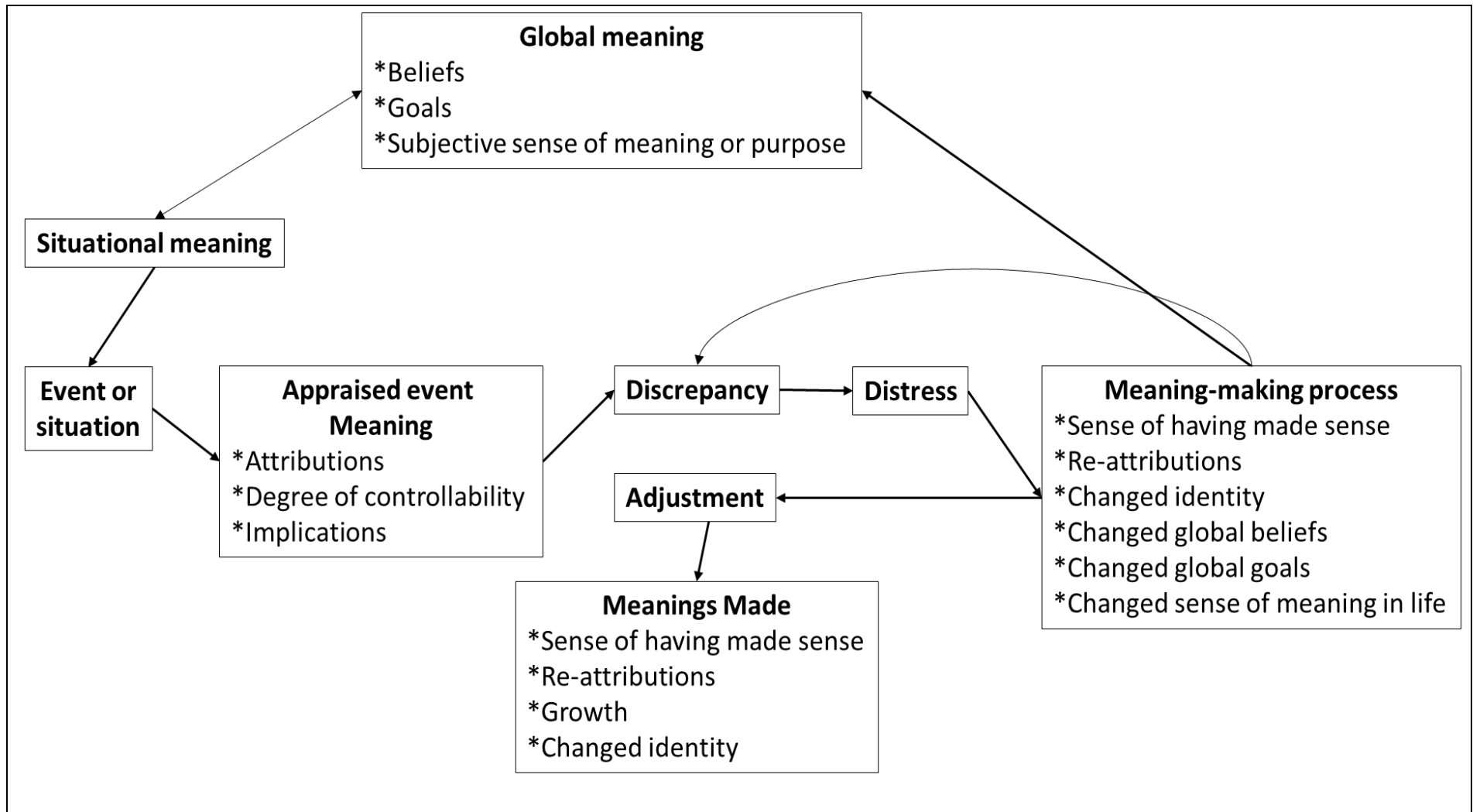


FIGURE 3: THE MEANING-MAKING MODEL (ADAPTED FROM PARK, 2010)

Insight into the meaning-making process is particularly relevant for people living with diabetes because it is not an option to undo the diagnosis. Diabetes can cause the young adult to lose their previous global sense of meaning (their goals and where they see themselves in the world) by exposing them to the unpredictable nature of the condition, including their own human vulnerability. The meaning-making process call for the individual to make constant changes to perceptions of themselves, their goals, their world, their sense of meaning, and their relationship with diabetes, to name but a few (Park, 2010).

The young adult living with type 1 diabetes was found to be neglected, as research focus (Monaghan, 2015), and this case study aims to gain an in depth understanding of the young adult on his journey of making sense of living with type 1 diabetes. By considering the meaning-making process as an important adjustment process to living well with diabetes, this study will also explore the experiences of the complex diabetes management behaviours as reported by a young adult. In order to create awareness of this highly personalised meaning-making process, this study focuses on a young individual who is currently living well with type 1 diabetes. No studies could be found that examined the relationship between global and situational meanings from the young adult's context and the resultant meanings made. By understanding the young adult's context, the researcher was able to interpret, analyse, and describe the meaning-making process of young adults living with type 1 diabetes in a holistic fashion, but at the same time, acknowledges the singularity and uniqueness of the process.

Methodology

Research design

The study was conducted from a qualitative, quantitative (QUAL – QUANT) research approach, embedded within a multi-methods design. A critical realism framework with concurrent triangulation approach was chosen to form a deeper understanding of the meaning making process employed by this young adult living with well-controlled type 1 diabetes (Creswell, 2014; Mertens, 2009). In adopting a critical realist stance, the contribution of both scientific and objective knowledge are documented. This implies that an individual's experiences and meanings can coexist and affect behaviours as well as wider social structures (Clark, Lissel, & Davis, 2008; Papadopoulou, Johnston, & Themessl-Huber, 2016). Furthermore, the case study design placed the researcher in the everyday context of the young adult living with well-controlled type 1 diabetes.

Participant information

Clive, a 25 year-old white male was diagnosed with type 1 diabetes in November, 2009 at the age of 18 years and has no diabetes-related physical problems. At the time of the study, he was on a multiple injection regimen, consisting of one long-acting and three short-acting insulin injections per day. It has been 7 years since his diagnosis and Clive maintained an average blood glucose level of 6.3, which placed him well within the range of near-normal and well-controlled. Clive lived in a rural area and limited his endocrinology appointments to the minimum as specialized diabetes care was not easily accessible to him.

Clive was unmarried at the time of the study and lived alone. He spent most of his weekends on adventure trips with his friends and called himself “*a real adventurous junky*”. Clive graduated as a mechanical engineer and described himself as a typical engineer “*who*

loves to measure because that's the only way to know". At the time of the study, Clive was employed as a mechanical drawing expert at a highly competitive aircraft manufacturing operation.

Although he was hesitant to openly discuss his personalised diabetes care plan at first, he later became comfortable relating his diabetes management experiences and frequently stated that, *"a cure to this thing should have been discovered a long time ago"*. Clive also mentioned that he did not really explain the condition to his colleagues as they were engineers and *"no-one here even thinks about it, less cares about it"*.

Materials and procedure

The participant was within the age range of 18 - 25 years and was invited to participate in this research study. Screening of the individual took place to ensure he met the inclusion criteria. The inclusion criteria applicable to this study were: the participant must have been diagnosed with type 1 diabetes, have well-controlled HbA1C levels (<8%), be fluent in English, and did not suffer from any other condition that may influence his diabetes management behaviours. The individual agreed to participate after a brief summary of the research project was given and then provided written, informed consent. Permission to audiotape the interview was obtained and this also assisted in establishing positive rapport with the participant. Efforts were made to ensure that the tone and feel of the interaction remained informal and conversational.

