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Declaration

I hereby declare that the Research Report submitted for the BA (hons) in psychology degree to The Independent Institute of Education is my own work and has not previously been submitted to another University or Higher Education Institution for degree purposes.

ABSTRACT

Chronic physical disorders, such as Type 1 diabetes, are conceptualised as an ongoing strain. Treatment methods include daily insulin administration, sticking to a healthy diet and exercise, as well as regular visitations to a diabetes healthcare team. Strand, Brostom and Haugstevdt (2016) argue that managing Type 1 diabetes may be especially demanding during adolescence, when various rapid cognitive, physical and social changes are taking place.

The current study, thus, aimed to explore the psychosocial factors that influence the management of adolescent Type 1 diabetes in a South African context, from the perspectives of healthcare providers. Six participants were included using convenience sampling. The researcher embarked on this study from an interpretivist stance in terms of which a qualitative research strategy was employed. Semi-structured interviews were used to collect data in order to gain an in-depth understanding of the lived experiences of managing Type 1 diabetes as an adolescent.

The results of this study revealed that various psychosocial factors act as risk and resistance factors to self-care behaviours. To be specific: the polarised healthcare system of South Africa, support structures, access to information, as well as the complexities of the adolescent developmental stage.

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1. INTRODUCTION

1.1 Research title

Exploring the psychosocial implications on the management of adolescent Type 1 diabetics: A qualitative study involving healthcare providers.

1.2 Contextualisation

Diabetes is a significant contributor to the burden of disease globally, and its prevalence, a great concern for public health (Dube, Van den Broucke, Dhoore, Kalweit & Housiaux, 2015). Recent estimates from the International Diabetes Federation (2019), indicate that 463 million people are living with diabetes worldwide, and that by the year 2035, this number will rise to 592 million. The International Diabetes Federation (2019) further asserts that diabetes is amongst the top ten global causes of death. Despite the stark truth the aforementioned data represents, there is a positive message: with early diagnosis and access to appropriate care, the disease can be managed and its complications prevented (International Diabetes Federation, 2019). This study aims to explore the management aspect of Type 1 diabetes.

Atkinson, Eisenbarth and Davis (2015) argue that managing Type 1 diabetes provides a daily challenge, as it requires frequent and continuous effort from the person living with the condition. This incorporates factors such as insulin administration, constant blood monitoring, exercise and meal planning (Atkinson et al, 2015). Since taking insulin injections is the ultimate treatment method, it is argued that living with Type 1 diabetes tends to be viewed in light of that physiological aspect on those affected, and not on the psychological implications that may arise as a result. As a supportive view on which the current study rests, Young-Hyman et al (2016), argue that complex emotional, behavioural, social and environmental factors, known as psychosocial variables, also influence the diabetics' management of the disease and psychological well-being, and should therefore, be considered as of equal importance.

In their review of the International Diabetes Federation's (2001) first global study on the influences of psychosocial factors on diabetes management, Young and Unachukwu (2012) criticised the study's findings, firstly, for being dated, but also for not being representative to the entire diabetes population at large, as none of the participants were from an African country, and the participants comprised of adults living with Type 2 diabetes. The current study hopes

to build on these findings, by focusing on the supposed disregarded group: adolescent Type 1 diabetics.

The research report will begin with a discussion on the research rationale, problem statement, purpose statement and objectives, followed by the review of previous literature key concepts linking to the study will be reviewed, alongside previous literature on the topic, as a means to acknowledging current information as well as the gap in the literature. The research design and methodology of this research study will then be discussed with high level details on how the research will be conducted on various factors pertaining to the data collection process. Furthermore, the anticipated contribution will be discussed, and lastly the ethical considerations and limitations of the study will be discussed. Following on from this, concluding statements will be made and the individual puzzle pieces of each section, will be combined to form a full picture, thereby answering the research question.

1.3 Rationale

Personal rationale

As a Type 1 diabetic, diagnosed from childhood, and a member of the Youth with Diabetes community, the researcher has always been keen on raising awareness on the prevalence of Type 1 diabetes, as well as the impact of the disease's management on normal cognitive, emotional and physical functioning. The researcher is of the opinion that Type 1 diabetes is a widespread childhood condition, seldom talked about, due to its lower prevalence rate compared to that of Type 2 diabetes, a lifestyle disorder.

Academic rationale

Strand et al (2016) argue that changes in various hormones influence the body's need for insulin. Therefore, living with Type 1 diabetes may be especially demanding during adolescence, when various rapid cognitive, physical and social changes are taking place (Strand et al, 2016). The researcher is of the opinion given the developmental changes that occur in adolescence, adolescents may even be a more vulnerable population as a result. For this reason, the researcher has chosen to focus on the adolescent experience of managing Type 1 diabetes. For ethical reasons such as avoiding any psychological harm that may arise, the researcher has chosen to involve healthcare providers in place of their diabetic patients.

A study by Hegelson and Palladino (2012), which looked at the implications of psychosocial factors for diabetes outcomes amongst children with type 1 diabetes, argued that psychosocial factors can act as both risk and resistance factors to self-care behaviours, on the management of the disease. Hegelson and Palladino (2012) further asserted that the manner in which this disease is managed during adolescence, is largely a determiner of how the individual is likely to manage the disease going into adulthood. Thus, if the pattern of behaviour is negative or counterproductive, there can be lasting health consequences (Hegelson & Palladino, 2012). A study on the psychosocial influences on the management of Type 1 diabetes, therefore, will contribute to the understanding of how adolescents take care of themselves with respect to the diagnosis.

1.4 Problem statement

A number of studies have been conducted on diabetes and its management. The Diabetes Attitudes Wishes and Needs (DAWN) study on psychosocial barriers and drivers to managing diabetes, for one, concluded that psychological health and healthcare provision, are the strongest areas of concern pertaining to effective self-management (Funnel, 2006). A second DAWN study was conducted in 2004, as a means to correct for the first DAWN study's limitations, such as the focus being on Type 2 adult management over Type 1 (Funnel, 2006). This study too, was criticised on the basis that the research participants were of western descent, and participants excluded adolescents and children.

Hegelson and Palladino (2012) have argued for more studies to consider the experiences of adolescents, as very little research has been done on these experiences. Young and Unachukwu (2012), and Mutyambizi, Booysen, Stokes, Pavlova and Groot (2015), have argued for the inclusion of developing countries in research surrounding diabetes care. This is because it is estimated that 77% of diabetics, reside in low and middle income countries, which suggests that many developing countries are faced with the double burden of communicable and non-communicable diseases (Dube et al, 2015).

To date, none of the existing studies have addressed understanding Type 1 diabetes management by adolescents, from the perspective of healthcare providers, within a South African context. This study, thus, aims to address this gap.

1.5 Purpose statement and research question

The purpose of this research study is to explore the psychosocial implications on the management of Type 1 diabetes amongst adolescents, from the perspective of healthcare providers, within the South African context. Since psychosocial factors impact greatly on the management of a chronic disease, what psychosocial factors influence the management of Type 1 diabetes amongst adolescents?

1.6 Research objectives

- To explore the psychosocial factors that constitute psychosocial influences on the management of adolescent Type 1 diabetes.
- To determine risk factors to self-care behaviours.
- To gain deeper insight into the development stage of adolescence, and to understand how this impacts the experience of managing Type 1 diabetes.
- To learn more about what healthcare workers believe needs to be in place for adolescents living with Type 1 diabetes, to effectively manage the disease.

2. LITERATURE REVIEW

This section will comprise of the discussion on the study's theoretical framework, followed by a review of previous literature and the conceptualisation of key terms.

2.1 Theoretical framework

2.1.1 The Five Factor Model

The Five Factor Model of personality refers to a hierarchal organisation of personality traits in terms of five basic dimensions, namely: neuroticism; extraversion; agreeableness; conscientiousness and openness to experience (Semenya, 2016). According to Semanya (2016), this model was developed by McCrae and Costa in 1990, who like most researchers studying factors of personality at the time, built elaborate taxonomies/classification systems of personality traits using factor-analytic techniques, to examine the stability and structure of personality.

The five basic dimensions are described as follows: neuroticism, which is essentially equivalent to emotional instability, and can be seen as moody and irritable behaviour. Extraversion also

known as surgency, encompasses more specific traits such as sociability, talkativeness and assertiveness. Agreeableness is indicated in sympathetic, empathic and kind behaviours. Conscientiousness refers to one's sense of responsibility and duty, as well as foresight. Finally, openness to experience concerns one's level of thoughtfulness, inquisitiveness and propensity for intellectually challenging tasks (Semenya, 2016).

Semenya (2016) acknowledges that this model is greatly criticised, mainly for not being a theory—it is argued that theories ideally go beyond a post hoc interpretation of observations, and lead to testable hypotheses. Feist, Feist and Roberts (2013), however, support the use of this model, by suggesting that taxonomies are an essential starting point for the advancement of science, even though they are not theories. For the current study, however, the use of this model as part of the study's theoretical foundation, was deemed applicable for the purposes of identifying the personality traits that can be linked to self-care behaviours. Previous research has shown the applicability of this model in understanding the link between personality traits and self-care behaviours, and how these traits tend to endure across the lifespan. A study by Hegelson and Palladino (2012) on the implications of psychosocial factors for diabetes outcomes among children with Type 1 diabetes, for one, found that behaviour plays a prominent role in caring for a disease, and that this behaviour is greatly determined by different personality traits.

In their study, Hegelson and Palladino (2012) found that conscientiousness was the most stable prediction of self-care behaviours amongst Type 1 diabetic adolescents, as this was evident in their ability to maintain appropriate glycemic control. They also assert that conscientiousness is linked to the adolescents' assumed role and control over their health. Further to this, Hegelson and Palladino (2012) found that neuroticism was strongly linked to poor glycemic control, which was characterised by poor adherence to treatment regimens. This insight suggests to the researcher that personality traits play an instrumental role to self-care behaviours.

Furthermore, a study by Hampson et al (2015) analysed the relationship between personality traits and health trajectories. This 40-year prospective study aimed to examine if self-regulatory processes originate from childhood personality traits, and affect patterns of self-rated health assessed over time in middle age (Hampson et al, 2015). They were able to observe conscientiousness to be the only personality trait that is associated with self-regulatory

processes, resulting in better healthcare behaviours (Hampson et al, 2015). Self-regulatory processes in this regard are viewed as goal-directed behaviours, that are focused on achieving desired health outcomes (Hampson et al, 2015).

Both the aforementioned studies have illustrated how the Five Factor Model can be useful in illustrating how personality traits influence healthcare behaviours, even though their findings have only addressed two traits, and are therefore limited in that regard. However, it can be presumed that this theory serves as an adequate underpinning for the current study.

2.1.2 The Biopsychosocial Model.

The Biopsychosocial Model refers to an interdisciplinary model that examines the interaction between biological, psychological and social factors, as contributing to both health and illness (Lehman, David & Gruber, 2017). Lehman et al's (2017) study on understanding health as a dynamic system, state that the Biopsychosocial Model was first introduced by Engel in 1977, as an opposition to the then dominant health and illness model, the Biomedical Model. Engel (1980) states the Biopsychosocial Model addresses the limitations of the reductionist perspective of the Biomedical Model, by introducing a comprehensive framework which includes all the factors that impinge on, and contributes to, changes in an individual's physical and/or mental health status.

