

**The impact of type 1 diabetes on the psycho-social well-being of
adolescents**

by

Melissa Spitz

Submitted in partial fulfilment of the requirements for the degree

**MAGISTER EDUCATIONIS
(LEARNING SUPPORT, GUIDANCE AND COUNSELLING)**

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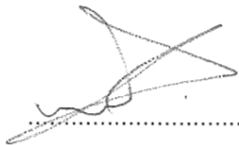
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**PRETORIA
15 DECEMBER 2017**

DECLARATION

I, Melissa Spitz, student number 10072366, hereby declare that this dissertation, “The impact of type 1 diabetes on the psycho-social well-being of adolescents,” is submitted in accordance with the requirements for the Magister Educationis: Learning Support, Guidance and Counselling degree at University of Pretoria, is my own original work and has not previously been submitted to any other institution of higher learning. All sources cited or quoted in this research paper are indicated and acknowledged with a comprehensive list of references.



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M. Spitz

15 December 2017

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ETHICS STATEMENT

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval. The author declares that she has observed the ethical standards required in terms of the University of Pretoria's *Code of ethics for researchers and the Policy guidelines for responsible research*.

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RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE

CLEARANCE NUMBER:

UP 15/11/01

DEGREE AND PROJECT

MEd

The impact of type 1 diabetes on the psycho-social well-being of adolescents

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This Ethics Clearance Certificate should be read in conjunction with the Integrated Declaration Form (D08) which specifies details regarding:

- Compliance with approved research protocol,
- No significant changes,
- Informed consent/assent,
- Adverse experience or undue risk,
- Registered title, and
- Data storage requirements.

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ABSTRACT / SUMMARY

THE IMPACT OF TYPE 1 DIABETES ON THE PSYCHO-SOCIAL WELL-BEING OF ADOLESCENTS

by

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Degree : MEd (Learning Support, Guidance and Counselling)

The purpose of this study was to explore and describe the impact of type 1 diabetes (T1D) on the psycho-social well-being of adolescents in a resource-constrained community. Historical and contemporary literature on the psycho-social issues of adolescents with this disease draws attention to the complexity of individual's experiences in this regard. This study contributes to a context-specific understanding of T1D, by exploring adolescents' subjective personal, family, school and hospital lived experiences. The relational impact that T1D has on adolescents is further situated in the context of its importance to their psycho-social well-being.

This research study adopted Engel's Biopsychosocial Model, Systems Theory and Phenomenology for the theoretical framework. The researcher consulted relevant literature relating to diabetes, specific to T1D; the adolescent with T1D, defining adolescence and disease-related adjustment; epidemiology, diagnosis, treatment, glycaemic control, management and complications of adolescents with T1D; family centred care for T1D and health related quality of life. A qualitative research approach was applied, guided by an interpretive phenomenological paradigm. Five adolescents, between the ages of 15 and 18 years, described their lived experiences of having T1D during semi-structured interviews. The data was subsequently analysed using interpretive phenomenological analysis (IPA).

Five main themes emerged from the transcripts, each of which is discussed separately as well as in relation to other prevalent literature. The critical investigation of the findings presented in this study revealed divergent aspects to those found in some of the current literature, as well as considerations comparable with earlier research.

The meanings that emerged from these adolescents' stories revealed complex cognitive, emotional, social and biological distress, all of which highlight the subjective experience of having T1D, the impact thereof, and the multi-faceted stress it has on their psycho-social well-being.

LIST OF KEY WORDS

- Diabetes
- Type 1 Diabetes (T1D)
- Chronic disease
- Insulin
- Glycaemic control
- Self-monitoring of blood glucose (SMBG)
- Diabetes self-management education (DSME) and support (DSMS)
- Adolescence
- Psycho-social well-being
- Resource-constrained community

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LIST OF ACRONYMS

ADA	American Diabetes Association
BMI	Body mass index
BPS	Biopsychosocial
CDE	Centre for Diabetes and Endocrinology
CGM	Continuous glucose monitoring
CSII	Continuous subcutaneous insulin infusion
HbA1c	Glycated haemoglobin
HRQOL	Health-related quality of life
IDF	International Diabetes Federation
IPA	Interpretative phenomenological analysis
ISPAD	International Society of Paediatric and Adolescent Diabetes
DCCT	Diabetes Control and Complications Trial
DKA	Diabetic ketoacidosis
DSME	Diabetes self-management education
DSMS	Diabetes self-management support
MDIs	Multiple daily injections
SMBG	Self-monitoring of blood glucose
SOC	Sense of coherence
T1D	Type 1 diabetes
WHO	World Health Organization

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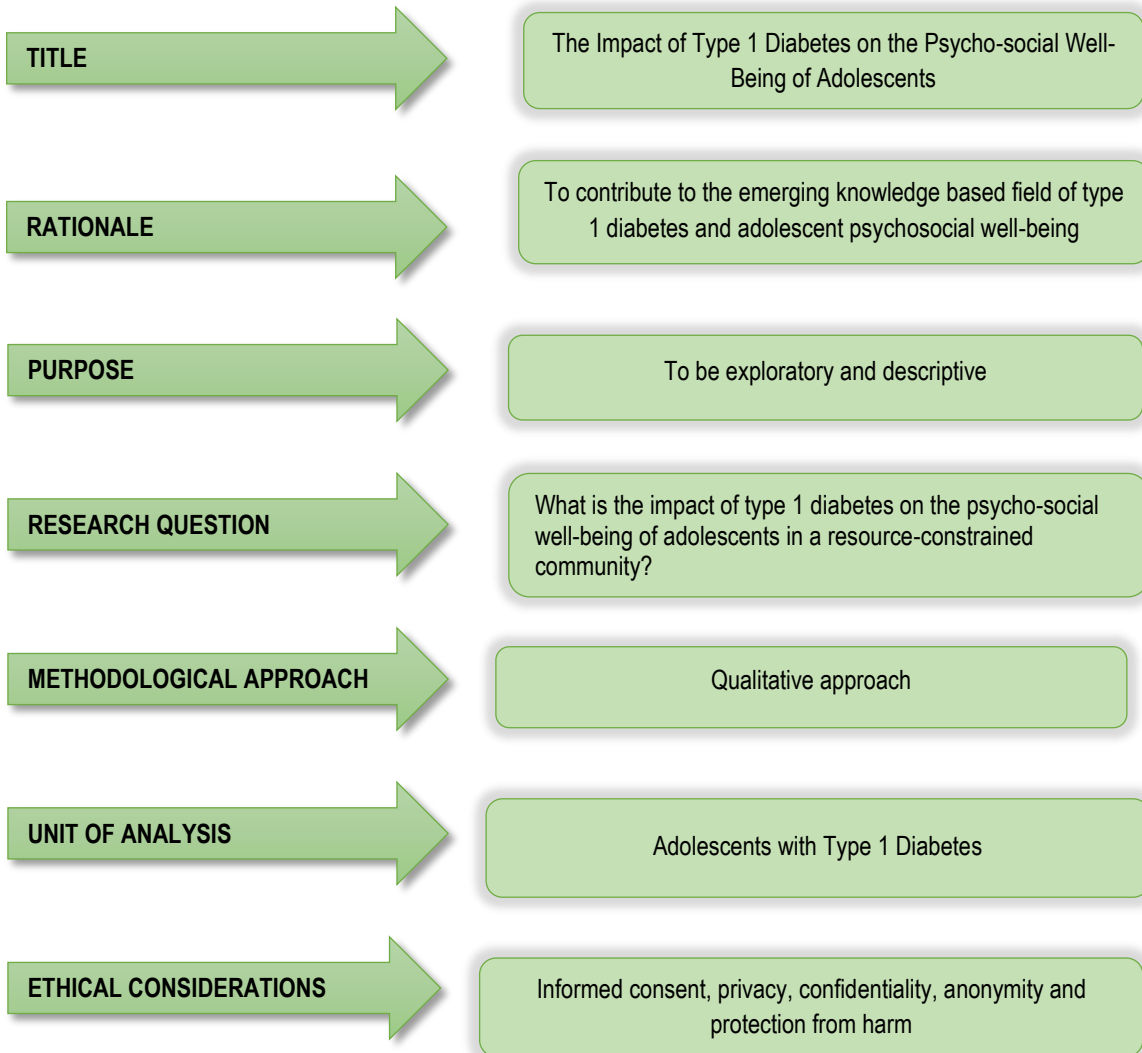
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APPENDICES

- APPENDIX A:** Letter of assent for the research participants
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- APPENDIX H:** CEO permission letter to conduct research at the public healthcare facility

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1. CHAPTER 1: OVERVIEW AND RATIONALE



1.1 INTRODUCTION

This study explored the phenomenon of type 1 diabetes (T1D) and its impact on the psycho-social well-being of adolescents in a resource-constrained community. Contemporary literature shows that there is limited context-specific data concerning the psycho-social well-being of adolescents with T1D in South Africa (Dhada, Blackbeard, & Adams, 2014; Hanas, Donaghue, Klingensmith, Swift, & Colagiuri, 2011; Hanas *et al.*, 2014; Shaw, Sicree, & Zimmet, 2010; World Health Organisation, 2016).

Currently, there is an increasing global epidemic of T1D in children and adolescents; therefore it is imperative to ascertain information regarding their psycho-social well-being in order for them to lead a life with ease and maintain optimal glycaemic control.

Studies have noted that a strong relationship exists between physiological, cognitive, behavioural, emotional, social and healthcare variables which contribute to metabolic functioning and treatment adherence for this chronic disease (Dhada *et al.*, 2014; Hanas *et al.*, 2014; Hilliard, Wu, Rausch, Dolan, & Hood, 2013). Chapter 2 and 3 provide an in-depth discussion of these areas. Furthermore, these variables may have an effect on the adolescent's stress, coping and psychological adjustment which may impede their health-related quality of life and well-being.

1.2 BACKGROUND

Adolescence is the transitional developmental phase between childhood and adulthood. It incorporates major biological and psycho-social changes which impose complex challenges to the adolescent with T1D, their family and the T1D healthcare team (American Diabetes Association, 2017a). T1D, formerly known as "*insulin-dependent diabetes*" (IDDM), "*juvenile diabetes*" or "*childhood-onset diabetes*", is a serious, chronic disease which is characterised by deficient insulin production in the body (Cartaya & Laffel, 2017). It frequently occurs during childhood and adolescence, but it can also occur at any life stage. Individuals with this disease require exogenous regular management of insulin to balance and regulate blood glucose levels; if insulin is not accessible then their survival is at risk (International Diabetes Federation, 2015). Treatment of T1D consists of lifelong insulin dependency, (through multiple daily injections or continuous subcutaneous insulin infusion [CSII] pump therapy), specific meal plan and routine physical exercise. For adolescents, maintaining this balance can be challenging due to changes in growth and lifestyle. Currently, there is no cure for T1D, the exact causes for the disease are unknown and it cannot be prevented. According to World Health Organisation (2016, p. 1407), there is an overall consensus that T1D "is the result of a complex interaction between genes and environmental factors, although no specific factors have been shown to cause a prevalent number of cases".

In 2017, the American Diabetes Association released a new position statement on psycho-social care in the treatment of T1D. The goal now is to address psycho-social issues in all aspects of care, namely: "self-management, mental health, communication, complications, comorbidities, and life-stage considerations" (ADA, 2017a, p. S109).

This further highlights the need to understand the individual's psycho-social well-being with regards to their chronic disease to ensure optimal care. Adolescence is a major transitional phase which incorporates distinctively different healthcare and emotional needs from younger children and older adults (Baumrind, 1991; Louw & Louw, 2014). It is important to recognise that chronic diseases, like T1D, may potentially inhibit quality of life and well-being if their psycho-social and physiological development is not understood.

Cameron, Amin, de Beaufort and Codner (2014) from the International Society of Paediatric and Adolescent Diabetes (ISPAD) state that poor metabolic control is experienced by many adolescents due to: endocrine changes leading to increasing levels of insulin resistance, irregular diet and activity trends, inappropriate compliance to T1D management, disordered eating behaviour, and harmful rebellious behaviours. Families, healthcare professionals and other adult authorities should develop effective communication skills to facilitate teaching and education for this age group. Stahl-Pehe *et al.* (2017) note that to improve T1D self-care a trusting and motivating rapport between healthcare professionals and the adolescent should be developed and maintained. Consistent parental involvement and support throughout this adolescent phase has also proven to be associated with better quality of life outcomes for the disease (King, Berg, Butner, Butler, & Wiebe, 2014; Oskouie, Mehrdad, & Ebrahimi, 2013; Palladino & Helgeson, 2013). Nonadherence to T1D management can lead to acute and/or long-term physical, neuro-behavioural and cognitive complications for the adolescent. According to Petersson *et al.* (2016, p. 3), in order for the adolescent to lead a normal and happy life s/he must adhere to an intensive T1D management plan, "which includes: insulin treatment, blood glucose monitoring, nutritional management, physical activity, education, rules for sick days, and psycho-social support".

As aforementioned, adolescence is a difficult period that entails major changes to the individual's life – biologically, cognitively and emotionally. Having T1D during this phase can be seen as a burden and daily interference. The required routine requirements of the disease can disrupt their freedom and spontaneity. Furthermore, adolescents with T1D may also experience stress and anxiety which might surface in diverse ways, such as: rebellious and risky conduct, emotional distress, depression and eating disorders (Ogle, Middlehurst, Silink, & Hanas, 2013). Thus, it is important to consider all factors surrounding the adolescent with T1D to ensure effective management and optimal psycho-social well-being.

1.3 STATEMENT OF THE RESEARCH PROBLEM

T1D is a chronic disease that requires ongoing interventions and adaptations; creating an additional burden to the developmental changes and challenges already faced during adolescence (Di Battista, Hart, Greco, & Gloizer, 2009; Wysocki, Greco, & Buckloh, 2003; Wysocki *et al.*, 1996). The adolescents' family, school and healthcare professionals should provide them with the necessary support to ensure that these stressors are dealt with appropriately to prevent maladaptive coping behaviours.

It is, therefore, important that exploration and investigation into the impact of T1D on the psycho-social well-being of adolescents is undertaken; especially in the South African context, as most of the current research has been conducted in other countries around the world (Davey & Segal, 2015; Gill, Huddle, & Monkoe, 2005; Kalweit, Briers, & Olorunju, 2015). Such research has provided useful background information regarding factors affecting treatment adherence, life satisfaction and blood glucose control for individuals with this chronic disease.

The research problem thus aims to qualitatively explore and describe the lived experiences of adolescents with T1D; and how this chronic disease impacts their psycho-social well-being.

1.4 RATIONALE OF THE RESEARCH

In developed countries, adolescents with T1D unlimited access to insulin analogues and various other important elements of T1D care, to ensure normal healthy lifestyles. The choice of treatment regimen for adolescents living with T1D should accommodate their age, daily routine, metabolic control target, and personal and family preferences (Kalweit *et al.*, 2015). However, diverse approaches for T1D treatment and management that may provide assistance with these particular requirements are not similarly available in South Africa.

The literature on adolescents with T1D is predominantly focused on Eurocentric and international empirical evidence (American Diabetes Association, 2017a; Dhada *et al.*, 2014; Hanas *et al.*, 2011; International Diabetes Federation, 2015; Roper *et al.*, 2009). These studies have shown the complexities involved when having to maintain effective T1D management and optimal well-being for youth. Risk factors that can contribute to nonadherence, life dissatisfaction and/or poor psycho-social well-being for adolescents with this disease are multi-faceted. Understanding the adolescent's sense of coherence (SOC) about T1D may be helpful in promoting effective self-care and self-management of the disease.

T1D is a chronic disease that can cause severe complications – physically, psychologically and/or cognitively (Nathan, 2014). Therefore, successful management of T1D requires major ongoing lifestyle changes and adaptations (Dhada *et al.*, 2014). Studies have shown that a prevalent barrier to managing T1D is the lack of appropriate coping skills, while having a positive attitude is a significantly effective strategy for self-care (Olshansky *et al.*, 2008; Oskouie *et al.*, 2013). It is vital for these adolescents to be positively motivated to embrace their disease and learn to live life with ease. Hence the psychological state of the adolescent is an important aspect to managing T1D, and not only about medical treatment and nutritional requirements. Effective T1D management consequently includes the acceptance of the disease, maintaining a positive viewpoint and coping with lifestyle changes.

Considering that T1D management is complex and requires constant intervention and adaptation strategies, little consideration is attributed to the lived experiences of adolescents in the South African context (Kalweit *et al.*, 2015). However, global literature has provided enough parameters to consider standards of care regarding adolescents with T1D; appropriate T1D management regimen thus needs to incorporate context-specific assessment of the adolescents' psycho-social well-being (International Diabetes Federation, 2015). This appears to be significant to the adolescent's overall quality of life, as psycho-social issues may impede all areas for effective T1D management.

It has been 23 years since South Africa became a democratic country, yet the country is still confronted with numerous socio-economic challenges and adversity at all levels of society. South Africa is a diverse multicultural country that encompasses various types of communities (Ebersöhn & Eloff, 2006). For example, adolescents who reside in a resource-constrained community have distinct differences in socio-economic circumstances, healthcare, schooling, family dynamics, cultural beliefs and emotional stressors to those in more affluent communities.

Roberts *et al.* (2012) explained that limited research exists on the best T1D practice to be employed in routine healthcare sectors, which can be attributed to different community settings and requirements. Thus, exploring the overall subjective experiences of these adolescents appeared relative in understanding the phenomena of T1D and its impact on their psycho-social well-being.

1.5 RESEARCH QUESTIONS

The research question stemmed from an interest in the phenomenon of T1D and its impact on the psycho-social well-being of adolescents lived experiences thereof. However, research participants also provided situational and subjective dynamics which enhanced the data, giving a kaleidoscope of experiences which highlighted other influential aspects. Much of the literature explored these facets and, in doing so, reinforced the value of unrestricting the impact of T1D variables on the psycho-social well-being of adolescents.

1.5.1 PRIMARY RESEARCH QUESTION

The goal of this research study was to explore and describe:

The adolescents experiences of T1D and its impact on their psycho-social well-being.

With the aim of answering the following **primary research question**:

What is the impact of type 1 diabetes on the psycho-social well-being of adolescents in a resource-constrained community?

1.5.2 SECONDARY RESEARCH QUESTIONS

- What impact does type 1 diabetes have on the adolescents' sense of self?
- How do adolescents experience family support when living with type 1 diabetes?
- What are the adolescents' experiences of living with type 1 diabetes in the school environment?
- What are the hospital experiences of adolescents living with type 1 diabetes?

1.6 PURPOSE OF THE RESEARCH

The purpose of this study was to qualitatively explore and describe the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community. Interpretative phenomenological analysis (IPA) was chosen to investigate the emergent themes from the semi-structured interviews that were conducted with five adolescents living with T1D.

Several justifications from the literature have been noted. Mainly, the study is significant as it can contribute to existing research, particularly with adolescents with T1D and their psycho-social well-being.

The research is exploratory, thus the aim is not to assess the chronic disease or psycho-social well-being, but rather to discover an understanding of this specific population. This study could provide future avenues for research, which may contribute to the management of T1D for this population. An idiographic approach was implemented. This implies that this research allowed for an in-depth exploration of a homogenous group. This study used a qualitative methodological approach to inform an academic line of inquiry. Additionally, investigation on the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community with specific emphasis on phenomenology and the meaning of their lived experiences has not been researched before in South Africa.

The primary aim of this study was to explore the adolescents' experiences of T1D and its impact on their psycho-social well-being. The following objectives served as means of attaining the primary aim:

- Identifying, through the construction of themes, the various psycho-social aspects in the adolescents' daily life and to gain an understanding of how these facets are impacted by T1D.
- Distinguishing prominent themes of how these personal, family, school and hospital T1D experiences affect the psycho-social well-being of these adolescents.
- Interpreting and analysing the data gathered, using a variety of available theoretical resources and practical knowledge pertaining to the field of T1D, adolescents and psycho-social well-being.
- Using the knowledge gained throughout the study to inform the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community.

The potential contribution of this study lies in the possibility of adding new knowledge to literature on the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community, from a South African subjective point of view. Furthermore, the adolescents' lived experiences of T1D in their personal, family, school and hospital environments may be beneficial in highlighting context-specific issues on this phenomenon.

The findings from this study could subsequently be helpful in establishing context-specific policies that may enhance the management of this chronic disease and the psycho-social well-being of these adolescents.

1.6.1 RESEARCH-CONTEXT

The contextual background against which the research study was conducted took place at a public (government funded) healthcare facility, located in Atteridgeville, South Africa. All research participants receive T1D treatment from this public healthcare facility. Atteridgeville, also known as a diverse township¹ or semi-urban area, for the purpose of this study is called a resource-constrained community.

The area was established by the South African government in 1939 as a settlement for ‘non-whites’ (Africans, Coloureds and Indians), nine years prior to the Apartheid government being established in 1948 (South African History Online, 2016). Today, Atteridgeville mainly encompasses a diverse group of Black African residents, of which speak many languages.

1.7 CONCEPT CLARIFICATION

In order to ensure a clear understanding of this research study, key theoretical concepts are briefly discussed below. However, a more in-depth overview of these concepts is provided in Chapter 2 and 3.

1.7.1 DIABETES

The term *diabetes*, a chronic disease, is used to describe a complex metabolic disorder which is characterised by hyperglycaemia (excess of glucose in the blood stream or high glycaemia) ensuing from problems in insulin production and/or insulin sensitivity (World Health Organisation, 2016).

With people who have diabetes, their bodies either cannot make enough insulin, cannot use the insulin it produces or, a collaboration of both. If the cells in the body cannot absorb the glucose, it accumulates in the blood and if not controlled over time can lead to serious damage to many of the body’s systems.

¹ In South Africa, “the term *township* has no formal definition but usually refers to underdeveloped urban living areas and are built on the periphery of towns and cities. Due to the historic social compression in racially segregated areas old townships are socially, culturally and economically diverse. Many of them – especially larger townships – contain middle and lower-income areas and additionally scattered middle-income houses. But socio-economic data show clearly that the majority of township residents are poor and that the unemployment rate is very high” (Pernegger & Godehart, 2007, p. 5).

1.7.2 TYPE 1 DIABETES (T1D)

Type 1 diabetes (T1D) also called insulin-dependent diabetes; previously referred to as “*insulin-dependent diabetes*” otherwise “*juvenile-onset diabetes*” because of the early childhood onset (American Diabetes Association, 2015a). It is the result of the body producing antibodies which attacks its own pancreas – an autoimmune deficiency. Despite active research, there is currently no cure or exact cause for T1D but it can be controlled through effective management (American Diabetes Association, 2017a). T1D is one of the most prevalent endocrine and metabolic diseases in youth.

1.7.3 CHRONIC DISEASE

Clark, Gong, and Kaciroti (2014) define *chronic disease* as an illness without a known cure. Examples of chronic diseases are asthma, heart disease, several forms of cancer, arthritis and diabetes. In this research study, chronic disease will refer to T1D.

1.7.4 INSULIN

The term *insulin* refers to a natural hormone produced by the pancreas (World Health Organisation, 2016). Its function in the body is to control glucose levels in the blood, allowing cells to use this glucose for energy. Without insulin, glucose cannot be absorbed into the body's cells.

1.7.5 GLYCAEMIC CONTROL

Every person with T1D should have HbA1c (two-three month average of blood glucose) targets set to maintain the lowest glycaemic levels without frequently moderate or severely low blood glucose levels (Chiang, Kirkman, Laffel, & Peters, 2014). Maintaining good *glycaemic control* decreases the potential risk of developing microvascular and macrovascular complications; although there is no single agreed target for T1D because it is dependent on various clinical and non-clinical factors (Ghosh & Collier, 2012). According to the World Health Organisation (WHO, 2016), the general HbA1c level should be below 7%, which is an estimated average glucose level of 8.5mmol/L.

1.7.6 SELF-MONITORING OF BLOOD GLUCOSE (SMBG)

The most commonly used strategy for effective T1D management is *self-monitoring of blood glucose* (SMBG). It is a fundamental component of T1D self-care and management (Ghosh & Collier, 2012). Adolescents with T1D experience daily variability in blood glucose levels. Thus, SMBG is a valuable technique to aid in optimal glycaemic control.

1.7.7 DIABETES SELF-MANAGEMENT EDUCATION (DSME) AND SUPPORT (DSMS)

The key to successful T1D *self-management* has proven to be ongoing *education* and *support* (Cooke *et al.*, 2013; Hopkins *et al.*, 2012). According to Chiang *et al.* (2014), “*DSME* and *DSMS* are the ongoing processes of facilitating the knowledge, skill, and ability necessary for diabetes self-care. These processes incorporate the needs, goals, and life experiences of the person with diabetes. The overall objectives of *DSME* and *DSMS* are to support informed decision making, self-care behaviours, problem solving, and active collaboration with the healthcare team to improve clinical outcomes, health status, and quality of life in a cost-effective manner” (p. 2041).

1.7.8 ADOLESCENCE

Adolescence is considered to be the period of transition from childhood into emerging adulthood (Arnett, 2014a; Sanders, 2013). It can be seen as the bridge between being a child and becoming an adult. According to Louw and Louw (2014), adolescence can comprise of three categories, namely: *early* adolescence (12-14 years), *middle* adolescence (15-16 years) and *late* adolescence (17-19 years). For the purpose of this research study the age range was narrowed down to the following: 15 to 18 years. Adolescence is one of the most rapid phases of human development; encompassing major changes in physical, cognitive, psycho-social, emotional and social development (Ginsburg & Kinsman, 2017).

1.7.9 PSYCHO-SOCIAL WELL-BEING

For the purpose of this research study, the term *psycho-social well-being* will be discussed in two parts to provide clarity.

The *psycho-social* development that takes place during adolescence can be characterised as progressive tasks that develop autonomy, establish identity and future orientation (Sanders, 2013). Thus, the term *psycho-social* underscores the combined influence that psychological factors and the surrounding social environment have on the individual’s mental and physical well-being, as well as his/her ability to function.

According to Khan (2013), the term *well-being* is a condition of holistic health in all its domains, namely: cognitive, physical, spiritual, economic, emotional and social.

Well-being encompasses an overall perspective of what is good for an individual: being part of a meaningful social role; experiencing optimistic and happy emotions; incorporating good values into everyday life; having a supportive and positive social environment; coping appropriately through challenges; and receiving protection and access to quality facilities.

During adolescence, psycho-social and hormonal changes (in relation to puberty) can cause complications and challenges to T1D management. In comparison to other age-groups, adolescents with T1D have shown the poorest glycaemic control (De Wit *et al.*, 2008; Delamater, 2007; Delemarre-van de Waal, De Wit, Pouwer, Gemke, & Snoek, 2007; Reynolds & Helgeson, 2011). The daily demands of T1D self-care can interfere with the adolescents' development; affecting their relationships and routines, comprising their social and emotional well-being. Furthermore, these adolescents are inclined to fulfil their psycho-social needs during this phase instead of focusing on the long-term preventative health actions required.

Research has shown that adolescents with chronic diseases tend to follow atypical developmental patterns when compared to their control group peers (Hartman, DePoy, Francis, & Gilmer, 2000; Maslow, Haydon, McRee, Ford, & Halpern, 2011); these adolescents are at potential risk of developing poor scholastic, professional and social outcomes (Verhoof, Maurice-Stam, Heymans, Evers, & Grootenhuis, 2014). Thus, understanding the *psycho-social well-being* of adolescents with T1D is significant as it can optimise their development and management of the disease.

1.7.10 RESOURCE-CONSTRAINED COMMUNITY

The term *resource-constrained community* will refer to a semi-urban area (Ebersohn & Ferreira, 2012); whereby health, education and residential areas have limited available resources. The participants interviewed in this research study all come from a resource-constrained community.

1.8 THE PHENOMENON OF T1D

This research study conceptualises the phenomenon of T1D as any form of subjective impact on the psycho-social well-being of adolescents in a resource-constrained community. The impact of T1D may influence adolescent development, as well as their well-being. The findings from this research study have highlighted this concept, as explained in existing literature, along with new knowledge not previously mentioned. Therefore, this phenomenon is not seen as an objective truth, but rather conceptualised through the subjective viewpoints of the participants and the meanings they attach to their lived experiences.

1.9 WORKING ASSUMPTIONS

Anney (2014) state that qualitative research is used to describe and investigate people's individual and social realities. This implies that the researcher's investigation and interpretation of the experiences of adolescents with T1D were based on the meanings and perceptions of the research participants. The research findings from this study were obtained from adolescents with T1D who all receive treatment from a public (government funded) healthcare sector in Atteridgeville, South Africa. This area is referred to as a resource-constrained community as it has limited available resources regarding health, education and/or living conditions.

Based on the qualitative nature of the study, the researcher is mindful that the findings obtained cannot be generalised as the purpose was to develop idiographic knowledge within the research-context (Lincoln & Guba, 1985; Nieuwenhuis, 2007a, 2007b, 2007c). Adolescents within a resource-constrained community may struggle with managing their T1D due to possible issues surrounding psycho-social factors, which can have a negative impact on their well-being. Nevertheless, the study will provide an objective understanding of the research participants' subjective world and the impact that T1D has on their psycho-social well-being.

1.10 QUALITATIVE RESEARCH IN PSYCHOLOGY OF HEALTH AND ILLNESS

A qualitative approach was used as a methodological paradigm that informed this study. In order to regard the impact of T1D on the psycho-social well-being of the adolescent from their viewpoint, the researcher must use appropriate and reliable research techniques. The use of qualitative methodologies has only become accepted over the last two decades to achieve such research aims (Henwood & Pidgeon, 1992; Smith, 1996a, 1996b; Turpin *et al.*, 1997). This approach does not search for fundamental laws but for socially constructed meanings that cannot be analysed through numerical data (Willig, 2013); which allowed the researcher a more sensitive approach to the numerous interpretations that individuals may construe in an attempt to uncover a clearer understanding of meaning.

According to Lyons and Coyle (2016), this analysis is mainly valuable with topics that have a limited body of knowledge and where there would be previously unknown variables that are complicated to recognise. The qualitative paradigm afforded an idiographic understanding of the participants, what T1D means to them, within their social reality, to live with T1D in a resource constrained community. It thus facilitated an understanding of the complexity of biopsychosocial phenomena and offered in-depth interpretative meanings to the adolescents' lived experiences.

1.11 RESEARCH DESIGN AND RESEARCH METHODOLOGY

A qualitative research design, using interpretative phenomenological analysis (IPA) as the research strategy, was selected on the basis of being a suitable method in accordance with the stated objectives and purposes of the study. Qualitative inquiry approaches the lived experiences of human beings, which allowed the researcher to describe and explore the topic from the participants' subjective viewpoints. Smith (2015) stated that a qualitative methodology is commonly conducted through exploration, description and interpretation of the participants' subjective and collective experiences.

Table 1.1 serves as a summary of the research design and the research methodology techniques employed during this research study, which will be discussed in detail in Chapter 4.

Firstly, table 1.1 indicates that the researcher employed an *interpretive phenomenological approach* research design to obtain in-depth personal experiences from the adolescents who have type 1 diabetes that live in a resource-constrained community (Denzin, 2009; Denzin & Lincoln, 2011). "IPA's theoretical underpinnings stem from phenomenology which originated with Husserl's attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation), and with symbolic-interactionism, which posits that the meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process" (Biggerstaff & Thompson, 2008, p. 4). IPA follows an interpretive phenomenological epistemology through which the results of the study can be interpreted.

The table further indicates that the researcher selected to work with the T1D patients at the public healthcare facility, as it is situated in a resource-constrained community. Therefore, a group of 5 adolescents was purposefully selected, aged 15-18 years, with T1D that attends regular check-ups at this facility. The participants were chosen with the following criteria in mind: Each participant had to have T1D and attend the public healthcare facility for diabetes-related appointments – homogenous in these characteristics (Smith, 2015). In addition, the table indicates that the following data collection methods were employed; (i) *semi-structured interviews* and (ii) *field notes* (Eatough & Smith, 2016). Further, as methods of data documentation; (i) *audio-recorder*, (ii) *note-taking* by researcher (during interviews), as well as (iii) *reflective journal* (Willig, 2013) were relied upon. *Interpretative Phenomenological Analysis (IPA)* for data analysis and interpretation was applied.

Table 1.1: A SUMMARY OF THE RESEARCH DESIGN AND RESEARCH METHODOLOGY TECHNIQUES

RESEARCH DESIGN	Interpretive Phenomenology
RESEARCH METHODOLOGY	
Unit of analysis	Adolescents with T1D
Selection of participants	Criteria for selection: T1D patients at a public healthcare facility in a resource-constrained community. Purposeful sampling: (a) 5 adolescents aged 15 to 18 years, (b) diagnosed with T1D for longer than 1 year, and (c) living with parent/guardian.
Data collection method	<ul style="list-style-type: none"> • Semi-structured interviews • Field notes
Data documentation methods	<ul style="list-style-type: none"> • Audio methods • Reflective journal • Note-taking (during interviews)
Data analysis and interpretation	Interpretative Phenomenological Analysis (IPA)
Measures to ensure rigour	Trustworthiness techniques: credibility, transferability, dependability confirmability and authenticity.
Ethical considerations	Informed consent, privacy, confidentiality, anonymity and protection from harm.

1.12 CHALLENGES OF THE STUDY

As this is an emerging field of knowledge in South Africa, a significant gap exists within the literature with regard to the knowledge pertinent to this study. Therefore, this highlighted a challenge for the research design and methodology process; however, it provided an area for new information within an existing body of knowledge with regard to the components in this study.

1.13 OUTLINE OF DISSERTATION CHAPTERS

To assure a well-structured research report in which the content flows in a chronological order and in which the research aims and questions are addressed, the chapters are outlined as follows:

CHAPTER 1 serves as the introductory chapter and presents the context of the study. Furthermore, this chapter provides an overview and rationale of the research report.

CHAPTER 2 provides the theoretical framework and literature review of the impact of type 1 diabetes on the psycho-social well-being of adolescents.

CHAPTER 3 provides a literature review of the management and complications of type 1 diabetes.

CHAPTER 4 describes the research design, research methodology and the research process that was applied in the study. Additionally, the methods of data collection, data analysis and interpretation are outlined and justified.

CHAPTER 5 focuses on the research findings and interpretations from the participants.

CHAPTER 6, the concluding chapter, links the results with relevant literature, providing an integrated account obtained in relation to new and consistent themes. The contributions as well as the challenges of this study are presented and recommendations made for further research, practice and training are suggested.

1.14 SUMMARY OF CHAPTER 1

This chapter highlights the need to study the impact of T1D on the psycho-social well-being of adolescents; providing an introduction to the chapters that follow. The rationale and purpose of this study were discussed, the selected key theoretical concepts were defined, and the selected methodological and epistemological assumptions, as well as the research design and research methodology were stated. Quality criteria and ethical considerations for this study were also stated. Finally, a broad overview of that which is to be discussed in Chapters 2-6 was presented.

2. CHAPTER 2: LITERATURE REVIEW OF THE IMPACT OF TYPE 1 DIABETES ON THE PSYCHO-SOCIAL WELL-BEING OF ADOLESCENTS

2.1 INTRODUCTION

In this section, the researcher will review literature pertaining to the impact of type 1 diabetes (T1D) on the psycho-social well-being of adolescents. There is limited information on the literature in the context of the researcher's study, and therefore, the literature review will be based on Southern African and international research.

2.2 THEORETICAL FRAMEWORK

According to Guba and Lincoln (1994), paradigms are categorized by their ontology (*what is reality?*), epistemology (*how do you know something?*), methodology (*how to go about finding out?*) and axiology (*the role of the researcher values in the research process*). All these characteristics create a holistic perspective for how the researcher views knowledge. This study adopted Engel's Biopsychosocial Model, Systems Theory and Phenomenology for the theoretical framework.

➤ ENGEL'S BIOPSYCHOSOCIAL MODEL

George Engel's (1980) biopsychosocial model has been of considerable utility to health and illness research. It is a scientific model constructed to incorporate the missing dimensions of the biomedical model; looking at biological, psychological and social elements (Adler, 2009). In this framework the role of biological factors are acknowledged, but suggests that psychological and social factors are also crucial; entailing a systems approach of complex interactions in understanding health and illness.

According to this model, single domain explanations are not adequate and argue that a change in one factor results in a change in other factors (Suls, Krantz, & Williams, 2013); if all factors are taken into account an improved understanding of human functioning will be formulated. Therefore, the biopsychosocial model states that the body, mind and environment are all part of an interconnected system that leads to a given outcome in health and illness.

➤ SYSTEMS THEORY

Systems theory states that human development is created through the interaction between the individual and the environment (Bateson, 1979; Capra, 1996; Hanson, 2014). The individual is seen as a system that interacts with other systems, namely: friends, family and the community. According to Visser and Moleko (2012), the theory explains how individuals grow and develop within a system, with different levels of the environment influencing their development.

As such, adolescent development and functioning is influenced by various systems in the community. Furthermore, the development and functioning experienced by the adolescent will in turn have an effect on the various systems which require an understanding of the interrelated social system. This idea follows the fundamental principle of this theory explained by Bateson (1979), if one wants to understand a phenomenon, one must analyse that phenomenon within the context of interconnected human relationships from which it exists.

➤ PHENOMENOLOGY

Phenomenology describes both a theoretical approach and research methodology in this study. According to Eatough and Smith (2016), the essence of phenomenology is to return to things themselves. Interpretative phenomenological analysis (IPA), developed by Jonathon Smith (1996a), allows for rigorous exploration of idiographic subjective experiences, specifically social cognitions. IPA's theoretical approach originates from interpretive phenomenology, making sense of the individual's personal and social world, allowing an understanding of how people view and interpret significant events in their life experiences. This idea reflects its phenomenological lens (Giorgi & Giorgi, 2008) which refers to a person's subjective account of a life experience as opposed to attempting to produce the life experience in isolation of personal viewpoint.

2.2.1 INTEGRATING THEORETICAL FRAMEWORK

Since the intention of the study was to explore and describe the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community, the researcher relied on all three theories in conducting the research. Engel's biopsychosocial model (1980) provided the three main elements concerned when understanding how T1D impacts the adolescent. Systems theory allowed for a conceptual framework to be constructed comprehending the complexity of the community processes that the research participants form part of.

Phenomenology served as a theoretical point of departure in this study, as well as underlying the methodological procedures used to conduct the research (Lyons & Coyle, 2016); allowing for T1D to be viewed as a phenomenon in the context of mutual interaction and influence within the adolescents' lived experience.

Thus, these theories assisted in directing attention away from T1D being viewed as a single entity, but rather to a broad context of interrelated psycho-social factors that can impact the well-being of these adolescents.

2.3 DIABETES: DEFINITION AND DESCRIPTION

The term diabetes, a chronic disease, is used to describe a complex metabolic disorder which is characterised by hyperglycaemia (excess of glucose in the blood stream or high blood glucose) resulting from problems in insulin secretion, insulin sensitivity, or both. All types of diabetes have something in common. The body needs energy found in food to function, which is done by breaking down fats, carbohydrates, sugars and proteins into a distinctive sugar termed glucose. This is needed to manage the cells in the body but the cells need insulin in order to absorb the glucose and use it for energy.

With people who have diabetes, their bodies either cannot make enough insulin, cannot use the insulin it produces or, a collaboration of both. When the body has problems regarding the absorption of glucose, it accumulates in the blood. According to Unger and White (2016), "chronic exposure to hyperglycaemia, glycaemic variability, and resultant oxidative stress in genetically prone individuals can result in both acute (diabetic ketoacidosis [DKA] and hypoglycaemia) and long-term (micro- and macrovascular) complications" (p. 782). The normal range for blood glucose levels is 4–6 mmol/L. American Diabetes Association (2017b) states that people who have this disease must adhere to specific management in order to bring blood glucose levels into the normal range, this management includes: insulin replacement (insulin injections/insulin pump); monitoring of blood glucose; strict eating plan; daily physical activity; and lastly, individually tailored insulin regimen.

The following categories classify the different types of diabetes (ADA, 2015a, p. S8):

1. "Type 1 diabetes (due to β -cell destruction, usually leading to absolute insulin deficiency)
 - Immune-mediated
 - Idiopathic;

2. *Type 2 diabetes* (due to a progressive insulin secretory defect on the background of insulin resistance);
3. *Gestational diabetes* ([GDM], diabetes diagnosed in the second or third trimester of pregnancy that is not clearly overt diabetes);
4. *Specific types of diabetes due to other causes*, e.g., monogenic diabetes syndromes (such as neonatal diabetes and maturity-onset diabetes of the young [MODY]), diseases of the exocrine pancreas (such as cystic fibrosis), and drug- or chemical-induced diabetes (such as in the treatment of HIV/AIDS or after organ transplantation)."

Type 1 diabetes (T1D) also termed "insulin-dependent diabetes"; formerly known as "*insulin-dependent diabetes*" or "*juvenile-onset diabetes*" because of the early childhood onset. It is the result of the body producing antibodies which attacks its own pancreas – an autoimmune deficiency. In people with T1D, the pancreas produces little or no insulin. A genetic predisposition may be the cause for this type of diabetes, as well as defect β -cells in the pancreas that produce insulin.

Mismanagement of T1D can cause a number of acute and long-term complications. Examples could be damage to small blood vessels in the eyes (diabetic retinopathy); nerve damage throughout the body (diabetic neuropathy); impaired kidneys; and even more severe cases, higher threat for stroke and heart disease. Treatment for T1D encompasses administering insulin using the following injection methods through the skin into the fat tissue: syringes; pens that use insulin cartridges and fine needles; or, continuous subcutaneous insulin infusion (CSII) pumps that release insulin through consumables to a catheter under the skin around the stomach area. Depending on the person other areas of skin can also be used besides the abdomen, such as: arms, legs and posterior regions. Regular blood glucose tests also need to be taken by means of pricking the finger and inserting the test strip into a glucometer. T1D requires significant lifestyle changes to diet, exercise and management of this chronic disease. Genetics, diabetes family history, infections and various environmental factors can influence the risk of acquiring T1D.

Type 2 diabetes is, by far, the most common form of diabetes worldwide, previously known as "adult-onset diabetes" and "non-insulin-dependent diabetes". However, the epidemic of obesity and overweight youth has resulted in youth also being diagnosed with this disease. It is often thought of as a 'milder form of T1D', however if badly managed it can also cause major health complications and similar treatment to that of T1D. Type 2 diabetes can also cause damage to the small blood vessels. "Risk factors that contribute to type 2 diabetes include: excess body weight, physical inactivity, poor nutrition, genetics, family history of diabetes, past history of gestational diabetes and older age" (ADA, 2015a, p. S9).

2.4 TYPE 1 DIABETES [T1D]

T1D is defined by the American Diabetes Association (2017a) and the World Health Organisation (2016) as a chronic disease with immune-mediated pancreatic islet β -cell destruction, which often leads to a disruption in insulin production and hyperglycaemia. The host is therefore dependent on exogenous insulin to prevent ketoacidosis from developing, an acute life-threatening complication of T1D (Atkinson, Eisenbarth, & Michels, 2014; Craig *et al.*, 2014; Klingensmith *et al.*, 2008; Svoren & Jospe, 2016).

Despite active research, there is currently no cure for T1D but it can be controlled through effective management. Therefore, the natural history of T1D includes four major clinical stages (Svoren & Jospe, 2016, p. 2761): “(1) preclinical β -cell autoimmunity with progressive defect of insulin secretion, (2) onset of clinical diabetes, (3) transient remission ‘honeymoon period’, and (3) established diabetes during which there may occur acute and/or chronic complications and decreased life expectancy. The onset occurs predominantly in childhood, with a median age of 7-15 years, but it may present at any age.” In T1D, a person that is genetically susceptible develops autoimmunity against the person’s own β -cells. The exact cause of this autoimmune reaction still remains unclear today.

This autoimmune deficiency, in some patients, results in a gradual destruction process of β -cells until too many cells are lost and insulin deficiency takes place. The onset of T1D clinical symptoms and signs is brought on from the insulin deficiency (Unger & White, 2016). During diagnosis, a partial remission of the disease (honeymoon period) may occur as some β -cells may still produce insulin. However, as time progresses most β -cells are destroyed, forcing the patient to become completely dependent on exogenous insulin in order to survive. A C-peptide test is performed when a person is newly diagnosed with diabetes to determine how much endogenous insulin is still being produced by the pancreas.

Over time, some patients with T1D may develop secondary microvascular and macrovascular complications of diabetes in relation to how well-managed blood glucose levels have been. According to Svoren and Jospe (2016), “the natural history of T1D involves some or all of the following stages: (1) initiation of autoimmunity, (2) preclinical autoimmunity with progressive loss of β -cell function, (3) onset of clinical disease, (4) transient remission, (5) established disease, and (6) development of complications” (p. 2766).

The natural history of T1D is shown in the following figure:

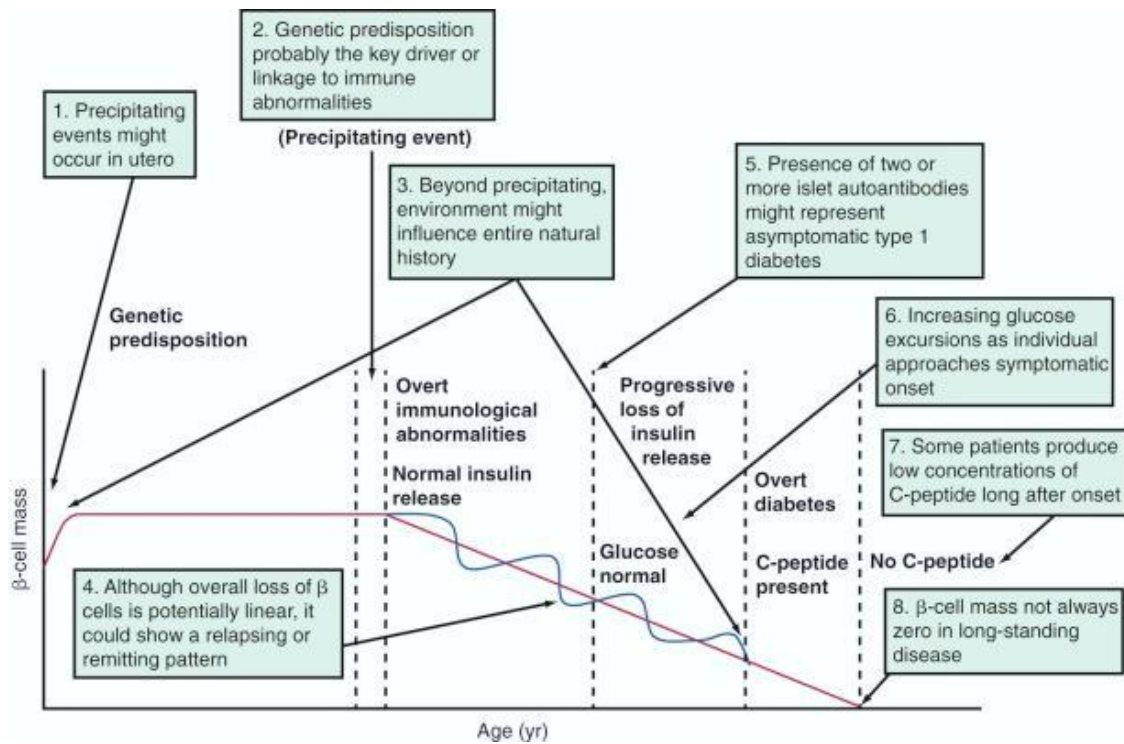


Figure 2.1: THE NATURAL HISTORY OF TYPE 1 DIABETES REVISITED

Note. Adapted from Atkinson M. A., Eisenbarth G. S., Michels A. W.: Type 1 diabetes. *Lancet* 383(9911):69–82, 2014, Fig. 4, p. 73.

As previously mentioned, T1D is characterised as an autoimmune deficiency whereby pancreatic islet β -cells are destroyed, usually leading to absolute insulin deficiency (Pettersson *et al.*, 2016). T1D incidence rate has had a steady increase in almost all regions globally. The pathogenesis of this disease can be attributed to environmental and genetic influences. The classification of T1D encompasses two forms, namely: immune-mediated diabetes and idiopathic diabetes (American Diabetes Association, 2013). For the purpose of this study the two forms of type 1 diabetes must be explained in order for the research being discussed regarding genetic and environmental factors to be fully understood in context.

ADA (2013, pp. S67-S68) classification of these two forms of T1D:

“Type 1 diabetes (β -cell destruction, usually leading to absolute insulin deficiency)

Immune-mediated diabetes.

