
# EXPERIENCES OF CAREGIVERS REGARDING HOMECARE OF CHILDREN WITH TYPE 1-DIABETES MELLITUS WITHIN VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA

**By**

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## DEDICATION

I dedicate this dissertation to my loving late mother, Margaren Ndou, Tshabungwa Johanna Ndou, my children, Mpho and Mulisa, for their relentless support throughout my entire educational chapter, and all my siblings.

## DECLARATION

I, Margaren Ndou, hereby declare that the dissertation titled: **"EXPERIENCES OF CAREGIVERS REGARDING HOMECARE OF CHILDREN WITH "TYPE 1" DIABETES MELLITUS WITHIN VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA** is my own work and all the sources that I have used, have been indicated and acknowledged by means of complete references, and that this work has not been submitted for any other degree at this or any other institution.

Signature

01/06/2021

Date

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# ABSTRACT

Worldwide, Type-1 diabetes mellitus (T1DM) was a devastating condition for both the diagnosed children and caregivers taking care of them. These challenges were drastically affecting caregivers in rendering the required homecare service for their patients. Vhembe District had been experiencing a rise in the number of children who were readmitted with T1DM-disease.

The purpose of this study was to investigate the experiences of caregivers regarding homecare of children with T1DM1-disease within Vhembe District, Limpopo Province. The study also adopted qualitative, exploratory and descriptive design approaches while collecting data. Fourteen (14)-caregivers of children diagnosed with T1DM were sampled using non-probability purposive samples. A qualitative nature of the study influenced the use of face-to-face interview technique for data collection which adhered to all precautionary measures of Covid-19 to ensure the safety of both the researcher and participant. Besides this, interviews also have a high response rate when being used for the data collection purposes as the participants are able to interact on comfortable. Tesch's 8 steps data analysis method was used to analyse the collected data. Ethical considerations and measures were used to ensure trustworthiness hence a qualitative approach had been used for data collection.

The current study revealed that caregivers faced various challenges when caring for children with T1DM-disease. Paradoxical experiences were stressed by the caregivers as one of the most challenging experiences when caring for children with T1DM. Similarly, the responsibilities entailed in the provision of care were among other challenges faced by caregivers. In addition, the level or exposure and knowledge related to the provision of care of diabetes patients played a significant role in ensuring sufficient care for children with diabetes.

Recommendations which emerged from the developed themes and sub-themes were also discussed in detail, followed by explanations of the findings which emerged before the recommendations had been made. The reason behind this being that findings in any research study came first prior to the explanations of the recommendations.

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| | |
|---|---|
| ADSA | Association for Diabetics in South Africa |
| CEO | Chief Executive Officer |
| DM | Diabetic Mellitus |
| HAR | Health Annual Report |
| HCP | Health Care Provider |
| IDDM | Insulin Dependent Diabetes Mellitus |
| NPDH | National and Provincial Department of Health |
| PTSD | Post Traumatic Stress Disorder |
| T1DM | “Type 1” Diabetes Mellitus |
| T2DM | “Type 2” Diabetes Mellitus |
| UHDC | University of Venda High Committee |
| WHO | World Health Organization |

# CHAPTER 1

# OVERVIEW OF THE STUDY

## 1.1 INTRODUCTION

There had been quite an outcry about the experiences of caregivers regarding homecare of children with “Type 1” diabetes mellitus (T1DM) within Vhembe District, Limpopo Province. However, You and Henneberg (2016) suggested that it also seemed to be a worldwide problem, hence it was reported to be happening in all countries all over the world. Furthermore, caregivers were ever used when children had been affected with this pandemic disease. The reason being that caregivers had the responsibility of providing children with care, good treatment and general psychological support during their developmental stages. Ideally, it did not matter where those T1DM-patients were coming from, whether it was from overseas or local places in our nine provinces, found in South Africa.

## 1.2 BACKGROUND OF THE STUDY

T1DM is a chronic disease associated with abnormally higher levels of the sugar (glucose) in the blood than in the normal procedure (Hockleberry & Wilson, 2011). T1DM is classified by the higher or lower abnormal insulin levels produced by the pancreas which releases insulin to help in the transportation of food to body cells. The type of treatment is required in order to classify the type of T1DM disorder that a sick child is suffering from, as revealed during the diagnosis process. Type 1-diabetes mellitus (T1DM), which forms part of the current study, was previously called ‘Insulin dependent’ diabetes (IDDM) or juvenile onset diabetes mellitus (JODM). According to the World Health Organization (WHO, 2017), over a million children in the world will have been affected by T1DM-disease by 2020, and 366 million in 2030 respectively.

According to Hockleberry and Wilson (2011), T1DM is associated with failure of the pancreatic beta cells to produce the required insulin levels required by the body for functioning. Furthermore, T1DM can further be categorised into two classes, namely: Idiopathic Type 1 diabetes (IT1DM) and Immune-Mediated Diabetes (IMD), (Huckleberry & Wilson, 2011). T1DM is caused by the obliteration of the autoimmune beta cells that affect children and teenagers at their earlier stages, and sometimes adults of any age

who are ectomorph or slender. On the other hand, T1DM is a more uncommon class of the disease due to the reason that its causes are still unknown. In addition to this, T1DM in aetiology is said to be more hereditary in nature but is not actually inherited. From the afore-said statements, it further surprises one how it occurs in such a manner, but scientists will obviously come with the answer as time goes on.

Caregivers have the responsibility to provide care to children during their early developmental stages of the T1DM-disease. More importantly, these responsibilities usually increase in rate when the children become sick at their early ages. By the way, after children have been diagnosed with T1DM, the responsibility becomes even worse, as caregivers are expected to provide the advanced homecare for those children. However, this includes giving correct nutrition and medication as prescribed by the health care professionals and the strict control of their foods while eating (Human Sciences Research Council, 2017). Consequently, children rely on their caregivers for instructions, support, physical practices and daily mutual assistance, so that they can cope with such a complex set of demands. Seemingly, caregivers face challenges when caring for T1DM patients at their homes, because they have to feed them, inject or bathe those children almost on a daily basis (Zysberg & Lang, 2015).

A study conducted in the United Kingdom (UK) by the World Health Organisation (2016) revealed that 51% of mothers and 41% of fathers were affected by Post-Traumatic Stress Disorders (PTSD) after offering care to their Type 1-diabetic children. By the way, this had occurred after they had been involved in providing care and treatment to the Type 1-diabetes mellitus children. Essentially, this could lead one to conclude that looking after the T1DM-patients is not an easy task, but rather a difficult one. For that matter, a study conducted in Britain by other researchers, also revealed that caring for children with T1DM is a challenging life event and should be considered a serious family issue (Zysberg & Lang, 2015). Seemingly, in another study conducted in America, results showed that 24% of mothers and 22% of fathers who acted as home-caregivers had reached a threshold of current PTSD (WHO, 2017). For example, some of them became ill, whereas amongst them, half of them were affected mentally while looking after the Type 1-diabetic children.

The main reason behind this being that they lived in a situation of great stress, depression, emotional bad feelings and traumatic conditions while taking care of those

patients (Type 1-diabetic mellitus patients). Furthermore, one could think of an instance where an elderly-grandparent is looking after a T1DM-patient who defies her advice of following the correct diet. However, such actions might keep on worrying the caregiver to an extent that it could cause stress or depression to her. Apart from this, in an incident where a T1DM-patient is being cared for by an elderly-grandmother, when a patient refuses to take an injection, it might also hurt her. The other reason being that grandmothers are naturally tender lovers of their grandsons or daughters in almost all the families.

Bowes, Lowels, Warner and Gregory (2013) emphasize that caregivers of children with T1DM start to experience emotional distress after they have realized that the responsibility required to take care of the child with T1DM at home is extremely difficult, thinking of the reluctant and naughty patients who could even be forced by their peers to eat the forbidden fruits immediately after being warned is quite more difficult to accept. Needless to say, the other responsibilities they encounter on a daily basis might include issues like: daily routine administering, medication, dietary, daily physical practices and lifestyle modification. In support of this view, Zysberg and Lang (2013) also noted that the required lifestyle changes also bring about extended stress levels to the caregivers, as a result of re-admission, decline in health, gradual immune system functionality and decline in weight that affect children diagnosed with T1DM. More importantly, every right-thinking person might agree that the caring of the T1DM-patients is without any further argument a difficult task. From the researcher's point of view, it appears that some other worse instances pertaining to the disease under study should be blamed on the naughty and reluctance of the T1DM-patients' behaviours.

In Malawi, caregivers experienced problems in controlling children with T1DM due to the fact that the patients were not willing to perform tasks such as: performing blood tests, balancing nutrition, monitoring, refusals of being injected on a daily basis and management of the physical practice activities (Zimba, 2016). A study conducted by Malunga (2016) in Zimbabwe revealed that T1DM children should always follow the daily compulsory nutrition and physical activity programs, so that they should stay healthy. On the contrary, children regard those prescribed instructions by the professional heath caregivers including the dieticians as boring and tiresome work to do. The same study further showed that working with children with T1DM is indeed a very difficult job to be

performed by the caregivers. The reason behind this being that the majority of those patients are naughty and ignorant in obeying the prescribed orders freely.

However, caregivers in most developing countries are faced with various experiences when dealing with children with T1DM (Zysberg & Lang, 2015). On the other hand, these challenges include amongst others, aspects such as: the routine monitoring of blood glucose levels, preparing and maintaining a balanced nutrition plan, and overseeing the children's physical activities. These experiences are challenging to caregivers who have not been professionally trained or counselled in relation to the treatment and management of children with T1DM. Moreover, Zysberg and Lang (2015) mentioned that various health professionals and researchers have identified some common challenges that are associated with the caring of children with T1DM as a difficulty category. Another matter of great concern is that one who is not working with the T1DM-patients should not just look down upon such a task, and regard it as a simple task.

Arising from all the examples or suggestions given so far, some of the challenges that are faced by the caregivers while looking after the T1DM-patients seemed to be so many. To mention only but a few, they might range from: preparing an adaptive family orientated childcare environment, psychosocial-related depression due to the readmission of children, and timely adherence to the prescribed insulin treatment. Additionally, Reddy and Pillay (2013) acknowledged that the level of awareness by caregivers relating to T1DM and DM-patients also plays an important role in terms of motivating those patients to always stay aware of their health status. Mind you, it also seems to be an established fact that if caregivers were not given such a caring task, most patients would often be locked in the hospital wards today. According to the National Paediatric Diabetes Audit (NPDA, 2017), 27.3% of the T1DM patients were recorded as being in a very serious status, which brings some challenging effects to most caregivers. However, a study conducted by Della Manna et al (2016), revealed that the condition under which caregivers are working has worsened by the rising presence of young and adolescent T1DM-patients in families, as 90% of admission were from children. From the above-mentioned statements, it leads one to the realisation that caregivers are having it hard while working with the young T1DM-patients in many families due to their ignorant or negligent characters regarding following the prescribed diet or treatments to be followed.

Consequently, the Association for Diabetics in South Africa (ADSA) stressed that caregivers of children diagnosed with T1DM, are, in reality, experiencing a journey filled with confusion and uncertainty (Adeniyi, 2015). In support of this view, Adeniyi (2015) pointed out that the stress and anxiety experienced by caregivers is the first sign of shock, as displayed at their health status check-up exercises. For example, it might be these actions that lead to the build-up of anxiety and stress amongst many caregivers today. In this context, it also further leads to many caregivers even becoming ill unnecessarily or resulting in them being readmitted at different hospitals. Besides this, it also shows that caregivers are experiencing financial, physical and emotional consequences while looking after those T1DM-patients at their homes. In addition to this, it is still the responsibility of the Department and its healthcare workers to see to it that the caregivers' lifestyles are well-protected.

Additionally, the statistical results recently revealed that the T1DM's young patients in Limpopo Province from 2015 to 2017 has risen to 36.2% (National Department of Health Annual Report, 2017). Seemingly, it drives one to further conclude that Limpopo Province has a higher number of the T1DM-patient's, percentage-wise. In this instance, and from a District's point of view, it shows Vhembe District has a high number of children suffering from the T1DM-disease as recorded during the financial years 2015 to 2017 respectively. The reason behind this is that statistics showed that 17, 6% of the T1DM patients are living in Vhembe District. Out of the 17.6% reported, 7.3% are frequently re-admitted at Tshilidzini Referral Hospital monthly. Moreover, it also further confirmed that most young children in Vhembe District are T1DM-patients.

Arising from the afore-gone local and global data statistics, it shows that there is also a gap of knowledge concerning how the patients should be looked after by the caregivers. For example, the researcher in this study stays at a village where there are T1DM-patients and they have never ever seen a professional healthcare worker addressing the caregivers on how they should perform their duties well outside the hospital setting. On top of this, hearing of some of the caregivers having forgotten to inject their patients sounds not to be a surprise, hence they do not have adequate knowledge of caregiving of their patients. Ideally, it is also due to lack of knowledge on the caregivers' side that their patients are regularly being readmitted with elevated blood glucose level; some even come with diabetes ketoacidosis as a complication for T1DM-patients. Nonetheless, if

caregivers could be well-trained on how to perform their caring duties, and the T1DM-patients really obey the given instructions from doctors or dieticians, the task of looking after those patients may even become easier to them.

## 1.3 PROBLEM STATEMENT

Approximately 370 admissions were recorded in the Paediatric ward per month, of which about 36% of them are readmitted at the Tshilidzini Referral Hospital suffering from the T1DM-disease. Generally-speaking, it also means that before any discharge attempts are made, caregivers are to be equipped with health education so that they could do their duties well. The researcher in this study had been working as a professional nurse for more than 10 years in the paediatric ward at Tshilidzini Referral Hospital in Vhembe District, Limpopo Province, in South Africa. Furthermore, during that period, the researcher observed that most children who were admitted with T1DM-disease had often been re-admitted complaining of the same conditions. However, on admission, these children would be usually very sick but usually look better after treatment. After some few days, their conditions could be improved and would be obviously discharged. Substantially, before the T1DM-patients could be discharged, caregivers were firstly taught how to take care of their patients while at their homes. In this context, these may include aspects such as: how to feed them and giving them the prescribed medications, and even the issue of advising them about the type of the foods they should eat.

