EXPERIENCES OF YOUNG ADULTS LIVING WITH TYPE 1 DIABETES MELLITUS REGARDING SELF-MANAGEMENT AND LIFESTYLE ADAPTATION IN THE NELSON MANDELA BAY HEALTH DISTRICT

BY

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TITLE OF PROJECT: *Experiences of young adults living with type 1 diabetes mellitus regarding self-management and lifestyle adaptation in the Nelson Mandela Bay Health District.*

DECLARATION: In accordance with Rule G5.6.3, I hereby declare that the above-mentioned treatise is my own work and that it has not previously been submitted for assessment to another University or for another qualification.

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28 November 2018
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ABSTRACT

Living with type1 diabetes mellitus (T1DM), which is a challenging disease, is especially difficult during the young adult stage of development. This developmental stage is characterised as complex; difficult even for healthy individuals. There is an estimated worldwide increase of 415 million young adults living with T1DM, and this number is projected to rise to 642 million by 2040. Recent statistics indicate that this increase holds true for South Africa. T1DM has an early onset and is treated with insulin injections up to four (4) times a day. The management of T1DM is best achieved through self-management of an individual living with the disease as well as support from the health care providers, community, and the family.

Young adults living with T1DM experience difficulties maintaining optimal blood glucose levels, ranging between four (4) and seven (7) millimoles, during this stressful transition period from childhood to young adulthood. Transitional actions include moving away from home for the first time to study at a tertiary institution, joining the work-force, or entering new relationships, such as getting married and becoming a parent. This phenomenon motivated the researcher to explore and describe the experiences of young adults living with T1DM regarding self-management and lifestyle-adaptation.

The study followed a qualitative, exploratory, descriptive, and contextual design. The research population included young adults living with T1DM between the ages of 18 and 25 years in the Nelson Mandela Bay Health District, attending a diabetic clinic at a public tertiary hospital. Purposive sampling was utilised to select the 11 participants. A pilot study was conducted with one (1) participant before the main study commenced to ensure the trustworthiness of the findings. The researcher obtained data through semi-structured one-on-one interviews. Tesch’s method was used to analyse the research data. Once data were analysed; the findings underwent literature control. Lincoln and Guba’s model of trustworthiness was utilised to ensure that the study was trustworthy and credible which consists of the following four criteria: credibility, transferability, dependability, and conformability. Ethical principles such as autonomy, informed consent, beneficence, and justice were considered throughout the study to ensure that participants do not experience any violations during the research study.

The results of the data analysis revealed the following main findings:

- Participants had negative experiences in relation to T1DM.
- Participants shared their experiences in relation to achieving self-management of T1DM.

Recommendations were made to assist registered nurses to manage young adults living with T1DM adequately. The study achieved its intended objective.

Keywords: Type1 diabetes mellitus (T1DM), young adult, lifestyle adaptation, public hospital

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LIST OF ABBREVIATIONS

ADA	American Diabetes Association
DKA	Diabetic Ketoacidosis
DM	Diabetes Mellitus
DoH	Department of Health
HCPs	Health Care Providers
IDF	International Diabetes Federation
MMOL	Milimol
NICE	National Institute for Health and Care Excellence
NMBHD	Nelson Mandela Bay Health District
SEMDSA	Society for Endocrinology, Metabolism and Diabetes of South Africa
STATSSA	Statistics South Africa
T1DM	Type1 Diabetes Mellitus

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Diabetes mellitus (DM) is one of the most common non-communicable diseases challenging public health in the 21st century (Hinkle & Cheever, 2014:1417). DM is divided into type 1 diabetes mellitus (T1DM), also referred to as insulin dependent diabetes mellitus and type 2, also known as non-insulin-dependent diabetes mellitus. T1DM is an autoimmune disease in which the beta cells of the islets of Langerhans in the pancreas are destroyed and stops producing insulin. T1DM usually starts in people under the age of 30 years and often occurs in very young children and even infants (Hammer, Stephen & McPhee, 2014:525).

The number of people living with T1DM is rapidly increasing worldwide (Hinkle & Cheever, 2014:1417). According to Xu, Liu, Sun, Snetselaar, Hu and Bao (2018:1), in 2017 the worldwide prevalence of T1DM was 415 million, 80% of which were living in low-and-middle-income countries. Xu *et al*. (2018:1), further affirm that this number is projected to rise to 642 million by 2040. The International Diabetes Federation (IDF, 2017:42) confirms the increase and predicts that the total number of people living with T1DM worldwide will rise from 451 million to 693 million by 2045. The IDF (2017:42), further states that this projected increase is due to an increase in the rate of bacterial and viral infections which trigger T1DM.

In sub-Saharan Africa, an estimated seven (7) million people live with T1DM, and this number is projected to reach 15 million by 2025 due to a multitude of factors such as an increased population rate; rapid urbanisation; westernisation of lifestyle; decreased physical activity; changes in dietary habits and other factors such as stress (IDF, 2017:42). According to Pheiffer, Pillay-van Wyk, Joubert, Levitt, Nglazi and Bradshaw (2018:1), the current prevalence of T1DM in South Africa is four (4) million and is expected to increase to six (6) million by 2035. This increase is primarily associated with stress; as millions of young adults are migrating from rural to urban areas for educational purposes or seeking employment opportunities (Pheiffer *et al*., 2018:2).

The IDF (2017:51) states that T1DM imposes a large economic burden on individuals and families, national health systems and countries.

Worldwide, countries spent between 232 billion in 2009 and 727 billion in 2017 of the total health expenditures on T1DM patients (IDF, 2017:51). The costs associated with T1DM included increased use of health services by young adults living with the disease, plus loss of productivity and disability resulting from chronic complications of the disease (IDF, 2013:48).

According to Rassart, Luyckx, Klimstra, Moons, Groven and Weets (2014:5), young adulthood combined with T1DM, might increase the stress of an already stressful developmental period. Young adulthood, which includes ages between 18 to 25 years, involves significant transitions, including competing educational, social, and emotional priorities and the need for increased independence. The many challenges and responsibilities accompanying T1DM may complicate these developmental tasks.

T1DM is a non-curable disease which is manageable through following a strict T1DM self-management plan (Rasmussen, Ward, Jenkins, King & Dunning, 2011:1982). Young adults living with T1DM thus need to follow a structured self-management plan that includes blood glucose monitoring, insulin injections two (2) to four (4) times per day, maintaining dietary restrictions and physical activities to sustain a healthy blood glucose level in the range of between four (4) mmol and seven (7) mmol (Garvey, Finkelstein, Laffel, Ochoa, Wolfdorf & Rhodes, 2013:762). According to the International Diabetes Federation (IDF, 2015:94), diabetes self-management education and on-going support are an essential part of diabetes care for young adults living with T1DM. The added stress generated through life transitions makes it difficult for young adults to adapt to daily demands of T1DM self-management and lifestyle adaptation.

In essence, living with T1DM entails a lifestyle adaptation. However, Barnard, Sinclair, Lawton, Young and Holt (2012:435) affirm that during life transitions, young adults living with the disease struggle to follow the protocol for T1DM care. Reasons for this include changes in extramural activities and socialisation, which could include an increase in alcohol consumption without parental guidance, which could result in lapses in self-management of T1DM.

Hanna, Weaver, Fortenberry and DiMeglio (2014:2) state that young adulthood, which is between 18 and 25 years of age is a critical period for T1DM related quality of life. The demands of T1DM self-management are challenging. Young adults who had been dependent on their parental support in the management of their disease such as meal planning, attending medical appointments and glucose monitoring must take definitive steps in the self-management of their disease.

According to Kumar, Abbas and Aster (2015:1114), life transitional changes in young adults living with T1DM such as going away from home for the first time, commencing studies in a tertiary institution, parenthood, seeking employment or increased financial responsibilities can all cause stress and reduce the ability to adapt to T1DM self-management, and accordingly optimal lifestyle adaptation to cope with the disease. Lack of management of the disease results in acute complications such as low or raised blood glucose concentrations, which are potentially life threatening and often require hospitalisation. Kumar *et al*. (2015:1114) indicate that a continuous rise in young adult’s blood glucose concentrations may result in an acute complication of T1DM known as diabetic ketoacidosis (DKA).

Chawla, Chawla and Jaggi (2016:13) state that young adults living with T1DM are also prone to developing long-term or chronic complications due to continuously raised blood glucose levels, as a result of lack of self-management which include microvascular and macrovascular complications. According to IDF (2015:108), microvascular complications incorporate diabetic nephropathy, caused by damage to the small vessels of the kidney and can result in chronic renal failure. Mahan, Escott-Stump and Raymond (2012:705) state that persistently raised blood glucose levels in young adults living with T1DM may harm the small blood vessels in the retina of the eyes leading to diabetic retinopathy, and these microvascular blood vessel changes can lead to blindness.

Huang, Refaat, Mohammedi, Jayyousi, Suwaidi and Khalil (2017:4) confer that microvascular blood vessel changes also incorporate diabetes neuropathy affecting the nerves and these are mainly skin-related, which often lead to delayed wound healing, ulceration and subsequent amputations. Deepa, Kiran and Galdwalker (2014:119) claim that frequently raised blood glucose levels in young adults living with T1DM may also lead to macrovascular complications such as cardiovascular diseases such as coronary artery disease. Long-term complications can also influence the prospect of employment/unemployment due to disabilities (Funakoshi Azami, Matsumoto, Ikota, Ito, Okimoto, Shimizu, Tsujimura, Fukuda, Miyagi, Osawa, Osawa & Miura, 2017:2). Young adults living with T1DM need to maintain optimal blood glucose levels in order to prevent long-term complications of the disease and to ensure optimal lifestyle-adaptation.

1.2 PROBLEM STATEMENT

According to the statistics obtained from the records of a diabetic clinic in a tertiary public hospital in the Nelson Mandela Bay Health District (NMBHD), every month an average of 30 young adults between the ages of 18 and 25 years living with T1DM make use of this public health care facility (Figures from Out Patient Department, 2016). Public health care facilities, in general, have a minimal number of health care providers who are required to provide care and health education to large numbers of patients with different health problems. They are also expected to provide specialised, continuous education on T1DM self-management and coping skills for young adults living with T1DM to achieve successful health-related outcomes, despite limited resources.

The researcher, who works in the diabetic clinic situated in the above mentioned tertiary public health hospital, has noticed that young adults living with T1DM between the ages of 18 and 25 years often present with raised or low blood glucose levels that require either hospital admission or further management in the clinic. Given the possible long-term effects of these observed uncontrolled blood glucose levels, the researcher is concerned about the apparent lack of knowledge and experience about diabetes self-management and the concurrent lack of lifestyle adaptation in the young adults attending the clinic.

These observations prompted the researcher to investigate the following research question:

“What are the experiences of young adults living with T1DM in a tertiary public hospital in NMBHD regarding self-management and lifestyle adaptation?”

1.3 PURPOSE OF THE STUDY

The purpose of the study was to explore and describe the experiences of young adults living with T1DM in a tertiary public hospital in NMBHD regarding self-management and lifestyle adaptation. Furthermore, to provide recommendations to public tertiary hospital managers in this District based on the findings of the study which should enable professional nurses to adequately manage young adults living with T1DM.

1.4 RESEARCH OBJECTIVES

The objective of this study was to:

Explore and describe the experiences of young adults living with T1DM in a tertiary public hospital in NMBHD regarding self-management and lifestyle adaptation.

1.5 CONCEPT CLARIFICATION

The following main concepts were defined and applied to the study:

Type1 diabetes mellitus

T1DM, also known as juvenile diabetes or insulin dependent diabetes mellitus, is caused by an autoimmune reaction where the body’s defence system attacks and destroys the insulin-producing beta cells in the pancreas, usually leading to absolute insulin deficiency (IDF, 2015:22). This research study will explore how young adults, living with T1DM in a tertiary public hospital in HMBHD, incorporate self-management within the context of the disease to their lifestyle.

Young adult

According to Barnard, Sinclair, Lawton, Young and Holt (2012:435), young adulthood is a transitional stage in which young adults who have been dependent on their parents now start taking definite steps to achieve measures of financial and residential independence. They could become a spouse, parent, and a worker during this time. In this research study, experiences of young adults (aged 18 to 25 years) living with T1DM in a tertiary public hospital in NMBHD regarding self-management and lifestyle adaptation will be explored and described.

Lifestyle adaptation

Whittemore, Jaser, Guo and Grey (2010:2), define lifestyle adaptation as the degree to which an individual responds both physiologically and psychologically to the stress of living with chronic illness. The experiences of young adults with regard to their self-management and lifestyle adaptation regarding T1DM will be explored and described.

Public hospital

A public hospital or a government hospital is a hospital which is owned and managed by the government and receives government funding (Taner & Anthony, 2013:7). Public hospitals provide health care to the public who are unable to afford private medical care. The study will be conducted at a diabetic clinic situated in a tertiary public hospital in NMBHD.

1.6 RESEARCH DESIGN

The research design is the logical framework that shapes the research project, and which enables the researcher to gather evidence that will provide answers to the research question (Creswell, 2014:296). Brink, van der Walt and van Rensburg (2012:217), define a research design as the plan for gathering data in the research study. The design will be qualitative, explorative, descriptive, and contextual. The concepts will be discussed in more detail in Chapter Two.

1.7 RESEARCH METHOD

Polit and Beck (2012:12) state that research methods are the techniques researchers use to structure a study and to gather and analyse information relevant to the research question. According to Grove, Burns and Gray (2013:707), research methodology refers to the process or plan for conducting the specific steps of a study. The researcher conducted semi-structured individual interviews with young adults, aged 18-25, living with T1DM, who were attending a diabetic clinic in a tertiary public hospital in NMBHD to explore and describe their experiences regarding self-management and lifestyle adaptation. The research methods will be discussed in Chapter Two.

1.8 DISSEMINATION OF RESULTS

The study will be made available to the Nelson Mandela University and the management of the public tertiary hospital where the study was conducted. A formal presentation may be given in the form of in-service training to the public tertiary hospital. The researcher will formulate an article which may be utilised for publication in a peer-reviewed journal.

1.9 OUTLINE OF CHAPTERS

Table 1.1 provides an outline of the chapters.

Table 1.1: Outline of Chapters

Chapter	Name of chapter
1	Overview of the study
2	Research Design and Methods
3	Data Analysis, Discussion of Findings and Literature Control
4	Summary, Limitations, Conclusion and Recommendations

1.10 CHAPTER SUMMARY

In this Chapter, the researcher has identified the topic to be researched. The problem statement, research question and objectives were shared with the reader. The concepts were clarified, and a brief overview given on the research design and methods used. Dissemination of the results, as well as outlines of the chapters, were discussed. Chapter Two outlines the description of the research design and methods.

CHAPTER TWO

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

In Chapter One, the researcher provided an overview of the research study; highlighting the problem statement, research question, purpose and objectives. A brief overview of the research design and methods were given. Chapter Two provides a detailed description of the research design and methods used to explore and describe the experiences of young adults living with T1DM regarding self-management and lifestyle adaptation.

2.2 RATIONALE OF THE STUDY

Type1 diabetes mellitus is an autoimmune non-communicable disease which destroys the beta cells of the islets of Langerhans in the pancreas and subsequently stops producing insulin (Hammer, Stephen & McPhee, 2014:525). During young adulthood, ages between 18 and 25 years, critical transitions include education, social and emotional priorities and the need for increased independence. The many challenges and responsibilities accompanying young adulthood may complicate self-management of T1DM (Rassart, Luyckx, Klimstra, Moons, Groven & Weets, 2014:5).

Young adults living with T1DM who are attending a diabetic clinic in a public tertiary hospital in NMBHD reported their experiences regarding self-management and lifestyle adaptation. They listed experiences such as being stressed and having a fear of rejection by friends, colleagues, and employers. This led the researcher to investigate the experiences of young adults living with T1DM, in a tertiary public hospital in NMHD regarding self-management and lifestyle adaptation. The reason behind the study is to understand how they experience T1DM and life transitions during young adulthood and to explore and describe the experiences of young adults living with T1DM, in a tertiary public hospital in NMBHD, regarding self-management and lifestyle adaptation. Furthermore, to provide public tertiary hospital managers in this district with recommendations based on the findings of the study which should enable registered nurses to adequately manage young adults living with T1DM.

2.3 OBJECTIVE

The objective of this study was to:

Explore and describe the experiences of young adults living with T1DM in a tertiary public hospital, regarding self-management and lifestyle adaptation.

2.4 RESEARCH DESIGN

The research design is a blueprint for conducting a study. The purpose is to establish control over factors that could interfere with the validity of the findings (Grove, Burns & Gray, 2013:692). It involves a set of decisions regarding what topic is to be studied, the population, the research methods and the purpose. The research design chosen for this study was qualitative, explorative, descriptive, and contextual.

2.4.1 Qualitative design

According to Grove, Burns and Gray (2013:23) and Nieswiadomy (2014:9), qualitative research is a systematic, interactive, subjective approach used to describe experiences and give them meaning. Polit and Beck (2012:739) state that qualitative research is used to explore, describe, and promote an understanding of human experiences and give them meaning. The qualitative research design allowed the researcher to gain insight into and understanding the experiences of young adults living with T1DM, in a tertiary public hospital, regarding self-management and lifestyle adaptation.

2.4.2 Explorative design

Brink, van der Walt and Rensburg (2012:211) state that explorative research is conducted when a little is known about the phenomenon that is studied. According to Nieswiadomy (2014:4), an explorative study is conducted to get an answer to the research question. Explorative research was used to explore the experiences of young adults living with

T1DM in a tertiary public hospital in NMBHD, regarding self-management and lifestyle adaptation.

2.4.3 Descriptive design

Grove, Burns and Gray (2013:692) state that a descriptive study enables the researcher to gain more information about the characteristics of an individual or group in real life situations to discover meaning. According to De Vos, Strydom, Fouche and Delport (2011:96), the description in qualitative studies is more likely to refer to a more intensive examination of phenomena and their deeper meanings, leading to a thicker description. The researcher used semi-structured individual interviews to gather information from young adults living with T1DM, in a tertiary public hospital, to explore and describe their experiences regarding self-management and lifestyle adaptation.

2.4.4 Contextual design

According to Holloway and Wheeler (2010:41), a contextual design takes into consideration where the research takes place as well as the environment of interaction. This includes cultural and historical implications which are essential for understanding the phenomenon under study. The context includes situating the phenomena of the study within its immediate setting (Creswell, 2013:43). In this study, a contextual design is used to describe the experiences of young adults living with T1DM attending a diabetic clinic in a public tertiary hospital in NMBHD to obtain treatment, management, health-care and support.

2.5 RESEARCH METHODS

The researcher utilised a variety of methods to assist in answering the research question. The following aspects will be discussed, namely: the target population, sampling method, data collection methods, pilot study and data analysis. The literature control process and the trustworthiness of the findings will also be discussed.

2.5.1 Target population

Brink *et al*. (2012: 216) and O'Leary (2010:161) defines the term population as a set of people, objects or events that possess some common characteristics that are of mutual interest to the researcher. Furthermore, the term population refers to all the individuals who meet the specific inclusion criteria of the study. The target population for this study consisted of young adults between the ages of 18 and 25 years living with T1DM in NMBHD attending the diabetic clinic in a public tertiary hospital.

The inclusion criteria for this study required the participants to be:

- Young adults between the ages of 18 and 25 years.
- Diagnosed with T1DM.
- Attending the diabetic clinic in a tertiary public hospital at the NMBHD.

Participants were excluded should they be experiencing any symptoms of raised or low blood glucose levels during data collection, as the participant will require urgent medical attention to relieve the symptoms.

2.5.2 Sampling method

A sample consists of participants that are examined and selected from a defined research population and who are eligible for actual inclusion in the study (Boeitje, 2010: 35). Polit and Beck (2012:309) state that a sample is a process of selecting a portion of the population to represent the entire population. Purposive sampling was the strategy used in this study which, according to Creswell (2013:156) involves the selection of participants that are suitable for inclusion in the sample as they possess relevant information due to their experience of the research problem.

After permission was granted to the researcher by the relevant authorities (see 2.7), the researcher contacted the registered nurse working at the diabetic clinic in the public tertiary hospital who was requested to be the gatekeeper for the study. The registered nurse was asked to aid with the purposive selection of the participants as she knew which participants best suited the criteria. The gatekeeper purposively selected the participants who suited the sample according to the inclusion criteria (Polit & Beck, 2012:312). Next, the gate keeper was asked to approach the participants individually during clinic visits. After the registered nurse, working in the diabetic clinic in a tertiary public hospital, made initial contact and received permission from the participants willing to take part in the research study, the telephone numbers of the participants were given to the researcher.

The researcher contacted the participants telephonically and discussed the objectives of the study, and to determine their willingness to take part in the study. Furthermore, the researcher discussed the means of protecting the identities of the participants during the study. The researcher made an appointment to meet face-to-face with the participants at a time and venue convenient for the participant; which was either their homes or at the diabetic clinic. During the contact session, the researcher supplied a detailed explanation about the research to participants (see information letter, Annexure C and section 2.5.3). After obtaining consent from participants (Annexure D) and ensuring that the participant did not experience any symptoms of low or high blood glucose, the researcher started with the one-on-one interviews.

2.5.3 Data collection method

The goal of data collection in this study was to gain an insight and understanding of the participant's experiences in a particular setting and to give them meaning. The most common form of data collection is the audio-recorded interviews; but other forms of data collection may also be used (Grove *et al.,* 2013:523). Careful planning and execution of the plan increase the accuracy of the data collected and the validity of the study findings (Grove *et al*., 2013: 517). Data collection started from January to April 2017. The researcher conducted semi-structured individual interviews with 11 voluntary participants. Data was collected using semi-structured individual interviews, observations, and field notes.

An appointment was made with each participant one week before the interview took place. The researcher compensated all those who spent money on transport. Before starting with data collection, participants were asked if they were experiencing any symptoms of raised or low blood sugar levels. This was done to prevent interruptions during interviews should they experience any acute complications of T1DM and be able to refer them to the relevant health practitioner. The information given to each participant included the objective of the study, expectations from the participant and potential benefits from the study. The researcher explained to participants that using the recording device during an interview assists in keeping the information safe. Thereafter, permission was requested from participants to utilise the recording device. The researcher informed each participant that only the researcher and the study supervisors will have access to the recordings. The researcher ensured that no participant names would be used during interviews, a number was assigned to each participant. The recording device was made visible to each participant and placed in such a way that it did not disrupt the participant or the researcher (De Vos, Strydom, Fouche & Delport, 2011:329).

At the end of an interview, the researcher summarised the interview and availed herself to answer any questions (De Vos *et al*., 2011:122). The time spent by the researcher with each participant was a minimum of 60 minutes. A pilot interview was undertaken with one participant and was considered successful by the study supervisor; therefore, it was included in the data analysis. Interviews continued until the researcher, and an independent coder, agreed that data saturation had occurred, and no further interviewing was necessary. Criteria used to determine data saturation was when themes were repeatedly mentioned by the participants, and no new themes were emerging, which occurred after the eleventh interview. The researcher transcribed the interviews and made use of Tesch's method of data analysis (Creswell, 2014:247). Data analysis involved the researcher familiarising herself with the data, organising data, coding into themes, and to sub-themes. The independent coder received a clean set of transcripts and the data analysis guide. The researcher and the independent coder reached agreement on the final themes and sub-themes of the research study.