The biological component of the Biopsychosocial Model suggests that many health conditions have an inherent genetic vulnerability, and refers to "all peripheral organ system functions as well as to all autonomy, neuroendocrine, and central nervous system functions that are automatic and outside conscious awareness" (Lehman et al, 2017). Type 1 diabetes is an ideal disease to examine, as it is heritable and not transmittable, thus supporting the need for biological influences of the condition to be examined. (Center for Diabetes and Endocrinology, 2019). Furthermore, the age group on which the research study is based, allows for the exploration of hormonal changes, such as puberty, and the role they play in the management of adolescent Type 1 diabetes.

The psychological component seeks to find a psychological foundation for the expression of a disease (Lehman et al, 2017). According to a study by Lehman et al (2017), psychological factors may aggravate a biological predisposition, by placing a genetically vulnerable person at risk for developing other health conditions. For example, depression may not cause Type 1

diabetes, however, Type 1 diabetes can contribute to the causes of depression. For instance, a study by Young-Hyman et al (2016) found depression to be common at the time of diagnosis, where individuals become overwhelmed by the perceived financial burden and healthcare demands. A personality trait such as neuroticism, as discussed earlier, may also support this notion, in the sense that feelings such as fear and anxiety towards the management of the disease, may later result in depressive symptoms.

Finally, social influences refer to the environmental contexts in which the individual develops, and are perceived to be either harmful or supportive for the improvement of the individual's health condition (Habtewold, Islam, Radie & Tegegne, 2016). These factors include one's socioeconomic status, family relationships and social support (Habtewold et al, 2016). For this study, Kail, Cavanaugh and Muller's (2019) research on diabetes care within South Africa, is used to provide the platform upon which to explore social context. According to Kail et al (2019), spirituality and cultural influences are important aspects to how health and disease are perceived and treated in a multicultural context, such as South Africa. For example, Kail et al (2019) share that Type 1 diabetes-related complications such as gangrene, tend to be attributed to witchcraft in certain cultures, and is, that it is curable through the use of traditional treatment.

Considering that the study aims to explore the psychosocial factors that influence the management of Type 1 diabetes amongst adolescents, this theory will position the researcher to view the disease holistically, by understanding how external factors or stressors interact with internal factors, and then impact on how the disease is managed.

2.2 Review of previous literature

2.2.1 Type 1 diabetes management

In their 2016 global report on the prevalence of diabetes, the World Health Organisation estimated that over 422 million diabetes diagnoses were made in 2014, of which only 10% of the cohort, were Type 1 diabetics. Prompted by these findings, Kakkar and Puri (2016) argued that although Type 1 diabetes is less prevalent than Type 2 diabetes, it is still a widespread childhood chronic disease, seldom talked about. Kakkar and Puri (2016) argue that the discussion on Type 1 diabetes, represented by the minority of the diabetic population, is often missed as a lot of emphasis tends to be placed on Type 2 diabetes—a lifestyle disorder mostly reported among adults, due to its high incidence rate, compared to that of Type 1 diabetes. A

study by De Wet (2018) which looked at the top ten natural killers in South Africa, found that Type 1 diabetes was only the fifth largest cause of death in 2013, and has now jumped to number two as of 2018. In addition to the psychological and financial burden that comes with the diagnosis, Kakkar and Puri (2016) share that in developing countries such as India, access to proper healthcare facilities and medical technologies, is poor or very little.

This insight indicates to the researcher that, whilst there is the issue of Type 2 diabetes being portrayed as the front-man of diabetes, there is also the concern around healthcare provision being influenced by socioeconomic factors, such as the accessibility to specially trained diabetes centers. Furthermore, Young and Unachukwu (2012) argue that standard Type 1 diabetes management, includes receiving medical care from a physician-co-ordinated team. Such teams may include, but are not limited to: dietitians, nurses, pharmacists, and mental health professionals, with expertise and a special interest in diabetes (Kakkar & Puri, 2016). It is essential in this collaborative and integrated team approach that individuals with diabetes assume an active role in their care. Thus, with this insight, the researcher seeks to explore if the concerns addressed above are also characteristic to the South African context, and to the Type 1 adolescent diabetic population.

2.2.2 Adolescent experience

Adolescence refers to the developmental stage in which young people experience physical, emotional, social and cognitive changes as they transition from childhood to adulthood (McLeod, 2018; Piaget, 1936). King et al (2017) assert the adolescent developmental stage is most difficult to negotiate the demands of Type 1 diabetes care regimen, and is therefore, a troublesome period, as self-care behaviour and glycemic control tend to deteriorate. While undergoing major physical changes and trying to establish independence, adolescent Type 1 diabetics are forced to consider the limitations of this disease on a daily basis (King et al, 2017). In their study on adolescents' perceptions of the transitional processes from parental management to self-management, Strand et al (2019) found that adolescents have an additional struggle toward the desired independent state of 'normal' development, dictated by their dependent state as a consequence of the need for self-care vigilance, daily insulin injections, and constant blood glucose monitoring.

Furthermore, Kakkar and Puri (2016) note that Type 1 diabetic adolescents are in an unenviable situation: on one hand, they confront developmental changes and problems, and on the other hand they are trying to improve their control over the disease, in order to achieve a desired quality of life. These developmental challenges are also referred to as life transition processes. As discussed in the introduction of this research report, these developmental challenges can be as a result of physical, cognitive and social changes that are occurring in the adolescent's life (Young-Hymen et al, 2016). A study by Strand et al (2019) expands more on the concept of life transitioning processes, and highlights that they can be developmental (becoming a young adult), related to health and illness (from being healthy, to being diagnosed with Type 1 diabetes), organisational (transferring from pediatric care to adult-focused care), and situational (from feeling fine, to experiencing hypoglycemic/hyperglycemic attacks). This information above highlights to the researcher, the need to consider the transitional experiences any adolescent navigates, and the impact of this on one who has been diagnosed with Type 1 diabetes. Now that these developmental challenges have been explored, it is necessary to consider their impact on self-care behaviours to the management of adolescent Type 1 diabetes.

2.2.3 Self-care behaviours

Webber, Guo and Mann (2013) as cited in Amelia (2018), define self-care as one's ability, with the support of one's family and the community, to promote health, maintain health, prevent illness and cope with disability and disease, with or without the help of healthcare providers. In this study, however, self-care focuses on the diabetic individuals' abilities to cope with the management of the disease, with the help of healthcare providers and family.

Amelia (2018) argues there are seven main self-care behaviours, which form part of Type 1 diabetes care, namely: blood glucose monitoring; insulin administration; healthy eating; physical activity; healthy coping; reducing risks and problem solving. Amelia (2018) further asserts that although self-care behaviours imply the individual assumes sole responsibility for managing and making decisions regarding coping with the disease, these behaviours are products of other influences. For example, in a study by Dehayem et al (2016), it is argued that healthcare providers play a vital role in motivating self-management, as they provide their diabetic patients with therapeutic education, which is central to the management of the disease. In addition to these findings, Amelia (2018) states that elements derived from the individual's

self-insight, such as their beliefs, knowledge, attitudes and concerns about their health, influence self-care behaviours too. So, in addition to therapeutic education, individuals are still able to adhere to the teachings, or disregard them, based on their attitudes towards treatment. Considering the mindset of an adolescent, as described by Piaget (1936), this insight

Following the guidelines of this study's theoretical foundation, it is therefore, necessary to consider the combination of both personal and socio-environmental factors as influential to self-care behaviours and as a result, to management of this disease. For the purposes of this study, these factors will be conceptualised as psychosocial influences.

2.2.4 Psychosocial influences

Young and Unachukwu (2012) argue that psychosocial influences can result in non-adherence to medications, poor quality of life, long-term complications, and even a lack of interest in managing health conditions. However, these factors can also contribute positively to the management of Type 1 diabetes (Hegelson and Palladino, 2012). In their study on self-care behaviours amongst Type 1 adolescent diabetics, Hegelson and Palladino (2012), found that risk factors impede adjustment, whereas resistance factors facilitate adjustment. This study, thus, aims to explore those risk and resistance factors that are deemed most relevant to the study's target population: adolescents. These factors will be categorised as personal and social characteristics.

2.2.4.1 Personal characteristics

Hegelson and Palladino (2012), argue that the personal characteristic which has received the most attention in literature on diabetes is the resistance factor, self-efficacy. Bandura (1994) as cited in Chew, Ghazali and Fernandez (2014) defines self-efficacy as having self-belief in one's own ability to carry out, or overcome difficulties inherent in specific tasks. This psychological factor is said to be embedded within the theory of self-regulation, and suggests that people with higher self-efficacy would keep improving in life, due to their positive self-feedback and setting higher new targets to achieve in progressive efforts (Chew et al, 2014). Although not a personality trait, self-regulation can be linked to personality traits such as conscientiousness and openness to experience of The Five Factor Model. For example, conscientiousness generally concerns an individual's sense of responsibility and duty, whilst openness to experience, concerns one's level of inquisitiveness (Semenya, 2016). Thus, with regards to exploring how

self-regulation as a personal characteristic influences self-care behaviours amongst adolescents, it is expected those adolescents who perceive themselves as capable of executing the required tasks, will enact better self-care behaviours.

Where risk factors to self-care behaviours are concerned, Hegelson and Palladino (2012) assert that psychological distress contributes greatly, to the decline in glycemic control and overall Type 1 diabetes management. Psychological distress may directly affect glycemic control via counter-regulatory hormones, or may indirectly affect glycemic control by detracting Type 1 diabetics from self-care behavior. Gonzalez et al (2008) as cited in Hegelson and Palladino (2012) specify diabetes distress as one such psychological distress, most prevalent amongst adolescents. Diabetes distress is caused by a significant negative emotional reaction to the implication of the disease's diagnosis on an adolescent's lifestyle, worry and fear regarding their health and life expectancy, as well as the behavioural restrictions (Gonzalez et al, 2008; Hegelson & Palladino, 2012). This suggests to the researcher that high levels of diabetes distress are linked to lower levels of self-efficacy, poor self-regulation and, therefore, reduced self-care behaviours.

2.2.4.2 Social characteristics

The social characteristic that has been observed to be a resistance factor to self-care behaviours, is the support provided by healthcare providers. According to a study by Young-Hyman et al (2016), the diabetes healthcare team is skilled to provide diagnostic and therapeutic actions that are known or believed to favorably affect health outcomes of patients with diabetes. The accessibility of such a team, although considered to be part of the standard diabetes care regimen, is not always readily available to the entire population. For example, in an Australian-Danish qualitative study on the adolescent experiences of managing diabetes, Rasmussen, Maindel, Livingston, Dunning and Lorentzen (2016), found that the healthcare system in each country, differs in terms of what is freely accessible and what comes at a cost.