This form of diabetes, which accounts for only 5–10% of those with diabetes, previously encompassed by the terms insulin-dependent diabetes or juvenile-onset diabetes, results from a cellular-mediated autoimmune destruction of the β -cells of the pancreas. Markers of the immune destruction of the β -cell include islet cell autoantibodies, autoantibodies to insulin, autoantibodies to glutamic acid decarboxylase (GAD65), and autoantibodies to the tyrosine phosphatases IA-2 and IA-2 β . One and usually more of these autoantibodies are present in 85–90% of individuals when fasting hyperglycaemia is initially detected.

Also, the disease has strong human leucocyte antigen (HLA) associations, with linkage to the DQA and DQB genes, and it is influenced by the DRB genes. These HLA-DR/DQ alleles can be either predisposing or protective.

In this form of diabetes, the rate of β -cell destruction is quite variable, being rapid in some individuals (mainly infants and children) and slow in others (mainly adults). Some patients, particularly children and adolescents, may present with ketoacidosis as the first manifestation of the disease. Others have modest fasting hyperglycaemia that can rapidly change to severe hyperglycaemia and/or ketoacidosis in the presence of infection or other stress. Still others, particularly adults, may retain residual β -cell function sufficient to prevent ketoacidosis for many years; such individuals eventually become dependent on insulin for survival and are at risk for ketoacidosis. At this latter stage of the disease, there is little or no insulin secretion, as manifested by low or undetectable levels of plasma C-peptide. Immune-mediated diabetes commonly occurs in childhood and adolescence, but it can occur at any age, even in the 8th and 9th decades of life.

Autoimmune destruction of β -cells has multiple genetic predispositions and is also related to environmental factors that are still poorly defined. Although patients are rarely obese when they present with this type of diabetes, the presence of obesity is not incompatible with the diagnosis. These patients are also prone to other autoimmune disorders such as Graves' disease, Hashimoto's thyroiditis, Addison's disease, vitiligo, celiac sprue, autoimmune hepatitis, myasthenia gravis, and pernicious anaemia.

Idiopathic diabetes.

Some forms of type 1 diabetes have no known aetiologies. Some of these patients have permanent insulinopenia and are prone to ketoacidosis, but have no evidence of autoimmunity. Although only a minority of patients with type 1 diabetes fall into this category, of those who do, most are of African or Asian ancestry. Individuals with this form of diabetes suffer from episodic ketoacidosis and exhibit varying degrees of insulin deficiency between episodes. This form of diabetes is strongly inherited, lacks immunological evidence for β -cell autoimmunity, and is not HLA associated. An absolute requirement for insulin replacement therapy in affected patients may come and go."

2.5 THE ADOLESCENT WITH T1D

T1D is a chronic disease which requires ongoing adaptations and interventions. There are progressive changes and adaptations that take place depending on the adolescent's age and development to emerging adulthood. "Many children and adolescents may find it difficult to cope emotionally with their disease. Diabetes can result in discrimination and may limit social relationships. It could also have an impact on a child's academic performance. The costs of treatment and monitoring equipment, combined with the daily needs of a child with diabetes, may place a significant financial and emotional burden on the whole family" (International Diabetes Federation, 2015, p. 63). Freeborn, Dyches, Roper and Mandleco (2013) reported that children and adolescents found it challenging to deal with low glucose levels, and self-care activities (blood glucose testing and administering insulin via injections) on a daily basis.

Furthermore, they expressed feelings of loneliness and being seen as different because of having to adjust to a more regular and healthy lifestyle in comparison to their peers (Freeborn, Dyches, Roper, & Mandleco, 2013; Roper *et al.*, 2009).

Additionally, adolescents with T1D may encounter illness flares or hospitalisations that necessitate absence from school; alongside mandatory appointments and medical treatment collection. As a result, their education can be disrupted and they may begin to lose touch with their peers resulting in feelings of isolation and struggling to keep up with academic work. Thus, this developmental stage can be seen as challenging due to various physical, psychological and social changes (Ogle *et al.*, 2013). T1D can also be seen as interference because of the daily routine disturbances that may impede their freedom and spontaneity.

This disease is seen by adolescents as a handicap when activities (e.g. holiday trips, sleepovers and social gatherings) with friends and family take place. Life dissatisfaction was felt as a result from the aforementioned. The T1D team must be cognisant of this and suggest alternative strategies that can help minimise these emotional reactions (Roper *et al.*, 2009). Activities such as attending a diabetes camp or support group can provide opportunities for adolescents to meet friends that share the same conditions as them (Buresova, Veleminsky Jr, & Veleminsky Sr, 2008; Petersson *et al.*, 2016). Regarding the school environment, studies have shown that adolescents with T1D often receive a lack of support (Chiang *et al.*, 2014; Jackson *et al.*, 2015).

In a study done by Jackson *et al.* (2015) a major concern for adolescents at school, regarding T1D, was not being able to recognise a hyperglycaemic event, hypoglycaemic event or inability to administer insulin themselves due to feeling embarrassed or ashamed. Although, the adolescents reported that a great amount of support did come from teachers and peers. This was only accounted in cases where teachers had prior knowledge of the disease. Therefore, the well-being of the adolescents with T1D is dependent on glycaemic control, quality of life, T1D management and support structures.

Successful coping techniques, improved health and psycho-social well-being can be developed by understanding what adolescents find stressful about T1D management. “The relationship between stress, coping, and adherence are often intertwined, with stress and coping indirectly affecting glycaemic control by interfering with regimen adherence” (Delamater, Patiño-Fernández, Smith, & Bubb, 2013, p. 55). Studies have shown that poor coping styles are connected with nonadherence and high glycaemic levels (Delamater, Kurtz, Bubb, White, & Santiago, 1987; Graue, Wentzel-Larsen, Bru, Hanestad, & Søvik, 2004; Seiffge-Krenke & Stemmler, 2003). Thus, coping skills and stress management training will enhance the lifestyles of adolescents who experience high levels of T1D-related stress; improving their psycho-social well-being and glycaemic control.

2.5.1 DEFINING ADOLESCENCE

Adolescence is considered to be the period of transition from childhood into emerging adulthood (Arnett, 2014a; Sanders, 2013). It can be viewed as the bridge between being a child and becoming an adult. In health psychology it is characterised by cognitive, psycho-social and emotional development (Sanders, 2013). According to the South African Constitution, adolescence legally ends at the age of 18 years (Louw & Louw, 2014). Generally, the more traditional perspective that adolescence spans from 12 to 18 years is followed but for the purpose of this research study the age range was narrowed down to the following: 15 to 18 years. Defining adolescent development often involves interdisciplinary collaborations for biological, cognitive and social changes. Adolescence can be defined biologically, as physical development is marked by the onset of rapid physical growth and sexual maturation (Gessell & Ilg, 1949; Hall, 1916; Tanner, 1978); cognitively, as moving from concrete thinking to the ability of abstract and logical thought processes (Howard, 1983; Piaget, 1951; Sternberg, 1984); or socially, as a period of becoming independent and preparing for emerging adulthood (Bandura, 1989).

There are various divergent opinions regarding the most common psychological characteristics of the adolescent. On the one hand, adolescence is viewed as having conflict with parents/guardian and other adult authority figures, moodiness and indulging in high-risk behaviour (Carr, 2015). On the other hand, the adolescent is seen as more knowledgeable and better principled, as well as being honest and tolerant towards others (Ginsburg & Kinsman, 2017). Although the aforementioned viewpoints are still being debated, adolescence has been agreed to be one of the most rapid phases of human development; encompassing major changes in physical, cognitive, psycho-social, emotional and social development.

It is important to note that childhood is the period from approximately 2-12 years of life, preceding adolescence (Louw & Louw, 2014). Childhood also has major changes that take place and if appropriate adjustment is not achieved then problems may arise during the adolescent phase. According to Louw and Louw (2014, p. 301), "adolescence can be divided into three categories, namely: *early* adolescence (12-14 years), *middle* adolescence (15-16 years) and *late* adolescence (17-19 years)". The following section will briefly discuss the major developmental changes that take place during adolescence.

2.5.1.1 Physical Development

In early adolescence, the individual experiences rapid and ongoing physical growth. This physical growth is known as the 'growth spurt' or 'accelerated growth' period. Sexual maturation also takes place during adolescence, known as puberty.

In healthy populations, rapid physical growth of girls generally begins at about 10-13 years and ends around 16 years or later, alternatively boys begin 12-15 years and ends at about 18 years or later (Louw & Louw, 2014). However, physical changes are unique to every individual and these differences could be attributed to the collaboration between environmental and genetic factors (Altıntaş *et al.*, 2014). Adolescents are acutely aware of their physical changes and accepting their changed physical appearance is an important developmental task. Such a task is not easy to all adolescents due to issues of weight, sexuality and self-image.

The adolescent's psychological development is affected by the age at which physical maturity is reached. Different psychological outcomes are seen when the adolescent reaches maturity either earlier or much later than the expected age (Carr, 2015). If the adolescent matures earlier he/she usually exhibits taller and heavier physical traits, along with sexual characteristics much earlier in comparison to the peer group. If the adolescent matures later he/she is smaller and lighter, and develops sexual characteristics considerably later than the peer group. Gender differences occur for the effects of early and late maturation for adolescent girls and boys.

During this phase adolescents are significantly concerned about their body shape and appearance (Norris, Spettigue, & Katzman, 2016). As a result, issues surrounding body image may lead to eating disorders. In the past, eating disorders have been associated with Western culture in which the ideal body type was slender and skinny. However, studies show that the frequency of disordered eating behaviour is increasing in developing and non-Western countries (Le Grange, Louw, Russell, Nel, & Silkstone, 2006; Szabo, 2015). In South Africa, research shows that there are no differences that exist among various ethnic groups concerning eating disorders and their symptoms (Caradas, Lambert, & Charlton, 2001; Gitau, Micklesfield, Pettifor, & Norris, 2014; Shelembe, 2014). A possible reason for the differences between cultures and subcultures to disappear is due to globalisation and media. It is important to note that there is still a difference between black rural and urban females in South Africa regarding weight.

“In rural areas, overweight is traditionally associated with dignity, respect and health (i.e. not suffering from AIDS), with the result that the obsession with thinness is not that overbearing” (Louw & Louw, 2014, p. 312). Pearson *et al.* (2017) states that although a concern for food-intake and weight plays a major role in eating disorders (see section 3.3.1.5), many other factors can also be the cause, such as: family and cultural pressures, psychological disorders, chronic diseases (i.e. T1D), and biological and genetic factors.

During adolescence physical and sexual development is determined by genetics and biology; making it a period of sexual excitement and anxiety (Louw & Louw, 2014). Puberty encompasses extensive physical development and adolescents become increasingly aware of their sexuality. This newly developed sexuality also starts to form part of their interpersonal relationships (Arnett, 2000, 2014b). They begin to feel a heightened sense of awareness towards others and this sensitivity is felt in a number of ways. The mixed emotions that come with sexual development can make the adolescent feel fearful, passionate, loving, aggressive and anxious in certain settings.

2.5.1.2 Cognitive Development

Cognitive changes are equally dramatic as the physical changes that occur during this developmental period. According to Sanders (2013), cognitive growth is the advancement of thinking from a child to an adult. For the purpose of this study the following three main approaches to understanding cognitive development during adolescence will be discussed: constructive perspective, componential approach and psychometric approach.

The *constructive perspective*, based on the work of Jean Piaget (1951, 2013), assumes that adolescents continually interpret or decipher all experiences. They develop more advanced reasoning skills; think hypothetically, developing alternate ways or hypotheses to solve a problem (deductive reasoning); and incorporate a logical thought process. “This enables the adolescent to plan ahead, anticipate future consequences to an action and give alternative explanations to events. The *componential approach* refers to the breaking down of the thinking process into various components. An example of this is the information-processing approach” (Louw & Louw, 2014, p. 328). In this approach adolescent thinking is broken down into separate components for attention, processing, storing and retrieving information. These cognitive changes are seen as refinements of existing abilities instead of emerging new ones.

Robert Sternberg (1984, 1998, 2004) takes a componential view of cognitive development and states that metacognition, performance and knowledge-acquisition components should be taken into account for adolescent problem-solving abilities. The *psychometric approach* is focused on the individual differences in the general capabilities that add to intellectual thinking (Louw & Louw, 2014). This approach is generally measured by intelligence tests to evaluate the adolescent's intelligence quotient (IQ). Howard Gardner (1999, 2011; 1983) shares this view and defines intelligence in terms of the individual's ability to solve problems as they arise. All these approaches can be applied to understand cognitive development in adolescents.

In adolescence the ability to think abstractly is developed. Adolescents move from concrete thinking to being abstract thinkers, which allows them to have capacity for love, spirituality and advanced logical processes. These advancements in cognitive development can affect their school performance because of their broader conceptualisation of intelligence. The adolescent now has capacity for effective argumentation, idealism and criticism; a higher level of understanding and intellectual stimulation (Louw & Louw, 2014).

The adolescent may struggle or have difficulty in the school realm as they transition through high school if they remain at a concrete thinker level (Sanders, 2013). This can be due to a number of reasons, such as: chronic diseases, psychological disorders, psycho-social issues, family problems or biological factors (Cato *et al.*, 2014; Gardner, 2011). During adolescence, the ability to take the perspective of others leads to them becoming less egocentric. Nevertheless, a new type of egocentrism develops in this stage of social cognition.

Piaget supposed that at this stage a new aspect of egocentrism evolves; adolescents are unable to discern their abstract perceptions of themselves from others. Adolescents' start to think more about themselves; they have the ability to reflect on personal views shared with their biological and emotional variations. David Elkind (1967, 1985, 2014) expanded on Piaget's ideas of egocentrism and included two distorted images of relation between self and others, namely: personal fable and imaginary audience. Being abstract-thinkers has resulted in the adolescent's personal fable, it is constructed on the premise that the imaginary audience (peers) is observing the adolescent; hence he/she must be different or special to the peer group. This type of egocentrism is believed to influence the personal fable of risk-taking behaviour and invincibility for adolescents (Louw & Louw, 2014). The personal fable may place negative consequences to irrational behaviour regarding health and safety.

The imaginary audience can also be detrimental to adolescents with chronic diseases (Sanders, 2013). For example, adolescents with T1D may hide/deny having the disease for fear and embarrassment that the audience may learn about it or show that they are not crippled by it. Such behaviours must be taken into account and the audience should be sympathetic to the adolescents concerns as it could disrupt their academic performance, behaviour and self-image (see section 3.2.9). Furthermore, peers can be an asset in the treatment of T1D and can provide a beneficial type of social support from that given by family members.

2.5.1.3 Psychosocial Development

The psycho-social development that takes place during adolescence can be characterised as progressive tasks that develop *autonomy*, *establish identity* and *future orientation*. This section will discuss the aforementioned three areas of psycho-social development.

During the creation of “*autonomy*, the adolescent strives to be emotionally and economically independent from their family. This endeavour starts during early adolescence (12-14 years), which is characterised by forming same-sex peer groups, with decreasing interest in family activities and parental advice. During this time adolescents are concerned with how they appear to others” (Sanders, 2013, p. 355). The typically same-sex peer group is commonly idealised and harbours an influential strength over adolescent development. Consequentially, this may impact their choices in physical appearance, linguistics and other components to gain acceptance and ‘fit in’ with their peer social groups (Arnett, 2016). Significant psychological difficulties during this phase may arise if adolescents do not establish these relationships; they could end up feeling isolated and/or rejected from their social peers (Alexander, Waldron, Robbins, & Neeb, 2013). By the end of puberty, less attention is given to bodily changes and the focus is shifted to integration of values and trends of larger social groups. According to Carr (2015), pubertal maturation may require the adolescent to readjust roles between family, friends and other social figures which may involve increased stress and conflicting issues.

Sanders (2013) explained that the individuals peer group becomes a mixed-peer group during middle adolescence (15-16 years). The mixed-peer group creates a significant social opportunity for the adolescent as they start to look for romantic relationships.

Studies have shown that family conflict reaches a peak during this phase as adolescents' independent functioning increases (Caruthers, Van Ryzin, & Dishion, 2014; Noller & Callan, 2015). The adolescent may also be examining their personal experiences, relating them to others and developing a concern for others well-being. A separate identity has been developed from the family by late adolescence (17-19 years). Simultaneously, the adolescent strives to establish an adult status, some might even move away from their peer group (Braun-Lewensohn, Idan, Lindström, & Margalit, 2017; Ginsburg & Kinsman, 2017; Gitau *et al.*, 2014). Family conflict may diminish during this phase due to the adolescent's responsible behaviour and mature value system outlooks. The mature independence that the adolescent is now discovering may lead to more rational or irrational behaviour; such an outcome is dependent on the individual's health, family, cultural and environmental factors (see section 3.2.6).

A sudden shift from family support could be an indicator that the adolescent is struggling with his/her transitional period as most adolescents seek independence in a gradual fashion (Sanders, 2013). For example, in adolescents with T1D independence when managing their disease is integral for effective development but constant support and guidance is still required from the family and healthcare team (Chamberlain, Rhinehart, Shaefer, & Neuman, 2016; Dhada *et al.*, 2014; Haas *et al.*, 2013). Self-management goals of T1D are further discussed in section 3.2.3.

Developing a sense of *identity* is another important task during adolescence; it is relative to the adolescent's sense of self. Identity can be separated into two parts, namely: self-concept and self-esteem. "Self-concept refers to an adolescent's perception of self - one's talents, goals, and life experiences. It can also relate to identity as part of ethnic, religious, and sexual identity groups. Self-esteem relates to how one evaluates self-worth" (Sanders, 2013, p. 355). In 1950, Erik Erikson provided the most comprehensive description of the psycho-social crisis during adolescence (12-19 years) as 'identity versus role confusion' (Erikson, 1959; Knight, 2017). The transition into emerging adulthood encompasses various processes for the adolescent; they start thinking about themselves as adults and interpreting their roles as such. Parenting, cognitive growth, personality, interpersonal relationships, school and wider community are factors which may contribute to identity formation (Louw & Louw, 2014). Role confusion about their identity is commonly experienced during this phase as they encounter mixed thoughts and emotions regarding their role in society. This may lead to experimenting in different behaviours or image styles as a forum for searching for their identity; which could also entail rebellious and risky behaviour in contrast to their parents' image.

Furthermore, Erikson explained that an adolescent's incapability to discover a strong identity or vocation option can result in an identity crisis. While having an identity crisis is likely to last for a short period, youth are taking longer to establish their identities due to globalisation and procurement of higher education levels or career development (Crocetti, 2017). Similarly, adolescents with T1D may find it difficult to establish a confident identity/self-image because of the disease impact and the ongoing daily pressures of managing the disease (see sections 2.8, 2.9 and 3.2). Poor self-esteem is directly related to the disrupted formation of self-identity in adolescence (Louw & Louw, 2014). Having a low self-image and self-esteem is associated with the following: severely poor adjustment (i.e. depression or suicide), low academic performance, substance abuse and other risk-taking behaviours (Sanders, 2013). Therefore, it is important to educate the family about supporting their adolescent through this hardship to ensure that a secure and stable identity can emerge.

The third area of adolescent psycho-social development is the ability for *future orientation*, which generally occurs during late adolescence (17-19 years). By this stage the adolescent has obtained the cognitive development needed for formulating achievable goals about future orientation; established a sense of self-identity; and, are making refinements to their sexual, spiritual and moral beliefs (Sanders, 2013). The adolescent would now like to be treated as an adult due to increased autonomy and the ability to handle more responsibility. The psycho-social development of the adolescent with T1D can be improved by allowing more freedom, autonomy and responsibility in aspects of self-care for the disease. However, this should still be accompanied by ongoing support from the family and T1D team. T1D self-management education and support are further discussed in section 3.2.2.

2.5.1.4 Social and Emotional Development

Adolescent development is furthermore characterised by social and emotional competence. "Emotional competence relates to the ability to manage emotions, whereas social competence focuses on one's ability to relate effectively with others. During this process adolescents become more aware of being able to identify and label their own feelings and the feelings of others. The rate of emotional and cognitive development is not related to the rate of physical maturation" (Sanders, 2013, p. 356). An imperative development in adolescence is being able to control their emotions; understanding the outcomes for both positive and negative emotions can assist them to deal effectively with emotional upheavals in life.

It is important for the adolescent to learn that positive emotions can enhance his/her academic performance and inter- and intrapersonal relationships, and that negative emotions could be harmful or counterproductive (Louw & Louw, 2014).

Adolescents experience certain emotional changes due to their physical, cognitive, personality and social development; resulting in more negative emotions and fewer extremely positive emotions. For example, adolescents feel more self-conscious, anxious, ashamed, awkward and isolated than in childhood (Berk, 2016; Larson & Lampman-Petratis, 1989; Rosenblum & Lewis, 2003). Additionally, they are also inclined to having more mood swings than adults or children, creating the impression of being less emotionally stable. For example, depending on the social environment, their emotions can alternate between happiness and sadness within the hour (Berk, 2016; Louw & Louw, 2014).

Gender differences² are also evident for emotional development in adolescence, and are often connected to hormonal changes. However, these emotional changes could also be related to cognitive and environmental factors. Studies have shown that girls commonly experience feelings of anger and depression, while boys encounter both negative and positive emotions (Brody, 1985; Rose & Rudolph, 2006; Van der Graaff *et al.*, 2014). On the one hand, boys feel more energised and attentive, but on the other hand, they also experience aggressive and irritated emotions. Cognitive refinements allow adolescents to think abstractly and in a more complex manner, showing insight into their own and others feelings. This enables them to enhance their empathic skills, which already started during childhood.

Gender differences in emotion can have significant consequences for adolescents' prosocial development and could lead to an increased risk of psychopathology. Adolescent girls have a greater propensity to externalise positive emotions by showcasing empathy and better social skills than boys (Chaplin & Aldao, 2013; Zimmermann & Iwanski, 2014). If such social behaviour is expressed while masking and internalising negative emotions (i.e. sadness, anxiety and distress), it may increase their risk for depression. Similarly, if adolescent girls express high levels of fear and anxiety towards stress it can also result in potential anxiety disorders (Bress, Foti, Kotov, Klein, & Hajcak, 2013).

² The term *gender differences* instead of *sex differences* is used because such diversities are not only depicted on biology but also impacted through social contexts.

Furthermore, it is notable that adolescent boys show greater externalising emotions, especially negative, than girls in social settings and alone (Klostermann, Connell, & Stormshak, 2016; Zimmermann & Iwanski, 2014). Such negative emotions, particularly anger expressions, could contribute to boys' greater risk for conduct problems. During adolescent development, it is therefore significant to examine circumstantial aspects prompting gender differences in emotional reactions. Adolescents with T1D must advocate for their special needs in a variety of social contexts, such as the school and healthcare settings. Neglecting these areas can lead to complications for their health and well-being (see section 3.3).

Parents/guardians and other adults can support emotional growth of adolescents by creating a supportive and safe environment for them to cope with their emotions in a healthy manner (Sanders, 2013). It is recommended that parents and guardians have ongoing involvement in the adolescents' life as they have a powerful influence on their identity development. The development of the adolescent's social maturity and social competence is largely dependent on the parental or supervisory styles (Louw & Louw, 2014). There are various techniques that have been demonstrated to be useful and most parents/guardians use a combination between authoritative, authoritarian or permissive styles (Baumrind, 1991); depending on what the adolescent situation requires more. The authoritative style is the most accepted style where the parent/guardian exercises an approach that is balanced with certain limitations, inductive discipline and unconditional love. Thus, the adolescents' social development is influenced by the parent/guardian and should be considered when understanding their emotions and behaviour.

For the adolescent with T1D, family factors are integral to treatment and management (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Lennon, Psihogios, Murray, Holbein, & Holmbeck, 2016; Wysocki *et al.*, 2003). "Family environmental factors such as parental support, social competence, family communication, problem solving, and conflict resolution skills are correlates of physical and psychological adjustment and are areas for intervention with families" (Wysocki, Greco, & Buckloh, 2003, p. 315). Parental involvement is also very important for the achievement of treatment goals, decreased family conflict and optimal glycaemic levels.

In summary, the main objective during adolescence is to obtain individuality and create a secure identity. Adolescence is a phase where rapid major changes take place physically, cognitively, psycho-socially and emotionally.

Major physical development takes place and changes occur both outside (sex organs, height, weight and muscle mass) and inside the body (brain structure and organisation). Their cognitive development encompasses the formation of abstract thinking which may predispose them to risk-taking behaviour and feeling invincible. Parental or supervisory monitoring is crucial to ensure the adolescent's safety while allowing for gradual independence to take place. The adolescent with T1D faces an additional enormous cognitive, affective and behavioural burden. In the face of significant developmental changes they must learn and adapt to a variety of skills to effectively manage their disease. Therefore, stress, coping and psychological adjustment must be discussed for the adolescent with T1D.

2.5.2 STRESS, COPING AND PSYCHOLOGICAL ADJUSTMENT

The treatment and management demand of T1D affects daily life for the adolescent. The management of this disease requires ongoing adherence to multiple daily tasks in home, school and community settings. Therefore, successful T1D management is dependent on the involvement of family, friends, school staff and healthcare professionals. Further, effective coping and adjustment skills are required to deal with adolescent development and the stressors of T1D.

2.5.2.1 Salutogenesis and T1D

In 1979, Aaron Antonovsky (1987, 1996) coined the term 'salutogenesis' and put forth the idea: Sense of Coherence (SOC), to comprehend an understanding of health and well-being rather than the causes of the disease. "The notion of health is characterised as a continuum, where each individual at a particular point of time exist somewhere on this continuum of health. To define where one stands on this continuum, people have 'general resilience resources' which can help them conceptualise the world as organised and understandable. SOC represents the motivation, and the internal and external resources one can use to cope with stressors, and plays an important role in the way one perceives challenges through life" (Bosacki & Steinberg, 2012, p. 15).

Furthermore, Antonovsky (1996) stated that a SOC involves three main prerequisites: (1) meaningfulness, wanting to cope; (2) comprehensibility, understanding the challenge; and (3) manageability, believing in the availability of coping resources. The degree to which these prerequisites are developed is determined by that person's SOC, which is strictly characterised by that person's own culture and context (socialisation). Antonovsky emphasised how fundamental this is to how an individual interprets the world and how strong their SOC will be.

Hence, salutogenesis analyses health and social capital³ as influences that can determine peoples SOC. It is important to note that there is not one specific style for coping; an adolescent who copes well and has a strong SOC will have the ability to choose the best method to deal with the particular stressor.

According to the World Health Organisation (2016), T1D is a non-communicable disease that has a profound and personal effect on people and their families. Due to the increasingly high prevalence and incidence rates (see section 2.6) of the disease it is crucial that adolescents are motivated to manage their own care as much as they possibly can. Thus, understanding the adolescent's SOC regarding T1D may be helpful in promoting effective self-care and self-management of the disease. As mentioned earlier, T1D is a chronic disease that can cause serious complications (Nathan, 2014). Adolescents with T1D are therefore required to make major lifestyle changes and adaptations to manage their disease successfully (Dhada *et al.*, 2014). Studies have shown that a prevalent barrier to managing T1D is the lack of appropriate coping skills, while having a positive attitude is a significantly effective strategy for self-care (Olshansky *et al.*, 2008; Oskouie *et al.*, 2013). It is therefore vital for these adolescents to be positively motivated to embrace their disease and learn to live life with ease. Therefore, understanding the psychological state of the adolescent with T1D can enhance the medical and nutritional requirements. As a result, effective T1D management encompasses the acceptance of the disease, maintaining a positive viewpoint and coping with lifestyle changes.

Antonovsky (1987) moved away from the traditional pathogenic perspectives which focus on disease to analysing factors that might improve health and well-being. This salutogenic orientation is a relatively new alternative perspective to health promotion and needs assessment. He explained that curative medicine and preventative medicine share a paradigmatic axiom which forms the basis of pathogenic orientation (1996). Furthermore, he advocated that multiple causation theory and biopsychosocial model do not dispute this axiom. Antonovsky highlighted the need to focus on the proponents of health promotion solely, as sharing this axiom has created barriers to theoretical progress. Hence, focusing on the proponents of health promotion would allow for a clearer image of the autonomous existence, which combined with curative and preventative medicine can lead to a more holistic understanding of the adolescent with T1D.

³ "Social capital can be described as levels of reciprocity in the community (i.e. trust, co-operation and social cohesion). Health capital can be factors which influence health, namely: socio-economic background, childhood history and coping skills" (Antonovsky, 1987, p. 19).

Antonovsky's (1996) concept can be directly applied to the adolescent with T1D. For example, the stronger the adolescent's SOC, the better he/she will be able to apply mental, emotional and practical strategies that can contribute to well-being and improved coping styles. An Israeli study, conducted by Cohen and Kanter (2004), studied the connection between SOC and glycaemic control. The results showed that people with T1D had higher levels of psychological distress in comparison to their control group. Further, their SOC was indirectly related to glycaemic control via adherence to self-care behaviours and psychological distress.

Similarly, strong SOC was associated with lower levels of psychological distress and successful adherence. Other studies support the notion that having a strong SOC has a positive impact on the coping ability of having T1D (Goldberg, 2015; Leksell, Wikblad, & Sandberg, 2005; Lundman & Norberg, 1993; Richardson, Adner, & Nordström, 2001). Most of the existing literature is predominantly quantitative which is contradictory to the qualitative elements of SOC. Hence more qualitative research is needed to examine the effects of having a strong SOC when coping with the stressors of T1D management in adolescence.

Unfortunately, healthcare sectors still predominantly follow a pathogenic orientation which makes it an ongoing challenge for applying salutogenesis. Most policies regarding T1D in countries do not integrate the components of SOC in the treatment and management for health or disease care (Pelikan, 2017). Antonovsky (1996) argued that SOC can be applied to all fields of healthcare; since then a number of studies have examined SOC in relation to T1D. It is recommended that "adolescents need to be helped to cope with the concomitant and interrelated developmental and self-management challenges. In order to do so, professional and family caregivers need to develop practices that are sufficiently autonomy-supportive. Such practices must acknowledge the adolescents' need to be addressed not only about disease and treatment-related issues (i.e., self-management issues), but also about general health issues (including communication about protective as well as risky health behaviours) and psycho-social issues (including awareness of their illness experience and the development of psycho-social competences)" (Aujoulat, Mustin, Martin, Pelicand, & Robinson, 2017, p. 341).

Therefore, SOC might be interconnected with significant therapeutic as well as psycho-social effects that are relevant to the adolescent with T1D's treatment and management. Such outcomes include the adolescent's compliance and self-care; identity; perceived health, well-being and life satisfaction; and overall health behaviours.

2.5.2.2 T1D Stress and Coping

Adolescents with T1D and their families face challenges of coping with stress and are at risk for developing certain types of psychopathology (Wysocki *et al.*, 2003). Glycaemic control and adherence is affected by stress. Metabolic functioning is also directly altered by neuroendocrine responses to stress. Thus, youth with T1D face a multi-faceted set of developmental variations as well as ever-changing disease-related burdens.

Previously, studies have been conducted to support this process which presented a direct influence of stress on glycaemic control in adolescents with T1D (Baucom *et al.*, 2015; Delamater *et al.*, 1987; Delamater *et al.*, 2013; McNally, Rohan, Pendley, Delamater, & Drotar, 2010; Miller *et al.*, 2013; Polonsky *et al.*, 1995; Reynolds & Helgeson, 2011). It has been suggested that stress may directly influence biological processes or regimen adherence. Hanson *et al.* (1989) found that instead of adherence being the *mediator* for the association between metabolic control and stress, adherence and stress were both *directly* connected to glycaemic control. Aikens, Wallander, Bell, and Cole (1992) also agree that adherence was not a facilitator between metabolic functioning and stress; more attention should therefore be placed on *both* adherence and stress affecting glycaemic levels.

Severe stress may also negatively affect family management of T1D. In 1984, a retrospective study was conducted by White, Kolman, Wexler, Polin and Winter on the psycho-social stress factors in youth with T1D; showing that poor metabolic control was associated with family stress and limited problem-solving skills. Since then more research has been done surrounding the links between stress, metabolic control and family influence (Baucom *et al.*, 2015; Compas *et al.*, 2001; Delamater *et al.*, 2013; Dhada *et al.*, 2014; Hessler, Fisher, Polonsky, & Johnson, 2016; Reynolds & Helgeson, 2011). Findings revealed that the occurrence of stress itself does not always lead to poor glycaemic regulation; family responses to stressors can influence the impact thereof (see section 3.4); and maladaptive coping strategies can also result in poor T1D management. Adolescents and their families must recognise the onset and impact of stress in order to adapt and cope effectively with the burdens of T1D; which may benefit them psychophysically.

Coping skills and stress management have revealed to have positive properties for adolescents with T1D. An early study found that after conducting stress management training with adolescents they reported decreased T1D-related stress (Boardway, Delamater, Tomakowsky, & Gutai, 1993).

Further studies revealed that teaching adolescents coping skills (which encompassed cognitive behaviour training, conflict resolution and problem solving) resulted in improved metabolic control and self-efficacy levels (Baucom *et al.*, 2015; Compas *et al.*, 2001; Delamater *et al.*, 2013; Lowes & Lyne, 1999). According to Svoren and Jospe (2016), adolescents with T1D are more likely to use avoidance coping and emotional venting strategies. These coping mechanisms were found to negatively affect self-care and metabolic control.

There are various types of coping styles which refer to the ways in which an individual deals with a problem and could be regarded as a strategy to cope with a wide range of stressors. Weiten, Dunn, and Hammer (2014) have identified different types of coping strategies; for the purpose of this research study the following two will be discussed: *problem-focused coping* and *emotion-focused coping*. On the one hand, problem-focused coping is associated with rational management of a problem; the aim is to change the situation that is causing distress by taking control, information seeking and evaluating the issue. On the other hand, emotion-focused coping involves various strategies to minimise emotional distress triggered by the stressful occurrence and regulate feelings that might result or accompany the stressor; this strategy is favourable for uncontrollable stressors (i.e. chronic diseases, death in the family). Emotion-focused coping can be employed through various ways, namely (Carver, 2010): social support, reassessing the stressor positively, acceptance of responsibility, implementing self-control, distancing and using avoidance.

Although, distancing and avoidance coping may alleviate the stressor for a briefly short period, it may lead to detrimental effects if applied over a prolonged period. Therefore, positive emotion-focused coping strategies (social support and accepting responsibility) have been associated with improved long-term outcomes (Carver, 2010; Dhada *et al.*, 2014; Seiffge-Krenke & Stemmler, 2003). Both of the aforementioned coping styles can be useful depending on what the adolescent's stress encompasses.

Lazarus (1993) made the association between his "defensive reappraisals" or "cognitive coping" and Freud's (1992) notion of "ego-defences", linking a person's defence mechanisms with their coping styles. Svoren and Jospe (2016) note that adolescents with T1D, who have mature defences and adaptive skills, are more likely to successfully cope with their disease and enhance their overall well-being.

2.5.2.3 T1D Psychological Adjustment

According to Palladino *et al.* (2013), adolescents with T1D have a higher risk for developing psychological problems such as anxiety, eating disorders and depression (see section 3.3.1). The presence of adjustment problems may affect their psychological well-being as well as optimal management of the disease. Studies show that depression and anxiety may impede treatment adherence and result in major life dissatisfaction (Palladino *et al.*, 2013; Perfect & Jaramillo, 2012).

The elevated risk for developing eating disorders is more common for adolescent females and can be attributed to weight issues (Eiser *et al.*, 2013). A multidisciplinary assessment and treatment plan is required for adolescents who present with the psychological and medical aspects of these disorders.

T1D may be detrimental to the adolescents' psychological adjustment, but it can also have a negative emotional impact on their family members (see section 3.4). It is important to have family support for optimal T1D management; maintaining a wholesome and positive home environment for their child can provide benefits for everyone involved. There is ample evidence that the behavioural and emotional burden of T1D affects mothers the most. Studies by Butler, Skinner, Gelfand, Berg, and Wiebe (2007); Young, Cameron, and Wiebe (2007); Jaser and Grey (2010); and Landolt *et al.* (2002) confirmed that the mothers of these adolescents with this disease experience more parental stress than the control group's mothers, that the potential risks associated with T1D contribute to that stress, and that parenting these adolescents is considered to be multi-faceted and challenging. Consequently, it is not unlikely for maternal depressive symptoms to manifest after diagnosis and have a negative effect on T1D management.

There is limited research on the impact of T1D on fathers and their specific roles in management. A study done by Maas-van Schaaijk, Roeleveld-Versteegh, and van Baar (2013) revealed that adolescent' fathers also showed considerably higher parenting stress compared to those of the control group. Further research shows that adolescents from single-parent households are at risk for poor metabolic control (Caccavale, Weaver, Chen, Streisand, & Holmes, 2015; Hessler *et al.*, 2016; King *et al.*, 2014). Given the importance of overall family support, it is necessary for parents/guardians involvement in daily treatment and management of T1D to facilitate better glycaemic control and family adaptation.

In addition to the possible behavioural and emotional effects of T1D, adolescents are also at risk for adverse cognitive effects on an acute and chronic level (see section 3.3.2). If diagnosed during early childhood (before 5-7 years) they might encounter learning disabilities if proper management is not adhered to. Cognitive complications are a result from poor T1D management, whereby the adolescent has uncontrolled glycaemic levels which impact executive functions, learning and memory (Biessels & Reijmer, 2014; Blasetti *et al.*, 2011; Cato *et al.*, 2014; Jacobson *et al.*, 2011). If the adolescent is displaying T1D-associated cognitive impairment then an evaluation of cognitive functioning should be administered, as well as an assessment of overall treatment and management.

Adolescents with T1D are faced with various threats to their psychological adjustment and cognitive functioning. Thus, it is significant to address these individual problems as soon as possible to ensure optimal management and well-being.

In summary, it is imperative to understand the stress, coping and psychological adjustments of the adolescent with T1D. This disease can have a major effect on adolescents; if inadequate coping strategies are used it could result in psychological and cognitive impairments. Therefore, all these areas must be considered for effective T1D management, allowing the adolescent to maintain optimal health and well-being.

2.6 EPIDEMIOLOGY OF T1D

South Africa, and the general African region, has limited data concerning the epidemiology of T1D. "It is also poorly characterised in the black population. In most western countries, T1D accounts for over 90% of childhood and adolescent diabetes, while across the lifespan, T1D accounts for 5–10% of individuals with diabetes" (Craig *et al.*, 2014, p. 9). This section will offer a summary of the global epidemiological statistics that have been collected on T1D, specific to children and adolescents, as well as the sparse information available in South Africa.

2.6.1 PREVALENCE

The prevalence rate is the measurement of youth affected by T1D at a particular time. In youth, T1D is a significantly common endocrine and metabolic disease. According to the International Diabetes Federation (IDF), approximately more than half a million (542,000) children globally, aged 14 and under, were estimated to be living with T1D in 2015. This was the first time that the number had reached such a high count.

“The total burden of deaths from high blood glucose in 2012 has been estimated to amount to 3.7 million. This number includes 1.5 million diabetes deaths, and an additional 2.2 million deaths from cardiovascular diseases, chronic kidney disease, and tuberculosis related to higher-than-optimal blood glucose” (World Health Organisation, 2016, p. 21). The magnitude indicates that high blood glucose caused by diabetes (predominantly T1D) places a large burden on mortality. High blood glucose age-standardised mortality rates are highest in African, Eastern Mediterranean and South-East Asia regions.

In 2015, the IDF released the top ten countries for highest number of children (<15 years) with T1D, namely (starting from highest to lowest): United States of America, India, Brazil, China, United Kingdom, Russian Federation, Saudi Arabia, Germany, Nigeria and Mexico (International Diabetes Federation, 2015). Table 2.1 shows the exact number of children with T1D for each country:

Table 2.1: TOP TEN COUNTRIES FOR HIGHEST NUMBER OF CHILDREN WITH T1D IN 2015

Top 10	Country	Number of children (<15years) with T1D
1	United States of America	84,100
2	India	70,200
3	Brazil	30,900
4	China	30,500
5	United Kingdom	19,800
6	Russian Federation	18,500
7	Saudi Arabia	16,200
8	Germany	15,800
9	Nigeria	14,400
10	Mexico	13,500

The highest number of children with T1D comes from Europe with around 140,000 and is estimated to increase by 21,600 new diagnoses per year. There is sparse data available and few articles in literature that shows the incidence and prevalence of T1D in South Africa and Africa in general. Therefore, it is principally difficult to evaluate the overall numbers with T1D in the African district, due to the fact that more than three quarters of nations do not have countrywide data (IDF, 2015). Hence, the 12 countries that have data were used to produce the regional estimate of people with T1D; the other 37 countries do not have data.

According to the IDF (2015), “it was estimated that between 9.5 million and 29.3 million people live with diabetes in the Africa region. Of these, three quarters are estimated to be undiagnosed, the highest of any IDF region” (p. 17). In African populations, the prevalence of T1D is lower than Western populations (Padoa, 2011). Geographical and ethnic variations are seen in the prevalence rates (American Diabetes Association, 2015b, 2017b; Hanas *et al.*, 2011). Although, it must be pointed out that data from prevalence studies must be analysed with caution due to variations in environmental risk factors, genetic predispositions and other research-related methodology issues.

Furthermore, the prevalence of T1D is low in comparison to that of type 2 diabetes. However, epidemiological data suggests that there is a parallel rise in the incidence rates for both of these types of diabetes (Dhada *et al.*, 2014; International Diabetes Federation, 2013, 2015; Neu *et al.*, 2001; Padoa, 2011; World Health Organisation, 2016).

2.6.2 INCIDENCE

The incidence rate is the frequency of T1D in youth within a specific period of time. While T1D is seen as less common, the increase every year is around 3%, mainly amongst youth under the age of 15 years (De Beaufort, 2006; International Diabetes Federation, 2015; Patterson *et al.*, 2009; World Health Organisation, 2016). An estimated 86,000 children are diagnosed annually and if insulin is not accessible, shortened life is expected for the child.

In South Africa, the incidence rates revealed a close link with the occurrence of HLA susceptibility genes in the general population (Craig, Hattersley, & Donaghue, 2009; Dhada *et al.*, 2014). African studies have made known that the general increase of T1D is higher in younger children which correlates with similar trends found in many other areas in the world (Moore, Hackworth, Hamilton, Northam, & Cameron, 2013).

T1D is generally easy to diagnose by looking at a history of symptoms, along with bedside tests such as glucose test strips and urine dipsticks (Reddy, Ganie, & Pillay, 2013). While, in very young children symptoms may be minor and often go undetected which can result in a delayed diagnosis. Therefore, the clinician must do a thorough history of the child to prevent a misdiagnosis. If an early diagnosis is not done then the initial presentation of T1D may be with diabetic ketoacidosis (DKA). According to Rewers *et al.* (2008), DKA is a life-threatening condition that can result in comas or death if prompt treatment is not given (see section 3.3).

Studies done in First-World countries have shown that it is an initial presentation of T1D, most frequent for children under the age of five and the type of ethnic group has no effect on presentation. “The incidence of T1D changes with age. The incidence increases from birth to 12 years, reaching a peak at 10-14 years of age, before falling to a much lower rate” (Padoa, 2011, p. 131). Incidence for pubertal peak for girls does precede boys by about one/two years (Delli & Lernmark, 2016; Pundziute-Lyckå *et al.*, 2002). Pubertal growth may be linked to the clinical onset of T1D and can therefore be explained by the fact that girls experience puberty earlier than boys (Karvonen *et al.*, 1997).

Studies examined sex differences in the incidence of T1D before 15 years of age and found that there is a slight male dominance in most European countries, whereas a female dominance was recorded in most African and Asian countries (Padoa, 2011; World Health Organisation, 2016). The increased incidence remains elusive but peaks of presentation have been known to occur in two major age groups, namely: at time of puberty and at 5-7 years of age.

Recently there has been a worldwide focus on reducing the incidence of DKA at diagnosis through diabetic management programmes. However, the lack of sufficient research done on characteristics of children presenting with T1D in South Africa and other developing countries has created an additional challenge in understanding how this population presents with this disease at diagnosis. However, a South African study was conducted in 2013 surrounding this topic and results showed that around 70% of participants presented with DKA at initial diagnosis (Reddy *et al.*, 2013). Furthermore, participants with DKA had shorter duration of symptoms in comparison to non-DKA group and overall there was a high rate of missed diagnosis of T1D. According to Elfgrén, Törnvall, and Grodzinsky (2012), 18.7% of Swedish children are diagnosed with metabolic acidosis. Although, about 30% of recently diagnosed children had developed DKA in countries such as the United States and other Western European countries (Berzina *et al.*, 2002; Neu *et al.*, 2001; Scaramuzza & Zuccotti, 2012). Therefore, it is important to receive the correct treatment upon diagnosis for youth as this will have a positive impact on their current and future well-being.

2.7 DIAGNOSIS OF T1D

The diagnosis of T1D in youth is usually straightforward, with classic symptoms being present (Cartaya & Laffel, 2017). T1D is characterised by a comparatively acute presence of disproportionate urine production (polyuria), abnormally great thirst (polydipsia), excessive desire to eat (polyphagia), weight loss and fatigue (Reddy *et al.*, 2013).

If left untreated, it can lead to extreme dehydration and an overproduction of acid in the body (metabolic acidosis) with lower glucose levels (ketosis), which in critical cases (pH < 7.30) can result in coma and/or death (Ghosh & Collier, 2012; Svoren & Jospe, 2016). If these symptoms take place over a prolonged time period then it may be followed by abdominal pain, vomiting, nausea, Kussmaul respirations (deep and laboured breathing pattern) and lethargy if diabetic ketoacidosis (DKA) develops. DKA may be present as an initial indicator of the disease in some children and adolescents. In others a manifestation of modest fasting hyperglycaemia is present at diagnosis and can quickly lead to severe hyperglycaemia or DKA as a result from infection or various stressors (American Diabetes Association, 2010, 2013, 2015a).

2.7.1 NEWLY DIAGNOSED T1D WITH DIABETIC KETOACIDOSIS (DKA)

According to Cartaya and Laffel (2017), “approximately 25–30% of children with newly diagnosed T1D present with DKA. Risk factors for DKA at diagnosis include young age (<5 years), absence of a first-degree relative with T1D, and lower socioeconomic status. However, the majority of DKA episodes occur in patients with established diabetes, rather than in those newly diagnosed. Risk factors for DKA in youth with established T1D include poor metabolic control, history of DKA, psychiatric disorders, low socioeconomic status, and being an adolescent female” (p. 1145). DKA indications can be arbitrarily classified into mild, moderate and severe forms. The depth of DKA will mitigate the range of symptoms.

If corrective management is not given, extreme fluid and electrolyte depletion develops, resulting in hypoperfusion (decreased blood flow) and low level consciousness due to cerebral edema (brain swelling). The development of cerebral edema warrants attention because it mainly occurs in children and adolescents and has increased morbidity and mortality (Delli & Lernmark, 2016). Thus, DKA is a dangerous medical complication of T1D and requires emergency hospitalisation for intravenous fluids and insulin treatment.

2.7.2 CLINICAL FINDINGS

To diagnose T1D a doctor will conduct a Glycated Haemoglobin (HbA1c) test. This blood test will indicate the average blood glucose level from the previous two/three month period. The test assesses the proportion of glucose found in haemoglobin, which is the oxygen-carrying protein in red blood cells. An HbA1c level of 6.5% or greater on two distinct tests will indicate the presence of diabetes. If this test is not available then the doctor may use a *random* blood glucose test or a *fasting* blood glucose test (Craig *et al.*, 2014; Diagnosis and classification of diabetes, 2014).

The *random* blood glucose test entails taking a blood sample at an arbitrary time, irrespective of food ingested. Random blood glucose level of 11.1mmol/L or greater, together with other indications of diabetes, such as polydipsia and polyuria, indicates T1D. The *fasting* blood glucose test entails an overnight fast and blood sample thereafter. A fasting blood glucose level lower than 5.6mmol/L is considered standard, whereas levels from 5.6-6.9mmol/L might indicate prediabetes (type 2) and levels of 7mmol/L or higher on two separate tests indicates T1D. After diagnosis of T1D, regular visits will be scheduled with the doctor to assist with diabetes management.

ADA recommendations for the diagnosis of T1D (2005, p. 187):

1. "Symptoms of hyperglycaemia (polyuria, polydipsia, unexplained weight loss) and a casual plasma glucose (any time of day without regard to time since last meal) \geq 11.1mmol/L (200 mg/dL) *or*
2. Fasting (no caloric intake for at least 8 h) plasma glucose \geq 7.0mmol/L (126 mg/dL) *or*
3. 2-h plasma glucose \geq 11.1mmol/L (200 mg/dL) during an oral glucose tolerance test after an 8-h fast (glucose load of 75 g anhydrous glucose dissolved in water or 1.75 g/kg body weight if weight < 43 kg) *or*
4. HbA1c \geq 6.5%

Note: Criteria 2 and 3 should be confirmed on a second day if child/adolescent is asymptomatic. The oral glucose tolerance test (OGTT) is not recommended for routine clinical use and should be reserved for the asymptomatic child with incidental glycosuria/hyperglycaemia or in the child with suspected diabetes but normal fasting plasma glucose. Criteria 4 should be confirmed with a repeat HbA1c using a certified laboratory assay (not point-of-care device)."