2.5.3.1 Semi-structured individual interviews

According to Maxwell (2014:241), a semi-structured individual interview is a planned, flexible type of interview intended to obtain views of the participants about the research problem. The goal of this type of interview is to obtain descriptions of the experiences of each participant, after which the researcher interprets and attach meaning to the responses per participant. According to Grove *et al.* (2013:272), researchers must give themselves the opportunity to practice interviews before they start interviewing study participants. The researcher had an opportunity to practice the interviewing technique through the pilot studying. The researcher conducted face-to-face interviews with the participants to gain as much information as possible (Mills & Birks, 2014:56). In a semi-structured interview, the researcher has a general topic in mind, and specific questions may be formulated once the interview is in progress, based on the participant's response (Grove *et al.*, 2013:173). The researcher wanted to gain insight and understanding about the experiences of young adults living with T1DM in a tertiary public hospital, regarding self-management and lifestyle adaptation. The interview questions used in the study were as follows:

- Tell me how it is for you to live with T1DM?
- Tell me about the role of the health care providers in the clinic regarding assisting you with T1DM.
- Tell me what in your opinion could be done to improve treatment, care, and support that you receive at this clinic?

The researcher organised an environment where there were minimal or no interruptions at the diabetic clinic or the participant's homes. This allowed for confidentiality and privacy. A seating arrangement that encouraged involvement and interaction was provided. The table with a jug of water and two (2) glasses was placed off to one side to avoid hiding the participant's body language which the researcher wanted to observe. The space between the researcher and the participant's chair was about one (1) meter apart, in order to make it easier to maintain eye contact and to provide adequate space between the researcher and participant. This was also to encourage the participant to observe the researcher's nonverbal communication, e.g. a smile and nodding the head that will indicate that the researcher agrees, accepts or acknowledges the participant.

The researcher established a relationship of trust with each participant prior to the interview by introducing herself and by explaining the purpose of the study. The researcher, as a registered nurse, had an established nurse-patient relationship with participants before the interviews as the researcher is working at the diabetic clinic in a tertiary public hospital. This relationship could have resulted in a risk of coercion. Therefore, before each interview, the researcher requested each participant to view her as a researcher, not as a nurse and emphasised that participation was voluntary and that the participant had a right to withdraw at any stage of the interview without consequences. Participants were also ensured of confidentiality. No participant refused to participate or dropped out of the interview. The researcher explained the process of the interview with participants and obtained permission to use an audio-recording device. The researcher informed participants that only the researcher and the supervisors would have access to the recorded interview. The researcher informed participants that no names would be used on the recorded interview. Each participant was assigned a number which corresponded with the audio recorded interview and transcript.

The information letter was handed to each participant with the same explanation as above about the research study (Annexure C). The researcher answered questions which the participants asked. The participants were requested to read and sign the consent form (Annexure D). The researcher adhered to the essential interviewing techniques, tips, and skills for an effective interview as mentioned by De Vos *et al*. (2011:343) which included the following:

- Participant must do 90 per cent of talking. This allowed the participant to tell the story.
- Ask clear, brief, and open-ended questions. The researcher used words that made sense to the participant and avoided pre-determined answers. The researcher did not rush the participant; periods of silence allowed participants to think before answering the question.
- The researcher concluded each interview by asking the participant whether they would like to add anything.

2.5.3.2 Observations and field notes

According to Polit and Beck (2012:352), observation permits the researcher to see the world as the study participants see it and to develop a rich understanding of the phenomena of interest. Phillipi and Lauderdale (2018:381) state that it is essential to make accurate notes of what goes on during interviews in the field. Field notes are the written account of the things the researcher hears, sees, experiences, and thinks during interviewing (De Vos *et al*., 2011:359). According to Creswell (2014: 235), the researcher takes field notes on the behaviour and activities of the participant at the research site. Field notes, for example, handwritten notes, were made during the interviews and used by the researcher to document the various responses of the participants. The researcher also used these notes to indicate facial expressions, emotions, and body language to add to recorded data.

2.5.4 Pilot study

A pilot study was conducted prior to data collection. According to Nieswiadomy (2014:8), a pilot study is a small-scale version or a trial run done in preparation for a major study. A pilot study is carried out to test an interview schedule, to evaluate each step in the research process and to adjust or improve on the quality of the study (Watson, McKenna, Cowman & Keady, 2010:184). The researcher conducts a pilot study in a manner similar to that for the proposed study, using similar participants, the same setting, and the same data collection method (Burns & Grove, 2011:49). For this study, one pilot interview was conducted with one of the participants to determine whether the relevant data can be obtained from the participants for the main study. The pilot study allowed the researcher to become familiar with the interview techniques. The pilot interview was considered satisfactory by the supervisor as discussed in 2.5.3 and included in the main study.

2.5.5 Data analysis

For the purpose of data analysis, the interviews were recorded with the participant’s permission and transcribed verbatim by the researcher. Streubert and Carpenter (2011:46) state that data analysis in qualitative research involves preparing and organising the data to generate meaning. Once data was collected and transcribed, the researcher commenced with data analysis. Creswell (2014:246) states that data analysis proceeds hand-in-hand with data collection. Immediately after each interview, the field notes were written down and added to the data analysis chapter. De Vos *et al*. (2011:335) state that field notes are taken as soon as possible after each interview, preferably within 24 hours. According to Phillipi and Lauderdale (2018:381), field notes aid in constructing thick, rich descriptions of the study context and are useful in understanding participant meaning. The identified themes were used to describe the findings (Creswell, 2014:247). The themes are recurring ideas or experiences that are mentioned by the participants.

An independent coder verified and identified the themes and sub-themes. Themes were identified by following Tesch's steps of data analysis (Creswell, 2014:247):

- The researcher carefully reads all transcripts and writes down the ideas.
- One interview document was analysed to familiarise the researcher with the entire process; the researcher wrote down thoughts that merged in the margins.
- After analysing more interview documents, the researcher made a list of topics and combined those that were similar.
- Codes were then attached to the topics. The researcher went back to the data and assigned the same codes to similar statements.
- Relevant topics were categorised, and categories grouped with descriptive wording.
- An abbreviation was assigned to each category.
- A preliminary analysis was performed by assembling data belonging to each category.
- A record of existing data was given to the researcher's supervisor for safe keeping.

2.5.6 Literature control

According to De Vos *et al.* (2011:134), the use of literature control assists the researcher to have a clear understanding of the nature and meaning of the interviews. Literature control creates a foundation, based on existing related knowledge. The researcher implemented a literature control after data analysis to contextualise findings derived from the themes in relation to the existing literature. Once the themes were analysed, the researcher used literature to find any additional data to support the findings with which to make recommendations that will assist young adults living with T1DM, in a tertiary public hospital in NMBHD with lifestyle adaptation (see Chapter Three).

2.6 TRUSTWORTHINESS

Trustworthiness of this study was demonstrated by using the processes supported by Lincoln and Guba (1985) as cited in De Vos *et al*. (2011:48) to describe operational techniques to support rigour of qualitative work. These processes include credibility, dependability, confirmability, and transferability (Streubert & Carpenter, 2011:48).

2.6.1 Credibility

According to De Vos *et al*. (2011:419), credibility refers to the concept of whether the study was conducted in a manner that the reader is sure that the subject has been accurately identified and described. Polit and Beck (2012:106) state that credibility refers to confidence in the truth of data and the interpretations of them. To ensure that the research study was credible, various strategies were implemented, namely:

- Saturation of data
- Member checking
- Peer review
- Journaling
- Field notes
- Audio recording
- Verb trails
- An Audit trail

Saturation of data: According to Brink, van der Walt and van Rensburg (2012:173), prolonged time spent in the field collecting data assists the researcher to obtain useful, accurate and thick data about the study. The researcher conducted one-on-one interviews with the participants until they could not generate new information; data saturation attained Brink *et al*., 2012:173). After the researcher conducted an interview with participant number 11, research supervisor confirmed the saturation of data.

Member checking: Polit and Beck (2010:499) state that member checking with participants can be carried out in an ongoing way as data are being collected, such as through deliberate probing to ensure that interviewers have understood the participant's meanings. The researcher allowed the participant sufficient time to describe their experiences by means of probing to explore further description and to ensure that the information given is a true reflection of what the participant intended to say.

Peer review: Cresswell (2014:252) states that peer review or debriefing involves locating people who are experienced in the phenomenon being studied to evaluate and ask questions about the research study and to ensure that the findings support participants other than the researcher. The researcher consulted her colleagues and discussed the research process and findings with them because of their knowledge regarding management of young adults living with T1DM.

Reflexivity: According to Polit and Beck (2010:504), researchers are responsible for data collection as well as data analysis process. Therefore, the credibility of data is enhanced if the study contains information about the researcher, such as personal or professional connections to the participants. Polit and Beck (2010:504) further affirm that the researcher needs to report any personal or professional information that may negatively affect data collection, analysis and interpretation. The researcher is a registered nurse working in the diabetic clinic in a tertiary public hospital where research was conducted and already built a nurse-patient relationship that could negatively affect data collection. Therefore, before commencing data collection, the researcher requested each participant to view her as a researcher, not as a registered nurse.

Field notes: Polit and Beck (2010:498) state that the researcher should prepare filed notes that are rich with descriptions of what happened in the field. The researcher wrote field notes on the behaviour and activities of participants at the research site to add to the recorded data.

Audio recording: Creswell (2014:245) states that the researchers record information from interviews by making handwritten notes, by audio recording or by videotaping. Cresswell (2014:245) further states that if audiotaping is used, the researcher needs to plan for transcription of the tape. The researcher utilised an audio recording to ensure no missing data during the interviews and transcribed verbatim. .

An Audit trail: According to Polit and Beck (2010:498), an audit trail is a systematic collection of data that would allow an independent coder to come into conclusions about auditing data. The researcher compared data that she analysed with the data of the independent coder to identify similarities and differences. The independent coder and researcher used Tesch's method of data analysis in a step by step manner (Cresswell: 2014:245). An independent coder was utilised to ensure that the information that the researcher attained from data was trustworthy. According to Lincoln and Guba (1985) as cited in Cresswell (2014:252), validity is the strength in qualitative research and is based on determining whether the findings are accurate from the researcher and the participant.

2.6.2 Dependability

Dependability refers to the provision of evidence that if the research study were to be repeated with similar participants, the findings would be similar to the findings of the original study (Brink, Van Der Walt & Rensburg, 2012:172). The following strategy was implemented to ensure dependability:

- Independent coding

To ensure dependability in this study, the researcher and an independent coder coded the data, identified themes and sub-themes; thereafter, compared the findings to ensure an accurate representation of data.

2.6.3 Conformability

Conformability relates to the fact that if the researchers should analyse the same data, they should obtain the same meaning (Brink *et al* 2012:173). The researcher used the following strategies to ensure conformability:

- Audit trail
- Independent coder

According to Streubert and Carpenter (2011:49), the way researchers document the confirmability of findings is to leave an audit trail, which is a recording of data collection activities over time that another individual who is independent to the study can follow. Streubert and Carpenter (2011:49) further state that the objective is to illustrate as clearly as possible the evidence and thought processes that led to the conclusions. Botma, Greeff, Mulaudzi and Wright (2010:292) state that there should be congruency between two or more independent people about the accuracy, relevance, and meaning of data. Therefore, the researcher obtained the services of an independent coder. Both researcher and the independent coder reached similar themes after analysing the transcripts of interviews. The researcher will keep field notes, audio recordings of interviews, transcriptions as well as the coding processes for a period of five (5) years.

2.6.4 Transferability

Polit and Beck (2012:494) and Botma *et al.* (2010:292) state that transferability or applicability refers to the extent to which the research findings can be transferred from one context to another. The responsibility of the researcher is to provide sufficient descriptive data to allow comparison and transferability (Polit & Beck, 2012:492). The following strategies were implemented to ensure transferability:

- Thick descriptions
- Comprehensive field notes

Thick descriptions: According to Brink *et al*. (2012:173), a thick description refers to a rich detailed and graphic description of the research setting. Eleven (11) participants who were young adults between the ages of 18 and 25 years took part in the research study. These participants had to be living with T1DM.Most participants were working while others were students, and the majority of them were single. The setting where the research was conducted was described and the challenged that the researcher encountered were discussed. The research design and method was discussed. The researcher explored the concepts of trustworthiness and ethical considerations, and indicated how these concepts would be applied throughout the research study.

The two themes and sub-themes that were identified were discussed and analysed, supported by verbatim quotations. Comprehensive field notes were added to verbatim quotes to give thick description of participant's experiences. Cresswell (214:240) states that field notes provide a rich context for analysis.

2.7 ETHICAL CONSIDERATIONS

Brink, Van der Walt, and Rensburg (2012:32) state that the researcher is responsible to ethically conduct research from conceptualisation and planning through implementation to the dissemination of results. May and Holmes (2012:96) state that research ethics concerns the principles aimed at ensuring the rights, safety, and well-being of participants supported by respect for human dignity and protecting the individual's interest and integrity. In this study, great care was exercised to ensure the protection of the participant's rights. The research study obtained ethical clearance (H16-HEA-NUR-042) from the Faculty Postgraduate Studies Committee (FPGSC, Annexure F) from Nelson Mandela University and permission from the Eastern Cape Department of Health (ECDoH, Annexure E) and the Public Tertiary Hospital (Annexure A). The following four ethical principles were considered in the study: autonomy, informed consent, beneficence, and justice, which will be described in detail in the following section.

2.7.1 Autonomy

May and Holmes (2012:96) state that autonomy refers to the freedom of the participants to make choices about issues that affect one's life and is intricately linked to respect for an individual's decision. May and Holmes (2012:96) further state that the researcher should under no circumstances coerce participants to participate in the research study. The researcher is a Registered nurse working in the diabetic clinic in a public tertiary hospital. The researcher maintained the principle of autonomy by not persuading participants or inducing participation in the research study. In addition, autonomy was ensured by allowing participants the right to make informed decisions to participate or withdraw from the study. The participants were made aware that they were free to leave the study anytime should they so wish.

According to Grove *et al.* (2013:172), researchers have a responsibility to protect the anonymity of the participants and to maintain the confidentiality of data collected during the study. The privacy and confidentiality of participants were maintained throughout the research study as no names were used during data collection; instead, participants were identified using a number such as Participant 1 (P1). The researcher handed the data to the study supervisor for safe keeping in encrypted documents on a password protected computer and will be kept for a period of five (5) years, whereafter, it will be destroyed as per legal requirement. Data was only accessible to the researcher and supervisor and only used for research purposes.

2.7.2 Informed consent

Informed consent is the principle that includes information and voluntariness and must be obtained after recruiting participants. Participants must be given clear and sufficient information about the study explaining why the study is needed and what is required from the participants (May & Holmes, 2012:96). The researcher contacted the pre-selected participants telephonically and asked them to participate after informing them about the objectives of the study, data collection method, and the estimated period for the interviews. Participants were also informed about their right to withdraw from the study anytime should they wish to do so.

2.7.3 Beneficence

According to Brink, Van der Walt, and Van Rensburg (2012:35), the principle of beneficence entails that the researcher needs to protect the well-being of participants from discomfort and harm that may either be physical, psychological, or emotional. Burns and Grove (2013:174) state that beneficence encourages to do good and to prevent harm. Burns and Grove (2013:174) further state that the researcher should try to bring about the highest possible balance of benefits in comparison to harm. A research benefit is something of health-related, psychosocial, or other value to the participant or that will assist in the acquisition of knowledge for evidence-based practice (Grove *et al*., 2013:175). Before obtaining the informed consent from the participants, the researcher explained the purpose of the study verbally and in writing. The researcher further explained to the participants about their right to refuse to participate and their right to withdraw from the study at any time. Participants were also made aware that the recommendations of the study will assist them to adapt their self-management and lifestyle.

2.7.4 Justice

The principle of justice refers to a participant's right to fair selection and treatment (Brink *et al*., 2013:36). The selection of the study population was just, and the selection of participants was according to the inclusion criteria of the study. Purposive sampling was the strategy that was used for the study which according to Creswell (2013:156) involves the selection of participants as they possess relevant information due to their experience of the research problem.

2.8 CHAPTER SUMMARY

This chapter explored the topics of research design, methodology, trustworthiness, and the ethical considerations relevant to the study. Chapter Three will discuss the identified themes and sub-themes together with a literature control to support the findings of the research study.

CHAPTER THREE

DATA ANALYSIS, DISCUSSION OF FINDINGS AND LITERATURE CONTROL

3.1 INTRODUCTION

In Chapter Two the researcher discussed the research design and method. The researcher explored the concepts of trustworthiness, and ethical considerations and indicated how these concepts would be applied throughout the research study. In this chapter, the data collection and analysis processes will be briefly outlined, followed by the characteristics of the participants, and a discussion on the identified themes which addressed the research question. The identified themes and sub-themes will be supported with relevant quotations and discussed in-depth using literature to confirm the experiences of young adults living with T1DM in a tertiary public hospital in NMBHD, regarding self-management and lifestyle-adaptation.

3.2 DATA COLLECTION AND ANALYSIS PROCESSES

The purpose of the research was to explore and describe the experiences of young adults living with T1DM in a tertiary public hospital in NMBHD, regarding self-management and lifestyle adaptation. Eleven participants who met the inclusion criteria of the study were purposefully chosen and interviewed. Data collection commenced as soon as the researcher received ethical clearance from the Faculty of Health Science’s FPGSC, the permissions from ECDoH as well as from the Management of the Public Tertiary Hospital to conduct the research (H16- HEA-NUR-042), as stated in 2.7. An appointment was made telephonically with each participant a week prior to an interview. Some interview dates had to be postponed due to busy schedules, changes in their duty roasters, or preparations for tests and assignments. Some participants delayed the process due to their inability to notify the researcher about changes in residential addresses and their availability. The researcher was restricted to collect data from young adults between the ages of 18 and 25 years. All these obstacles led to delays in the data collection process.

Field notes were written immediately after each interview, to provide a rich context for analysis (Creswell, 2014: 240). The field notes were linked with each interview via the participant number (Phillipi & Lauderdale 2018:381). Thereafter, the researcher transcribed the interviews verbatim. The researcher read and re-read the transcripts to familiarise herself with the data and thereafter, commenced with the coding process. The researcher requested an independent coder to identify themes and sub-themes. After coding the themes and sub-themes, the researcher and independent coder met to compare the identified themes and sub-themes. The researcher and the independent coder agreed on the identified themes and sub-themes. The research supervisors confirmed the final themes and sub-themes for the study.

3.3 PRESENTATION OF RESULTS

Table 3.1 outlines the characteristics of 11 participants that partook in the study.

Table 3.1: Participants and Characteristics of the Study

Participant (P) (n=11)	Sex	Age	Employment	Marital status
P1	Female	23 years	Unemployed	Single
P2	Female	25 years	Student	Married
P3	Male	25 years	Working	Single
P4	Male	18 years	Student	Single
P5	Female	21 years	Student	Single
P6	Female	25 years	Working	Single
P7	Female	23 years	Working	Married
P8	Male	25 years	Working	Single
P9	Female	25 years	Working	Single
P10	Male	25 years	Working	Single
P11	Female	22 years	Working	Married

Most participants were female (n=7). Participants were between 18 and 25 years of age, with most participants being 25 years of age (n=6). Most (n=7) participants were working while the majority of participants were single (n=8).

The identified themes and sub-themes are presented in Table 3.2

Table 3.2: Identified Themes and Sub-themes

THEME	**SUB-THEME**
Theme 1: Participants had negative experiences in relation to T1DM	**Participants related that:** 1.1 the restrictions that T1DM places on their lives are hard to manage 1.2 they feared being stigmatised due to T1DM 1.3 they are informed about exercise and diet but struggle to apply the principles to their lifestyle 1.4 they are unable to adhere to a diabetes diet due to difficulties in carbohydrate counting and lack of finances 1.5 they lack health care assistance in controlling their disease
Theme 2: Participants shared the experiences related to achieving self-management of T1DM	**Participants suggested that:** 2.1 there are areas that can be improved for patients receiving treatment, care, and support for T1DM at the clinics 2.2 self-management of T1DM necessitates adjustments to lifestyle and improvement of knowledge through continuous education, support, and counselling on controlling the disease 2.3 patients must be informed that to achieve self-management they have to acknowledge T1DM as a long-term illness

3.3.1 Theme 1: Participants had negative experiences in relation to T1DM

Pera (2011:64) refers to an undesirable or harmful experience as a situation that may have a profound psychological impact on the affected individuals and may, therefore, disrupt their quality of life. Quality of life can be defined as an individual’s perception of their position in life, in the context of the culture and value systems in which they live; in relation to their goals, expectations, standards, and concerns (Spasic, Radovanovic, Dordevic, Stefanovic & Cvetkovic, 2014:194). According to Lontchi-Yimagou, Mapa-Tassou, Dehayem, Essi, Saji, Takogu, Sobngwi and Mbanya (2017:1), the impact of T1DM is of such magnitude that it affects patients not only physically, but also emotionally, socially, and psychologically. T1DM has a direct effect on the psychosocial adjustment and physical well-being of patients, resulting from the complexity in regimens to manage the disease (Younis, Arshad, Yousuf, Salman, Massod & Khurshid, 2017:123).

Several studies have demonstrated that T1DM has a substantial negative impact on health-related quality of life (Lontchi-Yimagou *et al*., 2017:1; Sudhir, 2014:59 & AlBuhairan, Nasim, Otaibi, Shaheem, Jaser & Alwan, 2015:174). For example, Osei-Yeboah, Owiredu, Norgbe, Lokpo, Allotei, Doe and Attah, (2016:298) state that T1DM and its management can have a considerable effect on patient’s lives, for example, feelings of isolation, co-dependency, experience of loss of freedom, all which can have consequences for the optimal management of the condition. According to Rwegerera, Moshomo, Gaenamong, Oyewo, Rivera, Masaka and Godman (2017:111), health-related quality of life refers to the physical, psychological, and social aspects of health that are influenced by the beliefs and expectations of individuals living with a chronic disease.

Osei-Yeboah *et al*. (2016:298) confer that the health-related quality of life represents the effects of chronic disease from the viewpoint of a person living with the disease and yields information to the health care providers that could be incorporated into the strategies for chronic disease management. Osei-Yeboah *et al.* (2016:298) further state that health care providers must understand the effects of living with a chronic disease on the mental status of a patient. Depression is significant comorbidity prevalent in young adults living with T1DM and adversely affects health outcomes (Younis *et al*., 2017:123). Accordingly, living with a chronic disease should be expected to result in negative experiences for the person concerned (Iregbu & Iregbu, 2015:4). Figure 3.1 (below) shows theme 1 and the sub-themes.