The qualitative data were collected through a face-to-face, semi-structured interview. Following a thorough review of the relevant literature (Park, 2010; Steger, 2012; Steger, & Park, 2012) and previous work done by the researcher (Willemse, submitted for review), an interview schedule was devised. This interview schedule included questions related to the following: (1) the diagnosis with diabetes to gain a better understanding of the situational

meaning; (2) the experiences of diabetes management behaviours to gain a better understanding of the appraised meaning and adjustment (including questions on the participant's perception on how his life changed once he was diagnosed with diabetes and the implementation of the diabetes management behaviours into his daily schedule); (3) emotions experienced to gain a better understanding of the experience of distress and discrepancy (including questions on how his feelings and thinking changed since the diagnosis, which focused on his specific feelings and thinking with regard to his diabetes treatment plan e.g. feelings towards the restrictive dietary plan and social support); (4) reflection to gain a better understanding of the global meaning and meaning-making process (inclusive were questions related to his experiences of living with type 1 diabetes and the sense made from managing the condition).

In addition, the participant completed the following questionnaires:

The Pemberton Happiness Index (PHI) (Hervas, & Vazquez, 2013): The PHI produces a combined index of an individual's well-being that is the sum of different subscales. Subscales include 11 items on remembered well-being (general, meaning, psychological well-being, and social well-being) and 10 items on experienced well-being (i.e. positive and negative emotional events that have possibly taken place the day before). Each item is rated on a 10-point Likert scale from 0 (fully disagree) to 10 (fully agree). Examples of items on remembered well-being are: (1) *I am very satisfied with my life*; (2) *I enjoy a lot of little things every day*; (3) *I have a lot of bad moments in my daily life*. Experienced well-being items are: (1) *Something I did made me proud*; (2) *I gave myself a treat*; (3) *I was bored for a lot of the time*. The PHI reported a Cronbach alpha coefficient of 0.82-.0.83 (Hervas, & Vazquez, 2013).

The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002): This 70-item, self-report instrument identifies the

five subscales within the representation of an illness (identity; consequences; causes; timeline; cure, and control). Responses are on a 5-point Likert scale, ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Examples of items are: (1) *My diabetes will last a short time*; (2) *My treatment can control my diabetes*; (3) *I do not understand my diabetes*; (4) *I get depressed when I think about my diabetes*; and (5) *My diabetes may have been caused by chance or bad luck*. The IPQ-R reported a Cronbach alpha coefficient of 0.75-0.89 for the IPQ-R complete scale (Moss-Morris et al., 2002).

The Meaning in Life Questionnaire (MLQ) (Steger et al., 2006): This instrument consists of 10 items on a 7-point Likert scale ranging from 1 (*absolutely untrue*) to 7 (*absolutely true*). It is divided into two subscales, namely, (1) presence of meaning; and (2) search for meaning. Items on the presence of meaning subscale are concerned with the degree to which the individual feels that his/her life already has some source of meaning e.g. (1) *I understand my life's meaning*; and (2) *My life has a clear sense of purpose*. The search for meaning subscale examines the extent to which an individual is searching for meaning in his/her life e.g. (1) *I am always looking to find my life's purpose*; and (2) *I am searching for meaning in my life*. Steger (2010) reported that there were no formal cut-off scores to determine what constitutes a high score or a low score on the MLQ.

The Modified Diabetes Social Support Questionnaire (M-DSSQ) (Malik, & Koot, 2011): This instrument includes two subsections, namely, support from family (58 items) and support from friends (28 items) on a 5-point Likert scale ranging from 0 (*Never*) to 5 (*At least once a day*). The participant also completed a subscale on how he feels about the support behaviour mentioned in each item, also on a 5-point Likert scale ranging from 1 (*Unhelpful or not supportive*) to 3 (*Very supportive*). The family support subscale consists of five subscales, namely, (1) guidance and supervision; (2) encouragement of self-care and exercise; (3) support in critical situations; (4) nourishment; and (5) emotional support. The

friends support subscale consists of five subscales, namely, (1) guidance and encouragement; (2) help in critical situations; (3) nourishment; (4) empathy; and (5) help in exercise. Examples of items are: (1) *Give you insulin*; (2) *Nag you until you do your testing*; (3) *Do the grocery shopping for your meals*; (4) *Remind you to exercise*; and (5) *Give you things to read on diabetes care*. Both the M-DSSQ-family and M-DSSQ-friends reported Cronbach alpha coefficients of 0.76-0.92 (Malik, & Koot, 2011, 2012).

Analysis of data

The analysis of the data was done according to Braun et al's (2014) thematic analysis approach. Thematic analysis as a methodology was used as it offered the researcher the advantage of learning how the participant dealt with specific situations in specific contexts in great detail (Larkin, Watts, & Clifton, 2006; Smith, Flowers, & Larkin, 2009). This detail can reveal links and possibly discrepancies within this participant's process of how he makes sense of certain experiences. The interview transcript was coded by the researcher using ATLAS.ti™ software (Version 7), a co-coder, an independent third party with outstanding subject knowledge, as well as a panel of experts in the field of diabetes, discussed and compared emergent contributions on a regular basis with the researcher. Rigor of the study was ensured by this process (Braun, & Clarke, 2006; Braun et al., 2014). This study has differed from the thematic analysis method in the sense that the final analysis is reported on a by-person case study rather than a by-theme report. The reason for this deviation, is that the unique and holistic character of the participant's relationship with his diabetes needed reporting with more accuracy. Before reporting results, a deductive process was employed to extract the themes and issues identified as part of the meaning-making process (Willemse, submitted for review). The intention was never to abstract or separate the themes from the

participant's context, but rather to use the themes as a basis for understanding the diabetes management behaviours and the meaning-making process.

The end product of this analysis process was a thematic composition that represents the young adult's relationship with diabetes, constructed on the basis of the key themes identified by previous work done by Willemse (submitted for review), presented and expressed in and through his own words. Relevant citations are provided throughout. It is important though, to keep in mind that no claim to truthful representation is made (Stenner, 1993). However, the case study should be judged in relation to the overall clarity and salience. This case study, therefore, functions as a foundation to provoke discussion about existing meaning-making frameworks in the context of young adults living with type 1 diabetes (Watts et al., 2010).

For the purpose of this study, the questionnaires were hand-scored by the researcher. The results of the quantitative data were used to verify and enhance findings from the qualitative data. Integrating of the qualitative data with the quantitative data took place during the interpretation phase of the study (Creswell, 2014).

Ethical considerations

Permission to carry out the study was obtained from the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2015-0156). Independent, written, informed consent was received prior to the study. Participation was voluntary, the interview was audio-recorded and transcribed verbatim. The questionnaires were completed on the same day as the interview being conducted.

Rigor

Results from the interview transcript and the questionnaires were triangulated to emphasize similarities and differences in findings. To assure trustworthiness, the interview was independently coded and differences discussed with a knowledgeable professional until consensus was reached; memos documented the conceptualization of the meaning-making framework. To ensure credibility, an independent researcher reviewed the transcript, the meaning-making framework's conceptualization, and participant vignettes to ensure it correctly represented the interview. By maintaining an audit trail, confirmability was established. The triangulation method in itself increased validity of the results as Golafshani (2003) argued that it is a technique where investigators examine convergence of information amid various reliable sources.