In Denmark for instance, it was found that the healthcare system is tax-funded, and therefore access to general practitioners is free to all citizens (Rasmussen et al, 2016). Both types of diabetes are diagnosed and managed in general hospitals and in diabetes clinics, depending on the general practitioners' competencies (Rasmussen et al, 2016). In Australia, however, the expertise of general practitioners is reserved for Type 2 diabetes, which is argued to be more

easily managed in comparison to Type 1 diabetes, whilst specialists in diabetes care fall under private practice, which is accessible, but comes at a cost (Rasmussen et al, 2016). Furthermore, Landau (2013) argues that Type 1 diabetes care in South Africa is a tale of two sectors: the public sector and the private sector, and this division often implies that those within the private sector have access to what is referred to as 'standard care' for Type 1 diabetes, in developed countries.

The study by Hegelson and Palladino (2012), argues that family conflict around diabetes management is a risk factor for poor diabetes outcomes, whilst parental involvement in the diabetes regimen is a resistance factor. This statement, however, is argued to be situational, as parental involvement can also be a risk factor in cases where the involvement is 'too much'. For example, according to a study by Strand et al (2019), some Type 1 adolescents prefer to receive information on how to take care of themselves, directly from their healthcare providers, since parental involvement has become less necessary with the progression towards greater levels of independence. For situations in which parents insist on remaining overly involved, it can result in the delayed handover or self-management protocols and responsibilities to a developmentally ready adolescent. However, Strand et al (2019) assert that such an issue can be resolved through education sessions involving healthcare providers, diabetic patients and their parents, which aim to encourage family support and healthy/appropriate skills, while discouraging conflicts from arising.

2.3 Conceptualisation

- Adolescents: refer to a group of young people who are experiencing physical, cognitive, behavioural and emotional-development, as they transition from childhood to young adulthood (Piaget, 2936). Strand et al (2016) share that adolescent development occurs in three stages, namely: early-adolescence (ages 10-14), middle-adolescence (15-17), and late/young adolescence (18-24). For the purposes of this study, however, adolescents refer to those in the middle-adolescence stage.
- Glycemic control: medically refers to blood sugar levels (Hegelson & Palladino, 2012). For the purposes of this research proposal, glycemic control refers to the regulation of blood sugar levels amongst Type 1 diabetics.

- Healthcare provider: refers to any licensed physician or healthcare practitioner, who is certified to perform specified health services consistent with a healthcare facility (World Health Organisation, 2019). In this study, healthcare providers refer to physicians, dietitians and other medical personnel, who offer medical support to Type 1 diabetics.
- Psychosocial influences: refers to the combined influence of psychological and socio-environmental factors, on the individual's physical and mental wellness (Erikson, 1974, as cited in Lee et al, 2016). For the purposes of this study, psychosocial influences refer to the psychological and socio-environmental influences on the physical and mental health of Type 1 adolescent diabetics.
- Self-care behaviour: is broadly concerned with one's act of caring for one's self, and/or coping with a health condition (Hegelson & Palladino, 2012). In this study, self-care behaviour refers to the administration of insulin, the adherence to diet and exercise, and blood glucose testing.
- Type 1 diabetes: refers to a chronic endocrine disease, that occurs as a result of the immune system attacking the insulin-producing beta cells in the pancreas (World Health Organisation, 2020).

3. RESEARCH METHODOLOGY

This section of the research report provides a detailed discussion of the research design and methodology used in the current study.

3.1 Outline of paradigm

A research paradigm, originally proposed by Kuhn in 1962, refers to an integrated cluster of beliefs and dictates to a researcher, in a particular discipline, how research should be conducted, and how results should be interpreted (Jansen, 2019). Knowing to which paradigm to ascribe, as a researcher, is important because it determines which questions are worth investigating, and which processes are required to determine the answers that are deemed acceptable to these questions (Jansen, 2019). A research paradigm can be classified into three

philosophically distinct categories, namely: positivism, interpretivism and critical realism (Maree, 2019).

Thanh and Thanh (2015) share that in seeking the answer to the research question, a researcher guided by the interpretivist paradigm, uses the experiences of his/her informants to construct and interpret, as well as gain deeper insight into a phenomenon. As such, the researcher has chosen to use an interpretivist, as the researcher aims to gain an in-depth understanding of how psychosocial factors influence self-care behaviours on the management of Type 1 adolescent diabetes, from the expert opinions of healthcare providers. Maree (2019) further suggests that the researcher's view of the social world is guided by three paradigmatic assumptions, namely: ontology, epistemology and methodology.

Ontology refers to the researcher's beliefs about the nature of reality (Nieuwenhuis, 2019). Nieuwenhuis (2019) states that the ontological position of the researcher is concerned with questions on what reality is, and how it is constructed. According to Jansen (2019), there are three main types of ontologies: realism, relativism and materialism. The interpretivist paradigm, however, aligns with the relativist approach (Jansen, 2019). According to Jansen (2019), the relativist view suggests there are multiple realities that exist, as the social world is a space which is experienced differently from person to person. Thus, reality from this perspective, is socially constructed. The relativist ontological position is relevant to this study, as the researcher is interested in the lived experiences of managing Type 1 diabetes, as described by those whose roles lie in supporting those diagnosed with this disease.

Whereas ontology is concerned with the nature of reality, epistemology is concerned with how knowledge is acquired by the researcher (Nieuwenhuis, 2019). Epistemology focusses on the relationship between the researcher and his/her research participants (Nieuwenhuis, 2019). Jansen (2019) argues that there are two main ways in which the researcher gathers information, namely: objectively and subjectively. The subjective approach, also known as the emic position, suggests that the researcher's knowledge about the social world is generated through interaction with the research participants (Nieuwenhuis, 2019). Furthermore, it is argued that this subjective approach implies the researcher's direct involvement in gathering knowledge from his/her research participants, as opposed to relying on statistical evidence or merely observing the social experiences of those involved (Jansen, 2019). Thus, the above epistemological assumption is applicable to this study, as the researcher's aim is to understand,

analyse and interpret healthcare providers' opinions and insights of their patients, by interacting with them directly. Maree (2019) suggests that the researcher's ontological assumptions about the social world thus, dictates his/her epistemological assumptions, which then dictates the research methodology.

Methodology is concerned with how knowledge is discovered and analysed in a systematic manner (Nieuwenhuis, 2019). According to a study by Thanh and Thanh (2015), this refers to the philosophies that guide how knowledge should be gathered, and is shaped by the values of the researcher. The methods the researcher may choose in this regard, refer to the processes of collecting data such as text, interviews and reflective sessions, from the researcher's informants (Jansen, 2019). The research methodology applicable to this specific study, will be discussed in the sections to come.

3.2 Research approach and design

Due to the nature and purpose of this study, a qualitative research design is most applicable, as it aims to collect and interpret data that has been explored and understood from the participants' perspectives (Jansen, 2019). Therefore, by using a qualitative methodology, the researcher is able to generate rich and detailed information, collected from multi-faceted and complex phenomena, in a social context (Nieuwenhuis, 2019). Astalin (2013) argues there are four major types of qualitative research designs. This study, however, uses a phenomenology research design. In this study, the researcher seeks to understand Type 1 diabetes as a phenomenon, and to describe the lived experiences of managing the disease. Therefore, a phenomenological approach is applicable, as it focuses on the meaning that certain lived experiences hold for participants (Nieuwenhuis, 2019).

This study uses an exploratory approach. Maree (2019) suggests that exploratory research studies are conducted for obtaining a better understanding of the existing research problem of which, the researcher has very little, or no past information, to reference. Thus, the exploratory approach is suited to this study, as the researcher is interested in learning more about key issues pertaining to life as a Type 1 adolescent diabetic patient, within the South African context, so as to positively contribute to the information that currently informs how to support this community, without actually producing conclusive results.

Qualitative research is “primarily an inductive process of organising data into categories and identifying patterns amongst categories” (Astalin, 2013; McMillan & Shumacher, 1993). This insight, thus, suggests to the researcher that data and meaning emerge naturally from the research context, as the researcher is guided by the research question and objectives, and will ultimately reach broader generalisations and theories. For this reason, this study was conducted inductively.

A cross-sectional design is suited to this study. Nieuwenhuis (2019) mentions that a cross-sectional design is an observational research method, in which data is gathered once from the researcher’s sample, with no repeats. In this study, the research was carried out at a single point in time, and data was collected on one occasion, in the form of in-depth interviews.

3.3 Population and sampling

3.3.1 Population

3.3.1.1 Target population

A research population refers to a collection of individuals or objects, that is the main focus of a research study (Maree & Pietersen, 2019). A target population, therefore, refers to the total group of people from/about whom the researcher seeks to gather information (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014). The target population for this study is all adolescent Type 1 diabetes healthcare providers in South Africa. However, due to the target population being too large, the researcher had to draw a smaller, more manageable group from the target population, from which data could be collected—this is referred to as an accessible population (Astalin, 2013).

3.3.1.2 Accessible population

An accessible population refers to the subset of a target population, composed of individuals of the target population who are willing to participate, and will be available at the time of the study (Astalin, 2013). Du Plooy-Cilliers et al (2014) argue that the accessible population group needs to be completely representative of the whole target population, to ensure the generalisation of the researcher’s findings to the population of interest. In this research study, the accessible

population included all adolescent Type 1 diabetes healthcare providers, whose professional services are based in the Johannesburg region.

3.3.1.3 Population parameters

Population parameters refer to specific and definitive characteristics of a researcher's accessible population (Astalin, 2013). This suggests that every individual in the accessible population, need to have a specific set of characteristics as defined by the research study guidelines, in order to meet the requirements of being suitable to participate in the study.

The population parameters in this current study included:

- All Type 1 diabetes healthcare providers, who are based in Johannesburg, specifically physicians, dietitians and diabetes-educators.
- They must work directly and specifically, with Type 1 diabetic adolescents (aged 15-17).
- All participants needed to be accessible despite the impact of the Coronavirus at the time of the research study.

3.3.2 Sampling

3.3.2.1 Unit of analysis

A unit of analysis refers to the smallest element that can be investigated (Du Plooy-Cilliers et al, 2014). Atsalin (2013) suggests it is the 'what' and 'who' from which data was collected. In this study, data was collected from individuals, who serve as healthcare providers to adolescent Type 1 diabetics.

3.3.2.2 Probability or non-probability sampling

Maree and Pietersen (2019), argue that population samples tend to be large, which may pose time and financial constraints to the researcher. It is, therefore, necessary for the researcher to draw a population sample that will be most representative of the larger population of choice, so that findings can tell more about the general accessible population as a whole (Maree & Pietersen, 2019). There are two major classes to which sampling methods belong: probability sampling and non-probability sampling. Probability sampling is based on the principle that all

participants in the researcher's accessible population, have an equal chance of being selected for the sample group (Maree & Pietersen, 2019). Non-probability sampling on the other hand, suggests that the participants from the researcher's accessible population, do not have an equal chance to be selected for the sample group (Howitt & Crammer, 2017). For the purposes of this study, non-probability sampling was utilised, which entailed participants being selected purposefully, and not at random, to mirror specific characteristics of individuals within the population being sampled (Du Plooy-Cilliers et al, 2014).