HbA1c levels will be checked by the doctor during each of these visits and the target level may vary depending on the age of the person and various other factors. According to the World Health Organisation (WHO, 2016), the general HbA1c level should be below 7%, which is an estimated average glucose level of 8.5mmol/L. In comparison to regular blood glucose tests, HbA1c testing shows an overall average of how well the T1D treatment plan is working. A high HbA1c level will highlight the need to adapt a better insulin regimen, meal plan or perhaps both. People who struggle to reach their HbA1c goals are usually scheduled to see the healthcare professional (endocrinologist/physician) every three months; whereas people who reach their goals and showcase confidence in their diabetes management are normally seen twice a year by their endocrinologists. Additionally, the endocrinologist will also administer regular urine and blood sample tests to assess thyroid and kidney function, as well as cholesterol levels.

2.8 TREATMENT OF T1D

Insulin therapy, using short-acting insulin before every main meal and one nightly injection, began in 1921-1922. After 1935, newly designed types of insulin were developed. These had an intermediate and long-term effect whereby one or two injections per day were used (Atkinson *et al.*, 2014; Ghosh & Collier, 2012). In the present day children and adolescents are recommended to use a combination of long-acting (basal) insulin and rapid-acting/short-acting (bolus) insulin. This entails up to 5/7 injections per day for the adolescent (Danne *et al.*, 2014). The type of treatment regimen for adolescents living with T1D should be specific to the adolescent's "age, daily routines, targets of metabolic control, and individual and family preferences. However, different strategies for T1D management that may assist with these specific needs are not equally accessible in South Africa" (Kalweit *et al.*, 2015, p. 400). Every adolescent with this disease needs to have insulin pens/syringes and cartridges; glucometer and blood glucose test strips; and lastly, needles and lancets for treatment.

2.8.1 INITIAL MANAGEMENT

The objectives of initial management of youth with newly diagnosed T1D are to correct electrolyte and fluid imbalances, start exogenous insulin replacement and initiate T1D education (Cartaya & Laffel, 2017; Svoren & Jospe, 2016). The initial management can take place at various locations, namely: intensive care, inpatient or outpatient unit. The location is dependent on the "severity of the clinical presentation, the age of the patient, psycho-social family factors, and the availability of diabetes-related resources (e.g., an outpatient education program)" (Cartaya & Laffel, 2017, p. 1144). Generally 30% of youth newly diagnosed with TD1M present with DKA and require hospitalisation in an inpatient facility. The remaining 70% are not acutely sick; medical management is thus treated through outpatient care and self-management education (Silverstein *et al.*, 2005). Ideally, every child or adolescent newly diagnosed with T1D have to be assessed by a team of medical experts. The team should comprise of the following members: paediatric healthcare professional (endocrinologist/physician), certified diabetes nurse educator, dietitian, and mental health professional skilled to offer paediatric-specific support, education and training (Cartaya & Laffel, 2017; Dhada *et al.*, 2014). Unfortunately, such systems of healthcare are not always available in resource-constrained communities.

South Africa has two healthcare sectors, namely: public (government funded) and private. Adolescents that receive treatment from private healthcare have a wider selection of insulin types and T1D-related consumables than those in public healthcare. Diabetes educators and dieticians are also more frequently available to private healthcare patients, depending on the individual's respective medical insurance plan.

“Continuous subcutaneous insulin infusion (CSII) pumps are available in South Africa but only to adolescents and children on upper-tier insurance schemes owing to the high cost of the machine and its consumables” (Kalweit *et al.*, 2015, p. 400). This form of treatment was not prevalent in this study as the focus was on participants who attend a public healthcare facility and do not have access to private medical health insurance schemes.

2.8.2 TREATMENT GOALS

To achieve excellent T1D control encompasses many goals: “to maintain a balance between tight glucose control and avoiding hypoglycaemia, to eliminate polyuria and nocturia (frequent urination during the night), to prevent ketoacidosis, and to permit normal growth and development with minimal effect on lifestyle” (Svoren & Jospe, 2016, p. 2772). T1D therapy involves the process of initiating and adjustment of exogenous insulin, education to youth and caretakers, and adaptation to new lifestyle routines. Each aspect in therapy should be implemented at the beginning of overall care to ensure correct and effective treatment goals.

2.8.3 GLYCAEMIC TARGETS

According to Rewers and Chase (2016), adherence to these goals can result in the prevention of acute and long-term complications by decreasing chronic hyperglycaemia, avoiding hypoglycaemic events and enhancing the adolescent's overall well-being and quality of life. Each adolescent should have HbA1c targets set to maintain the lowest glycaemic levels without frequently moderate or severe hypoglycaemia (Chiang *et al.*, 2014).

Sustaining good glycaemic control decreases the potential risk of developing microvascular and macrovascular complications; although there is no single agreed target for T1D because it is dependent on various clinical and non-clinical factors (Ghosh & Collier, 2012). However, the International Society of Paediatric and Adolescent Diabetes (ISPAD) and the ADA have both recommended HbA1c goals of less than 7.5mmol/L (135mg/dl) for children and adolescents (American Diabetes Association, 2017a; Cartaya & Laffel, 2017; Rewers *et al.*, 2014).

Therefore, adolescents with T1D may have different glycaemic goals to adults as it depends on general treatment goals, co-morbidities and other patient-specific circumstances.

In 1993, the seminal Diabetes Control and Complications Trial (DCCT) were published, 50% reductions were observed in kidney, eye, cardiovascular, and neurologic complications of T1D with the HbA1c value being 7% in comparison to 9% (Nathan, 2014; Segal, 2012). According to the ADA (2017b), table 2.2 shows HbA1c levels classified for children and adolescents:

Table 2.2: HbA1c LEVELS FOR CHILDREN AND ADOLESCENTS

HbA1c classification	HbA1c, mmol/L (mg/dl)	
	Children (7-12 years)	Adolescents (13-18 years)
Good	≤8.0 (145)	≤7.5
Fair	8.0 – 10.0 (145 – 180)	7.5 – 10.0 (135 – 180)
Poor	≥10.0 (180)	≥10.0 (180)

The ADA guidelines show that target goals are slightly stricter for adolescents. The reason for this is due to the special consideration given to younger children, regarding vulnerability to hypoglycaemic events and spontaneity in physical activity. Thus, the present target is recommended to be between 6.5mmol/L and 7.5mmol/L in adolescents (Rewers *et al.*, 2014; Stahl-Pehe *et al.*, 2017). This evidence further proves that intensive management of T1D, targeting normal blood-glucose levels is safe and can be achieved.

2.8.4 INSULIN MANAGEMENT FOR T1D

T1D involves an autoimmune deficiency regarding insulin production due to the destruction of insulin-producing β cells of the pancreas. Thus, these cells cannot manufacture insulin appropriately to sustain normal glycaemic levels. This deficiency results in hyperglycaemia and weight loss. It can also be accompanied by ketoacidosis, when the body breaks down fat into fatty acids and ketones.

The hallmark for T1D diagnosis is the presence of DKA, which can also resurface in the absence of insulin therapy (American Diabetes Association, 2015a, 2017b; Chamberlain *et al.*, 2016). Therefore, insulin therapy is required to maintain lipid metabolism and normal glucose. There are different ways to administer insulin therapy but unfortunately there are no alternatives in the management of this disease.

According to Rewers and Chase (2016), there are three key functions of insulin: “(1) it allows glucose to pass into the cell for oxidative utilization; (2) it decreases the physiologic production of glucose, particularly in the liver; and (3) it turns off lipolysis and ketone production” (p. 8). The ideal of insulin replacement is to mimic insulin secretion (like a person without T1D) and attain good glucose control without frequently moderate or severe hypoglycaemia. After a meal has been consumed, insulin is required in a quick release form to balance blood-glucose levels during the postprandial state. A low continuous background insulin secretion maintains normal glycaemia between meal times and basal state to prevent liver overproduction of glucose. Appropriate combinations of these naturally occurring insulins are available through different insulin replacement types and regimens (Unger & White, 2016). Thus, the ultimate aim of insulin replacement treatment is to counter the rise of blood glucose levels in the body by mirroring the normal insulin response for both the fasting and postprandial states, preventing hyperglycaemia.

There are different insulin types that have diverse pharmacological properties regarding their onset, peak and duration of action (see table 2.3). Intensive insulin therapy (four or more injections per day/CSII pump) considerably improved blood glucose levels when compared with conventional insulin therapy (two injections per day) over a prolonged period of time (Chamberlain *et al.*, 2016; Ghosh & Collier, 2012; Segal, 2012). However, the benefits of intensive insulin therapy are dependent on the involvement of a comprehensive patient support element of diet, exercise routine and required clinical visits. The adolescent’s adherence to management is therefore a crucial factor in managing this disease.

2.8.5 INSULIN TYPES

Previously, insulin was taken from animal pancreas but has largely been replaced as it included impurities and resulted in allergic reactions in some people (American Diabetes Association, 2015b). Today, insulin formulations are manufactured using recombinant DNA technology and can be generally based into two categories: *human insulin* (identical to human insulin in structure) and *human insulin analogues* (one or two amino acids of human insulin are changed or substituted). These two insulin categories have numerous insulin formulations and can be classified as:

- ultra-fast or **rapid-acting insulin analogues**,
- regular or **short-acting insulin**,
- **intermediate-acting insulin**,
- **long-acting insulin analogues** and
- **premixed** or biphasic insulins.

Table 2.3 shows the different types of insulin with information regarding *onset*, *peak*, *duration* and *role in glycaemic control*. The onset of action concerns the amount of time it takes insulin to reach the body's bloodstream and lower blood glucose. Peak action regards the time period during which the blood glucose is being lowered. Duration of action shows how long the insulin continues to work and remain in the body. The last column explains the role of insulin in relation to mealtimes.

Table 2.3: CLASSIFICATION OF DIFFERENT INSULIN TYPES

Insulin Type & Brand Names	Onset of Action	Peak Action	Duration	Role in Blood-Glucose Management
a. Rapid-acting insulin analogue				
Aspart (NovoRapid)	10-20 min.	40-50 min.	3-5 hours	Rapid-acting insulin covers insulin needs for meals eaten at the same time as the injection. This type of insulin is often used with longer-acting insulin.
Glulisine (Apidra)	20-30 min.	30-90 min.	1-2 1/2 hours	
Lispro (Humalog)	15-30 min.	30-90 min	3-5 hours	
Short-acting human insulin				
Regular (R)	30 min. -1 hour	2-5 hours	5-8 hours	Short-acting insulin covers insulin needs for meals eaten within 30-60 minutes.
Intermediate-acting human insulin				
b. NPH (N)	1-2 hours	4-12 hours	18-24 hours	Intermediate-acting insulin covers insulin needs for about half the day or overnight. This type of insulin is often combined with a rapid- or short-acting type.
Long-acting insulin analogue				
Detemir (Levemir)	1-2 hours	6-8 hours	Up to 24 hours	Long-acting insulin covers insulin needs for about one full day. This type is often combined, when needed, with rapid- or short-acting insulin.
Glargine (Lantus)	1-1 1/2 hours	No peak time. Insulin is delivered at a steady level.	20-24 hours	
c. Pre-mixed insulin				
Humulin 70/30	30 min.	2-4 hours	14-24 hours	These products are generally taken two or three times a day before mealtime.
Novolin 70/30	30 min.	2-12 hours	Up to 24 hours	
Novolog 70/30	10-20 min.	1-4 hours	Up to 24 hours	
Humulin 50/50	30 min.	2-5 hours	18-24 hours	
Humalog mix 75/25	15 min.	30 min.-2 1/2 hours	16-20 hours	
<p>a. Prefilled pens and cartridges are available. Priming is necessary for use.</p> <p>b. Neutral Protamine Hagedorn</p> <p>c. Typically used in fixed doses in twice-a-day insulin regimens.</p> <p>*Pre-mixed insulins combine specific amounts of intermediate-acting and short-acting or rapid-acting insulin in one bottle or insulin pen. (The numbers following the brand name indicate the percentage of each type of insulin.)</p>				

Note. Adapted from Laffel, L. M., & Cartaya, J. B. (2017). Endocrine and Metabolic Disorders. In E. T. Bope & R. D. Kellerman (Eds.), *Conn's Current Therapy* (pp. 1115-1194). Canada: Elsevier.

The above range of insulins has been modified in basic structure with different rates of onset, peak and duration action to be suitable for various individual needs. Segal (2012) stated that “the ideal quick-acting insulin should have a very rapid onset of action, a peak within 1 hour and duration of action of less than 3 hours. Such insulin has not yet been created but some are in development. The ideal basal insulin should be ‘peak less’ and last for 24 hours or longer. Modern day analogues come very close to this” (p. 12). When establishing the adolescent’s insulin regimen, the insulin profile needs to be considered, analysing their exercise routine, diet and lifestyle to achieve optimal glycaemic target range and reducing hypo- and hyperglycaemia.

The more recent long-acting analogues have proven ability in decreasing low blood-glucose levels during the night when compared to intermediate-acting insulins that peak at night-time hours (Cartaya & Laffel, 2017; Ghosh & Collier, 2012). Furthermore, rapid-acting insulin analogues have reduced the peak during postprandial blood-glucose levels, reducing the problem of delayed hypoglycaemia (Unger & White, 2016). Both basal (Levemir and Lantus) and rapid-acting (Humalog, NovoRapid and Apidra) insulin analogues are preferred and widely prescribed in the treatment of T1D (Ghosh & Collier, 2012). However, there is a significantly higher monetary cost involved when considering these human insulin analogues but the benefit includes improved overall HbA1c control.

Rapid-acting insulin analogues such as **Humalog®**, **NovoRapid®** and **Apidra®** have an onset of action approximately within 30 minutes; peak at approximately 30 to 90 minutes and last for up to 2-5 hours. This is generally the current mealtime insulin of choice and should be injected 5-15 minutes (even 30 minutes) prior to eating. Insulin taken at mealtimes is also referred to as a bolus dose or injection. The bolus dose needs to act quickly and that is why rapid-acting insulin and short-acting insulin is used for this purpose. It is also used to correct high blood-glucose levels. The major advantage of rapid-acting insulin is the faster onset of action; allowing it to be injected quickly before meals, combining flexibility and convenience, unlike the difficulties of short-acting human insulin which needs to be injected 30 minutes prior. Rapid-acting insulin can also be injected after meals for those who may have forgotten to do it before or those with unpredictable mealtimes. The shorter duration of action is also more beneficial as it may reduce the need for snacks (American Diabetes Association, 2015b, 2017b; Segal, 2012; Svoren & Jospe, 2016; Unger & White, 2016).

The graph below (figure 2.2) shows the relative insulin effect after insulin dose has been injected for *rapid-acting insulin analogues*, as explained above.

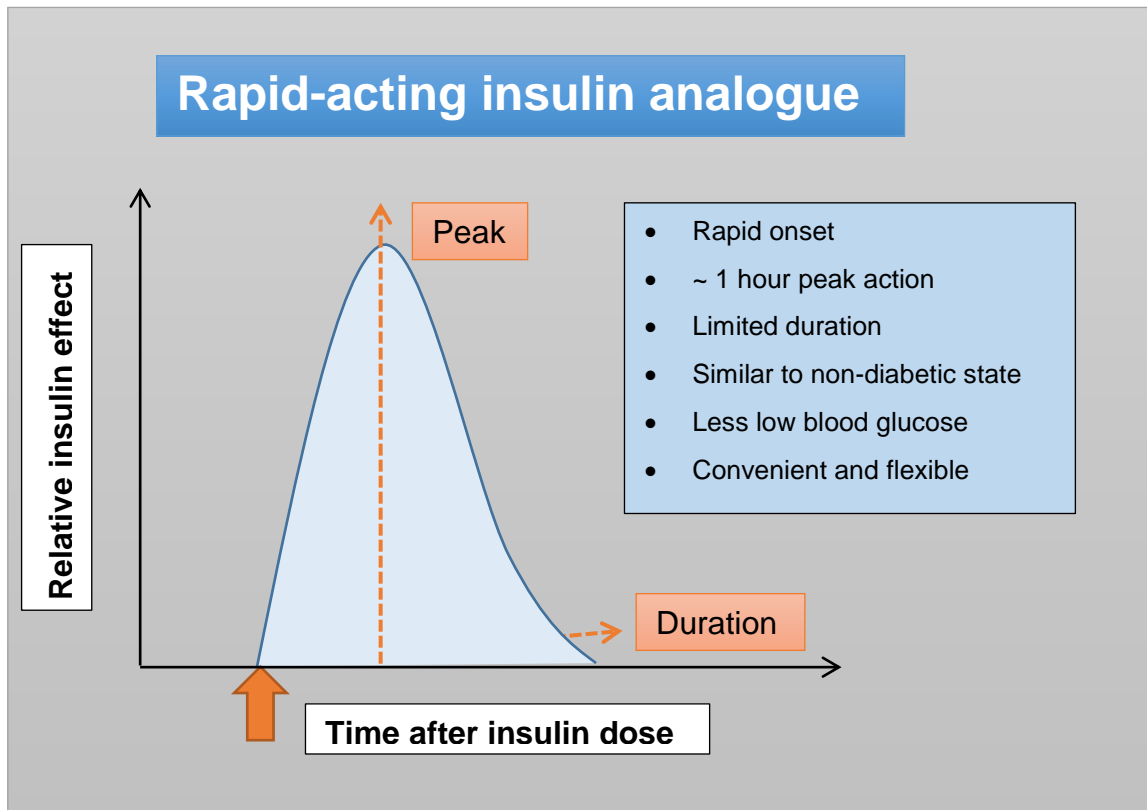


Figure 2.2: RAPID-ACTING INSULIN ANALOGUE

Short-acting human insulins such as **Humulin R®**, **Actrapid®**, **Biosulin R®** and **Insuman®** have an onset of action after 30-60 minutes which makes it necessary to inject up to 30 minutes before eating. The duration of action lasts approximately 5-8 hours. There is a required snack after the meal to prevent a drop in blood-glucose due to the delayed peak at 2-3 hours. However, if a large quantity of carbohydrates is eaten then the snack may not be a necessity. If the desired meal plan is made to include a snack then this delayed peak might be ideal to the adolescent. There is an increased risk for hypoglycaemia from the prolonged duration of action but it permits three injection doses per day. Short-acting human insulin can achieve good glycaemic control for those who do want to snack and eliminates additional injections. This can only be achieved if a stable meal and snack routine has been established (American Diabetes Association, 2017b; Segal, 2012; Silverstein *et al.*, 2005).

The graph below (figure 2.3) shows the relative insulin effect after insulin dose has been injected for *short-acting human insulins*, as explained above.

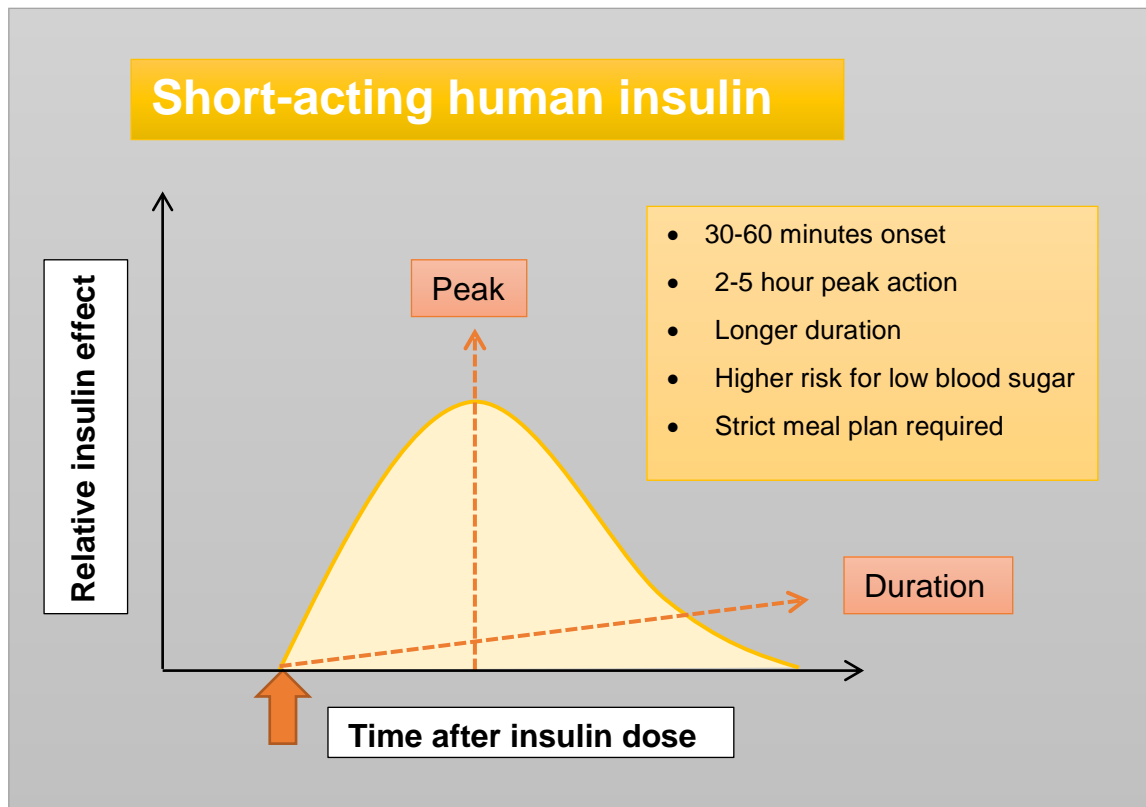


Figure 2.3: SHORT-ACTING HUMAN INSULIN

Intermediate-acting human insulins such as **Humulin N®**, **Protaphane®** and **Biosulin N and L®** are short-acting insulins that are attached to zinc or NPH (Neutral Protamine Hagedorn). It has an onset after 1-2 hours and a delayed peak at 4-8 hours. The duration of action is approximately 18-20 hours which allows for twice-a-day injections or even a single dose administered at bedtime. The delayed peak can be beneficial to adolescents as it is used to cover mid-morning snacks which occur during school hours. However, the peak has increased risk for night-time hypoglycaemia therefore necessitating a snack and higher glucose target at bedtime (American Diabetes Association, 2017b; Segal, 2012; Silverstein *et al.*, 2005; Svoren & Jospe, 2016).

Long-acting insulin analogues such as **Lantus®** and **Levemir®** have a slow onset and relatively do not have peaks. The duration of action for Lantus is 24 hours. It does not have a peak level and is administered through one injection daily. Levemir has close to 24-hour duration of action at high doses, but injected twice-a-day at smaller doses, thus making it dose-dependent for duration. Long-acting insulin analogues have relatively peak less action that reduces the risk of night-time hypoglycaemia.

It also places a limit to between-meal snacks unlike intermediate-acting human insulins (American Diabetes Association, 2017b; Cartaya & Laffel, 2017; Svoren & Jospe, 2016). The graph below (figure 2.4) shows the relative insulin effect after insulin dose has been injected for *different types of insulin*, as explained above.

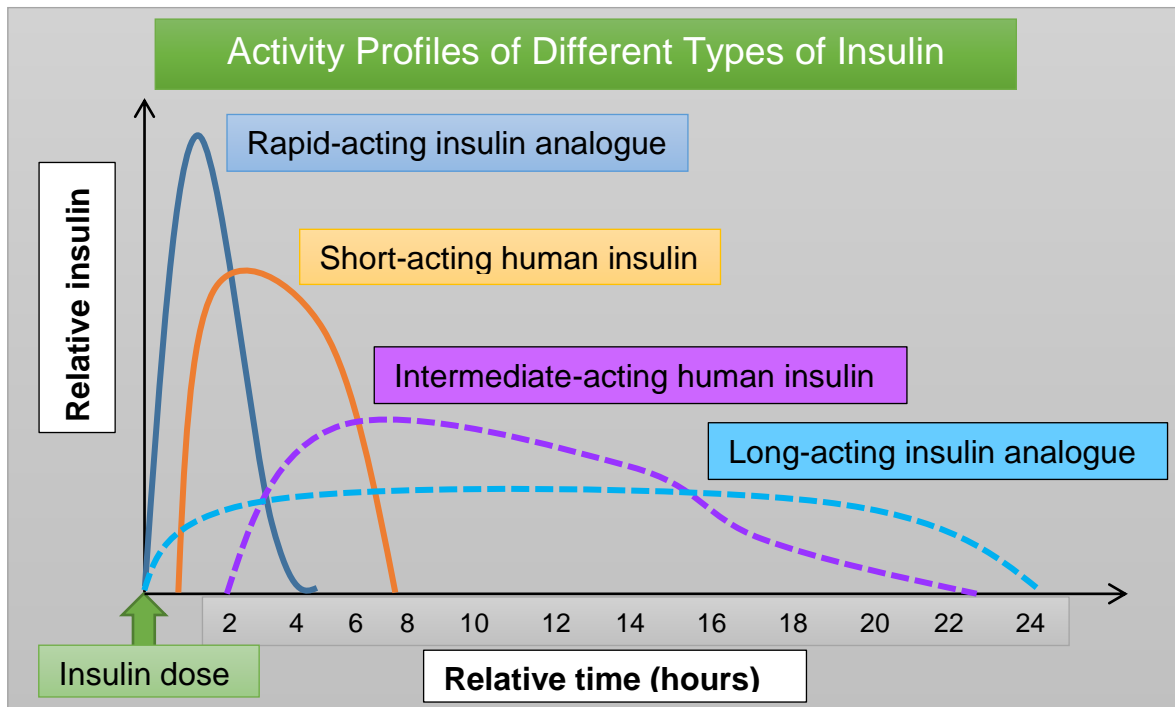


Figure 2.4: ACTIVITY PROFILES OF DIFFERENT TYPES OF INSULIN

Premixed insulins such as **Actraphane® (Humulin 30/70)**, **Humulin 50/50®**, **Novolin 70/30®**, **Novolog 70/30®** and **Humalog mix 75/25®** contain short- or rapid-acting insulin that is combined with an intermediate-acting human insulin. The simplicity of pre-mixed insulins allows for a reduced number of daily injections and caters for adolescents who have a semi-rigid meal and snack schedule. It is also favourable to those who follow the same daily routine. This insulin has an advantage of ensuring a safer and simpler regimen for adolescents who either struggle with intensive treatment or experience burnout. The fixed ratio of the two insulins creates a significant limit for changes in meal size and time. However, this limitation can be avoided by incorporating a short-acting human insulin dose for bigger meals, unplanned snacks or hyperglycaemic events (American Diabetes Association, 2017b; Cartaya & Laffel, 2017; Segal, 2012).

2.8.6 INSULIN REGIMENS

Appropriate combinations of the aforementioned insulin types can be tailored to the individual's requirements, close supervision and assistance from the healthcare professional will result in the correct insulin regimen (Ghosh & Collier, 2012). Although no precise insulin formula for establishing required insulin exists for youth, insulin formulas are usually established by assessing their physical mass, life stage and pubescent phase. Younger and prepubertal children generally require a lower dose; however, use of steroids, presence of DKA and hormone changes of puberty may result in higher doses (American Diabetes Association, 2017b; Laffel & Peters, 2011; Silverstein *et al.*, 2005). Therefore, several factors have an influential effect on the prescribed insulin dose per kilogram of body weight.

Adolescents with T1D regularly require multiple daily injections (MDIs) of insulin. Prescribed doses of rapid-, short-, intermediate-, or long-acting insulin are used prior to meal times and at night to achieve optimal glycaemic control. Frequent insulin administration and education is required for optimal glycaemic control, especially after the initial diagnosis and 'honeymoon period' (Atkinson *et al.*, 2014; Chiang *et al.*, 2014). Intensive insulin regimens usually involve four or more insulin injections per day which encompasses three bolus injections and one or two basal injections Table 2.4 below provides examples of insulin regimens. Some adolescents may receive a simpler insulin regimen in certain circumstances. If psycho-social factors suggest that fewer injections per day would be more practical for the adolescent, then the twice-daily regimen is used.

Table 2.4: EXAMPLES OF INSULIN REGIMENS

Intensive regimens:
<ol style="list-style-type: none"> 1. Rapid-acting insulin given at breakfast, lunch, dinner, and snacks, and glargine (Lantus) or detemir (Levemir) given at breakfast, dinner, or bedtime. 2. Continuous subcutaneous insulin infusion (CSII): Rapid-acting insulin given for basal requirements and as bolus at every meal/snack and periodically to correct hyperglycaemia (no more frequently than q2–3 h) via insulin pump. 3. NPH and rapid-acting insulin given at breakfast, rapid-acting insulin PRN* at lunch, rapid-acting insulin given at dinner, and long acting analogue (glargine [Lantus] or detemir [Levemir]) given at dinner or bedtime.
Simpler regimens:
<ol style="list-style-type: none"> 1. NPH and rapid-acting insulin given at breakfast and lunch (PRN), rapid-acting insulin given at dinner, and NPH given at bedtime 2. NPH and rapid- (aspart [Novolog] or lispro [Humalog]) or short-acting (human regular) insulin given at breakfast and dinner 3. Premixed insulin (70/30, 75/25, 50/50) given at breakfast and dinner

Intensive insulin therapy, noted above as regimens 1 and 2, is standard of care in type 1 diabetes, the most common type of diabetes in youth. Other regimens can be used when patients are unable to perform the necessary tasks to safely comply with intensive insulin therapy. Although rapid acting analogues are preferred, sometimes short acting insulin (human regular) is administered due to clinical circumstances. Additionally, morning NPH (as in regimen 3) may be utilised to avoid the need for lunch time injections.

*PRN: medical abbreviation for *pro re nata*, meaning to give medication as the situation demands or according to need.

Note. Adapted from Laffel, L. M., & Cartaya, J. B. (2017). Endocrine and Metabolic Disorders. In E. T. Bope & R. D. Kellerman (Eds.), *Conn's Current Therapy* (pp. 1115-1194). Canada: Elsevier.

Most adolescents with T1D receive insulin from CSII pumps or through a **basal-bolus insulin regimen** of MDIs. This regimen consists of injections (boluses) of rapid- or short-acting insulin administered three to four times daily (prior to mealtimes) and one (bedtime) to two (morning and evening) basal injections of intermediate- or long-acting insulin (Chiang *et al.*, 2014; International Diabetes Federation, 2011; Rewers *et al.*, 2014). Using this regimen provides good glycaemic control but adherence to meal plan and injections are crucial. The insulin doses are based on an insulin-to-carbohydrate ration (CR) and a sensitivity index or correction factor (SI or CF). The CR is calculated by the number of grams of carbohydrate covered by one unit of insulin for each meal or snack. The CF is normally given only after three hours postprandial to lower elevated blood-glucose to reach the target range, if necessary.

This regimen with long-acting analogues and rapid-acting analogues at meals does require between meal snacks. Adolescents who are using intermediate-acting human insulin (NPH) and rapid- or short-acting insulin require strict consistency because of higher carbohydrate intake during mealtimes (Dhada *et al.*, 2014; Segal, 2012). Bolus injections need to consider meal size and carbohydrate intake, as well as post-meal activity (e.g. exercise) in order to achieve glucose target range. Adjustments in long- or intermediate-acting insulins should be made if heavy physical activity is going to take place (e.g. sports day, hike or overnight events).

The graph below (figure 2.5) shows the *basal-bolus insulin regimen* principle, as explained above.

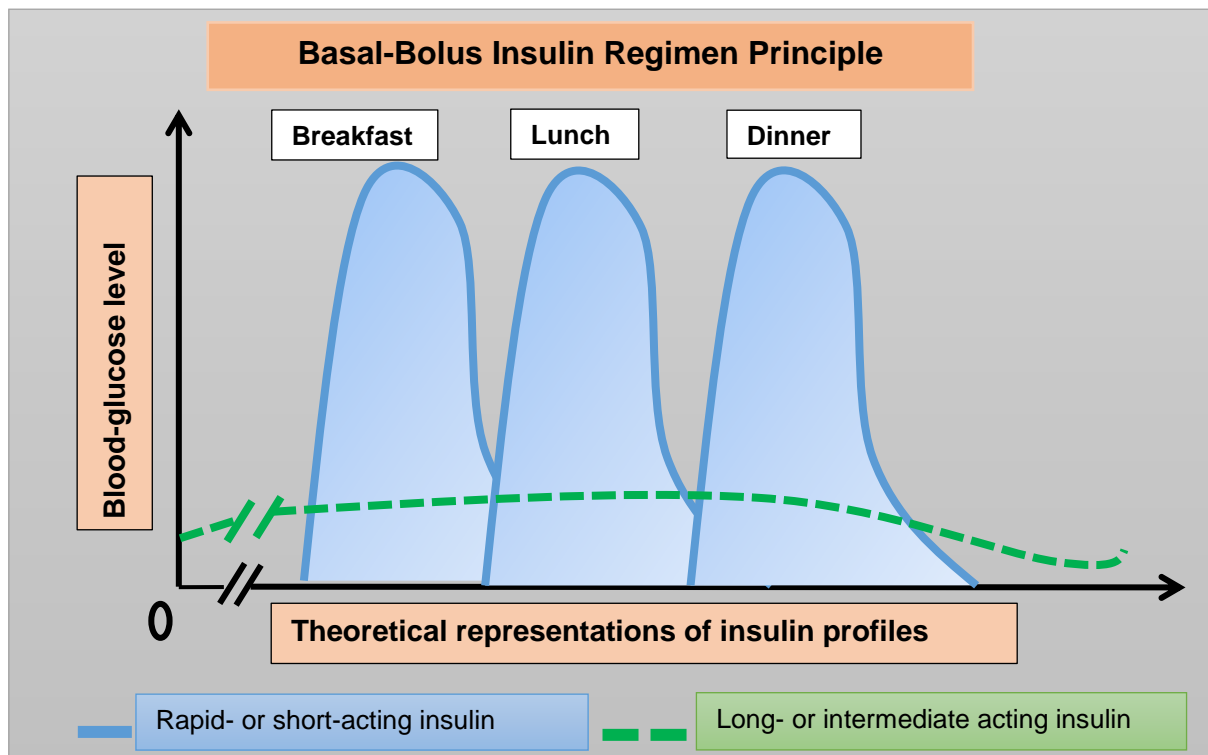


Figure 2.5: BASAL-BOLUS INSULIN REGIMEN PRINCIPLE

Some adolescents use a simpler **twice-daily insulin regimen** that consists of two daily injections of premixed insulin at breakfast and supper (Segal, 2012). Strict adherence to meal plan with minimal carbohydrate intake during midday and afternoon is required. For others, a third dose may also be given at lunchtime. In these cases a dose of short- or rapid-acting insulin can be added for higher blood-glucose or carbohydrates consumed at lunch. Hypoglycaemic events may happen during the night hours when the intermediate-acting human insulin is at its peak. To counter these low blood sugars adolescents should incorporate a snack at bedtime (American Diabetes Association, 2017b; Cartaya & Laffel, 2017). When compared to the basal-bolus insulin regimen, the twice-daily insulin regimen was inferior in achieving recommended HbA1c levels and avoiding hypoglycaemic events (Dhada *et al.*, 2014; Hanas *et al.*, 2011).

Table 2.5 shows factors that should be considered when prescribing insulin replacement therapy. Although, it should be emphasised that T1D therapy, such as different approaches to insulin doses, blood-glucose monitoring, nutritional education and insulin adjustment for exercise are all important components in effective management of this disease.

Table 2.5: FACTORS TO BE CONSIDERED WHEN PRESCRIBING INSULIN REPLACEMENT THERAPY

FACTOR	CONSIDERATION
Meal intake	<ul style="list-style-type: none"> ▪ Does adolescent skip meals? ▪ Are meals consumed on a scheduled basis? ▪ What are the approximate sizes and carbohydrate contents of meals? ▪ Has adolescent received meal planning education from a registered dietitian or certified diabetes educator? ▪ Does adolescent have an eating disorder?
School schedule	<ul style="list-style-type: none"> ▪ What type of school schedule does adolescent have? ▪ Does school schedule affect sleep? ▪ Does adolescent go on school trips? ▪ Does a school trip require flexible meal and insulin injection scheduling?
Adherence history	<ul style="list-style-type: none"> ▪ Does adolescent have a history of omitting insulin doses? ▪ Is adolescent willing to perform frequent Self-Monitoring of Blood Glucose (SMBG)? ▪ Does adolescent understand how to properly perform SMBG and interpret glucose values, patterns, and averages?
Physical activity	<ul style="list-style-type: none"> ▪ Does adolescent exercise? ▪ What type of exercise does adolescent do? ▪ What time of day does exercise occur? ▪ Does exercise time vary? ▪ Is adolescent a professional athlete? ▪ Is adolescent planning to initiate an exercise program for the first time? ▪ What are adolescent's glucose targets before, during, and after exercise? ▪ Does adolescent know how to predict and treat hypoglycaemia?
Hypoglycaemia history	<ul style="list-style-type: none"> ▪ Does adolescent have a history of hypoglycaemia unawareness? ▪ Does adolescent live alone? ▪ Does adolescent know how to predict and treat hypoglycaemia? ▪ Are there comorbidities (e.g., heart disease, chronic kidney disease, seizures, hypoglycaemia unawareness) that could preclude adolescent from being intensively managed and thereby increasing their risk of hypoglycaemia? ▪ Does adolescent have access to and wear a Continuous Glucose Monitoring (CGM) device? ▪ What is adolescent's target HbA1C?
Comorbidities of concern	<ul style="list-style-type: none"> ▪ Coronary artery disease or cardiac arrhythmias ▪ Preconception planning or pregnancy ▪ Cancer ▪ End-stage renal disease ▪ Mental illness ▪ Diabetic neuropathy ▪ Diabetic retinopathy
Learning skill deficiencies	<ul style="list-style-type: none"> ▪ Does adolescent have deficient reading, writing, or math (numeracy) skills? ▪ Is there a language barrier that may affect adolescent's ability to learn how to administer and self-titrate insulin?

Note. Adapted from Unger, J., & White, R. (2016). Diabetes. In R. E. Rakel & D. P. Rakel (Eds.), *Textbook of Family Medicine* (9 ed., pp. 782-816). United States: Elsevier.

2.8.7 INSULIN INJECTION SITES

The injection should be given into a pinched skin fold by using the thumb, index and middle finger. This method ensures that the skin used is not accompanied by the muscle area and avoids an intramuscular injection.

If the injection is given in a too shallow skin area it will be delivered intradermally, which can be painful (Ghosh & Collier, 2012). Furthermore, Ghosh and Collier (2012) explain important factors to consider regarding insulin injection sites:

- Insulin is absorbed the quickest in the abdominal area and slowest in the arm and buttock areas. Rapid- and short-acting insulin is most effective when delivered into the abdomen, and intermediate- or long-acting insulin into the thigh or arm. However, injection sites may vary depending on the most practical site available.
- It is important to note that the injection sites should be 'rotated' to avoid an accumulation of fat under the skin. This occurs if the same injection site is repeatedly used which can result in increased variability of insulin absorption. If the abdominal area is the site most often used then rotating around different points is a good method to enhance effective insulin absorption.
- If a person chooses to rotate from limb to limb, then a planned schedule should be adopted whereby the same injection site is used at the same time of day. For example, morning injection in the abdomen and lunchtime injection in the leg.
- Lastly, another important aspect to take into account is insulin absorption can be accelerated by exercise and this should be considered before the injection is given.

The image below (figure 2.6) shows the *recommended insulin injection sites*, as explained above.

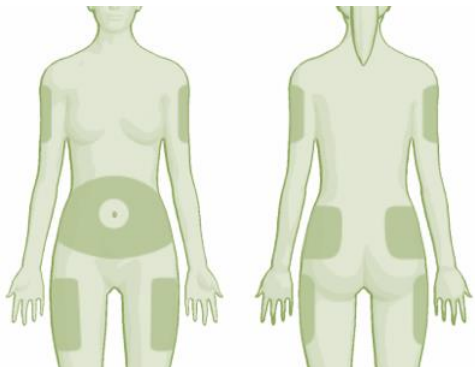


Figure 2.6: RECOMMENDED INSULIN INJECTION SITES

(Tenderich, 2010)

2.8.8 INSULIN PENS

According to Unger and White (2016), multiple daily injections (MDIs) should be delivered through the use of insulin pens instead of vials and syringes. The use of insulin pens allows for accurate, portable and flexible ease of delivery. Typically, insulin pens do not need to be refrigerated, which in turn aids with overall patient adherence regarding therapy. Each insulin delivery device has its own nuances which the adolescent must be familiar with (Unger & White, 2016). It is therefore important that the adolescent is giving the appropriate insulin doses for prandial or basal coverage to avoid errors in insulin delivery.

In some cases, adolescents whose HbA1c levels rise despite being given adequate dosing protocols for a basal-bolus insulin regimen may be noncompliant to their specific insulin regimen (Buresova *et al.*, 2008; Unger & White, 2016). One study revealed that 64% of patients with T1D were incorrectly calculating their prandial insulin requirements (Ahola *et al.*, 2010). More importantly, no matter the duration of this disease the estimation of the optimal prandial insulin dose cannot always be successfully assessed by the adolescent. Barriers which prevent intensive insulin therapy in T1D include fear of needles, weight gain, untimely dosing procedures, fear of hypoglycaemia and confusing mealtime-appropriate dosing (Cavan *et al.*, 2012). Thus, it is beneficial to use insulin pens rather than vials and syringes to assist adolescents with the hardships of insulin therapy.

Unger and White (2016) further highlight the advantages of insulin pens:

- Teaching insulin pen use is a quick and easy procedure;
- Insulin pens can use shorter needles which have significantly reduced the needle phobia associated with taking injections. Also, these needles are less painful as they do not have to be inserted through the rubber stopper of a vial, which wears down the fine tip needle and results in increased injection pain;
- Insulin pens are more travel-friendly than vials and syringes. It can easily be stored in a pocket or carry bag;
- Pen devices can deliver more accurate insulin doses ≤ 5 units, which can be beneficial to children and adolescents who usually require smaller doses;
- Lastly, patient surveys have shown that insulin pens are preferred over vials and syringes (Asamoah, 2008; Bossi *et al.*, 2016).

According to the American Diabetes Association (2003, 2004), it is suggested to not reuse insulin pen needles to avoid painful injections. Another potential issue of reusing needles is the inability to guarantee sterility. However, some individuals may reuse needles to lessen the daily inconvenience it poses to their lifestyle. "Most insulin preparations have bacteriostatic additives that inhibit growth of bacteria commonly found on the skin. Nevertheless, syringe/needle reuse may carry an increased risk of infection for some individuals. Patients with poor personal hygiene, an acute concurrent illness, open wounds on the hands, or decreased resistance to infection for any reason should not reuse a syringe or pen needle" (American Diabetes Association, 2004, pp. S107-S108).

2.8.9 INSULIN PUMP THERAPY

"Continuous subcutaneous insulin infusion (CSII) or 'insulin pump' therapy allows programmed insulin delivery with multiple basal infusion rates and flexible bolus dosing of insulin with meals" (Ghosh & Collier, 2012, p. 102). The use of CSII therapy is increasing for patients with T1D who are knowledgeable at carbohydrate counting and have undergone a comprehensive education course. Appropriate carbohydrate counting is needed for effective intensive insulin management in T1D.

This skill is used for both MDIs and CSII therapy. Thorough guidance, especially at the start, is required from the diabetes specialist nurse and/or doctor, as well as a dietician (Ghosh & Collier, 2012). CSII therapy enables adolescents to achieve improved blood glucose levels with the benefit of using less insulin on a daily basis (Unger & White, 2016). Furthermore, Unger and White (2016) state that insulin pumps have been available since the 1980s and are highly recommended for patients who are children or adolescents.

Regardless of randomised trials showing that CSII therapy provides some advantages over MDIs in T1D for children, adolescents and adults; MDIs are still the most commonly prescribed insulin regimen for type 1 diabetics in South Africa (Amod *et al.*, 2013; Cummins *et al.*, 2010; Pickup & Keen, 2002). Insulin pumps can improve the quality of life in adolescents who struggle or fear MDIs or simply want increased flexibility in their lifestyle. Even though CSII therapy has become more common, it remains to be expensive and costs are only covered by very few private medical aids.

2.9 GLYCAEMIC MONITORING FOR T1D

All guardians and family members involved in the adolescent's life need to learn about T1D. They should know how to administer insulin injections, perform blood glucose monitoring and handle any acute complications that the adolescent may encounter (Chiang *et al.*, 2014; Hanas *et al.*, 2011; Rewers *et al.*, 2014). While adolescents can be taught to perform all of the procedures needed for T1D management, their well-being is improved when supportive and understanding family members continue to be involved in managing this disease.

The family must be able to monitor glycaemic levels up to four times per day and sometimes more frequently in adolescents who have unbalanced glucose control or comorbid diseases. According to Rewers and Chase (2016) adolescents with T1D should be evaluated by a diabetes physician every 3 months to monitor compliance, make adjustments to insulin dosage (according to growth), measure HbA1c and analyse glycaemic patterns, as well as for routine laboratory tests and bodily check-ups.

2.9.1 BLOOD GLUCOSE MONITORING

There are many different types of blood glucose test strips and glucose meters (or glucometers) available and will continue to improve and progress as research grows. Glucometers outside the United States generate blood glucose readings in mmol/L values, rather than mg/dl values.

For the purpose of this study mmol/L values are used to explain blood glucose readings because it is done from a South African context.

Basic glucometers simply measure the adolescent's blood glucose, whereas more complex glucometers can store additional information such as extra carbohydrate intake and physical activity (Ghosh & Collier, 2012). Once the data has been stored on the glucometer the information can be downloaded and used to interpret overall management of blood glucose levels at specific intervals. Results may be misinterpreted, especially in lower range blood glucose, by trained healthcare professionals; therefore adequate training and system of quality control is imperative to both the adolescent and the family.

In T1D, it is required to perform a 'profile' of tests at different times during the day, usually prior to mealtimes. Typically the adolescent should perform a blood glucose test before: breakfast, lunch, dinner and bedtime (Ghosh & Collier, 2012; Rewers & Chase, 2016). Additionally, adolescents who struggle with nocturnal hypoglycaemia should test in the early hours of the morning (02:00-03:00am); to achieve better diabetes management. Furthermore, blood glucose monitoring should take place before and after exercise (sometimes during if physical activity exceeds 30 minutes) to assist with reductions in insulin dose or requirement of additional carbohydrates (Dhada *et al.*, 2014; Tonoli *et al.*, 2012).

2.9.2 SELF-MONITORING OF BLOOD GLUCOSE (SMBG)

The commonly used strategy for effective T1D management is self-monitoring of blood glucose (SMBG). It is a fundamentally recognised element to T1D self-care management (Ghosh & Collier, 2012). The advantages of intensive blood glucose control and SMBG on T1D problems were shown by the DCCT, confirming the crucial effect SMBG has on overall therapy (Chiang *et al.*, 2014). The increased occurrence of SMBG is connected with better HbA1c (Beck *et al.*, 2013; Ziegler *et al.*, 2011). It allows adolescents to assess their own reaction to treatment, giving them a sense of control and empowerment. The results give them the opportunity to evaluate whether glycaemic goals are achieved and beneficial in the prevention of hypoglycaemic / hyperglycaemic events, adjusting preprandial insulin dosages, and acknowledging the influence of correct diet and exercise (Chamberlain *et al.*, 2016; Haas *et al.*, 2013; Hilliard *et al.*, 2013).

SMBG schedule should be prescribed according to the adolescent's specific goals and requirements. Healthcare professionals need to ensure that the adolescent receives ongoing support and consistent evaluation of SMBG technique and comprehension of SMBG data to make adjustments to insulin doses and/or diet (Chiang *et al.*, 2014). Thus, the results from the SMBG should be downloaded and assessed at each T1D visit. People with T1D experience daily variability in blood glucose levels. SMBG is a valuable technique to aid in optimal glycaemic control.

"This variability is influenced by differences in insulin absorption rates, insulin sensitivity, exercise, stress, rates of food absorption, and hormonal changes (e.g., puberty, the menstrual cycle, menopause, and pregnancy). Illness, traveling, and any change in routine (e.g., increased exercise and a different diet during vacation) may require more frequent SMBG under the guidance of a physician" (American Diabetes Association, 2004, p. S109). Healthcare professionals should request SMBG results whenever patients require help regarding illness or stress. During illness, insulin therapy should continue even if the patient is vomiting or is unable to consume food. If illness is supplemented by hyperglycaemia, a positive ketone urine/blood test for ketones then an adjustment to insulin regimen is needed.