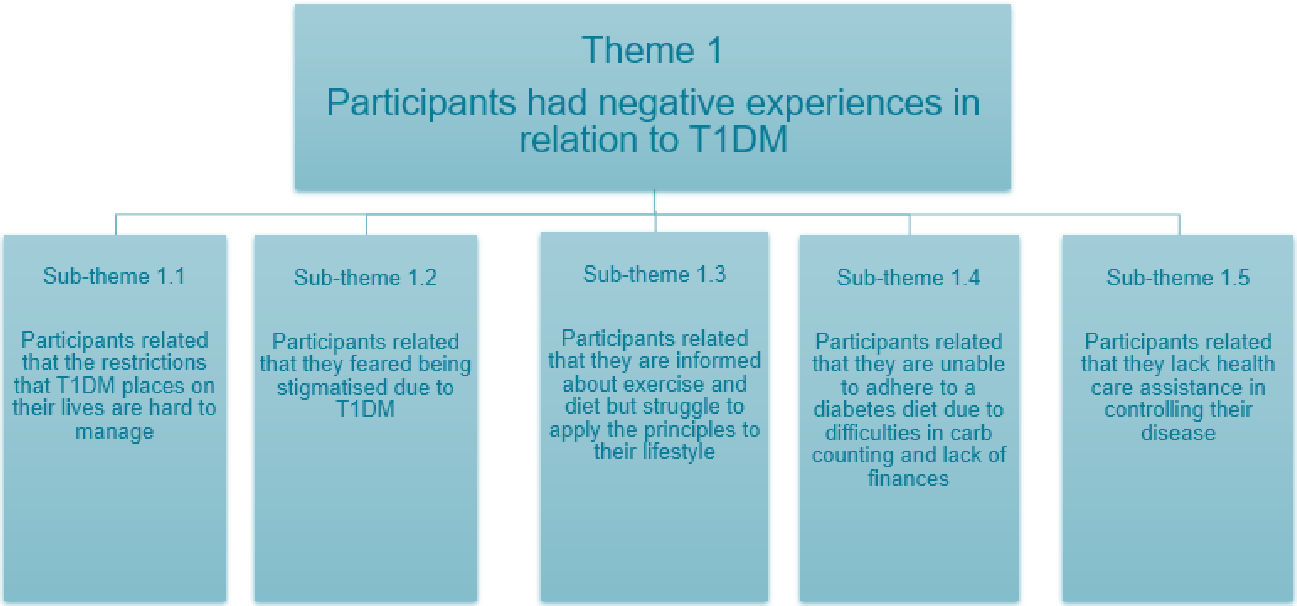

Figure 3.1: Diagrammatic Representation of Theme 1 and Sub-themes

3.3.1.1 Sub-theme 1.1: Participants related that the restrictions that T1DM places on their lives are hard to manage.

T1DM is a chronic disease requiring continuous medical care to prevent acute complications and to reduce the risk of long-term complications. The management of T1DM requires young adults living with the disease to be directly involved in their self-management by means of monitoring blood glucose levels, injecting insulin two (2) to four (4) times daily and maintaining a healthy diet and exercise (Garvey, Finkelstein, Ochoa, Wolfdorf and Rhodes, 2013:94). Embuldiniya, Veinot, Bell, Bell, Nyhof, Sale and Britten (2013:3) define self-management as the individual’s ability to manage the symptoms, treatment, physical and emotional consequences, and lifestyle changes that are inherent in living with a chronic condition. According to Inamdar, Kulkarni, Karajgi, Manvi, Ganachari and Kumar (2013:238), self-management of T1DM is affected by many factors such as age, psychosocial issues, and lifestyle changes.

Researchers argue that young adulthood is a divided developmental stage, with an early transitional phase (18–22 years) and a later stage (approximately 23–30 years) which is characterised by increased lifestyle stability (Balfe, Doyle, Smith, Screenan, Brugha, Hevey & Conroy, 2013:2). Balfe *et al*. (2013:14), divides young adulthood into two phases; the first phase called an early transitional phase ranges between ages of 18-22 years and the second phase or late transitional phase ranges between 23 and 30 years. Monaghan, Hegelson and Wiebe (2015:2) contend that an early phase in young adulthood ranges between 18 and 25 years and late phase in young adulthood ranges between 26 and 30 years. The participants in this study were in an early phase that ranges between ages of 18 and 25 years and according to Monaghan *et al*. (2015:2), falling within an early phase of young adulthood. Arnett (2009:39) describes the ages between 18 and 25 years as the transition to adulthood characterised by identity exploration, instability, self-focus, and possibilities. T1DM has been described as difficult, demanding, and never-ending (Rechenberg, Whittemore, Holland & Grey, 2017:2). For many young adults living with T1DM, there is a sense of the difference in their lives despite concerted efforts to maintain a sense of normalcy (Borus & Laffel, 2010:2). Young adults in this study expressed frustration when asked how it is to live with T1DM:

> "*For me, living with T1DM is very difficult because I'm young and it's like…you always wanna follow your friends and the crowd, but with diabetes, you are restricted to do certain things and eat certain things…* [Moving shoulders up and down, opening both hands].*"* (P11)
>
> *"I am very young; I am 23 years old…I like to go out partying with my friends; I have a habit not to take my insulin (when out) because I don't like …using my insulin in front of my friends* [Turning head, breaking the sentence and looking at the wall for few seconds] *…so it's difficult for me."* (P7)

The above participants appeared to experience difficulties in the self-management of T1DM and the restrictions it places on their lives, particularly during the stage of young adulthood. T1DM appears to impact the young adult's sense of normalcy in that although they might prefer to view the disease as one part of their lives, which has to be managed, this is difficult to sustain at all times (Spencer, Cooper & Milton, 2014:220). T1DM is a pervasive factor in the young adult's life, touching on their schedules, opportunities, personal feelings, relationships, and situational contexts. It is difficult to completely control the outcomes of the disease, both physically and psychosocially, which can lead to discouragement and confusion (Spencer *et al*., 2014:22).

Babler and Strickland (2015:2) state that living with T1DM, which is a challenging disease, is especially difficult during the young adult stage of development. Balfe *et al*. (2013:2) continue by explaining that young adults are in the developmental period of transitions characterised by new roles in their lives. According to Arnett's (Arnett & Tanner, 2009:2) theory of emerging adulthood, the young adult stage is an extended period between adolescence and adulthood. Arnett & Tanner (2009:2) further affirms that the young adult stage is characterised by establishing careers, committing to interpersonal relationships and new family roles. Accordingly, the young adult leaves the parental home for the first time in their lives to be on their own for educational purposes or to seek employment. They meet new friends, involve themselves in new relationships, marriage could occur, and they could become parents.

Young adults with T1DM are living with a chronic disease that requires tight blood glucose control not only through insulin injections but a healthy lifestyle including a healthy diet and exercise, which are essential to maintain the target blood glucose levels (referred to by participants in the study as HGT) between four (4) and seven (7) millimoles (Shrivastava, Shrivastava & Ramasamy, 2013: 4). Changes in cultural patterns can also affect young adults who are living with T1DM. Pilancinski and Zozulinska-Ziolkiewics (2014:124) define cultural patterns as a manner of living characteristic of an individual or a group and influenced by the socioeconomic status or educational background. The culture is closely related to health behaviour, defined as behaviours expressed by individuals to protect, maintain, or promote their health status including nutrition and physical activity. Pilancinski and Zozulinska-Ziolkiewics (2014:124) further state that culture is closely related to the lifestyle; therefore, in addition to the young adult's lifestyle, those that are living with T1DM have an essential role in the self-management of their disease. The American Diabetes Association (ADA, 2017:38) states that the best possible outcome of T1DM self-management is achieved by practising the culture involving healthy dietary choices and meal planning as well as structured and well monitored physical activity to prevent acute complications of the disease. Participants said:

> *"When I was growing up, living with my parents, it was very difficult to manage my diabetes because they did not understand what I needed to eat, and I needed to eat at specific times; every three hours and that I needed to inject. It was difficult for them to understand that I had a schedule* [Pause]*…the types of food that they were giving me were not the healthiest".* (P2)
>
> *"I know how to control my diabetes in certain circumstances like when I'm exercising…I check my sugar, and I know how to balance my diet and insulin to prevent my sugar from becoming too low".* (P3)

The above participants expressed an understanding that changing their behavioural patterns assisted them to achieve the necessary goals of healthy living and to prevent the acute and chronic complications of T1DM. Wilkinson, Whitehead and Ritchie (2013:112) state that young adults living with T1DM face the need for continuous adjustments in diet, medication and exercise in order to achieve optimal glycaemic control. According to Weller, Baer, Nash and Perez (2017:1), self-management of chronic disease is the process of actively engaging in the self-care activities required to control the adverse effects of the disease. Reyers, Tripp-Reiner, Parker, Muller and Laroche (2017:3) explain that self-management requires the acquisition of knowledge and the skills necessary to appropriately engage in a complex set of behaviours aimed at maintaining health, such as self-monitoring of blood glucose levels and insulin adjustments, in the context of daily living.

The process involves working with health-care providers to learn to make adequate decisions and to take appropriate action, which is dependent on blood glucose levels (Reyers *et al*., 2017:3). The ability to change and, or adapt behaviours to live with T1DM optimally is the crucial element and ultimate goal of self-management (Adachi, Yamaoka, Watanabe, Nemoto & Tango, 2017:7). According to Ebrahim, De Villiers and Ahmed

(2014:76), dietary management plays a vital role in self-management of T1DM as poor dietary quality leads to poor glucose control and is associated with an increased risk of acute complications such as hypoglycaemia or hyperglycaemia. The following participants in this study concur:

> "*…it's quite a big adjustment* [sighing]*…there are instances where I don't know how to balance my sugar into an acceptable level when you go out for a meal…you have to inject your insulin half an hour beforehand…you try to do that …it doesn't always work out…you find your sugar levels erratic* [sighing]*…I find it very difficult to get used to".* (P6)
>
> *"Whenever you are in a rush, you forget to take your insulin and mostly forget to eat, and you will eat something on your way without taking insulin…your sugar will be high because you did not inject your insulin".* (P10)

The above participants indicate the difficulties they encounter when attempting to incorporate self-management of T1DM into their daily activities. Health care providers need to assist with education on how to integrate self-management of T1DM into their lifestyle. Self-management of T1DM includes merging the activities related to the control and prevention of acute and chronic complications of the disease. These measures include self-monitoring of blood sugar, decision making about adjusting insulin depending on blood sugar levels, exercise, and dietary modifications, into their daily life activities such as work, school, and leisure time (Weller, Baer, Nash & Perez, 2017:3). Participants said:

> *"When I feel funny* [Quiet for a few seconds]*…I feel numb in my feet and hands, and sometimes I get pins and needles* [Standing up, moving to the examination couch while talking, climbed the foot-step up and laid on his tummy on the couch]*…I take my machine, I put the glucostrips into the machine and prick myself. When my sugar is above 20, I know it's very high…what I do in that case…in the insulin units that I use, I increase it by two (2) units…I got that advice from the doctor…then the insulin will adjust my sugar to a reasonable level which is between 7 and 10."* (P10)

> *"…I check my sugar, when it is below four (4) I drink sugar water and eat a snack, and when it is too high then I drink a lot of water because if you drink a lot of water and pee a lot then your sugar decreases* [Pause]*…I also do a bit of exercise just to keep my blood sugar levels on the right point."* (P4)

The above quotes indicate that health care providers informed participants about how to monitor and maintain their blood sugar levels within the target limits. Also, the participants are aware of the immediate management of acute complications of T1DM such as hypoglycaemia and hyperglycaemia and to make decisions about when and how to adjust their insulin according to the blood sugar level.

The challenges and responsibilities accompanying self-management of T1DM may clash with the developmental task at hand such as fitting self-management of T1DM with work tasks. For example, having to inject insulin at work, may be considered awkward due to the inconsistency of tea or lunch breaks, making it difficult for young adults to control their disease (Ruston, Smith & Fernando, 2013:2; Monaghan *et al*., 2015:2). Short-acting insulin such as Actrapid is often used by patients with T1DM and must be injected 30 minutes before each of the three main meals of the day to prevent the risk of hyperglycaemia. According to Tascini, Berioli, Cerquiglini, Santi, Mancini, Rogari, Toni and Esposito (2018:109), carbohydrates have the most significant impact on raising blood glucose levels after a meal, but when at work young adults mostly eat carbohydrates such as bread. Pisano (2014:867) concurs that the onset for short-acting insulin is 30 to 60 minutes, hence the need to inject insulin 30 minutes before meals. A participant shares the challenges related to self-management of T1DM while in the workplace:

> *"The job I am doing is not good for a diabetic…I wake up at 4am…walk a long distance to work…when I get to my job, I start to work…I don't get tea break and nothing…the first time I eat would be at 13:00…I can't take my insulin when I'm supposed to…"* (P2)

While another participant expounds on the frustrations and challenges experienced with managing T1DM and trying to earn a living:

> *“I am facing difficulties through the piece[odd jobs] jobs that I am getting…I have to get some food …I have to choose between work and going to the clinic to get medication…so I will miss my dates to go to the clinic and take* [fetch] *my medication* [Quiet for few seconds, looking down]*…I sacrifice medication for my work; if I don’t go to work, I won’t get paid…I won’t be having glucostrips; I won’t be having insulin…so I will go to work and default treatment.”* (P1)

Young adults between the ages of 18 and 25 years, who were previously under parental guidance and support, now have to begin taking definitive steps in their self-management of T1DM. Balfe *et al*. (2013:14) state that young adults in their mid-20’s are transitioning to long-term personal relationships, careers and parenthood while trying to manage their T1DM effectively. These competing developmental priorities can lead to some young adults living with T1DM feeling unsupported.

Participants relate:

> “*I was living with my family, my mother, my father and my sisters…everything was running smooth because I had the full support from my parents until my mother passed away, my father left home…so there are now difficulties* [Biting lower lip]*…I have to support my sisters financially…no one is supporting me, no one is guiding me about my medication.”* (P1)
>
> “*My mother was always there for me…then I am moving out of home; I am at tertiary level, I am having a little bit of problems…I went with my friends for the whole afternoon; I didn’t have my insulin…I was sick…I was taken to hospital.”* (P9)

The above participants experienced a decrease in parental support and guidance in the management of their disease for which they need to be prepared (Safaii, Raidl & Ramsay, 2013:6). The American Diabetes Association (ADA, 2016:86), states that parental involvement is a vital component of optimal T1DM management throughout childhood and adolescence. During childhood, an individual living with T1DM depends on parental guidance, supervision, and support in managing their disease. Parents thus need to be completely involved in the management of T1DM when the children are young especially the stage of 0 to the age of five (5) years. Monaghan, Hilliard, Cogen, Randi, and Streisand (2012:271) are of the opinion that T1DM management for a very young child requires a parent to assume total responsibility for the management of the disease. Babler *et al*. (2015:2) state that adolescents living with T1DM need to be taught how to self-manage their disease. This would be done with parental supervision and support and includes blood glucose monitoring, insulin injections, planning and preparation of meals and routine medical appointments. Parents and caregivers teach by showing, reacting to situations, and assisting, which the participants acknowledge as follows:

> *"I was with my mother …as we were talking, I felt wobbly, I was weak, I was shaking…I couldn't really talk nicely* [Imitating the symptoms with hands while talking] *…she quickly jumped, she made me sugar water, and she also made a snack for me".* (P9)
>
> *"My sugar was quite high; I was struggling to breathe, I was having diarrhoea…my granny noticed…she tested my sugar, and my sugar was 23…she phoned an ambulance, and I was admitted to hospital".* (P8)

The above quotes confirm that young adults were unable to manage the acute complications of their disease such as hypoglycaemia and hyperglycaemia without assistance and support from their family members. Health care providers must support and encourage young adult's full involvement in the management of their disease to ensure less reliance on family support in order to manage their disease. The transitional period should diminish parental monitoring, support and involvement and allow the young adult autonomy in self-management of their disease (Majumder, Cogen & Monagan, 2017:30).

Pyatak, Sequeira, Whittemore, Vigen, Peters and Weensberg (2014:1615) state that young adults have a difficult time maintaining control of T1DM because of competing priorities, psychosocial issues and participating in high-risk activities such as alcohol use, all of which create barriers to self-management. Among the responsibilities encountered during the stage of young adulthood are increased financial independence and changes in peer groups. An increase in alcohol use, possibly due to lack of parental restrictions, and peer pressure, could occur which could complicate self-management of T1DM. A participant concedes:

> *"…young adults these days, they always partying* [Moving her head and fingers as if she is listening to the music, rolling eyes, and smiling] *... It's all about alcohol; it's all about drugs… those things influence us and our sugar… if you drink too much, you'll end up in hospital hypoglycaemic…"* (P11)

Another participant expounded on the dangers of alcohol to young adults living with T1DM as follows:

> "*Alcohol is very dangerous for people living with T1DM, if you drink alcohol while using insulin then it (insulin) can throw your sugar upside down; your sugar can rise or drop…it can also let you go into a coma."* (P5)

According to Barnard, Sinclair, Lawton, Young and Halt (2012:435), alcohol may cause delayed hypoglycaemia and may inhibit the recognition of the symptoms thereof due to the effect of the carbohydrate content which may boost the blood sugar level. Blood sugar levels will then rapidly fall due to the action of insulin which leads to the uptake of glucose into the muscles and tissues and the alcohol that inhibits glucose release from the liver (Barnard *et al.*, 2012:436). Young adults living with T1DM need continuous education about the symptoms of hypoglycaemia and immediate management with the use of oral glucose, followed by a carbohydrate snack (ADA, 2017:38). Kim and Kim (2012:109) maintain that the health-care providers need to educate young adults living with T1DM about the risks of hypoglycaemic unawareness that may be caused by alcohol consumption and which may result to severe hypoglycaemia.

Participants expressed the difficulties of managing the disease specifically within their social lives and particularly the fear of being stigmatised due to T1DM as will be discussed in sub-theme 1.2.

3.3.1.2 Sub-theme 1.2: Participants related that they feared being stigmatised due to T1DM

Living with T1DM affects young adults not only physically but also socially, emotionally, and psychologically. The daily self-management routine needed in T1DM, together with the tasks and responsibilities accompanying young adulthood, may cause stress and negatively affect the young adult's ability to achieve and maintain optimal glycaemic control. According to Silverman, Krieger, Kiefer, Hebert, Robinson and Nelson (2015:1476), stress is associated with poor glycaemic control as well as inadequate adherence to T1DM regimens. Silverman *et al*. (2015:1476) further state that there is a phenomenon known as T1DM distress which refers to the emotional distress related to the burdens and requisite self-management required by the disease.

The management of T1DM focuses on achieving control and in preventing acute and chronic complications of the disease (Lontchi-Yimagou *et al*., 2017:1). Therefore, self-management of T1DM may be affected by health-related stigma or diabetes-related stigma (Irani, Abdolli, Bijan, Parvizy, Fatemi and Amini (2014:456). Health-related stigma is a psychological factor known to negatively influence the lives of people living with chronic medical conditions such as T1DM (Gredig & Bartelsen-Raemy, 2016:1620). Abdoli, Irani, Hardy and Funnel (2017:113) define diabetes-related stigma as a typical social process experienced or anticipated, characterised by exclusion, rejection, blame or devaluation. These results are experience, perception or reasonable anticipation of an adverse social judgement about a person or group living with the disease. Liu, Brown, Folias, Younge, Guzman, Close and Wood (2017:27) confirm that perceived stigmatisation or felt stigma occurs when an individual living with a chronic disease believes that the others perceive a personal characteristic as deviant and respond unfairly. In a study conducted by Williams (2007:83), stigma manifests most commonly as gossip, verbal abuse, and name-calling. Some people identify those living with chronic illnesses by using the name of the disease that they are living with, which according to Rose, Thornicroft, Pinfold and Kassam (2009:2) can be due to a lack of knowledge, negative attitudes or discrimination. A participant said:

> *"In some cases, they criticise people with uh* [sighing]*… diabetes and they call you names … it's always a pressure for us with diabetes."* (P4)

According to Abdoli, Abazari and Mardanian (2013:65), people can affect the identity of young adults living with T1DM by stigmatising them. According to Monaghan *et al*. (2015:6), young adults are creating an identity by interacting with significant others such as joining the work-force, meeting new friends and forming love partnerships. Wright & Hirsch (2017:2) refer to identity as the ability to construct the difference in a person's own life through an on-going articulation with others. Identity weaves itself through the relationship with the significant others. Participants in the study verbalised the fear of being stigmatised by significant others (such as friends) due to living with T1DM as follows:

> *"I feel embarrassed telling my friends that I'm living with type1 diabetes, I think they won't accept me…I'd rather keep quiet and keep it for myself* [not tell them]*"*. (P7)
>
> *"…I don't want people to know that I am diabetic* [Playing with his hands, lying on the couch] *…it is better for me to be quiet about it".* (P10)

A young adult living with T1DM believe that their friends perceive them as sick and therefore these young adults fear that their friends may exclude or reject them as follows:

> *"I don't know whether I can tell them [friends] what is going on with me, I don't know whether they will accept me as I am, or they will feel that I don't belong with them".* (P9)

Another participant engaged with friends to find out their views on the disease:

> *"I asked my friends about the disease…the responses I got from them were very negative…I decided not to tell them that I am living with type1 diabetes…from their response, I could see that they won't accept my medical status".* (P10)

From the above quotations, it is clear that participants fear sharing with their friends that they are living with T1DM as they feel that they (friends) might stigmatise them. Liu, Brown, Folias, Younge, Guzman, Close and Wood (2017:27) confer that feeling stigmatised can affect T1DM self-management because patients may be less likely to use recommended therapies that may be apparent in public.

Socially identifiable characteristics related to the self-management of T1DM can include insulin injections, blood glucose monitoring, dietary restrictions, and the episodes of acute complications of the disease such as hypoglycaemia and hyperglycaemia which may contribute to T1DM related stigma (Liu, *et al*., 2017:27). However, according to Schabert, Browne, Mosely and Speight (2013:7), young adults living with T1DM fear the stigma related to hypoglycaemic more than hyperglycaemia due to the behaviours and symptoms associated with hypoglycemic episodes. The symptoms may resemble being under the influence of alcohol, such as irritability and confusion or may be mistaken for an epileptic seizure. Fearing diabetes-related stigma can be a strong obstacle in the self-management of T1DM (Abdoli, Abazari & Mardanian, 2016:65). The following participants related:

> *"I was going to school using a taxi…I felt dizzy; I was feeling a bit shaky…I felt like telling the driver, but it's not easy to tell everybody about your sickness…especially type1 diabetes…they think that if you are diabetic, that's the end of the world…you are going to die anytime…I kept quiet* [Pause]*…I then fainted."* (P4)
>
> *"Living with type1 diabetes is quite challenging…you go out camping with friends; you go to the parties…you have to eat healthy…there are times when you have to inject…I will go away from the others [friends]…I don't want them to know that I am having diabetes…in case they put me up on a pedestal, or they are very careful around me, or they don't want to invite me for camping with them."* (P5)

The above participants described their discomfort about possibly being treated differently than others, which resulted in them not disclosing the fact that they are living with T1DM. Liu *et al*. (2017:28) state that young adults living with T1DM avoid full disclosure about their disease to their friends because they fear judgmental attitudes. One participant did not want to be a burden to friends and expressed fear of rejection as follows:

> *"…from my point of view, I think they won't accept me for being a friend of them…me being dependent on insulin, if we go somewhere they will always have to worry…does she have insulin* [Opening both hands at the same time]*…oh…she will have to eat, I feel embarrassed…."* (P7)

Participants in the study fear that their friends and peers may stigmatise them; they feel that living with T1DM define them as sick and different from others. According to Liu *et al.* (2017:27), a felt stigma is a psychosocial factor known to influence the lives of young adults living with a chronic medical condition such as T1DM. Liu *et al*. *(*2017:27) further state that stigmatisation or felt stigma occurs when there is a perception of stigma from a person living with a chronic disease, resulting in a negative feeling or response. The following participants said:

> "*I don't want them to know what I am going through…I just want to be normal as they are normal."* (P5)
>
> *"I was very shy to tell people about my medical status; because I didn't want them to know … because I always wanted to be normal…I don't want to be abnormal in front of people."* (P10)
>
> "*It's difficult to let them know (friends) that I'm living with type1 diabetes because I don't know how well they will react after knowing that I…I* [Voice breaks] *…I have diabetes."* (P4)

The above quotes indicate that the participants believed that living with T1DM suggests that they live an abnormal life compared to others not living with the disease. Furthermore, they were unsure as to the reaction of their friends and therefore, did not want to disclose their medical status. According to Browne *et al.* (2014:5), young adults are reluctant to disclose living with T1DM to their new social contacts; they do not want to attract attention. Browne *et al*. (2014:5) further state that young adults living with T1DM do not want to be seen as different from their friends and do not want to jeopardise the opportunity for friendship. Liu *et al*. (2017:32) further state that patients felt judged or blamed by friends for having diabetes as a result of overeating, poor diet, laziness, or by being overweight can cause T1DM. A participant relates:

> *“I don’t feel comfortable to discuss the thing that I am living with type1 diabetes with them [friends] because I am not sure whether they know type1 diabetes; what is going on with it.”* (P9)

The participant (below) indicated that after engaging with friends, it was discovered that they are not well informed about T1DM; hence the decision to not disclose their medical status to friends.