A qualitative research design is aimed at contextualisation rather than generalisation (Maree & Pietersen, 2019), therefore, it was not theoretically sensible to utilise probability sampling methods, as specific participants in this study, were selected by virtue of attributes/characteristics considered to be representative of the greater target population, and could provide more information about the research topic at hand. Accordingly, the non-probability sampling method adopted for this research study was purposive sampling. Maree and Pietersen (2019) reflect that with purposive sampling methods, the researcher purposefully chooses the elements to be included in the sample, based on a set list of characteristics. Thus, the population that consists of all the characteristics that are required by the researcher will be included, while the population that does not contain all the required characteristics will be disregarded (Du Plooy-Cilliers et al, 2014). The use of this sampling method, is not without a limitation, as it implies a level of bias by the researcher where ethical considerations are concerned. Furthermore, Maree and Pietersen (2019) assert that purposive sampling methods require participants to meet the study's criteria before they can participate—quantitative research emphasises the need for general, empiracle findings, whilst qualitative research values gaining depth and perspective (Du-Plooy Cilliers et al, 2014), and so fewer participants allow for this.

3.3.2.3 Sample size

This study's exact sample size depended on the number of participants willing to volunteer their time, and the kind of information they would provide to the researcher, in order to answer the research question. Even though the researcher had expected 5 participants, 6 participants confirmed to participation, with the 6th member obtained by referral, on the day of data collection. The inclusion of the 6th member was guided by the need to obtain data saturation. According to a study by Astalin (2013), saturation occurs when adding more participants to the study, does not result in additional perspective or information to be obtained. The addition of a

5th participant was not necessarily overly demanding on the researcher's time and resources, and so it made sense to include the person in the study. This is also an example of a snowball sampling method, such that from being in the vicinity as the previously 5 participants, the research

3.4 Data collection

3.4.1 Data collection method

In this study, data was collected through the use of in-depth interviews. Nieuwenhuis (2019) states that interviews are an important technique to use in qualitative research studies, as they involve verbal communication between the researcher and his/her participants, which can be a valuable source for the researcher, who seeks to understand the world through the eyes of his/her participants. The particular type of interviews the researcher conducted in this study were semi-structured interviews.

According to a study by Thanh and Thanh (2015), semi-structured interviews are commonly used in research to corroborate data emerging from other sources, and are usually based on a line of enquiry developed by the researcher prior to the interview. In this study, the researcher formulated a set of open-ended questions, with the aim of allowing for further probing and clarification. In doing so, detailed information would be gained regarding the healthcare providers' perceptions of adolescent Type 1 diabetes management.

In terms of how the interview questions were formulated, the researcher considered the research question, and broke it down into objectives that would guide the line of the researcher's questioning. This line of questioning was expected to help the researcher gain an in-depth understanding of the psychosocial factors that influence adolescent Type 1 diabetes management. The researcher sought to gain as much insight as possible by asking open-ended questions, to allow for the professionals to offer as much insight as possible. However, probing questions also enabled the researcher to gain clarity and for the researcher to get a sense of whether or not additional information needs to be considered that had previously not been identified as being valuable.

As much as collecting data through the use of a semi-structured interview provided a number of benefits, it must be noted that it also entailed certain disadvantages, where researcher involvement is concerned. One such a disadvantage includes the researcher's need to be

mindful of an interrogation error. An interrogation error occurs when the researcher phrases the questions differently from one participant to another, therefore, resulting in an inconsistent response to the questions (Thanh & Thanh, 2015). To avoid this, the researcher ensured to formulate a list of questions that were broad and general enough, to be asked from the different participants, as opposed to asking different questions from different participants.

An example of how the questions were formulated is revised in the table below, even though the questions were later restructured in a way that would not result in the participants' responses to be lead by the researcher:

Research question	Research objectives	Interview questions
What psychosocial factors influence the management of Type 1 diabetes amongst adolescents?	>To explore various factors that constitute psychosocial influences on the management of Type 1 diabetes.	>What kind of psychosocial factors influence the management of Type 1 diabetes amongst adolescents? >Can you tell me more about the psychosocial factors that promote adherence to self-care behaviours amongst adolescents? >Can you tell me more about the psychosocial factors that hinder adherence to self-care behaviours amongst adolescents?
	>To gain deeper insight into the developmental stage of adolescents, and to understand how this impacts their experiences of managing Type 1 diabetes.	>Can you tell me how the management of Type 1 diabetes differs between adolescents and other age groups? > To what extent, does personality makeup, play a role in Type 1 diabetes management?
	>To learn more about what healthcare providers believe needs to be in place for adolescents living with Type 1 diabetes,	> Can you tell me your thoughts around the amount of information Type 1 diabetics currently have access to in comparison to Type 2 diabetics? >How does the management thereof differ between Type 1 and Type 2 diabetic patients?

	to effectively manage the disease.	>What are some of the challenges that you, as a healthcare provider, have observed to be unique to the Type 1 adolescent diabetic population? >Are there differences in Type 1 diabetes care between low-income and middle-income groups in South Africa? >Are there differences in Type 1 diabetes care between South Africa and other countries?
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3.4.2 Application of data collection method.

Prior to the collection of data, the researcher sent each individual participant an email specifying the topic that will be covered. The purpose of the email was to invite the participants to voluntarily participate in this study, as well as to prepare them of what to expect, should they agree to participate. Once approval was obtained from the participant, an email was sent containing consent forms, which specified what the study was about, and what their participation would contribute to. Participants needed to give consent to being interviewed, and for the interview process to be audio-recorded. The use of an audio record was to ensure that information is recorded verbatim. Participants were also told that their confidentiality, as well as anonymity, would be observed. In terms of setting a time, the researcher could not provide a specific time-frame as the length of the interviews would be depended on the amount of time it would take the respondents to answer the interview questions. The researcher did, however, set a time limit of not more than an hour.

After the participants had given signed consent to participate, their availability was consulted, and a meeting was set on the day and time that best suited the participants. It is important to note that all interviews were conducted personally, at a venue chosen by the participants, which was their workplace. As such, all interviews were conducted at the Center for Diabetes and Endocrinology, based in Johannesburg. Upon meeting with the participants, the researcher firstly thanked the participants for their time, and reminded them of their right to not participate, and to end the interview at any time if they wanted to. The participants were also awarded an opportunity to ask questions prior to the commencement of the interviews.

Following this, the researcher conducted the interviews and asked ten open-ended questions that were related to the main research question, and research objectives. Thereafter, the researcher transcribed the interview in a notebook, whilst recording the interview, for further analysis and interpretation. The researcher took note of the participants' tone of voice as well as facial expressions. With regard to recording the interview sessions, Saunders, Lewis and Thornhill (2012) share that audio recordings have both advantages and disadvantages. For example, audio recordings allow the researcher to concentrate on the interview, while taking notes. On the contrary, it may inhibit some interviewee responses and thus, reduce reliability (Saunders et al, 2012). Saunders et al (2012) also added that the presence of a recorder may also result in the possibility of the interviewees being too focused on the recorder and not the interview process itself. To mitigate these limitations, the researcher made use of a credibility strategy, which will be discussed in later sections.

3.5 Data analysis

3.5.1 Data analysis method

The data analysis method in qualitative research is concerned with understanding the data collected from research participants, by adding order, structure and meaning to the collected data (Maree & Pietersen, 2019). For this reason, thematic analysis was carried out in this study.

Howitt and Cramer (2017) share that thematic analysis is usually applied to a set of texts, such as interview scripts, where the researcher closely examines the collected data to identify common themes that repeatedly surface. Identifying themes is important, for the purposes of this study, as they relate to the concepts from the literature review, thus, giving more meaning. The data collected from the semi-structured interview process in this study, was analysed, whilst careful attention was paid to information that would contribute to an easy categorisation of broad themes, observed to be meaningful to understanding the psychosocial factors that influence adolescent Type 1 diabetes. Maguire and Delahunt (2017) share that a combination of pitfalls exist when using thematic analysis, specifically that: there may be a non-coherence and inconsistency in the generation of themes, a mismatch between theoretical frameworks and analytical claims made, and utilising the interview schedule as the reported themes, to name a few.

Despite these pitfalls, the researcher still considered thematic analysis as a suitable data analysis method for this study, as the overall focus of the study is to obtain an in-depth analysis of the data collected. Moreover, the researcher took these pitfalls into consideration, and ensured that the analysis was directed by the study's research question and objectives alone, and observed potential biases.

Braun and Clarke (2006) propose six steps of analysing data using thematic analysis. However, the eight-step process will be used for this study, as guided by Du-Plooy Cilliers et al (2014):

Preparing the data: this stage requires the researcher to organise and transcribe the raw data collected from interviews and recordings into written text, before the official analysis process can begin (Maguire & Delahunt, 2017).

Defining the coding unit to be analysed: the researcher needs to decide on whether to use individual words, phrases, symbols, sentences or paragraphs as coding units (Du-Plooy et al, 2014). Thus, a means of organising data into manageable chunks will be achieved at this stage. Du-Plooy Cilliers et al (2014) note that coding is the process of reading carefully through one's transcribed data, line by line, and dividing it into meaningful analytical units.

Developing categories and a coding scheme or conceptual framework: this step involves grouping related coding units together, to form categories of codes (Maguire & Delahunt, 2017). Howitt and Crammer (2017) assert that the researcher may also construct his/her own labels for codes by using common properties of the codes, or concepts based on the data that is being analysed.

Testing the coding scheme on a sample text: this step involves testing the clarity and consistency of the researcher's category definitions on a sample of the researcher's data (Howitt & Crammer, 2017). If the level of consistency is low, coding rules and definitions need to be redefined (Maguire & Delahunt, 2017). At this stage, all doubts and problems related to the researcher's coding categories needs to be resolved.

Coding all text: this refers to the careful scrutiny of the researcher's data and taking note of all the relevant and meaningful sections and items (Maree & Pietersen, 2019).

Assessing consistent precision: once all the coding has been completed, the researcher needs to recheck the consistency with which the coding was conducted (Howitt & Crammer, 2017).

Drawing conclusions from the data: this step involves making sense of the data, and getting meaning of the information collected by comparing it to the literature and theories previously reviewed (Du-Plooy Cilliers et al, 2014).

Reporting methods and findings: this step involves compiling an official report of the interpreted findings, so as to address the study's research question(s) and objectives (Maguire & Delahunt, 2017).

3.5.2 Data analysis application

The identification of themes is one part of thematic analysis. The analysis itself, entails the interpretation and meaning attached to the data collected, as opposed to simply summarising it. This is done by linking it to the theory and literature analysed in the literature review section. Thus, in this study, the 8-step process was used as follows:

The researcher personally transcribed the audio-recorded data verbatim. This was done to ensure that all relevant data was captured, including the observational notes that were hand-written during the interview processes. Following the transcription process, the researcher then replayed the recorded data, whilst going through each transcription, to ensure that the data was collected completely, accurately and free from error. The participants' identities were then removed from the transcriptions, and were labelled interviewee 1 to interviewer 5, to ensure the anonymity of the participants. Thereafter, the researcher studied through the transcripts repeatedly, in order to familiarise herself with the data.