Adolescents with T1D should perform SMBG at the following times: before, and occasionally after, mealtimes and snacks; at night; prior to and after exercise, sometimes during if physical activity exceeds 30 minutes; suspected low blood glucose levels; after treating low blood glucose; and lastly prior to cognitive responsibilities such as driving or examinations. According to American Diabetes Association (2004), this may require 6-10 blood glucose tests daily, depending on the adolescent's needs. In cases where the adolescent is ill, then up to 10 SMBG tests daily or more may be performed.

Studies have shown that an advantageous connection is present between regularity of SMBG and decreased HbA1c in children and adolescents with T1D (Chiang *et al.*, 2014; Davey & Segal, 2015). According to Murata *et al.* (2015) and Ziegler *et al.* (2011), significantly less DKA is associated with increased blood glucose testing. The accuracy of SMBG depends on both the instrument and the adolescent. Therefore, evaluation of the adolescent's monitoring technique and proper understanding of the information is required, by the adolescent and physician, for optimal use of SMBG.

2.9.3 CONTINUOUS GLUCOSE MONITORING (CGM)

The continuous glucose monitor (CGM) devices are subcutaneous glucose sensors that operate by continuously measuring glucose levels in interstitial fluid (Svoren & Jospe, 2016; Unger & White, 2016). This device is suggested for use when individuals have specific difficulty in achieving glycaemic control or using CSII therapy (Chiang *et al.*, 2014). CGM technology consists of a disposable sensor that measures real-time blood glucose levels, a transmitter that is attached to the sensor, and a receiver that stores glucose readings.

It is inserted just under the skin of the upper arm or abdomen, and information can be downloaded onto a computer or displayed immediately on the CSII pump screen. The CGM sensors still require calibration with SMBG, and the user needs SMBG to make decisions regarding acute treatment. As with CSII therapy, intensive education and follow-up evaluations is required by specialised diabetes providers. One beneficial advantage of the CGM device is that it has alarms for hypo- and hyperglycaemic events that includes accurate level and alerts for rate-of-change (Chiang *et al.*, 2014).

In 2013, the United States Food and Drug Administration (FDA) approved a CGM device with a newly equipped suspend-before-low glucose feature. A study revealed that sensor-augmented insulin pump therapy with suspend-before-low feature lowered nocturnal hypoglycaemic events and improved HbA1c levels for children and adolescents (Bergenstal *et al.*, 2013).

According to Chiang *et al.* (2014, pp. 2045-2046), the following ADA recommendations regarding SMBG and CGM should be considered:

- “Patients with type 1 diabetes should perform SMBG prior to meals and snacks, at a minimum, and at other times, including postprandially to assess insulin-to-carbohydrate ratios; at bedtime; midsleep; prior to, during, and/or after exercise; when they suspect low blood glucose; after treating low blood glucose until they have restored normoglycaemia; when correcting a high blood glucose level; prior to critical tasks such as driving; and at more frequent intervals during illness or stress.
- Individuals with T1D need to have unimpeded access to glucose test strips for blood glucose testing. Regardless of age, individuals may require 10 or more strips daily to monitor for hypoglycaemia, assess insulin needs prior to eating, and determine if their blood glucose level is safe enough for overnight sleeping.
- CGM is a useful tool to reduce A1C levels in adults without increasing hypoglycaemia and can reduce glycaemic excursions in children. Glycaemic improvements are correlated with frequency of CGM use across all ages.

- Children and adolescents should have additional blood glucose checks if the parent/ guardian are concerned that the child's behaviour may be due to low/high blood glucose levels.
- School employees and guardians should be knowledgeable about SMBG and equipped with all necessary supplies.
- Capable children and adolescents should be permitted to self-manage their diabetes at school."

2.9.4 INSULIN THERAPY

The DCCT proved that intensive insulin therapy was an integral factor in improved glycaemic control and better health and well-being (Diabetes Control and Complications Trial Research Group, 1993; Nathan, 2014). Intensive insulin therapy is demarcated by injecting insulin three or more times daily or CSII therapy. The DCCT study was conducted with short- and intermediate-acting human insulin. The result showed an improvement in microvascular outcomes, for this intensive insulin therapy, but was associated with an increased rate of severe hypoglycaemia. Since the DCCT was completed, various rapid- and long-acting human insulin analogues have been manufactured to counter the problems found in short- and intermediate-acting human insulins (Vora, Christensen, Rana, & Bain, 2014). These analogues are related to a decreased rate of severe hypoglycaemia, improved HbA1c and lower insulin doses than human insulin (Hirsch, Franek, Mersebach, Bardtrum, & Hermansen, 2016). According to Shafie, Hui-Ng, Tan, and Chaiyakunapruk (2017), current research shows that human insulin analogues are cost-effective for T1D.

The following recommendations by the American Diabetes Association (2014, p. 2046) are helpful for a patient with T1D, regarding insulin therapy:

- "Most individuals with T1D should be treated with multiple daily insulin injections (three or more injections per day of prandial insulin and one to two injections of basal insulin) or CSII.
- Most individuals with T1D should be educated in how to match prandial insulin dose to carbohydrate intake, prandial blood glucose, and anticipated activity.
- Most individuals with T1D should use insulin analogues to reduce hypoglycaemia risk.
- All individuals with T1D should be taught how to manage blood glucose levels under varying circumstances, such as when ill or receiving glucocorticoids or for those on pumps, when pump problems arise.
- Adolescent guardians and school personnel should be taught how to administer insulin based on provider orders when an adolescent cannot self-manage and is out of the care and control of his or her parent/guardian."

Studies have confirmed that intensive insulin management, using CSII therapy and/or CGM devices, should be implemented (Chiang *et al.*, 2014; Phillip *et al.*, 2013; Wood *et al.*, 2013). This is strongly encouraged along with effective adolescent and family support which will contribute to successful management of insulin therapy and enhanced outcomes. However, as aforementioned, this type of therapy is expensive and costs are only covered by a small number of private medical aid schemes.

2.10 SUMMARY OF CHAPTER 2

This chapter pivoted on placing existing literature within the context of this study. The theoretical frameworks were discussed. The phenomenon being investigated in this study was then introduced. Thereafter, a thorough review of the epidemiology, diagnosis, treatment and glycaemic monitoring for T1D was discussed. Chapter 3 is a continuation of the literature review.

3. CHAPTER 3: LITERATURE REVIEW OF THE MANAGEMENT AND COMPLICATIONS OF TYPE 1 DIABETES

3.1 INTRODUCTION

In this section, the researcher will review literature pertaining to the management and complications of T1D. Thereafter, family centred care of T1D and health-related quality of life for T1D is discussed. There is limited information on the literature in the context of the researcher's study, and therefore, the literature review will be based on Southern African and international research.

3.2 MANAGEMENT OF T1D

A recent study by Oram *et al.* (2016) showed that nearly three-quarters of all T1D cases are identified in people under 18 years. "A multidisciplinary team of specialists trained in paediatric diabetes management and sensitive to the challenges of children and adolescents with T1D and their families should provide care for this population. It is essential that diabetes self-management education (DSME) and support (DSMS), medical nutrition therapy, and psycho-social support be provided at diagnosis and regularly thereafter in a developmentally appropriate format that builds on prior knowledge by individuals experienced with the educational, nutritional, behavioural, and emotional needs of the growing child and family. The appropriate balance between adult supervision and independent self-care should be defined at the first interaction and re-evaluated at subsequent visits. The balance between adult supervision and independent self-care will evolve as the adolescent gradually becomes an emerging young adult" (American Diabetes Association, 2017a, p. S105).

The empowerment of the patient and family to self-manage their T1D is one of the most significant goals of ongoing education. Self-management of T1D includes: blood glucose monitoring; measuring blood/urine ketone levels; appropriate nutritional plan; physical activity and exercise routine; and performing and adjusting insulin doses accordingly (Cartaya & Laffel, 2017). Thus, the key to effective intensive management is communication with the T1D team so that appropriate adjustments can be made to nutrition plan and/or insulin regimen. As previously mentioned, the management of T1D requires a multidisciplinary team approach. The members of this team should include: paediatric healthcare professional (endocrinologist/physician), paediatric CDE (Centre for Diabetes and Endocrinology), dietician and mental health professionals (Cartaya & Laffel, 2017). The family of the adolescent with T1D requires readily access to team members, especially during illness (Cartaya & Laffel, 2017).

Furthermore, the adolescent also requires ongoing routine medical care by a paediatrician or family doctor. Unfortunately, only members of certain private medical aid schemes in South Africa can participate in the CDE programme (www.cdediabetes.co.za). The CDE programme offers a comprehensive T1D team and provides ongoing support and education to the individual and family as required. If the family cannot afford to be a part of a CDE programme then they receive the T1D management from other medical providers.

After diagnosis, team members frequently see patients to assess the family's compliance, reinforce information and skills, and elaborate on intensive T1D management (Cartaya & Laffel, 2017). Once initial management of T1D is successful, patients are seen every 3 months, dietician check-ups are generally recommended annually or more often if required. "At each visit, the healthcare provider performs a focused interval history including: recent illnesses, ER visits, hospitalizations, medications other than insulin, types of insulin and doses, daily routine including dietary pattern and activity level, self-care behaviours and who performs them, episodes of hypoglycaemia, school performance, emotional health, and a review of systems focusing on symptoms of hyperglycaemia (polyuria, polydipsia, polyphagia, weight loss, candida infections) and the possible development of other autoimmune disorders. If appropriate, a history of tobacco, alcohol, recreational drugs, and sexual activity should be addressed. A focused physical exam should include blood pressure, heart rate, weight, height, body mass index (BMI), and examination of the thyroid, sites of blood glucose monitoring and insulin delivery. For older adolescents with diabetes since early childhood a comprehensive foot exam including monofilament test and vibration sense should also be performed annually" (Cartaya & Laffel, 2017, p. 1165).

Adolescents with T1D require age-specific treatment and care, including an overall comprehension of their individual requirements and restrictions. For example, the approach used for adolescents is different in comparison to infants and toddlers. Although, regardless of age, all patients with T1D have the same needs. All of them require an individualised T1D plan with ongoing support and education; regular check-ups for complications; as well as access to paediatric healthcare professionals (American Diabetes Association, 2017a; Chiang *et al.*, 2014). Therefore, the therapeutic approach must be adjusted appropriately to suit the individual's needs.

The healthcare professional needs to take into consideration the specialised factors concerning T1D management and care for adolescents. Some of these factors include: changes in insulin sensitivity in relation to sexual maturity and physical growth; self-care abilities; neurological vulnerability to hypo- and hyperglycaemia; as well as possible negative effects of DKA on neuro-cognition (American Diabetes Association, 2017a; Barnea-Goraly *et al.*, 2014). A successful T1D management plan is developed by assessing the adolescent's family environment, development and physical changes in relation to sexual maturity.

As adolescents transition into emerging adulthood, new challenges and adaptations to T1D management are faced. The ADA recommends an effective and practical transition plan to assist with upcoming changes (Laffel & Peters, 2011). The transition plan should be implemented on an early basis (i.e. early teenage years); to ensure success it must also include ongoing support between family and adolescent.

Medical providers, adolescents and their families should discuss financial and insurance related aspects, medical supplies, adult medical care provider options, psycho-social problems (e.g. depression, anxiety, eating disorders, support systems, etc.) and any other issues identified (Laffel & Peters, 2011). Regardless of how appropriate the T1D management, it can only be successful through the adherence of the adolescent and family. Table 3.1 provides further clarity on the major developmental stage issues and the effect it has on T1D for children and adolescents.

Table 3.1: THE EFFECT OF MAJOR DEVELOPMENTAL ISSUES ON CHILDREN AND ADOLESCENTS WITH T1D

Developmental stages (ages)	Normal developmental tasks	T1D management priorities	Family issues in T1D management
Early and middle adolescence (12–16 years)	Managing body changes	Increasing insulin requirements during puberty	Renegotiating parent and teenager's roles in T1D management to be acceptable to both
	Developing a strong sense of self-identity	T1D management and blood glucose control becoming more difficult	Learning coping skills to enhance ability to self-manage
		Weight and body image concerns	Preventing and intervening in T1D-related family conflict
			Checking for signs of depression, eating disorders, and risky behaviours

Later adolescence (17–19 years)	Establishing a sense of identity after high school (decisions about location, social issues, work, and education)	Starting an ongoing discussion of transition to a new T1D team (discussion may begin in earlier adolescent years)	Supporting the transition to independence
		Integrating T1D into new lifestyle	Learning coping skills to enhance ability to self-manage
			Preventing and intervening with T1D-related family conflict
			Checking for signs of depression, eating disorders, and risky behaviours

Note. Adapted from Chiang, J. L., Kirkman, M. S., Laffel, L., & Peters, A. (2014). Type 1 diabetes through the life span: A position statement of the American Diabetes Association. *Diabetes Care*, 37(7), 2034-2054.

Studies have shown that parents/guardians often have success and determination in managing the practical needs required for their adolescent with T1D, even though they find it challenging to gain acceptance of the disease into their new routine lifestyle (Allen, Channon, Lowes, Atwell, & Lane, 2011; Whittemore, Jaser, Chao, Jang, & Grey, 2012; Wiedebusch *et al.*, 2010). According to Allen *et al.* (2011), most of the parents/guardians reported that they cannot fully accept the disease diagnosis even if it seems as though they have adapted to the situation.

In previous research studies it was found that the adolescent and family had complications after coming home from the hospital discharge because the theoretical knowledge was not valid for home based management (Carter, Marshall, Rose, & Brotherton, 2009; Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998; Wennick & Hallström, 2007; Wysocki *et al.*, 1996). It must be taken into account that incorrect home based management can also be due to situational issues such as socioeconomic status, cultural viewpoints and lack of family support (Kalweit *et al.*, 2015).

Nowadays, the theoretical knowledge has been amended but parental/guardian psychological distress regarding the diagnosis of T1D can still have a negative effect on diabetes management; as it may cause significant family disruption (Hessler *et al.*, 2016; Whittemore *et al.*, 2012). Recent research in the United States conducted a study to assess parent-to-parent support in the context of newly diagnosed adolescent diabetes and found that their stress levels decreased significantly, although long term support was lower than expected (Channon, Lowes, Gregory, Grey, & Sullivan-Bolyai, 2016).

During the developmental stages of children and adolescents, it is apparent that there are various diverse issues to consider, regarding the effect of T1D, for both the family and youth (Malerbi, Negrato, & Gomes, 2012). For that reason it is pertinent for family and adolescent to adhere to an effective T1D treatment plan; healthcare professionals should also offer support for unforeseen problems that could arise.

3.2.1 T1D HEALTHCARE SECTORS IN SOUTH AFRICA

The specific care for youth newly diagnosed with T1D varies worldwide; the initial method of treatment is dependent on the individual's medical state upon diagnosis (Silverstein *et al.*, 2005). As previously mentioned, South Africa has two healthcare sectors, namely: public (government funded) and private. The participants in this study all attend a public healthcare facility to receive treatment for their T1D. Individuals that can afford to have a private medical aid can receive T1D care from private hospitals and CDE programmes.

Private healthcare facilities have a wider variety of T1D treatment and management options. There are distinct differences, regarding resources and services available, between public and private healthcare sectors. However, South African research cannot prove whether these two healthcare differences significantly impact the management of T1D. Rather, an analysis of various T1D management techniques used could provide insight because significant areas of treatment are not available to all South African youths. A study was conducted to investigate components in management approaches that are related to uncontrolled blood glucose and life dissatisfaction in South African children with T1D (Kalweit *et al.*, 2015). The results showed that premixed insulin (without access to rapid-acting human insulin analogues), short-acting and intermediate-acting human insulin regimen, absence of self-titrate insulin doses, and lack of insulin-to-carbohydrate counting was associated with poor T1D management. Implementing intensive care T1D management approaches in the public healthcare sector could improve this current problem.

As aforementioned, the prescribed T1D treatment regimen should be individualised and accommodate the adolescent's age, glycaemic target, daily routine and family requirements. However, the adolescent's specific needs regarding the most effective T1D management is not equally available in South Africa. According to South Africa's National Department of Health (2006, 2008), patients who are not covered by private medical insurance are issued insulin by the state. However, lancets, insulin needles, test strips and glucose meters are not on national tender which means the accessibility is dependent on the separate financial plan of each public healthcare facility.

In the public sector T1D educators are not regularly available, although *ad hoc* education is provided by the physicians and nursing staff (Kalweit *et al.*, 2015). The services of dietitians are only available depending on the individual public healthcare facility. Kalweit *et al.* (2015) further state that action plans in the public healthcare systems will implement an integrated approach to chronic care whereby T1D services will join other chronic diseases such as epilepsy, asthma and hypertension because of the increasing rate of comorbidity in the South African population.

In 2005, the first sub-Saharan African long-term outcome study of T1D in Soweto was published. The results showed that the outlook for African individuals remains poor due to insufficient healthcare systems, inadequate medical supplies, lack of health education programmes, and absence of appropriate healthcare providers and facilities (Gill *et al.*, 2005). Another study was conducted from 1999-2011 in sub-Saharan Africa; a systematic review was done on the epidemiology and public health implications for T1D. The findings of this study were similar to the results of the long-term outcome study because patients still faced significant challenges concerning diagnosis and accessing treatment, thus contributing to the high mortality and prevalence of complications (Thomsen, Hall, Henriksen, & Lohse, 2011). Therefore, the apparent connections between infectious diseases (i.e. HIV, tuberculosis and pneumonia) and T1D highlights the pertinent need for health action plans to be developed and integrate the responses to communicable and non-communicable diseases.

In South Africa, like other developing nations, public healthcare facilities training and education is sometimes difficult to manage as a result from limited resources being available (Kalweit *et al.*, 2015). A recommended treatment plan should be implemented at diagnosis by a multidisciplinary paediatric T1D team to the adolescent and his/her family. A specialised nurse, qualified in paediatrics and diabetes, can serve as a diabetic-educator and social-worker (Kalweit *et al.*, 2015). The key role is to provide DSME and DSMS to the individual and family. The healthcare professional must ensure that appropriate treatment is given to the adolescents and their families receive meaningfully applicable information in their culturally respective contexts. During the initial management and thereafter, both parents/guardian and adolescents are encouraged to be actively involved with the diabetes team (Kalweit *et al.*, 2015; Levitt, 2008). Unfortunately, this is not always followed in public healthcare facilities due to patients not being able to afford medical aid and cover the admittance costs, as well as limitations in this healthcare sector.

3.2.2 DIABETES SELF-MANAGEMENT EDUCATION (DSME) AND SUPPORT (DSMS)

There is a significant requirement of training and education needed when an adolescent in a family is diagnosed with T1D. To cope with the disease in an effective manner a major lifestyle change needs to take place. The key to successful T1D management has proven to be ongoing education and support (Cooke *et al.*, 2013; Hopkins *et al.*, 2012). According to Chiang *et al.* (2014), “DSME and DSMS are the ongoing processes of facilitating the knowledge, skill, and ability necessary for diabetes self-care. These processes incorporate the needs, goals, and life experiences of the person with diabetes. The overall objectives of DSME and DSMS are to support informed decision making, self-care behaviours, problem solving, and active collaboration with the healthcare team to improve clinical outcomes, health status, and quality of life in a cost-effective manner” (p. 2041). Across the life span, changes occur in both life and treatment conditions for T1D (Haas *et al.*, 2013). Accordingly, DSME and DSMS need to be adapted on a continual basis to ensure successful self-management.

Lowes *et al.* (2015) suggests that it is pertinent for adolescents to go for consistent check-ups regarding their emotional and psychological factors, in diabetes self-care. Baucom *et al.* (2015) suggested that depressive symptoms are interlinked with poor compliance and high levels of stress caused by general and diabetic-specific events. This provides further proof of the significance of giving psychological counselling to adolescents, understanding the effect that these factors have on the mental state of these individuals with T1D. Lowes *et al.* (2015) further states that social support does play a pertinent role in diabetes management. Therefore, social support is necessary for the psycho-social well-being of adolescents with T1D.

Continued parental/guardian supervision and involvement still remains a crucial component of effective T1D management for adolescents. Consequently, healthcare professionals should be skilled to assess the scholastic, behavioural and psycho-social elements that influence adherence to the T1D management plan. Additionally, they must also provide necessary assistance to the adolescent and their parent/guardian to overcome difficulties and make adjustments to objectives as needed. Table 3.2 shows the life stages and recommended DSME content.

Table 3.2: LIFE STAGES AND RELEVANT DSME CONTENT

Adolescence (12–18 years)	Young adults (18-25 years)
Begin transition care planning	Personal meaning of diabetes
Personal meaning of diabetes	Roles and responsibilities in care
Determine roles and responsibilities in care	Social situations and dating
Social situations and dating	Who or when to tell about diabetes
Who or when to tell about diabetes	Genetic risks, conception, and preconception
Driving	Travel
Sex and preconception counselling	Choosing or pursuing a career
Alcohol and drugs	Workplace rights
University/college and career planning	Health or life insurance
	Involving friends and significant others in diabetes care
	Safety
	Creating a support network
	Establishing or maintaining independence

Note. Adapted from Chiang, J. L., Kirkman, M. S., Laffel, L., & Peters, A. (2014). Type 1 diabetes through the life span: A position statement of the American Diabetes Association. *Diabetes Care*, 37(7), 2034-2054.

As the individual matures, different age-appropriate issues should be addressed (as highlighted in the table above). The T1D education should be tailored to each family's needs, regarding their educational level and cultural background. Additionally, the T1D educator must appropriately shift focus from parent/guardian to adolescent as required. According to national standards of diabetes care (Dhada *et al.*, 2014; Haas *et al.*, 2013), DSME and DSMS should start at diagnosis and transition through each developmental stage to adulthood as an ongoing process. The information should be culturally sensitive, individualised and adapted on a continuous basis to the adolescent's needs. Furthermore, DSME should be provided to relevant school personnel (Chiang *et al.*, 2014). A noteworthy section of an adolescent's day is spent in a school environment and having the support of T1D educated school staff can only improve overall management.

From the time of early-age diagnosis there is a process of diabetic care that takes place between the individual and their parents. Over time, into adolescence, diabetic care transitions into self-management (Haas *et al.*, 2013). Patients and relatives, as well as diabetic medical professionals must prepare for the abrupt change from paediatric to adult health. Studies done in the United States have shown substantial gaps in care and education during this period of later adolescence (Laffel & Peters, 2011). Therefore, it is critical to educate and properly care for T1D during adolescence as emerging adulthood encompasses further life stressors such as tertiary studies, work, etc.

Gaps in diabetes care and education can result in poorer glycaemic control; increased onset of acute impairments; undetected or untreated chronic complications; suboptimal healthcare, and; psycho-social, emotional and behavioural problems (Nasri, 2013). There is urgency for further research in this area and a prevalent need for context-specific education and care. The high occurrence of T1D in childhood, adolescence and young adulthood further stresses this need.

According to the ADA (Laffel & Peters, 2011, p. 2477), “substantial challenges relating to the transitional period include the following:

- The dearth of empirical evidence on the best approaches to the transition process;
- Fundamental differences in healthcare delivery between paediatric and adult healthcare providers;
- Lack of well-defined criteria for determination of transition readiness;
- The changing social and demographic characteristics of young adults that may influence their utilisation of healthcare;
- Gaps in health insurance during this transitional period;
- Differences in learning styles between individuals in this transition period compared with both younger children and adults beyond the period of emerging adulthood;
- Deficiencies in training of healthcare professionals in care delivery for emerging adults with diabetes.”

At the time of diagnosis, diabetes education is primarily about survival. The family and adolescent must acquire an appropriate understanding about T1D treatment and management before they can leave the healthcare facility (Funnell *et al.*, 2009). It is important that the individual and their relatives receive information based on how the diagnosis has been recognised and T1D predisposing factors. Together with vocal education, the parent/guardian should also receive paper-based information that is understandable and easy to read. Furthermore, information regarding insulin, glucose, practical skills and fundamental dietetic advice is also given. The family must learn about hypoglycaemia, hyperglycaemia, preventative measures for diabetic ketoacidosis (DKA) and management of T1D at school, during physical activity and at home (Funnell *et al.*, 2009; Haas *et al.*, 2013). Emergency telephone contacts must also be provided after diagnosis.

T1D education should follow requests of the adolescent and family which are continued over a longitudinal period. This encompasses knowledge and skills development for the individual, specific to age and intellectual level (Danned, 2014; Swift, 2009). It is recommended that the family and adolescent have ongoing sessions with the paediatric team during the first six months after diagnosis.

In this time period adjustments are made to T1D management to suit the adolescent and family's requirements. Danned (2014) further explains that both parents are given the chance to engage in training and planning for their adolescent's disease. Practical training in T1D management includes insulin regimen, glycaemic monitoring and nutritional plan, instructed by a dietician and/or physician (Eichner *et al.*, 2012; Hessler *et al.*, 2016). Personal meetings and telephone updates by the diabetes team take place after hospital discharge. The availability of the diabetes team in the beginning stages can result in effective compliance for later years.

3.2.3 SELF-MANAGEMENT GOALS FOR BASAL-BOLUS INSULIN THERAPY

It is important to comprehend the self-management goals for adolescents using basal-bolus insulin therapy. Four out of the five participants interviewed are using basal-bolus insulin therapy, with the remainder using premixed insulin.

Unger and White (2016) outline the following self-management goals for patients using basal-bolus insulin therapy:

- Healthcare providers should prescribe a successful and safe insulin regimen that will allow adolescents to reach ADA's HbA1c target;
- Target 2-hour postprandial glycaemic levels $>10\text{mmol/L}$;
- Reduce the rise of postprandial glycaemic levels from pre-meal baseline levels of $\leq 8\text{mmol/L}$;
- Healthcare providers should reduce risk of hypoglycaemia by educating adolescents about correct glucose monitoring technique, hypoglycaemic symptoms and proactive treatment;
- Allow adolescents to self-titrate their basal and bolus insulin doses according to specific treatment targets, such as fasting and postprandial exercise;
- Encourage DSME and DSMS through certified diabetes educators and/or dieticians to enhance overall T1D management;
- Healthcare providers should regularly assess injection and SMBG technique to ensure accuracy and effectiveness;
- Lastly, the treatment should be individualised to suit the adolescent's needs.

Adolescents with T1D must make many therapy-related decisions daily, often without the guidance of a healthcare provider. As a result, most adolescents become quite skilled at adjusting insulin doses accordingly for metabolic requirements (Cartaya & Laffel, 2017; Svoren & Jospe, 2016). However, cases may arise whereby adolescents have incorrectly self-titrated insulin doses accidentally. It is significant for the healthcare professional to never rebuke adolescents for not attaining glycaemic targets; as it is difficult to achieve for every individual with T1D, irrespective of age and duration of disease. Rather, ongoing support and education should be provided in order for optimal management of T1D.

3.2.4 SICK-DAY MANAGEMENT

Management of sick days aims to avoid progression to DKA or avoid severe hypoglycaemia (Cartaya & Laffel, 2017). In most cases, sick days can be managed from an outpatient setting with correct DSME and DSMS. To effectively manage sick days the adolescents and family should never omit insulin regimen, prevent dehydration, avoid low blood glucose, monitor glycaemic levels (every 2-4 hours), check ketones, provide correction insulin doses (if needed) based on level of ketosis and hyperglycaemia, and treat current illness.

According to Rewers and Chase (2016), during any illness, families must be instructed on how to check blood or urine ketone levels. These tests should be performed when fasting blood glucose level is above 13.3mmol/L (240mg/dl) or a randomly measured blood glucose level is higher than 16.6mmol/L (300mg/dl) (Dhada *et al.*, 2014; Hilliard *et al.*, 2013). The family should contact a healthcare provider if the adolescent presents with moderate/severe levels of ketonuria (excess of ketones in urine) or ketonemia (excess of ketones in blood), or signs of extreme dehydration. The overall aims are to maintain hydration and glycaemic control, as well as avoid ketoacidosis.

Adjustments should be made to insulin regimen until normal glycaemic levels are achieved. This treatment is necessary to prevent further progression to ketoacidosis and can be initiated from the adolescent's home. Furthermore, water is the recommended oral fluid to assist in high blood glucose if the level is above 13.9mmol/L (250mg/dl). If hypoglycaemia is experienced by the adolescent then glucose-containing fluid should be ingested as required. However, overtreatment of insulin during a sick-day that begins with hyperglycaemia and ketosis could end in unconsciousness and/or diabetic seizures (Davey & Segal, 2015). Thus, the importance in sick-day management is to prevent severe hypoglycaemia and carefully monitor high blood glucose levels.

3.2.5 MEDICAL NUTRITION PLAN

Nutritional plans are significant to T1D treatment. A provider, generally a dietician trained in paediatric nutrition and T1D and/or physician, should educate the adolescent and family at the time of diagnosis and have ongoing visits annually, or more often if needed (Cartaya & Laffel, 2017). Nutrition is of utmost significance during childhood and adolescence, as appropriate food intake is required for optimal growth and pubertal development.

An individualised meal plan should be developed to match the adolescent's daily schedule; food preferences, inclusive of cultural and ethnic considerations; and physical activity (Chiang *et al.*, 2014). The aim of nutrition therapy is to ensure that the adolescent and family understand "the impact food has on blood glucose, how food interacts with exercise and insulin to prevent hypo- and hyperglycaemia and to achieve glucose goals, and how to implement the food plan in a variety of situations. The food plan takes into consideration the adolescent's numeracy, literacy, engagement, and ability to adjust insulin" (Chiang *et al.*, 2014, p. 2042). Successful nutrition therapy is associated with families that adopt the meal plan into their established schedule and preferences.

The adolescent and family should therefore receive training in carbohydrate counting so that insulin-to-carbohydrate ratios can be implemented into the meal plan. Occasionally, the family can also make use of carbohydrate estimation or carbohydrate exchanges when considering meals. All youths should eat three meals per day, with snacks as required. It is recommended by the ADA that foods that contain high levels of cholesterol, saturated fats and concentrated sweets should be avoided; rather select foods with low-GI (glycaemic index) carbohydrates and dietary fibre (American Diabetes Association, 2017a, 2017b). The general advice for healthy eating is to: increase intake of starchy carbohydrate foods, increase fruit and vegetable intake, reduce fat intake, reduce sugar intake, reduce salt intake, and lastly, safe and sensible consumption of alcohol (Ghosh & Collier, 2012). Total daily calories and carbohydrates should be tailored to the adolescent's growth and development, and also consider whether weight gain or loss is needed.

At every 3-month T1D visit, growth velocity, weight and body mass index (BMI) must be recorded to review whether energy intake and energy requirements of the adolescent are appropriate (Svoren & Jospe, 2016). Poor glycaemic control is considered when unexpected weight loss or excessive weight gain is observed. Eating disorders, thyroid dysfunction, frequent hyper- and/or hypoglycaemia, and/or gastrointestinal diseases are all indicators of an incorrect nutritional plan and immediate re-evaluation of the adolescent's needs must be done by a healthcare provider (Svoren & Jospe, 2016). Nutrition therapy's key strategy to achieve optimal glycaemic control is by monitoring carbohydrate intake, through either experience-based estimation or carbohydrate counting. Foods that contain high-GI are released quickly into the body, while low-GI foods have a slower glycaemic response (Unger & White, 2016). Blood glucose levels are improved through foods with a slower glycaemic response, as it aids in bolus-insulin action. According to Ghosh and Collier (2012), diets with a low glycaemic index reduces glycaemic levels for individuals with T1D.

Adolescents who use short- and intermediate-acting human insulin need to adhere to a strict schedule of meals and snacks to match the anticipated peak-time of insulin action and maintain good glycaemic control. A less rigid meal plan is available to individuals who use rapid- and long-acting human insulin analogues, as this has been manufactured to address a more flexible insulin regimen and improved quality of life (Cartaya & Laffel, 2017; Svoren & Jospe, 2016). Thus, adjustments in meal plan should be made to accommodate the adolescent's needs and maintain T1D management goals.

Occasional 'treats' or excesses are permitted in the nutritional plan to prevent rebellious behaviour in youths; which must be accompanied by adjustments made to insulin doses and carbohydrate intake (Svoren & Jospe, 2016). Allowing the adolescent to indulge on special occasions while adhering to correct meal plan adjustments creates empowerment of T1D and promotes optimal overall compliance.

3.2.6 PSYCHO-SOCIAL SUPPORT AND MANAGEMENT

Rapid changes occur emotionally, developmentally and cognitively during childhood, adolescence and emerging adulthood. T1D management places further substantial burdens during childhood and adolescence which requires ongoing evaluation (at routine visits) of psycho-social status and T1D stress (Corathers *et al.*, 2013; Ducat, Philipson, & Anderson, 2014). A behavioural and/or mental health professional is an important member of the multidisciplinary T1D team. They can assist with the assessment of family needs and provide appropriate referrals. The issues experienced by adolescents with T1D are multi-faceted, highlighting the importance of screening for psycho-social distress and mental health problems.

The American Diabetes Association (2017a, p. S106) recommends the following regarding psycho-social issues:

- "At diagnosis and during routine follow-up care, assess psychosocial issues and family stresses that could impact adherence to diabetes management and provide appropriate referrals to trained mental health professionals, preferably experienced in childhood diabetes;
- Mental health professionals should be considered integral members of the paediatric diabetes multidisciplinary team;
- Encourage developmentally appropriate family involvement in diabetes management tasks for children and adolescents, recognizing that premature transfer of diabetes care to the child can result in nonadherence and deterioration in glycaemic control;
- Providers should assess children's and adolescents' diabetes distress, social adjustment (peer relationships), and school performance to determine whether further intervention is needed;

- In youth and families with behavioural self-care difficulties, repeated hospitalizations for diabetic ketoacidosis, or significant distress, consider referral to a mental health provider for evaluation and treatment;
- Adolescents should have time by themselves with their care provider(s) starting at age 12 years;
- Starting at puberty, preconception counselling should be incorporated into routine diabetes care for all girls of childbearing potential.”

Effective treatment options can be facilitated for early discovery of depression, anxiety, eating disorders and learning disabilities (Young-Hyman *et al.*, 2016). This can reduce the adverse effects on T1D management and associated complications. During follow-up visits, the adolescent and family should receive ongoing assessment for social, emotional and economic stressors disturbing T1D management and glycaemic control (Cartaya & Laffel, 2017). Encouraging family involvement and providing preventative counselling (or early intervention for poor HbA1c levels) can assist with improved management and avoid acute complications.

The complexities in T1D management for children and adolescents require ongoing parental/guardian involvement and support to achieve glycaemic control and maintain adherence (Holmes, Chen, Mackey, Grey, & Streisand, 2014; Katz, Volkening, Butler, Anderson, & Laffel, 2014). Family conflict related to T1D is associated with poor compliance and glycaemic control in adolescents with T1D. Such conflict should be assessed during visits and resolved if possible; otherwise referral to an appropriate mental health professional is needed. Social adjustments (i.e. peer-relationships) and school performance should also be monitored to facilitate adolescent well-being and academic success (Lansing *et al.*, 2017; Suchy *et al.*, 2016).

Increased school absenteeism and below average school performance is related to nonadherence and poor glycaemic control (Hoffman & Osipoff, 2015; Jackson *et al.*, 2015; Perfect & Jaramillo, 2012). “It is important to consider the impact of diabetes on quality of life as well as the development of mental health problems related to diabetes distress, fear of hypoglycaemia (and hyperglycaemia), symptoms of anxiety, disordered eating behaviours as well as eating disorders, and symptoms of depression” (American Diabetes Association, 2017a, p. S106). It is important to recognise the behaviour associated with disordered eating, which is predominantly seen in adolescent females with T1D (Wisting, Frøisland, Skrivarhaug, Dahl-Jørgensen, & Rø, 2013).

Disordered eating behaviours involves insulin omission for ideal weight control and results in poor glycaemic control. Screening for these behaviours should be assessed during visits to prevent or reduce nonadherence and suboptimal glycaemic levels.

All adolescent females with childbearing potential should receive education regarding preconception (American Diabetes Association, 2017a). The education should inform the adolescent females about the potential dangers of abnormalities in association with unplanned pregnancies and poorly controlled HbA1c. Furthermore, contraceptive methods and information about unplanned pregnancy preventative measures should also be explained (Charron-Prochownik *et al.*, 2013). Developmentally appropriate preconception counselling will enhance the adolescent female's decision-making regarding pregnancy, contraception and optimal well-being.

As aforementioned, T1D in youth has an impact on the family's interpersonal relationships and lifestyle. After diagnosis of T1D the families may experience various feelings such as shock, anger, denial, sadness, depression, guilt and fear (Ogle *et al.*, 2013). Adjusting to having T1D takes a considerable amount of time and acceptance is an everyday challenge. Adolescents may perceive the disease as a punishment or curse; blaming themselves and feeling like they have done something wrong. The parent/guardian commonly experiences feelings of anxiety and guilt, which are similarly felt by the adolescent (Svoren & Jospe, 2016). During the rebellious teenage years the adolescent may also experience feelings of denial and rejection (Schwartz, Axelrad, & Anderson, 2014). Thus, the importance of shared-responsibility in the management of T1D can result in effective adherence, enhanced quality of life and ideal glycaemic control.

These psycho-social aspects are considerably associated to reduced quality of life, poor glycaemic control and nonadherence for adolescents with T1D (Peyrot, Barnard, & Holt, 2012). These factors also result in elevated acute and chronic T1D complications if not dealt with appropriately by the youth and family, with the ongoing support of the healthcare provider and/or mental health professional.

3.2.7 EXERCISE AND PHYSICAL ACTIVITY MANAGEMENT

Physical activity and exercise have various benefits for successful health and emotional well-being; comprising of cardiorespiratory health, muscle mass and strength, weight control and improved insulin sensitivity. Furthermore, it also improves cognitive function and school performance (Riddell & Taplin, 2017).

It also creates a platform for enhanced self-esteem and social interaction opportunities. It is important for all youth with T1D to engage in daily exercise for 60 minutes (Cartaya & Laffel, 2017). The exercise should include moderate-intense aerobic, bone-strengthening and muscle-strengthening physical activities that are age-appropriate. However, individuals should be screened for cardio circulatory risk and other problems that may restrict physical activity (American Diabetes Association, 2017b). Exercise also increases the risk for both hypo- and hyperglycaemia which can be a challenge for adolescents with T1D if not managed correctly.

According to the ADA, the following should be considered (Chiang *et al.*, 2014, p. 2043):

- “Exercise should be a standard recommendation as it is for individuals without diabetes; however, recommendations may need modifications due to the presence of macro- and microvascular diabetes complications;
- Patients of all ages (or guardians of children) should be educated about the prevention and management of hypoglycaemia that may occur during or after exercise;
- Patients should be advised about safe pre-exercise blood glucose levels (typically 5.5mmol/L or higher depending on the individual and type of physical activity);
- Reducing the prandial insulin dose for the meal/snack preceding exercise and/or increasing food intake can be used to help raise the pre-exercise blood glucose level and reduce hypoglycaemia;
- A reduction in overnight basal insulin the night following exercise may reduce the risk for delayed exercise-induced hypoglycaemia;
- SMBG should be performed as frequently as needed (before, during, and after exercise) in order to prevent, detect, and treat hypoglycaemia and hyperglycaemia;
- Source(s) of simple carbohydrate should be readily available before, during, and after exercise to prevent and treat hypoglycaemia.”

During physical activity, several hormones (insulin, glucagon, catecholamines, growth hormone and cortisol) operate to metabolise and create equilibrium between hepatic glucose production and glucose use by muscle exertion (McDonald, 2016; Turinese *et al.*, 2017). The balance between insulin needed and hormones that counter the regulatory process is dependent on the exercise type, duration and intensity. Thus, the challenge in doing physical activity and exercise revolves around glycaemic control. The adolescent is required to make complex decisions regarding the various factors that impact glucose uptake for both aerobic and anaerobic exercises. Temperature, glycaemic levels, food intake and stress hormones should also be considered beforehand (Riddell & Taplin, 2017). Adolescents with poorly managed T1D are at risk for exercise-induced hypo- or hyperglycaemia.

Hyperglycaemia is the outcome from excess counter regulatory hormones with inadequate insulin, which leads to an overproduction of hepatic glucose and limits glucose from entering the skeletal muscles (Chiang *et al.*, 2014). Hyperglycaemia can occur at any time, even during and after various physical activities. Intense exercise should be avoided if the adolescent presents with severe hypoglycaemia and ketosis, especially if insulin has been omitted (Hanas *et al.*, 2014). *Hypoglycaemia* can be prevented during and after exercise by using frequent SMBG, adjusting insulin doses and by having an extra carbohydrate snack (Bally *et al.*, 2016). Fifteen grams of carbohydrates generally covers 30 minutes of moderate-intense exercise.

Adolescents with T1D can achieve many health benefits from doing physical activities. It positively affects cardiovascular and metabolic functioning. Regular exercise can have the following benefits: decreased fat mass, improved lipid profile, enhanced insulin sensitivity and cardiovascular fitness (Żebrowska, Sikora, Jarosz-Chobot, Głuchowska, & Plewa, 2014). However, in adolescents with T1D, it may be a contributor for the onset of adverse reactions if not managed appropriately. These reactions may include hypoglycaemia, hyperglycaemia, ketosis and other diabetes-related complications. The adolescent must therefore have a controlled glycaemic level and be aware of his/her starting glycaemic level, type of exercise, and amount of insulin required for the duration of play.

Overall, sporting activities do have more benefits to the adolescents with T1D as it improves their physical fitness, strength and well-being (Chimen *et al.*, 2012; Tonoli *et al.*, 2012). It also allows for a decrease in long-term health deficiencies (e.g. vascular complications) that these individuals are particularly susceptible to acquiring if no physical activity is incorporated into their lifestyle (Bishop *et al.*, 2009; Bishop, Wadwa, Snell-Bergeon, Nguyen, & Maahs, 2014). Therefore, strategies should be developed for different types of exercise and physical activity to maintain optimal glycaemic control.

3.2.8 MANAGEMENT OF T1D AT SCHOOL

As a great section of an adolescent's day takes place at school, ongoing communication with the school staff is beneficial for ideal T1D treatment and management, preventative and safety measures, as well as optimal academic performance. School personnel should undergo training to assist with T1D care in cases where a school nurse or licensed healthcare provider is not available (Chiang *et al.*, 2014). To provide a safe school environment for adolescents with T1D, school personnel should be trained and well-informed regarding T1D care.

The parents/guardian and healthcare provider should collaborate and submit the necessary information to school personnel to enable a wholesome school experience for the adolescent with T1D. An individualised T1D management plan should be established by the healthcare provider in partnership with the adolescent and family to outline the requirements during school time and relative school events.

According to the ADA (Jackson *et al.*, 2015, p. 1959), the T1D care plan should be submitted to the school to address the adolescent's particular T1D requirements and have instructions regarding the following:

1. "Blood glucose monitoring, including the frequency and circumstances requiring blood glucose checks, and use of continuous glucose monitoring, smartphone and smartwatch applications, or other technology, if applicable.
2. Insulin administration (if necessary) using the student's preferred insulin delivery system, including doses/injection times prescribed for specific blood glucose values and for carbohydrate intake, the storage of insulin, and, when appropriate, physician authorization of parent/guardian adjustments to insulin dosage.
3. Meals and snacks, including food content, amounts, and timing.
4. Symptoms and treatment of hypoglycaemia (low blood glucose), including the administration of glucagon if recommended by the student's health care provider.
5. Symptoms and treatment of hyperglycaemia (high blood glucose), including the administration of insulin if recommended by the student's health care provider.
6. Checking for ketones and appropriate actions to take for abnormal glucose and ketone levels, if requested by the student's health care provider.
7. Participation in physical activity.
8. Emergency evacuation/school lockdown instructions and emergency contacts and plans."

By joining educational and health systems, the adolescent with T1D is ensured the same quality of care within the school setting. Adolescents can fully and safely participate in the school experience if appropriate planning, education and training of school staff have been implemented (Ghosh & Collier, 2012).

During school, the adolescent should be allowed to SMBG, administer insulin doses, have access to snacks/meals, manage and treat hypo- and hyperglycaemia whenever necessary. If hypoglycaemia requires glucagon treatment a trained staff personnel or school nurse should be on-hand to assist.

Table 3.3 below further explains the T1D care tasks for school personnel regarding hypo- and hyperglycaemia.

Table 3.3: T1D CARE TASKS FOR SCHOOL PERSONNEL

1	Diabetes care task	Hypoglycaemia
	Signs	Catecholamine effect (sweating, jitteriness, tachycardia, and palpitations) or neuroglycopenia (behaviour change)
	Treatment	<ul style="list-style-type: none"> • Glucose, wait 15 min, recheck, give food if blood glucose is adequate • Know when and how to give glucagon • Know when to contact parents or emergency medical services • Have all contact information available on emergency plan
	Outcome if not treated	Seizure or coma
2	Diabetes care task	Hyperglycaemia
	Signs	Polyuria, polydipsia (most common), difficulty concentrating, headache, or irritability
	Treatment	<ul style="list-style-type: none"> • Rapid- or short-acting insulin • Dose and frequency should be clearly elucidated on emergency plan to avoid 'insulin stacking' and consequent hypoglycaemia • Insulin dosing technique (syringe/vial, pens, pumps) • Insulin required • Ketone checks and when to call parents • Correction factor calculations and insulin for hyperglycaemia and ketones
	Outcome if not treated	Check for ketones. Follow directions for ketones if positive to avoid ketoacidosis. Possible risk for DKA.

Note. Adapted from Chiang, J. L., Kirkman, M. S., Laffel, L., & Peters, A. (2014). Type 1 diabetes through the life span: A position statement of the American Diabetes Association. *Diabetes Care*, 37(7), 2034-2054.

Most school students that have diabetes are diagnosed with type 1. Proper management of T1D can delay or prevent acute and long-term complications. T1D needs to be monitored 24 hours a day, every day of the week, which includes school hours. "To keep students with T1D safe at school, guarantee long-term health, prevent complications, and ensure full participation in all school activities, proper monitoring of and responding to blood glucose levels must be attended to throughout the school day and during all school-sponsored activities" (Jackson *et al.*, 2015, p. 1962). Collaboration of care between the family, school and healthcare provider is therefore crucial in achieving optimal T1D management.

3.2.9 SPECIAL CONSIDERATIONS FOR T1D MANAGEMENT AT SCHOOL

There are other significant special considerations for T1D management at school, namely (Jackson *et al.*, 2015): self-management; recognition and treatment of hypo- and hyperglycaemia; nutrition and physical activity; field trips and extracurricular activities; attendance/absenteeism; and lastly, academics and standardised testing.

Self-management: Most adolescents can self-manage their T1D except in cases of a diabetes emergency. A school nurse and/or trained staff member may need to provide assistance to the individual when a diabetic emergency arises. Therefore, it is recommended to perform regular SMBG and respond to the glycaemic level as quickly and effectively as possible (American Diabetes Association, 2012). If there is a delay in monitoring and T1D treatment it may result in an emergency and further contribute to acute complications, so intensive management and action is crucial. Educational difficulties caused from classroom absence can also be minimised by avoiding delayed treatment. Therefore, the adolescent should be allowed to perform SMBG and any other T1D required treatment in the classroom or anywhere else on the school premises. However, some adolescents prefer privacy for SMBG and other T1D care tasks and this should also be respected at school

Recognition and Treatment of Hypo- and Hyperglycaemia: As previously mentioned, the school staff and nurse must be aware of the signs and symptoms associated with hypo- and hyperglycaemia (Jackson *et al.*, 2015). In case of a diabetic emergency they should be able to provide immediate treatment; such as glucagon for severe hypoglycaemia and insulin for hyperglycaemia.

Extracurricular activities and school excursions: “Students with diabetes should be able to participate in field trips and extracurricular activities such as before-school breakfast programs, intramural sports, after-school clubs, detention, and school dances where they will have access to their supplies and the school nurse or trained school staff who can provide diabetes care” (Jackson *et al.*, 2015, p. 1962). The school cannot require parental/guardian attendance to care for the adolescent.

Physical activity and Nutrition: The overall dietary requirements of adolescents with T1D must not be different to any other healthy student diet. Though, T1D requires insulin management for food intake which poses a challenge to the adolescent if the school does not provide nutritionally appropriate food options. Thus, the school needs to provide nutritional informational and carbohydrate content for school meals to the adolescent in advance to assist with optimal T1D treatment (Dhada *et al.*, 2014). Adolescents should also be able to participate in all school related sports and physical education classes. The responsibility of adjusting insulin doses and food intake during physical activity is on the adolescent.

Although, school assistance may be needed if a diabetic emergency arises (Cartaya & Laffel, 2017). To treat hypoglycaemia, a quick-acting carbohydrate snack should be made available.

Attendance/absenteeism: Adolescents with T1D should attend school on a regular basis. It is vital that school absences take place only for illnesses or T1D visits. An effort should be made to arrange appointments after school hours, if possible. If the adolescent is unable to schedule appointments outside of school time or had to take a sick day to manage illness then the school should be understanding and supportive (Hoffman & Osipoff, 2015; Perfect & Jaramillo, 2012).