> *“I’m too shy to tell them [friends]…I am scared because they are not well educated in what I am educated about by the health care providers…I know what is right for me, but they don’t know what is right…they don’t have knowledge about this disease* [T1DM].*”* (P10)

Gredig and Bartelsen (2016:1621) state that to be treated differently by others means the linking of negative attributes to the individuals or groups, and that facilitates separation between the stigma bearers and the majority. Thus, the young adults living with T1DM would prefer not to adhere to their routine of self-management while with their friends as follows:

> *“I feel very shy to inject insulin in front of my friends… I feel that maybe they don’t understand it…maybe they will make a joke out of it* [Moving head while looking up] *…so I will skip injecting my insulin when I am with them* [friends].*”* (P9)

According to Stradberg, Graue, Wentsel-Larsen, Peyrot and Rokne (2014:175); Abdoli, Irani, Hardy and Funnel (2018:113), there is a growing awareness across the world that people living with T1DM are stigmatised. The International Diabetes Federation (IDF, 2015:109) states that one of the organisation’s key priorities is to champion a world free from discrimination and stigma for people living with T1DM. Lee, Lim and Koh (2014:67) state that social stigma could be a barrier in T1DM self-management. Schabert, Browne, Mosley and Speight (2013:5) further state that fear of social embarrassment, rejection, being treated differently or damaging relationship with significant others are common concerns associated with self-management of T1DM.

According to Patel, Eborral, Khunti, Davies and Stone (2011:219), feelings of embarrassment or shame among young adults living with T1DM may lead them to avoid their self-management routine such as blood glucose monitoring, insulin injections and maintaining dietary restrictions in social environments. Patel *et al*. (2011: 219) further states that this may adversely affect their glycaemic control and contribute to the development of acute complications of the disease such as hypoglycaemia or hyperglycaemia. The following participants reflect:

> "*I was with my friends…I did not inject my insulin…I was scared to tell them that I am diabetic…I felt that they will judge me…I got sick…my friends had to call an ambulance for me; I was taken to hospital".* (P9)
>
> *"I was very sick while I was with my friends; I ate too much cake… I had diarrhoea…I was seeing double, and I didn't know whether I am coming or going…I was sent to hospital …"* (P5)

Participants in the study fear being discriminated by their friends and would prefer not to disclose living with T1DM which therefore places their lives in danger due to the nature of acute complications of the disease such as hypoglycaemia and hyperglycaemia. The above participants did not follow their routine of T1DM self-management while with their friends as they feared being stigmatised; hence they suffered symptoms of acute complications of hyperglycaemia. According to Borus and Laffel (2010: 2), peer influence may have a positive impact on adhering to self-management routines such as blood sugar monitoring and dietary adherence. Borus and Laffel (2010:2) further state that young adults living with T1DM believe that friends would have adverse reactions to their T1DM self-management routine even though friends may tend to provide encouragement and support.

According to Hegelson, Mascatelli, Reynolds, Becker, Escobar and Siminerio (2014:360), it is possible that some peer groups may exert a negative influence on compliance with

T1DM self-management. Hill, Gleadle, Pulvirenti and McNaughton (2014:2514) confirm that the lifestyle of young adults with poor compliance to T1DM self-management could be determined by perceiving their friends as having a negative attitude to their disease. Young adults living with T1DM may need to live the same lifestyle as their friends, which often makes it difficult for them to carry out the recommended self-management tasks as previously discussed.

> "*I am living an abnormal life…I have got a routine, I must prick myself, I have got a routine on how to eat, what to eat and all those things they are not going through…they are living normal lives…they have got their own pancreas that is helping them to secrete insulin…I depend on artificial insulin* [Touches abdomen, imitating the injection]*…I don't think they will understand…I am scared to tell them…they will judge me…I don't feel free to tell them."* (P9)
>
> *"Most of my friends are normal; I am the only person that have this disease…it is difficult to maintain my routine…I am scared because I don't know if they are going to accept me as I am, you know."* (P10)

Therefore, if young adults could experience the acute complications of T1DM while with friends, their friends may feel very bad not knowing about their friend's condition as they should have assisted in controlling the adverse effect of the disease (Peters, Nawijn & Van Kersteren, 2014:7).

The participants are generally well-informed about the causes and self-management of T1DM and how to control the disease and to prevent acute and chronic complications of the disease such as hypoglycaemia and hyperglycaemia. These young adults expressed that they observed that their friends do not carry the same knowledge about T1DM; hence the participants fear of being stigmatised mainly due to the behaviours portrayed during the periods of acute attacks especially hypoglycaemia as previously discussed. Due to fearing the negative responses of friends, young adults living with T1DM prefer not to disclose living with the disease. According to Yale, Paty, Peter and Senior (2018:104), the negative social and emotional impact of hypoglycaemia and hyperglycaemia can make young adults living with the disease prefer not to disclose living with T1DM and their reluctance to follow treatment measures within the company of friends or in public settings, i.e. at work. Patel, Eborral, Khunti, Davies and Stone (2011:218) agree that feelings of anxiety, shame, and embarrassment may lead young adults living with T1DM to avoid injecting insulin at work or in social environments.

Liu *et al*. (2017:27) state that most studies investigating the psychological consequences of T1DM stigma have reported that young adults living with T1DM experience feelings of fear, embarrassment, blame and judgement from their friends. *Liu et al.* (2017:27) further state that these negative emotions can result in depression. Therefore, the need for health care providers to educate the community about T1DM and the benefits of self-management such as to control the disease and to prevent its complications. Counselling about disclosing their medical status to friends and adjusting their lifestyle to integrate living with T1DM is required.

This study observed that young adults living with T1DM, aged between 18 and 25, are leaving their homes due to study or for employment purposes. They meet with new friends, experience changes in social interaction, and become involved in risky behaviour without parental control, such as alcohol and drug use. According to Monaghan *et al.* (2016:10), young adulthood is a period of exploration.

Gredig and Bartelsen (2017:1621) maintain that young adults living with T1DM depend on obtaining insulin from an outside source for survival, using injection and might, therefore, fear to be mistaken for drug users when injecting. Participants verbalised difficulties in using insulin in front of their friends and colleagues as they feared embarrassment and being labelled as using drugs:

> "*I have a habit not to take my insulin…I don't like using my insulin in front of my friends…it's so difficult…for me, if I don't take my insulin, I'm gonna end up in hospital…If I do…I'm gonna be embarrassed by my friends…"* (P7)
>
> *"…it is very uncomfortable to use a syringe at work; sometimes I skip my insulin…some people will think…you use drugs."* (P10)

From the above quotations, it is evident that young adults living with T1DM find it difficult to adhere to their self-management routines, such as injecting insulin when they are with others such as friends or colleagues because they fear being stigmatised. Liu *et al*. (2017:27) state that perceived stigma occurs when an individual believes that others will view a personal characteristic or condition as deviant, and respond unfairly, in this case to the fact that the person has T1DM. Participants said:

> "*I feel embarrassed telling my friends because they are so healthy, and according to what I can see…from my point of view, I think they won't accept me as their friend* [Looking at the ceiling] *…."* (P7)
>
> *"Uhm* [Pause]*…I felt like telling the driver that I am not feeling well, but it's not easy to tell people that you are living with diabetes…I ended up fainting…."* (P4)

While health care providers are required to educate young adults on the dangers of non-adherence to treatment and the importance of incorporating self-management into their lifestyle, it appears as though it is equally important to educate the public regarding the disease, its chronicity and the effects of not following an adequate medical regime (Liu *et al*., 2017:32). A participant said:

> *"I wish that the nurses could go out and teach the community about T1DM, especially in the firms, companies and at schools so that people can have a better understanding about the disease."* (P1)

Abdoli *et al*. (2017:113) state that fearing stigma may cause frustration in young adults living with T1DM by making them feel different, keeping their disease a secret and by avoiding self-management activities. Consequently, adhering to self-management plans may be difficult for young adults living with the disease. As most participants in this study expressed some fears or uncertainties which prevented them from disclosing that they are living with T1DM as follows:

> “*I am really, really in a ...in a* [Voice breaks] *…this side and that side type of faith thing…so I don’t know whether I can tell them* [friends] *what is going on with me….”* (P9)

Some participants feared being stigmatised in their jobs and decided not to share living with T1DM with their employers and colleagues. Worret (2012:708) states that stigma is an attitudinal devaluation and a form of demeaning by society towards an individual, or group of people, living with a chronic disease. Those with chronic diseases are thus judged, labelled, alienated and discriminated against because they are considered unable to fulfil expected social roles. Participants in this study verbalised their fear of discrimination:

> “*Sometimes I miss my dates to go to the clinic and take my medication because I can’t just tell my boss that: ‘Boss I’m diabetic’… in other firms or companies, they don’t take people with illnesses. So, I am afraid that if I tell my boss, I’m diabetic, I might be fired or replaced, or maybe I won’t be permanent…”* (P1)
>
> “*…I felt the symptoms…you know…the people at work like to talk behind people’s back, if I told them how I felt…there would be a story behind my back, I woke up in the hospital…results of not eating after injecting insulin*.” (P7)

It is vital to have a person at the place where the person living with T1DM is employed, with knowledge of the fact that the person is living with the disease in order for young adults to follow their medication regime. That person would be able to assist during any critical periods, particularly hypoglycaemia. According to Ahola*,* Saraheimo, Freese, Makimattila and Forsblom (2016:13), if hypoglycaemia is left untreated death could occur. One participant verbalised the importance of disclosing of T1DM as follows:

> “*If someone knows about your status* [referring to T1DM] *and something happens to you, they will know how to help you…I encourage people to tell what’s wrong with them.”* (P10)

However, despite the attitude significant others may have due to not understanding the disease, participants felt they could manage the disease and still live a normal life, as reflected in the following quote:

> *"They [friends] have that attitude with people living with diabetes that they are sick…when you are diabetic; it's not like the end of the road…if you control your sugar, inject insulin follow your diet and exercise…you live life like everyone".* (P4)

Apart from the fear of stigma affecting the young adult's ability to achieve self-management of T1DM, participants expressed difficulty, specifically in applying the principles of exercise and diet, which will be discussed in sub-theme 1.3.

3.3.1.3 Sub-theme 1.3: Participants related that they are informed about exercise and diet but struggle to apply the principles to their lifestyle.

Young adults living with T1DM need to follow a structured self-management plan as discussed previously. This is achieved best through continuous T1DM education and support from health care professionals. According to Allie, van Wyk, Coetzee and Louretta (2017:22), diabetes self-management education is an on-going process of facilitating knowledge, skill, ability, and motivation for T1DM self-management that involves the active participation of the young adult living with the disease. Participants verbalised that the health care providers at the clinic they attend do provide continuous education on diabetes self-management as follows:

> *"The nurses always educate you about the importance of rotating your injection…they emphasise exercise…it helps your sugar stay stabilised…they tell you what to eat; they say your weight contributes towards your sugar…."* (P5)
>
> *"The staff in the clinic give you all the information you require…they tell you to keep constant weight in order to control blood sugar levels…they instruct you about injecting your insulin…finger prick…they are reinforcing…."* (P6)

The researcher observed that when the participants were well informed about the importance of medication, exercise and diet, they were more aware of the benefits of these essential aspects of their healthcare. According to ADA (2016:7), young adults living with T1DM can lead a normal healthy life provided they are aware of the need to closely monitor blood glucose levels, daily insulin therapy, a healthy diet and regular physical exercise. This is evident from the following quotes:

> "*They* [nurses] *told me, I must do exercise and drink a lot of water…also to inject insulin…that also helps to control the sugar."* (P8)
>
> "*The nurses emphasise exercise, as a diabetic, it is very important to exercise, it helps your sugar stay stabilised and the free flow of the blood through your vessels and stuff* [Pointing at visible veins from her hand]*…it helps your weight…it helps you stay healthy… you won't have problems with your sugar rising up …and dropping."* (P5)

The above participants were aware that exercise plays a role in the control of blood glucose levels. According to Thent, Das and Henry (2013:3), physical exercise increases glucose uptake to the muscles, thus reducing blood sugar levels. Therefore, exercise restores insulin sensitivity by assisting with glucose uptake into the muscles. Thent *et al.* (2013:3) further state that exercise contributes to weight loss, decreases insulin resistance, improves circulation, and can have a direct effect on lowering blood glucose levels. Participants expressed awareness about the importance of incorporating exercise in their lifestyle:

> "*I was told at the clinic that weight messes with insulin units that I must get…the more weight I gain, the higher my dosage of insulin… every time I go to clinic, they would have to adjust insulin to accommodate my weight …it is best to keep constant weight in order to keep control of the blood sugar levels."* (P6)
>
> *"…we must not gain a lot of weight; it is not right for us...our sugar won't be controlled."* (P9)

Thent *et al*. (2013:3) advise that physical exercise reduces arterial stiffness, leading to a free flow of blood and prevents cardiovascular complications such as coronary heart disease. ADA (2016:8) confers that young adults living with T1DM are required to perform passive or aerobic types of exercise for 30 minutes daily. ADA (2016:8) further states that young adults living with T1DM must avoid strenuous types of exercise such as endurance training and resistance exercise requiring lifting heavy objects, as these may lead to hypoglycaemia. Strenuous exercise consumes more energy and takes up more glucose. Participants indicated the use of moderate exercise to manage their disease, as reflected in the following quotes:

> *“I like to go; I take my dog and go off for a walk …I like to do a brisk, in other words, a quick walk…the brisk walking works for me… I get some exercise.”* (P6)
>
> “...*exercise is very good for us…we don’t have to run, doing things at home is an exercise, walking around the block of houses or to the shop is very good.”* (P9)
>
> *“When my sugar is high, I normally drink lot of water and do some exercise by means of walking around the blocks of a house where I stay…after an hour I will check my sugar…my sugar will be much lower than what it was.”* (P5)

However, one participant expressed frustration as he was unable to comply with exercise in self-management of T1DM due to time constraints, despite being aware of the benefits as follows:

> *“I believe that exercise is the major thing that diabetics should do, that they don’t do…with the work and stuff* [Pause]*…I struggle to get time to do it.”* (P3)

The above participant needs support on how to find time to fit exercise into daily life activities. Monaghan, Helgeson and Wiebe (2015:8) state that young adults living with T1DM, ages between 18 and 25 years, encounter work-related challenges in the self-management of their disease. The challenges include fitting diabetes self-management into their work and life schedules such as coping with work-related time pressures and securing privacy for diabetes-related tasks. Additionally, they need storage space for diabetes-related supplies such as a fridge for insulin.

A healthy diet is a critical component in the self-management of T1DM. It plays a role in the control of blood sugar levels and to minimise complications of the disease. Chiang, Kirkman, Laffel and Peters (2014:2043) state that diabetic education about nutrition plans should aim to ensure that young adults living with T1DM understand the impact that food has on glucose and how food interacts with exercise and insulin to prevent hypoglycaemia or hyperglycaemia. Chiang *et al*. (2014:2043) further state that the food plan considers the patient's literacy, engagement, and the ability to adjust insulin. Participants expressed an understanding about their meal planning:

> *"They* [nurses] *taught us about carb counting…I count the carb* [making a fist with one hand] *…my glucose …I put all that and then I do the calculations…and then I get my insulin."* (P3)
>
> *"…we need to eat very small meals but frequently…our sugar won't be controlled if we eat big meals because the insulin that we are giving ourselves is not going to be enough to bring down the sugar."* (P9)

The above participants expressed an understanding about how to balance insulin and diet. Young adults living with T1DM, ages between 18 and 25 years, undergo a difficult period in their life. They experience new responsibilities accompanying self-management of T1DM related to their developmental phase (see sub-theme 1.1), which conflict with, and add challenges to their already established daily schedule of T1DM self-management. According to Arnett (2009:39), young adulthood is a stressful period of transitions from childhood to young adulthood. Rasmussen *et al.* (2011:1982) state that this transitional period includes moving away from home to commence studies at a tertiary institution or to join the workforce, meeting new friends, entering a new relationship and becoming a parent. This is apparent from the following quotes:

> *"…sometimes I go out with my friends…we go to braais and potjiekos…and there are some foods that I can't eat…I get tempted…I cheat my diet."* (P10)
>
> *"It's quite easy for me when I'm on my own but when I go out with my husband…it is very difficult to manage my diabetes."* (P2)

The same participant expressed the struggle to adhere to diet while being a parent as follows:

> *"…even if I joule* [measuring blood glucose level and eating a carbohydrate snack before exercise to avoid hypoglycaemia] *…I need to eat more; my carb intake is so high…it's quite difficult now that I have a baby."* (P2)

Participants were aware of their role in self-management of T1DM; however, they became overwhelmed by balancing the new roles in their lifestyle with self-management of the disease, leading to poor glycaemic control and acute to chronic complications. They feel overwhelmed by incorporating the responsibilities of young adulthood such as forming an identity to their daily schedule of T1DM self-management. Markowitz and Laffel (2012:3) emphasise that T1DM requires continuous vigilant attention to self-management tasks which are related to optimal health and well-being such as the previously mentioned blood glucose monitoring, insulin administration, strict diet, and exercise. Markowitz and Laffel (2012:3) further argue that young adults living with T1DM face many competing social, emotional, educational, and occupational priorities that often trump the demands of T1DM care. Majumder *et al*. (2017:30) affirm that the added responsibilities for young adults living with T1DM concurrent with managing their disease can cause stress that could lead to suboptimal glycaemic control. Participants aired:

> *"…it is quite difficult now that I have a baby and it is quite demanding job to be a mom…I cannot actually eat at the right time…I'm waking up at weird times …I am taking my insulin at weird times and stress level is through the roof* [Making soft voice]." (P2)
>
> "…*it's very stressful for me out there because now I am at tertiary* education*…I cannot really follow the* [diabetic] *routine…at times I am at school, and I stay longer*." (P9)

Participants in this study expressed the view that living with T1DM and the new responsibilities experienced during this stage of young adulthood causes stress and inconvenience in their lives. According to Rasmussen, Ward, Jenkins, King and Dunning

(2011:1981), life transitions are peak times of change which increase stress and affect coping abilities young to adults living with T1DM. The following participants confirmed:

> "*It is very difficult; you have to put a lot of effort just to stay well…you must first learn how to control* [T1DM] *how to live with it."* (P7)
>
> *"It's quite hard…I mean injecting yourself four times a day is hard* [Lifting left hand to show four (4) fingers] *… you must watch yourself everyday…"* (P8)

Rassart, Luyckx, Klimstra, Moons and Weets (2014:4) state that living with T1DM adds stress to the already stressful young adult's life. The challenges and responsibilities accompanying T1DM self-management might interfere with the developmental tasks such as forming an adult identity and settling into a life of their own (Rassart *et al*., 2014:4). The result of the difficulties experienced by this cohort of patients is hypoglycaemia or hyperglycaemia related emergencies, which requires stabilisation in hospital.

> *"I was late for work; I just ran out of the house… inside the taxi… when I came there* [Pause]… *it's at work, and the people are so full of lot of stuff* [Talking louder], *I started working… I felt I* [Voice breaks] *…took insulin, but I forgot to eat… I woke up in hospital."* (P7)

Another participant places the need to monitor their blood glucose stringently and timeously, and how long this takes, into perspective:

> *"…it does take a bit of a time … if you are in a rush, like if you are on your way to work…it takes time to do your blood reading and to inject …and then wait that time frame before you can have breakfast."* (P6)

Participants revealed that their daily schedule of T1DM self-management causes them stress as it involves daily monitoring of blood glucose level, insulin injections two (2) to four (4) times a day, dietary restrictions, and physical exercise. Participants verbalised that this causes delays when they are rushing to get to work. Failure to eat after injecting insulin can lead to hypoglycaemia or low blood glucose levels (referred to by participants in this study as hypo). Ahola, Marku, Freese, Makimattila, Forsblom and Groop (2016:14) define hypoglycaemia as a blood glucose level that is lower than four (4) millimoles (mmol) as opposed to the normal level ranging between four (4) and seven (7) mmol (Vindedzis Marsh, Sherriff, Satvinder & Stanton, 2013:68). Hypoglycaemia is characterised by symptoms such as hunger, irritability, tiredness, poor concentration, sweating, shaking, palpitations, confusion, aggression, seizures and if unattended, can result in a hypoglycemic coma (Ahola *et al*., 2016:14). These symptoms can occur due to injecting too much insulin, skipping a meal after insulin injection or strenuous exercise which may require extra glucose for the muscles and tissues (Kesavadev, Sandikot & Kaltra, 2014:5). The following participants contemplate the symptoms of hypoglycaemia:

> *"You start to shiver…your tongue gets so thick, you can't talk* [Closing eyes for a few seconds with a pause]*…and then I can't remember anything."* (P7)
>
> *"When my sugar is low, I tend to feel weak. I will be dizzy, I will be sweating a lot, and I will be very shaky."* (P1)

One participant acknowledged the enormity of hypoglycaemia, and thus her fear of low blood glucose levels:

> *"It is better for your sugar to be high than too low, if it is too low you can collapse at any particular time…and if you don't eat something that will increase your sugar level, it will be very dangerous for you to do anything else* [Changing positions on the examination couch]*".* (P10)

It is imperative that young adults who are living with T1DM receive education from health care providers on how to recognise the symptoms of hypoglycaemia, which range from mild to severe and are dependent on the young adult's ability to self-manage (Vindedzis *et al.*, 2013:68). According to Yale, Paty and Senior (2018:105), severe hypoglycaemia results from seriously low blood sugar and is characterised by confusion, coma, or seizures. During severe episodes, emergency medical care or external help from a relative, a friend or a health care provider is needed for survival (Yale *et al*., 2018:68*)*, as outlined by the following quotes:

> "*I remember one day I fainted, my sister told me that she gave me a teaspoon of jam and then after that everything was fine".* (P1)
>
> "*I collapsed in the kitchen…I could not speak, I needed to call my husband, I literally used all my energy…he said he found me in the corner in the kitchen, we always keep a bottle of coke in the fridge, he gave me half a glass…if my husband did not hear me…it would have been the end".* (P2)

Hypoglycaemia is only one of the crises that participants in this study have to contend with, symptoms of raised blood glucose or hyperglycaemia is another challenge they face. According to the National Institute for Health and Care Excellence (NICE) guideline on management of type 1 and type 2 diabetes in children and young people (2015:23), the recommended blood glucose level for a person living with T1DM ranges between five (5) and nine (9) mmol. Horton and Subauste (2016:7) state that hyperglycaemia occurs when the blood sugar level is higher than ten (10) mmol. Hyperglycaemia may be due to an inaccurate insulin prescription which may lead the patient to inject an inadequate dosage of insulin, excessive food intake, physical inactivity, illness, stress, or injury (Horton & Subauste, 2016:7). The symptoms include excessive thirst, frequent urination, tiredness and weakness, weight loss, and blurred vision. Participants relate:

> *"I just drink a lot of water …and it looks like the thirst doesn't wanna go away…"* (P7)
>
> *"I ate too much cake …I was having diarrhoea, and I was seeing double…my head was sore… I went to hospital".* (P5)

The above quotes indicate that participants were aware that eating incorrect foodstuffs results in raised blood glucose levels. Participants have indicated that they are knowledgeable about managing raised blood glucose levels, and do know the importance of maintaining adequate glycaemic control. Health care providers need to re-enforce all aspects of living with the T1DM, including the importance of compliance to the correct diet to prevent short-term complications of raised blood glucose levels, such as DKA.