The researcher was concerned with addressing a specific research question and analysed the data accordingly—each segment of data that was relevant to the research question and objectives, was coded. This process included using individual phrases as the coding unit. A colour-coding system was used to separate codes, and to categorise them into meaningful themes. Thus, every theme that arose from each transcript, was highlighted and classified as either main or subthemes. The unanticipated themes that came up were not redefined nor disregarded, but were added to the collection of existing themes, and perceived as meaningful in trying to answer the research question. This was done through the use of the microanalysis technique, where the researcher read through parts of the text line by line. After carefully analysing the text, the researcher scanned through the text once again, comparing it the literature and theories reviewed previously, so as to draw a conclusion of how the themes

address the study's research question: what psychosocial factors influence the management of Type 1 diabetes amongst adolescents?

4. FINDINGS AND INTERPRETATION OF FINDINGS

The purpose of this study was to explore the psychosocial implications on the management of Type 1 diabetes amongst adolescents, from the perspective of healthcare providers, within the South African context. Participants were asked to respond to ten semi-structured interview questions, formulated from the study's research question and objectives. These participants included healthcare providers who work directly with Type 1 diabetic adolescents, and consisted of: three endocrinologists; two diabetes educators and one dietitian. The participants' names were changed to interviewee 1 – interviewee 6, to ensure anonymity and confidentiality. The thematic analysis of the interview transcriptions led to the identification of four major themes, to be specific: polarised healthcare system, adolescent experience, access to information and support structures. This section, thus, serves as a presentation and interpretation of the main themes and subthemes, in relation to previous literature.

Theme 1: polarised healthcare system

The quality of healthcare provision from a South African context, compared to that of other countries, was noted by the researcher, as having an impact on the general outcomes of diabetes management, and potentially, constituting a psychosocial influence. In the review of previous literature section, it was noted that the accessibility to a diabetes-healthcare facility is a resistance psychosocial factor to self-care behaviours amongst Type 1 diabetics in general, although its availability is restricted in developing countries (Kakkar & Puri, 2016). The researcher thus, wanted to explore extent to which this is true in the South African context. When asked if there are any differences in Type 1 diabetes care between different income groups in South Africa, the participants agreed that there are differences, particularly in the availability of, and accessibility to standard Type 1 diabetes care. The participants emphasised that the healthcare system in South Africa is polarised, meaning it exists as two opposing systems: state care versus private care. The researcher noted these healthcare systems as subthemes:

State care

Young and Unachukwu (2012) argue that standard Type 1 diabetes care includes access to blood glucose testing and monitoring equipment, as well as regular access to a healthcare team: dietician, physician, and diabetes educators. Such care, however, seems to be more a luxury, than it is basic, in a South Africa context, as revealed by the participants' responses:

"Yes, other countries, like funded-countries—Canada, Israel, Australia, where there is state provision of quality care, everybody is entitled to the same, whereas in this country, if you can afford it, you can have it. If you can't, tough luck" (Interviewee 5).

"So the low-income...there is a huge lack of education. And with the medicine that's available to them, they do not always have the ability to do carb-counting and take short-acting insulin" (Interviewee 2).

Participants characterised state care as predominantly accessed by members of low income groups. Where Type 1 diabetes care is concerned, patients receiving state care were argued to be at a disadvantage, as it implies they have minimal or no access to medical technological advancements, due to them being costly.

Private care

Landau (2013) argues that Type 1 diabetes care in South Africa is a tale of two sectors: the public sector and the private sector, and this division often implies those within the private sector have access to what is referred to as 'general care' for Type 1 diabetes, in developed countries. The participants in this current study, supported this argument as follows:

"Absolutely, it's a major division. It's totally polarised. When patients come here, Type 1s, they get the best insulin, they get as many strips as they need, and most this medical aid is paying for them, they get full education, and full support. The public sector, they're getting inferior insulin, they can't get testing strips, there's minimal education...big difference" (Interviewee 1).

"...in private care, we have access to a much broader range of insulins as well as other oral agents, especially the newer ones for type 1 diabetes such as SGLT true inheritors and injectables like GLP1. So, and those are not at all available in state care...like at all." (Interviewee 6)

Thus, from these findings, the researcher notes private care doesn't only guarantee access to basic diabetes care, but to newer advances of technologies that will aid in even better management. Thus, it is evident that the accessibility to appropriate healthcare is more an ideal situation than a practical one, due to the division in South African healthcare system.

Theme 2: Adolescent experience

Adolescent experience as a theme, was one of the main themes throughout the research study, as the research was based on the adolescent experiences of managing Type 1 diabetes. Based on current literature, the researcher had anticipated that the adolescent developmental stage would add another level of complexity to Type 1 diabetes management. When asked about the challenges that they have observed to be unique to the adolescent population, participants made references to: developmental transitions and risk-taking behaviour.

developmental transitions

Strand et al (2019) broadly define developmental transitions as a process of becoming an adult. Strand et al (2019) further highlight three forms of developmental transitions that are typical to adolescent Type 1 diabetics: transitions related to health and illness (from being healthy, to being diagnosed with Type 1 diabetes), organisational transitions (transferring from pediatric care to adult-focused care), and situational transitions (from feeling fine, to experiencing hypoglycemic/hyperglycemic attacks). The participants from this current study, however, made reference to organisational transitions, as well as the adolescent's transitioning from parental to independent care as follows:

"I think the thing that comes in, especially with Type 1 diabetes is that your healthcare team becomes part of your life management team right, so you develop this relationship with your doctor, with your dietitian...all these healthcare teams. Then, when it comes to changing over to a new environment of management, it can be quite daunting because having to explain who you are as a person, you know, you'd rather just stay with who you know" (Interviewee 3).

"The struggle for independence from a parental caregiver, particularly at the transition, during adolescence" (Interviewee 5).

"So, obviously, the amount of care doesn't change between adolescents and adults, but there is now a transition of care, from parent to child. But as the child becomes older, and gets into adolescence, there now has to be the transition of who is in charge of their diabetes. So the adolescents then need to take over their management of type 1 diabetes, and this may be difficult for some" (Interviewee 6).

In short, the participants state that in addition to the developmental transition, the transition of Type 1 diabetes management amongst life transitions influence how smooth and/or difficult, the adolescents' adaptations will be in a new environment. If smooth, then adolescents will not struggle with maintaining optimal blood glucose levels. If difficult, then adolescents will most likely be challenged by the management of the disease.

Risk-taking behaviour

Risk-taking behaviour as a subtheme, was discussed mainly as rebellious behaviour.

“So, there are often patients with established Type 1 diabetes—so they had Type 1 diabetes for a number of years—may have previously been well-controlled, and they may start to rebel because of the large amounts of time that are actually spent in caring for yourself” (Interviewee 6).

Arguably, rebellion is most characteristic of the adolescent population—from underage drinking, to engaging in risky sexual behaviours, as noted from a study by King et al (2017). However, in this study, participants deviated from discussing rebellion as merely being linked to a certain personality trait, but addressed rebellion as a consequence of diabetes-burnout—having lived long with diabetes, that it becomes overwhelming:

“I think adolescence is quite tricky because people tend to...or depends on when the person got diabetes, so if they got it at a young age, and they now get to their teenage years, they actually become quite rebellious, and they almost just want to forget about their diabetes. Uhm they also might have something called ‘burn-out’—diabetes burn-out, where they’ve lived with diabetes for so long, and they also realise that diabetes is something that’s always with them” (Interviewee 4).

Participants also argued that with adolescent girls in particular, psychological distress such as an impaired self-image, result in them suffering from diabulima—an eating disorder described below:

“So one thing we see, also from an adolescent age-group, well especially with girls, is they tend to—there’s an eating disorder called ‘diabulimia’—and that is when girls are become very aware of their weight. So, what they do is that they actually withhold their insulin, or they give much less because they start to realise that by doing that, they can actually lose weight. It’s not a healthy way to do it at all, and there can be too many complications” (Interviewee 4).

This, thus, supports Hegelson and Palladino’s (2012) view on psychological distress as a risk factor to positive diabetes outcomes, common amongst adolescents. Diabulima as a psychological distress supports Gonzalez et al (2008) study on diabetes-distress and how it influences self-care behaviours, and therefore, optimal glycemic control.

Theme 3: Access to information.

In seeking to get a broader understanding of Type 1 diabetes management, the interviews started with a broad opening question about the healthcare practitioners’ thoughts on the amount of information that currently exists for Type 1 diabetics. From the participants’

responses, the researcher found that access to information was a prominent theme. Information in this regard concerned therapeutic education around diabetes as a health condition. The participants discussed this theme in relation to its perceived sources: social media and diabetes healthcare team.

Social media

Social media refers to interactive technological platforms that facilitate the creation and sharing of information, ideas and other forms of expression via virtual communities and networks (). These include platforms such as blogs, Facebook, and Instagram, to name a few.

“There is probably far more information available to people with Type 1 diabetes. Generally speaking, through a social media type of platform, probably because these people are generally younger, more savvy with online communication, and less dependent on their medical visits in order to assist them. They are not waiting for visits six-monthly, to gain information on their condition. However, I don’t think it gets as much limelight as Type 2 diabetes, and it’s still regarded as somewhat an ‘orphan’ disease” (Interviewee 5).

“And when it comes to the information, especially that the media portrays, and that there is access to it online, it’s very much Type 2 driven. This is because of the amount of people that live with type 2 diabetes—the prevalence is a lot higher for people with Type 2 diabetes, than it is for type 1 diabetes” (Interviewee 3).

Both interviewee 3 and 5 consider online communication as a dominant source of information amongst the adolescent group. They also argue, to some extent, that not only is the information around diabetes care available, but is likely to lead to a misconception of what Type 1 diabetes, particularly to those who may not be familiar with this health condition. This supports the arguments made by Kakkar and Puri (2016) on Type 1 diabetes being seldom talked about, due to its low incidence rate. The researcher also understands these responses as implying that the general public understands diabetes as largely Type 2 diabetes.

Interviewee 3, however, further argued the benefits of social media platforms:

“But I think that information is changing quite drastically, and leaning towards more information on type 1, from a social media perspective. So in the new era in which we live, I think peer-to-peer information is definitely increasing in the Type 1 community, just because they are sharing their stories, they are sharing their information, they are sharing their daily struggles with living with Type 1 diabetes. So social media is becoming this hub of information now, for people” (Interviewee 3).

Thus, the use of social media as a tool to connect individuals living with Type 1 diabetes creates a supportive community, which is likely to contribute positively to adolescents.

Diabetes healthcare team

The role of the diabetes healthcare team, particularly that of diabetes educators, was argued by the participants as being vital in motivating self-management, as they provide their diabetic patients with therapeutic education, which is central to the management of the disease.