Academics and standardised testing: Special concessions for tests and exams should be allowed for adolescents with T1D, if requested. The adolescent may request access to SMBG and insulin, as well as food/snacks during the time of academic assessment (Lansing *et al.*, 2017). Other requests may also be permitted through the guidance and supervision of a healthcare professional.

3.3 COMPLICATIONS OF T1D

Severe morbidity and mortality can occur from T1D complications. Adolescents with T1D are at increased risk of acquiring various acute and long-term problems. Furthermore, adolescents that regularly have high glycaemic levels can end up with severe diseases that affect the following areas in the body: nerves, eyes, kidneys, heart and blood vessels (Ogle *et al.*, 2013). There is also an increased risk for developing infections for this population. By maintaining optimal glycaemic control T1D problems can be delayed and even prevented completely (International Diabetes Federation, 2015; World Health Organisation, 2016). Through regular check-ups and T1D appointments many complications can be detected early and appropriate curative measures can be implemented to prevent further aggravation.

According to Ogle *et al.* (2013, p. 43), complications for youth may include:

- “Underinsulinisation leading to growth failure and pubertal delay,
- Retinopathy resulting in visual loss and blindness,
- Diabetic nephropathy causing hypertension and renal failure,
- Neuropathy causing pain, paraesthesia, muscle weakness and autonomic dysfunction,
- Macrovascular disease causing cardiac disease, stroke and peripheral vascular disease with limb loss.

Screening for subclinical complications, with early treatment can delay progression to clinical complications. Other known risk factors are high blood pressure, smoking and hyperlipidaemia.”

Short-term complications, according to Litmanovitch, Geva and Rachmiel (2015), are called *severe hypoglycaemia*. It is defined as a situation where the adolescent is experiencing severe low blood glucose levels and requires immediate assistance and care. A blood glucose level below 3.5mmol/L is defined as a low and as a result the brain is affected and operates at a lower cognitive level. Hypoglycaemia can cause unconsciousness (with or without seizures) in every one out of ten adolescents (Pedersen-Bjergaard, 2009). An adolescent with T1D that does not have a correct balance of food, physical activity and insulin dosage may temporarily suffer from a mild, moderate or severe hypoglycaemic reaction (Litmanovitch, Geva, & Rachmiel, 2015). Therefore it is pertinent to correctly manage insulin dosage and food intake when entering any physical activity.

Another complication is *hyperglycaemia*. If the body sustains poor glycaemic control which is defined by high levels of HbA1c it can be referred to as chronic hyperglycaemia. Insulin is thus needed so that the blood glucose can be absorbed into the body's cells and be used for energy (Arbelaez, Semenkovich, & Hershey, 2013). An additional complication in T1D is diabetic ketoacidosis (DKA). DKA can occur as a result from the body not producing enough insulin and it often develops over a period of time. In more extreme cases it can also develop over a short period of time if the person is ill (i.e.) excessive vomiting. Primary symptoms of DKA can surface in the following ways: increased urination frequency, thirst, high glycaemic levels and/or high ketone levels (by-products from the breakdown of fat) in the urine (Jefferies *et al.*, 2015). Long-term complications in relation to T1D are for example strokes, cardiovascular diseases, renal deficiency and chronic wounds (Atkinson *et al.*, 2014). High HbA1c values have a direct influence on long-term complications.

According to the Centre for Diabetes and Endocrinology in South Africa (www.cdidiabetes.co.za), the suggestion for check-ups regarding long-term problems are as follows: annual or every six month check-ups with a healthcare professional (endocrinologist/physician), certified diabetes educator, dietician, social worker, podiatrist (foot-care physician), ophthalmologist (eye-care physician), and psychologist (if necessary). This will help to maximise quality of life and ensure the adolescent's well-being. It is important to note that the T1D diabetes team is not accountable for the enforcement of these check-ups; the adolescent and his/her family is responsible for attending these appointments to ensure effective management.

3.3.1 NEURO-BEHAVIOURAL COMPLICATIONS

T1D is known to affect cognitive function and structure of the brain. This notion was first expressed by Miles and Root (1922), and since then the idea has interested researchers, particularly with regard to its influence on well-being in young children and adolescents.

It is an understood fact that T1D is connected to neuro-cognitive deficiencies; although there are a few disputes with regard to which cognitive skills are affected according to their origin of disease onset, as well as symptoms thereafter. Understanding the entire effect of T1D on glycaemic control and the brain can prove to be helpful in maintaining well-being in adolescents with this disease (Seaquist, 2010). There is key brain matter and cognitive function development that takes place during childhood and adolescence (Biessels, Deary, & Ryan, 2008; Colver & Longwell, 2013). During this phase of development it is important to remember that it is a challenging period of management as it encompasses comprehensive and difficult self-care guidelines of this chronic disease along with age group growth processes (Chiang *et al.*, 2014).

3.3.1.1 Behavioural Complications

According to Colver and Longwell (2013), there is a growing tendency for risk-taking and rebellious behaviour amongst adolescents who could require continued support regarding their healthcare. Furthermore, this is prevalent for adolescents with T1D as it is a life-threatening period for the acquirement of sustainable health practices. Having a balanced, wholesome life; and better-quality everyday routine (inclusive of school setting) are all components of resilience that will strengthen the adolescent's control over his/her environment (Perfect, 2014; Perfect & Jaramillo, 2012). Therefore, having controlled glycaemic levels is interconnected with life quality and resilience.

Perfect and Jaramillo (2012) further explain that both of these factors are also associated with improved schooling in adolescents with T1D. An American study by Palladino *et al.* (2013) was conducted to see what the life satisfaction levels were between a control group and that of adolescents with T1D. Findings showed that adolescents with T1D had lower levels of life satisfaction than the control group due to factors such as diabetes self-care, the challenge of optimal blood glucose control and T1D-related health outcomes.

Life satisfaction and quality of life are often discussed interchangeably and as a result the adolescent's well-being is associated with maintaining compliance of glycaemic control and the parameters surrounding a lower HbA1c level. Bad habits, such as smoking and drinking, have been noted amongst adolescents with T1D. These poor health behaviours can be more detrimental to these adolescents in comparison to their healthy peers (Palladino *et al.*, 2013; Wagner, Heapy, James, & Abbott, 2006). This creates an increased risk for life dissatisfaction for T1D.

3.3.1.2 School Complications

In many school environments teachers often do not have the adequate knowledge surrounding T1D. This can lead to confusing situations pertaining to the disease which can have dire consequences to the adolescent, especially in physical education. These implications may result in teachers excluding these adolescents from taking part in activities when they can actually participate. The opposite may even occur where the adolescent with T1D will use their disease to avoid taking part in activities (MacMillan, Kirk, Mutrie, Moola, & Robertson, 2014). This can lead to isolation amongst adolescents with T1D and therefore it is necessary to incorporate correct involvement techniques in the school environment to ensure their overall well-being.

Studies have shown that teacher and peer victimisation towards the adolescent with T1D can lead to anxiety, rejection, loneliness and depression (Nabors, McGrady, & Kichler, 2010; Storch *et al.*, 2006). According to Peters, Storch, Geffken, Heiderken and Silverstein (2008), such a negative schooling environment will ultimately lead to poor emotional and social adjustment for the adolescent. Although many youth are at risk for being victimised, children and adolescents with T1D may have increased vulnerability due to self-care behaviours and medical differences from their peers.

Lower academic achievement can be a result from school absenteeism and/or missing class time due to checking glucose levels. Kucera and Sullivan (2011) explain that due to disruptions of self-care behaviours and non-compliance learners who have T1D often end up missing class time which affects their learning environment. However, it was proven that adolescents with good compliance achieve better marks in school than those with badly managed glycaemic control (Demirel, Tepe, Esen, Buber, & Boztepe, 2013; Jackson *et al.*, 2015; Patiño-Fernández *et al.*, 2010; Wagner *et al.*, 2006). The exact process that provides this information is yet to be explained but glycaemic control directly has an effect on learning and acquisition of knowledge.

Furthermore, sleeping patterns of these individuals should also be considered. Being absent from school and low academic grades has been connected to poor T1D management in association with lack of sleep (Perfect, 2014). School performance is affected by the aforementioned and thus it is important to assess whether the adolescent is receiving enough sleep and managing his/her diabetes accordingly in order to have a well-balanced environment at school.

3.3.1.3 Sleeping Patterns

Everyone needs sleep in order to function (Perfect, 2014). The exact number of hours needed in sleep varies from person to person. Several reports have been conducted regarding the connections between sleeping patterns and T1D. Adolescents with T1D who suffer from sleep deprivation have shown reduced levels of insulin sensitivity (Donga *et al.*, 2010). Intensive insulin therapy is a prerequisite for T1D, thus the importance of insulin sensitivity is relative as it will assist in optimal functioning of the individual with this chronic disease (Turner, Queen, Butner, Wiebe, & Berg, 2016). According to Caruso *et al.* (2014), adolescents with T1D wake up more times during sleep due to glucose fluctuations.

Intermittent sleep can result in lower cognitive functioning as the brain and body do not rest equally. Furthermore, these individuals do not sleep as deeply as the control group (Perfect, 2014; Perfect & Jaramillo, 2012). In accordance with this it was found by Palladino *et al.* (2013) that adolescent males with T1D have increased sleep disturbances in comparison to females and the control group. Adolescents with T1D have increased and more recurrent sleep apnea (irregular breathing during sleep), frequent sleep awakenings and fatigue during the day. They also have decreased sleep time in total in comparison to the control group (Estrada, Danielson, Drum, & Lipton, 2012). This leads to them having a reduced amount of hours spent in deep, restorative sleep. Sleep-wake cycles were connected with the effect that T1D may have on glycaemic levels and management (Barone & Menna-Barreto, 2011). Having too little sleep and a high calorie diet can also negatively affect the glycaemic levels during sleep; which may be the cause for the sleep-wake cycle. Therefore, adolescents with T1D who have high glucose and HbA1C levels often experience less time in deep sleep and also face recurrent hyperglycaemia.

Parents have reported that adolescents who have less hours of deep sleep present signs of fatigue, depressive symptoms, psycho-behavioural problems, decreased school performance and overall low quality of life (Perfect *et al.*, 2012).

Thus, an improvement in the type of sleeping pattern can result in having a healthier lifestyle which will encompass better metabolic control. To improve their overall well-being it is prevalent that the appropriate analysis and management of sleeping conditions should take place.

3.3.1.4 Mood

During adolescence, school's educational and societal strains can lead to depressive symptoms for those who find it challenging. According to Lustman *et al.* (2000), adolescents with T1D who fall into this category may also show poorer glycaemic control and have increased risk for complications as a result.

A study done on school-related outcomes revealed that adolescents with this disease showed more mental health issues in comparison to other peers (Perfect & Jaramillo, 2012). Symptoms included higher levels of depression and anxiety when compared to the control group, although the variances have seemed to decrease in current research (Perfect & Jaramillo, 2012; Reynolds & Helgeson, 2011). Hanna, Weaver, Stump, Fortenberry and DiMeglio (2014) reported that adolescents with T1D show depressive symptoms in association with diabetes-related weight and diet.

Studies show that with aging, increased duration of disease, insulin administered through injections, and family conflict; depressive signs were discovered to be a mitigating factor for compliance and glycaemic control amongst these adolescents (Hanna, Weaver, Stump, Fortenberry, & DiMeglio, 2014; Hilliard *et al.*, 2013). Further research found that non-compliance and more long-term complications are associated with depression and anxiety as a result from the negative impact these symptoms have on the ability to follow the correct diabetes treatment (Hackworth *et al.*, 2013; Hudson, Bundy, Coventry, & Dickens, 2014; Reynolds & Helgeson, 2011).

The transition from adolescence (15-18 years) to emerging adulthood (18-25 years) is of importance in this study as it happens before adult responsibilities such as work, marriage and parenthood (Arnett, 2000, 2014b). Adolescence is regarded as an increased risk phase in terms of psychological distress and health behaviours (Arnett, 2014b). An American study reported that efficient and supportive parenting was connected with lower depressed signs in adolescence and in the beginning stages of adulthood (Helgeson *et al.*, 2014). Furthermore, the results of better support from the family can improve glycaemic control and emotional well-being (Levin, Kichler, & Polfuss, 2013).

Positive family dynamics and mood have a significant role to play in compliance, which can result in effective diabetes care and prevention of long-term complications. Addressing family relations during the onset of T1D diagnosis and health education can assist with the individual's sustainable well-being.

3.3.1.5 Eating Disorders

As aforementioned, family relationships have an impact on glycaemic levels for adolescents with T1D. It is essential to look at the family's daily food intake and organisation of gender-specific maturity factors. Findings show that adolescent females with this disease tend to develop diet problems more often than their healthy peers (Eiser *et al.*, 2013; Engström *et al.*, 1999); poor glycaemic control is also linked to these eating disorders (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000).

According to Eiser *et al.* (2013), adolescents with T1D may be more susceptible than the general population to develop eating problems. This is due to the following: controlled diet and counting the intake of carbohydrates, threats of weight gain from insulin and related body discontent (Eiser *et al.*, 2013; Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997). Thus, the impact of the individual's eating behaviour can cause negative effects for their health and well-being.

3.3.2 COGNITIVE COMPLICATIONS

In previous sections the following areas have been reviewed: physiological, psychological and academic. Exploring the cognitive complications that may explain some of these factors are important as it will provide further understanding of this disease and how to manage overall well-being. For the purpose of this study cognitive skills encompass learning abilities, such as memory, attention and thinking.

Various research has shown that cognitive problems exist for individuals with T1D, predominantly in child and adolescent phases (Battelino *et al.*, 2011; Chiang *et al.*, 2014; Ghetti, Lee, Sims, DeMaster, & Glaser, 2010; Korczak, Pereira, Koulajian, Matejcek, & Giacca, 2011; Royle, Barnard, Thomas, Noyes, & Waugh, 2010). Biessels and Reijmer (2014) reported that adults have deficits in cognitive functioning. The areas that are mostly affected are general mental ability (influences the performance on cognitive skills), psychomotor reaction time (physical movement related to cognitive processing) and cognitive flexibility (ability to handle different situations in various ways – especially adapting to new, complex scenarios).

Rewers *et al.* (2014) states that youth with T1D acquired lower IQ scores in comparison to their control group; evident differences were seen from those with early-age diagnosis (less than 7 years). Additionally, research indicates complications in cognitive flexibility, problem-solving skills, verbal memory (memory for words and verbal items) and response time for children with T1D (Arbelaez *et al.*, 2013; Biessels *et al.*, 2008; Hoffman & Osipoff, 2015; Kucera & Sullivan, 2011; Litmanovitch *et al.*, 2015). In comparison to their control group these complications have been found to be reasonably minor and unpredictable with marginal importance.

The development of these complications, in the absence of any small blood vessel impediments, is generally present yet the progression takes place slowly (Biessels & Reijmer, 2014; Hoffman & Osipoff, 2015). Within the first two years of diagnosis, cognitive impairments may arise (Cato *et al.*, 2014); afterwards more areas may become affected. After six years of T1D diagnosis the following areas showed a decline than those of healthy peers: attention, response time, long-term memory, self-regulation, intelligence measures and mental control; harsher impacts were found in response time, attention and executive function for individuals diagnosed under the age of four years (Northam *et al.*, 2001).

Adolescents with T1D, twelve years after diagnosis, showed a decline in short-term memory performance, in comparison to control group (Lin, Northam, Werther, & Cameron, 2015). Primary diagnosis showed deficiencies in learning, mental control and attention. Other studies have shown that this can be in relation to both hypoglycaemic and hyperglycaemic events (Cato *et al.*, 2014; Marzelli *et al.*, 2014). According to Lin *et al.* (2015), hypoglycaemic events cause dysfunctional memory and learning, and impaired cognitive efficiency, such as slow processing speed; hyperglycaemia events cause problems with short-term memory (working memory). Although research has shown a trend in these complications, results are not consistent in all areas. For example another study was done on pre-schoolers; results indicated that children with T1D had the same cognitive functions as their healthy peers (Patiño-Fernández *et al.*, 2010). However, individuals who had poor glycaemic control revealed impairments for fine motor speed, receptive language scores and cognitive skills.

During youth, specifically childhood, poor glycaemic control has a negative impact on verbal comprehension scores; having a history of hypoglycaemic events is associated with poorer skills in processing speed, short-term memory, perceptual reasoning and IQ scores (Aye *et al.*, 2011).

It is relevant to note the history of the adolescent's onset and management for this disease because it can provide further understanding to their cognitive functions (Lin, Northam, Werther, & Cameron, 2015). Therefore, the management and control of glycaemic levels has a direct impact on cognitive abilities that may affect executive functioning, learning, thinking and memory.

3.3.2.1 Learning and Memory

The effect of T1D on memory and learning was first discovered by Miles and Root (1922). The study revealed that individuals with T1D said they were experiencing loss of memory and problems with attention. Studies in later years reported that early diagnosis of T1D was related to psychomotor skills, verbal and non-verbal intelligence, attention, memory skills, verbal ability and visual learning (Aye *et al.*, 2012; Lin *et al.*, 2015). According to Cato *et al.* (2014), chronic hyperglycaemia, in adolescents, was linked to deficiencies in learning and memory.

Research findings have shown that young males with T1D present lower verbal memory in connection with poorly managed glycaemic levels; however, these studies could not render any major gender differences regarding neurocognitive abilities (Aye *et al.*, 2011; Dahlquist, Källén, & Group, 2007; McCrimmon, Ryan, & Frier, 2012).

It is significant to note that memory, specifically short-term memory, is impacted by various health-risk factors, such as extreme glycaemic fluctuations (Jacobson *et al.*, 2011). However, it was not proven that poor working memory, by itself, can be detrimental in causing ongoing harm in T1D (Blasetti *et al.*, 2011; Helgeson *et al.*, 2014). Although, being diagnosis at a young age could be an added threat in accordance with non-compliance.

3.3.2.2 Executive Functions

The adolescent who has early onset T1D may have deficits in executive functioning, which "includes the skills of impulse control, emotional control, flexible thinking, self-monitoring, working memory, planning and prioritising, organisation and task initiation" (Colver & Longwell, 2013, p. 904). The purpose of executive functions is significant for the compliance of T1D. There are many tasks that adolescents with T1D must manage every day.

These tasks involve administering insulin at regular intervals, checking blood glucose levels and monitoring dietary needs (McNally *et al.*, 2010; Miller *et al.*, 2013). Therefore, during the period where self-management is adapted and sustained, adolescents with T1D require executive functioning to learn and apply all necessary tasks.

Further research has proven that there is a strong relation that exists between self-care compliance and executive functions for adolescents with T1D (Miller *et al.*, 2013). Cato *et al.* (2014) noticed a trend in younger individuals with T1D; hyperglycaemia was associated with poor executive functioning. As a result this trend will become worse when the individual reaches adolescence or in cases where the diagnosis of the disease is longer.

Moreover, several studies have shown that T1D is also associated with impaired decision-making as well as cognitive complications, comorbid depression and unawareness of hypoglycaemia (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Rustad *et al.*, 2013; Ryan, Williams, Finegold, & Orchard, 1993). Rustad *et al.* (2013) explains that neuroimaging studies show a possible relation to white-matter microstructural impairments in adolescents with T1D. This cognitive detriment may influence glycaemic control and brain alterations negatively.

3.4 FAMILY CENTRED CARE FOR T1D

According to the Committee on Hospital Care and Institute for Patient- and Family-Centred Care in Australia (2012), “patient- and family centred care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families” (p. 2011). Garner *et al.* (2012) explained that these benefits include: effective understanding of family strength and care capacity, increased quality of life to adolescent and family with care received, and enhanced communication with the healthcare providers. According to Palladino and Helgeson (2013), in an *adolescent-centred care approach*, the perspective of the adolescent is enhanced when both the family and the adolescent can view the situation from their perspective.

3.4.1 FAMILIES AND T1D

According to Eichner *et al.* (2012), a family is defined as two or more people who are in relation through biological, legal and/or emotional terms. As previously stated, T1D is a chronic long-term disease. A chronic disease, such as T1D, requires a lifetime of regular treatment (Petersson *et al.*, 2016).

The age and developmental status of the adolescent largely affects the impact and diagnosis which the chronic disease has on the family (Ingerski, Anderson, Dolan, & Hood, 2010). When a child/adolescent is diagnosed with T1D it is a stressful event for every family member (Sparud-Lundin, Hallström, & Erlandsson, 2013). T1D has shown to change the lifestyle and relationships between family members as a result of the acclimatisation to the disease (Jerrett, 1994; Kyngäs, Hentinen, & Barlow, 1998; Lowes & Lyne, 1999; Nehring *et al.*, 2015; Nuutila & Salanterä, 2006). This may affect the relationship between the parents/guardians and other children in the family negatively (Nehring *et al.*, 2015). Upon and from diagnosis the T1D team in charge of treatment and the family should form a long-lasting relationship built on trust and mutual acceptance.

The family should be addressed in an appropriate and sensitive manner but a friendly rapport can also be established to enhance the relationship (Cheater, Smith, & Bekker, 2015; Fisher, 2001; Hummelinck & Pollock, 2006). Parents/Guardians of the adolescent with T1D are generally more capable and self-reliant than the clinical team assume; this can sometimes result in conflict if not handled properly. In turn, families are not always mindful of the assistance they can receive from the T1D team during or after hospitalisation (Nehring *et al.*, 2015). Parents/Guardians find the information about their adolescent's disease overwhelming and if contradictory statements are found then there is a decrease in confidence towards the healthcare provider which can impair management and treatment of T1D in the long term.

As mentioned, family and T1D healthcare professionals both have the responsibility of ensuring that the adolescent with T1D will learn and adapt to this disease, maintaining a sustainable and wholesome life. Smith *et al.* (2015) has noted management of diabetes requires steady supervision throughout the individual's adolescent phase. A South African study done by Kalweit *et al.* (2015) revealed that adolescents from single-parent homes had poor HbA1c levels and decreased quality of life, irrespective of management strategies and healthcare facility. The relationship between glycaemic control and parental marital status reinforces the significance of family support for adolescents with T1D and their management thereof.

Thus, there are psychological benefits to understanding the management processes and support structures involved with this disease; such as empowerment, increased levels of self-worth and confidence for the adolescent.

3.4.2 FAMILY EXPERIENCES OF CARING FOR AN ADOLESCENT WITH T1D

The onset of T1D also affects the parents and results in sensitive emotions. The parent/guardian often expresses feelings of grief and blame (Atkinson *et al.*, 2014). In some cases the parent/guardian cannot accept the child/adolescent's diagnosis, even after a long-term period (Palladino & Helgeson, 2013). According to Smith *et al.* (2015), parents/guardians have described the process as being an emotional rollercoaster with periods of bluntness and upset.

The reactions between mothers and fathers have been recorded to show differences. Fathers felt that mothers prevent them from taking full supervision and responsibility for their adolescent's T1D care. Mothers, on the other hand, experience disappointment as they interpret an absence of effort from the fathers regarding T1D management. Fathers often reflect that more time is needed to accept the disease and adapt to their new lifestyle (Sparud-Lundin *et al.*, 2013). Azar and Solomon (2001) discovered that mothers use a more orientated and planned approach, while fathers adopt a more distancing approach when dealing with their child's disease.

According to Guthrie, Bartsocas, Jarosz-Chabot, and Konstantinova (2003), most of the support and care comes from the mothers; fathers should therefore become more involved. A father should support the mother; express their acceptance and understanding about their adolescent's disease. In some cultural traditions, the father struggles to show care because T1D may be seen as a flaw in their child (Sparud-Lundin *et al.*, 2013). In this regard, time and education through society will assist in changing these traditional beliefs.

3.5 HEALTH-RELATED QUALITY OF LIFE (HRQOL) FOR T1D

A definition of *health* given by The World Health Organization (WHO, 1989) can be described as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (p. 1). Furthermore, WHO explains that a person's subjective perspective of life is based on their cultural and value systems in relation to their expectations and set goals (WHOQOL Group, 1995; World Health Organisation, 1989). Spieth and Harris (1996) elaborated that the different categories (social, mental and physical) mentioned in the definition of health have built the foundation for the construct: health-related quality of life (HRQOL).

This construct branches into four significant areas, namely: psychological abilities; functional level; disease-state and bodily signs; and lastly, social skills. Since then more research has incorporated these definitions when referring to HRQOL.

It is a broader term used to relate to aspects in life and is suitable as it includes areas that are typically not connected as health, such as income, freedom and environmental factors (Drotar, 2014). In paediatrics it is often the adolescent's parents/guardian that gives feedback of their adolescent's perspective of HRQOL outcomes from treatment. In the case of adolescents this may still be prevalent but it depends on age and cognitive development.

Therefore, it remains significant to measure the viewpoints of both adolescent and parent/guardian because they will have differing views on risk factors, satisfaction of care and application of healthcare (Bagshaw *et al.*, 2015; Drotar, 2014; Wilson & Cleary, 1995). Drotar (2014) suggests that in order to fully understand HRQOL it is important to include assessments at various intervals by implementing regulated questionnaires for the purpose of routine healthcare. According to De Wit *et al.* (2010), this is prevalent when looking at T1D care as using standardised questionnaires can help assist in uncovering information relating to specific areas.

3.5.1 SELF-CARE OF T1D

According to Hanna *et al.* (2013), "emerging adults with type 1 diabetes are assuming primary diabetes care responsibility (Wolpert *et al.*, 2009), graduating from high school (Aseltine & Gore, 1993) and leaving their parents' home (Furstenberg *et al.*, 2005). Living independently of parents occurs for up to 56% of emerging adults in general (Goldscheider, 1997; Arnett, 2003) and a similar portion (52%) of those with diabetes (Tebbi *et al.*, 1990). When considering that many youth move in and out of parental homes (Arnett, 2000), even more (90%) of emerging adults live independently of parents for at least a 4-month period of time (de Marco & Berzin, 2008)" (p. 62). Adolescents with T1D, who have administered effective adherence, concerning their disease, have advanced over time and acquired better control, flexibility and HRQOL (Stahl-Pehe *et al.*, 2017). These adolescents have accepted diabetes self-care responsibility which will allow them to lead an independent and healthy lifestyle.

3.5.2 SATISFACTION WITH CARE

In today's society, healthcare services are seen as complex and technical. The adolescent and family participation as well as satisfaction with care are important. Evidence supports that there is more satisfaction with healthcare and improved effects on treatment if the quality of care and interventions are successful (American Diabetes Association, 2017a, 2017b; Stahl-Pehe *et al.*, 2017; Tonoli *et al.*, 2012). Therefore, it is important to discuss factors associated with satisfaction of T1D care.

The needs of adolescents differ depending on the specific context and families can sometimes find it difficult to understand their needs. As a result more effective health outcomes will arise from such environments (Ali *et al.*, 2013; Spaic *et al.*, 2013). Various factors such as staff security, receiving support and involvement in T1D care can have an effect on family satisfaction. Parents/Guardians who feel safe and well-informed are more susceptible to share information to their adolescent to ensure their security (Varni & Eiser, 2013). Regarding earlier research (Auslander, Thompson, Dreitzer, & Santiago, 1997; Lessing, Swift, Metcalfe, & Baum, 1992) and more current literature, (Hays *et al.*, 2006; Tiberg, Steen Carlsson, Carlsson, & Hallström, 2012) both highlight that parents/guardian had satisfaction with adolescent's T1D care when effective healthcare was provided by the T1D team.

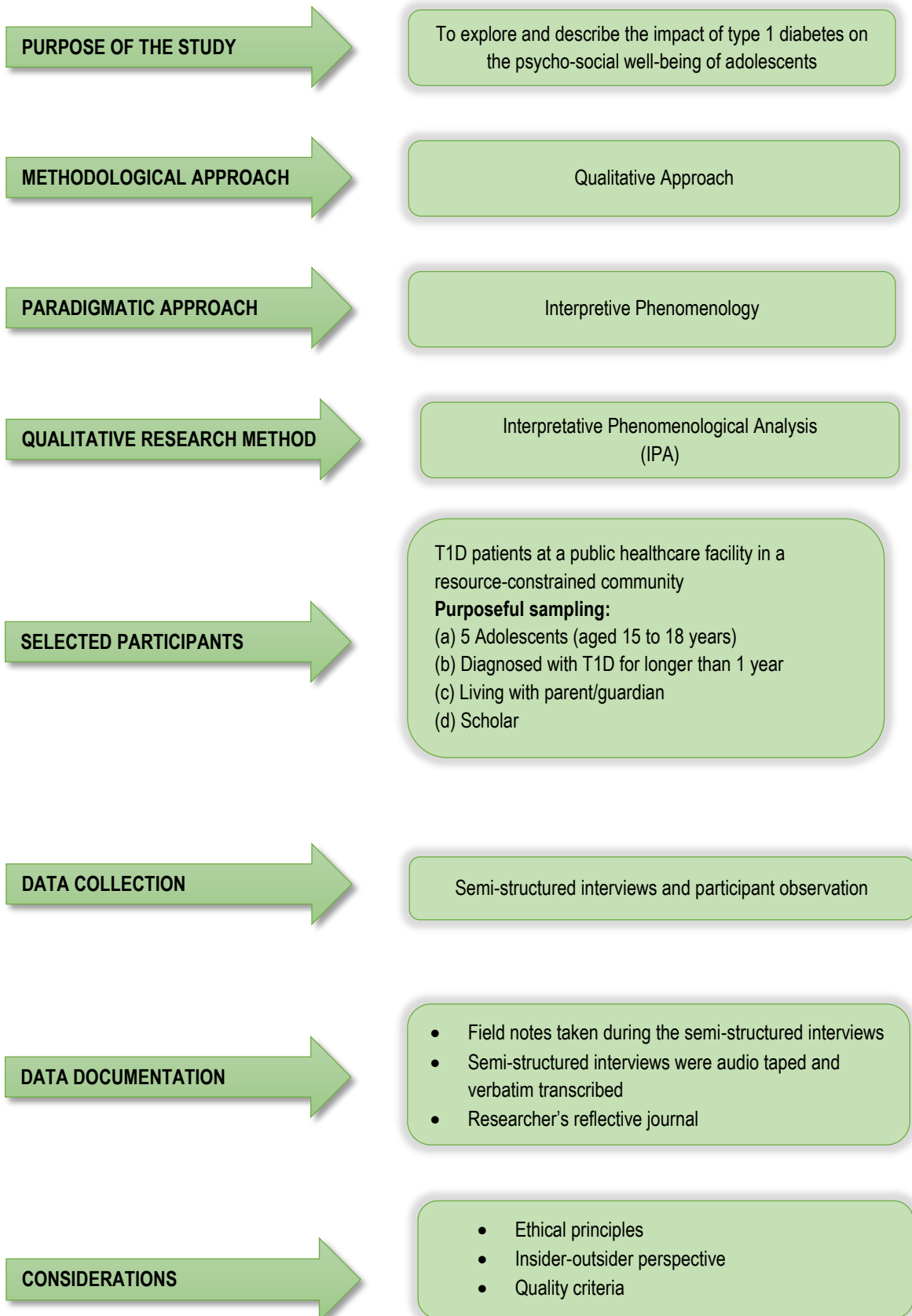
Since then there have been few studies conducted to follow newly diagnosed youth with T1D and their families longitudinally in relation to their satisfaction of care and HRQOL. Information pertaining to procedures on how T1D teams function with the adolescent and family in context-specific areas are rarely done (Kalweit *et al.*, 2015; Stahl-Pehe *et al.*, 2017). This creates a necessary area to uncover the impact of T1D on the psycho-social well-being of adolescents in South Africa. Such research is beneficial as it can be used to improve problem areas and enhance their quality of life.

3.6 SUMMARY OF CHAPTER 3

The theoretical frameworks which governed the research study were implemented throughout as the biological, psychological and social elements surrounding T1D and the adolescent were considered. This chapter allowed the researcher to discuss the management and complications of T1D. Thereafter, family centred care of T1D and health-related quality of life for T1D was discussed.

Chapter 2 and 3 pivoted on placing existing literature within the context of this study; exploring all facets in a systematic process from which they exist and interconnect, highlighting the importance of understanding it from the adolescent's viewpoint. Thus, the various factors surrounding the impact of T1D on the psycho-social well-being of adolescents were discussed and the existing literature relating to these factors were explored.

4. CHAPTER 4: RESEARCH DESIGN AND METHODOLOGY



4.1 INTRODUCTION

In Chapter 4 the selected paradigmatic perspective and research design, as well as the research methodology, data analysis and interpretation procedures that were employed to conduct the study will be discussed. The chapter will conclude with a discussion of the ethical techniques and quality criteria that were followed in conducting this study.

4.2 PURPOSE OF THE STUDY

This study is, by nature, descriptive and explorative. The researcher wanted to explore and describe adolescents' experiences of the impact of T1D on their psycho-social well-being, a relatively new subject of study from a South African perspective. By implementing a descriptive method of study the in-depth description of the experiences of the group of adolescents who participated in this study could be highlighted.

The study also had an explorative purpose, as the researcher intended to uncover new knowledge, leading to innovative insights and understanding into the research topic. However, a limitation surrounding exploratory studies is that they do not always provide adequate answers to research questions, although they can guide answers and provide suggestions to research methods that may constitute fixed answers (Babbie, 2013). A possible reason as to why exploratory studies do not yield definite answers is a result from representativeness, which entails that participants in this exploratory research may not be compared to the larger population (Babbie, 2015). However, the purpose of this study was not to generalise the findings to the global society (Seale, 1999).

According to Savin-Baden and Major (2013), research studies that are descriptive and exploratory add to the literature by creating new descriptions of multi-faceted conditions and provide suggestions and guidelines for future research. The exploratory and descriptive purposes of this study were to obtain new insights with regard to the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community. Therefore, by gaining rich and thick descriptions of such experiences, it may contribute to both the literature of T1D and factors surrounding the psycho-social well-being of adolescents.

4.3 RATIONALE FOR A QUALITATIVE RESEARCH DESIGN

From the literature review, it is apparent that research conducted on the topic of adolescents with T1D has predominantly used science methods and techniques that place prominence on objective reality.

In 2017, the American Diabetes Association released a new position statement on psycho-social care in the treatment of T1D. The goal now is to address psycho-social issues in all aspects of care, namely: “self-management, mental health, communication, complications, comorbidities, and life-stage considerations” (ADA, 2017a, p. S109). This further highlights the need to understand the individual’s psycho-social well-being with regards to their chronic disease to ensure optimal care. Adolescence is a major transitional phase which incorporates distinctively different healthcare and emotional needs from younger children and older adults (Baumrind, 1991; Louw & Louw, 2014). It is important to recognise that chronic diseases, like T1D, may potentially inhibit quality of life and well-being if their psycho-social and physiological development is not taken into account.

Consequently, the notion of understanding is not solely based on the experiences of the participants, as they have not been consulted or involved in the selected data used to interpret their experiences. Rather, the *objective*, as perceived by the researcher’s point of view, is imposed on the participants. Qualitative research implies a process of inquiry that is based on the collaborative input between researcher and participants to construct a meaningful understanding of the participants’ lived experiences (Yin, 2015). Natural science methods have recognised potential in contributing to studies relating to aspects of human behaviour. However, it is considered inappropriate for studies concerned with in-depth understanding of human experiences to use these methods, due to the nature being descriptive and exploratory.

This research study aimed to obtain an in-depth understanding of a complex aspect of human experience by implementing a suitable qualitative research design. According to Willig (2013), qualitative research approaches, *phenomenology* in particular, allows the researcher to cross the threshold and explore the core of the participant’s lived experience of a specific phenomenon. Interpretative phenomenological analysis (IPA) is one such method and, in this study, was applied to explore the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community.

4.4 QUALITATIVE RESEARCH

Qualitative research is an inquiry-based process that encompasses certain common features (Creswell, 2013a, 2013b), such as: a holistic approach, a focus on human experiences, sustained contact with individuals in their natural settings, high levels of researcher involvement and the creation of descriptive/narrative data. The goal of qualitative research is to explore and understand a particular phenomenon by interpreting the experiences of the participants within it.

Research, according to the qualitative approach, strives to answer questions through the process of examining various social settings and the individuals who inhabit those settings (Denzin & Lincoln, 2011; Patton, 2005). Furthermore, it explores the essence of how people construct and give meaning to their lives, as well as exploring how people comprehend and learn about themselves and others. The primary aim of qualitative research is to obtain in-depth descriptions and understandings of situations; also to understand social actions in context-specific circumstances (Garner & Scott, 2013). Thus, qualitative research views the world through the participants' perspective in the research study and the qualitative researcher interprets and makes meaning from the experiences of the participants' viewpoints.

The researcher chose to adopt a qualitative approach, to understand the subjective meanings and personal experiences of the adolescents with T1D in a resource-constrained community. The study is regarded as descriptive, which means the qualitative research focused on descriptive detailed information about the interpreted social worlds. The descriptive detail enriched the researcher's understanding of the experiences of the adolescents with T1D who partook in this study (Denzin & Lincoln, 2000, 2011; Savin-Baden & Major, 2013). As a qualitative researcher, the viewpoints of the participants and what they experience as being important and influential – provided the point of orientation for this research study. Additionally, the researcher also sought to understand the participants' behaviour, as well as their morals and beliefs (Lyons & Coyle, 2016); to gauge a genuine understanding of their worldly viewpoints.

Lyons and Coyle (2016) offer a description of qualitative research as an investigative process of understanding, using certain distinct techniques and/or traditions of inquiry to explore human/social events. In qualitative studies, various dimensions of an issue are analysed, as displayed in all its complexity. Often, this is achieved by implementing a specific theoretical lens; in this study, the selected qualitative method is informed by phenomenological principles.

Considering the aforementioned, it appears that an interpretive frame of reference should be discussed. Terre Blanche and Durrheim (2006) elaborate on this by intimating that within the interpretive approach, subjective human experiences are authentic and should be seen as such. In philosophical terms, this consideration of subjective experiences then suggests the *ontological* view of this study.

Further, the intended discernment of human experience forms the *epistemological* paradigm of the research. Therefore, Terre Blanche and Durrheim (2006) stated that a qualitative methodology is best equipped to carry out these incumbencies. Any qualitative investigation typifies the collaboration between the participant's report and the researcher's interpretative methodological representation. In IPA, the methodological schema is both phenomenological and interpretative (Smith, 1996a, 1996b, 2015), which advocates the implementation of an interpretative framework within the current investigation.

Bryman (2015) indicates that a significant feature of qualitative research is to acknowledge that people have the ability to ascribe meaning to their environments and experiences; qualitative researchers propose to understand experiences from another's perspective, through personal interaction. The traditional concern of phenomenology is placed on the subjective human's experience to explore cognition. In social science research, phenomenology is one qualitative approach (Lyons & Coyle, 2016), which has clear ties within the field of psychology. The approach focuses on specific themes; such as openness, empathy and enigmatic life; rather than a problem-solving method (Giorgi & Giorgi, 2008). This focal point proves well the epistemological connection with phenomenology.

As there are limited studies that explore the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community in the literature, a phenomenological approach, using IPA as a method, best lends itself to explore this particular issue.

4.5 PHENOMENOLOGY: THEORY AND METHOD

According to Creswell (2013a; 2013b), a paradigm is a platform of beliefs and interconnected assumptions concerned with the social world, which stipulates a philosophical and conceptual framework which directs the structured study of that realm. Furthermore, paradigms serve as the lens (or structured principles) through which reality is interpreted. The selected paradigm guides the researcher in philosophical assumptions concerning the research and in the choice of tools, implements and approaches to incorporate in the research study (Marshall & Rossman, 2014; Maxwell, 2012; Merriam & Tisdell, 2015). The interpretive phenomenological approach is the paradigm that informed this qualitative research and shaped the practice of this research (Creswell, 2013a; Denzin & Lincoln, 2011; Guba & Lincoln, 1994; Nieuwenhuis, 2007a).

Phenomenological suppositions provided two functions in this study. It formed the theoretical point of departure of the research, as well as the underlying methodological procedures used to carry out the research study. The theoretical framework for this study is phenomenology, specific to interpretive phenomenology. IPA was chosen, as the method, to investigate the impact of T1D on the psychosocial well-being of adolescents in a resource-constrained community. In this section, the researcher will discuss phenomenology as a philosophy and as a method.

The term, *phenomenology*, seems to be supplemented with uncertainty when understanding its nature in research; being both a philosophical paradigm, as well as a research methodology. Willig (2013) defines phenomenology as being interested in the world as it is perceived by people within a specific context and time; the study of phenomena identifying the personal meanings held through an individual's experience. The term originated in the 18th century, and was used in philosophical texts to understand the philosophy of presences which were central to empirical information.

4.5.1 INTERPRETIVE PHENOMENOLOGY

As mentioned in Chapter 1, this research was conducted from an interpretive phenomenological paradigmatic viewpoint. Qualitative research is formulated from a particular set of assumptions about the foundations or options for knowledge, in other words **epistemology**. The term 'epistemology' "refers to a branch of philosophy that is concerned with the theory of knowledge and that tries to answer questions about *how* we can know and *what* we can know" (Lyons & Coyle, 2016, p. 11). The aim of the study was to understand the **lived experiences** from the viewpoint of the research participants, which occur within a historical social reality. Additionally, the research participants' lived experiences may not be in their immediate awareness but through deep reflection can be acquired. This type of reflection can be extracted through interactive researcher-participant information flow, hence only through such interaction can lived experiences be discovered and deeper meaning obtained. Co-construction of findings from the interactive dialogue and interpretation - between participant and researcher - must therefore take place (Ponterotto, 2005).

The phenomenological philosophy, started by Husserl, was proposed as a descriptive initiative (Lyons & Coyle, 2016). Martin Heidegger (1889-1976), Husserl's student, contested that the phenomenological approach was fundamentally interpretive and reinterpreted phenomenological analysis. Both Husserl and Heidegger agreed that description and interpretation are significant approaches, but have differing views regarding which is important (Kumar, 2012).

Table 4.1 below shows the key distinctions between Husserl’s descriptive phenomenology and Heidegger’s interpretive phenomenology. From an epistemological perspective, Husserl stated that description is primary and that interpretation is a specific style of description. From an ontological perspective, Heidegger explained that interpretation is a central concern and that description is a specific style of interpretation. Thus, the difference in priority is relative to the particular starting point.

Table 4.1: KEY DISTINCTIONS BETWEEN DESCRIPTIVE AND INTERPRETIVE PHENOMENOLOGY

DESCRIPTIVE PHENOMENOLOGY	INTERPRETIVE PHENOMENOLOGY
1. Emphasis on describing universal essences	1. Emphasis on understanding the phenomena in context
2. Viewing a person as one representative of the world in which he/she lives	2. Viewing a person as a self-interpretive being
3. Belief that the consciousness is what humans share	3. Belief that the contexts of culture, practice, and language are what humans share
4. Assumption that self-reflection, and conscious ‘stripping’ of previous knowledge, help to present an investigator-free description of the phenomenon	4. Assumption that as prereflexive beings, researchers actively co-create interpretations of phenomenon
5. Assumption that adherence to established scientific rigor ensures description of universal essences or eidetic structures	5. Assumption that one needs to establish contextual criteria for trustworthiness of co-created interpretations
6. Assumption that bracketing ensures that interpretation is free of bias	6. Assumption that preunderstanding and co-creation by the researcher and the participants are what makes interpretations meaningful

Note. Adapted from Kumar, A. (2012). Using phenomenological research methods in qualitative health research. *Journal of Human Sciences*, 9(2), 790-804.

Heideggerian phenomenology is based on the perspective that an individual’s culture, social context and historical period in which he/she lives needs to be considered when understanding human experience (Smith, 2015). Heidegger believed that humans are interpretive/hermeneutic and have the ability to attribute meaning to their lived experiences. Thus, a person gains a meaningful understanding through a subjective process of interpretation. Nieuwenhuis (2007a, 2007b, 2007c) highlights interpretivism’s roots in hermeneutics, the study of interpretation through theory and practice. Furthermore, he states that the interpretive perspective is founded on the subsequent assumptions, which were taken into account during the research process. Assumption 1: *Human life can only be understood from within*; infers that human life cannot be understood from some external reality and emphasis is placed on a person’s subjective experience. This entails how they ‘construct’ the social world by shared meanings and how they relate to (or interact with) one another. Assumption 2: *Social life as being distinctively a human product*; adopts that reality is socially constructed, not objectively understood.

The individuality of a particular setting is significant in comprehending and interpreting the individuals' meanings that are constructed. Assumption 3: *The human mind is the main source or origin of meaning*; concerned with the exploration of the phenomena from a rich, in-depth and complex perspective. Hence, we can engage a sense of understanding of the meanings that are imparted by the individuals to phenomena and their social context. Assumption 4: *Human behaviour is affected by knowledge of the social world*; there are multiple realities of phenomena, which can differ across place and time. This knowledge, which encompasses a social world understanding and the realities constructed from within, increasingly enriches our theoretical and conceptual framework. Assumption 5: *The social world does not 'exist' independently of human knowledge*; human knowledge is interrelated with the social world. As the researcher proceeded through the research process, humanness and knowledge provided enlightenment and guidance. Other subtleties, such as values, intuition, prior knowledge and belief systems, placed an additional influence of understanding for the investigated phenomena.

Thus, as interpretive phenomenological researchers, it is important to note that personal culture, experiences and history may influence the research process and results of the research study (Tuohy *et al.*, 2013). Therefore, the interpretive phenomenological paradigm is subjective. Taking into account that this paradigm harbours a criticism of subjectivity, which implies that researcher bias might occur, is not a challenge *per se*. In this study, it was acceptable for the researcher to be subjectively involved in the research process. Research is reliable if the researcher can demonstrate interpretative awareness (Manion, Cohen, & Morrison, 2013). Furthermore, interpretive phenomenologists believe that researchers have to acknowledge the subjective viewpoint they add to the research process and carry out the necessary procedures to confront the implications of their subjectivity.

This entails that they are aware of their research actions and the effect it can have on the research objects they examine. An inverse reaction also takes place, whereby the researchers understand that their research objects can also affect them (Manion *et al.*, 2013; Nieuwenhuis, 2007a). In this regard, there is an interdependent relationship that exists between the researcher and the research object. According to Willig (2008, 2013), phenomenological psychology is concerned with the research participant's report being the phenomenon with which the researcher engages. This directs focus unto the variety and unpredictability of human experience rather than with the identification of essences in Husserl's sense (Benner, 1994).

Phenomenological psychology began with Heidegger who placed emphasis on the term *dasein* instead of consciousness, where the question of *being human* takes premise and its task is to interpret the *meaning of being* (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). Heidegger advocated an interpretive methodology, which consequently converges with the tradition of hermeneutics. Furthermore, Gadamer (1900-2002), Heidegger's student, reinforced the interpretive tradition (Eatough & Smith, 2016; Smith, 1996a, 2015). The focus of this approach is on the question of being and as such does not employ the Husserlian phenomenological reduction. Rather, the attempt to *bracket* the phenomenon is achieved through the researcher's *reflexivity* and *quality assurance* (Smith, 2015). The interpretive (hermeneutic) phenomenological approach is based on the interpretation of lived experiences, how these are understood by the research participant and the researcher.

Interpretive phenomenology has a principal emphasis on understanding individuals, which entails a complex understanding that cannot occur in isolation as cultural and social contexts provide integral appreciation of the individual's unique lived experience. Discerning, articulating and elaborating on these particular elements of specific individuals allows for the researcher to understand the nature of that person's unique *being-in-the-world*, and make connections between that and the conventional socio-cultural world in which the person exists (Kumar, 2012; Smith, 2015; Willig, 2013). Furthermore, Heidegger's phenomenology addresses the *situatedness* of a person's *dasein* relative to their external cultural and social contexts (Smith, 2015; Tuohy *et al.*, 2013). Therefore, to understand the impact of T1D on the psycho-social well-being of adolescents the researcher had to incorporate the context of personal, family, school and hospital experiences.

The assumptions of *dasein* and *situatedness* created the foundation for pre-understanding. Heidegger (1962) explained pre-understanding as the *fore-structure of understanding*, comprising of three elements: fore-having, fore-sight and fore-conception. Firstly, fore-having refers to the practical familiarity or background practices of a phenomenon. In that people approach situations from a practical level of familiarity, which is dependent on their personal lived experiences; making interpretation possible. Secondly, Fore-sight is concerned with the socio-cultural background that provides the viewpoint from which to make an interpretation. Lastly, the third element, fore-conception, takes into account the socio-cultural background as it provides the basis for what can be anticipated from the research findings regarding the investigated phenomenon.