Despite the discharge plan and health education that caregivers are given prior to such a discharge, children with T1DM are often re-admitted with higher blood glucose levels. Some of them come with diabetic ketoacidosis as a complication of T1DM, which leads to some difficulties in managing it, while others die due to these complications. A high rate of children are admitted in the paediatric ward per month, while about 36% were readmitted with T1DM within a short time. A study conducted by the Association for Diabetes in South Africa (2018) revealed that caregivers of children diagnosed with T1DM do experience a journey filled with confusion and uncertainty. Furthermore, as explained earlier on, there seems to be a gap of knowledge concerning the causes of T1DM and how the caregivers might look after those patients. Ideally, such research should, in fact, be conducted within Vhembe District of Limpopo Province, South Africa as the area appears to have a higher rate of the T1DM-patients. In short, the researcher believes both

the caregivers and the patients must be taught about the causes of the T1DM, and how the former should take care of their patients.

## 1.4 RATIONALE OF THE STUDY

The research sought to find out what caused the blood sugar level of children with T1DM to rise when they are at their homes. Furthermore, the study also intended to see the caregivers being taught how to look after their patients, as they sometimes seemed to forget how the given instructions from both the doctors and dieticians should be carried out.

## 1.5 PURPOSE OF THE STUDY

The purpose of this study was to investigate the experiences of caregivers regarding homecare of children with type 1 diabetes mellitus within Vhembe District of the Limpopo Province.

## 1.6 OBJECTIVES OF THE STUDY

The objectives of this study were structured as followed:

- To explore the experiences faced by caregivers regarding homecare of the children with T1DM-disease within Vhembe District, Limpopo Province.
- To describe the experiences faced by caregivers regarding homecare of children with T1DM within Vhembe District, Limpopo Province.

## 1.7 SIGNIFICANCE OF THE STUDY

**Body of knowledge**

The research study findings added value to the body of knowledge relating to the experiences regarding homecare of children suffering from the T1DM-disease within Vhembe District of Limpopo Province, South Africa. Besides this, the study also assisted the beginner-researcher to further conduct the other researches on the same topic.

**Care givers**

The study's recommendations also assisted caregivers who are caring for children diagnosed with T1DM-disease to obey the provided instructions.

**Department of health**

All in all, this study also helped the Department of Health's leadership to send the trained healthcare-workers to help the caregivers with better strategies of caring for the T1DM-patients. Additionally, after making a thorough study of the findings developed in this study, nurses also discovered mechanisms of looking after patients stress-free. The Department of Health also benefited using the study's findings, because they would know exactly what was indeed needed to manage the hospital costs of managing the T1DM-patients well.

## 1.8 THEORETICAL FRAMEWORK: NORMALISATION THEORY AND THE INVITATIONAL EDUCATIONAL THEORIES OF PRACTICE

Brink, Van der Walt and Van Rensburg (2012) stated that the term 'theoretical framework' is based on propositional statements resulting from an existing theory and integrates observations and facts into an orderly scheme. In support of the previous view, Neuman (2016) mentioned that the theoretical framework of a research project relates to the philosophical basis on which the research takes place and forms the link between the theoretical aspects and practical components of the investigation undertaken.

In this present study, two theories developed by Ward and Burton in 2007 called Normalisation theory and the Invitational Educational Theories of Practices were used. By the way, each of them had its own main principle as they are not the same. Furthermore, the Normalisation theory's principle had its emphasis based on normalizing the risky situations in which people might be involved in (e.g., caregivers experiencing problems about the homecare of the T1DM-patients within Vhembe District, Limpopo Province, South Africa). On the other hand, another one was the Invitational Education Theories of Practices where its principal concern is that after people who are involved in illnesses, diseases and any stressful situations recover, they later become excited, satisfied and use the experiences to control the consequences by themselves.

In pursuit of how these theories were suitable to be used in this study, the theories have been explained separately one after the other, as followed:

**Normalisation theory**

The Normalisation theory cropped up to be suitable to this study when it said children appeared to be more exposed to the risky factors than being protected health-wise (attacked by the T1DM-disease). The relationship between the two further emerged when it talked about normalization of the situation. The topic under study was also seeking to find out a solution of how caregivers might be assisted through whatever strategies to work in harmony with their T1DM-patients well. Apart from this, the proper suitability between the theory and the topic also became visible when each of them mentioned things happening outside that could be normalised. For that reason, the study normalised the theoretical requirements or aspects such as: feeding rules, giving of the injections and regular physical exercises, which would then be practiced normally rather than following the factors mentioned by the theory.

**Invitational Educational Theories of Practices**

The Invitational Educational Theories of Practices mentioned its principle as being based on aspects like bringing excitement, satisfaction and the enrichment of the troubled stakeholders with the experiences of controlling the situation. Furthermore, it meant that if one had listened to it carefully, both the caregivers and the T1DM-patients would gain the experience of improving their relationship after using this type of a theory (suitability). By the way, the topic in its innermost part, concerned the experiences of the caregivers regarding homecare of children with T1DM-disease within Vhembe District, Limpopo Province. However, the situation under which the caregivers were working with their T1DM-patients appeared to be difficult and, may be improved after using the above-mentioned theory. Ideally, the suitability of the two theories and the topic again showed up when each of them mentioned the term ‘people’ in their explanations.

From the afore-said examples or suggestions so far mentioned, one could simply conclude that both were dealing with people, and not animals. In this instance, the researcher decided to use the Normalisation theory to explain how the stubborn and reluctant behaviours of the T1DM-patients might be minimised. Who knows, maybe, after

studying the findings of this study, the bad relationship as it was now happening could be remedied. Ideally, the Invitational Educational Theories of Practices was used while trying to empower the structures such as: social workers, dieticians, doctors, nurses, the selected religious leaders and motivational speakers in an effort of trying to address the two stakeholders (caregivers and T1DM-patients). Nonetheless, such an attempt of normalising the relationship between the caregivers and T1DM-patients would enable the patients to obey the dieticians or the doctors' instructions; so that they might then live longer.

## 1.9 DEFINITION OF KEY CONCEPTS USED THROUGHOUT THIS DISSERTATION

### 1.9.1 Experiences

Experience is the witnessing of various circumstances that emanate from the participation or involvement in an activity or engagement of some sort (Cowie and Hornby, 2012). An experience refers to a process of receiving or feeling an emotion of difficulty, joy, loss or pain (Wehmeier, McTosh, Turnbull and Ashby, 2016). In this study, experiences were perceived as circumstances that are felt by the caregivers and emanating from the homecare of children diagnosed with T1DM-disease.

### 1.9.2 Caregivers

Johnson (2013) states that normally, the concept of a caregiver refers to anybody, either an adult individual whose responsibilities are to look after the likelihood of children including their biological or adoptive children with children care, support or treatment.

In the present study, caregivers included parents, guardians and babysitters who provided care, support and treatment to type 1 diabetes mellitus children at home.

### 1.9.3 A child

A 'child' refers to any individual who has not yet reached a maturity age of development who is still dependent upon others for survival's sake. In this context, professional people even go to the extent of defining children as persons whose age ranges from 18 and

below, who are indeed affected by diabetes mellitus. WHO (2017) mentions that children are persons below the age of 18 years who are affected by T1DM.

For the sake of this study, the term ‘child’ referred to an individual between the age of 28 days to 12 years who is diagnosed with T1DM, and is also receiving home care and support from the caregivers.

### 1.9.4 Type 1 diabetes Mellitus (T1DM)

According to Reddy, Ganie and Pillay (2013), T1DM is a disorder in which the body does not produce insulin, which converts sugar, starches and food into energy. This T1DM affects either children or young adults.

For the purpose of this study, T1DM referred to a type of a disease that usually attacks children ranging from the ages of 28 days to 12 years and are treated at any hospital’s paediatric care unit.

### 1.9.5 Homecare

‘Homecare’ refers to home-based care-center formed to denote or give every care to patients who are non-hospitalized but keep on receiving care, support and treatment from their hospital healthcare-givers or other health care provider at their own households (Cherachi, Shamsei, Mortazavi & Moghibeigi, 2015).

In the present study, ‘homecare’ referred to any entity with the researcher especially conducting a research study with some type of care, support and treatment which is provided to diabetes-suffering children between the age of 28 days to 12 years. In one way or another, these should be children who receive care, support and treatment from caregivers at their home environment.

## 1.10 RESEARCH METHODOLOGY

Research methodology describes the appropriate methods and procedures available to a researcher to achieve specific research objectives of any study. The research design

refers to a blueprint for conducting a study (Burns and Grove, 2011). A qualitative explorative, descriptive and contextual research design was adopted in this study with the aim of describing and exploring the experiences of caregivers regarding homecare of children with T1DM in the Vhembe district of the Limpopo province.

### 1.10.1. Qualitative Research Design

A qualitative research approach guided the current study due to its interpretive nature in which the researcher can interpret a phenomenon under study through people's values, variable social contexts, language and perception (Oates, 2006). Caregivers of children with T1DM gave different views on the homecare of these children. These views were elicited through one-on-one interactions.

### 1.10.2. Study Site

The study was conducted in clinical settings, in a primary health care facility of the Tshilidzini Hospital in the Vhembe District of the Limpopo Province. The Vhembe District comprises of four local municipalities: Makhado, Thulamela, Musina and Collins Chabane. There are 6 district hospitals in Vhembe. These are Siloam Hospital, Memorial Hospital, Elim Hospital, Malamulele Hospital, Donald Fraser Hospital and Musina Hospital. In the Vhembe district, there is only one referral hospital, called Tshilidzini.

### 1.10.3. Population and sampling

The population of the current study were caregivers of children with T1DM who were referred to the Tshilidzini Hospital when consulting from primary health care facilities of the Vhembe District. A non-probability purposive sampling was used and the participants were selected according to inclusion criteria. The population was targeted at 14 participants but continued until data saturation was reached (Brink, van der Walt & Van Rensburg, 2018).

### 1.10.4. Data Collection

A semi-structured interview guided the data collection for the study. The use of an interview guide and probing questions assisted the researcher to achieve the objective of the study. Similarly, a voice recorder was used to capture the participants' voices and helped the researcher to transcribe verbatim respondent's responses together with its analysis.

### 1.10.5. Data Analysis

Data was analysed using the Tesch's open coding technique which required the researcher to begin by transcribing the collected data and in the final stage of analysis, draw out themes and sub-themes that emerged during the transcribing of data.

## 1.11 ETHICAL CONSIDERATION

The current study adhered to the ethical norms for conducting research with human subjects by avoiding misinterpretation and exploitation while promoting knowledge and truth. As a measure to ensure this, ethical clearance was obtained from the University of Venda Research Ethics Committee, as detailed in Annexure F, and permission to collect data in the health facilities was obtained from the Limpopo Department of Health, attached in Annexure G. Participants were informed about the purpose of the study and requested to sign the consent form if they are willing to take part in the study. Participants signed the consent form and handed it to the researcher willingly before the interviews were conducted. All participants were assured of their privacy, confidentiality and anonymity.

## 1.12 LAYOUT OF THE DISSERTATION

The structure of the research document followed the following sequence to achieve the objective of the study:

Chapter 1

This chapter provides a general introduction and background of the study, the problem statement, aims of the study, objectives of the study, research methodology and significance of the study were described in this chapter.

Chapter 2

This chapter explored and discussed the review of relevant literature of the study.

Chapter 3

The chapter focuses on the research methodology, research design, population, sample, the setting and the data collection method adopted for the study. Also, the data analysis technique together with the measures to ensure trustworthiness and ethical considerations of the study were described.

Chapter 4

This chapter discusses the data analysis and provides a presentation and description of the main themes and sub-themes identified.

Chapter 5

In this chapter, a summary of the entire study's findings is discussed and conclusions are drawn. Also, recommendations are made for the purpose of further research originating from the limitations of the study.

## 1.13 SUMMARY

This chapter discussed the introduction and overview of the study. The problem statement, the aims and the objectives of this study were discussed while the research methodology was summarised and will be discussed in chapter three. The following chapter will discuss the literature review of the study.

# CHAPTER 2

# LITERATURE REVIEW

## 2.1 INTRODUCTION

Babbie and Mouton (2013) asserted that: “literature review is an important opportunity to work through one’s own interests and concerns in relation to the work of other people” (p.34). Murray and Beglar (2009), also acknowledged that literature review usually provides the framework of the research and identifies the area of knowledge that the study is intended to expand to. Literature review of this study was explicitly explained using the topics and sub-topics, but they were strictly based on the objectives of the study, together with its framework as followed:

## 2.2 TYPE 1-DIABETES MELLITUS

According to Hockenberry and Wilson (2013), Type 1-diabetes mellitus is a disorder that occurs when the body does not produce insulin which converts sugar, starches and food into energy. Furthermore, T1DM was previously called *insulin dependent diabetes mellitus* (IDDM), and that it affects both children and young adults. T1DM is one of the most chronic diseases that is presumably caused by several factors. In support of this view, Johnson (2013) also stated that T1DM has a cause which only becomes visible immediately when the pancreas of a child is injured. However, T1DM only happens when there is no insulin to let glucose get into the cell. This results in sugar building up in the bloodstream where it can cause a life-threatening complication. In a case where the T1DM-patient is due to use the insulin injection during treatment, caregivers are the only persons who are provided with health education concerning the giving of insulin to such patients outside the hospital setting. In this instance, children above 10 years of age are also taught how they could inject themselves. By so doing, it would have assisted the elderly-grandparents who could inject them wrongly due to their forgetfulness. Ideally, insulin injection can be injected into any area in which there is adipose (fat) tissue over the muscles. More importantly, if caregivers could stick well to the prescribed instructions from the doctors or dieticians, their patients (T1DM) might always stay in a healthier state.