The results section presents findings of the case study in relation to the meaning-making framework identified as cornerstone for this study. The discussion section provides an interpretation of the results for the purposes of improving the understanding of the meaning-making process used by young adults to make sense of diabetes management behaviours.

Results

Clive was diagnosed with type 1 diabetes at the age of 18, emerging to the developmental stage of young adulthood and facing challenges such as developing an own identity, taking on new life roles, and more importantly, taking responsibility for self-care. Clive defined himself as “*a real adventurous junky*” who “*pretend to be tough, and I loved it*”. He was comfortable with himself and said that, “*my friends know who I am ... I don't need to proof anything*”.

Clive defined his relationship with diabetes as one where his personal identity was not equal to the condition and said, *“I am still a normal human being”*. Clive was experiencing conflict as he wants to be seen and treated the same as his peers, while he knew very well, that he was different, *“the guys go out to party and drink a lot.... I wonder what I’m supposed to do”*. He went on to assert a sense of autonomy from the condition and declares normal continuation of life as he knew it *“we go out for drinks when my friends celebrate, social events are still the same”*. This emphasised the fact that Clive wanted to be the same as his peers, he wanted to experience life in the same way they did. He did not want to be different, and most of all, he did not want to change his life to accommodate the required diabetes management behaviours.

Clive was not very fond of the diabetes treatment plan and said, *“I don’t like it”*. Clive was no exception as research found that young adults were poor in their adherence to the diabetes treatment plan (Rapoff, 2010). Clive believed that his diabetes treatment plan would not control his diabetes and ended up believing that, *“your life is up, bro”*. Clive believed that he would not enjoy the privilege of old-age as his diabetes treatment plan will never be able to control his diabetes, regardless of all his efforts. This belief was supported by his very low score on the IPQ’s treatment control subscale. As a result of his perception that the diabetes treatment plan failed to control his diabetes, he tend to have negative perceptions of his relationship with diabetes and said, *“it’s a sad situation”*.

Due to his negative emotions in relation to his diabetes treatment plan, he experienced emotional distress *“you have to survive, but you cannot because you have this thing”*. This quote indicate a level of hopelessness that he experienced, as well as having these negative perceptions about his diabetes treatment plan and the resultant emotional distress. These negative emotions were verified by his score on both the IPQ-R emotional representation subscale and the PHI with scores indicating high levels of negative emotions and low levels

of experienced happiness. Clive found the restrictive dietary plans to be especially challenging and frustrating, *“eating is challenging”*. This finding supported findings by previous research that highlighted the distress experienced by young adults through the restrictions being placed on their dietary habits (Willemse, submitted for review). Furthermore, Clive expressed that he experienced frustration when family and friends try to support him with his meal plans, *“it’s irritating...don’t tell me what I can or cannot eat”*. He strongly felt that *“they [family] think they know but in the mean time they have no idea what’s good for me”*. Clive expressed frustration as he was of the opinion that his family intervened in his meal plans when they only had generic information. He was the expert on his body and his meal plans, and did not appreciate their interference and telling him what to eat and what not to. His elevated levels of distress and frustration could be linked to the DSSQ scores, which were very low, suggestive that he experienced others’ support frustrating and not at all helpful. This finding was in direct contrast with research that found social support to be a cornerstone for effective diabetes management behaviours and near-normal blood glucose levels (Gallant, 2003; Kaplan, & Hartwell, 1987; Levy, 1983; Rosland et al., 2008; Schiotz et al., 2011).

Clive’s experience of emotional distress was increased when he mentioned the physical consequences of not adhering to the diabetes treatment plan, *“your eyes get bad”* and *“everything deteriorates more when you have this...it gets more difficult”*. Clive’s score on the IPQ-R’s consequence subscale was testimony to his experiencing emotional distress connected with the consequences of not adhering to the diabetes treatment plan. These findings were supported by research, which argued that young adults were well-known for their non-adherence behaviours and poor self-management of type 1 diabetes, which will result in serious consequences for the individual (DiMatteo, 2004; Hagger, & Orbell, 2003; Kravitz et al., 1993; Rapoff, 2010). In Clive’s case, these possible negative, physical

consequences had a negative influence on his dreams and aspirations. Clive had aspirations to build and become the pilot of his own Gyrocopter [small aeroplane] but, *“I am not allowed to fly my Gyro”* which led to his experience of disappointment. Clive only studied the South African law regulations after his completion of *“13 hours of flying, training and completing my radio communication examination”*. The law unambiguously stated that a person diagnosed with type 1 diabetes was not allowed to pilot aeroplanes in South Africa, *“I cannot do anything about it ... no flying for me ... I was so upset”*.

Clive also experienced disappointments in other situations, *“you have to complete a trail run in the same time as before...but it is impossible, you can’t”*. Clive found it challenging to do trail runs and other adventure activities with his friends as he had to frequently check his blood glucose levels while competing and needed to manage his diabetes accordingly. This created challenges of personal identity for the adventurous Clive who explained that, *“I need to be busy ...outdoors”*. He remarked that he used to go away on adventurous holidays and weekend breakaways where he only paid attention to the most basic needs and did not really give a second thought to his diabetes treatment plan, as *“you go away with friends and try to survive on pals (a type of sweet, white bread), rusks and R&R (a mixture of Rum and Raspberry cold drink)”*. After returning from one such an adventure, he was hospitalised for several weeks and realised, *“I could have lost consciousness and died”*. Clive’s experience of emotional distress was increased as, *“you have to survive, but you cannot because you have this thing”*.

Clive’s experiences of distress lead to the point where he realised that he had to change his behaviour *“I must calm down...do nothing”*. This was the direct opposite of the type of person he described himself to be. The diabetes management behaviours apparently stripped him of the type of person he identified himself to be – the outdoor, adventure loving, always-on-the-go, young man. This conflict permeated every facet of his life, to the point where he

said, “...*I will die early anyway*”. This quote, once again, gave an indication of Clive’s experience of hopelessness. His experience of hopelessness could enhance Clive’s non-adherence behaviour to the diabetes treatment plan.

At this stage in his life, adhering to the diabetes treatment plan was mostly driven by Clive’s need to “*convince them I am still normal*”. This longing for normality came with an emotional toll as he realised, “*I have to fool myself in thinking I am like everyone else*”. This longing served as motivation for Clive to search for meaning in his life. The search for meaning score on the MLQ was high, indicating that he was actively searching to make sense of the world as viewed from the perspective of living with type 1 diabetes. This search also incorporated Clive’s desire to find the value and significance of his life, but moreover, the purpose of his life, “*my reason for getting up in the morning is not exactly to try and make sense of my life why do I get up in the mornings?*” The search for meaning score was also linked to Clive’s demand for his environment to be structured and predictable “*don’t break routine ...I need constant structure*”. Then again, amidst the unpredictable nature of diabetes, Clive searched to understand his new normal, living with type 1 diabetes “*you have to figure it out for yourself*”.