According to Gosmanov, Gosmanova and Dillard-Cannon (2014:255), blood glucose levels that are consistently above 15 mmol can lead to a condition called DKA. DKA is a serious acute complication which usually results from a severe shortage of insulin (Kumar, Abbas & Aster, 2015:1116). Due to the severe lack of insulin which is responsible for the transportation of glucose from the blood into the adipose tissues, muscle tissues and cells, the liver converts fatty acids into ketones releasing it into the blood for use as energy. If the ketones are left untreated, bodily fluids such as blood and urine will become acidic, hence the term acidosis (Dyanne & Westerberg, 2013:337).

Young adults living with T1DM may experience the following symptoms of DKA, nausea and vomiting, abdominal pains, shortness of breath, sweet smelling fruity breath, blurred vision, drowsiness, and coma (Hammer, Stephen & McPhee, 2014:527). The following participants describe their experiences of DKA which always requires hospitalisation:

> *"……I have suffered multiple DKA's…I was hospitalised so many times; I was in coma…."* (P1)
>
> *"…my sugar was quite high; I was struggling to breathe… I was having diarrhoea, my sugar was 23… and my granny phoned an ambulance… they admitted me."* (P8)

Chawula, Chawula and Jaggi (2016:13) state that continuously raised blood glucose levels over a prolonged period often cause young adults living with T1DM to develop long-term or chronic complications of the disease, including microvascular and macrovascular complications. According to the International Diabetes Federation (IDF, 2015:108), microvascular complications incorporate diabetic nephropathy, which is caused by damage to small vessels of the kidney and resulting in chronic renal failure. Mahan, Escott-Stump and Raymond (2012:705) state that persistently raised blood glucose levels in young adults living with T1DM may harm the blood vessels in the retina of the eyes leading to diabetes retinopathy, and these are referred to as microvascular blood vessel changes leading to blindness. Participants echoed:

> “*…your sugar…ever high…you are at risk of losing your eyesight…”* (P8)
>
> *“If your sugar is always high…you can be blind…you can lose your eyesight”* (P9)

Deepa, Kiran and Galdwalker (2014:119) state that the continuously raised blood glucose levels in young adults living with T1DM may also lead to some cardiovascular diseases. According to IDF (2015:28), the cardiovascular diseases that accompany T1DM include angina, myocardial infarction, stroke, peripheral artery disease, and congestive heart failure. These may be due to the narrowing of the coronary arteries causing the restriction of blood flow to the heart resulting to heart problems, and these are referred to as macrovascular complications. IDF (2015:28) further maintains that macrovascular complications also incorporate nerve damage or neuropathy and the most common type is peripheral neuropathy that mainly affects the sensory nerves in the foot. This can lead to pain, tingling, loss of sensation, and serious infections that may cause gangrene and subsequent lower limb amputations. Participants expressed their fear of long-term complications of T1DM as follows:

> *“Your sugar ever high* [Opening eyes wider] *… you are at risk of getting your leg amputated”* (P8)
>
> *“If your sugar is not controlled, meaning that it is in your blood… if you’ve got a wound the germs will stay there, and the wound will take longer to heal…may be the wound is in your leg, you can lose that leg…it can be cut off because with us living with diabetes* [Deep breath]*…we are having a problem with the wounds that don’t heal.”* (P9)
>
> “*…diabetes is the silent killer…it takes long to get to the point…it is very dangerous… you can lose your limbs* [Sitting up and pointing at his leg] *… and for me, that is the most dangerous thing.”* (P10)

Therefore, it is necessary to continually update young adults living with T1DM about the disease and the complications in order to improve their self-management skills and to prevent acute and chronic complications (Wiley, Westbrook, Long, Greenfield, Day & Braithwaite, 2014:300). Young adults living with T1DM cannot live without stringent monitoring and insulin. Therefore, T1DM is a labour-intensive chronic illness which requires that young adults living with the disease to monitor blood glucose levels two (2) to four (4) times a day and constantly consider the interactions between insulin, food, and daily activities. Young adults living with T1DM must also consider the short-term risks of hypoglycaemia, hyperglycaemia and DKA while integrating the demands of diabetes self-management into their daily lives, which can be experienced as restricting on one's social life which was further elaborated in theme 1.1. The following participants concur:

> *"It is very challenging when you go out with friends, they eat everything they want to eat, but it's difficult for me to eat everything with them due to knowing that my HGT* [Haemoglucotest] *will grow up and so forth"* (P4)
>
> "*Living with type1 diabetes is quite challenging…you go camping…with your friends…you go to parties, you have to eat healthy and eat what diabetics normally have to eat."* (P5)

The participants above were aware that adherence to a healthy diet is essential to prevent short-term complications of the disease such as hypoglycaemia, hyperglycaemia, and DKA. According to Folorunso and Oguntibeju (2013:89), young adults living with T1DM can achieve control of the disease by reducing the use of saturated fat, because these lead to elevated blood glucose levels. Folorunso and Oguntibeju (2013:89) further state that young adults living with T1DM should eat at the correct time, which means the same amount of food each day at the same time and avoid missing a meal after insulin injection. This will help to minimise both the inevitable peak of blood glucose as well as hypoglycaemia.

The new roles and increased responsibilities experienced by young adults living with T1DM are making it difficult to adhere to an exercise and diet regime. Participants also experience a lack of financial means as contributing to the difficulties, especially with regards to carb counting, resulting in their inability to adhere to a diabetes diet which is outlined in the following sub-theme.

3.3.1.4 Sub-theme 1.4: Participants related that they are unable to adhere to a diabetes diet due to difficulties in carb counting and lack of finances

Nutrition is considered as one of the essential components in self-management of T1DM. A nutritious or healthy diet suitable for people living with T1DM is high in protein, vegetables, fruits, low in fat and carbohydrates is very important for T1DM self-management (Gucciard *et al.,* 2014:324). Ebrahim, De Villiers and Ahmed (2014:76) state that dietary management plays a vital role in the self-management of T1DM as poor dietary quality leads to poor glucose control, associated with increased risk of acute complications as reflected in the following quotes:

> "*They* [nurses] *tell us that we must not eat a lot of food* [Making a sign with both hands, imitating big bowl] *because the insulin that we are giving ourselves is not going to help us…is not going to be enough to bring our sugar down…we need to eat small meals frequently".* (P9)
>
> *"It was emphasised to me that eating a big meal covers the units of insulin that I am injecting…insulin will seem small because I will get more glucose from the food, I ate…eating small meals will allow insulin to stabilise my sugar".* (P5)

The above quotes indicate that the participants were informed by the health care providers about the benefits of eating frequent small meals. Young adults living with T1DM should be able to balance the carbohydrate content of a meal with the amount of insulin to be injected. According to Gucciard, Vahabi, Norris, Del Monte and Farnun (2014:324), young adults living with T1DM must learn to coordinate the carbohydrate component of their meal with the amount of insulin to be used. Mastering carbohydrate counting also referred to as carb counting, is an essential skill needed in order to control blood glucose levels. Monagan, Hegelson and Wiebe (2015:11) state that most food contains carbohydrates which supply the body with glucose. Monagan *et al*. (2015:12) point out that self-management of T1DM requires young adults to pay attention to their food intake; hence counting carbohydrates is one of the essential basics for self-management of T1DM.

According to Margo, Hanlan, Griffith, Patel and Jaser (2015:2), the amount of carbohydrates contained in food can be counted by means of carbohydrate exchanges. A carbohydrate exchange refers to the different types of food containing approximately the same grams of carbohydrates. These carbohydrates in different types of food can be exchanged for one another to consume the same amount of carbohydrates, such as a slice of whole wheat bread or a half cup of cooked rice which contain the same amount of carbohydrates (Margo, Hanlan, Griffith, Patel & Jaser, 2015:2). According to Tascini, Berioli, Gerquiglini, Santi, Mancini, Rogari, Tomi and Esposito (2018:6), another way to count the amount of carbohydrates in food is by counting carbohydrate portions. A carbohydrate portion is the amount of food containing the grams of carbohydrate that may be used against units of insulin to get the amount to be injected, such as 10 grams carbohydrate is equal to one (1) unit of insulin (Tascini *et al*., 2018:3). The nutrition information panel on food labels shows the total grams of carbohydrates per serving (Edwards, 2015:73). Young adults need to calculate the amount of insulin depending on the grams of carbohydrates in food as outlined in the following quotation:

> *"…I use carb counting* [Rolling his fist and showing it up to indicate the amount of carbs in his food] *with how much my glucose is…obviously in the food I am eating, and then I get my insulin."* (P3)

However, some participants indicated that this carb counting was also seen as restricting and affecting the participant's social life, especially when going out to eat in restaurants where it is difficult for the young adult to judge the carbohydrates in each item on the menu accurately, as meals are not adapted for people living with T1DM. According to Edwards (2015:76), restaurants do not indicate the total carbohydrate values per meal. Participants reflect:

> *“When I’m with my friends…out to a restaurant…problem there is that I can’t count my carbs, I need to take my own food with, which is not socially acceptable to do…I feel like an outcast when I have to do this.”* (P2)
>
> *“There are instances where I don’t know how to balance my sugar…when you go out for a meal…it doesn’t always work out… meals are not adapted for the diabetics…”* (P6)

Young adult responsibilities combined with self-management of T1DM causes stress to those living with T1DM resulting in difficulty controlling the disease. This results in acute complications such as hypoglycaemia, hyperglycaemia and DKA. Therefore, young adults living with T1DM, ages between 18 and 25 years, require continuous education, counselling, and support regarding adjusting their diets in order to live with the disease. Participants confirmed:

> *“The nurses at the clinic taught me to do exercise, drink lot of water, watch my diet…as a diabetic you can’t eat everything…they also encouraged me to inject my insulin…that helps to control my sugar.”* (P8)
>
> *“The nurses told me that I need to inject insulin four (4) times a day and they also told me that I need to eat small meals frequently and that helps to bring my sugar down.”* (P9)

Although a healthy diet is very important for T1DM self-management, it is, however, expensive and the costs associated with nutrition may impact the young adult’s ability to achieve glycaemic control (Gucciard *et al*., 2014:324; Okolie, Ijioma, Pauline & Ogbu, 2010:2009). Onwudiwe, Mullins, Winston, Shaya, Pradel, Laird and Saunders (2011:27) state that the healthy food required for young adults living with T1DM is expensive. For young adults experiencing a problem with finances, maintaining a healthy diet is challenging. Thus, they rely more on energy-dense food than a recommended diabetic diet. Energy-dense foods consist of processed food cooked in fats or food containing large amounts of sugar. Such foods can result in sustained periods of high blood sugar levels which can hamper the young adult’s ability to manage their blood sugar levels and could lead to chronic complications such as blindness, kidney failure and cardiovascular diseases (Gucciard *et al.*, 2014:324). Iregbu *et al*. (2016:6) state that the financial costs associated with a diet adequate for the optimal management of T1DM contribute to the additional strain on the finances of young adults living with the disease. Participants in the study of Iregbu and Iregbu (2016:6) expressed that a lack of finances was a contributory factor in the non-compliance to adequate self-management of T1DM. They were aware that eating nutritious food is beneficial to control their blood glucose levels; however, due to lack of finances they were unable to maintain good nutrition, which is reflected in the following quotes:

> "*Well, I try to keep my glucose under control obviously it's not an easy thing to do because food is quite expensive, so…I can't always afford to eat as healthy as I'd like to."* (P3)
>
> *"Sometimes I eat food that is available at home…not suitable for diabetes, I don't have money to buy healthy food…my sugar will be high."* (P8)
>
> *"I am having difficulties…I struggle to get food…my life is stressful…I am going up and down looking for a job…I am getting piece jobs. Through those difficulties…how will I control my sugar?"* (P1)

Due to not maintaining a healthy diet suitable for T1DM due to lack of finances the participants in this study often had to deal with the acute complications of the disease such as hypoglycaemia or hyperglycaemia. Majidi, Wadwa, Bishop, Klingensmith, McFann, Rewers and Maahs (2014:1) state that a lower socio-economic status often predicts poor glycaemic control as well as an increased rate of complications. These may include hypoglycaemia resulting from hunger or hyperglycaemia which may result from consuming excess glucose or a high-fat diet. Some of the participants in this study were unemployed and living in poverty which is a further cause of stress for young adults living with T1DM. Lack of financial resources makes it difficult for young adults living with T1DM to eat nutritious food, leading to potentially uncontrolled blood glucose levels. One participant said:

> *“I can’t control my sugar…I really do need a financial support…even if there are food parcels.”* (P1)

During the interviews, the researcher became aware that young adults who did not complete high school and consequently did not have tertiary level qualifications experienced more difficulties in finding jobs compared to those with tertiary level qualifications. According to Statistics South Africa (Stats SA, 2018:1129), out of 10.3 million young adults, 3.3 million were unemployed in the first quarter of 2018, and one in every three had not completed matric. Stats SA (2018:1129) further states that being a graduate, particularly in possession of a degree, increases one’s chances of finding employment. Stats SA (2018:1129) confirms that among the young adults employed during the first quarter of 2018, 93.7% were graduates and 52.9% were below matric level. Participants in this study have similar challenges:

> “*The time when my mother died* [looking down], *I was doing grade 11…I didn’t continue with school…I have many difficulties; food, the stressful life… I am having to go up and down looking for a job…even if you have matric now, it’s like you have nothing…you have to go to the university…I have suffered multiple DKA’s…I was defaulting treatment; I was hospitalised so many times, I was in coma…”* (P1)
>
> *“Some of us are not working…we are still looking for jobs… we try to get money that will cover us for transport costs to and from the hospital, thus we don’t have money for food*.” (P9)

Some participants experienced low blood glucose levels due to hunger, and this may result in hypoglycaemia. Ahola *et al*. (2015:14) state that one alternative to treat hypoglycaemia is by increasing the amount of food to eat or eat more carbohydrate-rich food. Participants proclaim:

> *“… our sugar drops … we starve …there is no money to buy food and cook at home or a snack to eat and avoid hypoglycaemia due to lack of finances.”* (P9)

The above participants experienced a lack of finances making it difficult to afford to buy food, and therefore they would sometimes not be able to eat. The ensuing result would be severe hypoglycaemia. According to Zoungas, Patel and Chalmers (2010:1410), severe hypoglycaemia includes the transient dysfunction of the central nervous system that cannot be self-treated, and without immediate intervention, death may follow. Gubitosi-Klung, Braffet, White, Sherwin, Service, Lachin and Tamboralne (2017:1010) confirm that severe hypoglycaemia is associated with cognitive impairment requiring assistance for recovery. Participants in this study have had similar incidences:

> *“Yhaa, you feel dizzy…it’s like you feel weak, and sometimes you go to other state where you can’t remember…especially when your sugar is below two (2) …your brain is not working when you are in that state; when your sugar drops very bad”.* (P8)
>
> *“I was at work, and I injected my insulin at 12:30 as I thought to eat my lunch at 13:00, but I still had some work to do, I decided to finish my work before taking lunch…I continued to work without checking the time…I felt funny…if you do not eat after taking insulin you will feel funny; I ignored all the signs…I wanted to finish the work…I don’t know what happened* [Moving shoulders up and down]*, I woke up in hospital.”* (P10)

Health care providers are required to encourage the involvement of a family member or a friend in the diabetes education who will be able to assist during the critical period of severe hypoglycaemia. The health care provider has to re-enforce the dangers of severe hypoglycaemia to the participants and encourage them to eat a healthy diet and look for jobs that provide sufficient time and finances in order to assist with the dietary requirements for the management of T1DM.

At the opposite end of the T1DM spectrum is the complication of hyperglycaemia which participants experience with raised blood glucose levels due to stress related to, among other problems, their job or lack thereof. These acute complications, both hyperglycaemia and hypoglycaemia, can lead to repeated hospital admissions:

> "*I have many difficulties…even the stressful life that I am living, the food I eat is not good for diabetes, I am having to go up and down looking for a job…I can't do everything with the money that I am getting from the piece jobs…I suffered multiple DKA's; I was admitted several times to the hospital."* (P1)
>
> "*I wake up at 4 am every morning…the job I am currently doing is too stressful and not suitable for a person with type1 diabetes* [Pause]*…I walk quite a distance to get to my job…this affects my glucose…when I get to my job, I work the whole morning…no tea nor lunch break, if I feel a bit hungry, I eat chocolate or something just to keep my sugar stable so as to be able to do all the activities."* (P3)

It was evident that some participants experience difficulties in eating nutritiously due to a lack of finances. Some difficulties related to self-management of T1DM could also be due to lack of assistance to control the disease, as will be discussed in sub-theme 1.5.

3.3.1.5 Sub-theme 1.5: Participants related that they lack health care assistance in controlling their disease.

Young adults living with T1DM are engaged with the routine of self-management by means of monitoring blood glucose levels through finger prick and injecting insulin to the maximum of four (4) times daily. T1DM self-management also involves maintaining strict dietary restrictions and exercise to control blood glucose levels and to prevent acute and chronic complications of the disease (Garvey, Finkelstein, Laffel, Ochoa, Wolfdorf & Rhodes, 2013:94). Although self-management is best achieved through the support from family, friends, and health care providers some participants shared that they were unable to control their blood sugar levels while living with their families:

> *"It's easier for me being on my own…being independent…most of the time they* [the family] *don't understand because they are not living with the disease…when I was with my parents, they made bad choices as to what to eat…."* (P11)
>
> *"When I was growing up with my parents, living in their house, it was very difficult to actually manage my diabetes…they didn't quite understand what I needed to*

> *eat…and how much insulin I needed to inject…it was difficult for them to understand that I had a schedule…the type of food they were giving me wasn't the healthiest."* (P2)

The above quotes indicate that the participant's families did not understand the need for a healthy diet in order to manage T1DM. Therefore, the health care providers in the clinic need to include the family members living with young adults with T1DM in the health education provided and to consider the level of understanding of parents during diabetes education.

Further, not understanding the disease is linked with non-adherence to treatment recommendations (Yap, Thirumoothy & Kwan, 2015:64). Inamdar, Kulkarni, Karajgi, Manvi, Ganachari and Kumar (2013:239) state that adherence implies passive submission of the patient to the prescriber's authority and obeys treatment regimens. Inamdar *et al.* (2013:239) further state that adherence implies the self-initiated choice of the patient to closely follow the treatment plans.

According to Miller and DiMatteo (2013:422) non-adherence describes the extent to which patients do not follow treatment recommendations given by their health care providers. Miller and DiMatteo (2013:422) indicate that non-adherence can be intentional or unintentional, where treatment advice is misunderstood, carried out incorrectly or ignored. Participants had instances where they did not adhere to treatment recommendations which led to hospital admission:

> *"I took insulin, but I never ate* [quiet for a moment] *…I forgot to eat. I woke up in hospital…results of not eating after an insulin injection".* (P7)
>
> *"I was feeling tired, my eyes were a bit blurry, I was drinking lot of water as I was feeling excessively thirsty, my mother took me to the hospital, and I was admitted."* (P3)

Although the above participants showed an understanding of treatment recommendations, they were non-compliant. For this reason, health care providers are required to re-enforce the importance of adherence to treatment.

Self-management of T1DM is also possible when there is a sufficient supply of commodities necessary for optimum control of the condition such as insulin, syringes or pen sets and glucose testing strips. Pisano (2014:10) states that insulin injections can be given via the vial and syringe method or through insulin pens and cartridges. Pisano (2014:10) further states that young adults living with T1DM must be able to continuously monitor blood sugar levels by means of finger pricks and glucose testing strips to adjust insulin for activity and food intake. Participants concur:

> *"I always test my glucose because if I know what my glucose is, then I know what to do with my insulin and then what to do with the food I'll be eating…I eat my food, and then I try to do some exercise."* (P3)
>
> *"…my routine is basically that…I check my sugar; I will inject my insulin according to my insulin regime and then half an hour later obviously I will have my meal."* (P2)
>
> *"…in the morning, I test my sugar…then I inject insulin, when the insulin kicks in like half an hour after injecting then I eat breakfast…."* (P8)

Participants were well informed about monitoring their blood sugar, the target level and how to manage themselves depending on blood sugar levels. A finger prick gives young adults living with T1DM their blood sugar reading, which helps them with dosages if their reading is not within the target range (Klonof & Fellow, 2014:439). According to the American Diabetes Association (ADA, 2017:33), the goal of self-management is to keep the blood glucose as near as possible to the levels ranging between four (4) and seven (7) mmol. The ADA (2017:33) further states that this is best achieved by measuring the blood glucose using the drop of blood from a finger prick. This enables the patient to measure their blood glucose levels. However, participants in this study expressed difficulty in maintaining the accepted levels of blood glucose because the diabetic clinic that they attend does not supply them with an adequate quantity of glucose testing strips, leading to young adults living with T1DM not being able to monitor their blood glucose levels as follows:

> *"… hospital gives one box of glucose testing strips …you test yourself four (4) times a day…you test before you inject… your sugar can be lower, and you don't know, you inject yourself…anything can happen … they* [glucose testing strips] *are expensive from the chemist…I wish they can give us more strips, without those glucose testing strips you are* [Pause]*…will never be able to test our sugars and see what is happening."* (P8)
>
> *"When I feel funny during the day… I was educated that before I do anything, take any medication, I need to test my sugar first …. but how you can test your sugar if you don't have any glucose testing strips* [Moving shoulders and opening both hands] *… I think that they really need to improve that on us …and work out the exact amount of medication [glucostrips] until the next date."* (P5)
>
> *"I need to check my sugar constantly, and one of the reasons I don't check my sugar constantly is because I do not have enough glucose testing trips…I never run out of insulin… glucostrips is a problem."* (P2)

It is evident from the participants that without glucose testing strips, young adults living with T1DM are unable to manage their disease effectively. Glucose testing strips are provided to the participants in this study free of charge by the diabetic clinic in a public tertiary hospital. Health care providers from these clinics encourage young adults living with T1DM to monitor their blood glucose levels before injecting insulin to prevent hypoglycaemia. These young adults are taught to take decisions on how to decrease insulin if the sugar level is found to be low or to increase if the level is high. However, the glucose testing strips are not always available.

Without sufficient glucose testing strips, young adults living with T1DM are unable to self-manage their condition adequately. According to Chiang, Kirkman, Laffel and Peters (2014: 2047), young adults living with T1DM need to have unimpeded access to glucose testing strips for blood glucose testing to monitor for hypoglycaemia, to assess insulin needs prior to eating and to determine if the blood glucose level is safe enough for overnight sleeping. Lack of glucose testing strips could lead to acute complications of the disease resulting in unnecessary hospital admissions. In the absence of an adequate supply of glucose testing strips health care providers should educate young adults living with T1DM on how to recognise the symptoms of raised and low blood glucose levels so that they can still manage their blood sugars effectively by being able to detect and manage the signs and symptoms of low blood sugar levels.