## 2.3 CARE AND MANAGEMENT OF T1DM-DISEASE

According to Cathey and Gaylord (2014), caregivers are experiencing or encountering many challenges when they try to manage the T1DM disease as their patients (Zyberg and Lang, 2015). T1DM is a life threatening condition which needs to be closely managed on a daily care basis. Thus, the treatment of T1DM-patients should be done almost on a daily basis. By the way, it is not that type of treatment to be used today, and further used after some few more days to come. In this instance, caregivers are to be alerted not to miss even a single day without treating their patients, hence T1DM is a pandemic disease. Lovemore and Brummer (2013), stressed that of all the diseases that affect children during our day to day life, T1DM seemed to be the most dangerous one. On the other hand, its consequences could be simply prevented only if treatment is given to the patients on a daily basis. Care and management of T1DM helps to control blood sugar levels and may reduce the risk of other chronic illnesses like heart failure.

However, monitoring of blood sugar levels regularly or as directed by a doctor could help T1DM-patients to live longer in a fine condition. All in all, following a healthy diet and eating a planned diet may influence the T1DM-patients to stay healthier as taking regular exercises. The main aim of management of T1DM is to keep the blood sugar levels as close to the target range as possible between 4 to 6 months. In addition to this, sometimes blood sugar levels vary, depending on the individual's circumstances because it could be high in a certain patient and lower on the other one.

Regardless of all the examples or suggestions so far that have been given in this section of the study, it always keeps on advising that long-term management requires a multidisciplinary approach in its usage. For that matter, it further means that such an approach should include aspects such as: the presence of physicians, nurses, dieticians, social workers and selected specialists during its practice (Corrin, 2014). Mphanza (2012) also emphasised that it is very difficult for children suffering from T1DM-disease to consume some foods such as transient foods and meals that have to be prepared. For example, if such patients need the other type of foods, which would have been prescribed by either doctors or dieticians, they should be provided with. Food rejection by T1DM children might result in caregivers becoming discouraged in providing the full T1DM children with the required foods. Mind you, it then also further means that those patients must be advised to eat the recommended foods that the caregivers offered them to eat.

On the other hand, the refusal to eat such type of foods might bring worries to the caregivers leading to them being overstressed or depressed. Ideally, this is not a good symptom hence it could cause some diseases to them as elderly-people. Several studies conducted by Zysberg and Lang (2015) in relation to T1DM revealed that motivating the caregivers towards performing regular physical activities, diet and lifestyle might prevent the severity of the T1DM disease to their patients.

## 2.4 EXPERIENCES OF CAREGIVERS REGARDING HOMECARE OF CHILDREN WITH T1DM

Corrin (2014) noted that caregivers, particularly those looking after the children affected by T1DM-disease outside the hospital setting are indeed experiencing more problems than what their own parents are encountering. The reason being that those caregivers have the duty of seeing to it that the T1DM-children are regularly getting proper treatment, adequate nutrition and physical exercises. Besides this, it is also the task of caregivers to supervise the patients' treatment and nutritional diets almost on a daily basis.

Seemingly, dietary restriction is another experience that the caregivers face, hence they must strictly always abide by it. Children under the guidance of caregivers are not easily controlled while at their homes. For example, they may sometimes refuse to be injected, or even eat what they have been advised not to eat intentionally. Children are children, everybody knows, they are all interested in eating sweet diets, whether being prohibited not to eat or not. However, during the daily maintenance of treatment, caregivers normally forget the way insulin is given, or not giving the correct dose. As already being explained earlier on in this study, caregivers' failure to follow some instructions correctly is due to forgetfulness caused by their old ages. To mention only but a few, these are part of the experiences that caregivers face while caring for the T1DM-affected children at their homes. In a case where the caregivers are workers, it clearly shows that T1DM-children might stay for the whole day without getting treatment. The main reason behind this being that caregivers would have forgotten to implement such an instruction due to their ages. Nonetheless, it seems poverty also contributes to such experiences in relation to the caregivers because they would also be running short of money for transport to attend the check-up programs at hospitals. Additionally, and still concentrating on the issue of poverty, caregivers also experience some challenges in terms of places where to store

the insulin injections, they should in normality have a special place in houses to put those apparatuses. By so doing, they will have eased their tendency of always forgetting where they have placed those useful tools when needed. Why do we regard them as special tools? The reason is that, if they are put everywhere, they could easily get lost or be contaminated with dirt and ultimately become useless for use.

## 2.5 DIABETIC MELLITUS IN CHILDREN AND ITS EFFECTS ON CAREGIVERS' MENTAL HEALTH

Earlier on in this section of the study, it has been illustrated that taking care of the DM-affected sick children is not an easy job, but a difficult one. Furthermore, the caring of children with Type 1-Diabetic mellitus has, of course, a negative effect on the mental health of the caregivers and other family members. For example, after a sick son or daughter who is being taken care of complains of pain but still goes to school, a caregiver would not be knowing what will happen later. Besides this, other family members who have been informed about it, would also keep on worrying. However, the most hurt person amongst all the concerned stakeholders would be the caregiver, hence he/she is the one who is concerned with all the responsibilities of looking after such a sick child. By the way, on the side of the caregiver, there would be no happiness until they see the sick child walking freely back home. Another matter of great concern is that while at home, a caregiver should see to it that a sick child has eaten the right foods and given the usual bath before leaving home. Apart from this, it is also the duty of a caregiver to control that a sick child has followed the diet rules, which further include the drinking of the right drinks. Looking carefully at the examples so far mentioned which lead one to simply conclude that some other jobs despite the caring of the Type 1-Diabetic Mellitus sick children cannot match other duties, as far as the hardness is concerned.

From the afore-said views, it also further reminds one that doing such duties demands the strict use of the brains. No wonder why the caregivers always suffer from mental health. The other reason is that such a duty could not be matched with one of a young woman who is only selling sweets on the streets. Furthermore, but still showing the importance of the caring of the sick children task, their job could also be made easier through the help of the professional health caregivers (doctors, nurses, physicians and dieticians). On the other hand, although always claimed to be difficult or tiresome, the

assistance of family members, the invitation of selected religious leaders and professional health caregivers, the primary caregivers could bring harmony or comfortability to their job. Despite all the examples or suggestions so far cited, the caring of the T1DM-disease patients is still difficult. On the other hand, health care providers (HCPs) should, by the way, stay aware of the fact that there exists a difference between the caring of the DM – patients other than the other children suffering from some mild diseases. Nonetheless, it is always the duty of the caregivers to stay alert of the strategies of how to assist in improving the well-being of their sick patients wisely. Diabetes mellitus is, of course, the type of the disease which falls under the metabolic form of the diseases. The reason being that its hyperglycaemia results from either defective insulin secretion or insulin action or sometimes both.

## 2.6 CHALLENGES OF CAREGIVERS OF CHILDREN WITH DIABETES MELLITUS

### A South African Context

Diabetes Mellitus (DM)-disease in sick children is quite a complex type of a sickness which needs the quality support from the concerned stakeholders, such as: the involvement of the biological parents, relatives and secondary caregivers (nurses, doctors, physicians and dieticians) so that it could be effectively managed (Dhada & Blackbeard, 2019). Furthermore, it should also be realized that the DM-disease is terrible, chronic and a life-limiting disease. Essentially, the other reason is that it influences the young children to die before they have even reached the old ages. For example, we are also confronted with a situation in which young children are passing away at the ages of 6 to 7 unexpectedly. Caregivers are therefore also compelled to carry out the responsibilities of fulfilling their daily supportive duties of monitoring of the sick children well at their homes. Arising from the afore-going example, it means that caregivers should time and again consult secondary caregivers so that they can take care of sick children properly. By doing so, it also means that such sick patients would then stay healthier than before. From the researcher's perception, it then also means that the caregivers cannot work alone but should always seek assistance from some concerned stakeholders.

Nevertheless, visiting the professional health workers regularly might time and again help ensure that the DM-patients can remain safer and healthier for a long time. Regarding the South African situation, caregivers are offered enough chances of consulting the professional health caregivers freely. It is at these check-up sessions where the secondary caregivers had taught them about the strategies of looking after the Type 1-diabetic sick children well. For example, in cases where a sick child could just with immediate effect display some illness actions, caregivers should always quickly apply the taught knowledge in assisting the child. During the said consultations, themes like: fear of a child's failing health, information sharing, service transition for other family members with chronic illness, shielding or avoidability and language, including all the cultural barriers are deeply addressed. In addition to this, South African caregivers seem to be fortunate because at all the clinics or hospitals, they are provided with the highly-qualified professional health education. Moreover, it means every caregiver has all the priorities of using them freely. Yes, the fact that the giving of care to the Type 1-diabetic sick children is a difficult job is beyond any reasonable doubt an obvious issue. For example, after a sick son or daughter is readmitted to the hospital, it usually leaves a grandparent with a stressed or traumatized situation. The reason should be that she will be worried about what will happen to the child.

More significantly, this might be the reason why some elderly grandmothers are usually readmitted at the hospitals for several times. Worrying about the regular readmission of the sick children could be the cause of such an event. In one way or another, the dedication to offering support to all the concerned stakeholders, including the family members, is of much importance in relation to giving the DM-patients the mutual assistance. On the same note, regular visits to the check-up points especially addressed by the professional health workers enable the caregivers to exactly confirm how and when the provided medications are to be used properly. Substantially, such visits keep on alerting the effectively and efficiently caregivers to be aware of when and how an injection is to be applied to a sick patient at the right time. Nonetheless, it is at these check-up sessions where the concerned caregivers might be helped in sharing the knowledge they had learnt in the past freely. Suppose one caregiver has attended the physical activity meeting but the neighbour has failed due to certain circumstances, they can then just share so that each of them end up having the same information. Despite all the examples, including the suggestions thus far cited, it then compels one to conclude that taking care of Type 1-diabetic sick children is indeed a heavy task.

By doing so, it then compels the caregivers with the strong powers to can only carry out all the duties of looking after the sick children extremely well. Ideally, in such an adventure, caregivers should then stay alert of what to do and when, pertaining to the way in which an injection must be applied to the sick patient properly. After sharing the provided information from the attended check-up sessions, caregivers would be able to give good services to their patients. Needless to also say that the communication aspect could make any kind of discussion go well while sharing information so that a sound benefit to the caregivers may be obtained. However, the communication type of discussion could succeed, when it starts with the carefully listened and understood of the shared experiences. More significantly, this could be easily achieved using the following factors, such as: the clinical consultation, a regular face–to–face interaction with the secondary caregivers, might serve as an extremely valuable opportunity to review careful care and, to alternatively implement the plans aiming at achieving the predetermined treatment goals.

In cases where a caregiver has forgotten which and when a certain medicine must be used, during the shared discussion, caregivers can be helping each other unaware in such a situation. Moreover, this could simply emerge after the caregivers have attended the check-up sessions together but opted for a discussion meeting together. For that matter, such an attempt could easily lead all caregivers to perform the caring of the DM-affected patients perfectly well. Apart from this, the secondary caregivers are the only persons invested with the suitable knowledge and skills of knowing how and when, the Type 1-diabetic sick children are to be carefully looked after. Generally-speaking, it seems as though the regular check-up sessions that are usually held at different health care centres could be used by the caregivers towards gaining wisdom of looking after their patients well.

Finally, it also further shows that the guarantee of good caring of the DM-patients can be well-mastered after a good communication between caregivers and the other already-mentioned caregivers have been consulted. Additionally, this aspect (thorough communication) appears to be one of the most beneficial features towards enabling the trained caregivers to thoroughly open a way through which the Type 1-diabetic sick children may be monitored.

## 2.7 EXPERIENCES OF FAMILY CAREGIVERS OF THE SICK CHILDREN

### Exploring Burdens and Coping Experiences

According to Holstrom, Haggastrom, and Solderberg (2018), when every child whether young or grown up is diagnosed with a long-time illness, both the biological and family members find it stressful or traumatic to look after him or her in reality. As also been mentioned in the previous section of this study, the reason for this would be that taking care of sick children with Type 1-diabetic disease is not an easier job, but a more difficult one. Furthermore, this appears to be a heavy task especially when caregivers are not supported in their adventures. The other reason being that they should always be assisted by the various stakeholders or the trained professional health care workers.

In cases where the sick child could just fall without firstly displaying any illness symptoms, the very caregiver under whose supervision the sick child falls should quickly look for assistance. The caregiver is the one who is well-invested with the knowledge of how and when the sick child must be cared for properly. Ideally, it is only the caregiver who knows how and when a sick child must be treated while found under any painful situation. Who knows, sometimes when such attempts are made, the sick child can be simply cured of the terrible disease conditions and become well again. In one way or another, it could be accepted as true evidence that the optimum support must be offered to both the caregivers and the biological parents when in need. Who is then responsible for giving such assistance? On the other hand, it then shows us that the professional health caregivers are the only ones who deserve to give such assistance. By the way, it also means that both the caregivers and parents should get a chance of devising the strong strategies of making use of both the rightful medications and the correct diet rules while eating.