It is important to note that fore-sight and fore-conception appear similar as both take socio-cultural background into account when making an interpretation. However, these two elements differ in the fact that fore-sight is concerned primarily with one's socio-cultural background as a gateway to making an interpretation, whereas fore-conception values one's own anticipated prior experiences that also play a role in the encountered interpretation (Kumar, 2012). Interpretive phenomenology is thus concerned with the manner within which people attribute meaning to their lives.

Heidegger (1962) assumed that how one understands the world is closely linked with fore-structure and that understanding is connected to how reality is interpreted. Consequently, interpretive phenomenologists uphold that prior to conducting inquiry of such phenomena as adolescents with T1D. In this study the researcher must return to previous experiences of caring or being cared for during adolescence, predeterminations about healing and completeness regarding adolescent development, and preconceptions about what it means to be an adolescent with a chronic disease (Benner, 1994). This method of reflexivity assists throughout the interpretive process. In doing so, the researcher can more accurately access the research participants' forestructure of understanding.

Heidegger (1962) explained the interpretive process as circular, migrating back-and-forth through the whole and its respective parts. This process also entails moving between the researcher's forestructure of understanding, as well as what was experienced throughout the investigation. According to Heidegger, this procedure is termed as a 'hermeneutic circle of understanding', whereby a blend of meanings are revealed as expressed by the study participants and the researcher; creating a co-constitution of meaning (Koch, 1995). Therefore, "the goal of interpretive inquiry is to ascertain the study participants' meanings from the blend of the researcher's understanding of the phenomenon, participant-generated information, and data obtained from other relevant sources" (Kumar, 2012, p. 795).

Benner (1994, p. 71) summed up Heideggerian assumptions of interpretive phenomenology as:

1. "Human beings are social dialogical beings;
2. Understanding is always before us, in the shared background practices of the human community, within societies and cultures, in the languages, in our skills and activities, and in our intersubjective and common meanings;
3. We are always ready in a hermeneutic circle of understanding;
4. Interpretation presupposes a shared understanding between the researcher and the participants;
5. Interpretation involves the interpreter and the interpreted in a dialogical relationship."

The researcher was interested in how the research participants interpreted their experiences, how they constructed their worlds and the meanings they attributed to their experiences (Creswell, 2013b; Huberman & Miles, 1994; Patton, 2005; Robson & McCartan, 2016). This was implied by the aforementioned assumptions and concepts discussed, basing this research study from an interpretive phenomenological paradigmatic perspective.

Ontology is concerned with the assumptions made about the nature of being, reality or existence (Willig, 2013). The researcher's ontological stance views reality as personal and impacted by the perspective of a particular situation; namely the individual's insights and experiences, researcher-participant interaction, and social setting. Moreover, the interpretive phenomenological paradigm proposes multiple, constructed realities instead of one true universal reality (Smith, 2015). Regarding the **epistemological approach**, interpretive phenomenology upholds that there are socially-constructed realities. In other words, the unique relations formed between researcher and research participant is integral to capture and describe the lived experiences of the participant. The role of the researcher values in the research process is a philosophical study, referred to as **axiology**. Interpretive phenomenologists maintain that the research process cannot be seen separately from the researcher's lived experiences and axiology (Denzin & Lincoln, 2011). The researcher should recognise, describe and marginalise their values but not dispose of them entirely when working from an interpretive phenomenological approach. Furthermore, interpretive phenomenologists are prompted to make use of reflective journals. The language used to present the research process and results to the researcher's proposed audience is referred to as **rhetorical structure**. This notion of natural text coherence is the systematic way in which the researcher can analyse and build on the research study. **Methodology** refers to the procedures and methods of the research. In this regard, qualitative research methods that involved interactions between researcher and participant were selected (Manion, Cohen, & Morrison, 2007; Ponterotto, 2005; Schwandt, 2000; Weber, 2004).

Relying on the interpretive phenomenological paradigm provided the researcher with the necessary forum to interpret and understand the adolescents' experiences of T1D on their psycho-social well-being (Manion *et al.*, 2013). As the researcher held prior insight of the research context, this paradigm allowed for interpretative awareness of personal understanding concerning the phenomenon being investigated. Therefore, during the course of the study the researcher remained cognisant to new knowledge elucidated from the participants' dynamic perceptions of their reality (Mack, 2010; Maxwell, 2012; Robson & McCartan, 2016; Weber, 2004).

In summary, interpretive phenomenology is a research methodology used in this study for describing adolescent T1D lived experiences of “caring, healing and wholeness in relation to historical, social, and political forces that shape meanings of wellness, illness, and personhood. Interpretive phenomenology is grounded in the belief that the researcher and the participants come to the investigation with fore-structures of understanding shaped by their respective backgrounds, and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied” (Kumar, 2012, pp. 795-796).

Phenomenological suppositions provided two functions: a theoretical lens and the methodological procedures used in conducting the research. The aforementioned concepts are all applicable to the present study in how information about the phenomenon is approached and conceptualised; as well as the method used to investigate and bring about this conceptualisation, namely Interpretative Phenomenological Analysis (IPA).

4.6 INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

Over the last 20 years, Interpretative Phenomenological Analysis (IPA), a qualitative based method, has provided a distinctive approach not only to psychological research but also many disciplines beyond psychology today (Smith, 2015). IPA has theoretical underpinnings in phenomenology, hermeneutics and idiography (Eatough & Smith, 2016).

Interpretative phenomenological analysis (IPA) is a method used to explore the detailed accounts of the participants’ experiences and using self-reflection as a tool when looking at the researcher’s interpretation of their accounts (Willig, 2008). IPA studies focus on the participants’ meanings from their specific events, experiences and conditions hold for participants. This method is suitable to explore matters surrounding clinical, health and social psychology. These topics showcase a necessity to investigate and understand how people experience important happenings in their lives; reflecting IPA’s phenomenological lens.

IPA emphasises a dynamic research process with an active role for the researcher throughout that process. The researcher invariably brings a subjective and personal bias into the research which is acknowledged through the researcher’s reflexivity and quality assurance; thus a strong connection to the interpretative or hermeneutical tradition (Smith, 2015).

“Access to the participant’s experience depends on and is complicated by the researcher’s own conceptions. These are required in order to make sense of that other personal world through a process of interpretative activity. Thus a two-stage interpretation process, or a double hermeneutic, is involved” (Eatough & Smith, 2016, p. 51). This process involves an initial stage, where the research participants convey their personal experiences, and a secondary stage, where the researcher tries to understand and represent the meanings ascribed to various phenomena in their lives. This double hermeneutic gives a neat illustration for the dual role of the researcher. Therefore, a meaningful connection is formed between the language used to describe an event and the event itself.

It appears constructive to further highlight that IPA has a “theoretical dedication to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people’s talk and their thinking and emotional state” (Eatough & Smith, 2016, p. 51). At the same time, the researcher is aware that there are restrictions to what a participant is able to verbally communicate. People find it difficult to express what they are feeling and thinking; there may be reasons preventing them to self-disclose. As such, the researcher is left to interpret, to the best of their ability, what the participant may be trying to convey other than what is being said. This process allows for a more meaningful understanding of the individual’s lived experiences.

IPA has three important features; namely *idiographic*, *inductive* and *interrogative* (Guest, Namey, & Mitchell, 2012). IPA’s idiographic nature of interpreting the data is seen as a subjective and reflective procedure in the research process. The participants’ lived experiences and relational worlds are conveyed, along with important generic themes in the analysis (Willig, 2008). It is inductive which entails that IPA is not limited to hypotheses to confirm or refute; the methods are flexible and open-ended, allowing participants to discuss aspects of their experiences that could reveal unanticipated information (Lyons & Coyle, 2016). These methods allow unpredicted themes to emerge during data collection and analysis. Semi-structured interviews are used during the interview process, placing the researcher in an advantageous position to further investigate interesting and important topics. Furthermore, IPA is interrogative because themes and patterns that surface do not occur in isolation but are connected to mainstream psychology’s critical assessment and analysis of theoretical knowledge (Brocki & Wearden, 2006; Quinn & Clare, 2008).

IPA is mainly concerned about how individuals see the world and in what way this is done (Guest *et al.*, 2012). Further, IPA assumes that individuals can experience the same situation in different ways. As such, people can attribute their own meanings to an event and then formulate their own experiences of that event. IPA refrains from making statements about the external world. It is concerned about the experiences of the participants in an event (relativist ontology). Also, it looks at the social interactions and processes that shape people's experiences. Lastly, this method typically relies on small, specifically chosen, participant samples. In this study, the impact of T1D on the psycho-social well-being of adolescents was explored, IPA was chosen as a suitable investigative tool.

4.6.1 SAMPLING AND SAMPLE SIZE

Lyons and Coyle (2016) suggest that when using IPA, the sample must be theoretically consistent with the qualitative paradigm in general. In the chosen method, samples are collected purposively as it provides the researcher with specific insight into an experience.

Participants are selected on the premise that they allow the researcher to gain access into a particular perspective of the phenomenon being investigated (Guest *et al.*, 2012). In the current study, adolescent T1D patients at a public healthcare facility in a resource-constrained community were eligible for participation.

These adolescents had to be within a certain age group, namely aged 15 to 18 years. Furthermore, they had to be diagnosed with T1D for longer than a year, still be living with a parent/guardian and attending school. Thus, purposive sampling was applied, in that the participants of the selected populace were based on predetermined criteria (Smith, 2015). IPA studies require a fairly homogenous group which can be recruited through means of purposive sampling. The researcher is thus ensured the ability to be idiographic and interpret a specific group of individuals. As a result, participants were selected by precise features centred on the following four predetermined inclusion criteria:

- (1) Adolescents (aged 15 to 18 years)
- (2) Diagnosed with T1D for longer than 1 year
- (3) Living with parent/guardian
- (4) Scholar

Finding participants who matched the above predetermined criteria of the study proved to be quite challenging for the researcher. The biggest struggle in the inclusion criteria was that of obtaining patient information relative to the criteria from the public healthcare facility database. Although a large sample was made accessible to the researcher of adolescents with T1D, locating participants with these specific criteria required further investigation. Potential participants were shortlisted and contacted telephonically to find out if they truly matched what the research needed. This resulted in a significantly reduced sample size than anticipated.

According to Willig (2013), IPA studies make use of small sample sizes, allowing for an in-depth detailed analysis of each case rather than making a broad generalisation from a large population. This idiographic approach produces insights from the rigorous analysis of a small number of cases. There is no right answer to the amount of participants required in an IPA study – it is dependent on various factors – the emphasis is on quality rather than quantity. “It partly depends on the degree of commitment to the case-study level of analysis and reporting, the richness of the individual cases and the constraints under which you are operating. There seems to have been some consensus that between six and eight participants is an appropriate number for an IPA study” (Eatough & Smith, 2016, p. 54). The sample size for this study was initially projected to consist of ten adolescents with T1D, from the same public healthcare facility, in a resource-constrained community.

However, various unexpected challenges resulted in the sample size being five participants. The difficulty in finding ten participants that fulfilled the predetermined criteria was such that only five participants were available for the research. The public healthcare facility deals with many walk-in patients⁴; from these patients, some never return but their details are kept on record regardless. This created a few misleads for potential participants found on the database. The researcher collaborated with the two relevant doctors from the adult and paediatric diabetic wards to recruit the participants needed.

According to ADA (2017, p. 105), a “multidisciplinary team of specialists trained in paediatric diabetes management and sensitive to the challenges of children and adolescents with type 1 diabetes and their families should provide care for this population”. In the end, the researcher discovered that all participants used for this study were already placed in the adult diabetes ward, contrary to global diabetes healthcare support.

⁴ The public healthcare facility provides medical care to patients that have not made appointments.

Once the five participants agreed to be a part of the study and were deemed eligible, participant information was given to them either telephonically or via e-mail. This served to inform both the participants and their parent/guardian about the study in greater detail as well as providing another opportunity to decide whether they would like to participate or not. When the participant and parent/guardian both confirmed their involvement, they were contacted again for an appointment date and time. Thus, participants were selected for the study after permission was obtained from the participants themselves, the participants' parent/guardian and their attending doctor in accordance to the public healthcare facility regulations. The participants and their parent/guardian were also requested to sign written assent and consent forms (see Appendix A and B). Table 4.2 indicates the age, gender and race of the participants who partook in this research study.

Table 4.2: PARTICULARS OF PARTICIPANTS SELECTED FOR THE RESEARCH STUDY

PARTICIPANTS	AGE	GENDER	RACE
Participant 1	16	Male	Black
Participant 2	15	Male	Black
Participant 3	16	Male	Black
Participant 4	18	Female	Black
Participant 5	18	Female	Black

4.6.2 DATA COLLECTION

After the researcher purposefully identified and selected the relevant research participants and setting, the data was collected in order to explore and describe the impact of T1D on the psychosocial well-being of adolescents. According to Eatough and Smith (2016), majority of IPA studies have been conducted to almost exclusively involve semi-structured interviews to obtain data. Although, for the current study, multiple data collection and documentation techniques were employed, namely semi-structured interviews, field notes and a reflective journal from the researcher (Lyons & Coyle, 2016). The methods used during the data collection process are discussed below.

Semi-Structured Interviews

Semi-structured interviews were employed in this study. "In semi-structured interviews, the investigator works from a pre-constructed schedule but the interview will be guided by the schedule rather than dictated by it. Hence the ordering of questions is less important. The interviewer is freer to probe interesting areas that arise and can follow the participant's interests or concerns" (Eatough & Smith, 2016).

Regarding the abovementioned, a great deal of meaning can be conveyed from the individual's experience. It is the predominant method for data collection in an IPA study (Guest *et al.*, 2012). Further, semi-structured interviews are flexible and dynamic; it places focus on the interview which aims to answer the research question through open-ended questions on the matter under exploration.

As suggested above, the interview was guided by these questions (see section 1.5), and were modified or supplemented as necessary in cases where particular areas could be further explored. The interview schedule consisted of the following parts:

- Part 1: Personal experiences of living with T1D
- Part 2: Family experiences of living with T1D
- Part 3: School experiences of living with T1D
- Part 4: Hospital experiences of living with T1D

In fashioning the semi-structured interview, queries were carefully constructed in line with the aims of the research and the literature review. These questions created an all-inclusive understanding of the participants experience and method in which meaning was made possible; allowing for detailed articulation of the experience.

Smith (2015) suggests that a neutral stance should be adopted during the construction of the interview questions; questions should be open-ended, avoiding jargon or assumptive technical proficiencies. The researcher attempted to adhere to these guidelines when the interview schedule was constructed. See Appendix C for the semi-structured interview protocol.

One, face-to-face, individual interview was conducted with each participant. Each interview focused on exploring the topics and areas of experience regarding the impact of T1D on the psycho-social well-being of each adolescent; to gain an in-depth, comprehensive understanding of the complexity of the participants' lived experiences.

During the interviews it was important that the researcher used appropriate language terms when addressing the participants. An interpreter was present in two of the interviews and assisted where necessary. See Appendix D for the Interpreter's personal declaration of responsibility. As a result, it was pertinent not to view interviews as an isolated segment of meaning, but rather consider them in relation to the discourse within which they were formed (Guest *et al.*, 2012). Linguistic variability took place during the interviews.

Therefore, the researcher had to, at some points during the session, restate previous comments to verify understanding and clarity on topics discussed. This process guaranteed consistency and continuity throughout the interview.

Cultural diversity was taken into account when questions were asked and the researcher ensured that the participants' were not given questions that were considered irrelevant or unworthy (Eatough & Smith, 2016). The researcher consulted with the interpreter in context to ensure it was culturally relevant.

The duration of the interviews conducted varied with each participant, but on average lasted approximately sixty minutes. Prior to each interview, the participant information was discussed once more and the procedures explained. Thereafter, the participant and parent/guardian signed their respective assent and consent forms. Interviews took place at the public healthcare facility on days that conveniently suited the participant and parent/guardian. A private conference room, nearby the adult diabetes ward, was made available for the researcher to use for every interview.

The interviews were audio-recorded to ensure that no information was lost. Willig (2013) states, that in qualitative methods the analysis of data involves the information to be transcribed accurately (or near verbatim), indicating both verbal and nonverbal communication. The recorder was placed in an appropriate position when recording took place during the interviews.

Field Notes

The researcher relied on field notes to document the observations during the semi-structured interviews that took place with the research participants. This type of data collection assisted the researcher in capturing the process of researcher-participant interactions (Denzin & Lincoln, 2000; Garner & Scott, 2013; Patton, 2005; Taylor, Bogdan, & DeVault, 2015). Further, the interactions could be described and interpreted in the researcher's own words to draw subsequent conclusions from the notes. These field notes included the researcher's experiences from the research process and additional inquiries to questions that arose and further readings based on the phenomena observed.

According to Garner and Scott (2013), the input from the researcher will place further understanding to what is being noticed in the research field, as well as the elements chosen to be written down as part of the field notes. There are two types of field notes, namely salient hierarchy strategy and comprehensive strategy (Taylor *et al.*, 2015).

The researcher chose to use the salient hierarchy strategy for field note-taking. This entailed the researcher to choose which features of the research were noticeable and important, as well as highlighting areas of uniqueness to become part of the field notes. Although, the researcher's subjective knowledge influences this strategy it remained constant to acknowledge the awareness concerned with the researcher-participant relations. Primarily, the researcher recorded what was observed as significant and note-worthy against the background of the research questions (Creswell, 2013b). The participants' interactions and relations with the researcher were recognised and considered during the field notes.

Reflective Journal

As previously mentioned, the interpretive phenomenological approach is based on the interpretation of lived experiences, how these are understood by the research participant and the researcher. The attempt to *bracket* the phenomenon is achieved through the researcher's reflexivity and quality assurance (Smith, 2015). Confirmability also makes use of reflexivity, which involves a methodological self-aware viewpoint on how the research was introduced and documented (see section 3.7.4).

Therefore, throughout the research process, the researcher recorded self-reflections on the research in the form of a reflective journal. See Appendix E for researcher's reflective journal.

4.6.3 DATA ANALYSIS

Data obtained from the interviews was transcribed verbatim to ensure accurate interpretation of the information. During transcription, the researcher kept a record of initial thoughts, comments and points of potential significance. IPA, as a method, aims to capture the quality and context of individual experience during data analysis (Eatough & Smith, 2016). Meaning is central when conducting an IPA study, participants attach meanings to phenomena. Thus, the researcher's task was to understand and convey the context and complexity of these meanings.

In IPA, data analysis works with texts generated by participants. Each case is analysed individually and thereafter integration of all cases takes place. "IPA takes an idiographic approach whereby insights produced as a result of intensive and detailed engagement with individual cases are integrated only in later stages of the research" (Willig, 2013, p. 57). According to Eatough and Smith (2016), there are several stages involved in the investigation of an IPA study which will now be discussed.

The first stage for analysis of each individual case included the reading and rereading of the participant's transcript. The researcher used the left-margin to annotate any interesting thoughts and observations in response to the text (Smith, 2015). This was useful as it assisted the researcher in the process of ensuring that the participant's view was central during analysis. Notes produced during this initial encounter with the text constitute the most open form of annotation. In addition, repeatedly reading the transcript gave the researcher insight into the patterns of how the interview process started and progressed from beginning to end.

The second stage involved returning to the transcript; using the right-hand margin was used to transform the researcher's initial notes and thoughts into more specific themes or phrases (Eatough & Smith, 2016). Psychological concepts and abstractions were utilised to capture the essential quality of what was represented by the text. Caution was crucial during this stage to safeguard the link between the participant's own words and the researcher's interpretations thereof. Thus, these emergent themes are expected to reflect the participant's personal concepts and words, as well as the researcher's interpretation thereof.

The third stage consisted of establishing connections between the emergent themes and allocating them appropriately into clusters (Tuohy *et al.*, 2013). During this stage, the researcher formulates linkages between preliminary themes that have been chronologically ordered as they appear in the transcript. Some of these themes formed natural clusters of concepts that shared meanings or references, whereas others were characterised by hierarchical relations with one another. The researcher ensured that the clustering of identified themes made sense in relation to the original data. This was achieved by moving back and forth between the list of themes the researcher attempted to structure and the text that generated these themes.

The next stage entailed the production of a summary table, comprising of the structured themes, together with quotations that represented each theme (Quinn & Clare, 2008). During this stage, the researcher made use of a summary table to include themes identified to the participant's lived experiences of T1D and the possible impact it has on his/her psycho-social well-being. Further, the researcher's decision concerning which themes to retain or abandon was inevitably influenced by the research question and aim of the study. The summary table included cluster labels, subordinate theme labels and brief quotations to show where pertinent extracts (i.e. page and line numbers) were uncovered in the interview transcript. The participant's account was reflected through the meanings that structured his/her experiences in this table (Brocki & Wearden, 2006; Lyons & Coyle, 2016).

The researcher approached integration of the five participant cases in the following manner. IPA guidelines were applied to each case and only when disclosure was reached was the next transcript interpreted (Smith, 2015). After producing the summary table for every participant, the researcher integrated these into an inclusive list of master themes that reflected the experiences of the group of participants as a whole. This final table showed the superordinate themes and the underlying themes that comprised them. In this study a purposive sample was used, meaning that the group was homogenous, enhancing a superordinate themed table of all the participants' experiences (Willig, 2013). Therefore, the process of integration was performed in a cyclical style.

4.7 QUALITY CRITERIA

The aim of this study was to gain an in-depth understanding of the impact of T1D on the psychosocial well-being of adolescents. A debate remains among researchers to ensure trustworthiness in qualitative research. Trustworthiness refers to the manner in which the inquirer is able to prove to the audience that the findings of the study are accurate and high quality standards of research was maintained (Maree, 2007; Robson & McCartan, 2016; Schwandt, 2007). The researcher adopted Lincoln and Guba's (1985); as well as Speziale, Streubert and Carpenter's (2011) principles of trustworthiness. Therefore, to ensure the trustworthiness of this study the following four criteria was applied: *credibility*, *transferability*, *dependability* and *confirmability* (Maree, 2007; Smith, 2015; Willig, 2013). The four concepts were kept in mind throughout the research process and will now be addressed.

4.7.1 CREDIBILITY

The purpose of credibility is to demonstrate that the inquiry was implemented in such a way that the subject was properly described and recognised (Smith, 2015). Thus, credibility entails the extent to which findings are truthful. According to Lincoln and Guba (1985), credibility is one of the most important concepts in maintaining trustworthiness in a qualitative research study. A qualitative researcher establishes rigour of inquiry by using the following credibility techniques: an adapted and well established research method, early development of familiarity towards participants approaches to ensure honesty, iterative questioning, member checking and the researcher's reflective commentary as well as rich descriptions of the phenomena under scrutiny (Anney, 2014; Shenton, 2004; Yin, 2015).

Credibility was achieved through collaboration with participants regarding the interpretation of the data. Iterative questioning is applied to decide whether participants are being untruthful. This was applied during the interviews by returning to formerly spoken material and rearticulating queries (Shenton, 2004). If any information was unclear the researcher consulted with the participants over the telephone after the interviews took place. Member checks refer to checking the accuracy of the data. The transcribed data was shown to the research participants for review and comment. The study was also reviewed by a research supervisor. The supervisor provided alternative or confirming suggestions throughout the procedures and data analysis.

4.7.2 TRANSFERABILITY

Transferability in qualitative research refers to the possibility of the study being applied in a different setting (Lincoln & Guba, 1985; Schwandt, 2007; Shenton, 2004). The parameters of the study need to be clearly identified in order for this to be applicable. Since this study cannot be generalizable to the larger population, the researcher relied on transferability due to subjectivity being a key element in qualitative research. Therefore the importance of the researcher's detailed explanations of the research methods, context and assumptions of the study was integral for the reader to discern the transferability of the findings (Smith, 2015). The researcher employed rich, thick descriptions of the participants and contexts by supplying an in-depth and clear account of the impact of T1D on the psycho-social well-being of adolescents.

4.7.3 DEPENDABILITY

The dependability of the research refers the extent to which a researcher accurately defines the findings of a study (Speziale *et al.*, 2011). This implies that the research findings can be replicated within a similar study-context. Dependability, in qualitative research, is equivalent to reliability in quantitative research; however reliability in its traditional meaning is not applicable to qualitative research (Lincoln & Guba, 1985). Rather, dependability (reliability in this type of research) is assessed through whether or not the research findings are consistent with the data collection.

As aforementioned, the aim of the study was not to generalise to a larger audience but rather to obtain in-depth understanding of the impact of T1D on the psycho-social well-being of adolescents. The researcher continually sought contributions from others during the data analysis process (i.e. research participants and supervisor) ensuring that the findings were fairly dependable and would be transferable to other similar groups of individuals and environments (Shenton, 2004; Smith, 2015).

4.7.4 CONFIRMABILITY

Confirmability is concerned with the extent to which the research findings can be confirmed or agreed by other readers, which are founded on the participants' understanding and experiences (Glaser & Strauss, 2009; Seale, 1999). Lincoln and Guba's (1985) confirmability audit trail infers that an appropriate trail is created by the researcher that enables the auditor to ascertain whether the interpretations, conclusions and recommendations can be traced to their respective sources, which also support the inquiry of the study.

In this study, a trail was piloted by the use of recorded audiotapes, synopses and summarised notes and themes that were developed, as well as personal notes from the researcher. Furthermore, Seale (1999) affirms that confirmability also makes use of reflexivity, which involves a methodological self-aware viewpoint on how the research was introduced and documented. Thus, during the research process, the researcher recorded self-reflections on the research process in the form of a reflective journal.

4.7.5 AUTHENTICITY

Authenticity refers to the acquirement of an overall view of various perspectives, beliefs and values of the research participants; in other words, the fair representation of different realities (Seale, 1999; Speziale *et al.*, 2011). Thus, in order for qualitative research to be authentic the researcher must accurately describe the reality and meaning of the research participants' experiences. This study applied a methodology that could empower the research participants to: become cognisant of their *social milieu* (ontological authenticity); enter freedom of expression / speech during the semi-structured interview (educative authenticity); motivate them, through the research process, to take action for circumstantial change and address challenges (catalytic authenticity); and lastly implement suggestions made to enhance their psycho-social well-being (tactical authenticity) (Lincoln & Guba, 1985; Lyons & Coyle, 2016; Schwandt, Lincoln, & Guba, 2007).

4.8 ETHICAL CONSIDERATIONS

In conducting this qualitative study, the researcher interviewed adolescents with T1D - at a public healthcare facility setting - to uncover their experiences of having this chronic disease and the impact it has on their psycho-social well-being. Research should always be carried out in an ethically-sound manner (Creswell, 2013b; Lincoln & Guba, 1985).

The nature of this study involved collecting data from human participants thus requiring the researcher to adhere to and be cognisant of pertinent ethical considerations. The following ethical considerations were carried out during the research process, namely: informed consent; privacy, confidentiality and anonymity; honesty and trust; and protection from harm (Lyons & Coyle, 2016). These considerations are explained below.

4.8.1 INFORMED CONSENT AND ASSENT

The research study obtained written informed consent and assent (Gravetter & Forzano, 2015). These forms enclosed a statement of all the aspects mentioned under *protection from harm* (see section 4.8.4). It also contained an overview, description of procedures used (audio recorded interviews), confidentiality, voluntary participation, and inconveniences for the participants (Birch, Miller, Mauthner, & Jessop, 2012). The researcher provided feedback (results, nature and conclusion of the study) to the participants. Participants who needed further clarity were provided with additional information and answers to other queries regarding the research process (Birch *et al.*, 2012).

4.8.2 PRIVACY, CONFIDENTIALITY AND ANONYMITY

The research study ensured participants' anonymity. To ensure the confidentiality of the data a coding system was used (Ritchie, Lewis, Nicholls, & Ormston, 2013). This strategy was required because the study established links between the data and names of participants' (Creswell, 2013b). From this coding system the research participants were given pseudonyms to further protect their identities. The researcher also ensured that the research did not contain plagiarism or fraud (Bryman, 2015).

4.8.3 HONESTY AND TRUST

It is the researcher's duty to promote honesty and respectful behaviour towards individuals that are indirectly and directly affected by the research conducted. Gravetter and Forzano (2015) state that there are two categories in relation to research when considering ethical responsibility. In the first category it is the responsibility of the researcher to sustain the dignity and welfare of participants. Secondly it is their responsibility to report their research as truthfully and precisely as possible (Ritchie *et al.*, 2013). The researcher obtained trust from the research participants by building a good rapport through professional integrity, personal attributes and by paying close attention to detail. Further, the researcher displayed good interpersonal skills through respectable behaviour, mindfulness, tact, compassionate attitude and approachable demeanour.

4.8.4 PROTECTION FROM HARM

Necessary steps must be taken to prevent harm to the participants and to protect the rights and welfare of participants (Ritchie *et al.*, 2013). Diversity of the participants were respected and taken into account (Bryman, 2015). Participants' were provided with appropriate explanations about the research; taking into account their best interests (Creswell, 2013a, 2013b).

The participants' were notified about their right to decline participation in the study and their right to withdraw at any point during the research (Ritchie *et al.*, 2013). Any information and contacts for questions that the participants' had were made available (Creswell, 2013a). Ethical clearance was obtained from the Ethical Committee at the Faculty of Education and Faculty of Health Sciences (ethics reference no.: EP 15/11/01), see Appendix F and G. Permission to conduct research at the public healthcare facility was also granted, see Appendix H.

4.9 ROLE AS RESEARCHER

Throughout the study the researcher needed to consider her role as this contributed to the value of the research process. The role of participants' and researchers' in qualitative research differs between qualitative methodologies (Willig, 2013). Therefore, it is necessary to explain the roles of the researcher.

In this study the researcher made sure the participants' understood what the study entailed and how they, as participants', were involved. The researcher was also available to answer any questions the participants' wanted to ask at all times throughout the study. Any problems that arose were dealt with appropriately by the researcher. During the semi-structured interviews the researcher assisted and ensured that the participants' understood what was being assessed. Throughout data analysis, the researcher rechecked the data to ensure that meaning was properly interpreted and consistently considered. After the interviews were conducted, the researcher informed the participants' on the results of the findings and overall analysis of the study so that they understood how the data was interpreted. The researcher was available for any questions from the participants and parent/guardian after the interview was completed.

In an IPA study the researcher is implicated through the analysis of the data (Smith, 2015). This means that the analysis was phenomenological (representative of the participants' viewpoint) and interpretative (the researcher represents the data through his/her own understanding).

A reflexive attitude was thus required from the researcher (Eatough & Smith, 2016). This recognised importance of the researcher's perspective shows that the analysis of the participants' data into meaning was of central significance in this study.

4.9.1 REFLEXIVITY

Reflexivity is an important factor to acknowledge in qualitative research because it allows for consideration of research findings and reflections of the participants' data in accordance with the researcher's findings (Willig, 2013).

This means that the researcher's personal bias was taken into account along with the notion that in doing so will highlight further insight and knowledge acquisition. The researcher kept a reflective journal throughout the research study and the analysis will show reflexivity and not only a descriptive approach. A personal account was included after the study. During the data analysis of the study the researcher provided a discussion of the themes. The findings, in light of the literature aforementioned, are discussed attributing to the reflexivity. To avoid bias and assumptions throughout the study the researcher was self-reflective and interpretatively aware.

In qualitative research, it is significant to consider reflexivity as it allows the researcher to reflect on their personal experience of the research process (Smith, 2015). Further, epistemological reflexivity entails the reflection of assumptions made throughout the course of the research; assisting the researcher to consider possible implications for the research and the findings that surface. See Appendix E for researcher's reflective journal.

4.10 DISSEMINATION OF RESULTS

The results of the current study are reported as a full-dissertation, which is also made available in electronic format.

4.11 SUMMARY OF CHAPTER 4

In Chapter 4 the paradigmatic perspective, research design, methodology and data analysis and interpretation procedures that were employed in the research study have been thoroughly discussed. Furthermore, the ethical guidelines, quality criteria of the research, as well as the role of the researcher were explained. In Chapter 4, the results of the data analysis and data interpretation processes are presented.

5. CHAPTER 5: RESEARCH FINDINGS

5.1 INTRODUCTION

In this study, the researcher set out to explore the subjective experiences and meanings of T1D and the impact thereof on adolescents' relational worlds. This chapter includes a brief overview of the research process. Research participants are introduced and a summary pertaining to each participant's context is provided. Themes, which transpired during the analysis process, characterising adolescents' experiences of T1D and the impact thereof on their psycho-social well-being are then extrapolated.

Since the topic centres on the impact of T1D on the psycho-social well-being of adolescents, it appeared possible to separate themes according to subject areas which allowed for more clarity regarding psycho-social development and holistic health. Themes which are presented thus relate to the overall experiences of T1D and its impact on adolescent psycho-social well-being. The themes introduced in this chapter are relative to the adolescents' lived experiences of T1D and provide significant answers to the research question. Furthermore, the researcher chose to present the themes pertaining to each subject area in separate sections so as to define each more clearly. Formal terms were used to name the themes, with the intention to implement a method whereby these themes could be more comfortably juxtaposed against existing themes in literature.

It is once more pertinent for the researcher to highlight the use of interpretation during the process of analysis for this study. As aforementioned in Chapter 4, meaning is of central importance when using Interpretative Phenomenological Analysis (IPA) as a research method. The aim is to capture and interpret the meanings attached to phenomena; the researcher attempts to comprehend the content and complexity of these meanings. According to Smith (2015), these meanings may not always be so evident and are best acquired through a process of continued and consistent engagement of the participants' transcripts. From this, the development of interpretations of the content of the transcripts can take place. Thus, this process required the researcher to acknowledge and take into account her own thoughts and perceptions to obtain the best understanding of each participant's lived experience.

Although themes presented in this chapter are true accounts of the lived experiences of T1D, they do not represent the participants' absolute or only truth; rather one of many interpretations of their lived experiences. Having explored the above mentioned considerations, an overview of the research process will now be discussed.

5.2 OVERVIEW OF THE RESEARCH PROCESS

Five adolescents, living with T1D, participated in this study. The number of participants falls within the prescribed range for IPA. All of the participants were interviewed within a one month time span and feedback was given thereafter. All of the participants met the criteria stipulated in Chapter 4 and none of the participants withdrew from the study. Participants were given the chance to reflect on the interview process and to add comment or information where needed, after the interview and telephonically.

Before each interview, the research study was once more explained, in detail, to participants and parent/guardian. Thereafter, they were afforded an opportunity to ask questions, convey any concerns/uncertainties and/or clarify specific details pertaining to the study. The interviews were informal and appeared to be comfortable for both participant and researcher. The follow up communication allowed the participants to review and comment on the various themes that were constructed from their transcripts; changes or clarifications were then made accordingly. Participants were to a large extent satisfied with how their experiences were interpreted and conveyed. All interviews were audio recorded and transcribed verbatim; field notes were also made during the interview by the researcher. Detailed notes were made by the researcher to record general feelings about each interview as well as significant verbal and non-verbal interactions and communications observed, which were used later to inform interpretations where necessary.

Throughout the research process, the researcher adhered to all of the methods to ensure research quality and ethical considerations. Pseudonyms are used to safeguard the participants' identities and other identifying details were amended as needed.

5.3 INTRODUCING THE PARTICIPANTS

The researcher collaborated with the two relevant doctors from the adult and paediatric diabetic wards at the public healthcare facility to identify the participants needed. Adolescent T1D patients, at the same public healthcare facility, in a resource-constrained community were eligible for participation. Adolescents, who met the sample criteria, were contacted regarding the study.

The context, scope and motivation of the research study were discussed with each participant and parent/guardian telephonically. From the pool of possible participants, five adolescents were selected to participate as they met prescribed criteria.

Without deliberate intent, the adolescents selected were all Black and obliged to be participants. Additionally, no predetermined attempt was made regarding specific genders; the sample consisted of three males and two females. The participants' ages ranged between 15 and 18 years. Other relevant demographic information is discussed when each participant is introduced.

In getting to know the participants, the researcher became aware of how each adolescent emanated a distinctive feeling to having and living with T1D. Each participant left an impression of their experiences that embodied the unique meanings attached to their lives and subjective viewpoints of living with T1D. The researcher strived in capturing and portraying their true essences in all its complexity, with the attempt to reveal each adolescent's life world. To best describe their lived experiences, the researcher provided important fragments of their stories to illuminate the impact of T1D on their psycho-social well-being. Information discussed is also accompanied by verbatim quotations taken from the participants' transcripts to further illustrate unique truths and meanings.

5.3.1 NELSON

Nelson is a 16-year-old, Black male with T1D. He was 12-years-old when he was diagnosed with this chronic disease and has been living with it for approximately four years. Since his diagnosis of T1D, Nelson has been admitted to hospital twice for DKA. His HbA1c is high and not within normal range; glycaemic levels above 12mmol/L. As a result, he has mild diabetic retinopathy and symptoms of nephropathy. Due to his poorly managed blood glucose levels, Nelson is now facing complications from having T1D. If not better controlled in the future he could be facing blindness, kidney disease and other problems associated from mismanaged T1D (Cartaya & Laffel, 2017). He is using premixed insulin.

Currently, he lives with his mother, a single-parent, in a township. He has an aunt with T1D but she is not involved in his life. The researcher encountered his mother as being authoritative and protective over her son throughout the interview. Nelson is in grade 9 and explained that he struggles to concentrate in school. During class, he often falls asleep. He failed grade 8 due to his poor academic performance. His school is situated in Atteridgeville.

An interpreter was required for his interview. The researcher found Nelson to be a quiet and reserved individual who seemed emotionally detached from talking about his T1D. This demeanour could be attributed to his mother's presence in the interview. His physical health is at risk; he is underweight and showed signs of fatigue throughout the interview. When asked about how he felt physically before diagnosis he was able to comprehend the typical T1D symptoms (see section 2.7) he had experienced. Further, Nelson expressed how he felt sad about everything because he did not know what was wrong with his body. It was a period of confusion which upset him very much:

Sad and confused. When I go to toilet. Second by second I go...I feel like my mouth has too much sugar.

Nelson became much more aware of his situation after he was diagnosed. Even though he expressed that "nothing changed" when he found out, there were major life adjustments that took place. He monitors his blood glucose twice a day (morning and night), eats three meals per day (sometimes two if his glucose level is too high) and injects his premixed insulin into his stomach. When asked about rotating his injection sites he said that he did not know where else to do it. It became apparent to the researcher at this point that Nelson did not have full knowledge on how to manage T1D. He experiences frequent high and low blood glucose levels every day; lows mostly occur in the late afternoon and at night. He often forgets to check his blood glucose and does not follow a routine healthy diet. Nelson is embarrassed to test his blood sugar in front of others, he had this to say:

Nah I don't like [testing blood glucose or insulin injections] because they shame of me... (facial expression changes from a smile to a frown, eyes casted down on floor)

He went on to describe that he receives support from his teacher and principal at school if he ever gets low blood glucose. The teacher will take him to the principal's office where he will be given porridge to raise his blood glucose. He also receives help if this happens during sport. During the week he needs to rest as he becomes tired from experiencing high blood glucose levels. He sees himself as physically weaker now from his peers, this has affected his self-esteem:

Like I have changed...I can't control myself...I start to shake sometimes – I don't feel strong. I feel less confident...it makes me very sad.

He also explained how having T1D causes him a lot of stress every day. To counter this he plays sport and speaks to his friend about it. He is reluctant of telling his peers and other people about his chronic disease because he does not want them to treat him differently.

His other teachers at school do not know about his T1D. He is not a religious or spiritual person. He seemed very reluctant to express how he deals with having T1D which reflects an avoidance coping behaviour.

Although Nelson explained that his mother is there to support him, the researcher felt that her support was more seen as constant worry or concern for his T1D. When asked how his mother feels about him having this chronic disease, he had this to say:

She feels bad...because this thing is too dangerous. She stressed for me. When I am sick it is difficult for my mom.

Regarding his T1D appointments at the public healthcare facility, Nelson is fearful. He is scared of being admitted and always gets nervous before each check-up. Once again, he seemed unwilling to further explain his hospital experience but added that the doctors and nurses are “nice” to him.

Overall, Nelson seemed insecure and had a difficult time discussing himself and his T1D. He is sad about having this chronic disease and prefers not to elaborate on how he feels. Emotionally, he is not coping and his poor management of T1D creates a constant struggle in his daily functioning. School awareness about T1D was an area which he said he would like to have improvement on and once out of school he has thoughts of studying engineering. He hopes that his T1D will be better controlled in the future.

5.3.2 THABO

Thabo is a 15-year-old, Black male living with T1D. He was initially misdiagnosed in December 2013 but recurring symptoms brought him back to hospital where doctors diagnosed him with this chronic disease at the young age of 11 years. At the time of his diagnosis and after, Thabo has been admitted to hospital three times for DKA. His HbA1c is above normal range; glycaemic levels higher than 11mmol/L. Even though Thabo does not have any diabetic complications, he is at risk of developing problems in the future if he sustains such uncontrolled glycaemic levels. Actrapid and Protaphane are the human insulins that he is currently using. No one else in his family is diagnosed with T1D.

He lives with his parents, grandparents, younger brother and younger cousin in Saulsville, a township near Atteridgeville.

Both of his parents work, his father is a carpenter and his mother is an accountant. He comes from a very supportive family; when asked about the roles they play in his T1D management he had this to comment:

I would say my little brother...my little cousin...they don't know or understand such things because they don't understand the disease. They too small. I'd say my parents are the one who give me the support mostly. They understand the disease more. My mom, she has this diabetes book, very thick, it was written by... I don't know...forgot the author. But she reads it, she understand mostly the disease and my father is the one who helps me control it and come to check-ups.

His parent's support was further highlighted when he spoke about how they incorporate his diet into theirs by making use of informative food pamphlets; allowing the whole family to eat healthy. His family is worried about his grandfather maybe having diabetes so it is another reason for the healthy living, which Thabo feels happy about. He expressed his joy that now they both share the same food choices and altogether this helps him to manage his T1D better.

Thabo is in grade 9 and is a high achiever at school; maintaining good grades in all subjects. The school is situated in his residential area. He spends a large amount of time falling asleep during lessons at school, which can be attributed to his imbalanced blood glucose. Transport is organised for him to get to school in the morning and after school he walks home with his friends. Thabo was overweight prior to T1D diagnosis and afterwards started losing weight to the point where he is now quite satisfied with how he looks. The weight loss is a result of mismanaged T1D and he still is not involved in any school sport or exercise. Diet seemed to be the biggest change that took place at that time. Prior to his diagnosis Thabo did not engage in any sporting activities and loved eating all types of sweets and junk food:

I didn't do sport, I used to stay with my friends and just talk, talk and talk...or maybe just listen to music while I did my homework or just listen to music in general. Before they [doctors] found out it was sweets, mostly sweets. Ish [African slang word]...I had to leave the sweets I loved behind. I was eating a lot of different kinds. Also I was eating a lot of junk. Bunny chows, burgers, chocolates and chocolates bigger than my hand (laughs loudly)...

The researcher found Thabo to be introspective, reflective and emotionally mature regarding himself and his experiences of living with T1D. He confidently explained that the time surrounding his diagnosis and hospitalisation was emotionally stressful:

(Sighs deep and heavily) Mostly I was sad and angry because of –you know– not seeing my family and staying here [hospital] because of the DKA and all the things that took me to come to this stage of staying in the hospital. It was the highs and lows which made me sad but most of the time I was happy because finally it was being controlled...until last year. At the time I stressed...very stressed. Because of the high they [doctors and nurses] say I need to stay for a longer period of time, so that they can take care of me. But when I went back home it stressed me...I didn't do much with my school work, everything wasn't fine...mentally I was stressed.

He happily reflects back on that time now because he is glad it did not get worse; he could start improving his health and making the correct adjustments to his life. He is educated about T1D treatment and shows no shame regarding his chronic disease:

I mostly test four times a day and I inject four times a day. Uhhh - 10 units in the morning and before lunch, then 12 units in the evening of which it is specifically specified for Actrapid and then 10 units of Protaphane at 10 o' clock at night... I'm not afraid of people seeing me or me with my sugar and diabetes issue. I mostly do it in public. When I inject, I inject in public. I do it on my thighs and my stomach. Sometimes when I've injected mostly here (points to his stomach) then I go to here (points to his thigh)... Ya, I don't mind showing people. I like to educate them about what I have. Sometimes my friends will ask why my sugar is high or if it is 22... they will ask when is it too low or too high or when is it controlled. So I feel kinda... I have the upper-hand there because they want to know about me and I don't wanna know about them. That's why I feel like I have the upper-hand because I am not afraid of taking out my equipment because they wanna know more and get educated.

Along with his positive mind-set, Thabo showcases acceptance and understanding about T1D. He carries snacks around for when his blood glucose drops, tries to eat correctly, applies insulin-to-carbohydrate ratio and maintains a certain ownership/familiarity over his chronic disease:

I've had it for about four years...now I am aware of what could happen and I am scared because when I am at the school I am tempted to eat the sweets that my friends eat. So I am mostly scared. Back then [before DKA] I wasn't scared because I didn't know what could happen so when my mum told me "eat this, eat that" I didn't always do it...I sometimes cheat.

His learnt through time that applying a healthy lifestyle will help his management of T1D. Although he continues to try his best he sometimes "cheats" by eating food that will raise his glycaemic level. Coupled with this he described that through certain family and friend gatherings he forgets or neglects to inject Actrapid or test his blood glucose. Thabo went on to describe that this happens due to peer pressure and that he sometimes also forgets to take his insulin with him when he leaves his home. Further, he expressed resilience towards the hardships associated with having T1D:

(Takes a deep breath) Hmmm... it's nothing compared to what HIV can do because that breaks down the immune system. This one [T1D] just breaks down the insulin in the body. Meaning that I can get medication for the insulin that I - that I don't have in my body. But HIV is taking away your life because it's breaking down your immune system. Meaning that if you have flu you may not die, but with HIV you might die because it breaks down your immune system. But this disease [T1D], I see it as soccer. Soccer you may break down but you can come back from it.

When the researcher asked him to elaborate, he went on to say:

Ya, but, let's say, broken bones may take a while for you to get used to that. Such as my granny. My granny has a broken leg; she's had it since I was three years old. So diabetes is like soccer, you break down but then you can come back from it. But like broken bones, you may heal but the original state will never be the same. So it sometimes depends on how you break down and what you do to come back from it.

The introspection shown by Thabo allowed the researcher to extract deep meaningful reflections about T1D. It was apparent that he spends a lot of time reflecting on his chronic disease and what it means to him. However, he stated that he still faces daily stress regarding his T1D and does not handle surprise tests at school well as it results in imbalanced blood glucose levels. To cope with this Thabo listens to music which makes him feel calm as it enables him to drift away from the pressures building up inside his mind and “run away” from his disease. Further, he regards himself as a religious person and engages in prayer to become “spiritually healed”. The support he receives from his friends and family is also mirrored in his school environment. A profile about his disease is available to all teachers and contains relevant information for emergencies and contact numbers. The lunch lady assists him with constructive food advice during break; a good rapport exists between them. Thabo would like his teachers to become more aware of how stress affects his T1D; this could help improve his management. Further, the school food could also accommodate his diet better which would allow for less temptation regarding his “cheat” meals.

Thabo is nervous before each T1D appointment. He described his experiences of the doctors and nurses as “mostly quite comfortable” but sometimes “scary” because they were unsatisfied with his management, high blood glucose levels and neglecting to fill in his T1D logbook. The stress Thabo has in this regard is due to his previous encounters with having DKAs and being admitted as a result. In the past, he has written false blood glucose levels in his T1D logbook which he now realises is only detrimental to him.

Since diagnosed with T1D, Thabo has experienced what can happen when a person does not take this chronic disease seriously. He wants to manage it better and is determined to follow a stricter lifestyle in this regard to improve his HbA1c and listen to what his doctors instruct him to do. Currently, he is not partaking in any school sport or exercise except walking home from school.

Overall, the researcher found Thabo to be emotionally coping with his T1D. His talkative, outgoing and positive personality showcased his enthusiastic and optimistic outlook over his disease.

His supportive friend, family and school environment also play a vital role in assisting him with self-care behaviours. Although his management of T1D needs improvement, his persevering and resilient attitude is a strong indicator that over time he will instil better habits. When asked about his future, he had this to comment:

I think my sugar will be a whole lot more controlled because now that I know that...I know that, err, consequences of what may happen if I don't look after myself. So I see myself, there, up there in university finishing school...with the sugar controlled (smiles broadly)

5.3.3 ALBERT

Albert is a 16-year-old, Black male with T1D. In 2013, he was diagnosed with this chronic disease during school holidays. His HbA1c is not within normal range; glycaemic levels above 11mmol/L. From having poorly managed T1D he has developed mild diabetic retinopathy. If not better controlled in the future he could be facing blindness and other T1D associated complications. Currently, he is using Actrapid and Protaphane human insulins.