Most participants in the study expressed frustration as they could not be aided by being offered adequate treatment in the form of glucose testing strips from the diabetic clinic in a public tertiary hospital to manage brittle diabetes as outlined by one participant as follows:

> *"According to my understanding, as I was told by the health care providers there at the hospital, is that uhm…brittle diabetes is when my sugar is getting high or low…it is not controllable."* (P9)

According to Voulgari and Tentolouris (2011:50), brittle diabetes mellitus is the term used to describe particularly hard to control T1DM. Voulgari and Tentolouris (2011:50) further state that young adults living with brittle diabetes experience frequent, extreme swings in blood glucose levels resulting to hypoglycaemia, hyperglycaemia and diabetic ketoacidosis which often warrants repeated hospital admissions which are outlined in the following quotation:

> *"My sugar was up and down, and I think it was uncontrolled…I stayed in hospital for a week because the health care providers were struggling to control my sugar."* (P1)

According to Pelizza, Bonazzi, Scaltriti, Milli and Guiseppina (2014:23), brittle diabetes refers to severe instability in blood glucose levels. Pelizza *et al*. (2014:23) further state that brittle diabetes affects young adults who do not understand the self-management of T1DM and who suffer from psychological problems such as stress. Voulgari and Tentolouris (2011:58) expound that the first step in the management of brittle diabetes is to ensure that the young adult understands diabetes self-management especially blood glucose monitoring and injecting insulin. This is apparent from the following quotation:

> *"My sugar isn't very controlled; it can be either very high or very low in the same day at different times… every day, and it's just uncontrollable* [Deep breath] *…it's difficult diabetes to manage…"* (P2)

Some participants became stressed as they could not understand what makes their sugar levels unstable, despite the recommended measures to control the disease such as blood glucose monitoring, insulin injections, keeping dietary restrictions, and physical exercise. Participants expressed stress as follows:

> *"I was just sick, and I was getting worse and worse, I was having stomach cramps, I had diarrhoea, I was vomiting… I was checking my sugar; I was following my routine, I was taking my insulin and then it went worse…I was taken to hospital…I don't know… it varied at times* [Pause]*…it confuses me…the doctor just told me I've got brittle diabetes."* (P9)

The Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA, 2017:34) recommends that more intensive testing is necessary in certain situations such as acute illnesses that may cause raised blood sugar level, periods of poor glycaemic control such as in brittle T1DM and frequent hypoglycaemia. According to Safaii, Raidl and Ramsay (2013:6), young adults are responsible for their self-management of T1DM with the support from their families, friends and health-care providers. Therefore, the family and friends could assist young adults with brittle diabetes especially with the management of severe hypoglycaemia. In order to control their disease, SEMDSA (2017:34) further recommends that health care providers should encourage young adults living with T1DM to perform self-monitoring of blood glucose levels by means of self-monitoring. This can be achieved with the use of glucose testing strips up to four (4) times daily or when they experience symptoms of low or raised blood sugar, provided they have an adequate supply of glucose testing strips.

This study was conducted in a tertiary public hospital where young adults receive education on how to recognise the symptoms of low or raised blood sugar levels and how to manage themselves depending on the symptoms. However, Muller (2009:241) states that public hospitals are generally overburdened with an ever-increasing number of patients and severe financial constraints which leads to certain medications being subsidised and affects the treatment of T1DM, keeping in mind the excessive cost of glucose testing strips and insulin pen. A participant agrees:

> *"…the problem is that diabetics when they come to a public hospital, they don't always get enough treatment... the government subsidises only certain amount of medication to people* [referring to glucose test strips], *but I need to have enough medication… to manage my diabetes."* (P2)

Participants in this study would prefer equipment that is more convenient to inject insulin and to reduce defaulting on treatment. Powers, Bardsley, Cypress, Duker, Funnel, Fischl, Maryniuk, Siminerio and Vivian (2015:1372), state that insulin is broken down in the stomach; therefore, it must be injected. The recommended regimen is to give short-acting insulin 30 minutes before the three main meals and the intermediate-acting insulin at night. Powers *et al*. (2015:1373) further state that the introduction of U100 syringes is marked in units of insulin and make it easier to draw up to the required number of units. Insulin pens contain a cartridge of insulin which is automatically injected and thus makes this device more comfortable to use and consequently more convenient for the patient (Powers *et al*., 2015:1373).

Most participants in the study preferred to use insulin pens, referred to as pen-sets, than the syringes:

> "*I feel frustrated when I must take out the insulin bottle, withdraw with the syringe, …I think what can be done to improve our care at the clinic is to at least give us the pens instead of insulin syringes… much easier …looks smarter and convenient…".* (P9)

> *“...when I was at school, I usually got the pen set…it was very convenient for me…now I receive a syringe... this is the main reason why I sometimes skip my insulin dosage…it is very uncomfortable to use a syringe at work…to prevent this…you have to receive something more convenient and easier for yourself.”* (P10)

Most public health clinics prioritise patients who should obtain pens, according to set criteria, such as providing insulin pen-sets to the school going children. Patients who are blind also receive insulin pen-sets as they are unable to see the units marked in the insulin syringe. As previously stated, the public tertiary hospitals, in general, are overburdened with an increasing number of patients leading to financial constraints which affect the treatment of all patients, particularly the T1DM patients in this study, particularly in the form of glucose testing strips and insulin pen-sets. Inamdar *et al*. (2013:260) state that young adults feel guilty about taking medication as they see it as a social stigma (see theme 1.2). Inamdar *et al*. (2013:260) further state that young adults should be encouraged to correlate their drug intake with daily events, to maintain required modifications and obtain support from family members and friends in order to achieve optimal glycaemic control.

The hospital and its health care providers thus play a vital role in enabling young adults to manage T1DM. In the following theme, the focus will be on the experiences related to achieving self-management of T1DM. Figure 2 (below) shows theme 2 and the sub-themes.

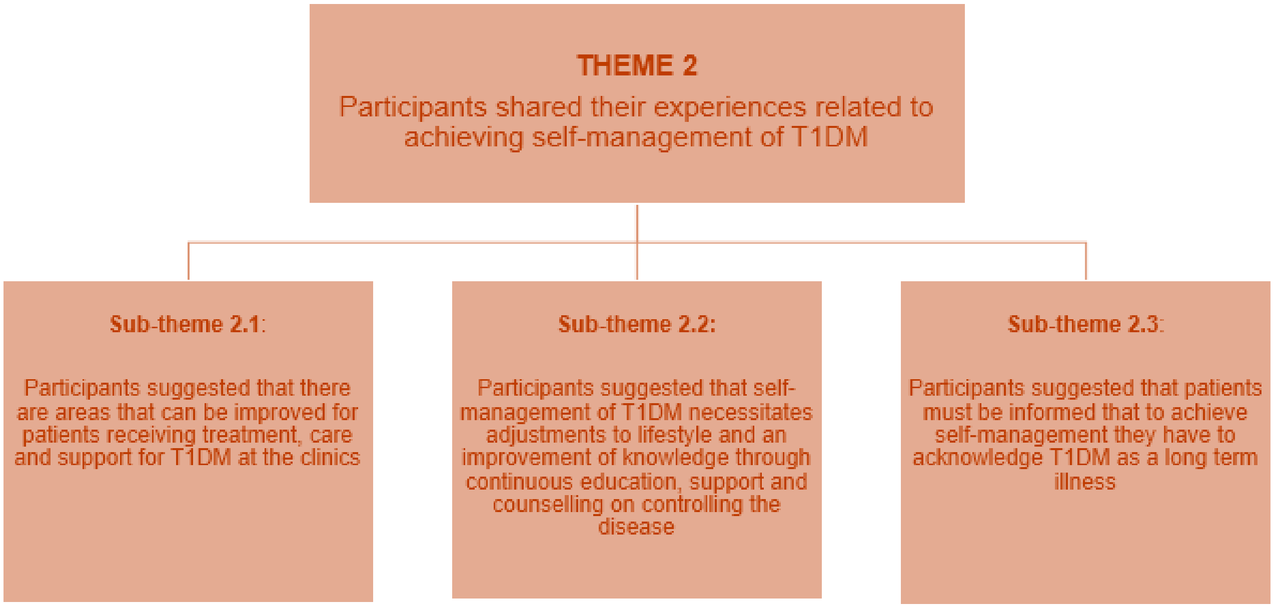

Figure 3.2: Diagrammatic Representation of Theme 2 and the Sub-themes

Theme 2 and the sub-themes will be discussed in the following sections.

3.3.2 Theme 2: Participants shared their experiences related to achieving self–management of T1DM

Young adults living with T1DM, who have to adjust to self-management of the T1DM experience competing life priorities, decreasing parental support, adherence to self-management declines and accordingly glycaemic control may deteriorate (Garvey, Beste, Luff, Castillo, Wolpert and Ritholz (2014:190). Hanna, Weaver, Slaven, Fortenberry and DeMeglio (2014:399) affirm that young adults living with T1DM are at risk for adverse health outcomes including acute and chronic complications of the disease such as hypoglycaemia, hyperglycaemia, diabetic ketoacidosis, retinopathy, neuropathy, and nephropathy. Participants in the study verbalised that living with T1DM is incredibly stressful as they feel that they are still young and need to explore life on their own, independent from their parents. They experienced challenges with T1DM self-management combined with the usual responsibilities of young adulthood:

> "*My experience with this illness* [Pause]*… it is very difficult…I am still very young, I am 23 years old* [Deep breath] … *I like to go out partying with my friends, sometimes I feel like eating stuff that they eat."* (P7)
>
> *"What happens is this: it is me, it is my home with my parents, it is my diabetes type1, and there are also friends* [rolling eyes]*…at this time of my life, my friends are more calling, and I would like to be with them…I feel I am a little bit grown up…most of the time I will be with them* [friends]*, I cannot take my injections with them…I am not sure whether they know about type1 diabetes…."* (P9)

The participants above were aware that they need to achieve self-management of T1DM to avoid complications but experienced this to be challenging. These participants further provided both positive and negative experiences and recommendations regarding treatment, care and support that they receive from the clinic and will be discussed in sub-theme 2.1

3.3.2.1 Sub-theme 2.1: Participants suggested areas that can be improved for patients receiving treatment, care, and support for T1DM at the clinics

The participants expressed concerns about the services rendered at the records and pharmacy departments that are involved in the execution of care to the patients receiving treatment for T1DM at the clinic in the public tertiary hospital. According to Nabbuye-Sekandi, Makumbi, Kasangaki, Kizza, Tugumisirize, Nshiye, Mbabali and Peters (2011:516), patient satisfaction is a key criterion by which the quality of health care services is evaluated. Schoenfelder, Klewer and Kugler (2011:503) describe patient satisfaction as the patient's reaction and suggestions to several aspects involving the health care service delivery. Schoenfelder *et al.* (2011:503) further state that patients evaluate the health care services as well as the providers from their subjective point of view. This evaluation may influence health care utilisation. This can be a predictor of subsequent health-related behaviour such as non-compliance to follow updates, non-adherence to treatment and whether patients are willing or not to recommend the health care service to their families and friends. Nabbuye-Sekandi *et al.* (2011:516) further confirm that the patient's judgement of the hospital service quality and their feedback are essential in the quality of case monitoring and improvement in the services for rendering patient care.

Romaniello, Renna and Cinque (2011:2) uphold that quality monitoring and improvement refer to the monitoring of performance in an organisation to maintain the high levels of quality care. Romaniello *et al.* (2014:2) further maintain that quality monitoring is performed and guided by the presence of a clear vision, mission, objectives, indicators and the operational plans that are relevant to the departments situated in an institution. Romaniello *et al*. (2014:2) confirm that a monitoring system or instrument is necessary to measure the achievement of targets and the deviation from the department's objectives.

Participants in the study expressed both positive and negative experiences encountered when attending the diabetic clinic in a public tertiary hospital and made the suggestions to improve. Participants highlighted certain areas within the diabetic clinic have long waiting periods to receive services before and after consultation with the doctor. Poor record keeping in terms of their files was also mentioned as contributing to the long waiting times. This caused patients stress and a subsequent rise in blood glucose levels. Participants expressed dissatisfaction and concern about this as outlined in the following quotations:

> *"…the place where you get your file…you will stay for three to four hours waiting…us diabetic people, by the time you wait…sugar is going low…some of us …sugar will be very high due to stress…I wish that files for diabetic patients can be kept in diabetic clinic."* (P8)
>
> *"We wait for a long time at the records department… queues are very long there…we faint there…there is a tendency of giving us new files, it is very stressful …your illness and your medication are written in your old file…it will be difficult for a doctor…the doctor won't know your history…."* (P1)
>
> *"…waiting period at the pharmacy is very long…causes stress … the records and the pharmacy...I think that they could be made more aware that they are dealing with people that have conditions…not conducive to sitting around and waiting*

> [Biting lower lip] *…they should be dealt with as quick as possible to lower stress levels for all of us.”* (P6)

As mentioned above, patient satisfaction is a key criterion by which the quality of health care services is evaluated. Oche and Adamu (2013:588) state that the amount of time a patient waits to be seen by a doctor is one factor that affects the utilisation of health care services. Tran, Nguyen, Nong and Tran (2017:13), define patient waiting time as the time patients must wait and is calculated from the time of entering the facility, taking into consideration an official opening time of the facility until the patient leaves the facility. The South African National policy on Management of Patient Waiting Time in Out Patient Departments (2015:8) states that the average patient waiting time in an outpatient department that is situated in tertiary hospitals is four (4) hours. Oche and Adamu (2013:589) further state that patients perceive long waiting times as a barrier to obtaining services, and keeping patients waiting unnecessarily can be a cause of stress for both patients and health care providers.

Another aspect of poor-quality care that was mentioned by the participants was poor record keeping which contributes to the long waiting times and which affects the continuity of care. According to Stevens and Pickering (2011:48), record keeping reflects the continuity of care given to the patient. Stevens and Pickering (2011:48) state that another important consideration of record keeping is its legal significance; a record is the only proof that a health care provider carried the duty of care to the patient and therefore may provide evidence in case of litigation. The service providers, therefore, need education on the importance of safe record keeping as confirmed by one participant:

> *“It is very stressful to be given a new file…your illness and your medication is written in your old file…it will be difficult for the doctor to check whether the last time she/ he saw the patient …what the doctor and the patient were talking about, what tests were done …people in the records department always lose our files.”* (P1)

Long waiting period causes stress, and as one participant mentioned, young adults living with the disease also experience acute complications such as hypoglycaemia and hyperglycaemia. Hypoglycaemia can result from long periods of not eating, which can occur due to having to wait in a queue for a long time, a factor that was alluded to by one of the participants. A participant also mentioned that young adults living with T1DM can experience hyperglycaemia which is generated from the stress of enduing long waiting times. Therefore, the service providers, especially in the dispensary and records departments, would benefit from training on how to reduce waiting times so as to alleviate the stress in patients.

One participant indicated the need for a more conducive clinic environment, particularly regarding noise. Excessive noise has been identified as having a negative impact on the health care service rendered at the diabetic clinic used in this study, and which affects the health education provided by staff. A participant said:

> *"The other thing that needs to be improved is the space… in our clinic, the phones are ringing around us now and then…the doctor is trying to explain something to you, and the phone on the other side is ringing* [Pointing the phone]*…and our clinic is nearby the dispensary… they have those mikes which are noisy* [Raising the voice]*…the doctor is trying to explain whatever…there is this mike…turning out loud…you will miss other things…those things need to be improved in our clinic… I think we need some more space."* (P4)

Lunenburg (2010:4) states that the presence of background noise may be a barrier in the transmission of a message, resulting in poor reception of a message. Therefore, the noise in the diabetic clinic can be minimised by requesting nurses to attend to ringing telephones to prevent disturbing the consultation immediately. Security could be taught to control noise from the pharmacy area and if the volume of the speakers were turned down, noise would be reduced.

Participants further suggested that self-management of T1DM necessitates adjustments to lifestyle and improvement of knowledge to apply the principles of treatment. This will be discussed in sub-theme 2.2.

3.3.2.2. Sub-theme 2.2: Participants suggested that self-management of T1DM necessitates adjustments to lifestyle and an improvement of knowledge through education, support, and counselling on controlling the disease

According to Kosti and Kanakari (2012: 655), T1DM self-management education provides young adults living with the disease the skill to monitor and control the symptoms and to prevent acute and chronic complications of the disease. Participants verbalised their ability to prevent acute complications such as hypoglycaemia, hyperglycaemia and DKA as a result of being educated by the health care providers about it as follows:

> "*When my sugar drops, I feel weak, I feel dizzy* [Dropping hands to both sides of the chair] *… I go to my machine and test my sugar…when I see my sugar is three (3) or two (2), I eat half banana, and I drink sweet juice…it normally brings up my sugar… when my sugar is high…I normally drink lot of water…that is what a nurse told me."* (P5)
>
> "*Uh, when the sugar is too low* [Pause]*...it's below four (4), it's always a danger…the nurses have been educating us that…my sugar…below four (4), I must have a snack, and when it's too high, I drink lot of water...go to pee then it decreases…and then I do a bit of exercise to keep my sugar levels at the right point…."* (P4)

Iregbu and Iregbu (2016:2) state that T1DM self-management is the ability of an individual living with the disease together with the family, community, and health care providers to manage the symptoms, treatment, lifestyle changes and to prevent complications of the disease. T1DM self-management support from the family, community and health care providers can effectively improve glycaemic control (Gucciardi, Vahabi, Norris, Monte and Farnum (2014:329). The care and support from health care providers, family and friends motivate young adults to adhere to treatment and how to achieve acceptable blood glucose levels as follows:

> "*The nurses told me that type1 diabetes is about controlling your sugar…they told me that I need to inject four (4) times a day…I am listening to the nurses, and I am getting more knowledge."* (P9)
>
> "*At the clinic, I was taught to teach one of my sisters about my illness so that she can help me when I am off…one day my sister told me that I collapsed, and she gave me a teaspoon of jam…after that everything was fine."* (P1)

Diabetes education, support and continuous counselling are the cornerstones of self-management of T1DM. Health care providers should encourage the attendance of a family member, especially during the first session. According to the SEMDSA guidelines (2017:22), diabetes self-management education is an on-going process of facilitating knowledge, skill and ability for diabetes self-care that involves the active participation of young adults living with the disease. Powers, Bardsley, Cypress, Duker, Funnel, Fischl, Melinda, Maryniuk, Siminerio and Vivian (2015:70) state that the effective delivery of diabetes self-management education involves family members and significant others such as peers.

Participants suggested that the sharing of their experiences of living with T1DM could assist in gaining knowledge on T1DM, as they felt overwhelmed by lack of knowledge about the disease. According to Rasmussen *et al.* (2011:1982), a support group can enhance the coping abilities of young adults living with T1DM during transitions. Qi, Liu, Qi, Wu, Tang and Xiong (2015:10) define a support group as the support from people who possess experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population. Tejada-Tayaba and Lugo (2014:1986) confirm that through the support group, patients can share their experiences with others that are undergoing the same medical or behavioural tasks as an effective means of gaining mastery of tasks and improving disease outcomes. Participants said:

> *"If we type1 diabetes patients, can form a WhatsApp group whereby we can on a daily basis be checking on each other, posting our experiences… share nice stories just to encourage each other ...that will make us feel that we are dealing with it, we feel in control of it… we will be sharing with each other* [Smiling]*… there won't be any shyness… if the nurses at the diabetic clinic can help us by going to the churches, colleges…teach people about type1 diabetes…we will feel that there are people that know, we will be sure that people know what we are going through."* (P9)
>
> *"I think what can be done, is to form groups as we are patients which we share the experiences that we have …uhm with each other…we discuss how it feels to live with diabetes…."* (P4)

Participants expressed that the health care providers assist them in managing their T1DM, for example by encouraging them to be compliant with their treatment and the review dates. According to Inamdar, Kulkarni, Karajgi, Manvi, Ganachari and Kumar (2013:237), to be compliant on treatment entails the ability of young adults living with T1DM to closely follow treatment plans. Inamdar *et al.* (2013:237) further state that the health care providers must monitor young adult's adherence to medication by ensuring their ability to practice the correct treatment usage instructions including insulin injections as outlined by the following participants:

> "*…when you come to the clinic…the nurses reinforce and make sure that you know what you are doing as far as applying your medications like giving yourself injections and you are aware of the sites in your body…if they feel that you are not doing an adequate job, they will show you again…they will reinforce."* (P6)
>
> "*The nurses always emphasise that you must be on time on your date that they give you to come back to the clinic…they need to know if you take your medicine correctly and they always ask you…how do you feel…are there any side effects…."* (P5)

Safaii *et al*. (2013:6) state that young adults living with T1DM are responsible for their self-management and the health care providers will often ask them to describe their experiences and reactions on their current metabolic control. The health care providers further assist them to set their own goals on how to make changes in regimens for self-management that will suit their lifestyle, including diet and their daily activities such as at work. From the above quotations, it is evident that continuous education, support and counselling by health care providers encourage young adults living with T1DM to be able to adjust their lifestyle to living with the disease.

According to Sister Callista Roy’s theory which is also known as Roy’s adaptation model, a person, also called a biopsychosocial being, is a human being that is in constant interaction with the changing environment; therefore, a person is continually changing and attempting to adapt (Roy, 2009:31). Meleis (2012:533) confirms that the changing environment stimulates the person to make adaptive responses. As the environment changes, the person has the opportunity to continue to grow, to develop and to enhance the meaning of life (Meleis, 2012:324). The characteristics of internal and external stimuli influence behavioural responses and emotional processes (Meleis, 2012:533). Therefore, according to Roy (2009:30), families, friends and communities must be able to accommodate changes in the environment and support during the adaptation process. Roy (2009:45) further states that the nurse’s role is to promote adaptation in situations of health and illness and to enhance the interaction of human systems (individuals, families, and friends) with the changing environment, thereby promoting health. Therefore, within the context of this study, the health care providers need to assist young adults living with T1DM to be able to incorporate self-management of the disease to the new and increasing responsibilities of young adulthood, through continuous education, counselling and support.

According to ADA (2017:34), diabetes self-management education is a fundamental aspect of T1DM care to facilitate the knowledge, skills and abilities necessary for optimal T1DM self-management and incorporate the needs, goals and life experiences of an individual with the disease. American Diabetes association (ADA, 2017:34) further states that the goal of T1DM self-management education is to support informed decision making, self-management behaviours, problem solving and active collaboration with the health care team to improve clinical outcomes. This is evident from the following quotations:

> *"They* [health care providers] *always counsel me on a monthly basis whenever I come for my checkup, always make me aware of the dangers that diabetics have…they will always give me lessons about diabetes, what can I do or what can I not do…without the information they give me, I can do my own thing which can be dangerous for my health…because I have no knowledge…"* (P10)
>
> *"I am listening to the nurses …getting more knowledge, they told me that type1 diabetes is about controlling your sugar, it's what I am doing…I am injecting myself, and I am keeping to the schedule …."* (P9)

It was apparent that the participants in the study acquired knowledge and skills from the health care providers through continuous diabetes education and counselling about self–management of T1DM on how to prevent complications of the disease. According to the International Diabetes Federation (IDF, 2013:94), T1DM self-management education and ongoing support are an essential part of T1DM self-management. This enables young adults living with T1DM to manage their disease, improve health outcomes and to become the key figure in the management of their disease. Participants in the study expressed an understanding of the disease and its progress as follows:

> *"I had diabetes when I was six years old* [Pause]*… my sugar was out of control… I actually learnt a lot about diabetes… it helps me to know how to control my sugar* [Voice breaks] *…when it is too high or too low… in those situations what to do."* (P3)
>
> *"I've been a diabetic since 2010…and my life has basically changed... I used to be a very healthy eater, err, but because type1 diabetes mellitus is genetic, there is nothing that I could have done to prevent it obviously…I have to be a lot active … I have to watch what I'm eating; I have to make sure that I have enough water …I*

> *think that I do understand my condition well enough for me to manage it on my own."* (P2)

It was apparent that the above participants did have some understanding of the fact that T1DM is a long-term illness; this will be discussed in more detail in sub-theme 2.3.