On the side of the caregivers, a chance of doing it well after the concerned caregivers have regularly attended the convened check-up sessions should always exist. On the other hand, during such an event, the entire family members would have been faced with a difficult life situation of knowing what to do or not. The worst side, with reference to the caregivers, they are the ones who usually play a major role pertaining to what needs to be done or how in such a situation. For example, it also means that, for headaches, giving a sick child some tablets could save the whole stressful atmosphere. Nevertheless, this

could either be regarded as a stressful or depressive situation, hence it requires that both the caregivers and parents should use their expertise in giving the remedy to the very illness. By doing so, the remedy in this instance has beyond any further doubt, been effectively and efficiently achieved through working in unity with the other members. To be more precise and sticking to the topic under discussion, it should also not be forgotten that the remedial efforts done to the sick children is a stressful event especially to the caregivers. The reason being that they are the only ones who are invested with the whole duties of looking after those sick children. People have different opinions pertaining as to how the caregivers are, of course, giving enough care to the sick children or not. The biological parents sometimes stay stressed or depressed due to the hearings from the gossip mongers or any other gossip-lovers without making any visible visits to the sick children' homes per se. In such an instance, one could simply conclude that caregivers are indeed working under a very heavy situation. The reason being that they sometimes receive unnecessary accusations from the parents of the sick children and face the reluctant reactions that the sick children usually caused to them.

Despite all the severe circumstances that they are faced with, caregivers often stay as if nothing has happened. The reason being that they love their sons and daughters more than any other thing to such an extent that they are always prepared to stand for any obstacle hampering them from looking after their sick children better. As stated above, caregivers are working under heavy pressures, but they keep on tolerating them. Over and above, they always keep wishing their sons and daughters a speedy recovery after falling sick. Suppose a sick child could just feel pain in any part of the body, a caregiver can stop talking and sometimes stay alone. This is done in an effort of showing how important a situation is to her. In cases where such a child could not quickly become healed, it could be causing a stressful situation to the caregiver. In addition to this, also in an event where the adolescent sick child might start refusing to be injected by the caregiver, a caregiver can just begin to worry. All in all, such worries could result in herself becoming emotional or even traumatized to an extent that she could soon become ill. Sharif, et al (2010) cautioned that a human is not an object or a stone, but a person with feelings that has a certain rate of tolerating bad reactions. From the afore-said statement, it always keeps on alerting one of the situations under which all the caregivers are working under today. It also further shows that feelings or senses in a human being could be irritated, they can also become tired or burnout resulting in the very person simply dying. While taking care of the Type 1-diabetes sick children, caregivers are to be offered the

whole quality support they deserve. By so doing, they would then work tirelessly and keep the sick children in good health. Ultimately, it would also clearly mean that such sick children would obviously stay healthy and strong enough to live longer, although being declared the long-term patients.

On the other hand, the primary caregivers are to follow the care factors such as: challenge solutions, coping devices, quality support, perceptions of public awareness from other people' emotions respectively. In this context, it also means that if the other reliable co-caregivers can say it is windy and cold specifically in June, the other sick child should also stop attending lessons in schools. Seemingly, this may serve as a preventative major towards saving the poor sick children from getting involved in a dangerous event. Apart from this, immediately after the challenges have just emerged, caregivers should always stay prepared to use their taught strategies to help the sick children in future. The main reason being that challenges are a long-life event, which people should stay well-prepared for, because human beings are natural features often ready to live with whatever nasty situation in life (Kock & Jones, 2018). Essentially, caregivers are to stay ready with strong tools in the form of education to help the sick children. Apparently, caregivers need to stay armed with those tools for resolving or tackling these fearful challenges that usually occur in their duties of looking after Type 1-diabetic sick children. Another matter of great concern appears to be that the DM type of a disease has come to this earth with the intention of staying forever especially in young children. It is also a matter of importance that both caregivers and the sick children's' parents should not ignore the perceptions of the public awareness, including messages from the co-people.

In the case where the neighbours' children are down with the terrible flu symptoms, caregivers should with immediate effect take the necessary measures aiming at protecting their sick children. Presumably, the fact that the Type 1-diabetes mellitus has indeed come to stay amongst the young children seems to be an acceptable point, and it is widely reported in our everyday media. In support of this view, Mahfouz, Mohammed and Rafael (2016) stressed that the global rate of the T1DM has increased in the last decades, specifically amongst children younger than 5 years of age. Basically, this leaves us with no other alternative actions but to agree with the published statistical reports. In respect of the T1DM-disease, the overall increase of the incidence of the DM occurrences is reported to be at the rate of 63%. On the other hand, about 7800 children under the age of 15 years are developing the T1DM-symptoms while still very young today. Finally,

it should also be accepted that a diagnosis of a child with the T1DM-disease symptoms has a substantial and automatically represents a challenge to the whole family when it has happened. The only fact being that mothers of children suffering from the T1DM-disease set to face challenges related to diagnostic presentation. This is, of course, of severe and high proportion of children as compared to the other adult-infected diseases in life. As explained in the previous parts of this very study, management of the T1DM-pandemic disease is a complex task which requires frequent monitoring of the blood glucose levels.

By the way, it also means that monitoring and controlling of the food intake, frequent insulin administration, and modifying the insulin dose, should be kept in such a way that it always matches with the diet situation, and the activity levels. To sum up this section on a high note, every individual in their right mind must be honestly on alert that caregivers of the DM disease should always consult the professional health workers while looking after the sick children so that they should often stay healthy and strong. Irrespective of whether taking care of the (T1DM)-disease children is difficult or not, caregivers must always consider it as their tool of keeping the sick children well. All in all, children with the T1DM-disease are often in dire need of care, despite whether challenges or problems are happening today or the other day, and, then, caregivers should always stay alert of those challenges.

## 2.8 EXPERIENCES FROM PARENTS TO CHILDREN WITH THE (DM) TYPE OF A DISEASE

Bearing in mind that it has been explained earlier on, T1DM is a pandemic and a life-long disease which could be tackled by the caregivers who are prepared to look after the T1DM-sick children, whatever action which might happen (Delamater et al., 2018). In respect of these different experiences, it further shows that children with the T1DM-disease are faced with difficult and bitter experiences while living. Suppose the grown-up sick child could just suddenly refuse to be then injected, and nobody could be found to replace him or her. What will be the after-effects thereof? Nevertheless, it simply means that the serious bad effects would be the order of the day. Consequently, even such a child could sometimes come back being carried by the other peers, due to lack of control of the rate of insulin in his or her blood per se. The most important point would be that the

very child has also come back in an unconscious state. The chances for asking him what might have happened were then not available, as the only important measure was to carry him to the nearest health care centre. The only important treatment that then needs urgent attention was firstly the confirmation of the temperature rate, insulin in the blood and the sugar-diabetes state. Immediately, after such tests, it would be confirmed whether such a child should be taken to a hospital or not. Mind you, also to some people who are not trained caregivers, it would simply mean a minor event could be tantamount to becoming stressed or depressed. Still on the other hand, it might drive the concerned grandparents to also be admitted to the hospital. As previously has been explicitly explained, it shows us that the experiences emerging from the other diseases' repercussions are different from that of the T1DM-pandemic.

For that matter, let us say another sick child has just started coughing continuously during the night, and crying, it could also suddenly cause some confusions to the caregiver. The real fact being that she will then have also forgotten which or how to apply the suitable medication treatment medication or an injection. Besides this, such a caregiver was taught which or how the treatment to the very incident is to be implemented, but the very caregiver could then be confused. In such an instance, the recent-factor in relation to the type of the experiences as encountered by the caregivers might be the cause-factor. On the same note, also in a case where a T1DM-disease patient unexpectedly gets injured or dies, the experiences as received by the caregiver could be more severe and hurtful in nature than to any other person. The biological parents or even the other family members would take it in their own thinking, rather than looking at the healthy causes of such a death. It should also not be forgotten that caregivers are not neither doctors nor nurses, but mere people who have just volunteered to assist in looking after the sick children. In a real fact, what should have been done, was to thank the caregiver's service during the same child's life span. Honestly-speaking, it becomes obviously true that, in such situations people are always afraid to come out with the whole truth, but could only tell the fabricated lies being levelled to the poor caregivers. The worst part of such an incident could be that the caregivers themselves would have already mentally gone "to another world," known by themselves only. The reason being that most grandmothers usually love their sons and daughters more than their biological parents from people's perspective. An undeniable reason might be that having a grandson or daughter is a token of praises culturally amongst most people. More significantly, grandmothers are always

very proud of their sons and daughters, because it even shows that they have grown up enough, and no longer have “girls” as they might say in their own cultural praises.

After the experiences of the death of a sick child, a most stressful and traumatic situation usually prevails amongst the caregivers. The fact being that the caregivers of the sick child that passed away could with immediate effect also die. This could eventually lead one to conclude that all the people who are taking care of the T1DM-patients seem to be the only workers who have the more severe experiences than those working somewhere-else. Furthermore, but still focusing more precisely on the topic under study, it also reminds us of what could also happen if in a family of a sick child, the sick child just suddenly takes a quick sleep and even stops breathing while at his home. Moreover, and in this instance, without any further doubt, the lonely elderly grandmother could feel as if she were dead. Even after the unconscious child could later get awakened, it would leave the caregiver, of course, in a hurtful and traumatic condition. Basically, as already been explained in the earlier sections of this study, taking care of the T1DM patients is not an easier task, but the most dreadful and difficult one to do in life. The main reason behind this being that caregivers are always confronted with very bitter and severe experiences than those working somewhere-else in their working places. Until so far, there are, in fact, several examples or ideas that have been cited in confirmation that taking care of the DM patients has bad experiences in abundance. Over and above, every problem in life has a rigid solution only if strictly studied, but people often fail to get such solutions. It exactly means that it does not matter whether experiences are happening as challenges or problems in life, they could also at last be solved.

Seemingly, while growing up we have witnessed many types of diseases occurring, but at last, they were remedied using the newly-established scientific methods. By the way, it simply teaches us that the bad experiences brought about by the occurrence of the DM pandemic disease can also be gotten rid of, as it had happened to the previous diseases. Despite saying when and how, it appears solutions to problems whether in the form of diseases or other natures, could also be solved. In support of this view, Qian et al (2020) suggested that even the recently occurring pandemic disease called the Coronavirus (Covid19) would soon or later get a remedy. Therefore, it thus clearly shows us that even the bad experiences that the caregivers are confronted with today, would also soon get its solution. Nevertheless, the discoveries of the remedies for the previous diseases’ challenges brought about by the former diseases display to us that the future caregivers

would take care of the DM patients in a safer atmosphere than the present ones. The very reason being that the solution for the existing experiences would then have been found. It also easily shows us further that the caregivers looking after the T1DM-patients would enjoy more privileges in terms of performing their duties. As it is today, it appears most caregivers are agreeing to look after the DM patients since grandparents are seeing that their children or daughters have no other alternative, but to use voluntarily. It also appears the situation would have changed in future, hence the fearful and nasty consequences as faced in the caring of the T1DM-patients, would maybe, have been eliminated.

## 2.9 EXPERIENCE OF PARENTS OF CHILDREN ADOLESCENTS WITH TYPE 1-DIABETES MELLITUS

### Coping and caregiving experiences

Stages that children undergo while growing have different effects on their behaviours in life (Moloi, 2013). For instance, the crucial stage in children' lives is the one where they seem to be ever submissive while growing and do not even show any reluctance towards anything. To be more precise and even trying to stick to the topic under study, the Type 1-Diabetes Mellitus patients despite in which gender they belong to, are liable to be submissive to whatever medication or injections which are applied to them at their earlier ages. By the way, children are children, as young ones they could sometimes cry while feeling the injection pains. Later on, they are even quiet during the injection application because they would have become used to them. All in all, before leaving for schools, the grandparents might even politely instruct them without any form of reluctance to take the prescribed foods or fruits, or even apply the injections well to them. Generally-speaking after having reached the adolescent stages, they could start to intentionally refuse to be injected by the grandmothers. This even happens after the grandparents would have tried to plead them not to do it. At the end of the day, such sick children will be taken to the professional health workers so that they could inject themselves. As far as the forbidden foods are concerned, while in schools or somewhere-else with their peers, the sick children forget that they are real patients, and they eat the prohibited foods. Still in the presence of their friends, they will even go to the extent of drinking sweet yoghurts including the fatty stuff. Nevertheless, such sick children could sometimes fall

unexpectedly. The reason being that they would have eaten the foods which have been declared not good for their health status while trying to please their peers. These sick children will keep on being readmitted to the hospitals, and, thus, making the lives of the caregivers to stay at a risky situation.

In one way or another, when those sick children are readmitted at the hospitals, caregivers would stay worried or stressed to an extent that some could even be admitted to the hospitals. Still in support of the consequences that caregivers are faced with, especially when the sick children have reached the adolescent stage, one interviewed participant said: *"Yes, taking care of the DM sick children is not a child's play, but a very difficult job, specifically to a person faced with the consequences found within it. It needs a united collaborative effort on the part of both the caregivers and the professional health caregivers together. Truly-speaking, I can say that an easily-offended type of a person, could hardly tolerate to stay even a single day while doing such a task. Mind you, the situation usually becomes tiresome and stressful after the sick children have become adolescents in life."* In such a situation, they would have undergone a crucial stage where abiding by the diet rules or being injected by the caregivers will be a thing of the past. In addition to this, at this very stage, the very sick children will without any apparent reason keep on being readmitted to the hospitals due to their then rude behaviours. On the other hand, caregivers, especially those who are taking care of the T1DM-disease causes them to undergo the process of being involved in very hard experiences at least every hour in their homes. Furthermore, concentrating on the experiences that the caregivers usually confront after the sick children have reached the adolescent stages could automatically lead one to agree with the point that looking after the T1DM-patients is not an easy job, but a difficult one.