He lives with his two brothers and mother, a single-parent, in a township. There are no other members in his family with T1D. His school is situated in the same residential area. Albert is in grade 10 and considers himself an “average achiever” at school. The researcher encountered him as reserved at the beginning of the interview but as time progressed he became talkative and more engaging. An interpreter was not required for his interview but the researcher would like to highlight that his use of English was not proficient. His father passed away in 2015 but at the time of diagnosis he remembers his parents being very concerned. Finding out that he had T1D was a difficult period in Albert's life; both physically and emotionally:

Ya, lost lots of weight. I think during those two days I went to the hospital and then –like- I was asleep for two weeks. I was asleep for two weeks...and then I awoke and then the doctors came and my parents were sitting on the side, telling me –uhh- this is my new life. I'll have to start living with it...they were very worried. I felt like –errr- everything was starting to change around me. Even though I used to drink products where that included suga and other sweets and snacks. It made me feel like I can't live a life like this, eating only fruits and vegetables because I love the cold drinks, I love the everything...but that made me really sad because I really couldn't do that anymore...really sad (looks down and sighs deeply)

Prior to his diagnosis, Albert had misconceptions about T1D. He did not realise what it entailed and how it would impact his life:

Before I thought it was a minor thing... that it would go away. But after acknowledging that I have diabetes –err- it really, it really changed my life... (Murmurs softly under his breath) it really changed my life forever...

Albert went on to describe how he experienced everything in a negative light after his diagnosis. He felt that his “simple life” had been taken away from him and was afraid of how his friends would react:

*Uhhh, my lifestyle...uhhh...was the simple life. I liked people, talking to people. I liked sitting in groups with my friends. So my lifestyle was basically open to everyone and that was –uhhh- basically my thing. Then after getting diagnosed with diabetes everything started changing from there...**everything** started changing. Some of my friends wondered what was going on –uhhh- I didn't wanna tell them that I was diagnosed but I didn't feel the need to tell them... I feel like, what was going through my mind...what will be their reaction when I tell them or their feedback.*

It became apparent to the researcher that he saw this as a traumatic life event that negatively impacted his social setting. When asked what overwhelmed him the most, he had this to say:

Everything! It became hard for me because they [his school peers] thought I was different from them. Like, yes like, in our class we would have children with mostly -err- mostly asthma. People –err- they know much about asthma than diabetes so they would understand his situation than understand mine situation and that made me feel like I'm left out on...stuff.

Feeling excluded from his school peers made it challenging for him to concentrate in school; creating a stressful learning environment. This was further aggravated by the lack of understanding by his teachers. Diet was another big change he had to face but acknowledges that a healthier lifestyle was needed. Even though Albert struggled in the beginning, he showcased a good understanding of his T1D treatment:

I wake up at six o' clock and take my machine [glucose meter] and test. If it is between 8 and 4 –err- I inject the Actrapid, 15 units. But if it is above, above...hmmm 10, ya I will actually add 2 more units to that 15 to keep it controlled and get it balanced, yesssh.

Albert being able to self-correct his insulin dosages show that he has learnt how his body reacts to insulin; a positive indicator for self-care behaviours. Although he sustains high glycaemic levels, Albert explained that his sleeping pattern is normal. He stopped playing sport in 2016 but reflected that he would get tired easily after playing for a short while compared to his peers. Fatigue from exercise could be attributed to his high blood glucose. He considered his lifestyle to be unhealthy prior to onset and jokes that having T1D has helped him to not become obese.

Since diagnosis, Albert has learnt how to emotionally cope with having T1D. Encountering many hardships allowed him to overcome his initial depressive thoughts and improve his life overall. This transitional phase helped him define his career interests:

I wanted to work as a social worker but I saw that –ahh- like, I used to cry on my own when I think I have diabetes. So I couldn't imagine myself helping others, children with the same needs as me or those who don't have parents. Couldn't imagine myself there but cause –ummm- I'm a visual artist so –err- I chose my interests in career changed from being social worker to being an architect.

Having T1D has made him aware of where his true interests lay. It seemed that the difficulty he faced displayed a negative outlook on himself and his coping behaviours, which caused him to redirect his career choice away from emotional settings. He went on to describe how he would like his school to become more aware about T1D. His teachers know he has the disease but they do not treat him appropriately in the classroom because of misconceptions. Further, he faces junk food temptation during break because his friends regularly offer him sweets. To counter this he has been educating his friends about his diet. Opening up about his chronic disease has assisted him to cope better socially.

Regarding his family and friends, Albert expressed how he would like them to not frequently worry about his diet and behave normally towards him. It seemed that he was concerned about their treatment of him and that this may be placing additional stress on his T1D management:

If –ah- I would like them to be –erm- open with me. Sometimes they will be like –ah- like –ah- “you cannot eat this because then you will die”. So I'd like them to live their life free and not be distracted by my disease because –ah- it's like they are living their life to please me, wabona? [African term for 'do you understand']. I want them to be the way they used to be with me.

To cope with having T1D Albert goes to church and receives support from his Bible teacher. He enjoys talking to him because he feels understood and can share his feelings in a safe environment. They spend time conversing about his future career and how he will manage his T1D. Becoming financially independent is a major factor for him as he explained this would grant him more freedom and allow him to provide for himself as well as control his T1D better.

Albert's mother is the sole provider for the family. He described that she undergoes financial and emotional stress regarding his chronic disease:

...my mother is the breadwinner at home so sometimes it's very hard for her to buy food which I'm mostly supposed to eat, which are mostly expensive for her. Her monthly salary is not –err- let's say...it can support both me and my brothers but on the other side I have a disease and I need special things. Sometimes it will make her feel like...sometimes she will cry, she will cry because my father died when I was in grade 8. I think it was ...my third year with diabetes so like my father would usually shows me that and that all the time. He would be the one who buy the stuff like what I need...yeah.

His father played a vital role to him; providing emotional and financial support for his T1D and to the rest of his family. Furthermore, his father passing away has placed additional pressure on his mother and it seems that her struggles upset him too. When asked what his family thoughts on T1D are he had this to comment:

I think my mom will say it's a disease that my child has because –err- because she doesn't have much knowledge about my disease but my two brothers will actually say the same answer.

The family's lack of T1D understanding was further highlighted when Albert described that they do not accommodate his dietary needs in their daily meals:

When they cook at home, they don't cook separately for me...they cook for the whole family. So they'll put salt and if –err- they making bread they put the suga in it...yessshh.

This has a detrimental effect on his management and treatment of T1D. Albert also went on to explain that sometimes he overeats and does not sustain a healthy diet when preparing food. Such behaviour could be the result from his family not incorporating his meal requirements. At school, he buys lunch and tends to indulge in “cheat” meals.

Due to Albert's poorly managed T1D he has been admitted to hospital three times; extreme dehydration caused by severe hyperglycaemia. Being admitted has made him scared of attending T1D appointments. He described being admitted in a negative light:

It felt different from what I usually do at home because –err-...they did a lot of tests. I hate hospitals, the tests that they must do, the needles...I hate hospitals. Sometimes –err- actually I must say most of the time usually we don't have our private...err...space. Many of them [other patients] will be infected and they will cough, they will not cover their mouth so...yessssh...so it's not good.

The public healthcare facility is overcrowded and this places stress on Albert when he comes to collect his T1D medication. He explains that it is expensive to travel there and if you do not arrive early there is a chance that you may not obtain your package that day. The doctors and nurses are friendly and he thinks their treatment of him is “okay”.

Overall, Albert is a positive yet sensitive individual. The struggles he faced at the beginning of his T1D journey has allowed him to grow as a person and even though he is still learning to accept his chronic disease he displays resilience and maturity.

His optimistic outlook for the future demonstrates his perseverance at managing his blood glucose better and adopting a healthier lifestyle. Although, he has high hopes that one day the doctors will find a cure.

5.3.4 LEBO

Lebo is an 18-year-old, Black female living with T1D. She was 16-years-old when she was diagnosed with this chronic disease. Since diagnosis, she has sustained high glycaemic levels; HbA1c above 11mmol/L. As a result, she has mild diabetic retinopathy. Due to her poorly managed blood glucose levels, Lebo now faces complications from having T1D. If not better controlled in the future she could be facing blindness and other problems associated from mismanaged T1D (American Diabetes Association, 2017a). Actrapid and Protaphane are the human insulins she is presently using for treatment. No one else in her family is diagnosed with T1D.

Currently, Lebo's living situation is quite unique. Her mother cannot take care of her financially; she now lives with her grandmother in a one bedroom flat in Irene, an area situated within the town of Centurion. Her grandmother, a domestic worker, lives and works on the premises for a White family. The family's mother has taken the liberty to become Lebo's guardian and pay for her schooling. However, she receives her medical treatment from the public healthcare facility in Atteridgeville. Prior to the interview the researcher spoke with her guardian to further understand the family environment. The guardian explained that Lebo was emotionally struggling with having T1D; showing signs of depression. An interpreter was required for the interview.

The researcher encountered Lebo as shy, sensitive and nervous throughout the interview. During the briefing session, she started crying because she was distressed about having T1D. Later she commented on why she was feeling sad:

I don't like it [T1D]...it's hard. It makes me feel emotional.

This behaviour reflected her lack of coping towards her disease. She maintained that she wanted to be a part of the study regardless of her emotional episode. Her physical health is at risk; she is overweight and does not partake in school sport or regular exercise. Her meal plan is unbalanced; she eats large portions and does not administer insulin-to-carbohydrate ratios. Although, she could clarify her T1D treatment, she later explained how she "forgets to test and inject". Also, she only tests her blood glucose once a day, in the morning.

When asked about the changes to her lifestyle Lebo was adamant that she was “fine”, that there was “no difference” and she was still “normal”. Her responses were seen as defensive and avoidant to speaking about T1D specifically. The researcher observed that her behaviour showcased feelings of denial and rejection towards having this disease. Furthermore, her improper T1D management was highlighted by her incorrect food and snack choices and negligence towards treatment; it seemed that she was undergoing a complete loss of control.

T1D demands intensive treatment and management which affects the adolescents’ lifestyle. The management of this disease requires ongoing adherence to multiple daily tasks in home, school and community settings (Palladino & Helgeson, 2013). Thus, effective T1D management is reliant on the involvement of family, friends, school staff and healthcare professionals. Lebo does not receive support from her friends, family and school. She attends a school in Irene; her friends are not aware of her chronic disease:

None of them know...only one knows. She was there when I was diagnosed. I won't tell them, I don't like to talk about diabetes...

Lebo elaborated on how she feels socially and the conflict she encounters with her grandmother:

When I am with my friends I feel normal and when I am at home I get angry. If they shout at me...my granny she shouts at me...maybe if I forgot to do something...inject...or if I forgot to do something that she told me to do. She [grandmother] asks me to help her at the house [domestic work chores].

She went on to explain that her family is not involved in her T1D management. She only visits her mother during school holidays. The father does not live with her mother and Lebo does not have any contact with him. Her guardian provides emergency medical help when needed but does not play an emotional supportive role for her T1D. Lebo’s grandmother has minimal knowledge on T1D:

I don't think she understands...she only knows about the sugar but she doesn't know the type 1 or type 2. She makes me food.

The school that she attends is not aware about her having T1D. Lebo does not want to notify her school about her chronic disease. It became apparent to the researcher that she felt insecure and embarrassed about having T1D. She experiences stress frequently and described her glycaemic levels as being “very high all the time”. In 2016 she failed grade 11 and is repeating it again. Her poor academic performance could be the result from her nonadherence and high HbA1c levels. When asked how she performs at school she commented that she is a “slow” learner.

Regarding her T1D hospital experiences, Lebo expressed a negative outlook:

They take too long...when they fetch the file. Today I came at 6:30[AM]...then I only finish at 12[PM]. I have only eaten since this morning.

She has been to many appointments but still neglects to cater for her T1D needs; carrying a snack is vital in cases such as these to ensure correct management. Lebo was reluctant to elaborate further but it seemed that her anger towards the doctors and nurses stemmed from her nonadherence:

Some are rude and some friendly...the rude ones are shouting, they get angry when they test my suga. Like then I get angry because I don't like some of them.

Overall, Lebo is not coping; her poor glycaemic levels and nonadherence are negative outcomes from this. She does not have emotional or social competence regarding her T1D. Discussing the disease was an emotional topic for her as she struggled to express herself. This has had a detrimental effect on her psycho-social well-being. She advocated her love for children and wants to be a child nurse or social worker after school, describing herself as the following:

I am the friendly one. I am the quiet one...who loves a lot.

Although, she faces many problems now, having this chronic disease has made her want to help other children. The researcher observed that her withdrawn and detached demeanour towards her disease has impacted her life. She does not harbour any foresight regarding her future T1D management and is “worried” about her health. Her lack of understanding about T1D was reflected in her responses to dietary requirements, not being aware that it is a chronic disease and that it is not inherited biologically. It seemed to the researcher that Lebo must still gain acceptance of having T1D and apply appropriate self-care behaviours in order to improve overall management and psycho-social well-being.

5.3.5 SARAH

Sarah is an 18-year-old, Black female with T1D. She was 13-years-old when she was diagnosed. Her HbA1c is above normal range; glycaemic levels above 12mmol/L. Due to poor management of this chronic disease she has developed mild diabetic retinopathy. If T1D management does not improve in the future she could be facing blindness along with other T1D associated complications. Since diagnosis, Sarah has been admitted to hospital every year for DKA and/or extreme dehydration.

Due to financial issues she only obtained a glucose meter in 2016; prior to this she attended monthly blood glucose tests at the public healthcare facility. She is presently using Actrapid and Protaphane human insulins for treatment. No one else in her family is diagnosed with T1D.

She lives with her younger sister and mother, a single-parent, in a township. Her mother is the sole provider for the family and is struggling to find a permanent job as a domestic worker. The family support she receives motivates her to improve her T1D and maintain a positive mind-set. The researcher experienced Sarah to be conversational, outgoing and confident regarding herself and discussing her T1D. She was eager to share her story and did so very expressively and in vivid detail. Despite her smile and laughter however, her concerns regarding people's perception of her reflected a deep sadness and vulnerable view of herself. During the period just after diagnosis, she admits to facing major emotional challenges:

...you know I was sad, I was so sad. I used to cry every day and think I'm being punished for something that I did or didn't do. Ya, because I was thinking "why do I have to be diabetic" or "why me"... I was -er- muddled. I was feeling mad, I had a lot of stress... thinking every day. Thinking to commit suicide.

Along with feeling distressed she also encountered a loss of self-image:

When I was walking on the street I felt like everybody was look at me and saying "she's diabetic". Then I wasn't myself that time...I was going through a lot of stress, being diabetic at such an earlier age. No sweets, no chocolates...that was the main thing that was stressing me...or foods was the main thing that was stressing me. It was a big change because my friends would be having the nice stuff at school and I would be having just bread with polony [processed meat] only.

Being diagnosed with T1D caused Sarah to feel victimised by the world; adjusting her diet and experiencing negative thoughts made her upset:

Yeah, it was tough...I had to stop eating the things I love and felt like people were looking at me. Like when I was walking I could feel this sadness inside me, this pain and hurt that I was feeling...

Sarah went through a difficult time coping in the beginning but the support from her mother has encouraged her to persevere:

You know I wasn't myself at first...at first when I found out I thought I should rather die...because no one has this disease and I am the only one...it's like HIV/AIDS that diabetes at my age you don't see it in other people...I thought I was the first one. But my mom told me "No, my daughter, you are not the first one. Some other have the diabetes when they are born"...so that's when I started to say no...I have to listen to what she said...I gotta take care of myself...ya.

Having a supportive family contributes to appropriate T1D management but having high glycaemic levels daily causes Sarah to stress. Even though she tries to adhere to her T1D regimen, she still maintains high blood glucose:

Yes, I'm more worried about what I need to do all the time. The most part...when it worries me...is when it's high [blood glucose level]. But no I'm being strict but still this happens...that's when it starts to stress me. I cry...I cry [looks sad but musters a small smile]

The researcher observed that although her blood glucose is not controlled, she has good awareness regarding her T1D treatment and management; she applies appropriate self-care behaviours such as regular self-monitoring of blood glucose, adjusting insulin units based on readings and insulin-to-carbohydrate ratios. She now understands how T1D is associated with living a healthy life and tries to follow the correct diet, exercise and treatment to improve her HbA1c.

Sarah described herself as being a “slender gal” before being diagnosed with T1D and has since been gaining weight. The researcher observed that she was concerned about diet, weight and exercise throughout the interview, indicating a possible disordered eating problem. She went on to explain that she has two close friends and a boyfriend that are also supportive when it comes to her diet. She feels embarrassed and scared to tell her other friends and school peers that she has T1D. She is fearful that having this chronic disease might subject her to negative name-calling and as a result administers her treatment privately. It became apparent to the researcher that she did not want other people to know because it would create a more stressful environment for her; making her not “normal”.

A close relationship exists between Sarah and her mother, sharing the hardships of T1D. The emotional support she receives motivates her to stay positive:

My mom is my best friend. She's my best friend...I'll tell her stuff and she'll tell me stuff...this this this...and then I tell her that “you don't have to do this to yourself”...like she's always crying because I'm high [blood glucose level], thinking of better things for me or something like that. I think my mom would say that she'd like my diabetes to go to type 2...stuff like that. But she stressing about going to the hospital and the money for me for the month or next month.

The researcher observed how Sarah had a global misconception about T1D:

One day it will be better - I'll have type 2 because I always hear people saying type 2 is good...it's controllable.

Having high hopes that T1D can convert into type 2 diabetes is a myth which many people in resource-constrained communities believe. The same misconception was expressed by her mother in the above aforementioned quote. Sarah understands T1D as “the one that is not easily controlled” and a disease that is “unstable”.

Generally, Sarah applies appropriate T1D management but sometimes she requires the help from her friends and family to remind her to test blood glucose and inject Actrapid. This occurs during gatherings and school holidays. Also, she mentioned that she used to indulge in sweet treats during the school holidays and when her mother was not around.

Sarah is currently repeating grade 10 again. In 2015 her family relocated from Lesotho and the school made the decision to hold her back in grade 10 for the following year. She went on to explain that having poorly controlled glycaemic levels has made her experience fatigue quite often and cause her to miss school:

I feel a lot more tired now because of this [T1D]...everyday...I'm the one just saying I have to take a nap. Wake up in the morning, lazy to get up. I even have to take a nap on Saturdays... Yeah I do miss school sometimes...like in school holidays I say “Why's the sugar high?”... Eighteen in the morning and even at school I have to balance myself all the time...it's [blood glucose level] high all the time. The sugar doesn't change if I'm at home or at school. I'm sometimes too tired to go to school but I can't just miss school...I enjoy my friends company so, ya.

Further, she described that it was difficult for her to concentrate during tests and exams. Struggling to manage her T1D, missing out on school work and obtaining poor grades resulted in her failing last year. She is concerned about her image and commented that her peers think she is a “slow learner”. The school is aware that she has T1D but does not allow her test concessions. Not all her teachers understand or know about her chronic disease and she is reluctant to talk to them. While explaining her school's meal plan she shared a moment of frustration towards her T1D:

(Casts head to the floor) Sometimes I just feel angry- I'm angry like... (Looks up and frowns, body hunched forward and foot shaking) I'm not supposed to skip a meal...but what should I do? I'm trying to eat this...I'm trying to eat that...it's high [blood glucose level]...so I think I need to get it down so I inject myself. I'm so angry - I know it's bad but -ya- (sighs deeply) it affects my everything...

To cope with having T1D she talks to her mother, friends and boyfriend. Communicating about the disease helps her feel understood and regulates her emotions. Sarah would like her insulin treatment to be improved so that she can have better control over her blood glucose levels. To deal with the stress she turns to religion and prayer.

Regarding hospital experiences, Sarah is satisfied with her public healthcare facility. According to her, the care she receives now is much better since she relocated from Lesotho. Even though she has to wait in long queues, she is pleased with the treatment from the doctors and nurses.

Overall, Sarah was open about discussing her T1D. Emotionally, she is still adapting to the hardships but shows resilience and perseverance. The support she receives from her friends and family create a safe environment for her to express herself. Even though she is struggling to manage her T1D, her mind-set is positive and over time she will strive to implement more appropriate T1D behaviour. Furthermore, Sarah is optimistic about the future; she believes that she will not be stressing about her T1D anymore and studying either human resources in the army or law.

5.4 CONTEMPLATING THE STORIES

Hearing each adolescent's story made the researcher aware of the diversity with which the phenomenon of T1D can be experienced. Each narrative was unique and brought to light the different elements of T1D and its impact on adolescent psycho-social well-being. The themes that emerged from these narratives emphasised that although each adolescent had a different interpretation and understanding regarding their T1D lived experiences, similar experiences and meanings were also shared. The themes are presented in a manner that attempts to capture the subjective truth of each adolescent's experience, as well as the shared truths and meanings surrounding this particular phenomenon. Thus, a cyclical pattern of variance and similarities will now be discussed.

5.5 EMERGENT THEMES

As discussed in Chapter 4, a number of superordinate themes emerged during the analysis of the research participants' transcripts. The themes reflect the participants' experiences and meanings of T1D and the surrounding areas that are impacted. Further, themes were constructed based on areas that are associated with the adolescents' psycho-social well-being. All or most of the participants' reported variations of each theme represented in this chapter. By using verbatim quotations from each participant's individual narrative account, individual and unique differences within themes are elucidated. Thus, the superordinate themes represent the shared experiences of the impact of T1D on the psycho-social well-being of adolescents, specific to the individuals who participated in this particular research study.

As aforementioned, the research question aimed to address the impact of T1D on the psycho-social well-being of adolescents and themes are presented accordingly. The complex essence of the subjective experiences and meanings of T1D is introduced, after which the impact of T1D on the various areas surrounding the adolescents' psycho-social well-being is discussed. Figure 5.1 shows the interconnected themes representing the impact of T1D on the psycho-social well-being of adolescents. Thereafter, an illumination of the themes is discussed.

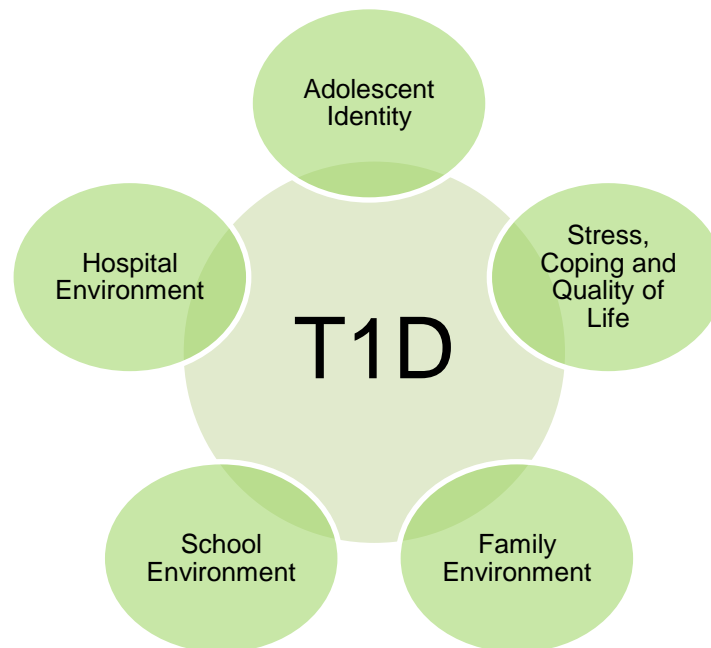


Figure 5.1: THEMES REPRESENTING THE IMPACT OF T1D ON ADOLESCENTS

5.6 IMPACT OF T1D ON ADOLESCENTS' IDENTITY

All five participants expressed meanings and experiences that demonstrated an impact of T1D on their identities. This was apparent in their narratives regarding their sense of self before and after being diagnosed with T1D. All participants went through confusion and loss of control prior to diagnosis. The initial symptoms of T1D made them struggle not only physically but emotionally and mentally as well. After diagnosis, most of them experienced an intense period of emotional distress which impacted their whole world; causing them to undergo major social adjustments.

Consider Nelson's description of what type of person he is:

I like to be quiet. Talking – eish! I don't like talking. Even in class. I am the quiet one but I make the jokes. But sometimes in the group, me and my friends we are talking.

He regards himself as a shy and reserved individual who occasionally enjoys telling jokes. Having T1D has made him feel weak and socially withdrawn. His perception of himself is negative because he explains that he “can’t control himself” and feels “less confident”. Even though he says that he is doing better, he still is not happy about having T1D. The disease has made him view himself in a different light. Also, his poor metabolic control has impacted his confidence and overall functioning:

I feel very bad with my sugar about three times a week where I need to lie down.

Thabo, on the other hand, expressed his relief when he was diagnosed. Knowing what was wrong with him gave him the opportunity to understand his health and lead a balanced life once more:

I was glad after the diagnosis because it could have gotten a lot worse if I found out later or at the wrong time. Maybe if it was too late –ya- I would have had too much complications than now. I am glad they got it earlier than expected.

He regards himself as “normal”; having this chronic disease has not altered his personality or social behaviour:

I would say that I am normal...as other children but from my diabetes...I have a normal life, I have friends. My best friend now, he’s the one that is mostly supportive. I would say I am normal because I have friends like other children, I’m not discriminated, not stereotyped...not gender stereotyped. When I say gender I mean girls who...I have best friends who are girls. They are not gender stereotyping me. I don’t know how to explain this one but...I know I am normal, like other children apart from my diabetes.

He went on to elaborate that he is the “talkative and outgoing one in the group”. Even though he showcases confidence and a strong personality, he still encounters periods of upset regarding his T1D:

...think that the world was trying to get at me, why did it choose me? Why did the disease choose me? Instead of other people. Mostly, I’m always angry at the world...or the people who diagnosed me for the disease but now I am aware that they tryna help me...I’m not so scared anymore and I am not so angry.

Thabo explains that the first two years were the hardest; he battled emotionally getting used to his new lifestyle with T1D. Regarding poor T1D management, he blames himself for not administering appropriate care but also felt a lack of support from his friends the last time he was admitted to the hospital:

It happened two years after they diagnosed me, but recently I was angry again because I had to come back to the hospital...because I was uncontrolled again and my friends didn’t help me. So it has its ups and downs.

Lebo’s unwillingness to disclose about herself or her T1D revealed an intense fear of judgement and low self-esteem. Similarly, she also finds herself getting upset regularly but due to her reserved and emotional demeanour during the interview she only had this to comment:

I am the friendly one. I am the quiet one...who loves a lot. When I am with my friends I feel normal and when I am at home I get angry.

In contrast to Lebo, Albert had no issue stating the impact that this chronic disease had on him:

But after acknowledging that I have diabetes -err- it really, it really changed my life... (Murmurs softly under his breath) it really changed my life forever...

His reflections on having T1D were detailed and emotionally expressive. Like Thabo, he seemed excited to tell his story:

I'd say...I'm an open person. A loving person who likes -err- I like telling jokes and stuff. Yessshh [laughs] and I love a lot. I'm actually shy at some points so I don't talk a lot.

While some participants appeared to be more affected, and differences were observed in their self-reflections before and after being diagnosed, it was apparent that T1D has an impact on all the participants' sense of self. Sarah is deeply concerned with how T1D has altered her physical appearance:

It does make me see myself differently, sometimes. You know when I take a mirror. When I look at my picture [looks sad]...my face wasn't the way it was.

She went on to explain how T1D has made her self-conscious in public:

When I was walking on the street I felt like everybody was look at me and saying "she's diabetic". Yeah, it was tough...I had to stop eating the things I love and felt like people were looking at me. Like when I was walking I could feel this sadness inside me, this pain and hurt that I was feeling...always from a distance everybody can see what's wrong with me. They know is not right. The fact that being ill sometimes -stuff like me- like they know I'm diabetic...my family, my friends, my boyfriend. They just know...this lady is diabetic.

Most participants highlighted the negative impact T1D has on their social identity. To most of them, having T1D is not something they would like others to know about or discuss. They felt ashamed, embarrassed, scared and/or nervous to showcase this chronic disease to their peers and friends. This has a detrimental effect on their self-care behaviours and overall management of T1D.

Nelson is afraid of embarrassing his friends and as a result administers his T1D treatment in private:

Nah I don't like [testing blood glucose or insulin injections] because they shame of me... (facial expression changes from a smile to a frown, eyes casted down on floor)

Lebo and Sarah are also worried that their school peers will judge them for having this disease; they perform their self-care behaviours in private. Sarah had this to say:

I do it privately at school...because if I do it publically –you know- sometimes you find that people fight over things in class like “borrow me a pen” and then you don’t want to...then they will start insulting you maybe about like “you, you have the diabetes” then I think I will get embarrassed.

The fear of being bullied has made some participants not want to share their T1D with their classmates or teachers. Sarah expressed her intense fear for what she considers a stressful classroom situation:

Yeah, no it’s like if there was a time - like if one day if I collapse or my class teacha will tell the whole class “no take care of Sarah, she’s sick” then they will say “heeeey, diabetic lady”...I’ll have all those...those names. Ya, I don’t even want to stress about my type 1 diabetes but sometimes I stress like I can’t have other people making me stress about it.

The principal at Albert’s school has asked him to perform his self-care behaviours in his office which impacts his insulin regimen and class time. Worried about what his friends would think of him at first, he withdrew himself socially for a while:

Naaah, like it took me some weeks to tell them so...basically I did tell them. Some were so comfortable with my situation and understanding but some were like I was going to die...yeah, things like that. So –but errr-some were so friendly...some were so like “nah this guy he might diagnose us with his diabetes”. It became hard for me because they thought I was different from them.

The lack of understanding from his school peers made him feel excluded and judged. It seemed that all participants’ encountered a stigma formed around T1D which caused them to be victimised; putting strain on their interpersonal relationships at school. Albert had this to say:

*But now that I am in secondary school some are understanding, some **don’t understand**. Others, some are scared because –err- they don’t know much about diabetes.*

Thabo also confirmed that his friends were not knowledgeable about T1D; they thought he had “old people’s disease”. Although, he was not upset by their responses and saw it as an opportunity to educate them about what he has:

I explained and I explained and I explained...then they started saying “ok, this is how it is”. Then their reaction was like, “you are normal but there is something that is making you...that is taking a little away from you”. That’s what they said.

Even though they see him as having a “handicap” he had this to say:

*I'm special even if I have it because some of you don't know what's happening. I am learning a lot more about life having this disease...more than you are, I am having more of a chance to learning more. So the disease that I have, you don't have it, you may have your own disease. In such a way, you have a **mental** disease but I have a **chronic** disease.*

Furthermore, Thabo's confident personality empowers him to promote his chronic disease and perform his self-care behaviours publically:

I'm not afraid of people seeing me or me with my sugar and diabetes issue. I mostly do it in public. When I inject [insulin injections], I inject in public... Ya, I don't mind showing people. I like to educate them about what I have. Sometimes my friends will ask why my sugar is high or if it is 22... they will ask when is it too low or too high or when is it controlled. So I feel kinda... I have the upper-hand there because they want to know about me and I don't wanna know about them. That's why I feel like I have the upper-hand because I am not afraid of taking out my equipment [glucose meter and insulin pen] because they wanna know more and get educated.

5.7 STRESS, COPING AND QUALITY OF LIFE

T1D-related stress was experienced by all participants. It seemed that treatment and management of the disease places additional pressure on these adolescents; causing variations in their psychological adjustment and adherence. Stress was mainly associated with having poor glycaemic control and T1D appointments at the public healthcare facility. Different coping strategies were observed from each participant. Through verbal and non-verbal observations it was apparent that T1D had an impact on their quality of life.

Nelson experiences stress on a daily basis concerning his T1D. Even though he mentioned that he has a friend that he can talk to it seemed he is not receiving appropriate emotional support and is struggling to cope. Signs of depression were observed in his interview:

I stress a lot every day...I feel sometimes I not want to go to school, work or do anything. Just want to stay in bed.

For Thabo, stress has a direct effect on his blood glucose levels. Emotions play a significant role on his glycaemic control; he often experiences high glucose as a result. In the past he displayed risky behaviour by not being honest with the doctors regarding his daily glucose levels.

This led him to be admitted for DKA and extreme dehydration. Thabo has learnt through these experiences to adhere to his T1D management and stresses as a result:

I don't lie anymore because I don't wanna come back here [public healthcare facility] because if I lie I may not know when its high and it can lead me to serious complications. I may think it's controlled but I'm lying to myself which could lead me to come back here.

His understanding of T1D reified the stress he faces:

Deadly disease...very deadly, but controllable. It's critical but stable, that's what I think when I think of it. Such as the buildings that are around my house...like you know shacks [primitive shelter]...we used to do shacks that were critical but stable. That's what comes to my mind when I think of my disease. So sometimes like if I sit here it might go there [gestures from his current spot of sitting to the other side of the room]...such is a shack, you might put the stick there but the stick might not be strong enough to hold what I want, so such is the disease. It is like trying to keep the place you are living in strong and stable all the time. It is also maybe if I take a whole lot of sweets...it's either there or there [gestures with hand to show that his blood glucose level could either go very high or very low]. You never know...

Sarah shared a similar understanding of T1D by referring to it as “the one that is not easily controlled” and an “unstable” disease. Defining T1D proved difficult for the other three participants. Due to Lebo’s avoidant behaviour throughout the interview it was noted that this could be related to her not coping and distancing herself from the disease completely. Albert and Nelson found it challenging to formulate their words, consider Albert’s definition of T1D:

[Takes a while to reply]...type 1 diabetes is when a person has like...his...how do I put this. He can no longer produce insulin so that makes it –err- let me say –err- hard for his cells to move around because there will be too much sugar and if his body is unable to produce insulin...the suga in his or her body will not be able to go everywhere...ya.

It was interesting to note how mature and introspective Thabo’s reflections of T1D were compared to the other participants. His ability to understand and interpret his disease showed a deep connection and familiarity. To cope with the stressors of T1D he turns to music:

I would say music is...something I use to runaway...to take refuge to run away from this disease because when I am listening to music I tend to get calm. Because I love music and I am doing music at home. So when I am doing music –uh- listening to music is like I am listening to myself spiritually. I am being calm, kinda like self-hypnosis, as I would say.

All participants said that they only use the medication given by the public healthcare facility. It seemed that most of them were scared of using any other spiritual medicine or traditional healers. Most of the participants stated that they were religious, using prayer to cope spiritually. Thabo explains why he is religious:

*I would say religion because I don't believe in healers because that's the thing that got people mostly afraid of superstition. Thinking that there's witchcraft mostly. Such as **us**, I would say that Black people because we are afraid of being bewitched. Even though it is something...something that is mostly belief. I know there are some traditional healers, which are witch doctors. I know some of them use their...whatever it's called, they say it's a gift, they use it for evil. Some use it for good, so I don't believe in such things because it may lead me unto a path where I may go to different types of healers and then when I come back home they may say you are rotten in yourself inside because you take things that you use medication for. I'm always praying because I want to be spiritually healed of the disease but I know it is there physically. So I'm always praying, **every single day**, asking God for help to help me control it, help my family give me support, control it so I am always praying. Even when before I come here [hospital] early in the morning, I'm praying that they do not admit me...hmmm [looks away and takes a deep breathe]*

Albert prays and also receives support and guidance from his Bible teacher:

Usually I'll go to church and since my bible teacher is so open to me like...his mother was diagnosed with diabetes and so he would share some notes on how to cope with diabetes.

Self-acceptance seemed difficult for most of the participants. All of them would like to be seen as “normal” and not “sick/ill”. For some, acknowledging the impact of T1D only took place after they experienced physical complications due to mismanagement. Albert and Sarah also reflected that the fear of what could happen to them makes them stress:

*Albert: Not very happy. I feel like –err- I'm getting to the point where my life is going to end like...like it's over...I don't have anything to do or add to life. Everything became **so hard for me**. Yesssshh, ya...2015 I started acknowledging more about diabetes –err- when the doctors were telling me what to do –err- if my blood glucose is like this and that...during those years they will scare me because if my glucose is high then there is these chances of my leg being cut off or my sight.*

Sarah: Later on cause...now I was reading about diabetes and as I read on social networks and research – let's say- I saw that this thing was very dangerous. So the fact that I used to hear “no we are going to cut your feet...see this man, this woman only has one leg” then I was crying too much. It stress me so much – ish.

Adhering to their disease requirements is a constant challenge for all the participants. The stress felt daily from unbalanced blood glucose control upsets them emotionally. Sarah was open about how this made her feel:

Ya, it makes me sad. That's the most problem I have from this. I just have a little bit of stress and then it goes. After crying I feel like the pain...the pain on the inside can go away...so after crying I feel like the pain is going away.

All participants explained that their diet was a big change that they are still adapting to. Further, nonadherence to treatment, meal plans and exercise was observed from most. Thabo tends to “forget” his treatment:

Hmmm...yesterday, I forget to take my insulin, I left it at home. I'm supposed to have it with me but I forgot it. Also, it used to happen at family gatherings because I was overexcited and I forgot to take my medication and check my sugar because my cousins were mostly saying “let's go eat this” or “let's go do that”...ya.

Problems adhering to portion size and healthy food were also experienced:

Nelson: Sometimes – ish- is too high because I eat too much. Sometimes I don't check and then it's too high.

Albert: Hmmm...most of the time it'll be after school like...I already ate at break so I'll be hungry the same time but then I rush home, find out that they haven't cooked yet so I take whatever is there to eat and eat it and then I find out that I –err- actually ate too much. So then my sugar will go high. I normally buy lunch at school...sometimes I feel like I will cheat a little bit –ah- because if I don't buy fruits I normally buy snacks, like chips and sometimes sweets.

Sarah: You know in school holidays, sometimes –ish- I forget to inject...that's what I do sometimes. I'm having cakes, especially when my moms isn't around. I used to do that. I used to steal a piece of cake. Go to steal a muffin –you know- the things I mustn't have...especially in holidays when there is a big family [gathering], is hard not to [laughs at herself]

Overall, all participants expressed areas in their lives that underwent changes. Their physical well-being is impacted by T1D, falling asleep during school lessons and exercise. Fatigue was a noticeable trend:

Thabo: During the week I sleep during periods [at school], such as English, maths and home language, which is Sepedi, and sometimes –maybe- when the teacha isn't in the class then I sleep. When I return home from school, I sleep because I wake up early in the morning but during the weekends I sleep late then I wake up late...so during the day I can sleep.

Sarah: I feel a lot more tired now because of this [diabetes]...everyday...I'm the one just saying I have to take a nap. Wake up in the morning, lazy to get up. I even have to take a nap on Saturdays.

Lebo: Tired...very tired...more than the other kids.

Albert: Like playing for a long period whereas –ah- I can't play for that long period...I can only play, let's say, for like an hour or two. At that time I still have to check my glucose and also inject so –ya- I do other stuff than them now.

Adjusting to a different lifestyle with T1D has created additional pressures on each adolescent. Only two adolescents are participating in school sport and regular exercise. All participants have ineffective T1D management due to incorrect diet and nonadherence to treatment.

5.8 T1D AND FAMILY ENVIRONMENT

Each adolescent had a unique family environment but similarities were observed regarding family structure, family support and parent/guardian grief. All participants come from low-income families and cannot afford medical aid schemes or attend private healthcare facilities. Three of the participants come from single-parent households and experience financial and emotional hardships. Consider Albert's family situation:

My mother is the breadwinner at home so...sometimes it's very hard for her to buy food which I'm mostly supposed to eat, which are mostly expensive for her. Her monthly salary is not –err- let's say...it can support both me and my brothers but on the other side I have a disease and I need special things. Sometimes it will make her feel like...sometimes she will cry, she will cry because my father died when I was in grade 8. I think it was ...my third year with diabetes so like my father would usually shows me that and that all the time. He would be the one who buy the stuff like what I need...yeah.

Financial strain also places pressure on accommodating the adolescents' T1D dietary requirements. Sarah explains how her family is affected:

I used to eat all the food I want...now I can't get anymore, my mom is trying because we can't really afford to do that...I think my family doesn't treat me differently but they don't have the things they want like the meals they supposed to have but they have to take my brown rice just to make me feel...like my mom is supportive, my lil' sister is supportive but due to the thing that she's young...she still doesn't know about the diabetes.

Lebo comes from a single-parent household but has moved in with her grandmother because her mother cannot support her financially. The lack of family involvement has caused her immense emotional stress. She added that her guardian is concerned about her health. However, parental support and T1D guidance was observed from Thabo:

I would say my little brother...my little cousins...they don't understand such things because they don't understand the disease. They too small. I'd say my parents are the one who give me support mostly. They understand the disease more. My mom, she has this diabetes book, very thick, it was written by, I don't know...forgot the author. But she reads it, she understand mostly the disease and my father is the one who helps me control it and come to check-ups.

Most of the participants do not have the same family T1D involvement as Thabo. It was noted that they attend appointments on their own and family members had a lack of understanding regarding their chronic disease. Albert's brothers often tell him that he cannot eat what they are eating; he is not considered when the family makes meals. He feels unsupported and reflects that it negatively impacts his general T1D management:

When they cook at home, they don't cook separately for me...they cook for the whole family. So they'll put salt and if –err- they making bread they put the suga in it...yesshhh.

Parent/Guardian grief was observed from all participants. They all stated that their families experience blame, stress and/or sadness. Nelson's mother is overwhelmed and feels helpless:

She feels bad. Because this thing is too dangerous. She stressed for me. When I am sick it is difficult for my mom.

Thabo's parents, although supportive and strong minded, are also experiencing grief:

Mostly, my mom is mostly sad...because she thinks that she failed me by not helping me exercise my body enough...back then. So she feels disappointed in herself. And my father...my father is a bit of both. He's happy when I can control it and sad when it is not controlled and I am here at the hospital [referring to when he gets admitted to the public healthcare facility].

Sarah is concerned about her mother's grief. She explained that her poor glycaemic control causes her mother stress and emotional upset:

...like she's always crying because I'm high [blood glucose levels], thinking of better things for me or something like that. I think my mom would say that she'd like my diabetes to go to type 2...stuff like that. But she stressing about going to the hospital and the money for me for the month or next month. You know what, sometimes, I'll always have to inject myself...she'll be looking at me [pulls a frown on her face] and then suddenly the tears will be flowing. It's not kind of like she'd be happy in that but every day she appreciates and says that God you know why this is happening, ya.

Overall, it was apparent that the participants were aware of how T1D impacts their family environment. It has caused parent/guardian grief and added additional stress on finances. Appropriate family support and involvement was not present with all participants. Families who have lack of T1D awareness and understanding negatively impacts the adolescents' management.

5.9 T1D AND SCHOOL ENVIRONMENT

A large portion of the adolescents' day is spent in school and to ensure a safe learning environment school staff should be knowledgeable about the provision of T1D care. The parents/guardian and healthcare provider should collaborate and provide the school with the necessary information to address the specific needs of the adolescent and provide instructions regarding blood glucose monitoring, insulin treatment, T1D care tasks (for hypo- and hyperglycaemic events), participation in physical activity and emergency contacts. Furthermore, special considerations for T1D management at school should be implemented for self-management, nutrition and academic assessment.

The aforementioned was not reflected in the adolescents' experiences. It appeared that T1D school awareness and teacher support was an issue. As mentioned earlier, most of the participants' schools are located in a resource-constrained community. Even though most of the participants have notified their schools about their T1D, the proper understanding and care is not implemented in the classroom. Consider Thabo's experience:

There is a profile for me at my school and it is written there for my teachers. There is even a question there that asks about health and what cell phone number is there for my doctors but it is non-applicable because I don't have a real doctor...I don't know how to say it, but I don't have a doctor. And then, all my teachas at my school, everybody that attends my school...knows that I have the diabetes but mostly my class and my teachas...the others some few.

Lebo refuses to tell her school about having T1D; as a result she does not receive any support or care. Similarly, Sarah refrains from discussing her disease with her school; she says "it hasn't been so bad at school where I need help".

It seemed that she wants to hide her T1D from her teachers:

They [teachers and principal] haven't called me to ask about my diabetes –you know- like when I'm asleep [in class] my teacha just calls me "Just come". Then I go to her and she asked me if I'm alright and I'll say I'm alright... then there was once a time with my gym teacha and she said, "No, just come with me"...she was wondering what's wrong with this child, she was looking at me funny, looking at my face...then she just called me "Sarah, are you alright?" I said "Yes ma'am, I am alright" she said "No, aren't you diabetic?" Then when I looked surprised she knew I was diabetic. She told me to treat [help/manage] myself...eat healthy, all this stuff, ya.

Albert and Thabo experience conflict with their teachers. The teachers' lack of understanding has had an impact on their classroom and academic performance. Thabo experiences stress related to random assessments which cause his blood glucose to fluctuate:

...my teachers are sometimes like this and sometimes like that [gestures with hands in opposite directions]... But when they [teachers] give us a surprise test it affects my relationships with my teachers. When there's a surprise test I don't know what to study or what I was supposed to study so now I am afraid of what is going to happen in future...what are the results going to be on my report. So I am mostly scared and then my sugar [blood glucose] goes high.

It appeared that Albert's teacher was not supportive. He faces a stressful classroom environment:

... my teacha she understood my situation but in a way...I would put –err- he will criticise me for what I am diagnosed with and other learners for how they look and their physical appearance...their backgrounds.

He went on to mention how T1D-awareness could improve his management:

Ah- in school if they are open...with their disease and such. That could help me a lot because I know some of the people in my school, we are related because of our diseases...in a point –err- we can help each otha if we are in need...yessshhh.

All participants explained that keeping to a strict meal-plan was a challenge at school. Their friends "tempting foods" cause them to "cheat" and the school cafeteria does not provide healthy food choices. When asked what could be improved on in their school environment most responded that they would like more meal options catered for their T1D. Thabo had this to comment:

I think at school if they start serving more type 1 diabetic foods, maybe my sugar will then be a whole lot more controlled. Maybe I'll start using less insulin that I am using now...I will inject a little bit less than I am injecting now...There is this lunch lady who works at my school and one cleaning lady who has the diabetes so that helps. The lunch lady and is always checking my lunch box and at break is always coming to me and checking what I am eating...am I eating right or am I eating wrong. If I cheat then she says eat a little and then takes some of it and then gives it to my friends.

Academic performance is impacted by poor T1D management. Uncontrolled glycaemic levels have had an effect on the participants' concentration and general physical health. Nelson had this to say:

If I am getting dizzy, I can't concentrate, you see. Then my teacher comes and asks me what's wrong...During class, when the teacha is busy teaching. I feel so tired, eh.

Although Thabo is a high achiever and maintains good grades, he also experiences the effects of unbalanced blood glucose during school:

Hmmm...I mostly feel the lows, when it's high I have a headache and when it's low I shake, shake, shake...shiver, maybe I even sweat a lot. Sometimes I also feel weak...If it's high I get stressed, sometimes when the teacha approaches me in class, my heart beats so loud and fast and when I test I see it is 15 or 17.

Poor academic performance has caused three of the participants to fail a grade since they have been in high school. Both Nelson and Lebo failed the following academic year after they were diagnosed with T1D the previous year. It was not clear whether their low grades were directly affected by T1D mismanagement and uncontrolled glycaemic levels. Some of them stated that they were “slow” learners and encounter emotional stress while at school. Sarah explains her frustration regarding school performance:

You know sometimes –especially last year- I didn't expect to fail. The time I got my report I was surprised! Then I started complaining...I even believe that sometimes I even feel like I'm studying. As I write...they gone...the time when I'm writing, they gone [studied information]...Yeah [Looks frustrated and irritated]

For most of the participants, the school setting is a stressful environment due to high glycaemic levels, social identity and T1D management. It seems that this perceived stress may also have a negative impact on their academic performance. Furthermore, having mismanaged T1D has impacted the participants' school attendance. Most of them have been admitted at the public healthcare facility for extreme dehydration and/or DKA. Others noted that on some days they were feeling “ill”, “too tired” or emotionally drained; causing them to be absent from school. Sarah had this comment:

Yeah I do miss school sometimes...like in school holidays I say “Why's the sugar high?”... Eighteen in the morning and even at school I have to balance myself all the time...it's [blood glucose level] high all the time. The sugar doesn't change if I'm at home or at school. I'm sometimes too tired to go to school...

5.10 T1D AND HOSPITAL ENVIRONMENT

All participants receive T1D treatment and care from a public healthcare facility in Atteridgeville, South Africa. The public healthcare facility is funded by the government and has limited available resources. None of the participants can afford medical aid schemes, Continuous Subcutaneous Insulin Infusion (CSII)/insulin pump therapy or continuous glucose monitors (CGM). The public healthcare facility only has access to short-acting human insulin (Actrapid) and intermediate-acting human insulin (Protaphane) which is used for either a basal-bolus insulin regimen or a twice-daily insulin regimen (premixed Actrapid and Protaphane).

Further, only basic glucometers and limited glucose test strips, needles and lancets are available. All participants collect their insulin and glucose test strips on a monthly basis. The T1D multidisciplinary team consists of adult healthcare professionals, nurses and dieticians. Unfortunately, there are not enough certified diabetes educators available. Some of the participants showed signs of depression and anxiety related to T1D, although no referral was made to see a social worker or mental health professional.