“But besides coming to the center or getting education from us, I don’t think there’s a lot of information out there, and I don’t think a lot of Type 1 diabetics meet other Type 1s, whereas a lot of Type 2s know someone else with Type 2 diabetes” (Interviewee 4).

Here, Interviewee 4 addresses another informatory aspect: peer-to-peer relationships. Dehayem (2016) argue that such is achieved through means such as youth camps, where adolescent Type 1 diabetics gather and form a supportive community amongst each other. The need for patients to unite as diabetic community, as opposed to dividing themselves in accordance to their diabetes types, was further argued to be beneficial in fighting against the broader society’s stigmatisation:

“I think there’s a lot of stigma attached to diabetes right...there’s still this stereotypical concept that it’s your fault, and you did something in order to get it” (Interviewee 3)

Both social media and diabetes educator provide a connection between people of the same condition, however social media raises huge concerns of misconceptions, especially since it is most the dominant source hub of information amongst adolescents. Whereas diabetes educator provides credible knowledge and physically creates a diabetes community through youth camps and workshops, but is only accessible to those from private care.

Theme 4: Support structures

Considering the aim of the research study, which is to explore the psychosocial factors that influence the management of adolescent Type 1 diabetes, the researcher found that each participants made reference to the availability of support structures, and the lack thereof, as contributing both risk and resistance psychosocial influences, unique to the adolescent population. Specifically: family dynamics, peer relationships and the schooling.

“But I think that the big thing around adolescence is not only the way in which they manage their own condition, but the way in which their support structure is helping them manage their condition” (interviewee 3).

This, thus, supports Young and Unachukwu’s (2012) argument on Type 1 diabetes requiring an integrative approach, and not an individualistic one.

Family dynamics

Strand et al (2019) argue that parental involvement is the crux of adolescent Type 1 diabetes management. This is because at this age (middle adolescence), adolescents are not independently taking care of themselves, and are, therefore, still the responsibility of their parents.

“Then you have the immediate family that a person with diabetes is associated with, and if that is dysfunctional, abusive, nurturing or any of these adjectives, that will also have an impact—sometimes for better, and sometimes, for worse” (Interviewee 5).

Interviewee 5's statement supports Hegelson and Palladino's (2012), statement on family conflict around diabetes management, being a risk factor for poor diabetes outcomes, whilst a cohesive family environment results in better health outcomes. However, as seen in an argument by Strand et al (2019), too much parental involvement can also act as a risk factor to self-care behaviours, as it often results in the delayed handover or self-management protocols and responsibilities to a developmentally ready adolescent. Thus, an issue of what the correct amount of family support is, arises as noted:

“Difficult, I think it depends on family. And that's a very difficult balance because if the parents are too...restrictive, they rebel. If parents don't supervise them enough, they tend to drift away. They need proper parental supervision, at the right level. I think that's the most important factor” (Interviewee 1).

Peer relationships

Hegelson and Palladino (2012) share that in diabetes literature, peer-relationships are often considered as both support structures, and also obstacles, to appropriate Type 1 diabetes care amongst adolescents. Compared to parents, peers provide more diabetes-related emotional support and companionship, but less diabetes-related instrumental support (Hegelson and Palladino, 2012). This study's participants, however, discussed peer relationships in the light of peer pressure:

“Peer pressure is a major challenge. When you've got an adolescent who's uhm in a crowd of friends, and he's not a leader but a follower in that crowd, and they wanna go to McDonalds for a milkshake, he finds it very difficult to say 'no'. I am talking alone from drugs and smoking and alcohol and so forth, it's a bigger deal. But even in terms of just what they are doing day by day, they want to be with their friends. They don't want to say 'I am different'. When friends go to McDonalds's, they also don't want to say “let's go to Nando's because its healthier” (Interviewee 1).

Schooling environment

Although not discussed in great depth, the researcher was still able to make sense of the mere mentioning of the schooling environment, as a very important psychosocial factor. This is because, apart from those who are home-schooled, adolescents spend most of their time at school—about eight hours a day, and five days a week. Thus, whether or not they receive some level of support or even acknowledgement of their condition by their school teachers for instance, their management of the disease during school hours will be highly impacted. One participant notes:

“an understanding in the schooling environment, where there are teachers who understand diabetes, and allow them to have some sugar if they’re going low, allow them to test their blood sugars, that’s really what works for them” (Interviewee 1).

Bullying in schools was also addressed by the participants as being a risk factor to an adolescent’s management of their disease in the schooling environment:

“Others will be ashamed to inject at school, ashamed to test at school; they are teased called uh... ‘sugar babies’, and drug addicts, so that situation is very hard to control, and that’s ‘outside’ influences” (Interviewee 1).

As discussed in the data analysis section, the researcher had anticipated the likelihood of an unexpected theme to emerge from the collected data, given that the participants were considered experts in this topic, and therefore, could not be limited in their contribution to the study. Bullying is one such a theme that the researcher has perceived to be a meaningful addition to the previously reviewed literature, and generally to answering the research question.

4.2 Trustworthiness of findings

Once data has been collected and analysed, the researcher needs to ensure that his/her findings are trustworthy, which simply poses the question: can the findings be trusted? (Nieuwenhuis, 2019). According to Lincoln and Guba (1985) as cited in Korstjensa and Moserb (2018), trustworthiness is the equivalence of validity from quantitative studies, and is determined by four main criteria, namely: credibility, transferability, dependability and confirmability.

Credibility refers to how accurately and truthfully, the data collected from research participants, is interpreted by the researcher (Korstjensa & Moserb, 2018). Nieuwenhuis (2019) adds that

credibility is enhanced through the use of four main strategies: prolonged engagement with participants, persistent observation of the data collected, data triangulation, and member check. In this study, however, credibility was enhanced particularly through persistent observation. This implies that the researcher identified those characteristics and elements that were most relevant to the problem under study, and focused on them in detail, in order to ensure that the final theory provides the intended depth of insight. The researcher notes that spending more time with participants would have enhanced the findings' credibility further, as familiarity with the setting and context, testing of misinformation, a building of trust, would have been achieved. However, due to the time constraints posed by the participants' work schedule, the researcher was limited in that regard.

Transferability refers to the extent to which the researcher's findings can be applicable to similar situations, time, participants, and contexts; and deliver similar results (Korstjensa & Moserb, 2018). Korstjensa and Moserb (2018) note that unlike generalisability from quantitative research studies, a researcher following a qualitative research design makes explicit connections to the cultural and social contexts that surround data collection, to help provide a richer and fuller understanding of the research setting. Therefore, in this study, transferability was enhanced through thick description of the data collected from the healthcare providers. This description does not just describe what factors influence the management of Type 1 diabetes, but describes them from the perspective of lived experiences, so that they become understandable and meaningful to an outsider.

Lincoln and Guba (1985) as cited in Korstjensa and Moserb (2018) state that dependability is linked to the findings of the research, and demands the reliability and consistency in those findings, creating a golden thread. In this study, the researcher transparently described the research steps taken from the start of the data collection process, all the way to the end, as a way to keep record of the research path itself. By doing so, the research findings' dependability is enhanced, as the degree to which research procedures are documented allows those outside the research to follow, audit and critique the research processes in similar research contexts (Nieuwenhuis, 2019).

With regards to confirmability, Lincoln and Guba (1985) as cited in Korstjensa and Moserb (2018), describe confirmability as the extent to which the researcher's findings are shaped by the participants, and not by the researcher's interests, motivation or bias. Nieuwenhuis (2019)

argues that confirmability is similar to dependability, such that it is enhanced through the use of an audit trail. This means that the researcher can avoid any form of bias in their findings, by tracing the course of research step by step, using the procedures recorded, and procedures described (Korstjens & Moser, 2018; Lincoln & Guba, 1985). In this study, the researcher examined the analytical process, the records and the minutes of the semi-structured interviews for accuracy, and assessed whether all analytical techniques of the phenomenology methodology had been used accordingly. The researcher also reviewed the thematic analysis of data, to see whether they emerged from the data (raw data, analysis notes, coding notes, process notes, and report) as means of ensuring accuracy.

5. CONCLUSION

5.1 Addressing the research question

The following section answers the question, “what psychosocial factors influence the management of Type 1 diabetes amongst adolescents?”. The research objectives help understand the overall main question that this research focuses on. Although the previous section has answered the research question, this section shows more explicitly how the research objectives helped in answering the question.

Objective 1: To explore the various factors that constitute psychosocial influences on the management of Type 1 diabetes.

The researcher found that complex environmental, social, behavioral and emotional factors, constitute psychosocial influences on the management of adolescent Type 1 diabetes. These factors were considered by the current research study’s participants, to be acting as both risk and resistance factors. These include personality traits, perceptual beliefs of the disease, family structures, and availability of healthcare. These findings support The Biopsychosocial Model approach to understanding illness, as it is argued that one’s health, or illness, should be viewed in relation to their biological properties, their psychological makeup, as well as their societal context (Lehman et al, 2017).

Although not discussed in great length, the researcher has noted some references to personality traits from the participants’ responses. In the previous review of literature section of the researcher’s research study, it was found that self-efficacy is a common resistance psychosocial factor to adolescent Type 1 diabetes management. In this current study, however,

when asked if personality makeup plays a role in Type 1 diabetes management, participants responded with reference to particular adolescent behaviors:

“Those patients who are mostly willing to do the hard work, and especially people who are always positive or optimistic, definitely can see the benefit of managing their diabetes well” (Interviewee 6).

“so we see with some personalities that are very conscientious and very strict about everything, they will test, they will do exactly as they are told, they will write everything down so nice and neatly” (Interviewee 4).

From making inferences, willingness to effectively care for the disease, persistence in glucose monitoring and testing, as well as rebellion can be argued to be representing openness to experience, conscientiousness and neuroticism from the Five Factor Model of Personality (Semenya, 2016).

Objective 2: To determine resistance factors to self-care behaviours.

Resistance factors are those that promote adherence to self-care behaviours (Hegelson and Palladino, 2012). According to the current research study's participants, resistance factors to self-care behaviours amongst adolescents include: family support, supportive peer relationships, a supportive schooling environment, and conscientious personality traits.

In a broader sense, resistance factors as discussed by the current research study's participants, are further enhanced by better socio-economic conditions—access to blood glucose testing and monitoring equipment, higher levels of educational literacy, as well as self-efficacy.

Objective 3: To discover risk factors to self-care behaviours.

According to the current study's participants, the inability to access educational information on how to take care of the disease, acts as a barrier to positive diabetes outcomes. Also, where family, peer and school relations are concerned, conflicts or any dysfunctional elements resulting from such relations, are bound to have a negative impact on the adolescent's management of the disease.

The researcher has also noted that diabetes-burnout is a key factor in adolescent Type 1 diabetes management, which can occur in both poor and well-controlled groups. When not detected and therefore, not treated, diabetes-burnout may result in rebellion and diabulimia.

Objective 4: To gain deeper insight into the developmental stage of adolescence.