In support of the above-mentioned example, after some sick children have grown up especially at the adolescent stage, some even skip some days without injecting themselves. By the way, this is happening at the time when they have been granted an opportunity to inject themselves after making a protest. At the end of the day, the sufferers would be the sick children themselves. Over and above, such children would even stay on being readmitted to the hospitals for a long time, which would lead to them losing their school times. Who knows, even after spending some lost time not attending lessons, it could result in them repeating the same grades for several times. Suffice it to say that, by so doing, they would be unaware that they are squandering their precious time of

achieving the future predetermined educational goals. On the same note, it clearly also shows that the main blames pertaining to everything that leads to their failures in the process of taking care of the sick children would be put on the caregivers' shoulders. The reason being that there are, of course, some caregivers who would fail to apply the prescribed rules of looking after the sick children due to their lower levels of literacy. Basically, experiences as undergone by many caregivers who are taking care of the Type 1- diabetic sick children have taught us that looking after the DM-patients is a difficult job. The reason is that it needs either patience or even tolerance on the side of the caregivers. Taking the previously-mentioned statements so far cited, it indeed drives one to clearly conclude that coping to a situation where the caregivers are involved in while caring for the DM-young patients could be overcome if both the patients and caregivers might try to live in harmony with each other. The reason being that it is the mutual understanding and free communication that could mediate in such a difficult type of a work.

Still concentrating on the same note, it further means that professional health caregivers should not get tired of offering caregivers the valuable health education, hence it could enable them to perform their duties to their maximum best. By doing so, despite the wrongs that either the caregivers or sick children have done, the caregivers also as parents of their sons and daughters, should practice looking after the children as if they are theirs. According to The Holy Bible: King James Version (2012) in (Ephesians, 1-3), cautioned that: *"Children, obey your parents in the Lord: Honour thy father and mother, which is the first commandment with compromise, that it may be well with thee, and thou may live long on the earth."* From this quoted biblical extract, children including even the sick children are warned to always respect their parents on a daily basis. In addition to this, this would enable them to be offered some more days of living longer on this earth. To one's surprise, most of the children appear to be defiant of those biblical words, hence they intentionally keep on ignoring what their caregivers (parents) advise them to do as the DM patients' at their homes. In short, they usually do all these negative reactions while in the presence of their loved peers, who appear to influence them seriously towards all those bad reactions. Seemingly, one could not be surprised to even see so many graves at our cemetery places belonging to the young people rather than old people. Furthermore, one could then realise that most of those young people' graves could not be happening if they do respect their parents. For example, it also means that the reluctant sick children, especially those suffering from T1DM are also indeed violating God's rules.

Apart from this, some sick children even go to the extent of using the wrong reactions of even convincing their caregivers that they would inject themselves. While admitting to their requests, the caregivers have much trust in their sons or daughters. In the light of the fore-going statement, it also compels one to simply conclude that the grown-up sick children could then inject themselves timeously. On the contrary, instead of doing those prescribed instructions as shown, some sick children might even skip many days without injecting themselves or even taking in the medications. Arising from the fore-going example, it ultimately results in those sick children being always readmitted at the hospitals. Taking all the different examples or suggestions mentioned in this study into consideration, it will also drive one to a conclusion that caregivers exclusively those who are taking care of the Type 1-Diabetic sick children are getting it hard to cope with them. The other reason being that when the sick children have reached the adolescent stages, they usually start not to obey the prescribed health rules well. In such stages, the sick adolescent children would have reached the stages where they begin to either ignore or even neglect all the professional health rules definitely. More significantly, the duties as performed by caregivers usually become difficult and sometimes tiresome after the sick children have reached the adolescent stages. At those stages, the adolescent sick children would resort to not obeying any prescribed eating or drinking rules intentionally. However, it seems at those stages, the sick children will have surely forgotten that they are patients and start to defy all the rules due to be followed by them. Finally, and taking into consideration all the ideas and suggestions thus far cited, it further then without any doubt also drives one to conclude that caregivers specifically those working with the sick children are doing the most difficult job.

Additionally, all the attempts that the caregivers are making in an effort of trying to cope with the nasty and bad effects being displayed by the sick children, show us that they have got the real love for their sons and daughters. Generally-speaking, the fore-said examples also show us that the circumstances under which the caregivers are working would have today influenced strikes after strikes happening, if it were at the other working places.

## 2.10 SUMMARY

This chapter presented an in-depth literature review pertaining to T1DM. The care and management of T1DM as a disease was explored together with the various experiences of caregivers regarding the homecare of children with the disease. The effects of diabetic mellitus in children and how it influenced their caregiver's mental health was described. Similarly, the challenges and perception of caring for children with T1DM were reviewed from a South African context. In addition, the experience of family care together with that of the parents of children with diabetes mellitus was explained.

# CHAPTER 3

# RESEARCH METHODOLOGY

## 3.1 INTRODUCTION

Research methodology can be defined as the way of studying various methods of obtaining superlative research data, which allows the researcher to conduct a more in-depth and meaningful research (Polit and Beck, 2012). Methodological research addresses the need for appropriate research tools and analytical methods required to conduct developing research. Furthermore, Polit and Beck (2012) highlighted that the rising need for credible and vivid research has drawn more interest to the various methods and tools researchers required in order to qualify their observations and findings.

## 3.2 QUALITATIVE APPROACH

In the present study, a qualitative research approach was used. The reason being that it helps to offer the researcher an opportunity to adopt the descriptive and exploratory research designs (Dornyei, 2016). Furthermore, Polit and Beck (2012) defined a qualitative research approach as a method based on the idea that there is no phenomenal objective that could be scrutinized. Similarly, the opinions of the personnel directly involved in the activity to be studied can bring about a lucid understanding of the social world. Polit and Beck (2012) mentioned that a qualitative method provides a pliable method of conducting data collection, data analysis and interpretation of the entire research under investigation. The adopted research approach of the study would be exactly informed by the objective of the study that seeks to explore the experiences faced by caregivers regarding homecare of the children with T1DM. However, the qualitative approach allows the researcher to gather genuine data because it relies on the experiences and ingenuity of the caregivers of children with T1DM. Over and above that, the experienced participants might offer the valid and reliable data (information) sounded to be more likely true evidence, hence they are full of information.

### 3.2.1 Exploratory design

The aim of an exploratory designs to allow the researcher to conduct a preliminary investigation into the research area under study. The current study explored the

challenges faced by caregivers at their respective homes when caring for children with T1DM within the Vhembe District of Limpopo Province, South Africa. Moreover, an exploratory design indeed enabled this researcher to employ an open, flexible, and an inductive approach to the research phenomena under study.

### 3.2.2 Descriptive design

Descriptive studies are usually aimed at describing a phenomenon under study. In the present study, the researcher accurately described the experiences of caregivers regarding homecare of children with T1DM as narrated by the caregivers.

## 3.3 STUDY SETTING

In this study, the study setting is the Vhembe District, which lies in the Northern part of Limpopo Province, which is one of the nine provinces in South Africa. Vhembe covers 18,569 square kilometres and a population of 1,3 million people. The cultural population that resides in the Vhembe District are the Venda and Tsonga people. Vhembe is one of 5 districts in Limpopo Province. Vhembe District comprises of four local municipalities: Makhado, Thulamela, Musina and Collins Chabane. There are 6 district hospitals in Vhembe. These are Siloam Hospital, Memorial Hospital, Elim Hospital, Malamulele Hospital, Donald Fraser Hospital and Musina Hospital. In the Vhembe district, there is only one referral hospital called Tshilidzini. This hospital had been serving communities around Siloam, Elim, Malamulele, Donald Fraser, Memorial, around Tshilidzini and Musina, and it is still offering them the good services as needed. This study was conducted at homes of children with type 1 diabetes who were readmitted at Tshilidzini Referral Hospital.

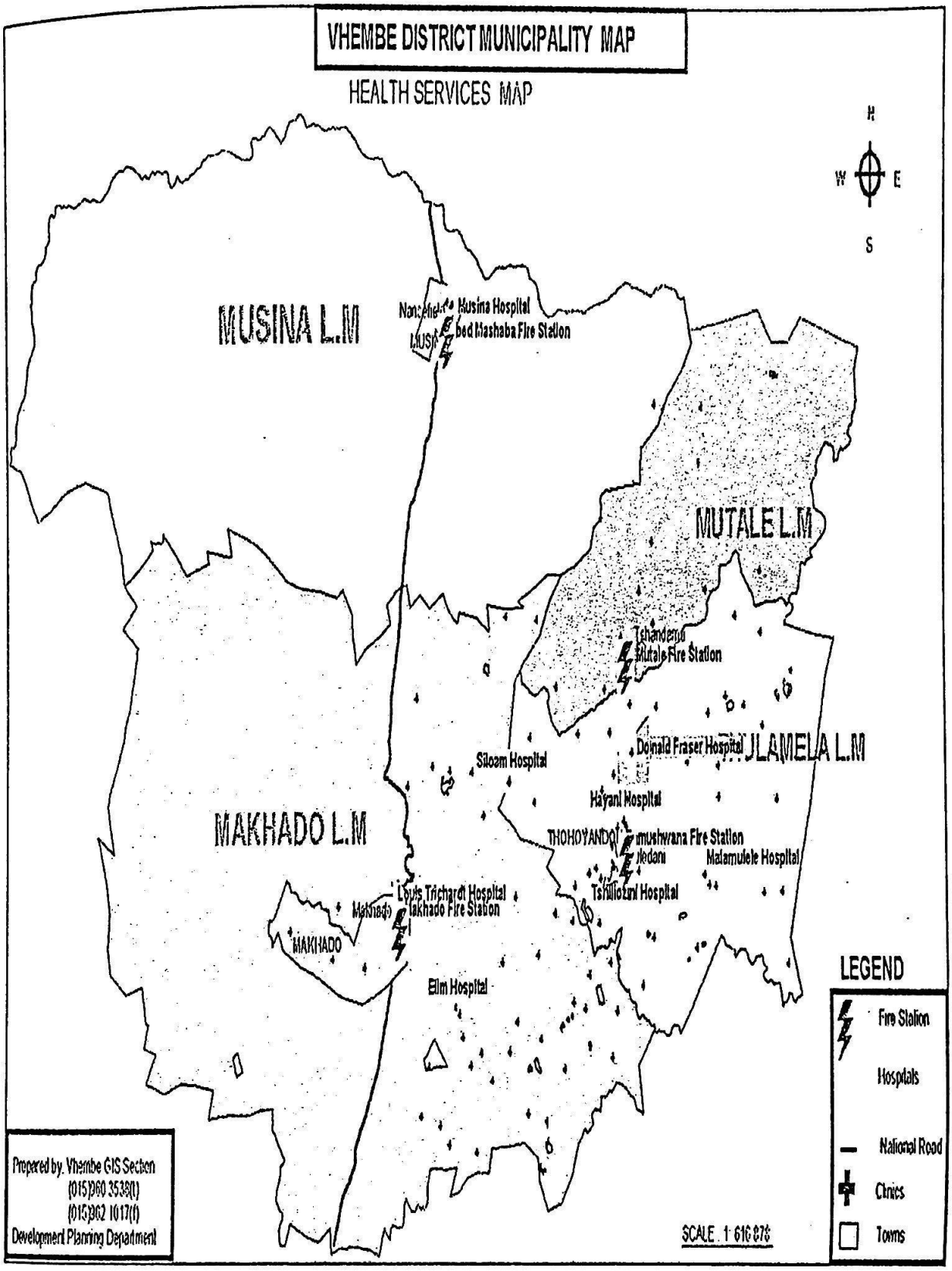


**Figure 3.1: A structure of the Vhembe Municipality Map.**

Source: (World Press, 2010).

## 3.4 STUDY POPULATION

Zikmund et al. (2013) acknowledged that a 'population' refers to any completed group of people, companies, hospitals, stores, college students, or the people who share some set of characteristics. In the present study, the population were the caregivers of children with T1DM in Vhembe District, Limpopo Province. In this regard, the population was composed of caregivers (grandmothers and young mothers) whose T1DM-patients are treated at Tshilidzini Referral hospital.

## 3.5 STUDY SAMPLING

Monette, Sullivan and De Jong (2013) highlighted the fact that a 'sample' is often drawn from a population which refers to all possible cases of what we are interested in studying. Furthermore, Bless, Higson-Smith and Kagee (2012) also held the view that a 'sample' is a procedure by means of which a given number of subjects from a population is selected from a population to present that population.

In the present study, the researcher used non-probability purposive sampling to select the caregivers who are taking care of children with T1DM at their homes. The reason being that purposive sampling enables the researcher to obtain data from the ingenuous, experienced participants, and /or the previous study's findings. Another matter of great concern for the use of the purposive sampling is that it enables a researcher to even make use of the face-to-face interviews which in normality results in providing a higher response rate during the data gathering processes.

### 3.5.1 Sampling size

A sample size is the actual size of an adequate sample that depends solely on how homogeneous or heterogeneous the population is or how different its members are, in terms of the characteristics of whether the correct research interests have been selected or not (Maree, 2016).

In this study, the researcher anticipated to use 20 participants (grandmothers and young mothers), although the actual number of 15 participants was determined by data saturation point, which was reached reached during the study.

### 3.5.2 Inclusion criteria

Brink, Van der Walt and Van Rensburg (2012) defined the term 'inclusion criteria' as the eligibility criteria which form the basis for the researcher's decision to conclude the subject.

Regarding this study, the 'inclusion criteria,' was made up of the following aspects:

- Caregivers whose children have been re-admitted with T1DM,
- Caregivers who are willing to participate in the study.

The exclusion criteria included children with type-2 diabetes mellitus, new admission cases and caregivers who were not willing to participate in the study.

## 3.6 DATA COLLECTION METHOD

Before all the other appointments pertaining to the data collection process were made, the researcher first sought permission to conduct the research from the Chief Executive Officer (CEO) of Tshilidzini Referral Hospital. The researcher also sought to obtain the records and schedule appointments of the caregivers from Tshilidzini Referral Hospital, and made appointments to visit the caregivers at their homes with the aim of data collection. The main aim of collecting data at their homes was actually to observe how T1DM management or home caring were being conducted by those caregivers.