Even though there is a paediatric diabetes ward all participants are currently being treated by the adult diabetes ward. They are all struggling to reach their HbA1c target and are scheduled to see the healthcare professional every three months to improve their T1D management. This is also done to do routine check-ups regarding possible acute and long-term complications. All participants have been admitted to the public healthcare facility for extreme dehydration and/or DKA. Being admitted has been traumatic for most of them; emotionally and physically. As a result a collective fear was experienced prior to and during appointments at the public healthcare facility:

Nelson: I am feeling bad because I too scared to be admitted.

Thabo: I like to have two small bananas but no more sweets or chocolates...I don't want to come back here again [frowns and casts eyes to floor]

Albert: Sometimes before I come I will actually feel stressed because it will be high only some days...and I know some doctors are so concerned –err- with the diabetes people. They will want you to be extra careful and super healthy and stuff. So they will actually admit me and I don't like to be admitted.

It is noteworthy to state that upon diagnosis the adolescents' received T1D education and training from the healthcare professional and dietician. However, follow-up education and training regarding specific T1D care was unclear from the interviews. Regarding T1D management, it appeared that nurses and healthcare professionals are reprimanding these adolescents instead of providing ongoing support and education. A personal connection with their healthcare professional does not exist; with each visit a different healthcare professional is on duty for that specific period of time. Consider Thabo's experience:

Sometimes when I come to the doctor-when they say "you're not a child...we're not supposed to tell you one thing over and over"...I sometimes wonder if they really know what I'm going through... [Looks irritated and anxious, smile disappears and is replaced by a big frown] this is where the stress also comes from...I have had a lot of check-ups. Firstly it was controlled and then it was two months apart when the check-ups or the follow-ups-neh. Then after it wasn't controlled I was admitted, my longest day was close to two weeks, say one week and six days, then after...mostly...the experience is quite comfortable because the nurses now know me personally who when I get here they always asking me questions. "Why am I eating this? Why wasn't I testing? Why wasn't I filling up my diary?"...those such things. So, sometimes my hospital experience is nice but mostly it's scary.

Although he generally is stressed about his appointments he reflected positively on the one he had had that day:

Hmmm...today was the most...today was the happiest day of my life because the doctor that I saw today was the most friendly, because he mentioned everything that may happen to me in the most friendly way. She wasn't harsh, she wasn't impatient but she was listening to my opinions and what I had to say to her. So today was the most –err- epic experience I've ever had. The treatment [referring to his insulin medication] for today, I don't know because they didn't change anything.

According to the adolescents' experiences, it seemed that the general treatment by healthcare professionals and nurses centred on rebuking the adolescents for not attaining glycaemic levels and/or administering appropriate self-care behaviours. Consider Lebo's experience of treatment:

[Referring to healthcare professionals] Some are rude and some friendly...the rude ones are shouting, they get angry when they test my suga. Like then I get angry because I don't like some of them.

Albert expressed his overall immense dislike for public healthcare sectors:

I hate hospitals, the tests that they must do, the needles...I hate hospitals. Sometimes –err- actually I must say most of the time usually we don't have our private...err...space.

All participants stated that when collecting T1D consumables or coming for appointments they encounter queues that are “too long”. Even when they arrive early it would end up taking most of the day, impacting their school attendance. Albert feels that he receives “equal” treatment and that they are “very nice” to him but highlights a negative factor which is shared amongst all participants:

Ever since I started coming to the hospital, here for me treatment and my doctor's appointments. Right now I'll say –ah- the biggest problem for us patients in this hospital...is we always too much... too many. So some will not receive their medication because the pharmacy will close at a certain time and if we are too many there will usually cut the line and some will not receive their medication and the will have to travel back again tomorrow which is quite far...which adds to their expenses because...the travel money, ya...

As aforementioned, the public healthcare facility has limited resources and the only insulin available is Actrapid and Protaphane. Nelson is the only adolescent using a twice-daily insulin regimen; the others are on specifically tailored basal-bolus insulin regimens. The basal-bolus insulin regimen encompasses four injections per day (basal insulin prior to breakfast, lunch and supper; bolus insulin at night). It is interesting to note that even though all participants could explain their insulin regimen, nonadherence to T1D treatment and management was observed. It was unclear whether poor glycaemic levels are associated with the specific insulin regimen prescribed to each adolescent. Sarah questions her insulin regimen:

Ya, I always wonda about it and sometimes decided that I'm going to see the docta. I must tell him or her that I think the medicine [insulin regimen] is maybe needs more units because it's high. Most of the times it's high... so maybe it's not my diet this time maybe is the units [prescribed insulin dose] I'm taking.

However, poor self-care behaviours were documented regarding self-monitoring of blood glucose [SMBG] and insulin regimen. A general complaint was observed surrounding blunt lancets and insulin pen needles; reuse of these needles is painful. When performing SMBG, Thabo explains the discomfort:

When I am pricking these two fingers [shows his index and middle finger] they are not so painful than the thumb. When I prick too often I can feel it going through the bone [frowns].

Pain is also associated to insulin pen injections. Although, most participants mentioned appropriate injection sites (i.e. abdominal and/or buttock area), it was unclear whether pain was caused directly from reused needles or incorrect rotation technique. All participants receive the same amount of glucose test strips, lancets and needles monthly from the pharmacy at the public healthcare facility. Each adolescent receives 100 blood glucose test strips every month; this equates to approximately three blood glucose tests that can be performed daily. Thabo elaborates:

I am not supposed to change it frequently. If I do then they will get used up too quickly. I get used to the needle for a while, I can't change it twice a day or every day. I get every time I come for my appointments. So every month I get my lancets and needles. I am not sure how many, they give according to how much they think it will last me until the next time I have to come collect. This is either for one months or for two months. I have a lot more needles for my 'injecter' [insulin pen] than for my glucometer.

Nonadherence to T1D management was observed through experiences of incorrect frequency of SMBG and neglecting insulin injections. Some participants only perform SMBG once or twice per day, while others tend to "forget to test or inject" prior to mealtimes.

5.11 SUMMARY OF CHAPTER 5

This chapter centred on providing the results of the research process. The themes presented are considered integral to exploring the phenomenon under investigation. Having presented verbatim quotations from the participants for each theme, the chapter developed truthful accounts indicative of the experiences of adolescents with T1D. The presented themes focused on the adolescents' subjective experiences of T1D and the impact it has on their psycho-social well-being. Since the themes appeared to be interrelated, they were not presented in any specific or chronological order. Noteworthy answers were obtained regarding the exploration into the adolescents' experiences and meanings of T1D and the impact thereof on their relational worlds.

6. CHAPTER 6: RESEARCH OVERVIEW AND CONCLUSIONS

6.1 INTRODUCTION

This chapter offers clarity and refinement of the results obtained by this research investigation. The results of the present study provide an informative description of the subjective experiences and meanings of the impact of T1D on the psycho-social well-being of adolescents. It is evident that this is a multi-faceted and emotional phenomenon for the adolescents who partook in this study. Five adolescents with T1D offered accounts of their stories during in-depth interviews. Several themes were uncovered through Interpretative Phenomenological Analysis (IPA) of the interview data and were presented in Chapter 5. This chapter presents a critical discussion of the findings in relation to other relevant literature. Thereafter, possible strengths and limitations of the study are discussed, followed by recommendations for further research.

6.2 CRITICAL APPRAISAL OF THEMES

Considering the research question, the aim of the study was to explore the impact of T1D on the psycho-social well-being of adolescents. A comprehensive review of the available literature on adolescent development and T1D highlighted various aspects regarding the phenomenon of T1D. Aspects relating to the adolescents' psychological, physical, cognitive, spiritual and social well-being were explored. Furthermore, the interpretative process allowed for themes to emerge during the analysis of the participants' transcripts. Five main themes were identified concerning the meanings and subjective experiences of T1D, namely:

- Impact of T1D on adolescents' identity
- Stress, coping and quality of life
- T1D and hospital environment
- T1D and family environment
- T1D and school environment

It is significant to once again explain adolescent psycho-social development and well-being to provide clarity and understanding for this study and to the research question. The psycho-social development that takes place during adolescence can be characterised as progressive tasks that develop autonomy, establish identity and future orientation (Sanders, 2013).

Thus, the term psycho-social underscores the combined influence that psychological factors (e.g. thoughts, emotions and behaviour) and the surrounding social environment (e.g. relationships, traditions and culture) have on the individual's mental and physical well-being, as well as his/her ability to function. According to Khan (2013), the term well-being is a state of universal health in all its domains physically, cognitively, emotionally, socially, economically and spiritually. Studies have shown that adolescents with T1D have the poorest metabolic control in comparison to other age-groups (De Wit *et al.*, 2008; Delamater, 2007; Delemarre-van de Waal, De Wit, Pouwer, Gemke, & Snoek, 2007; Reynolds & Helgeson, 2011). The daily demands of T1D self-care can interfere with the adolescents' development; affecting their relationships and routines, comprising their social and emotional well-being.

Since the intention of the research was to explore and describe the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community, the researcher relied on Engel's biopsychosocial model, Systems theory and Phenomenology in conducting the research. Phenomenology served as a theoretical point of departure in this study, as well as underlying the methodological procedures used to conduct the research (Lyons & Coyle, 2016); allowing for T1D to be viewed as a phenomenon in the context of mutual interaction and influence within the adolescents' lived experience. These theories assisted in directing attention away from T1D being viewed as a single entity, but rather to a broad context of interrelated psycho-social factors that can impact the well-being of these adolescents.

The stories presented in this study emphasise the hardships experienced by these adolescents with T1D in a resource-constrained community. Further, these hardships highlight an overall sense of disruption to the adolescents' lives regarding their psychological, physical, cognitive and social well-being. This perceived disruption has had an emotional impact on all of them, irrespective of positive or negative outcomes. Themes relating to the aforementioned will now be discussed in accordance with relevant literature.

6.3 IMPACT OF T1D ON ADOLESCENTS' IDENTITY

Adolescence is considered to be the period of transition from childhood into emerging adulthood (Arnett, 2014a; Sanders, 2013). It can be seen as the bridge between being a child and becoming an adult. Major changes take place physically, cognitively, psycho-socially and emotionally during this phase. In the face of significant developmental changes they must learn to adapt to a variety of skills to effectively manage their disease, obtain individuality and establish a secure identity.

In accordance with the literature, the participants experience difficulty establishing a positive self-image because of the impact of T1D and the ongoing daily pressures of managing the disease (Chamberlain, Rhinehart, Shaefer, & Neuman, 2016; Dhada *et al.*, 2014; Haas *et al.*, 2013). Maintaining a 'normal' identity was of pivotal concern for most participants; having T1D causes them to encounter negative ideas and feelings about the way they fit into society as a whole (Knight, 2017; Louw & Louw, 2014). Aspects of discrimination, rejection, bullying and social anxiety have disrupted their social identity and treatment adherence (Alexander, Waldron, Robbins, & Neeb, 2013). It appears that most participants hide/deny having the disease for fear and embarrassment that their peers may learn about it; such behaviour cause them to neglect their T1D self-management at school and/or other social gatherings (Sanders, 2013).

According to Louw and Louw (2014), poor self-esteem is directly related to the inadequate development of self-identity in adolescence. Adjusting to this chronic disease during this transitional period of development is physically and emotionally challenging to these participants. Intense trauma and complete loss of control were experienced at the time of diagnosis. The perceived meanings and experiences surrounding this lifestyle adjustment highlighted feelings of loneliness, isolation and social exclusion (Freeborn, Dyches, Roper, & Mandelco, 2013; Roper *et al.*, 2009). Thereafter, the participants illustrated various behavioural and emotional experiences that indicate that adjusting to T1D is an ongoing challenge which impacts their pre- and post-T1D perception of themselves.

During middle and late adolescence, autonomy is also established (Erikson, 1959). Significant lifestyle changes need to be adopted for T1D treatment. Considering the adolescents' experiences, it seems their identity goals are further disrupted by the disease itself and the treatment. Understanding and administering self-care of T1D have given some of them a certain form of autonomy but for most it is seen as a major disruption to daily routine. This identity disruption causes anxiety and distress which provokes some adolescents to not adhere to treatment and revert to risky behaviour (incorrect diet, omitting insulin doses and neglecting SMBG). This experience is along the lines of Piaget's (1951, 2013) ideas of egocentrism and the constructive perspective. Adolescents' start to think more about themselves; their ability to reflect on own thoughts combined with their physical and psychological changes. In this study, the imaginary audience is detrimental to the participants' behaviour and self-image (Elkind, 1967, 1985, 2014). Sanders (2013) states that peer support can be an asset in the treatment of T1D and can provide a beneficial type of social support from that given by family members.

All the adolescents in the present study have experienced a lack of support from their school peers. Stigma and judgement surrounding T1D appears to be a common trend at school. Furthermore, misconceptions about the disease have made them feel victimised and viewed differently in the classroom.

Regarding teacher and peer victimisation, studies have revealed that adolescents with T1D experience anxiety, rejection, loneliness and depression from such discrimination (Nabors, McGrady, & Kichler, 2010; Storch *et al.*, 2006). According to Peters, Storch, Geffken, Heiderken and Silverstein (2008), the adolescent may develop poor emotional and social adjustment from such a negative schooling environment. Although many youth are at risk for being mistreated, these adolescents with T1D have greater susceptibility due to self-care behaviours and medical dissimilarities from their peers.

Therefore, a significant connection can be made between adolescents accepting T1D as part of their identities and adherence to treatment regimens (Perfect, 2014; Perfect & Jaramillo, 2012). In an attempt to be 'normal' most participants rebel against their T1D by not adhering to treatment and/or healthcare management.

6.4 STRESS, COPING AND QUALITY OF LIFE

During adolescence, specific emotional changes take place due to their physical, cognitive, personality and social development (Berk, 2016; Larson & Lampman-Petratis, 1989; Rosenblum & Lewis, 2003). These emotional changes can result in mood swings; mixed positive and negative outcomes depending on their psycho-social factors. "Emotional competence relates to the ability to manage emotions, whereas social competence focuses on one's ability to relate effectively with others. During this process adolescents become more aware of being able to identify and label their own feelings and the feelings of others" (Sanders, 2013, p. 356). The rate at which the adolescent matures physically is not directly related to their emotional and cognitive development. Being able to control their emotions is a significant development which takes place in adolescence; to deal effectively with emotional events they must understand the outcomes for both positive and negative emotions.

According to Louw and Louw (2014), it is imperative for the adolescent to understand that positive emotions can enhance his/her academic performance and inter- and intrapersonal relations, and that negative emotions could be detrimental to their health and well-being.

Based on the adolescents' non-verbal cues and subsequent inquiry from the researcher's personal observations, it was discovered that most of the participants became uncomfortable when they had to discuss having T1D. Their body language and specific choice of words when explaining their experiences further highlighted a sense of avoidance or distance from their disease. Although, all participants expressed realistic future orientation regarding their vocation or career it seems that some of them decided these choices based on the impact T1D has had on their emotional and social competence.

Studies have shown that gender differences also play a role for emotional development in adolescence; often associated to hormonal changes, as well as cognitive and psycho-social factors (Brody, 1985; Rose & Rudolph, 2006; Van der Graaff *et al.*, 2014). In accordance with the literature, the females in this study commonly experience feelings of anger and sadness relating to T1D, while the males express both negative and positive emotions (Chaplin & Aldao, 2013; Zimmermann & Iwanski, 2014). Sarah seems to externalise positive emotions when she is around her friends and peers at school; masking her sadness, anger and distress associated with her disease. Similarly, Lebo internalises her negative emotions which has made her emotionally unstable and at risk for depression.

The daily demands of T1D treatment and management affects the adolescent; ongoing adherence to multiple daily tasks in home, school and community settings can interfere in their routine (Dhada *et al.*, 2014). Consequently, effective T1D management is dependent on support from family, friends, school staff and healthcare professionals. Adolescent development and T1D-related stress requires effective coping and adjustment skills. To understand the origins of T1D health and well-being, Antonovsky's (1987, 1996) salutogenesis and Sense of Coherence (SOC) can be applied in this study. All participants struggle to achieve HbA1c target and experience T1D-related stress as a result. The adolescents' SOC can be assessed by looking at their meaningfulness, comprehensibility and manageability of T1D. It is noteworthy to highlight that each adolescent has different methods for coping; the extent to which these coping styles assist with particular stressors has an impact on their overall well-being. A lack of appropriate coping skills has caused acute and/or long-term complications to most of the participants (Olshansky *et al.*, 2008; Oskouie *et al.*, 2013). It was observed from the adolescents that not adhering to T1D regimen, lack of understanding and sustained high blood glucose has resulted in all being hospitalised for DKA and/or extreme dehydration; most have also acquired mild diabetic retinopathy. These negative self-care behaviours are influenced by poor emotional and social competence.

Full acceptance of the disease is another problem area for these adolescents. Integrating the disease into their identities and adapting to major lifestyle changes has proven to be an ongoing challenge. In relation to this, Dhada *et al.* (2014) explain that effective T1D management encompasses the acceptance of the disease, maintaining a positive viewpoint and coping with lifestyle changes.

Furthermore, salutogenesis analyses the adolescents' social and health capital to determine their SOC (Antonovsky, 1996). All participants come from a resource-constrained community; whereby their health treatment has limited available resources. Attending a public healthcare facility highlighted experiences of stress and discomfort from fear of being admitted, treatment and over crowdedness. The stronger the adolescent's SOC, the better he/she will be able to apply cognitive, emotional and practical approaches that will likely improve coping and enhance well-being. An Israeli study, conducted by Cohen and Kanter (2004), examined the relationship between glycaemic control and SOC; people with T1D had higher levels of psychological distress in comparison to their control group. Considering that the participants all experience higher levels of psychological distress, it appears that a connection can be made to their maladaptive coping skills and poor glycaemic control. Further, the adolescents' SOC was indirectly related to glycaemic control via adherence to self-care behaviours and psychological distress (Cohen & Kanter, 2004). Thus, it can be assumed that most of the participants do not have a strong SOC due to unsuccessful compliance and T1D-related psychological distress (Goldberg, 2015; Leksell, Wikblad, & Sandberg, 2005; Lundman & Norberg, 1993; Richardson, Adner, & Nordström, 2001). The adolescents' T1D health and disrupted emotional development has negatively impacted their treatment adherence, sense of self and quality of life.

Participants explain that their uncontrolled glycaemic levels cause them daily stress. Further, nonadherence and stress also has an effect on their blood glucose; metabolic functioning is directly altered by neuroendocrine responses to stress. Studies have been conducted to support this process, indicating an interrelated relationship whereby adherence and stress should both be taken into account concerning the effect on metabolic control (Baucom *et al.*, 2015; Delamater *et al.*, 1987; Delamater *et al.*, 2013; McNally, Rohan, Pendley, Delamater, & Drotar, 2010; Miller *et al.*, 2013; Polonsky *et al.*, 1995; Reynolds & Helgeson, 2011). Considering that stress is common for all participants, it is important to mention that stress was not solely felt, that family and/or friends responses to stressors also influence the adolescents emotionally (Baucom *et al.*, 2015; Compas *et al.*, 2001).

Studies found that training adolescents to effectively manage stress and develop appropriate coping skills resulted in improved metabolic control and self-efficacy levels (Baucom *et al.*, 2015; Compas *et al.*, 2001; Delamater *et al.*, 2013; Lowes & Lyne, 1999). Positive and negative emotion-focused coping was observed from all the participants. It seems that Nelson, Lebo and Sarah are currently distancing themselves and avoiding T1D (Svoren & Jospe, 2016). Albert and Thabo showcase aspects of avoidance coping but only regarding their treatment regimen. These strategies are generally used by adolescents with T1D and negatively affect self-care and metabolic control (Dhada *et al.*, 2014). Although, distancing and avoidance coping may alleviate the stressor for only a shortened time period, it may lead to detrimental effects if used over an extended period (Weiten, Dunn, & Hammer, 2014). Nelson and Lebo are at risk of developing depression; verbal and non-verbal cues during their interviews highlighted a deep sadness and emotional distress. Positive emotion-focused coping was also perceived by most of the adolescents. Seeking social support is helping them to deal and cope with the pressures of T1D. Furthermore, acceptance of the disease and acknowledging responsibility were perceived through positive future orientation and learning about the consequences that follow poor T1D management. It seems that all participants underwent a transitional period of adapting to T1D during their first two years of diagnosis. Lebo is the only participant who is still trying to adapt to this new lifestyle because she is still within this duration bracket. None of the participants are successfully coping with their disease; glycaemic control, complications (physical, cognitive and emotional), SOC and identity formation are observable stressors that they encounter. According to Svoren and Jospe (2016), appropriate adjustment and adaptive skills will assist them to successfully cope with T1D and enhance their overall well-being.

Symptoms of depression, anxiety and potential eating disorders were detected from some of the participants. The presence of these adjustment problems affects their psychological well-being as well as optimal management of the disease. According to Palladino *et al.* (2013), adolescents with T1D are at higher risk for developing psychiatric problems such as anxiety, depression and disordered eating behaviours. T1D self-care, the challenges of optimal glycaemic control and diabetes-related health outcomes have negatively impacted their quality of life (Hanna, Weaver, Stump, Fortenberry, & DiMeglio, 2014; Hilliard *et al.*, 2013). It seems the well-being of these adolescents is associated with maintaining compliance of glycaemic control and the parameters surrounding a lower HbA1c level. An American study reported that efficient and supportive parenting was connected with lower depressed signs in adolescence (Helgeson *et al.*, 2014). Furthermore, the results of better support from the family can improve glycaemic control and emotional well-being (Levin, Kichler, & Polfuss, 2013).

Most participants state that their families are aware about their disease but it appears that they do not fully understand it. A lack of support in this regard is detrimental to their emotional well-being and self-care behaviours. The elevated risk for developing eating disorders is more common for adolescent females and can be attributed to weight issues (Eiser *et al.*, 2013). The females in this study expressed T1D-related weight issues; gaining weight after diagnosis has made them upset. Also, some of the participants showcase disordered eating behaviours by skipping meals due to poor glycaemic levels. All adolescents use short- and intermediate-acting human insulin (premixed or basal-bolus insulin regimen). Therefore, they need to adhere to a strict schedule of meals and snacks to match the anticipated peak-time of insulin action and maintain good glycaemic control (Cartaya & Laffel, 2017; Svoren & Jospe, 2016). All of the participants struggle to keep to their controlled diet; the burden of T1D self-care behaviours with regards to counting the intake of carbohydrates, strict meal plan, SMBG and MDIs cause them life dissatisfaction (Svoren & Jospe, 2016).

Self-management of T1D is inclusive of the following: blood glucose monitoring; measuring blood/urine ketone levels; appropriate nutritional plan; physical activity and exercise routine; and performing and adjusting insulin doses accordingly (Cartaya & Laffel, 2017). As aforementioned, the adolescents experience difficulty regarding these self-management areas. Most of the participants do not have a balanced physical activity and exercise routine. The challenge in doing physical activity and exercise revolves around glycaemic control. The adolescent is required to make complex decisions regarding the various factors that impact glucose uptake for both aerobic and anaerobic exercises. Temperature, glycaemic levels, food intake and stress hormones should also be considered beforehand (Riddell & Taplin, 2017). It seems that participants do not take this into consideration and as a result experience exercise-induced hypo- or hyperglycaemia.

Overall, the adolescents in this study are facing significant distress, behavioural self-care difficulties and repeated hospitalisations (DKA and/or extreme dehydration). According to the American Diabetes Association (2017a), such psycho-social issues are grounds for concern and referral to a mental health provider for evaluation and treatment should be considered. None of the participants have been referred for an evaluation and treatment on their psycho-social well-being.

6.5 T1D AND HOSPITAL ENVIRONMENT

As aforementioned in chapters 1 and 4, the American Diabetes Association released a new position statement on psycho-social care in the treatment of T1D. This position statement was released in early 2017 with the goal to address psycho-social issues in all aspects of T1D care. The ADA (2017a, p. S106) recommends that paediatric healthcare providers should “at diagnosis and during routine follow-up care, assess psychosocial issues and family stresses that could impact adherence to diabetes management and provide appropriate referrals to trained mental health professionals” when needed. According to the participants, it appears apparent that such assessments have not taken place for them at the public healthcare facility.

Applying Antonovsky’s (1987, 1996) salutogenic policy and psycho-social support for these adolescents is an ongoing challenge due to limited available services and resources at the public healthcare facility (Kalweit *et al.*, 2015). Unfortunately, healthcare sectors still predominantly follow a pathogenic orientation which makes it a continuing task to implement salutogenesis. Pelikan (2017) states that most policies regarding T1D in countries do not integrate the components of SOC in the treatment and management for health or disease care. Aujoulat, Mustin, Martin, Pelicand and Robinson (2017, p. 341) recommend that “adolescents need to be helped to cope with the concomitant and interrelated developmental and self-management challenges. In order to do so, professional and family caregivers need to develop practices that are sufficiently autonomy-supportive. Such practices must acknowledge the adolescents’ need to be addressed not only about disease and treatment-related issues (i.e., self-management issues), but also about general health issues (including communication about protective as well as risky health behaviours) and psycho-social issues (including awareness of their illness experience and the development of psycho-social competences)”. In accordance, the participants struggle to effectively self-manage their disease; depressive symptoms and emotional outcomes surfaced regarding acceptance, self-care behaviours and inability to reach HbA1c targets. Thus, their emotional distress is interlinked with poor compliance and high levels of stress caused by general and T1D-specific events (Baucom *et al.*, 2015; Lowes *et al.*, 2015).

The participants’ experiences surrounding healthcare professional and nursing care seems to highlight a reprimanding behaviour towards their T1D treatment and management instead of ongoing support and education (Cartaya & Laffel, 2017; Svoren & Jospe, 2016).

Further, it is difficult to achieve optimal glycaemic control for every individual with T1D, irrespective of age and duration of disease, emphasising the importance of ongoing appropriate DSME and DSMS by healthcare professionals, dieticians and paediatric T1D educators (Unger & White, 2016). In relation to this, the participants' narratives illustrated that they attend regular clinical visits but do not receive specific attention towards their psychological adjustment of T1D. These appointments encompass general T1D-related check-ups, as well as possible adjustments made to nutrition plan and/or insulin regimen (Cartaya & Laffel, 2017). T1D educators are not readily available at the public healthcare facility, although *ad hoc* education can be provided by healthcare professionals, dieticians and nursing staff.

In South Africa there are two healthcare sectors, namely: public (government funded) and private (Kalweit *et al.*, 2015). The participants in this study all attend a public healthcare facility to receive treatment for their T1D. Families that can afford to have a private medical aid receive T1D care from private hospitals and CDE programmes; within this sector advanced intensive treatment and management of T1D is available. It is noteworthy to once again mention that there are distinctive differences between these two sectors concerning the availability of resources and services. In accordance with South African studies, the participants in this study exhibit poor T1D management and increased life dissatisfaction (Gill *et al.*, 2005; Kalweit *et al.*, 2015). According to South Africa's National Department of Health (2006, 2008), patients who are not covered by private medical insurance are issued insulin by the state. Currently, they only have access to short-acting human insulin (Actrapid) and intermediate-acting human insulin (Protaphane) which is used for either a basal-bolus insulin regimen or a twice-daily insulin regimen (premixed Actrapid and Protaphane). Further, most of them showcased poor T1D management by absence of self-titrate insulin doses and lack of appropriate insulin-to-carbohydrate counting.

Research shows that improved T1D management was associated with effective collaboration between the adolescent, his/her family and the T1D team (American Diabetes Association, 2017a; Barnea-Goraly *et al.*, 2014; Chiang *et al.*, 2014). At diagnosis and thereafter, parents/guardian are encouraged to be actively involved with the T1D team and management of the disease. The healthcare professional plays a key role in dispensing apt training and education of T1D management that is meaningful to them in their sociocultural contexts (Lowe *et al.*, 2015). Additionally, they must also provide necessary assistance to the individual and family to overcome problems and make adjustments to goals as needed.

Most of the participants attend appointments on their own; this was observed to be associated with increased independence and autonomy regarding their disease. As such, ongoing support and education between the family and healthcare professional cannot be effectively sustained; continued parental/guardian supervision and involvement still remains a crucial component of successful T1D management for adolescents (American Diabetes Association, 2017a).

According to ADA (2017a) and Chiang *et al.* (2014), regardless of age, all patients with T1D require an individualised T1D plan with ongoing support and education; regular check-ups for acute and chronic complications; and access to physicians with specialised training and experience in T1D. However, age-appropriate care needs to be considered for adolescents with T1D; developmental stages and physiological differences in relation to sexual maturity should be taken into account. As adolescents transition into emerging adulthood, new challenges and adaptations to T1D management are faced which requires specialised care regarding changes in insulin sensitivity (in relation to sexual maturity and physical growth) and self-care abilities (Barnea-Goraly *et al.*, 2014; Laffel & Peters, 2011). As most participants were diagnosed during late childhood/early adolescence, paediatric specific T1D care relative to their age and developmental stage should have been distributed. Currently they all receive treatment from the adult diabetes ward so clarity on age-appropriate care was not established. Although, at diagnosis, education and training was provided to both the individual and their families to develop an effective T1D management plan. A possible assumption can therefore be made that substantial gaps in care and DSME could be areas contributing to poor T1D management and treatment for these adolescents.

Studies have shown that adherence to T1D treatment is crucial for successful self-management of the disease (Chamberlain *et al.*, 2016; Haas *et al.*, 2013; Hilliard *et al.*, 2013). In 1993, the seminal Diabetes Control and Complications Trial (DCCT) confirmed that the increased regularity of SMBG is related to improved HbA1c; it allows adolescents to evaluate their own reaction to therapy, giving them a sense of control and empowerment. According to Chiang *et al.* (2014, p. 2045), the ADA recommends that “individuals with T1D need to have unimpeded access to glucose test strips for blood glucose testing. Regardless of age, individuals may require 10 or more strips daily to monitor for hypoglycaemia, assess insulin needs prior to eating, and determine if their blood glucose level is safe enough for overnight sleeping”. Lancets, insulin needles, test strips and glucose meters are not on national tender in South Africa which means the availability is dependent on the separate financial plan of each public healthcare facility (Kalweit *et al.*, 2015).

All participants in this study receive 100 blood glucose test strips per month which prevents them from checking their glycaemic levels more than three times per day. This has a detrimental effect on their T1D management as all have uncontrolled blood glucose and encounter T1D-related stress (Chiang *et al.*, 2014). Furthermore, they expressed discomfort regarding the painful process of insulin injections and SMBG which may be associated to the limited amount they receive from the public healthcare facility causing them to reuse insulin needles and lancets (ADA, 2003, 2004). However, it was unclear whether this discomfort could also be associated with incorrect rotations regarding injection and SMBG sites (Ghosh & Collier, 2012). Having such a limited amount of test strips indicates that they can only test their blood glucose prior to meals which effectively prevents them from checking at other significant periods (i.e. hypoglycaemic/hyperglycaemic events, adjusting preprandial insulin dosages, and acknowledging the impact of incorrect nutrition and exercise).

Regarding insulin therapy, the DCCT (1993) study found problems in short- and intermediate-acting human insulins. Since then various rapid- and long-acting human insulin analogues have been manufactured; these are not available to the participants due to the expensive cost and budget restriction at the public healthcare facility (Hirsch, Franek, Mersebach, Bardtrum, & Hermansen, 2016). Four out of the five participants interviewed are using basal-bolus insulin therapy, with the remainder using premixed insulin. Adherence to meal plan and insulin regimen is crucial for both these therapies to obtain optimal glycaemic control (Dhada *et al.*, 2014; Segal, 2012). It was observed that all participants find it difficult to administer successful compliance regarding meal size, carbohydrate intake and intensive T1D management resulting in subsequent high HbA1c levels and complications (Chiang *et al.*, 2014; International Diabetes Federation, 2011; Rewers *et al.*, 2014).

6.6 T1D AND FAMILY ENVIRONMENT

Family and T1D healthcare professionals both have the responsibility of ensuring that the adolescent with T1D will learn and adapt to this disease, maintaining a sustainable and wholesome quality of life. Thus, successful management of T1D requires ongoing parental/guardian supervision throughout the individual's adolescent phase (Smith *et al.*, 2015). In South Africa, a study revealed that adolescents from single-parent households had poor HbA1c levels and decreased quality of life, irrespective of healthcare system and management techniques used (Kalweit *et al.*, 2015). The findings showed an association between glycaemic control and parental marital status; reinforcing the significance of family support for adolescents with T1D and their management thereof. As mentioned, all participants come from a resource-constrained community; most of them from a single-parent household and a low socioeconomic status.

Having T1D has caused disruption to all the participants' worlds; they are facing emotional distress, physical complications and poor HbA1c levels. Studies have been conducted around the links between stress, metabolic control and family influence (Baucom *et al.*, 2015; Compas *et al.*, 2001; Delamater *et al.*, 2013; Dhada *et al.*, 2014; Hessler, Fisher, Polonsky, & Johnson, 2016; Reynolds & Helgeson, 2011). In accordance with the literature, all of the participants experience T1D-related stress which is associated with their self-care behaviours and metabolic control. It appears that most of the participants' family experiences were centred on emotional distress surrounding their chronic disease. This affirms with recent studies that show that maladaptive coping strategies and negative family responses to stressors can also result in poor T1D management (Caccavale, Weaver, Chen, Streisand, & Holmes, 2015; Hessler *et al.*, 2016; King *et al.*, 2014). Thus, it is important to have appropriate ongoing family support for optimal T1D management.

Aspects of prosocial family behaviour were observed from some of the participants' family members, incorporating an adolescent-centred care approach (Palladino & Helgeson, 2013). Thabo and Sarah receive emotional guidance and support from their mothers, while everyone expressed a shared experience that the burden of T1D has caused financial, behavioural and emotional distress on their families (Smith *et al.*, 2015). Furthermore, most participants state that their families are aware about their disease but it appears that they do not fully understand it. A lack of support in this regard is detrimental to their self-care behaviours and T1D management (Sparud-Lundin *et al.*, 2013). All participants perform T1D self-care behaviours and management on their own with no involvement from parent/guardian. The ADA (2017a) recommends that ongoing family supervision and shared-responsibility in T1D management can benefit the adolescents' quality of life and improve glycaemic levels. An assumption can therefore be made that lack of support from the family in this regard may be associated with poor T1D management and uncontrolled glycaemic levels.

According to Atkinson *et al.* (2014), parent/guardian grief and blame is often experienced at diagnosis and throughout the duration of the adolescents' disease. Parent/Guardian grief was observed from all participants. They all stated that their families experience blame, stress and/or sadness concerning their T1D. It is noteworthy that some of the participants have experienced additional stress and upset as a result from seeing the effect their chronic disease has placed on their family. In accordance with literature, the participants' interpretations of their family setting highlighted a deep sadness and self-disappointment experienced by their mothers; such distress hinders T1D management (Ogle *et al.*, 2013; Schwartz, Axelrad, & Anderson, 2014; Svoren & Jospe, 2016).

It can be perceived that these participants have a strained family environment regarding their T1D; the disease has upset their family dynamic and created an emotional atmosphere which negatively impacts compliance and T1D care (Levin, Kichler, & Polfuss, 2013; Palladino & Helgeson, 2013). Given the importance of overall family support, it is essential for these participants' parent/guardian to be involved in daily treatment and management of T1D to facilitate improved glycaemic control, emotional well-being and family adaptation.

6.7 T1D AND SCHOOL ENVIRONMENT

According to Chiang *et al.* (2014), management of T1D is extremely pertinent within the school environment for the adolescent. Most of their days are spent at school; close communication with the school personnel is valuable for ideal T1D management, preventative and safety measures, as well as optimal academic performance. Collaboration between the adolescent's parent/guardian and healthcare provider can further assist the school personnel with the requirements and information necessary to ensure a holistic and safe learning experience (Ghosh & Collier, 2012). "To keep students with T1D safe at school, guarantee long-term health, prevent complications, and ensure full participation in all school activities, proper monitoring of and responding to blood glucose levels must be attended to throughout the school day and during all school-sponsored activities" (Jackson *et al.*, 2015, p. 1962). As perceived from the adolescents' stories the aforementioned was not reflected in their school experiences; it appears that T1D school awareness and teacher support is an issue which has caused significant disruption to their social and emotional adjustment.

In accordance with literature, the participants felt that their teachers did not have adequate knowledge surrounding T1D (International Diabetes Federation, 2015; MacMillan, Kirk, Mutrie, Moola, & Robertson, 2014). However, it is noteworthy to mention that most of the participants are reluctant to inform their schools about their disease. It seems that at diagnosis the school was notified but follow-up information and support has not been given which has resulted in many of their school personnel not being aware about their T1D. Furthermore, the lack of collaboration between the family, school and healthcare provider has also contributed to their school complications. A major concern for these adolescents surrounds embarrassment and fear of administering T1D self-care behaviours in front of their teachers and peers (Jackson *et al.*, 2015). As most of them are struggling to emotionally cope with their disease, the perceived additional stress from outsider-perspective has a detrimental impact on their treatment adherence, identity and glycaemic control (Freeborn, Dyches, Roper, & Mandelco, 2013; Roper *et al.*, 2009). As a result, the participants expressed feelings of loneliness and being seen as different from their peers.

Relevant to the abovementioned, studies have shown that teacher and peer victimisation towards the adolescent with T1D can lead to anxiety, rejection, loneliness and depression (Nabors, McGrady, & Kichler, 2010; Storch *et al.*, 2006). Some of the participants explained that misconceptions about T1D have caused them distress and social anxiety at school, such a negative schooling environment has ultimately led to poor emotional and social adjustment (Cartaya & Laffel, 2017).

The ADA released a position statement regarding special considerations for T1D management at school which highlighted areas of disruption for these participants (Jackson *et al.*, 2015). Considering the participants experiences, self-management of T1D at school is a difficult task due to restrictions of where to perform self-care behaviours. Some of the participants have been told to perform SMBG and insulin regimen privately which disrupts classroom learning, while others have decided to do this because of peer and teacher victimisation. Furthermore, they all expressed that an improvement in the school meal plan would be beneficial to their strict nutritional requirements. Four out of the five participants have problems associated with academic performance but none of them have requested special concessions for tests and exams (Lansing *et al.*, 2017). It seems that most of them neglect their treatment adherence during these academic assessments which could be associated to their poor grades. Studies have shown that glycaemic control directly has an effect on learning and acquisition of knowledge (Demirel, Tepe, Esen, Buber, & Boztepe, 2013; Jackson *et al.*, 2015; Patiño-Fernández *et al.*, 2010; Wagner *et al.*, 2006). The participants' uncontrolled blood glucose levels have caused disruption to their learning; often they feel that they cannot concentrate in the classroom and experience ongoing fatigue.

According to Barone and Menna-Barreto (2011), adolescents with mismanaged T1D have increased fatigue during the day due to a reduced amount of hours spent in deep, restorative sleep. In relation to this, all the participants have high blood glucose levels and incorrect dietary behaviour which impact their glycaemic control and sleeping patterns; they experience less time in deep sleep and recurrent hyperglycaemia. Most of them present with signs of fatigue, depressive symptoms, psycho-behavioural problems, decreased school performance and life dissatisfaction (Perfect *et al.*, 2012).

Most of the participants' school performance is negatively impacted by their poor T1D management. It can be assumed that their high HbA1c levels, T1D-related emotional distress and hospitalisations (due to acute complications) have an impact on their academic performance (Perfect, 2014). Hospitalisations have caused them to miss a number school days which in turn disrupt their education, causing additional stress and upset (Jackson *et al.*, 2015).

Studies show that cognitive complications exist for individuals with T1D, primarily in child and adolescent phases (Battelino *et al.*, 2011; Chiang *et al.*, 2014; Ghetti, Lee, Sims, DeMaster, & Glaser, 2010; Korczak, Pereira, Koulajian, Matejcek, & Giacca, 2011; Royle, Barnard, Thomas, Noyes, & Waugh, 2010). Most of the participants' struggle academically, they reflected that they are "slow" learners compared to their peers. Furthermore, they encounter issues when studying school material or paying attention in class (Rewers *et al.*, 2014). An assumption can thus be made that their uncontrolled glycaemic levels have a negative impact on their general mental ability, psychomotor reaction time and cognitive flexibility (Cato *et al.*, 2014; Marzelli *et al.*, 2014).

From their experiences, it became apparent that hypoglycaemic events cause dysfunctional memory and learning, and impaired cognitive efficiency, such as slow processing speed; hyperglycaemia events cause problems with short-term memory (Lin *et al.*, 2015). A strong relation exists between self-care compliance and executive functions for adolescents with T1D; as most of the participants have ongoing hyperglycaemia an association to poor executive functioning can be established (Cato *et al.* (2014; Miller *et al.*, 2013). This was further highlighted by their lack of emotional control and nonadherence to T1D management (Colver & Longwell, 2013). Therefore, their mismanagement and uncontrolled glycaemic levels have a direct impact on cognitive abilities that affect executive functioning, learning, thinking and memory.

6.8 POSSIBLE STRENGTHS AND LIMITATIONS OF THE STUDY

A significant strength of this study is the abundance of rich, descriptive and explorative knowledge about the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community. The individual, as well as the shared meanings, that were uncovered during the research process, are valuable in deepening the understanding of the T1D phenomenon and how it affects adolescents' relational worlds. The findings obtained from the participants accounts also complemented existing literature on the topic. Implementing IPA allowed for an understanding of the subjective experiences of the research participants. Thus, through IPA, the T1D lived experience of each participant could be explored.

Further, the study contributed to preliminary research regarding adolescent's subjective experiences of living with T1D in a resource-constrained community. This includes information on the impact of T1D on personal, family, school and hospital experiences.

The study also provided an opportunity for the participants to speak freely about their chronic disease and their experiences thereof. For some, this was a chance to express feelings over topics that were never discussed before. Most participants commented that the process allowed them further insight into themselves and their T1D. They appreciated the opportunity to share their experiences in an environment where they felt safe and understood.

The exploratory nature of IPA aims to discover subjective lived experiences and their respective meanings attached (Eatough & Smith, 2016; Smith, 2015). This permits little room for testing relationships among constructs or providing experimental evidences. While a quantitative study may have determined correlations, a qualitative study allowed for the exploration of lived experiences.

In this study, a limited number of participants were involved. Along with the small sample size, the homogeneity of the sample creates a limitation for generalisation of results to the larger population. The participants of this study represent a small section of the South African adolescent population with T1D. All of the participants were black adolescents with T1D in the same resource-constrained community. The lived experiences from other adolescents, cultures and backgrounds were not explored. Therefore, this study only represented a fraction of the possible information regarding this phenomenon's entirety.

Other limitations refer to the specific method used in this research study, namely IPA. The interpretative approach of IPA provides one such constraint. In interpretation, there is always a risk of not accurately reflecting or obtaining all aspects of the participant's lived experience. Even though, during data analysis, a relatively structured guideline is followed, the likelihood is that the findings do not fully capture the entire T1D experience of these and other adolescents.

For IPA, the issue of subjectivity is also pertinent. In accordance with the specific principles of qualitative research and interpretive phenomenology, the interpretation of the interview data is viewed in context and influenced by the researcher's own ideas, values and preconceptions. Although the researcher attempted to be as self-aware as possible, a complete suspension of previous knowledge is idealistic and not permissible. As a result, preunderstanding and co-creation by the researcher and the participants are what made these interpretations meaningful.

6.9 RECOMMENDATIONS FOR FURTHER RESEARCH

This study aimed at exploring the lived experiences of the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community. Various areas associated to the adolescents' psycho-social well-being were highlighted by the participants, signifying that the impact of T1D is multi-faceted and subjectively complex (Cartaya & Laffel, 2017; Svoren & Jospe, 2016). The phenomenon appears to fall within an interrelated and open-ended web of meaning, suggesting possible areas to be investigated for future research.

Themes were obtained regarding the adolescents' identity, stress, coping, quality of life, family, school and healthcare sector. The participants' stories expressed their meanings and experiences surrounding this disease from a personal, family, school and public healthcare perspective. Qualitative research may explore these themes further, while quantitative research may analyse the interconnected components of these experiences. An example of a qualitative study may incorporate separate, in-depth explorations of each identified theme surrounding the impact of T1D on South African adolescents in resource-constrained communities. With regards to qualitative studies, an example may consist of analysing which themes are perceived as most impacted by T1D on South African adolescents in resource-constrained communities.

As aforementioned in the purpose of this study, literature review and the abovementioned recommended areas for future research, a significant need exists to cultivate South African based data for this context-specific population. There is limited data available regarding the incidence and prevalence rates for this population in the African region and more precisely South Africa (WHO, 2016; IDF, 2015). Thus, conducting further research may contribute to a better understanding of this population and consequently provide new knowledge that could enhance the management of T1D and quality of life for these adolescents.

In terms of broadening the context of this study, it would be noteworthy to consider other methodological designs to obtain diverse aspects of information pertaining to the lived experience of T1D and the impact thereof on the adolescents' psycho-social well-being. Such research projects may supply valuable data to academia, healthcare sectors, family and school environments so as to benefit this population and provide comprehension of the experiences of adolescents with T1D.

Future research may also consider correlational studies regarding private and public healthcare facilities and intervention studies regarding training and education programmes based on coping and stress management. Furthermore, this may aid in establishing context-specific management programmes that can provide improved T1D care and support to these adolescents. It is therefore recommended that this research data be made available to families, school and healthcare sectors as a prospect to further develop existing management programmes and direct specific attention to this population with T1D.

6.10 SIGNIFICANT CONTRIBUTION TO KNOWLEDGE

This study highlighted the impact of T1D on a specific population's psycho-social well-being. From the findings the researcher was able to formulate a comprehensive understanding of the adolescents' lived experiences surrounding this phenomenon. Considering that all of the participants come from a resource-constrained community, a collective experience of economic strain regarding medical treatment was observed. These adolescents have additional hardships to manage along with the complexities of this chronic disease. Having T1D has impacted their identity-formations due to situational, cultural and traditional constraints. As a result they all harbour a weak SOC in accordance with T1D which further impacts their emotional and social competence.

Maladaptive coping strategies and emotional distress to T1D-related management has negatively impacted their intra- and interpersonal relationships. It is noteworthy to consider that adolescence is a transitional period whereby various developmental changes take place and that T1D places additional stress on the adolescent and his/her family. The financial, physical and emotional burden has impacted their family structure and created a distressed environment. Furthermore, their nonadherence to treatment and management has impacted their physical health, resulting in hospitalisations and complications. T1D appointments and collection of treatment consumables takes a whole school day from these adolescents, sometimes more than one day if they do not arrive early enough at the overcrowded public healthcare facility. This is detrimental to their education and interferes with their school attendance. Academic performance has also been affected by poor metabolic control. The lack of collaboration between the family, school and public healthcare facility is another area of concern that impacts the adolescents' treatment adherence.

From observable T1D mismanagement and adolescent experiences it appeared that ongoing appropriate support and education was absent from their families, schools and healthcare professionals.

As aforementioned, adolescence presents various changes and adaptations to the individual which are further aggravated by the presence of T1D. These adolescents have the challenging task of maintaining a balanced lifestyle and accepting the responsibilities of their disease which has negatively impacted their psycho-social well-being.

6.11 CONCLUSION

According to Petersson *et al.* (2016), in order for the adolescent to lead a normal and happy life s/he must adhere to an intensive T1D management plan, which includes: insulin treatment, SMBG, strict nutritional plan, physical activity, DSME, DSMS and psycho-social support. Five main themes emerged from the transcripts, each of which was discussed separately as well as in relation to other prevalent literature. The critical investigation of the findings presented in this study revealed divergent aspects to those found in some of the current literature, as well as considerations comparable with earlier research. The meanings that emerged from these adolescents' stories revealed complex cognitive, emotional, social and biological distress, all of which highlight the subjective experience of having T1D, the impact thereof, and the multi-faceted stress it has on their psycho-social well-being.

The themes obtained responded to the research question by providing in-depth interpretations of the impact of T1D on the psycho-social well-being of adolescents in a resource-constrained community.

6.12 SUMMARY OF CHAPTER 6

In this chapter, it is apparent from the investigated findings that the experiences and meanings of adolescents' with T1D are subjective. The participants' stories seem to be limited to their individual understanding of their relational worlds. However, it is notable that each participant's personal narrative is not so idiosyncratically different; shared experiences were observed regarding the impact of T1D through attributed meanings in their lives.

The broader community may view T1D as a disease that just entails a physical adaptation to medical treatment and self-care but the process of adjustment and management is far more complex; requiring constant adaptation to lifestyle and developmental changes in adolescence. The researcher's aim was to highlight the impact of this chronic disease on the adolescents' psycho-social well-being to create awareness and understanding of this multi-faceted phenomenon.

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