Clive presented his diabetes management as an issue he was prepared to relinquish control over as, “*I don’t like to measure it [blood glucose levels]*”. Clive’s management strategy at that stage was to admit that he did not like to manage the condition, but he realised that he needed to take responsibility for his self-care, whether he liked it or not. He was dismissive of the diabetes management behaviours “*there is no time now for this thing [diabetes management]*” as he found it difficult to spent time on such tedious tasks. However, he has not relinquished control, “*I quickly learn what is good for me and what is not*”. This was exactly his way of exerting control over his diabetes, his strategy for managing his diabetes, “*I need to measure [blood glucose levels] to know, constantly*”.

Through personal mastery of the diabetes care plan, Clive effectively exerts control by constructing a new life to the effect that, *“diabetes is easily managed, nothing seriously”* to *“diabetes is easy, other people really suffer with a lot worse, and nothing to help them”* and even *“I might still live to see 50 [years of age]”*. Clive’s believing in himself and his abilities to successfully manage the condition was observed in his extremely high score on the IPQ-R’s personal control subscale. Individuals scoring higher on the IPQ-R’s personal control subscale tend to achieve near-normal blood glucose levels as was evident in Clive’s case (Davies et al., 2008; Hagger, & Orbell, 2003; Keogh, 2011; Rassart et al., 2015).

Clive’s new normal came to be in the following way: He was diagnosed at the age of 18 years and did not understand the significance and lifelong nature of the relationship he was entering into. He was of opinion that, *“diabetes treatment will not be a lifelong thing”*. Clive had no idea what diabetes was all about and thought, *“a cure must be out there, it will be found, maybe not within the next 15 minutes, but it will be found”*. Due to him not understanding the characteristics of diabetes as being lifelong and unpredictable, Clive *“never know what to expect from my sugar, it’s always a surprise”*. Clive also said, *“there is no consistency and no predictability”*, a factor that hampered Clive in living the life he envisaged for himself. Clive’s score on the IPQ-R’s cyclical subscale was testament to this belief that diabetes was an unpredictable, lifelong condition. This result was no surprise as diabetes is seen as an unpredictable, lifelong condition (Davies et al., 2008; French, 2008; Glasgow et al., 1997; Mc Sharry et al., 2011).

However, he was adamant, *“no, I will not leave it...I will keep trying”*, but he came to the realisation that, *“you have to adapt to it”* [the changing nature of diabetes]. Clive became aware of the importance of a diabetes care plan in order for him to be able to enjoy the future he envisaged, *“you must take responsibility for yourself”*. His near-normal blood glucose level was testimony to his realisation that he needed to take care of himself and

incorporate the management behaviours into his daily existence “*I just need to do all these strange things in between living my life*”. This statement was evident that he accepted the responsibility to self-manage his diabetes to the best of his abilities.

Discussion

This research sought to explore the meaning-making process employed by young adults to make sense of diabetes management behaviours. Meaning has been operationalised in many different ways, from integrating life events and learning life lessons (Bluck, & Gluck, 2004; Singer et al., 2007) to gaining insight in life events (McLean, 2005). Humans have a strong need to create meaning of events in their lives (Alea, & Bluck, 2013; Frankl, 1959). By the experiences Clive had with his diabetes, awareness of conflict between pursuit and satisfaction of personal and diabetes related goals were evident. Moreover, aspirations of living a normal life, on the one hand, and the ever looming need to satisfy the diabetes-related demands, on the other hand, were apparent.

This case elaborated on components reflected in the meaning-making model that was proposed by Park (2010). This proposed model was adapted to report on the process of meaning-making as was found to be applicable to this case study. Components of the meaning-making model for young adult living with type 1 diabetes are described below.

Global meaning: This refers to a person’s general orienting system and is inclusive of personal beliefs, goals, and subjective feelings regarding control, predictability, and the person’s self-view (Dittman-Kohli, & Westerhof, 1999; Janoff-Bulman, 1992; Leary, & Tangney, 2003; Reker, & Wong, 1988). The journey to adulthood poses challenges such as defining desired health outcomes or goals that the young adult wants to reach, establishing an identity and taking responsibility for self-care. Clive, the adventurous, young adult started

training to become a qualified pilot but due to his diagnosis, he will never be allowed to pilot any aircraft. This realisation changed his global meaning system in that his subjective sense of purpose (Reker, & Wong, 1988) or direction became defeated. From this core schema, Clive interpreted many experiences in his life.

Situational meaning: This refers to meaning created in the context of a specific event, thus it begins with a potentially stressful event taking place in one's life (Reker, & Wong, 1988). The stressful event in Clive's life that impacted on his meaning-making process was the diabetes diagnosis. From that event forward, all processes, events, and outcomes are assigned some sort of meaning (appraised meaning). Initial appraised meaning involved, for example, the impact of the diagnosis on one's future (for reviews see Aldwin, 2007; Sweeney, 2008). Clive appraised that initial diagnosis with some hostility because he realised that he will not be able to join his friends on long extended "survival-type" trips or pilot his own aircraft. He also found it difficult to compete with his friends on trail runs and that challenged his identity in such a manner that he needed to employ a meaning-making process in order to find a new sense of identity, purpose, and meaning

Discrepancies between appraised and global meaning: Perceptions of discrepancies between the appraised meaning of an event and a person's global meaning, create distress that drives the meaning-making process (Carver, & Scheier, 1998; Janoff-Bulman, & Frieze, 1983; Watkins, 2008). In this study, emotional distress, the result of challenging meal plans, frustrating social support, and his overall negative perceptions of his diabetes treatment control, were found to be strong driving forces towards the meaning-making effort. It was found that once the young adult's global goals were rendered less attainable, the associated loss of sense of purpose was powerful in generating distress. Efforts to reduce the distress led to the meaning-making process, which involved reducing the discrepancy between an

event's appraised meaning and the individual's global meaning system (Joseph, & Linley, 2005).

Meaning-making process: This process refers to the processes in which the young adult engages to reduce the discrepancy between global meaning and situational meaning. These processes have been conceptualised as automatic and unconscious processes (Creamer et al., 1992). Clive employed processes beyond deliberate effort as was apparent from his remark, *"my reason for getting up in the morning is not exactly to try and make sense of my life"*. Yet, Clive used deliberate efforts or meaning-making to cope with situations (Park, & Folkman, 1997), for example, he re-appraised the control diabetes has on his life from a very negative *"your life is up, bro"* to a more positive *"I might still live to see 50 [years of age]"*. Another strategy that Clive used to his advantage was making comparisons with less fortunate others than himself *"diabetes is easy, other people really suffer with a lot worse, and nothing to help them"*. Clive also used to fabricate worst-case scenarios, such as *"I could have lost consciousness and died"*. By creating worst-case scenarios, one feels relatively fortunate and that helps in reducing discrepancies (Buunk, & Gibbons, 2007; Taylor et al., 1983; White, & Lehman, 2005). Finally, when discrepancies between global and situational meaning are to be resolved, either one or both need changing (Thompson, & Janigian, 1988). Clive's global belief was reminiscent of a belief that a cure for diabetes is imminent *"a cure must be out there, it will be found, maybe not within the next 15 minutes, but it will be found"*. But as time went by and he experienced the unpredictability of diabetes *"I never know what to expect from my sugar; it's always a surprise"*, he came to realise that treatment adherence plays a more important role in living well with diabetes, than focusing on a cure (that might never materialise). In this case, he changed both his appraisal of the situation and his global meaning.