Before data was collected, the researcher provided information to the caregivers regarding the purpose of the study, so that they could willingly sign the informed consent forms. By the way, the informed consent forms serve as an insurance policy for the participants' lives during the investigation. Besides this, they also helped in case a risky situation befalls any participant during the investigation. Essentially, in this study, caregivers were each given a free chance for an interview on experiences of caregivers regarding homecare of children with T1DM-patients. The interviews lasted for approximately 45-60 minutes and were held in an arranged private room for privacy. For that matter, participants had been firstly asked for permission to use a tape-recorder before using it. Who knows, some might not be used to being recorded during the interviews. An unstructured interview was conducted using participants' language. One broad open question was asked, as: "**What are your experiences regarding homecare of children with T1DM?**"

The following communication techniques were used to address the above question:

**Probing:** Caregivers were encouraged to talk during an interview by making vague comments that could have multiple meanings to obtain in-depth information.

**Paraphrasing:** This was done to convince the caregivers that the researcher was with them, and that they had then understood what they were going on about. Paraphrasing helped the interviewer to check her own perspective which would enable the researcher to indeed understand what the caregiver had been describing. The researcher often repeated what had been said in a more conscious manner to crystallize caregivers' comments.

**Summarizing:** This allowed the interviewer to condense and crystallize the given responses from the participants.

**Clarification:** This involved the interviewer's response and the interviewee's verbalization clearly. The purpose of clarification was to highlight caregivers' meaning that was not clearly initiated.

**Listening:** This was a process of turning in carefully to the caregiver's message and responding accurately to the meaning behind the message**.** Listening enhanced interviews, as the caregivers were encouraged to talk freely. Observation during the interview was made to field notes taken. After data collection, each interview was tape-recorded and transcribed with immediate effect to ensure validity and reliability during the data analysis process (Royse, 2008).

### 3.7 Data Management and Analysis

Burns and Grove (2013) maintained that 'data analysis' is regarded as a true test when a competent qualitative researcher intends to analyse properly and uses the ability to capture the understanding of the data in writing. In support of this view, Brink, Van der Walt and Van Rensburg (2012) also stated that 'data analysis' entails categorizing, ordering, manipulating and summarizing the data and describing them in a meaningful term, with the aim of highlighting useful information, suggesting conclusions and supporting the decision-making.

In the present study, data was audio-recorded and transcribed verbatim, using participants' language. This meant that the collected data had been firstly translated into

English by a qualified English editor before use. Data was processed and analysed in some orderly, coherent fashion, so that patterns and relationships were discerned for using the Tesch's eight steps, listed as follows (Creswell, 2012):

**Step one**: **Getting a sense of the whole.**

The researcher firstly read through the transcripts carefully to get a sense of the whole opinion several times. It helped the researcher to become acquainted with data collection. Some of the ideas, which came into mind were jotted down.

**Step two**: **Picking one interview.**

The researcher then selected the short test document from the transcribed interview, and this was given to the caregivers, and thereafter, the researcher read the transcribed responses in order to find the principal meanings.

**Step three: Creating a list of the topic.**

When the researcher had completed the task with caregivers, she had made a list of topics and clustered them with similar topics. However, lists were converted into columns, so that they would then be arranged as merger topics that had been unique and could be left over for later use.

**Step four**: **Observing the list of topics and transferring them back to data.**

From the list, the researcher assigned each topic to abbreviate and identify the codes. Then from the abbreviated list of topics, the researcher then wrote data segments next to the recommended codes.

**Step five: Describe topics.**

From the topics, the researcher found the descriptive words and turned them into themes or categories and the topics that were related together for groupings, thus reducing the list of themes.

**Step six**. **Abbreviated categories.**

The researcher had then finalized the abbreviations for each theme and alphabetized the codes.

**Step seven: Data Assembling.**

Data belonging to each category was assembled and preliminary analysis performed. This would help the researcher to come up with the themes and sub-themes on the group's data.

**Step eight: Data recording, if necessary.**

Finally, a chance was then ripe for the researcher to start with the interpretation, reporting and recording the researcher's findings properly.

## 3.8 MEASURES TO ENSURE TRUSTWORTHINESS IN A QUALITATIVE APPROACH

Maree (2012) stated that any instrument can be declared valid, only if it always measures what it is supposed to measure in pursuit of a valid and reliable findings. On the other hand, Wagner, Kawulich & Garner (2011) argued that when one is reading a research study, he or she needs to be assured of the validity of the results. Furthermore, Lincoln and Guba (1989) as cited in (Kumar, 2014), encouraged the researchers to describe their studies in rich, thick details because it enables the reader to determine that the methods used were appropriate and the results are indeed viable interpretations. The measures to ensure trustworthiness involved the credibility, dependability, transferability and conformability of the data being collected and analysed. In the present study, trustworthiness in a qualitative approach was ensured as followed:

**Credibility**

In the present study, credibility was ensured by using prolonged engagement with the caregivers to fully understand the experiences they face relating to homecare of children with T1DM. Furthermore, a prolonged engagement was provided to the researcher regarding the in-depth understanding of the experiences of home care of children with T1DM. The researcher spent 45 to 60 minutes with the caregivers to build trust by explaining the purpose of the study and ethical issues involved clearly. The researcher also further ensured credibility by asking different questions related to the caregiver's experiences when caring for children with T1DM at home. Essentially, also while conducting the interviews at the caregivers' homes, the researcher used different methods of communicating with the caregivers based on the home environment they lived in. These measures assisted in ensuring triangulation of data which helped in identifying

the common characteristics and elements that were relevant to the caregivers' experiences.

**Dependability**

In the present study, the researcher helped in addressing the issue of dependability by ensuring that the reliability of the field notes and audio recordings are cross referenced. The accuracy of the audio recordings and the field notes taken were cross-checked against each other over various time intervals. The accuracy also allowed the examiner to verify the transparency of the study undertaken.

**Transferability**

The present study also ensured transferability by describing in detail the background and the home environment of the caregiver. Furthermore, the researcher described the research context which is the behavior and experience of the caregivers. By doing so, the researcher had allowed the examiners and other readers to evaluate how transferable the findings had been especially to the readers. In addition to this, transferability was allowed for the findings of this study to be adopted by similar researches in different settings.

**Conformability**

Conformability was ensured by replaying the audio recordings to the caregivers for them to verify that what had been recorded was a true reflection of their experiences. By the way, the researcher also maintained a non-biasness form by only reflecting the experiences and conditions of the caregivers rather than showing the researcher's perspective only. Observation was recorded on the researcher's field notes so that it should act as part of the data collected and would obviously be kept by the researcher for future use.

## 3.9 ETHICAL CONSIDERATIONS

Punch (2014) asserted that:

> "Ethics involves the responsibility of the researcher towards those who participate in a research, those who sponsor it, and those who are beneficiaries of it".

In this instance, it often leads one to conclude that whenever every researcher is conducting a study, he or she should realize that the participants being used are people and not animals. For that matter, rules or ethical regulations should be enacted whereby their security might be assured during the investigation. On the other hand, Du Plooy-

Cilliers, Davis and Bezuidenhout (2014) highlighted the fact that ethics are to research what impartially is to judge. It is the cornerstone of research, and, without it, the delicate and complex interweave of research falls apart in undesirable ways.

### 3.9.1 Permission to conduct the study

- Presentation of the research was permitted by the Department of Advanced Nursing Science through the offering of the research ethics to the researcher.
- Presentation was also done by the University's Higher Degrees Committee.
- Permission to conduct the study was considered when the research proposal had been submitted to the University of Venda's Higher Degree Committee (UHDC) for approval to conduct the study.
- After the approval by the (UHDC), the proposal was requested to the University's Research and Ethics Committee.
- Permission to conduct research was also requested from the provincial Department of Health Research Committee's Chief Executive Officer of the selected hospital in Vhembe District of the Limpopo Province, to obtain consent to conduct the study and to recruit their clients as participants.

For the purpose of this study, only four (4) criteria's pertaining to the ethical considerations were to be used as followed:

**Informed consent**

Before the research study could even start, this researcher ensured that all caregivers had signed their informed consent forms under their leaders' supervision. This served as a security agreement in case any harm might occur during the investigation.

**Protection from harm**

Prior to the start of the main investigation, the researcher firstly informed all the caregivers about all risks (dangers) that might befall them during the investigation. However, the caregivers also assured the participants that their names or identities won't be disclosed to somebody hence it could harm the personalities, and they may lose their dignity and integrity during or after the investigation.

**Voluntary participation**

In the present study, the researcher used the pre-test session periods to the caregivers on the important issue of voluntary participation. By doing so, it was also the researcher's right to inform all the caregivers that participation in any research study is not compulsory, but each caregiver must participate in his or her free-will. Even after the investigation has started, a caregiver who feels not protected, is at liberty to withdraw.

**Confidentiality (Rights to privacy)**

In this study, the researcher informed the caregivers that their names and surnames would not be published to any media before or after the investigation. The researcher also further allowed the caregivers to ask questions pertaining to the 'confidentiality' issue. Besides this, the researcher clearly assured them that the findings together with their identities, would not be revealed to anybody.

## 3.10 DISSEMINATION AND IMPLEMENTATION OF RESULTS

The term 'disseminate' refers to the spreading of information or knowledge so that it could eventually reach many people who can use it in future (Cowie & Hornby, 2012). The university at which the researcher is a student was requested to convene seminars, workshops and conferences, so that the researcher could get a chance to address the caregivers of children with the T1DM-disease. By so doing, different caregivers obtained the information on how the T1DM-affected children could be treated. Furthermore, the researcher under the guidance of the supervisors helped the very researcher to publish a journal article on the topic under study. The researcher convened seminars, workshops or even conferences at the other places aiming at spreading the information on the same topic. Finally, it is at those meetings that the caregivers accumulated knowledge on how the T1DM-patients could be treated or cured.

## 3.11 SUMMARY

In this study, a qualitative research approach was described from an explorative and descriptive perspective that aimed at determining the experiences of caregivers regarding the homecare of children with T1DM. A non-probability purposive sampling was adopted to identify and select the relevant caregivers for the study. A schedule guided structured interview was used to collect data. Subsequently, a tape recorder was used to record the interview session, then later transcribed to develop themes and sub-

themes. Tesch's open-coding procedure was used in analysing the data (Polit & Hungler, 2011).

# CHAPTER 4

# DATA ANALYSIS AND DISCUSSION OF FINDINGS

## 4.1 INTRODUCTION

In the previous chapter, much emphasis had been put on the following aspects, namely: research designs and methodologies, the population, sampling, sample size, research instrument, including data collecting procedures and data analysis strategies. Furthermore, in this section, data collecting procedure was selected in relation to the developed main themes so that they should tally with the topic which goes: “Experiences of caregivers regarding homecare of children with Type 1- diabetes mellitus (T1DM) within Vhembe District, Limpopo Province, South Africa”. Furthermore, and in pursuance of this section’s main items, it consisted of data analysis and interpretation. More importantly, and before leading the readers of this study astray, the objectives of the study would firstly be shown. Kumar (2018) cautioned that the research questions should be based on the objectives of the study. The same researcher (Kumar, 2018) also stressed that if the objectives are three, the research questions should also automatically be three (3) in number. Apart from this, the same researcher also further maintained that topics must also be formed in relation to the research questions, but the sub-topics could be as many as possible.

## 4.2 DEMOGRAPHIC PROFILE

The demographic information provided a broader description and representation of the study participants who were interviewed as follows:

**TABLE 4.1: DEMOGRAPHIC PROFILE**

| | |
|---|---|
| **Total number of caregivers interviewed:** | 15 |
| **Age range**<br>18-24 years<br>25-34 years<br>35-44 years<br>>45 years | <br>05<br>04<br>02<br>04 |
| **Marital status**<br>Single<br>Married<br>Widowed | <br>14<br><br>01 |
| **Level of education** | |

| | |
|---|---|
| Illiteracy<br>Below Matric<br>Matric | 02<br>06<br>07 |
| **Source of income** | Government Grant (13 participants)<br>Local street vendor (2 participants) |

## 4.3 SUMMARY OF THE EMERGING THEMES

The following are the four main emerging theses developed from the data collected:

- Description of paradoxical experiences of provision of care to children with T1DM.
- Descriptions of the responsibilities entailed in provision of care to T1DM children.
- Knowledge related to all factors of taking care of a T1DM child.
- Challenges experienced by caregivers during provision of care to T1DM children.

## 4.4 DISCUSSION OF THEMES AND SUB-THEMES

Table 4.2 below presents themes and sub-themes reflecting the experiences of home caregivers of children with T1DM. Using the Tesch's open-coding method, four themes were developed before the carrying out of the data analysis and interpretation processes from the responses as given after the interviewing of the sampled participants. In addition, major findings were linked back to the reviewed literature as a supporting measure to validate the findings.