The adolescent stage of Type 1 diabetics, as discussed by the participants of this current study, is characterised by risk-taking behaviours, as well as developmental transitions, which are both influenced by the hormonal changes that take place during adolescence. A smooth transition to the caring of the disease and self-reliance, contribute to appropriate glycemic control as well as adherence to medical treatment.

Objective 5: To learn more about what healthcare workers believe needs to be in place for adolescents living with Type 1 diabetes, to effectively manage the disease.

The healthcare providers' perceptions of what may result in effective management amongst the adolescent population, has been discussed in this current research study in terms of recommendations and guidelines.

Firstly, it is argued that what may drive Type 1 diabetics to take better care of their condition, is the accessibility of technological advances such as insulin pumps. These are argued to be less time consuming and complicated to use, yet quite costly. The availability of educational material, particularly at the time of diagnosis, has also been considered important. Some patients may think that their life goals, such as starting a family, or living a long and healthy life will not be possible. However, with the correct information, particularly at an early stage, certain misconceptions can be avoided.

Secondly, Type 1 diabetics are encouraged to approach their condition with an assumed responsibility—merely being part of a diabetes healthcare team, does not imply that it is the healthcare provider's sole responsibility to manage the adolescent's health.

5.2 Benefits of the study

The research study was conducted to address a gap in current literature, around the topic of Type 1 diabetes. The researcher found that to date, none of the existing studies have addressed understanding Type 1 diabetes management by adolescents, from the perspective of healthcare providers, within a South African context.

Hegelson and Palladino (2012) argue that the manner in which this disease is managed during adolescence, is largely a determiner of how the individual is likely to manage the disease going into adulthood. Thus, if the pattern of behaviour is negative or counterproductive, there can be lasting health consequences. Therefore, by conducting this study, the researcher's findings

hope to contribute to the existing body of knowledge on the kind of challenges that are common in the adolescent Type1 diabetic population.

According to the World Health Organisation (2016) report, one way to control the severity of non-communicable diseases is to focus on reducing the risk factors associated with these diseases. This includes, lessening the impact of these diseases on individual and society through means such as a comprehensive approach that includes: health, education, transport and planning; that will collaborate to reduce the risks associated with non-communicable diseases, as well as promoting interventions to prevent and to control them (World Health Organisation, 2016). Thus, with the recommendations made by the current research study's participants, will contribute to the development of effective intervention tools for the healthcare professionals working with Type 1 adolescents, as well as the larger society which includes their family, peers and schooling environment.

5.3 Ethical considerations

Ethical issues related to the participants:

Informed consent: Maree (2019) asserts that it is crucial for any participant in a research study, to know the nature of the study in which they are about to participate, what the study entails, whether and how their identities will be protected, and the participant should provide legal consent to their participation. In this study, the researcher provided an informed consent sheet to all research participants.

Influence of the researcher on the participant: Maree (2019) shares that researchers need to consider both the participant's psychological and physiological well-being when interacting with them. In this study, the researcher ensured to stick to the Coronavirus safety measures that were put in place during the timeframe of data collection. This included wearing a mask throughout the duration of the interviews and maintaining social distance between participants.

Dealing with sensitive information: research studies should avoid revealing sensitive information about participants (Maree, 2019). Thus, in this study, the researcher ensured to avoid asking confidential information about the healthcare providers' patients. However, in the

event that sensitive information was to be shared with the researcher by any chance, the researcher was prepared to deal with this information as sensitively as possible.

Ethical issues related to the researcher:

Falsifying information: this refers to the deliberate fabrication of data, which is also an unethical means of collecting data (Maree, 2019). Data tends to be fabricated for several reasons, with one of the reasons being to avoid difficult, and/or time consuming aspects of data collection and analysis (Maree, 2019). In this study, the researcher guarded against falsifying information by ensuring that the results are gathered from the respective population sample, and that the information gathered from the interviews was analysed in such a manner that it is most representative to the overall aim of the research study, and not modified in any way that includes the researcher's opinions on the findings, as a source of information as well. This was done to ensure an accurate description of the research findings.

Bias: this refers to the desire or expectation of achieving a particular result (Nieuwenhuis, 2019). Bias is much subtler than falsifying or distorting information, as the researcher themselves may not even be aware of it, because it is subconscious, and may influence the the findings with regards to how and where the researcher collects her data, and how she may interpret it (Nieuwenhuis, 2019).

In this study, because the research design is qualitative, thus implying a degree of subjectivity by the researcher, the researcher ensured to reserve her feelings and opinions on the research topic by strictly analysing the collected information in the context of the respondents' answers to questions.

5.4 Limitations

Maree (2019) acknowledges the limitations of a study as the constraints on the generalisability, applications to practice, and/or utility of findings, that are the result of the ways in which the researcher initially chose to design the study, or the method used to establish trustworthiness, or the result of unanticipated challenges that emerged during the study.

One limitation this study has, is the use of a very small sample size from which to infer data. This may result in a lack of the generalisability of the study's findings, to the larger population,

as a smaller sample size limits the overall representativeness of the study's findings. However, with this small sample size, the researcher was able to construct 'qualit' interview questions that can be answered by a larger population, if the study was to be repeated. That is to say, through the type of questioning used in this study, the same questions would still be relevant if the study was to be conducted elsewhere.

Another limitation includes the study's sampling geographical area, being a private-care clinic, therefore, raising a concern of the transferability of the study's findings to public-care settings. However, collecting data from the healthcare providers working in this particular clinic does not necessary imply that they do not have experience working with patients from different socioeconomic backgrounds. This 'variation' of the different adolescent patients in terms of their historical backgrounds, may contribute to the study as being representative of different patients across the city, and South Africa at large. Despite the decreased level of transferability in this regard, the study's findings are relevant because they are aimed at creating a foundation for future studies on the same topic for a larger population, not to provide conclusive results.

Lastly, the use of a cross-sectional timeframe suggests that the researcher spends minimal time with research participants, therefore, resulting in limited in-depth understanding of the research participants and their contexts, and the credibility thereof. In this study, however, through strategic structuring of the interview questions, the researcher was able to gain a rich in-depth understanding of the research, that the researcher would have obtained, if the study was conducted from a longitudinal timeframe. Through persistent observation of the data collected, thick description of the data collected was possible

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6. ANNEXURES

6.1 Annexure A – Consent form

ANNEXURE C: EXPLANATORY INFORMATION SHEET AND CONSENT FORM FOR PARTICIPANTS

To whom it may concern,

My name is Michelle Mashiane and I am a student at IIE Varsity College Sandton campus. I am currently conducting research under the supervision of Megan-Lee Coetzee about the psychosocial implications of managing Type 1 diabetes among adolescents. I hope that this research will enhance our understanding of the various factors that constitute psychosocial influences on the management of the disease, as well as the risk and resistance factors to self-care behaviours, amongst adolescent Type 1 diabetics.

I would like to invite you to participate in my study. In order to explain to you what your participation in my study will involve, I have formulated questions that I will try to fully answer so that you can make an informed decision about whether or not to participate. If you have any additional questions that you feel are not addressed or explained in this information sheet, please do not hesitate to ask me for more information. Once you have read and understood all the information contained in this sheet and are willing to participate, please complete and sign the consent form below.

What will I be doing if I participate in your study?

I would like to invite you to participate in this research because I am conducting a research study involving Type 1 diabetes healthcare providers. If you decide to participate in this research, I would like to ask you questions pertaining to Type 1 diabetes management, through means of an interview.

You can decide whether or not to participate in this research. If you decide to participate, you can choose to withdraw at any time or to decide not to answer particular interview questions.

Are there any risks/ or discomforts involved in participating in this study?

Whether or not you decide to participate in this research, there will be no negative impact on you. There are no direct risks or benefits to you if you participate in this study. You might, however, indirectly find that it is helpful to talk about your experiences as a healthcare provider to the diabetic population. If you find at any stage that you are not comfortable with the line of questioning, you may withdraw or refrain from participating.

Do I have to participate in the study?

- Your inclusion in this study is completely voluntary;
- If you do not wish to participate in this study, you have every right not to do so;
- Even if you agree to participate in this study, you may withdraw at any time without having to provide an explanation for your decision.

Will my identity be protected?

I promise to protect your identity. I will not use your name in any research summaries to come out of this research and I will also make sure that any other details are disguised so that nobody will be able to identify you. I would like to ask your permission to record the interviews, but only my supervisor, I and possibly a professional transcriber (who will sign a confidentiality agreement) will have access to these recordings. Nobody else, including anybody at The IIE Varsity College, will have access to your interview information. I would like to use quotes when I discuss the findings of the research but I will not use any recognisable information in these quotes that can be linked to you.

What will happen to the information that participants provide?

Once I have finished all interviews, I will write summaries to be included in my research report, which is a requirement to complete my BA Honours in Psychology. You may ask me to send you a summary of the research if you are interested in the final outcome of the study.

What happens if I have more questions about the study?

Please feel free to contact me or my supervisor should you have any questions or concerns about this research, or if there is anything you need to know before you decide whether or not to participate.

You should not agree to participate unless you are completely comfortable with the procedures followed.

My contact details are as follows:
Michelle Mashiane

The contact details of my supervisor are as follows:
Megan-Lee Coetzee

Michelle, Mashiane
17597357

Consent form for participants

I, _____, agree to participate in the research conducted by Michelle Mashiane about the psychosocial implications on the management of Type 1 diabetes, amongst adolescents.

This research has been explained to me and I understand what participation in this research will involve. I understand that:

1. I agree to be interviewed for this research.
2. My confidentiality will be ensured. My name and personal details will be kept private.
3. My participation in this research is voluntary and I have the right to withdraw from the research at any time. There will be no repercussions should I choose to withdraw from the research.
4. I may choose not to answer any of the questions that are asked during the research interview.
5. I may be quoted directly when the research is published, but my identity will be protected.

Signature

Date

Consent form for audio-recording/ video recording

I, _____, agree to allow Michelle Mashiane to audio record my interviews as part of the research about psychosocial implications on the management of Type 1 diabetes, amongst adolescents.

This research has been explained to me and I understand what participation in this research will involve. I understand that:

1. My confidentiality will be ensured. My name and personal details will be kept private.
2. The recordings will be stored in a password protected file on the researcher's computer.
3. Only the researcher, the researcher's supervisor and possibly a transcriber (who will sign a confidentiality agreement) will have access to these recordings.

Signature

Date

6.2 Annexure B – Interview schedule

1. Can you tell me how the management of Type 1 diabetes differs between adolescents and other age groups?
2. How does the management thereof, differ between Type 1 and Type 2 diabetic patients?
3. What are some of the challenges that you, as a healthcare provider, have observed to be unique to the Type 1 adolescent diabetic population?
4. What kind of psychosocial factors influence the management of Type 1 diabetes amongst adolescents?
5. Can you tell me more about the factors that promote adherence to self-care behaviours amongst adolescents?
6. Can you tell me more about the factors that hinder adherence to self-care behaviours amongst adolescents?
7. To what extent, does personality makeup, play a role in Type 1 diabetes management?
8. Are there differences in Type 1 diabetes care between low-income and middle-income groups in South Africa?
9. Are there differences in Type 1 diabetes care between South Africa and other countries?