Key themes in the meaning-making process progressively emerged through analysis. The first theme that became evident was the complexity of the process. Even though a question posed during the interview focused Clive's attention on the sense-making of living with diabetes, he rather spent time reflecting on the nature of diabetes and its influence on his life, avoiding the answer as to how he made sense of living with type 1 diabetes. Another theme that emerged was that the meaning-making process reflected a specific, observable outcome generated by the meaning-making process. This observable outcome is discussed as his new normal way of life (renegotiated identity). Indeed, Clive's new normal is at times synonymous with meaning made, as Park (2010) referred to in the meaning-making model. Therefore, meaning-making is not simply a process of reducing discrepancies between global and situational meanings, but a process of working towards a new normal for the individual (an outcome of the meaning-making process). Figure 4 shows elements that were used by Clive when discussing the nature of the meaning-making process

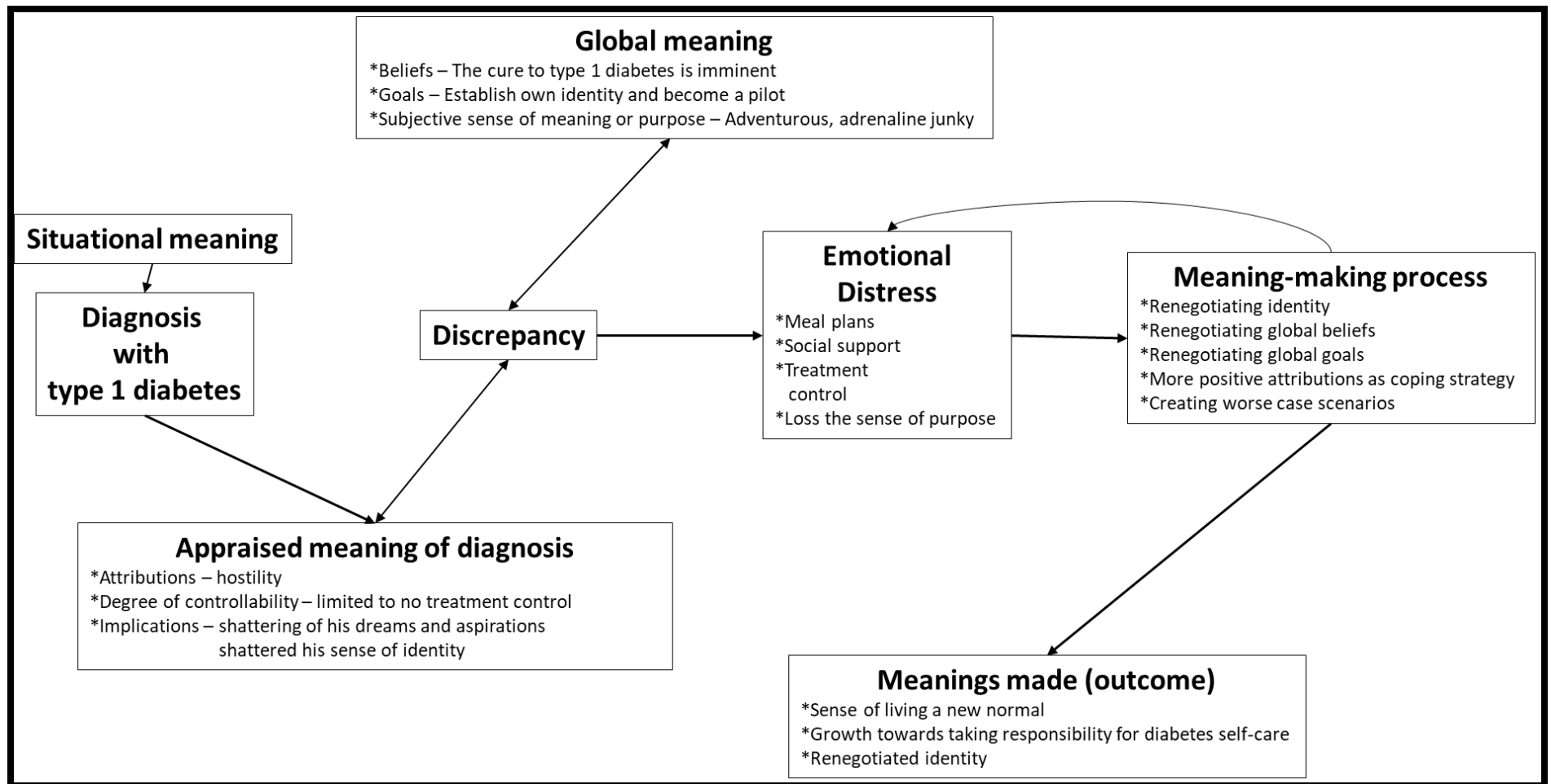


FIGURE 4: THE MEANING-MAKING PROCESS OF YOUNG ADULTS LIVING WITH TYPE 1 DIABETES

Meaning-making is considered a dynamic process that unfolds over time as the young adult ventures towards adulthood. This study only examined the participant once, hence changes taking place over time was not accounted for. It would be recommended that later studies include a longitudinal element where important aspects, such as a renegotiations in global meaning, could be examined in context of the impact it will have on appraised situational meaning.

It is recommended that future studies investigate not only the efforts that the young adults attempt to make meaning, but investigation should also be done on whether or not the attempts at making meaning actually resulted in meanings made. Only if meaning-making efforts resulted in actual meanings made can it be termed successful meaning-making.

Conclusion

This study has documented the proposed meaning-making model for young adults living with type 1 diabetes. This model highlights the association between situational meanings that were discrepant to the individual's global meanings. This discrepancy then resulted in emotional distress, which powered the meaning-making process towards a new normal and psychological well-being. These issues should be the subject of focus in diabetes clinics as it has shown to affect the young adult's adherence to the diabetes treatment plan, which is crucial and determinant of meaning-making and psychological well-being. It seems likely, therefore, that effective diabetes treatment plans must be based on understanding of the young adult's meaning-making process and should acknowledge that attainment of personal goals is as important as physical health. Every young adult living with type 1 diabetes should have access to much needed personal and psychological support as type 1 diabetes is not just a physical condition, but a psychological one as well (Watts et al., 2010).

Implications, limitations of the study

Every year, more people are being diagnosed with type 1 diabetes (IDF, 2015) which emphasises the importance of medical professionals' tasks to educate these people on how to manage their diabetes towards an acceptable HbA1c outcome. The present study focused on understanding the meaning-making experiences of a young adult living with type 1 diabetes. These meaning-making experiences are very personalised and the medical professionals should acknowledge not only how experiences differ, but should address such differences in a tailor-made diabetes treatment plan for the individual. Medical professionals should make young adults aware of the meaning-making process and refer them to health professionals if appropriate. The young adult's perception of their global meaning as well as the meaning they appraised to every situation could be worth addressing in the diabetes clinics. In addition, this study adds to the body of literature on young adults and how they experience not only diabetes management behaviours, but also how they make meaning of living with type 1 diabetes towards experiences of psychological well-being.

As this study was cross-sectional, it limited the ability to establish causal relations between the factors influencing meaning-making and meaning made of young adults living with type 1 diabetes. There is a need for long-term follow-up studies to longitudinally identify causality in the meaning-making process as well as the meanings made. For any of the reported associations, reverse causality is equally plausible. Research into causal pathways needs to be done in future research.