**TABLE 4.2: THEMES AND SUB-THEMES OF THE EXPERIENCES OF HOME CAREGIVERS OF CHILDREN WITH T1DM**

| | |
|---|---|
| **Themes** | **Sub-themes** |
| **1. Paradoxical experiences of provision of care to children Type 1-Diabetic Mellitus**. | 1.1. Suffering of T1DM children, over dosage and low socioeconomic status hampering medical check-up.<br>1.2. Care of T1DM children is a journey with several uncertainties leading to feelings of anxiety.<br>1.3. Feeling of stress, fear and self-blame experienced when children' conditions worsen.<br>1.4. Dual role played as a caregiver and health professional which pose difficult various emotions.<br>1.5. Children fear for injections as compared to tablets leading to caregivers begging to give treatment.<br>1.6. Prolonged existence of medical complications burdens caregivers.<br>1.7. Health education received from various health professionals. |
| **2. Responsibilities entailed in provision of care to Type 1-Diabetic children.** | 2.1. Family and neighbours' as support during provision care to Type 1-Diabetic children explained.<br>2.2. Continuous support of caregivers of Type 1-Diabetic children viewed as a responsibility of various stakeholders.<br>2.3. Responsibilities for care is assigned to another caregiver due to parents' work commitments.<br>2.4. Relevant care to provide to Type 1-Diabetic child when experiencing complications.<br>2.5. Caregivers hold health education information to give Type 1-Diabetic child under their care.<br>2.6. Consistent health education sessions to enhance knowledge of caregivers on the care of Type 1-Diabetic children. |
| **3. Knowledge related to all factors of taking care of Type 1-Diabetic children .** | 3.1. Lack of knowledge related to care of Type 1-Diabetic children explained.<br>3.2. Lack of knowledge related to signs.<br>3.3. Lack of knowledge related to diabetic diet explained.<br>3.4. Lack of knowledge related to medications and their side effects explained.<br>3.5. Lack of knowledge related to disease conditions and all related factors explained. |

| | |
|---|---|
| **4. Challenges experienced by caregivers during provision of care to Type 1-Diabetic children .** | 4.1. Lack of adherence to scheduled clinic and medication instructions**.**<br>4.2. Poor understanding of medication and health instructions.<br>4.3. Low level of caregivers' literacy<br>4.4. Poor care performance from caregivers.<br>4.5. Factors leading to primary caregivers releasing roles to secondary caregivers.<br>4.6 Lack of adherence to diabetic diet, medication instructions and health education.<br>4.7. Fear of administering insulin injection to children. |

### 4.4.1. The Discussion of Themes and Sub-Themes in a Literature Form

**THEME 1: Paradoxical experiences of provision of care to children with Type 1-Diabetes Mellitus**

According to Sharif, Basri, Alashafi, Alasmee and Wright (2020), looking after the Type 1-Diabetic children from a global view context appears to display the mental disorders on the rise within the caregivers, impacting on the socio-economic status's health and human rights. The main reason being that after the caregivers of children suffering from the T1DM had seen the actions being demonstrated by those patients, they eventually also become affected. For example, after seeing a grandson experiencing the half dead status of a T1DM sick child, the elderly caregiver could also somehow become traumatized or stressed. A human being is a human being, and not an animal or even an object like a stone, he or she has feelings. However, if a stressful or depressive situation could just happen specifically to grandparents due to the love they always have for their grandsons and daughters, they quickly become stressed or depressed.

The following sub-themes emerged after the analysis of the first main theme:

1. Explanation that taking care of Type 1- Diabetic child is an experience that causes suffering at multiple levels (experiencing pain as caregiver sees one of their suffering, experiencing children overdosing themselves, lack of money to go for medical check-ups and low socio-economic status).

2. An explanation that taking care of a Type 1–Diabetic child is a journey with several uncertainties leading to feelings of anxiety (bad and good outcomes which one cannot anticipate).
3. Feelings of stress, fear and self-blame experienced when children's condition worsens.
4. Explanation of the dual role played as a care giver and health professional which poses difficult various emotions (indicating that sometimes e.g., carers must inject the children).
5. An explanation that the carers are afraid to inject their children.
6. Description that existence of complications always causes emotional stress to caregivers.
7. Description of health education received from various professionals and its importance accepted by caregivers.

**Sub-theme 1.1: Suffering of T1DM children, over dosage and low socioeconomic status hampering medical check-up.**

The participants explained how their experiences of caring for children with T1DM affected them to the extent of suffering at multiple levels. This was confirmed by the caregiver who mentioned that:

*"Yes, when one looks at it from faraway, it might lead one to conclude that looking after the T1DM-patient is an easy job. Mind you, it is a more difficult task. For instance, one might find the very patient not willing to abide by the prescribed rules pertaining to either eating or drinking. Then, to me, as a caregiver, it could end up bringing stress or depression".*

Taking care of a T1DM child is not an easy job, but a difficult one**.** Furthermore, it could look simpler to someone who is not doing it, but only watching it from faraway. In this context, there could be many reasons that could be given in support of this statement. Suppose a caregiver is alone at home before offering the grandchild an injection, she falls and keeps quiet for a couple of minutes. How would an elderly grandmother feel? By the way, the fact that the caregivers are also "walking patients," should not be forgotten. It is also an obvious fact that, after watching either a grandson or daughter being involved in such an incident, she could also become traumatized or stressed. However, one should also not forget to think of what would have happened, if there has been no person in the neighbours' place. On the other hand, it also means the one who would wake up first,

may save such a situation. In this regard, it also simply drives one to easily realise that a grandparent could also become ill by merely seeing a grandson or granddaughter being readmitted to the hospital for several days. By the way, those are some of the reasons why we could say that to be a caregiver for a T1DM Mellitus-patient is an acute problem. Sometimes, even after the bigger children have been taught how to take medicines by themselves, they would usually take some overdose due to forgetfulness. In addition to this, some T1DM children keep on being readmitted to the hospitals, hence the elderly caregiver would have forgotten to visit the check-up sessions due to forgetfulness or lack of transport funds. In some instances, the sick children's parents do forget to give them transport money because they are unemployed.

**Sub-theme 1.2: Care of T1DM children is a journey with several uncertainties leading to feelings of anxiety**

During the discussions with caregivers for the diabetic child, they illustrated their knowledge and understanding on diabetics. It was observed that the caregivers understood that the diet of a diabetic patient plays a major role. One caregiver explained that one can get diabetes from what he/she eats. Another diabetic patient explained that he has been controlling his condition through diet not medication. The following quote supports this:

*"Eish! Eish! I have tried every effort of pursuing him to stop from eating the sweet and fatty foods while with friends at schools. By the way, he is always readmitted at the hospitals."* *[P.2].*

As already explained in the previous paragraphs, T1DM is really a stressful and depressive type of a disease to both the sick children and caregivers. Furthermore, they keep on thinking when will their grandsons or daughters be cured and their everyday conditions lead them to stay ever worried (Corrin, 2014). Similarly, the caregivers, especially grandmothers expressed how they looked forward to their grandchildren's speedy recovery. All in all, if it does not happen that way, those elderly caregivers stay worrying of the sick children's conditions (WHO, 2017). Besides this, in case when the sick children do not abide by the diet rules, it also earnestly keeps on worrying the caregivers. The reason being that it could lead to those patients being readmitted at the hospitals for a long time. In this context, it could result in those who have already begun

schooling missing more lessons, which may result in them repeating the same grades for a long time (Human Sciences Research Council, 2013).

The participants expressed that taking care of T1DM children is a demanding journey to that requires travelling by both the caregivers and the biological parents respectively. For example, those parents who do not always see their sick children, become even worried when discovering that their children's conditions are not improving. For that matter, they even become stressed or traumatized that their children do not obey the diet rules, which lead to them being regularly readmitted at the hospitals.

**Sub-theme 1.3: Feeling of stress, fear and self-blame experienced when children' conditions worsen**

This sub-theme elaborates on the different types of emotional and psychological difficulty caregivers experience when the children they are taking care of are showing signs of a worsening condition. This was confirmed by the caregiver who mentioned that:

*"Yes, my granddaughter, works are there and usually done by several people in life, but looking after the T1DM patients, appears to be a stressful and tiresome one, the reason being that, it involves aspects, like: fear of a child's failing health, information sharing service transition, even to the other family members with also chronic illness and cultural blames." [P.3].*

Dhada and Blackbeard (2019) asserted that: "Diabetic Mellitus (DM) is a very complex type of a disease specifically to the elderly caregivers who are looking after those patients, and, thus, it then requires that active support and involvement of parents along with the health care providers (HCP's) in order to effectively and efficiently manage such a pandemic, chronic and life-limiting disease from destroying the precious lives of our children while still very young." Having a good look at the recently-mentioned extract, it further compels one to even realise that Diabetic Mellitus (DM) is a bad type of a disease, hence it brings fear, feeling of stress and the self-blame experience especially when the conditions of a sick child worsen at least on daily basis. Another matter of great concern is that when the elderly caregiver sometimes forgets to inject their sons or daughters, they usually put the whole blame on themselves. However, in such an instance, fear overwhelms them, and they eventually become stressed. Still on the same note, the

elderly caregivers even go to an extent of even blaming themselves for the worsened conditions in which their sick children are involved in. Apart from this, the caregivers should always make it a point that 'the sick children are given baths and offered treatment before going to schools'.

Essentially, it also sounds more than likely to be true evident that taking care of the Diabetic Mellitus (DM)-patients is a difficult job, because it leads us to a situation of feeling stressed, fearful and the attitude of self-blame when the children' conditions become worsened (Reddy & Pillay, 2013).

**Sub-theme 1.4: Dual role played as a caregiver and health professional which pose difficult various emotions**

At times, caregivers are faced with a situation where they have to perform both caregiver and health professional duties which may be emotionally demanding. One caregiver mentioned that:

*"Yes, I agree, the task of taking care of the T1DM children is tiresome or even a difficult job, hence a caregiver is faced with other duties to perform instead of the prescribed one. Furthermore, one has to act as a worker and a parent." [P.4].*

In support of these findings**,** Cathey and Gaylord (2014) stated that most people at their working places, are only doing the tasks they have been employed to do, but to the caregivers of the children with T1DM, it seems to be contradictory. The reason being that caregivers have some extra work to do, they act as workers and as parents of the sick children. The caregiver also stressed that "we must cook and take care of our children which is tough". This implies that, instead of looking after the sick children, they must also inject or even teach them the correct eating and drinking rules. In an instance, where an elderly caregiver might give the patient an injection on the wrong part or at the wrong time, it could lead a sick patient to becoming sick. Who knows, such a child may even end up being readmitted at the hospital.

In short, it then also means that, working as a caregiver further leads to acting as a worker or a professional worker. Consequently, this could be well-understood when one thinks of working in the types of works, we know. Moreover, to a caregiver this appears to be

the opposite, because a caregiver has also some extra duties to perform while looking after the T1DM child at his or her home.

**Sub-theme 1.5: Children fear for injections as compared to tablets leading to caregivers begging to give treatment**

When the caregivers were asked about which treatment methods were children susceptible to, the injection method proved to be less favourable to children. One caregiver mentioned that:

*"Alright! I used to give an injection to my grandson, when still young, after he had grown up; he started to refuse to be injected by me. I had later succeeded in applying an injection to him after requesting the neighbour's bigger boys to hold him for me. The problem health-wise was that, during their absence, he had never been injected, which resulted in him always being readmitted at the hospital." [P.5].*

According to the NPDA (2019), children despite the disease they are suffering from, appear to be always afraid of injections rather than tablets. Furthermore, it seems that most sick children are more interested in taking tablets for treatment's sake than opting for injections. Consequently, even at our local clinics on a daily basis, one would often hear children crying at their loud voices during the application of injections, but when the tablets are taken in, no noise would indeed be heard. From my own perception, it then appears children do fear the injections than the taking in of tablets. The reason behind this could be that the sick children experience more pains while being injected rather than during the taking in of tablets. To one's surprise some tablets are also more sour or bitter, but could never ever lead children to cry.

**Sub-theme 1.6: Prolonged existence of medical complications burdens always causes emotional stress to caregivers**

The study findings revealed that the existence of complications always causes emotional stress to caregivers as indicated by caregivers based on the following direct statement:

*"Ok, my granddaughter! The T1DM is, of course, an acute problem to us, less than it is to the sick children in everyday life. The main reason behind this being that it automatically brings stress accompanied by a really depressive situation to us". [P.6].*

In life, complications do exist, and they are even unavoidable irrespective of whether a person is rich or poor in life (Nengovhela, 2017). Similarly, it has been shown that complications are the order of the day especially regarding the pandemic where T1DM patients are looked after by the elderly caregivers. This, of course, would then result in elderly caregivers to be traumatically stressed or depressed, to an extent that they could even be admitted to the hospitals. For that matter, it can eventually lead them to even become ill, as most elderly people do just walk as if healthy, but being in a "walking" patient status. In this context, some children with T1DM are often brought to their homes being carried by their friends, while being in a conscious state. What usually causes such situations? In most instances, they would have taken in either the forbidden foods, certain drinks or fruits, while under the influence of their peers.

**Sub-theme 1.7: Health education received from various health professionals**

Health education plays an important role in mitigating the severity of any disease as during the interviews one caregiver participant answered the posed question, like:

*"Yes, of course, we usually attend the check-up sessions where the professional health workers teach us important lessons including rules of how to look after the T1DM children well. While we are with our patients, we do our best to also teach them to always follow the diet rules on which foods to eat and drink. Apart from this, they are also warned to follow the physical activity exercises with much care, because they enable their bodies to always remain healthier." [P.7].*

Furthermore, the professional health care workers are often teaching us good lessons, but our sick children do listen when we explain the instructions to them and later seem to ignore or neglect the implementation part of our teachings. For example, a caregiver could while being fresh from the check-up sessions call a sick child and tell him or her about everything that has been taught including all the needed treatments. To one's surprise, the very patient who has been advised refuses to be injected and only agrees to take in tablets. On the one hand, it should be accepted that caregivers are doing everything in

their best abilities in trying to help the sick children to stay healthier, but the patients themselves, are always subjected to defying the prescribed rules from the professional health workers.

One the other hand, health education provided by health care professionals is important in the fight against diabetes, especially in children. This is supported by one caregiver highlighting that “the type of education given to us by the health professionals is indeed of utmost importance, and hence it further teaches us about the very physical activities to be adhered to, the correct diet in the form of foods, fruits and how to apply injections to our patients.”

**THEME 2: Responsibilities entailed in provision of care to Type 1-Diabetic children.**

Caregivers do always try to let the patients know the prescribed rules as given by the professional health workers, but they defy them indirectly when it comes to following them properly. In support, Dhada and Blackbeard (2019) asserted that: “T1DM is a very complex task and it requires the active support and involvement of parents or the primary caregivers along with the health care providers (HCPs) to effectively and efficiently manage this pandemic, chronic life-limiting disease from destroying the precious lives of our children while still very young.” Furthermore, it also drives one to further conclude that the Jack of all trades and master of one tendency cannot function in terms of taking care of the T1DM children. However, in this type of work, it always needs people who are prepared to work with other people, but not alone. For example, if a caregiver could just be summoned to bring a T1DM child for some emergency vaccinations at the hospital, he or she should with immediate effect be prepared to obey such a request quickly. Another matter of great concern is that caregivers should always realise that it is therefore their responsibility to be often aware of the demanding daily care, support and supervision.