3.3.2.3 Sub-theme 2.3: Participants suggested that patients must be informed that to achieve self-management they have to acknowledge T1DM as a long-term illness

Rassart, Luyckx, Klimstra, Moons, Groven and Weets (2014:4) state that T1DM is the most common metabolic condition requiring patients to be on a life-long treatment regimen, including daily dietary restrictions and insulin administration. According to the ADA (2013:22), young adults living with T1DM need insulin every day to control the level of glucose in their blood. ADA (2013:22) further state that without insulin, a person with T1DM will die. Participants are on lifelong treatment to maintain blood glucose levels within normal limit ranging between four (4) mmol and seven (7) mmol; hence T1DM is also called insulin dependent diabetes mellitus as confirmed by the following quotes:

> *"The pancreas that I am having is depending* [Pause]*…it doesn't produce enough insulin. I am dependent on the artificial insulin."* (P1)
>
> "*…the nurses told me that I should keep my injection and my times…if I skip an injection, I will die."* (P9)

It is evident from the above participants that they understand that their pancreas does not produce sufficient insulin; they depend on obtaining insulin from an outside source for survival, such as using daily insulin injections. Furthermore, participants expressed that they had T1DM from childhood. According to the International Diabetes Federation (IDF, 2013:22), the disease usually starts in people under the age of 30 years and often occurs in very young children and infants, which is reflected by the following participants:

> "*I knew that I am having type1 diabetes when I was nine (9) years old* [Sigh]…*the first time I fell sick, I was admitted in the hospital, and the nurses taught me that I need to inject myself four (4) times a day….*" (P4)
>
> "*…seven (7) years being a diabetic, um-hmm…since I was 18 years….*" (P2)

Rassart *et al*. (2014:4) further state that for young adults, the presence of a chronic illness such as T1DM can be considered stressful. The challenges and responsibilities accompanying self-management of the disease might interfere with many developmental tasks at hand such as forming adult identity and settling into a life of their own. This is evident from the following quotations:

> *"I was sixteen years when I was diagnosed with T1DM… I had to adjust and learn how to live with my new medical status…it was very difficult …I had to learn to use insulin four (4) times a day…my body got used to insulin…but it is very difficult now, I started working…sometimes I skip my insulin dosage…I sometimes get temptations when I am with my friends and cheat my diet* [Turning the head to the wall]*…"* (P10)
>
> *"Type1 diabetes is about controlling your sugar…now I am at a tertiary level…I am having a little bit of problems; I went with my friends…I know that I must inject, I didn't have my insulin…I was sick, and I was taken to hospital."* (P9)

The researcher observed that many of the participants in the study were living with T1DM from childhood, as early as the age of six (6) years. Participants were also aware that the principles of adherence to the schedule of self-management of the disease assist in achieving target blood glucose levels, and will prevent acute and chronic complications of the disease. The responsibilities accompanying the stage of young adulthood add to the difficulties for young adults to achieve the target blood glucose levels, as discussed previously. Therefore, young adults require continuous education on how to adjust their lifestyle to integrate T1DM self-management. Shrivastava, Shrivastava, and Ramsamy (2013:2) state that self-management of T1DM involves the young adult's ability to manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent to living with the disease. Shrivastava *et al*. (2013:3) further state that the interventions that health care providers offer to promote self-management of T1DM are also important to assist young adults to adjust their lifestyle into living with T1DM.

One participant verbalised that adaptation with T1DM is particularly important in self-management of the disease.

> *"It's just an adjustment… really… to a different type of lifestyle and to include it into your lifestyle, which takes time…but it's not really an inconvenience as such."* (P1)

According to Pilancinski and Zozulinska-Ziolkevics (2014:4) lifestyle is closely related to the behaviour expressed by individuals to protect, maintain, or promote their health status. Pilacinski and Zozulinska-Ziolkevics (2014:4) further state that in addition to the young adult's lifestyle, there is a vital role for an appropriate T1DM regimen. This statement indicates the importance of adjusting young adulthood to living with T1DM to be able to achieve control of the disease.

3.4 CHAPTER SUMMARY

This chapter discussed the themes and sub-themes relating to the experiences of young adults living with T1DM regarding self-management and lifestyle adaptation. Theme 1 stated the negative experiences of participants in relation to T1DM. Participants indicated the challenges of T1DM self-management during the stage of young adulthood. They also highlighted that it is exceedingly difficult to control T1DM due to the real stress of young adulthood causing them to experience acute complications such as hypoglycaemia, hyperglycaemia and DKA resulting in frequent hospitalisations.

Participants described the role that the health care providers play in their management of T1DM. They expressed that health care providers play a crucial role in assisting them in the form of continuous diabetes education on how to maintain their blood glucose levels within the accepted limits ranging between four (4) and seven (7) mmol. In theme, 2 participants shared suggestions about the areas that can be improved for patients receiving treatment, care, and support for T1DM at the clinics. Theme 2 also discussed that the participants were aware that they depend on insulin from an outside source such as an injection to be able to survive and that it necessitates adjustments to lifestyle and improvement of knowledge through continuous education, support, and counselling on controlling the disease. In order to do so, people living with T1DM must acknowledge that T1DM is a lifelong disease.

In Chapter Four, the researcher will focus on developing the recommendations that will assist the registered nurses to adequately manage young adults living with T1DM.

CHAPTER FOUR

SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

4.1 INTRODUCTION

In Chapter Three, the focus was on the presentation and discussion of findings. The researcher identified the themes and sub-themes related to the experiences of young adults living with T1DM regarding self-management and lifestyle adaptation. This chapter will begin with the objectives of the study as stated in Chapter One. This chapter will also present a summary of the research findings and limitations of the study. The recommendations that will assist the registered nurses to manage young adults living with T1DM adequately were developed. These recommendations will be brought to the attention of the management at the tertiary public hospital where the study was conducted. Finally, a conclusion is provided.

4.2 OBJECTIVES OF THE STUDY

- The first objective was to:

  Explore and describe the experiences of young adults living with T1DM in a tertiary public hospital, regarding self-management and lifestyle-adaptation.

- The second objective was to:

  Develop recommendations that will assist registered nurses to adequately manage young adults living with T1DM.

4.3 SUMMARY OF THE RESEARCH FINDINGS

The researcher achieved the first objective through data collection by using a qualitative, explorative, descriptive, and contextual design to conduct the study. The research population of the study comprised of young adults between the ages of 18 and 25 years living with T1DM in the NMBHD and attending a diabetic clinic in a public tertiary hospital. Purposive sampling was used to select the research sample. Data saturation was achieved after conducting 11 semi-structured individual interviews with the participants and thereafter, the interviews were transcribed. The content was coded, and Tesch's method was used to analyse the research data (see Chapter Two for more detail). Two main themes and eight sub-themes emerged from the data analysis. A summary of the research findings is presented as follows:

4.3.1 Theme 1

In theme one, the focus is on the participant's negative experiences in relation to T1DM. The participants expressed frustration due to the restrictions that T1DM places on their lives which they indicated are challenging to manage. Most participants shared that in order to survive, they were restricted in that they have to comply with a specific diet, suitable for T1DM patients, plus exercise, continual monitoring of their blood glucose levels and strict adherence to medication, which necessitates injecting insulin two (2) to four (4) times a day. Participants concurred that their freedom to enjoy going out with their friends is restricted because most restaurants, for instance, do not serve meals that are suitable for people living with T1DM, which leads to them declining such invitations in order to maintain optimal T1DM self-management.

Another challenge is the fear of being stigmatised due to living with T1DM. The participants could not disclose to people, especially their friends and colleagues, about living with the disease due to anxiety that they would be excluded from friendship groups or rejected or blamed for causing their illness. They also felt restricted from disclosing their illness to their employers because they feared losing their jobs. This situation leads to a dire situation whereby treatment is not taken as prescribed resulting in acute complications of the disease such as hypoglycaemia, hyperglycaemia, and diabetes ketoacidosis with the requisite hospital admissions to regain equilibrium.

Participants agreed that they were informed about exercise and diet by the health care providers, but they struggled to apply the principles to their lifestyle consistently. They experienced new responsibilities accompanying self-management of T1DM related to their developmental phase. Participants experienced work-related challenges in the self-management of their disease, including fitting diabetes self-management into their work schedule, such as securing privacy for diabetes-related tasks such as monitoring their blood glucose levels and injecting insulin two (2) to four (4) times a day. A participant shared that he was struggling to get time for exercise due to his work schedule.

Participants also verbalised concerns as they were unable to adhere to the prescribed diabetes diet due to difficulties in carbohydrate counting and lack of finances. Most participants indicated that food is expensive, especially the foods suggested for T1DM, and due to lack of finances resulting from unemployment; it was not possible to purchase the suitable food required to maintain glycaemic control adequately.

A concern for most participants was the lack of equipment supplied to them monthly with which to adequately monitor and control their disease, specifically the lack of glucose testing strips. The glucose testing strips supplied were insufficient and did not allow an adequate amount of testing prior to injecting insulin for the duration of the month, which could lead to hyperglycaemic or hypoglycaemic situations. These issues could be avoided if the participants were supplied with sufficient glucose testing strips. The participants felt that this led them to experience unnecessary hospitalisations as it caused them not to be able to monitor their blood sugar levels adequately and therefore exposed them to acute complications of T1DM.

The researcher noted that the participants in the study were well informed about the self-management of T1DM. They could not incorporate self-management of the disease with the new responsibilities accompanying the stage of young adulthood, resulting in raised or low blood glucose levels which require management in a diabetic clinic or admission to a tertiary public hospital. The registered nurses working in the diabetic clinic in the tertiary public hospital need to give attention to all the aspects that were stated by the participants. The registered nurses working in the diabetic clinic also need to give special attention to educating the participants about acute complications of the disease and how to manage them, especially hypoglycaemia as it is potentially dangerous. There is also a profound need to educate family and friends about the disease and its management to minimise stigmatisation of people living with T1DM. Registered nurses need to continuously educate young adults living with T1DM on how to incorporate the activities of daily living into living with the disease, such as finding time at work to administer insulin injections and to eat and also to attend clinic appointments.

4.3.2 Theme 2

In theme two, the participants shared their experiences related to achieving self-management of T1DM. Suggestions were provided by the participants that could improve areas for patients receiving treatment, care, and support for T1DM at the clinics. For example, due to the long waiting times in the records and pharmacy departments, some participants described experiencing low blood glucose levels due to lack of food. Other participants experienced stress which raised blood glucose levels. Both conditions are a concern and potentially hazardous to their health. Accordingly, it is suggested that the patient waiting times in these areas be reviewed, by assisting staff to develop better patient flow strategies.

Self-management of T1DM necessitates adjustments to lifestyle and improvement of knowledge through education, support, and counselling to achieve control of the disease. Participants suggested that support groups be established whereby they can share experiences and learn from one another. Most participants stated that they would feel at ease sharing with others who have T1DM; they will be able to relate to the challenges of living with T1DM. Participants felt overwhelmed by the lack of knowledge and support from their family, friends and other people regarding the disease.

A participant experienced noise during consultation with the doctor and suggested more space for the diabetic clinic or at least a quieter area for the consulting area. It is apparent that the environment was not conducive to provide necessary care, treatment, and support to the participants. Environments for patient care must be as free from noise as possible to combat stress which is a known barrier to effective communication (Juang, Lee, Yang & Chang, 2010:705). Noise can deprive the patient of hearing vital information about treatment and self-management, leading to incomplete implementation and subsequent complications.

Participants indicated that although they were aware of the long-term complications of the disease, such as retinopathy, nephropathy and neuropathy, all on the physical spectrum of the disease, staff had not adequately covered the emotional component of T1DM. The consequences of having to live with a lifelong chronic illness, and continuously to adjust their lifestyle to control the disease and achieve best possible self-management optimally have an emotional impact on participants. Health care providers (HCPs) thus need to explain the intricacies of self-management of T1DM fully and that it is continual practice, all the time, every day and thus will take considerable effort on the part of the patient. Furthermore, HCPs need to assist their patients to achieve self-management within the confines of the developmental stage that they are such as young adulthood in the case of this study. Balancing a chronic disease with developmental phase challenges such as leaving their homes for the first time, studying at tertiary institutions, establishing new relationships and, or joining the workforce are all potential stressors and can interfere with daily schedules, making it difficult to adhere to a lifestyle that is conducive for optimal management of T1DM.

The results of the study indicate a need for the registered nurses in the diabetes clinic to provide more assistance to enable participants to adapt their lifestyle to accommodate the self-management of the disease. The researcher observed that there is a need for continuous education, support, and counselling for the participants.

4.4 LIMITATIONS OF THE STUDY

The researcher experienced the following limitations during the study:

The small sample size of the study and using only one facility, while congruent with qualitative research design, means that generalisations of the results cannot be made.

4.5 RECOMMENDATIONS

Based on the research findings, the following recommendations for nursing practice, nursing education, and nursing research were formulated:

4.5.1 Recommendations for nursing practice

The following recommendations are made in line with the results of the data analysis in which the participants indicated their challenges with regards to self-management of T1DM. However, the researcher is mindful of the fact that the HCPs are unable to carry out the implementation of functional strategies if action is not taken on a macro or meso level. With this in mind, to assist HCPs working with young adults at diabetic clinics to provide adequate self-management of T1DM, the following recommendations are suggested:

- Provide sufficient glucose testing strips so that patients can monitor and manage their blood glucose levels adequately. Accordingly, hospital management needs to address this critical area in order to ensure that patients can monitor their blood glucose levels appropriately and at all times.
- Reduce waiting times by working on outpatient flow and optimising each stage of the consulting process. Participants indicated that they have to take a day off work to attend the clinic, which is monthly and means a wasted day with no pay. Although this is a hospital management issue, HCPs can start the process of recording patient flow and identifying areas where there are hold ups or bottlenecks that they could perhaps deal with while awaiting further directives.
- Ensure spaces where participants can be consulted in an area conducive to optimal consultation. The area in which the diabetic clinic in this study is situated was described as noisy and not conducive to optimal consultation, which, given the needs of the participants, is a concern. They were unable to hear what the doctor said which led to non-adherence to medical directives. It is recommended that hospital management structures attend to this critical aspect to optimise the self-management of T1DM.
- Ensure that guideline documents pertaining to T1DM are readily available and that HCPs adhere to the guidelines and implement them so that all patients receive the correct and cost-effective treatment.
- Provide training for staff working with patients with T1DM on all aspects of self-management of the condition.

- Consider reviewing discharge planning for those patients who have brittle T1DM or have been hospitalised for other difficulties related to management of blood glucose levels. Furthermore, to ensure that there is a link from the ward to the clinic via the planning to ensure continuity of care for at-risk patients.

4.5.2 Recommendations for nursing education

The following recommendations are suggested for nursing education:

- Although Diabetes Mellitus is presented in all nursing education curricula, the emphasis is mostly focused on the pathophysiology, treatment and nutrition which are not necessarily linked to the impact of the developmental stages related to dealing with a chronic disease. Thus, the developmental stages of the patient and their needs per stage linked to potential challenges that could be encountered in living with T1DM need to be added to basic training course curricula.

- Delegating a registered nurse to be a primary diabetic educator, who would be able to provide continuous in-service education to registered nurses and patients on the importance of maintaining optimal glycaemic levels.
- Registered nurses working with T1DM patients in the clinic used for this study should be given an opportunity to attend relevant courses to update themselves on the management of T1DM.
- Registered nurses who attend courses should provide feedback to their colleagues at specially arranged staff meetings to ensure that all staff are kept up to date.

The following recommendations are suggested for patient education, that registered nurses will:

- Provide participants with continuous diabetes education, counselling, and support to motivate for the disease control, to prevent acute and chronic complications of the disease and to enhance adaptation to living with TDM.
- Facilitate support groups that are formed with the patients attending the diabetic clinic and encourage patients to attend the groups. Patients can thus be motivated

to assist each other in adapting their lifestyle to achieve self-management of T1DM.

- Organise, and accompany, T1DM patient's diabetes camps, which will assist in adapting their lifestyle to living with the disease by achieving self-management. Fundraising could assist to fund much-needed interventions.
- Encourage the community to attend diabetes awareness events so that they gain knowledge about the causes, signs and symptoms and management of T1DM. Knowledge should assist to reduce stigma, which was vocalised by the participants in the study as hindering their self-management.

4.5.3 Recommendations for nursing research

The following recommendations for nursing research are proposed:

- The same study could be done using a quantitative approach to a more significant sample, which would then cover a larger geographic area. The themes and sub-themes identified in the interviews could be used to develop a questionnaire.

- A quantitative, comparative study could be done to compare the experiences of young adults, 18-25 years, living with T1DM regarding self-management and lifestyle adaptation among various public and private health facilities to review the efficacy of treatment, care, and support in all health sectors and share good practices.
- Studies highlighting challenges experienced in the other developmental life stages for those living with T1DM and the corresponding lifestyle adaptation required could be considered since this study has accentuated the essential aspects of care specific to the developmental stage chosen for this study. The researcher is convinced that equally valuable information can be collected from similar studies using other age groups and developmental life stages.

4.6 CONCLUSION

The researcher noticed that the period of young adulthood, between 18-25 years, is a period during which there are considerable developmental changes which can be quite stressful due to the added responsibilities incurred by the young adult at that time. Adding a chronic disease to this period of critical development adds to the stress experienced by young adults living with T1DM. In this study, young adults who are adapting to living with T1DM related their experiences of incorporating the already challenging daily schedule of T1DM self-management into the new and increasingly exacting responsibilities accompanying the stage of young adulthood. Consequently, young adults living with T1DM frequently experience symptoms of raised or low blood glucose levels which could require emergency management in a diabetic clinic or hospital admission. The researcher is of the opinion that there is a need for health care providers working in diabetic clinics to invest their time in continuous education, counselling and support of young adults living with T1DM. From the findings of the study, the researcher has made pertinent recommendations that could assist registered nurses to optimally manage young adults living with T1DM.

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ANNEXURE A: LETTER TO PUBLIC TERTIARY HOSPITIAL MANAGER

• PO Box 77000 • Nelson Mandela Metropolitan University
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Nelson Mandela
Metropolitan
University
for tomorrow

M.T. Fayindlala
44 St Leonard Road
082 2140 832

S205017720@nmmu.ac.za

08 December 2016

Dr Maseloa
Medical Superintendent
Livingstone Tertiary Hospital
Port Elizabeth

Dear Dr Maseloa

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN PUBLIC TERTIARY HOSPITAL

My name is Meliswa Theodora Fayindlala, and I am a master's student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth. The research I wish to conduct for my masters is entitled: *Experiences of young adults living with Type 1 Diabetes mellitus regarding self-management and lifestyle- adaptation in the Nelson Mandela Bay Health District.* The project is being conducted under the supervision of Dr M. Williams and Ms M. Spagadoros at the Department of Nursing Science at the NMMU.

The goal of the study is to explore and describe the experiences of young adults living with Type 1 Diabetes mellitus in a tertiary public hospital, regarding self-management and lifestyle-adaptation in Nelson Mandela Bay Health District. The information will be used to make recommendations that will assist young adults living with Type 1 Diabetes mellitus to optimise lifestyle-adaptation.

I wish to interview young adults with Type 1 Diabetes Mellitus between the ages of 18 and 25 years attending the Diabetic clinic at your institution. The data will be collected by conducting a semi-structured individual interview with each participant. Each interview will last approximately 45-60 minutes. The questions that they will be asked are:

- Tell me how is it for you to live with Type 1 Diabetes Mellitus?
- Tell me about the role of the health care providers in the clinic regarding assisting you with T1DM?

- Tell me what in your opinion could be done to improve the treatment, care, and support that you receive at this clinic?

Participants will not be coerced, and they may withdraw from participating in the study at any time. The information gathered will be managed confidentially. Quotes from interviews may be used in the research report or in an academic article. However, the actual names of the participants will be replaced with pseudonyms. The recommendations to be made from the study will assist the participant to be able to optimise self-management and lifestyle-adaptation to a chronic disease.

I am hereby seeking your consent to do research at your hospital. I have attached a copy of my proposal, and I have included a copy of the consent form to be used in the research process, as well as a copy of the approval letter which I received from the NMMU Research Ethics Committee (Human).

Upon completion of the study, I undertake to provide your institution with a bound copy of the full research report. If you require any further information, please do not hesitate to contact me:

Cell:	082 2140 832	**Tel.:**	041 405 2256
Fax:	041 405 2247	**Email:**	s205017720@nmmu.ac.za

Thank you for your time and consideration in this matter.

Yours sincerely,

M.T. Fayindlala

ANNEXURE B: CONSENT FOR THE MEDICAL SUPERINTENDENT

Experiences of young adults living with type1 diabetes mellitus regarding self-management and lifestyle adaptation in the Nelson Mandela Bay Health District.

I give consent for you to approach patients in my institution and that they may participate in the above-mentioned project.

I have read the accompanying letter explaining the purpose of the research project and understand that:

- The role of the institution is voluntary.
- I may decide to withdraw the hospital's participation at any time without penalty.
- Only patients who have signed will participate in the project.
- All information obtained will be treated in strictest confidence.
- The participants' names will not be identifiable and used in any written reports.
- Participants may withdraw from the study at any time without penalty.
- A report of the findings will be made available to the institution.
- I may seek further information on the project from **Meliswa Theodora Fayindlala** on:

Cell nr:	0822140832	**Tel. nr:**	041 4052256
Fax nr:	041 405 2247	**Email:**	s205017720@nmmu.ac.za

Name:________________________ Signature:

____

Date: ________________________

ANNEXURE C: REQUEST FOR PERMISSION TO INTERVIEW PARTICIPANT

• PO Box 77000 • Nelson Mandela Metropolitan University
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Nelson Mandela Metropolitan University
for tomorrow

M.T. Fayindlala
44 St Leonard's Road
0822140832

S205017720@nmmu.ac.za

08 December 2016

Dear Participant

RE: REQUEST FOR PERMISSION TO INTERVIEW PARTICIPANT

My name is Meliswa Theodora Fayindlala, and I am a master's student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth. The research I wish to conduct for my masters is entitled: *Experiences of young adults living with Type 1 Diabetes mellitus regarding self-management and lifestyle-adaptation in the Nelson Mandela Bay Health District.* The project is being conducted under the supervision of Dr M. Williams and Ms Spagadoros at the Department of Nursing Science at the NMMU.

The goal of the study is to explore and describe the experiences of young adults living with Type 1 Diabetes mellitus in a tertiary public hospital, regarding self-management and lifestyle- adaptation in NMBHD. The information will be used to make recommendations that will assist young adults with Type 1 Diabetes mellitus to optimise lifestyle-adaptation.

I am hereby seeking your consent to interview you for the purposes of this study. I will be interviewing young adults with Type 1 Diabetes between the ages of 18 and 25 years attending the diabetic clinic at a public Tertiary hospital. Each interview will last approximately 45-60 minutes. The questions that you will be asked are:

- Tell me how it is for you to live with Type 1 Diabetes Mellitus?
- Tell me about the role of the health care providers in the clinic regarding assisting you with T1DM?
- Tell me what in your opinion could be done to improve the treatment, care and support that you receive at this clinic?

You should not feel coerced. You may withdraw at any time and information will be managed confidentially. Quotes from the interviews may be used in the research report or in an academic article. However, the actual names of the participants will be replaced with pseudonyms. The recommendations to be made from the study will assist you to optimise lifestyle-adaptation.

Upon completion of the study, I undertake to provide your institution with a bound copy of the full research report. If you require any further information, please do not hesitate to contact me:

Cell:	0822140832	**Tel.:**	041 452 2759
Fax:	041 405 2247	**Email:**	s205017720@nmmu.ac.za

Thank you for your time and consideration in this matter.

Yours sincerely,

M.T. Fayindlala

ANNEXURE D: CONSENT FORM FOR THE PARTICIPANT

Experiences of Young Adults living with Type 1 Diabetes Mellitus regarding self-management and lifestyle- Adaptation in the Nelson Mandela Bay Health District.