6.3 Annexure C - Ethical clearance letter



29 July 2020

Student name: Michelle Mathabo Mashiane

Student number: 17597367

Campus: IIE's Varsity College Sandton

Re: Approval of Honours in Psychology Proposal and Ethics Clearance

HONOURS/PGDIP ETHICAL CLEARANCE LETTER

Your research proposal and the ethical implications of your proposed research topic were reviewed by your supervisor and the campus research panel, a subcommittee of The Independent Institute of Education's Research and Postgraduate Studies Committee.

There are some aspects that you still need to address in your proposal. You will need to address these aspects in consultation with your supervisor before you may proceed (see below):

Please discuss with your supervisor/navigator/lecturer how you will address these issues listed below:

Please note: **Your fieldwork may only proceed once you address the following issues:**

- Please make all the changes suggested/recommended by your supervisor.
- Your final interview schedule/questionnaire needs refinement. Your supervisor needs to sign off your final interview schedule or questionnaire. Be careful when phrasing your questions.

In the event of you deciding to change your research methodology in any way, kindly consult your supervisor to ensure all ethical considerations are adhered to and pose no risk to any participant or party involved. A revised ethical clearance letter will be issued.

We wish you all the best with your research!

GENERAL CONDITIONS TO BE FULFILLED IN RELATION TO RESEARCH

Permission is granted to proceed with the above study subject to the conditions listed below being met and may be withdrawn should any of these conditions be flouted.

Please note: The panel has not considered the merits, accuracy or ethical soundness of the research. The only merits examined are the use of The IIE as a sample.

Permission is granted subject to the following conditions:

1. The researcher(s) will need to obtain informed consent in writing from all of the participants in his/her sample if the study is not anonymous.
2. The researcher(s) may only use the data collected for research purposes and in no other way.
3. Photographs of human subjects may only be taken if relevant to the research, informed consent was obtained, and even with informed consent, the photographs may not be published on any online platforms.
4. The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.
5. No names or identifying information of participants may be used within the research and the research must be voluntary.
6. Please make it clear that the information will not be used punitively in any way and participants may in no way be counselled/advised based on this.

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6.4 Annexure D – Example of data collected

Interviewer:	Can you tell me your thoughts around the amount of information Type 1 diabetics have access to in comparison to Type 2 diabetics?
Interviewee 1:	[deep sigh] Inside or outside the CDE environment?
Interviewer:	Both.
Interviewee 1:	Inside the CDE environment they would have access to pretty much information—both online and with their individual nurse educators. Outside there, in the general world, they've got minimal access...when you look at it as far as I understand it.
Interviewer:	Okay, secondly, can you tell me how the management of Type 1 diabetes differs between adolescents and other age groups?
Interviewee 1:	The basic principles are the same. The problem is that the adolescents will have issues with the...well adolescence itself: hormonal changes and so forth, which makes it difficult to control diabetes. But, the basic theory and treatment is the same: its insulin, its testing, its exercise... eating properly.
Interviewer:	How does the management thereof, differ between Type 1 and Type 2 diabetic patients?
Interviewee 1:	Well, you don't see much Type 2 adolescents in this practice. Although it seems to be common, its mostly in the States. But not so much here. I've got no Type 2s that I am treating as adolescents.

Interviewer:	Wow, okay that is interesting. What are some of the challenges that you, as a healthcare provider, have observed to be unique to the Type 1 adolescent diabetic population?
Interviewee 1:	Taking insulin regularly, major challenge. Eating appropriately...eating disorders, major challenge. Peer pressure is a major challenge.
Interviewer:	Can you tell me more about peer pressure being a 'major challenge'?
Interviewee 1:	Yeah, well, when you've got an adolescent who's uhm in a crowd of friends, and he's not a leader but a follower in that crowd, and they wanna go to McDonalds for a milkshake, he finds it very difficult to say 'no'. I am talking alone from drugs and smoking and alcohol and so forth, it's a bigger deal. But even in terms of just the what they are doing day by day, they want to be with their friends. They don't want to say 'I am different'. When friends go to McDonalds's, they also don't want to say "let's go to Nando's because its healthier".
Interviewer:	Hmm okay, interesting. And what kind of psychosocial factors influence the management of Type 1 diabetes amongst adolescents?
Interviewee 1:	Family, particularly the biggest problem we have is number 1: single-parents, divorced parents, ehm lifestyle... a lot of our patients come from areas where both parents are working, early morning, late at night, they are home alone all day. Often, they do not have telephone

	access, some of them, no food in the fridge. Those are not psychological nor social, but, psychosocial aspects, psychological side, particularly with girls, it's their weight.
Interviewer:	Can you tell me more about the psychosocial factors that promote adherence to self-care behaviours amongst adolescents?
Interviewee 1:	I don't understand that.
Interviewer:	Which psychosocial factors push them to take good care of themselves?
Interviewee 1:	Difficult, I think it depends on family. And that's a very difficult balance because if the parents are too...restrictive, they rebel. If parents don't supervise them enough, they tend to drift away. They need proper parental supervision, at the right level. I think that's the most important factor. Okay, secondly, an understanding in the schooling environment, where there are teachers who understand diabetes, and allow them to have some sugar if they're going low, allow them to test their blood sugars, that's really what works for them. But also the ability these days, to produce good glucose monitoring, depending how financially okay their parents are, also very important. Unfortunately, expensive, and a lot of that hurts most people.
Interviewer:	Can you tell me more about the psychosocial factors that hinder adherence to self-care behaviours?
Interviewee 1:	As I mentioned, I've said it already: your peer pressure, single parents, you know lack of supervision, maybe over-dominant parents...becomes a problem. I mean, some kids...depending on their own mental status, are happy to stand up at school and say 'hey I've got diabetes, and this is who I am'. Others will be ashamed to inject at

	school, ashamed to test at school, they are teased called uh... 'sugar babies', and drug addicts, so that situation is very hard to control, and that's 'outside' influences.
Interviewer:	To what extent, does personality makeup, play a role in Type 1 diabetes management?
Interviewee 1:	Major. Kids who are dominant children, outgoing, who aren't ashamed to be who they are, who are leaders of the pack. I have always said that when a child was sent for the first time to me, as an adolescent, if he tells you he's a school prefect, he's captain of the rugby team, he's captain of the netball team...you know you have a lot of problem. The kids who are quiet at the back of the class, wanting to come out of the crowd, you're going to have a problem.
Interviewer:	Are the differences in Type 1 diabetes care between low-income and middle-income groups in South Africa?
Interviewee 1:	Yes, it's the availability to care. I mean, getting insulin, in low-income groups...giving the right insulin, getting appropriate therapy, getting strips for testing, getting meters for testing...With a low income-group, that's the problem. Furthermore, getting food, and the right food.
Interviewer:	So there is a division between the public sector and private sector in healthcare?

Interviewee 1:	Absolutely, it's a major division. It's totally polarised. When patients come here, Type 1s, they get the best insulin, they get as many strips as they need, and most this medical aid is paying for them, they get full education, and full support. The public sector, they getting inferior insulin, they can't get testing strips, there's minimal education...big difference.
Interviewer:	Okay, uhm the last question is: are the differences in Type 1 diabetes care between South Africa and other countries?
Interviewee 1:	It depends, again, you're talking about polarised care. Type 1 care in the private sector, here in the CDE environment, is probably amongst the best in the world. I'll come show it...HbA1c, you name it. The public sector care it must be very low down the scale, and could be most probably the worst in Africa. That's because of the unavailability in the world insulin, the right education, the right understanding, testing strips and so on.

6.5 Annexure E – Updated concept table

Research Purpose To explore the psychosocial implications on the management of Type 1 diabetes amongst adolescents, from the perspective of healthcare providers, within a South African context	Primary Research Question What psychosocial factors influence the management of Type 1 diabetes amongst adolescents?	Research Rationale This study is important to the researcher as the researcher shares the experiences being investigated. Findings of the study hope to provide insight on what influences adolescent Type 1 diabetes management	Seminal Authors Bandura (1994) Engel (1980) Funnel (2006) Gonzalez et al (2008) Piaget (1936)	Literature Review Theme 1: Type 1 diabetes management Theme 2: Adolescent experiences Theme 3: Psychosocial influences	Paradigm Interpretivism Epistemology To contribute expert opinions on the lived experiences of adolescent Type 1 diabetes, to existing studies. Ontology Reality is a social construct governed by differing worldviews. Axiology Research should value uniqueness amongst people and objects.	Approach Qualitative Population parameter >All Type 1 diabetes healthcare providers, based in Johannesburg. >They must work directly and specifically, with Type 1 diabetic adolescents (aged 15-17). >All participants needed to be accessible despite the impact of the Coronavirus at the time of the research study.	Data Collection Method Semi-structured interviews	Ethics Informed consent: Participants should be well informed prior. Sensitive information: facilitators will not be asked to disclose confidential information pertaining to the patients. Falsification/distortion of information will be avoided by the researcher.	Anticipated Findings Insight into the types of psychosocial factors that influence Type 1 diabetes management, and how they influence self-care behaviours.	References Mutyambizi, C., Booyesen, F., Pavlova, M. & Groot, W. (2019). Landau (2013) International Diabetes Federation (2019) Hegelson & Palladino (2012) Maree (2019) Young & Unachukwu (2012)
Research problem Not enough studies have been done on the influence of psychosocial	Objectives >To explore the various factors that constitute psychosocial influences on the management of Type 1 diabetes.	Key Concepts >Type 1 diabetes management. >Psychosocial influences. >Glycemic control >Adolescents.	Key Theories >Five Factor Model of Personality >Biopsychosocial Framework			Sampling Non-Probability Purposive sampling 6 participants	Data Analysis Method Unit of analysis All Type 1 adolescent	Limitations >Non-generalisability of findings, as it is qualitative study >Limited time frame of the study to infer an	KEY Contribution The research study aims to add on knowledge to existing studies conducted so far, on the	Recommendations focus on reducing the risk factors associated with these diseases. This includes,

factors on the management of Type 1 diabetes, amongst adolescents, from a South African context.	>To discover risk factors to self-care behaviours. >To determine resistance factors to self-care behaviours. >To gain deeper insight into the developmental stage of adolescence, and to understand how this impacts the experience of managing Type 1 diabetes. >To learn more about what healthcare workers believe needs to be in place for adolescents living with Type 1 diabetes, to effectively manage the disease	>Healthcare providers. >Self-care behaviours					diabetes healthcare providers Thematic analysis	in-depth understanding >A qualitative study also implies researcher-subjectivity on the study's findings and analysis of results.	topic, particularly from a South African perspective and from lived experiences.	lessening the impact of these diseases on individual and society through means such as a comprehensive approach that includes: health, education, transport and planning; that will collaborate to reduce the risks associated with non-communicable diseases, as well as promoting interventions to prevent and to control them
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