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Chapter 5: Diabetes management behaviours of young adults towards psychological well-being

Preface to chapter 5

The aim of this exploratory multi-methods research study was to develop a greater understanding of the psychosocial variables that influence diabetes management behaviours and psychological well-being of young adults living with well-controlled type 1 diabetes. The main research question guiding this thesis was: “How do the personal model, meaning and social support shape diabetes management behaviours of young adults towards psychological well-being?” In order to answer the main research question, secondary objectives were set for this study, namely, (1) to conceptualise psychosocial variables and diabetes management in the context of young adults living with type 1 diabetes; (2) to describe interactions that exist between the personal model of diabetes, meaning-making, social support and diabetes management behaviours of young adults living with type 1 diabetes; and (3) to apply the proposed model of meaning-making to a young adult living with type 1 diabetes.

The following section provides an overview of the conclusions that have been drawn from this study to provide an integrated understanding of this phenomenon. The limitations are then outlined, after which the recommendations for future research and practice are offered.

5.1 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.

5.2 Conclusions

The overall aim of this study was to explore the influence of psychosocial variables on diabetes management behaviours and the psychological well-being of young adults living with well-controlled type 1 diabetes as relatively little is known about this age group's experience of living with type 1 diabetes.

For this study, psychological well-being was conceptualised as a process of self-realisation (Ryff, 1989). This self-realisation process, normal to human functioning, included components such as finding the true self (identity), meaning (and meaning-making), living one's potential, and experiencing lasting relatedness with others (Ryan, & Deci, 2001; Ryff, & Singer, 1996; Tamir, & Gross, 2011). Findings point toward six dimensions (Ryff, 2014) of this process to be relevant to the young adult's experience of psychological well-being. These dimensions were: (1) autonomy and taking responsibility for self-care; (2) mastery of the diabetes treatment plan; (3) personal growth; (4) positive relations and social support; (5) purpose in life; and (6) self-acceptance.

Frankl (1963) is commonly cited as one of the founding muses of research on meaning in life. He suggested that people need to perceive a sense of meaning and live a life of purpose. Even though meaning and purpose is sometimes used interchangeably, Steger (2012) suggests that meaning is superordinate to purpose which represents the overarching long-term goals and aspirations, as well as the motivations towards those goals. In this study, meaning

was conceptualised as consisting of two components: a presence of meaning and a search for meaning (Steger, 2009). Once stressful events challenge a person's meaning in life, efforts are made to renegotiate meaning systems. This renegotiating process is understood to be a process of meaning-making. Meaning-making was conceptualised as making sense of life through a process of goal directed behaviour as proposed by Park (2010).

The research process identified several variables that contributed to the diabetes management behaviours and psychological well-being of this age group. The nature and significance of these variables were presented in the preceding chapters, which were the focus of articles submitted for publication.

5.2.1 Article 1: Life stories: Young adult's experiences of adjusting to diabetes management

The analysis of the life stories and the identification of emergent themes influencing the diabetes management behaviours of young adults living well with type 1 diabetes, fulfilled the research objective of the first article. The guiding question was: *"How can the psychosocial variables and diabetes management behaviours be conceptualised in the context of young adults living with well-controlled type 1 diabetes?"* Thematic analysis was done to bring greater insight into the themes that emerged. The data gathered in relation to the variables influencing diabetes management behaviours and the individual experiences of the management behaviours, provided underpinning to three emergent themes. These themes are shown in table 2.

TABLE 2: EMERGENT THEMES FROM ARTICLE 1

Themes
(1) The challenges experienced in <i>identity development</i> were linked to the young adults trying to fit in with their peers and still trying to do the same things and living a “normal” life.
(2) The <i>emotional distress</i> that was associated with diabetes management behaviours was mainly due to experiences of the restrictive meal plan and the loss of dreams and aspirations they held for their futures that were now unattainable due to the condition.
(3) The experiences of <i>diabetes management activities and social support</i> were described as very personal and resulted in a lonesome journey. The diabetes management process was experienced as an unpredictable process, just as diabetes was an unpredictable condition. Though diabetes management was experienced as complex, it was experienced as manageable. Social support was described as the pillar of strength for young adults living with well-controlled diabetes.

In conclusion, through this article the different psychosocial variables influencing diabetes management behaviours were identified. However, this article furthermore highlighted the need to form an in-depth understanding of the themes identified and how these themes relate to the psychological well-being and meaning-making process that young adults use to make sense of living with well-controlled type 1 diabetes.

5.2.2 Article 2: Understanding young adult’s meaning making in adjusting to diabetes management behaviour: Multi-methods approach

This article aimed at gaining understanding of the process or strategies that young adults used to make sense of living with type 1 diabetes. Key findings from the previous article served as a conceptual guide to develop insight into the interactions between the psychosocial variables captured in the themes and diabetes management behaviours. The guiding question to this exploration was: “*What kind of interactions exist between the personal model of diabetes, making meaning of the condition, social support received and diabetes management*

behaviours of young adults living with type 1 diabetes?” This question was answered by making use of a multi-methods approach including semi-structured interviews as well as questionnaires. This analysis identified three distinctive themes influencing the way in which the individuals made sense of living with type 1 diabetes as seen in table3. These themes corresponded to themes documented in article 1, although variations were seen.

TABLE 3: EMERGENT THEMES FROM ARTICLE 2

Themes
(1) The challenges that were faced in <i>developing their own identity</i> were experienced very intensely. Significant challenges were mentioned such as taking responsibility for diabetes self-care and autonomy in decision making towards the diabetes treatment plan. The young adults needed to be part and parcel of the treatment plan decision-making process in order for the treatment plan to be deemed successful.
(2) The diabetes treatment plan and associated diabetes management behaviours caused the young adults to experience <i>emotional distress</i> . Most of the emotional distress was caused by the restrictive meal plan and this resulted in the young adult’s poor adherence to the diabetes treatment plan.
(3) The experiences of the <i>diabetes management behaviours and social support</i> was described as being frustrating. The young adults had different views of the value added by social support. The process of making sense of living with type 1 diabetes were resultantly influenced by experiences of social support as some felt social support contributed to the sense-making process. Others experienced social support as non-valuable and frustrating and not contributing to the process at-all.

Regarding the nature and context of diabetes management behaviours, this study confirmed that the experiences of diabetes management behaviours depends on a combination of several interrelated variables under which the personal model of diabetes,

meaning, meaning-making, and social support occurs. This study draws attention to the fact that the emergent themes represented elements of the meaning-making model as proposed by Park (2010). This study also found that the process of personal growth and having or searching for one's purpose in life can minimise non-adherence behaviour to the diabetes treatment plan but it may increase the levels of emotional distress experienced. Briefly, this study revealed that the young adults did not necessarily experience happiness, but could experience some level of psychological well-being and meaning.

Considering the complexity of the diabetes treatment plan, this study found that although the young adults were continuously challenged by adhering to the diabetes treatment plan and the diabetes management behaviours, they tend to engage in personal strategies to assist them in making sense of their circumstances, which perhaps limit the distress they experiences.

5.2.3 Article 3: Diabetes management behaviours and meaning-making: The young adult's sense making process of living with type 1 diabetes

Based on previous studies, this article's objective was to develop an understanding of the way young adults made meaning of living with well-controlled type 1 diabetes, by suggesting and applying the meaning-making model of Park (2010) to a case study (see figure 5).