I give consent for you to interview me and I am willing to participate in the above-mentioned project. I have read the accompanying letter explaining the purpose of the research project and understand that:

- My participation is voluntary
- I may decide to withdraw at any time without penalty
- All information obtained will be treated in the strictest confidence
- My name will not be identifiable and used in any written reports
- A report of the findings will be made available to me via my institution
- I may seek further information on the project from on:

Cell: 082 2140 832 **Tel.:** 041 405 2256
Fax: 041 405 2247 **Email:** s205017720@nmmu.ac.za

Participant	Signature

ANNEXURE E: LETTER TO DEPARTMENT OF HEALTH

• PO Box 77000 • Nelson Mandela Metropolitan University
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Nelson Mandela
Metropolitan
University
for tomorrow

M.T. Fayindlala
44 St Leonard Road
0822140832

S205017720@nmmu.ac.za

22 August 2016

Mr Z. Merile
Deputy Director: Epidemiological Research & Surveillance Management
Department of Health
BISHO
Tel.: (040) 608 0830

Dear Mr Merile

<u>RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN PUBLIC TERTIARY HOSPITAL</u>

My name is **<u>Meliswa Theodora Fayindlala,</u>** and I am a **<u>master's</u>** student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth. The research I wish to conduct for my masters is the experiences of young adults living with Type 1 diabetes mellitus in regarding self- adaptation in the Nelson Mandela Bay District. The project is being conducted under the supervision of **<u>Dr M. Williams and Ms M. Spagadoros</u>** at the Department of Nursing Science at the NMMU.

The goal of the study is to explore and describe the experiences of young adults living with Type 1 diabetes mellitus in a public tertiary public hospital, regarding self-management and lifestyle -adaptation. The information will be used to make recommendations that will assist young adults with Type 1 diabetes mellitus to optimise self-adaptation.

The participants that will be taking part are patients with Type 1 diabetes mellitus between the ages of 18 and 25 years attending the Diabetic clinic at a tertiary hospital. The data will be collected by conducting a semi-structured interview with each participant. Each interview will last approximately 45-60 minutes. The questions that they will be asked are:

- Tell me how is it for you to live with Type 1 Diabetes mellitus?
- Tell me about the role of the health care providers in the clinic regarding assisting you with T1DM?
- Tell me what in your opinion could be done to improve the treatment, care and support that you receive at this clinic?

Participants will not be coerced, and they may withdraw from participating in the study at any time. The information gathered will be managed confidentially. Quotes from interviews may be used in the research report or in an academic article. However, the actual names of the participants will be replaced with pseudonyms. The **recommendations** developed from the study will assist the participants to be able to optimise self-adaptation to Type 1 Diabetes Mellitus.

I am hereby seeking your consent to conduct research in the following Nelson Mandela Bay Health District Public tertiary hospital: Livingstone Tertiary Hospital. I have attached a copy of my proposal which includes copies of the consent forms to be used in the research process, as well as copies of the approval letters which I received from the NMMU Faculty of Health's Research, Technology and Innovation (FRTI) committee and the NMMU's Research Ethics Committee (Human).

Upon completion of the study, I undertake to provide the Department of Health with a copy of the summary report. If you require any further information, please do not hesitate to contact me:

Cell: 082 2140832 **Tel.:** 041 452 2759
Fax: 041 405 2247 **Email:** s205017720@nmmu.ac.za

Thank you for your time and consideration in this matter.

Yours sincerely,

M.T. Fayindlala

ANNEXURE F: ETHICS CLEARANCE LETTER

• PO Box 77000 • Nelson Mandela Metropolitan University
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Nelson Mandela
Metropolitan
University
for tomorrow

Copies to:
Supervisor: Dr M Williams
Co-supervisor: Ms M Spagadoros

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Student number:
205017720
Contact person: Ms M Afrikaner
21 November 2016
Ms MT Fayindlala
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Road
Algoa Park
Port Elizabeth
6001

FINAL RESEARCH/PROJECT PROPOSAL: QUALIFICATION: MCUR ADVANCED PRIMARY HEALTH CARE COURSEWORK

TITLE: **EXPERIENCES OF YOUNG ADULTS LIVING WITH TYPE 1 DIABETES MELLITUS REGARDING SELF-MANAGEMENT AND LIFESTYLE ADAPTATION IN THE NELSON MANDELA BAY HEALTH DISTRICT**

Please be advised that your final research project was approved by the Faculty Postgraduate Studies Committee (FPGSC) subject to the following amendments/recommendations being made to the satisfaction of your Supervisor/s:

<u>COMMENTS/RECOMMENDATIONS</u>:

1) Proposal
   Remove
   tracking.
2) Purpose of the study was too wordy.
3) The problem statement could be clarified.
4) REC-H form:
   Minor corrections to be made on REC-H form.

Please be informed that this is a summary of deliberations that you must discuss with your Supervisor/s.

FPGSC grants ethics approval. The ethics clearance reference number is **H16-HEA-NUR-042** and is valid for three years.

We wish you well with the project.

Kind regards,
Ms M Afrikaner
Faculty Postgraduate Studies Committee (FPGSC) Secretariat
Faculty Administration: Health Sciences

ANNEXURE G: LETTER FROM LANGUAGE EDITOR

Ms Liezl Wales
3 Eugene Marais Street
Jansensdal
Uitenhage, 6229
South Africa
Tel.: +27 41 922 0468
Cell.: +27 72 238 7052
Email: xliezlx@yahoo.com

21 November 2018

To Whom It May Concern.

I hereby certify that I have language edited the dissertation written by Ms Meliswa Fayindlala entitled: ***Experiences of young adults living with Type 1 diabetes mellitus regarding self-management and lifestyle adaptation in the Nelson Mandela Bay Health District.***

I am satisfied that, provided the changes I have made be affected to the text, the language is of an acceptable standard and fit for publication.

Liezl Wales
MPhil (Stell.)

ANNEXURE H: EXAMPLE OF A TRANSCRIPT

Participant 9

Interviewer: Good afternoon.

Participant 9: Good afternoon.

Interviewer: My name is Meliswa Fayindlala. I am a Masters student in Nelson Mandela Metropolitan University. The research I am conducting is entitled: *The experiences of young adults living with type 1 diabetes mellitus regarding self-management and lifestyle adaptation.* The purpose of my study is to explore and describe the experiences of young adults living with type 1 diabetes mellitus regarding self-management and lifestyle adaptation.

I am going to ask you a few questions, and as you respond to the questions, please feel free to say anything. That is everything regarding your experiences of living with type 1 diabetes mellitus, because you will be identified anonymously. I am not going to mention your name in this study. I am going to identify you by the use of a number. So you must just feel free.

And I will send the recording which I will be doing only to my supervisor; so meaning which the information that you will be saying will remain between me and you. And any recommendations from the information that I will be getting will be used to assist you to adapt with self-management and lifestyle-adaptation as you are living with type 1 diabetes mellitus. Please forget that I am a sister in the clinic, you must please take me as a researcher today. So I will start asking you the questions. And the other thing: you are free to leave the study any time if you wish so, and all I am asking from you is to be with you for 45 minutes to an hour.

So our first question goes like this: Please tell me, how it is for you to live with type 1 diabetes mellitus? In other words, your experiences.

Participant 9: With me, I knew that I am having type 1 diabetes when I was nine years. That time I used to go to the private doctors and be admitted there. I remember the first time that I fell sick because of my sugar. I was shown and taught how to inject myself with this medication; insulin. And the nurses they told me that I should keep my injection and my times, and they told me that I need to inject myself four times a day, and then if I skip an injection, I will die.

This really scared me. And it made me to always remember, because my mother was just there for me but I always used to remember and then told my mother. So it was part of my routine. It didn't worry me. And then it was worse when my mother, my mother's mother – grandmother – died last of last year. And she was also diabetic.

So it really scared me. So I – when she died, it came to me that, really, the nurses meant what they were saying. That was the reason. So I was very scared and I kept on. But as I grew – I am now above 18, I turn in here at the government hospital.

So now I am listening to the nurses and then as I listen I am getting more knowledge and then they told me that type 1 diabetes is about controlling your... your sugar. It's what I am doing.

And then I am injecting myself and I am keeping to the schedule of the nurses there at the clinic, so I know that. But now as I am moving out of home, I am at tertiary level, I am… I can say now that I am having a little bit of problems because I can see now that I am growing and I am reaching a stage whereby I feel at times that I am a little bit confused, because I remember the other time I went with my friends and then I went for a whole afternoon. And then I know that I must inject myself but I didn't have my insulin that time and then I was sick with my friends.

So what happened now is that my friends had to call an ambulance and then I was taken to the hospital, and then that is a problem that I experienced, that I can say that can be a problem.

Interviewer: You mentioned about your routine. Can you please tell me more about it?

Participant 9: When I wake up, I wake up and then I wash quickly and then I check my sugar, and then I inject myself. After, let's say I inject myself about half past six and then about seven o'clock I will eat my breakfast cereal and then I will do whatever things. And then, you know *mos,* with the diabetes, we get hungry quickly, and then at the clinic they tell us we must not wait too long before we eat something. So there at about ten o'clock'/eleven o'clock I will eat just a snack. Something small. And then I will do something, keep myself busy, and then at about again half past twelve I will check my sugar, and then I will inject myself. And then at about one o'clock – because they say that one must inject yourself and then after thirty minutes you can have something. So I will eat something again for one o'clock for lunch. And then I will do something as I am busy during the day. And then there at about two/three o'clock I will eat something again. Because you know you get hungry – you get hungry quickly.

You eat and then other people they complain that we eat a lot. But I don't worry because my family knows what is wrong with me. And then I will again at about half past five, I will check my sugar, and then inject myself again. And then about six o'clock I will eat now. And then, I will stay and then just have the time, winding, read something, and then about ten o'clock I will check my sugar for the last time now, and then I will inject myself. And then I will eat something big because I am going to sleep. I don't want it to drop when I am sleeping, because that also can happen.

There at the hospital this is what they are telling us when they teach us about diabetic type 1. Then I will eat nice big meal and then I will sleep. That is my routine.

Interviewer: You also mentioned that, at this stage, now, you are confused. Can you please explain for me about that?

Participant 9: What happens is this: it is me, it is my home with my parents, it is my diabetes type 1, and there are also my friends. At this time of my life my friends are more calling and I would like to be with them, because now I feel that I am a little bit grown up. So at home I cannot sit with my parents, and my parents cannot do everything for me.

So now, most of the time, I would be with them [friends] as a result now, if I am more with them, I cannot take my injections with them. And also I don't feel comfortable to discuss everything with them, because I am not sure whether they know type 1 diabetes; what is going on with it.

I don't know how much information they know, because with me I know there at the hospital they tell me everything, so I know what is going on with me, so I am not sure what is going on with them. So I don't know whether I can tell them what is going on – I don't know whether they will accept me as I am or they will feel that maybe I don't belong with them.

That is the things that I feel deep down with me. So I am really, really in a... in a… this side and that side type of faith thing. It is this thing that I don't know how to deal with it.

Interviewer: You mentioned that you eat a lot. Please explain for me what happens when you eat a lot?

Participant 9: No, I don't mean that I eat, like, big food. What I mean is this: I eat small meals – small, small, small, small snacks in between. But the time is not so very far apart. It is very frequent. Because at the clinic they tell us that you must not eat a lot, because the insulin that we are giving ourselves are not going to be enough to help us with the… to bring down the sugar. So we need to eat very small meals but very frequently. We must also not get hungry, because they also tell us at the hospital if we… We must not gain a lot of weight. It is not right for us. Our sugar won't be well controlled if we eat big meals. So those are the small meals that I am eating, but my times are very close together.

Interviewer: Earlier you mentioned that sometimes your sugar drops. Can you please explain to me what happens when your sugar drops?

Participant 9: The other day, I was with my mother. I was helping my mother, cleaning in the house. So we were talking and talking and talking, and then as we were talking I was standing. I was dusting the unit. So I felt wobbly. Then I was weak, and then I was shaking. And then I quickly sat down. And then I was shaking. And then I just kept quiet. My mother kept on asking questions, as we were talking I was answering. So she… I tried to answer to her, but I couldn't really feel that I was talking. And then she quickly came over and then she found me shaking, sitting down, and then I couldn’t really talk nicely.

And then she quickly jumped and then she made me sugar water, and then she gave me and she also made a small snack for me. And then she sat with me and then after that she told me what happened to me. Then she saw that I was fine.

Interviewer: You just mentioned that your mother told you that your sugar was low. Please tell me more about it?

Participant 9: My mother told me that, as we were talking whilst we were working in the house, she noticed that I was not talking back what… I was not answering what she was telling me, she was asking, and then I was keeping quiet in between. And then she couldn’t make up what I was saying. So she quickly came over and checked me. And then she said that she saw me looking funny. I was not how she knows me. I was weak. She quickly jumped and checked my sugar; my sugar was below three. So she made quickly sugar water for me, made me to drink it, and then she also made a snack for me to eat. And then after let’s say, after 35 minutes, she checked my sugar. So my sugar was five. And then she told me that, that time, my sugar was low. That is why I was feeling weak.

When I was still going with her to the hospital she was also told how to look after me. So she could help me with my sugar that time, because everything was explained to her when I was a child. She was the one that was there, looking after me, knowing, monitoring, all of these signs. So now she could remember from then, and then she could see when my sugar was low.

And you know, it’s quite very much stressful for me out there, because now I am at tertiary. So I cannot really follow the routine, because at times I am at school and then I stay longer. Now I must also keep in mind and try and remember my insulin times. And I feel frustrated when I must take out the insulin bottle, withdraw with the syringe, because at the hospital they are giving me the insulin syringe. I wish I can get the pen. Because the pen is much smarter and I think that nobody will notice, or nobody will look at me when I am doing with the pen, because I can do it. It's quite smart. But with the injection, at times I would remember it but I feel very shy and I feel that maybe my friends – I don't know how they understand it, whether they will make a joke out of it.

So really, life is a bit difficult for me, but I am trying my best to control my sugar. I am trying but those are the things I am just mentioning, you know.

Interviewer: Please tell me the role of the healthcare providers in the clinic regarding assisting you with your illness?

Participant 9: At the clinic, when we get there at the clinic, there is a sister that is with us. I always see her. She is always with us. So she takes us, she is always asking us how do we feel. And then she is really concerned about us. She will ask how do you feel, like is there anything you would like to tell me since I last saw you. And then she encourages us that we must report everything that does not make us happy. She will give us pamphlets to read about things. If she saw anything interesting in the papers she will share with us and ask how do we feel about it. Because like, like, she sees the small kids together and then she will have a small talk with us that are at least above 18. And she will also check our sugar. And she praises us if your sugar is kept nicely, and she will encourage also the ones that are not… she asks us to talk to each other, encourage each other. She will weigh us because she does not want us to gain a lot of weight, and then she will tell us if maybe we are a little bit gaining a little bit of weight she will also tell us how to work it.

Because she will also tell us that exercise is very good for us. So, but she says that you don't have to run, but doing things at home is an exercise. Walking to the shop, or walking around the block of houses is also good for us. We must not gain weight because it is not good for us. She also checks and encourages us that we must report when we have got sores, because with us that are diabetic we are not supposed to have wounds because they take long to heal.

And then it complicates… Even she's… At times even she will took up a tape of all the other things that diabetics suffer, and she reassures us that she is not trying to scare us, but she is just making us aware. Because if she is not telling us these things she will feel guilty if they happen to us and she never told us. So she will open a video for us, show us, and ask us what did you hear, what did you make of the video, so she is really helping us. And then if there is anything that we need to share with her or she would like to see the doctor… or she will refer us to the doctor if she thinks we need to see the doctor. And then if maybe your sugar is a bit up she will ask you, and if there is anything; maybe at times, if maybe like if I am at the college, if I am going to write a test, at times you will find that my sugar goes up so she will take me to the doctor, she will refer me to the doctor and then I will see the doctor.

But she will see I didn't get a lot of admissions this year, I was only admitted once at the hospital.

Interviewer: You mentioned that the sister at the clinic encourages you to talk to each other. Can you please tell me how does that assist you?

Participant 9: You know it is much comfortable when we talk at the clinic. We – us, the people that are people that are sick with diabetes – because we are all suffering from this illness and then we understand each other and we know, we are talking out of our experiences. When we talk we always advise each other about how to control it better. Somebody will come with an advice that, when you feel that it is a bit high you can drink a strong coffee without sugar. The other one will say you must drink something bitter – it does drop it down.

So we talk and talk and we understand each other and we are very comfortable with each other. We are not scared because we know that we grew up together, because we attend the clinic from nine years and then you grow. Every time you go the clinic you find that you have the same date so you get the same date so you get to be comfortable and close with these people. So you can talk anything with them.

When you hear something you also share with them. So it is nice at the clinic. And then we also talk about if you control it nicely you avoid the complications, so it's what we are trying to help each other so that we don't get the complications.

Interviewer: Can you please tell me more about the complications of type 1 diabetes mellitus?

Participant 9: With type 1 diabetes you need to control your sugar. You need to eat right, at the right times. And you also need to keep your body right by exercises, walking, those things. So that you cannot suffer from things like, like… if your sugar is always high high all the time, you can be blind, you can lose your eyesight. And the other thing that you can also have a problem with your kidneys, you can also have a problem with your legs. If you've got a wound you will find that your wound is not getting better because your sugar is always high. And at the clinic they also told us that with the sugar, if it is not controlled, it meaning that it is in your blood, so now what happens is if you've got your wound, the germs will go and stay there. And the wound will take longer to heal and if maybe the wound is on your leg, that leg, you can even lose that leg because it can be cut off. Because with us you are having a problem with the wounds that don't heal, so they take long.

So those are the things that you must avoid when you are having a sugar, diabetes.

Interviewer: Please tell me, have you ever tried to explain about type 1 diabetes mellitus to your friends?

Participant 9: Actually, I don't think I can explain my condition to my friends because they are the friends from the college. They don't know me from when I was growing up because I was diagnosed with type 1 diabetes when I was still young. So they only meet me now, so I am not sure whether they will understand it, how they will take me, because with me I know I grew up with it and I see myself as somebody who is sick. I'm living an abnormal life because I have got a routine whereby I must prick myself. I have got a routine, how to eat, what to eat, and all of those things, they are not going through them. So with them – they are living normal lives because they have got their own pancreas that is helping them in secreting normal insulin so everything is normal as they were born. And with me, I depend on this artificial insulin. So I don't think they will understand. I am actually not sure I have been very scared to even try, because what if they don't understand me, they don't accept the way I am? They feel… they judge me, my life, I depend on artificial things. So I don't feel free.

Interviewer: Please tell me, have you been recently admitted to the hospital?

Participant 9: Yes, it was in February. Yes, yes, *ja*, it was in the beginning of February. It just went worse this day. I was just sick and I was getting worse and worse because I was having cramps in my stomach, and my stomach started running, I had diarrhoea and then I was… I started now with vomiting, I was vomiting. It was getting worse and worse and then I was checking my sugar, I was following my routine, I was checking my sugar, I was giving myself, I was taking my insulin, and then it went worse, and then I was not getting better. So my mother said it was better for us to go to the hospital. And then I was taken to the hospital. In the hospital they put a drip for me, and then I was in the hospital for about four days and then I was feeling better after that with – I don't know – it varied at times. It confuses me, because I was doing everything I was told. I just happened out of the blue. And now, what is happening now; the doctor has just told me I've got brittle diabetes.

Interviewer: Please tell me more about brittle diabetes?

Participant 9: According to my understanding, as I was told there at the hospital, is that, um, brittle diabetes is when my sugar is high, gets high, is low, getting high and low, it is not standing in one place, it is not controllable. So that is it. It is what they told me.

Interviewer: Please tell me what, in your opinion, could be done to improve treatment, care and support that you receive at this clinic?

Participant 9: I think what can be done to improve our care at the clinic is to at least give us the pens instead of the insulin syringes, which as I have mentioned earlier on, is much easier, and it looks smarter, and it is convenient for using the pen instead of the insulin syringes. Because we don't have to withdraw in front of the people.

When you are using the pen nobody really takes notice of what you are doing as it is nice, it is presentable, it looks nice and elegant. And the other thing; if we type 1 diabetes patients, we can form a Whatsapp group whereby we can on a daily basis be checking on each other, posting our experiences and our difficulties, and also nice stories just to encourage each other. That will also make us to feel that we are dealing with it, we feel in control of it because we will be sharing with each other, than to be us that are having these diabetic type 1 disease. So it will be us sharing with each other, so there won't be any shyness or anything, we will be talking with the people that we know.

And the other thing; if the nurses at the clinic can also help us by going out to the churches, they can even go to the college, and then teach the people about type 1 diabetes so that the people can understand us. Maybe that can also make us feel more accepted and then we will feel that there are people that know, we'll be sure that people will know what we are going through.

And also the other thing is that when we get our medication we wait, because we follow the same waiting queue with the other people. With us, as I have mentioned, that our sugar goes down with the waiting, so now we wait there for long and most of the time you will find that we do collapse there because our sugar gets low. So now if there can be somebody who is only taking care of us, like going to the dispensary, take our medication before we can collapse, before our sugar can go down. Because you wait very long there. So if that can also be done it will really help us.

And also for us, if you find that you come here at about eight o'clock and then still when they close and at times they will close the clinic, the pharmacy, the dispensary must still be open for us because it is getting very full and then we find that we are staying there, you are here the whole day at the clinic. We are finish quickly with the clinic but now you wait there by the dispensary for your medication. So if that can be done it will be much better.

Another thing that I think it close and needs to be changed is that the other, one other time, here at the diabetic clinic, I was borrowed – loaned – a machine for three months and then, during that period, I had to get my own machine. So that that thing stressed me, really, because my mother is not really working. She is just getting piece-jobs. And then I am at the college. I am getting a bursary. So now during that three months I was very much stressed because I had to sit with that I do get money to… From the bursary money I had to set aside money to buy myself a machine because as a type 1 diabetes I cannot stay without the machine, because I need to check my sugar, I need to know how much was my sugar in order for me to inject myself. So I cannot only inject even if I don't know my sugar. How am I going to see if my sugar is low?

So if that can be changed. There is those that can buy the machine, they can be asked to buy the machine, but those like me that don't have somebody to support them; if the hospital can give us the machine without putting us under pressure that you need to buy your own machine, because that really stressed me out during that time.

If at least the hospital can at least address that problem I'll be very glad.

Another thing here at the diabetic clinic; if we can be given soup or bread or food parcels so that we can eat whilst we are waiting, because at times it takes so long. Especially when we are waiting there at the dispensary, some of us, especially the diabetic type 1 patients, our sugar drops. And then we are hungry and some of us, there is no food at home to even cook and we don't have money to buy the food here when we are at the… when we are attending the diabetic clinic at the hospital, so those soup or the bread or the food parcels can help us to prevent those hypoglycaemia episodes that we suffer from. That will really really help us, because here at the clinic at times you come very early and the whole day you didn't eat anything. And we don't even have money to buy something and still you must go and wait at the dispensary. So other people there its worse, they experience this low sugar and then they get sick there and it's not a nice thing. Because if now you get sick in the hospital, just now you also don't go home – you must lie in the hospital again. So that is not a nice thing. If that can happen to us I would be very very glad.

And here, here is another thing that I almost forget: here by the file counter where we get our files we also wait very long there. If there can be somebody who is helping us diabetic patients because the other problem is this; you keep on making the new file, and the new file, because our files they get missing there. Nobody really is looking after our files and our files are very important to us because all our history is there. So now if maybe there is another sister or there is a doctor or anybody we are referred to anybody, I think that it is very much important that they must know you because there is some of the times I cannot remember everything, but everything that happened with me at the diabetic clinic or even when I am admitted is there in the file. So now if somebody can be made to check us and help us with our files that will be a nice thing. It will prevent all of these problems we are encountering, because if it starts there, you get your file, you go to the clinic, at the clinic you get a snack, and then you also there by the dispensary you don't wait too long, before that snack is out of you, you get hungry, you are home. So if those things, really, they can help, it would be very nice, that would be very nice. Really, it will be very nice.

Interviewer: Now we are going to end our interview session, but I would like to know if there is anything that you would like to add or you would like to ask from me?

Participant 9: No, um, there is nothing that I want to add. I think during our talking I have said everything about my experiences of my type 1 diabetes, I have said everything there, I have said everything.

Interviewer: Ok, thank you very much for participating in my study.

END