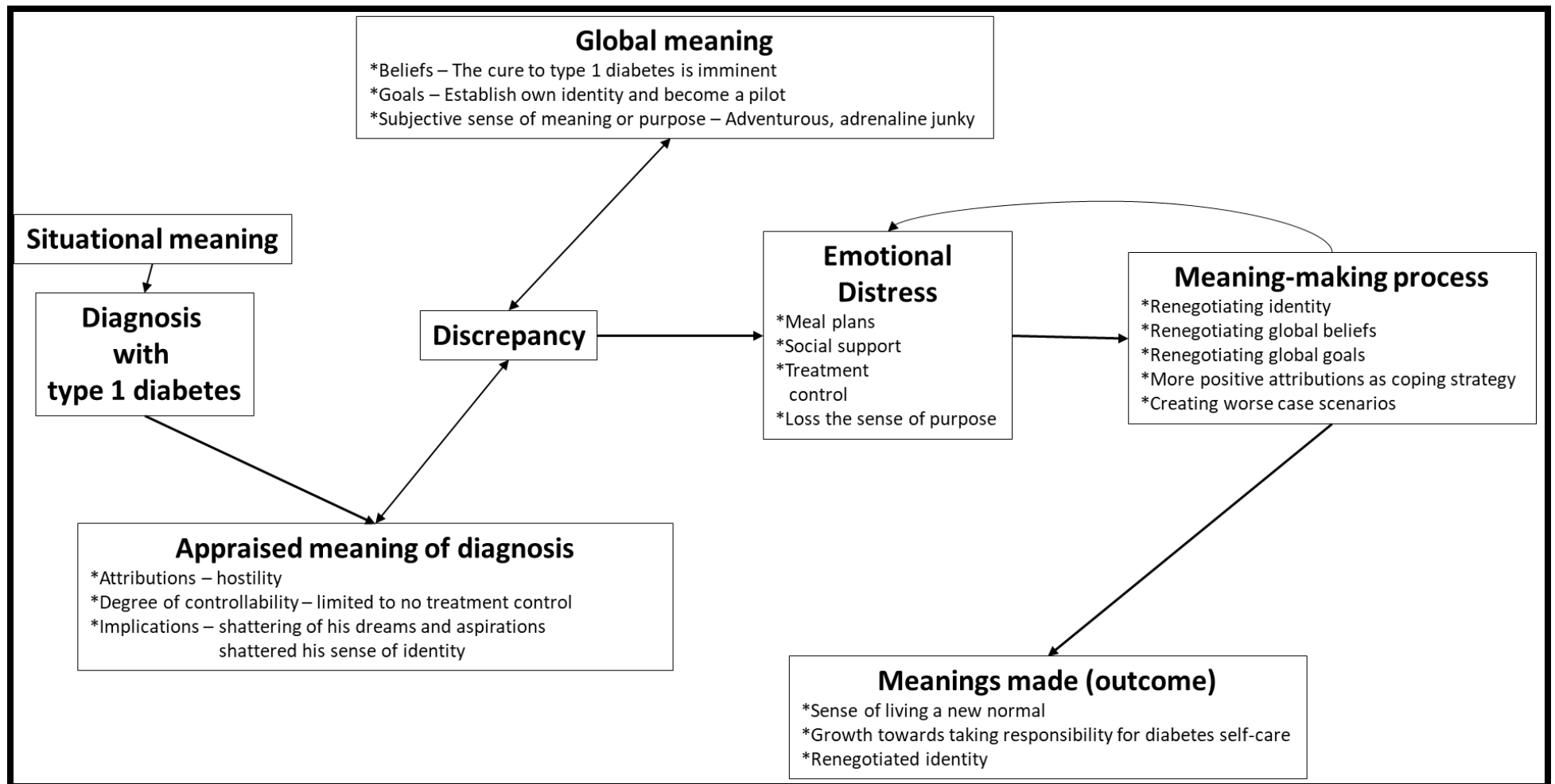


FIGURE 5: THE MEANING-MAKING PROCESS FOR YOUNG ADULTS LIVING WITH TYPE 1 DIABETES

By appraising meaning to every life event, meaning was created and as such, influenced the participant's psychological well-being. The experience of emotional distress was resultant of conflict between pursuit and satisfaction of personal and diabetes-related goals and aspirations. The outcome of the meaning-making process was seen in the creation of a new normal way of living that included aspects such as a new identity with room for diabetes self-care, taking responsibility for self-care and more importantly, making use of deliberate efforts or meaning-making coping (Park, & Folkman, 1997). The influence of not only diabetes management behaviours, but meaning-making as well, on the psychological well-being of the young adults living with well-controlled type 1 diabetes could clearly be seen in this article. Empirical results suggested that young adults experienced meaning in life, despite the complex and challenging diabetes treatment plan faced every day.

This study found that the young adults experienced a process of self-realisation while making meaning of living with the condition. This related well with Ryff's (1989) conceptualisation of psychological well-being which included six dimensions: (1) *autonomy*, the young adults managed their diabetes independently; (2) *environmental mastery* took place in that the young adults were able to renegotiate global meanings that allowed for the young adults to successfully manage their condition; (3) *personal growth* was evident as the young adults empowered themselves to overcome emotional distress caused by the discrepancy between the global meaning and the appraised meaning; (4) *positive relations with others* were experienced for the greater part of the time; (5) *purpose in life* was found by the individuals after renegotiation of global meanings took place; and (6) *self-acceptance* was ultimately the new identity that was created to include living with type 1 diabetes. However, from the results of this study, it became evident that experiencing psychological well-being was not as simple as maintaining a blood glucose level within the near-normal range;

embracing and understanding individual differences is what will mark a successful diabetes treatment plan.

5.3 Limitations of the research

Potentially limiting factors included the availability of research participants. This study drew from a very small pool of research participants. Firstly, this study only included young adults between the ages of 18 to 25 years of age, living with well-controlled type 1 diabetes. Literature indicated that adherence to the diabetes treatment plans were problematic, therefore, not a lot of young adults reported HbA1c within the near-normal ranges, hence limiting the participant pool dramatically. Secondly, this study only included participants receiving their diabetes treatment at the CDE, Parktown, South Africa. This was done to limit the possibility of any treatment variance between participants. Although successful to ensure homogeneity in the participant pool, it limited the amount of participants included in this study.

Young adults with poor diabetes control – that will be HbA1c levels not within the near-normal ranges, and or not receiving diabetes treatment from the CDE were excluded and future studies would benefit from greater inclusion. Greater inclusion will ensure diversity in the participation pool as more socio-economic sectors of the community will be included, which will imply greater depth in the data being generated.

While a small sample size was appropriate for this research purposes, it is important to indicate that these young adults only represent a very small group of young adults living with type 1 diabetes. This might influence the results and it is, therefore, recommended that more young adults are invited to share their experiences in similar studies.

The researcher is mindful of the scepticism in the field of psychology towards the multi-methods approach (Bishop, 2015; Creswell, 2014; Mertens, 2011; Tashakkori, & Creswell,

2007; Tashakkori, & Teddlie, 1998, 2003). However, it allowed for in-depth understanding of the experiences of living with type 1 diabetes in the context of young adults. Rather than focusing on the limitations of multi-methods research, this study utilised the strengths of this research method to assist in answering the research questions. Some of the strengths reflected in this study are that words and narratives were used to add meaning to numbers, and numbers were used to add precision to the words and narratives.

5.4 Contributions of this study

This study provided the first known exploration into the diabetes management behaviours of young adults from a positive psychology perspective. The results support positive psychology literature, with psychological well-being relating to a sense of autonomy, personal growth and social support which link the experiences of young adults living with well-controlled type 1 diabetes to the on-going meaning-making process reflected on in this study. This study evidently concluded that successful adjustment to a diabetes care plan and constant renegotiation of meanings result in personal growth, enhancement of autonomy and psychological well-being for young adults living with type 1 diabetes.

Moreover, this study makes an authentic contribution to the field of psychology and diabetes management in that it provided the first known meaning-making model for young adults living with well-controlled type 1 diabetes. Despite the limitations of this study, the meaning-making model increases understanding of the nature of making sense of living with type 1 diabetes.

The study makes a strong case for the importance of the young adult's beliefs as to why diabetes management is important, and this must be a vital discussion point in every professional's encounter with the young adult. Health care professionals should help young adults to explore the meaning-making process so as to identify goals, dreams or desires that

would provide the motivation required to adopt and enact the challenging diabetes behaviours that are known to result in good glycaemic control.

5.5 Recommendations for future research and practice

In the process of answering the research questions at the centre of this study, other questions were raised that suggested areas for future research. It is recommended that more research be undertaken to confirm the findings presented within this study and explore new factors emerging in young adults living with type 1 diabetes; this should typically be done through focus group discussions with young adults living with well-controlled type 1 diabetes. The documented findings in this study should, therefore, serve as guideline and motivation for future research to continue the process of uncovering the root of psychological well-being and meaning-making as experienced by young adults living with type 1 diabetes.

Given the limitations of the participation pool, it is strongly recommended that future research address these limitations by expanding the inclusion criteria for future studies. Larger quantitative studies could be used to develop a reliable meaning-making model for young adults living with type 1 diabetes. In addition, comparative studies could prove valuable to evaluate psychological well-being, diabetes treatment plans, and meaning-making across various heterogeneous groups.

Intervention studies are needed to investigate the causal relationships between the psychosocial variables, meaning-making, and the promotion of diabetes management behaviours towards achieving near-normal HbA1c levels. It is recommended that the findings from this study be incorporated in the clinical practice when diabetes treatment plans and diabetes treatment interventions are designed. Educational intervention programs should include generic information about the characteristics of type 1 diabetes as well as personal skills needed to manage the condition. This type of interventions should be done initially (at

diagnosis), but also over time, as misconceptions may misconstrue the individual's motivation to persist with adherence to the complex treatment plan. Medical practitioners should understand the importance of respecting and supporting the young adult's decisions pertaining to their management behaviours, but at the same time, address the underlying factors causing non-adherence in their education, support and care of young adults living with type 1 diabetes.

5.6 Reflection

The “human science” model defined the researcher's role as finding a pattern or meaning based upon the interdependence of the individual and the world.

(Giorgi, 1970)

Giorgi (1970) encapsulated the essence of what a researcher's role is when investigating any phenomenon related to human sciences. This was the quote that constantly motivated me to do more, read more, and interact extensively with the young adults living with type 1 diabetes, in order to form a better understanding of their unique challenges.

My primary concern was to develop a comprehensive understanding of the psychosocial variables (including the meaning-making process) influencing diabetes management behaviours and psychological well-being of young adults living with type 1 diabetes. I chose a multi-methods analysis approach in order to deepen and enrich my understanding of the psychological well-being of young adults living with type 1 diabetes in the context of their developmental challenges.

I deemed it important to utilise and appreciate both qualitative and quantitative research, and by doing so, applauded the intense debate that modern-day scholars must advance the social and behavioural science field by not restricting themselves to only one

research paradigm (Onwuegbuzie, & Leech, 2005). I began exploration of the research problem from a qualitative perspective. I interpreted the complex relationships between diabetes management behaviours and the psychosocial variables towards psychological well-being by collating both qualitative data and quantitative data. This was a challenging process as I aspired to offer a valuable way of understanding and organising the data. I intended to present the data in such a manner as to explain the variables and the relationships between the variables in a practical way with the intention to produce learning. Therefore, diabetes management behaviours had to be understood in a holistic way. During this entire study I constantly strived towards holistic learning, I tried to view the theory behind diabetes management behaviours and the practice of such behaviours as an integrated whole, never separately. In summary, the multi-methods design fitted well with my keen sense of examination in order to facilitate holistic learning. This methodology allowed for me to organise and collate data in a professional manner so as to serve the greater need of people living with diabetes. Where possible, I wanted to do more than just identify issues of concern; I wanted to understand the young adult's psychological well-being and how the non-adherence to the diabetes treatment plan may be improved upon. The only way was through understanding the variables from their perspective.

Although I have an exuberant interest in the complexity of the meaning and meaning-making concept, I am mindful that only individuals can create meaning in their own lives. I view the creation of meaning as a recursive loop in which individuals constantly and retrospectively examine the world and their place in it. Therefore, I understand continual improvement and growth to be the result of deliberate and continuous reflections. Through my involvement in this study, I wanted to offer that opportunity of empowerment to young adults living with type 1 diabetes.

Additionally, as a novice researcher, I came to appreciate the tremendous dedication and perseverance of other well-established researchers. While conducting this laborious research, I realised that perseverance is not only needed to reach the research end goal in a set time but perseverance is also paramount on your journey through life. This journey has been challenging and a time of deep reflection and personal growth. Reflecting on my research journey, I now know that I have acquired more self-confidence and a deeper awareness and appreciation of my inherent strengths. I have also identified areas in which to invest as researcher and lifelong scholar. However, this journey consumed my total existence as it required complete devotion and focus. I struggled through desperate lows and periods of writer's block, but luckily, also wonderfully addictive periods of highs and surprising discoveries. I am convinced that the findings of this study will prove to be valuable to medical professionals assisting young adults living successfully with type 1 diabetes. Therefore, I am proud to have contributed to the field of Psychology.

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Addendum A: ETHICAL CLEARANCE CERTIFICATE



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ETHICS APPROVAL CERTIFICATE OF PROJECT

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

Project title: Diabetes management behaviours of young adults towards psychological well-being.																																	
Project Leader: Mrs M Willemsse																																	
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>H</td><td>S</td><td>-</td><td>2</td><td>0</td><td>1</td><td>5</td><td>-</td><td>0</td><td>1</td><td>5</td><td>6</td></tr><tr><td colspan="4">Institution</td><td colspan="4">Project Number</td><td colspan="4">Year</td><td colspan="4">Status</td></tr></table> Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation	N	W	U	-	H	S	-	2	0	1	5	-	0	1	5	6	Institution				Project Number				Year				Status			
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Institution				Project Number				Year				Status																					
Approval date: 2015-10-14	Expiry date: 2018-10-14																																
Category:	N/A																																

Special conditions of the approval (if any): None

General conditions: While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following: • The project leader (principle investigator) must report in the prescribed format to the NWU-IRERC: - annually (or as otherwise requested) on the progress of the project, - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project. • The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-IRERC. Would there be deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited. • The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-IRERC and new approval received before or on the expiry date. • In the interest of ethical responsibility the NWU-IRERC retains the right to: - request access to any information or data at any time during the course or after completion of the project; - withdraw or postpone approval if: - any unethical principles or practices of the project are revealed or suspected, - it becomes apparent that any relevant information was withheld from the NWU-IRERC or that information has been false or misrepresented, - the required annual report and reporting of adverse events was not done timely and accurately, - new institutional rules, national legislation or international conventions deem it necessary.

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

Yours sincerely

Linda du
Plessis

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