The following sub-themes had emerged after the analysis of the second main theme:

1. Existence of family and neighbours’ support during provision of care to Type 1-Diabetic children explained.
2. Continuous support of caregivers of Type 1-Diabetic children viewed as a responsibility of various stakeholders (neighbours, relatives and health professionals).

3. Description that responsibilities for care giving is sometimes assigned to grandparents due to parents' work commitments.
4. Existing understanding of relevant care to provide to a Type 1-Diabetic child when experiencing complications.
5. Explanation that caregiver's hold health education information to give to Type 1-Diabetic children under their care.
6. Consistent health education sessions to enhance knowledge of caregivers on the care of Type 1-Diabetic children.

**Sub-theme 2.1: Family and neighbours' support during provision of care to Type 1-Diabetic children**

It is still a challenge for many families and neighbours to support caregivers during provision of care to Type 1-Diabetic children. Despite these challenges, other caregivers are hopeful of the entire situation. One caregiver responded during the interviews, by saying that:

*"These T1DM children are somehow, while still young, good and agree with whatever is said to them. I have been taking care of a sick grandson and he has been good and follows all the instructions, at the age of 10 he changed and even refused to be injected by me." [P.8].*

Children will forever be children in that, you do not know with them when it comes to behaviours whether they are sick or well in their daily lives (Corrin, 2014). Furthermore, while caregivers are attending the health education lessons at least on a regular basis, they are even advised to seek assistance from the other family members or a neighbour to look after the T1DM children well. However, as already explained at the beginning of other paragraphs, children's behaviour could hardly be a correct judgement to this problem. The reason behind this being that it could also be that the sick children keep on changing their behaviours towards obeying the professional health workers' rules. For example, if a child can refuse to be injected, a neighbour, teachers and religious leaders can be asked to assist the caregiver by motivating the sick child to welcome their medication. Apart from this, teachers should be informed about such incidents, maybe they could talk to him or her to keep on obeying the professional health workers' instructions. In addition to this, even the selected religious leaders could be made use of

towards motivating the sick children to follow the professional health workers' important rules.

From the above statements, it drives one to easily realise that caregivers should without any further doubt, obey the rules from the professional health workers while busy taking care of the T1DM children.

**Sub-theme 2.2: Continuous support for caregivers of Type 1-Diabetic children viewed as a responsibility of various stakeholders**

Continuous support for caregivers was discussed with the caregivers of children with T1DM. During this session, caregivers voiced how caring for children with T1DM should be the responsibility of the entire community rather than a single individual. This was evident during the interviews, as one participant responded to the posed question in the following manner:

*"Hmmm! Taking care of the T1DM-patients can become easier, if all the concerned stakeholders (family members, neighbours, relatives and caregivers themselves) work together. In such an instance, the duty of looking after those types of patients could be like any other job, being done in life. The reason being that, there would then be a co-operation amongst the concerned stakeholders. Truly-speaking, I am telling you, it is not happening in that manner. On the other hand, it could be the reason why it seems to be a really tough type of work ". [P.9].*

Generally-speaking, caregivers who are taking care of the T1DM children due to their parents' commitments are faced with some heavy challenges. Nonetheless, the only manner in which their problems could be easily solved pertains to the regular attendance of the professional health education. The reason being that while attending those check-up programs, they even can be taught how some of the pending problems might be tackled (Lawrence et al., 2015). On the other hand, it should also be remembered that taking care of the T1DM children could never be regarded as a one man's problem. The reason being that, it should include stakeholders like: neighbours, relatives and health professionals. This is to say that, where caregivers are left alone to look after the T1DM-patients, one could find the sick children being regularly readmitted at the hospitals.

In the light of the afore-said statements, it then further means that the other stakeholders should also be requested in pertaining to aiding the sick children. For example, in cases where an elderly grandmother keeps forgetting how some medications are used, young neighbours should be called to help. A trusted relative must also be requested to remind the elderly grandmothers about the exact check-up sessions' occurring dates. In this regard, the elderly caregivers should also keep on consulting the professional health workers so that they could give assistance to the grandmothers concerning how to follow some recommended instructions.

**Sub-theme 2.3: Responsibilities for care is assigned to another caregiver giving is sometimes assigned to grandparents due to parents' work commitments**

The pressure to make ends meet in the current economic climates poses a challenge for caregivers of children with T1DM. In the event of a caregiver working long and extensive hours, the grandparents are affected, one way or the other. One caregiver responded to the question posed like:

*"Yes, we are old, and our daughters cannot do any other thing, hence they are committed to their work. It seem, they do not trust the "outsiders" as far as the caring of their sick children is concerned, but only have their wholly trust in their grandparents." [P.10].*

Most of the parents today are working and cannot look after their children when they are sick or not. The reason being that parents are always committed to their work. For that matter, it is not like in the past, hence the parents could not look at their children by themselves (WHO, 2013). On the other hand, this is the reason why most of the T1DM children's parents cannot themselves look after their own sick children, owing to the work commitments. Furthermore, some parents work at faraway places, and could only come back home once per year or even twice in the whole year. In this instance, some might only come during the night and find their children asleep. It is therefore, thus, the reason why we often find only the grandmothers looking after the T1DM children today. It also sounds more likely to be true evidence regards to the high rate of the sick children' readmission at many hospitals. Ideally, most grandparents are so old that they always forget all the messages they may have been taught by the professional health care workers during the regular check-up programs. On the same note, others even go to the extent of not injecting their sick sons or daughters. Thus, those sick children end up being readmitted at the hospitals.

**Sub-theme 2.4: Relevant care to provide to Type 1-Diabetic child when experiencing complications**

In handling T1DM complications, elderly people are more experienced and knowledgeable on how to provide the required care. This was evident in the sessions as when a question was posed, a participant responded in the following manner:

*"Hey, my granddaughter! I always know what must be done, because the professional health workers have taught us how to take care of the sick children. Nevertheless, people might say what they may say, but the presence of the professional health care workers in hospitals, is a clearer fact that the professionals are indeed willing to give assistance to the caregivers when in need. In this context, it is also true evidence because on agreement, they could even offer service over the weekends; if requested." [P.11].*

It is important to note that everywhere where illnesses or any serious problems do occur, complications are often the order of the day. For example, a T1DM child could one day wake up during the night and keep on crying for a long time. By the way, strategies should be devised so that the caregivers must stay ever ready to implement them when such a situation might happen. Moreover, such an action does happen, the caregivers should know what next to do after such an action has just occurred. Furthermore, the effective and efficient caregivers are well-armed with the knowledge of knowing what to do, hence they are well-taught during the attendance of the regular check-up sessions conducted at most hospitals. However, even if a sick child could just cry, complaining of pain in the stomach, a well-prepared caregiver would obviously be in the know of what to apply to such a child. If a sick child can make whatever action which may warrant assistance, a caregiver would just know what to do unlike other family members.

**Sub-theme 2.5: Caregivers hold health education information to give to Type 1-Diabetic children under care**

Caregivers should always be encouraged to equip themselves with T1DM related health education to understand and give sufficient care to children under their care. In light of the importance of health education, one caregiver answered the posed question like:

*"We, as caregivers do agree that the presence of the regular health education information is, in fact, helping to take care of the T1DM children properly. Over and above, attending the check-up programs and not being taught anything would make the situation for us caregivers difficult." [P.12].*

Based on the views and suggestions in the previous paragraphs, it was stressed that the health education information, of course, plays a vital role in ensuring that T1DM children are well-cared for by every caregiver. Furthermore, if the health education information had not been there, the T1DM children would have unnecessarily died. From my own perception, it is the one that is assisting the perception of grandparents' caregivers to keep on enabling them to look after the T1DM children well. Essentially, it is using the health education that the caregivers are in the know of when utilizing the injection to a sick child. Who knows, what would have happened if the health education information was absent? Seemingly, it sounds to be more likely than true evidence that T1DM sick children would be readmitted on a high number or even died.

**Sub-theme 2.6: Consistent health education sessions to enhance knowledge of caregivers on the care of Type 1-Diabetic children emphasized**

Consistency in providing health education sessions was highlighted as a key requirement in caring for T1DM children. One caregiver recommended that:

*"Truly-speaking, it seems the word "health education" is rapidly mentioned so that the caregivers realise the importance of the health education offered to them by the health professional workers to us." [P.10].*

From every right-thinking person, it appears the ever regular health education is held so that the caregiver should be enhanced in knowledge of taking care of the T1DM sick

children in different homes. In support of these views, Cathey and Gaylord, (2014) cautioned that we must all appreciate the way in which the health education sessions are held, hence they are at least equipping the caregivers with a vast knowledge enabling them to wisely take care of the T1DM children properly. In this context, it might also be the reason that the rate of the T1DM patients seems to be going down, instead of moving upwards in many villages today. A caregiver mentioned that “health professionals also conduct educational session on some weekends”. This is done when some other caregivers would need some other advice during whatever time of the day. Nonetheless, caregivers are now in the liberty of knowing the health education rules like the palms of their hands, and the sick children would stay in safer conditions.

**THEME 3: Knowledge related to all factors of taking care of the Type 1-diabetic children**

Essentially, the health education provided by the health professionals to the caregivers is also of paramount importance, because it helps to always keep on remembering the rules to be followed while giving foods or even injecting the T1DM children some treatments. Nonetheless, caregivers should at least try to attend the check-up treatment programs to stay well aware of the precautions to be often followed while looking after the T1DM children. The other fact being that it is during those check-up exercises when the health professionals give themselves enough time to teach everything that should be followed or recommended for use, such as: physical activities, the correct diet, fruits, foods and how injections are to be applied to the sick children. To sum this up, it simply means that caregivers should without any failure try to attend health education lessons on a regular basis. Besides this, some elder caregivers are even taught how to seek assistance from the neighbours while being confronted with the reluctant or ignorant T1DM sick children who refuse to be injected by them (elder grandparents). In some instances, the relatives could also be consulted to assist the grandparents in carrying out the responsibilities on behalf of the elder caregivers.

Immediately after the introduction of the main theme, five sub-themes had emerged as followed:

1. Lack of knowledge related to care of Type 1-Diabetic children.
2. Lack of knowledge to signs, symptoms and complications of Type 1-Diabetic children.

3. Lack of knowledge related to diabetic diet.
4. Lack of knowledge related to medications and their side effects.
5. Lack of knowledge related to disease condition and all related factors.

**Sub-theme 3.1: Lack of knowledge related to care of Type 1- Diabetic children**

It was realised that many caregivers lacked knowledge on the care of T1DM children. This was evident in one of the caregiver's responses to the posed question who mentioned that:

*"Ok! I agree that I sometimes forget when and how my grandson is to be injected. There is a relative who keeps on reminding me about those applications of treatments. I also sometimes miss the days of attending the check-up programs. It is indeed hard for me to perform the duties of taking care of the T1DM-patients, but there is nothing I can do. This is one of the reasons why such patients are often admitted to hospitals." [P.8].*

Never mind why the elderly caregivers do sometimes forget as to when to utilize an injection treatment. The reason, therefore, might be that there are many factors that are to be followed or even applied during the taking care of the T1DM children. For example, caregivers have the duties of applying injections to the sick children or even bathing them before leaving for schools. In this context, this is not just done, but caregivers must know when or where the very injections should be applied. Apart from this, caregivers should also give themselves time to advise their patients about which foods or fruits to eat, and how the physical activities must be done. On the other hand, they must also be in the know that it does not matter whether their friends at school are eating something sweet and fatty, they should always refuse to take them. The reason being that, those who are eating have not yet been forbidden, hence they are not yet patients. The T1DM children are to always abide by the instructional rules as prescribed by either doctors or dieticians (Lawrence et al., 2015). On the contrary, many sick children especially those looked after by the elderly grandmothers, end up not given the right treatments or even not receiving the intended treatment due to forgetfulness. Nonetheless, some of them are always being readmitted at the hospitals.

**Sub-theme 3.2: Lack of knowledge related to signs, symptoms and complications of Type 1-children.**

In stressing the importance of health education, one area that is still lacking was related to the level of knowledge caregivers had about the signs, symptoms and complications of T1DM in children. During the interviews, one caregiver answered the posed question in the following manner:

*"No one can fairly put the blame on the professional healthcare workers as far as the taking care of the T1DM patients is concerned. These are the types of people who keep on making good explanations on how the sick children are to be treated while taking care of them. Furthermore, it enables the caregivers not to even panic when seeing signs and symptoms which lead to complications happening. The main reason behind this being that they know what to do and when, in terms of treating their sick children. However, the fair blame in this case, could be rightfully put on the caregivers themselves. After teaching us during the professional health session programs, they give us a chance to ask questions if we have missed the other points of their explanations." [P.12].*

Taking into consideration the quoted extract from the above paragraph, it confirms that professional health workers are indeed giving themselves enough time that is aimed at helping the caregivers to remain thinking of the treatment to be given to their patients. Despite this, the caregivers go to an extent of not offering the proper treatment to their patients due to forgetfulness.

Besides this, while blaming them, we should not forget that some of those elderly grandmothers did not even proceed to further studies educationally during their times. Irrespective of having gone so far educationally, some could not even write their names while asked. In addition to this, knowing the time during which a medicine must be used or how a certain treatment is to be used, is not an easier task to the elderly caregiver. On the other hand, it then goes without saying that the T1DM children that are being taken care of by the young mothers seem to be in the safer hands. These young mothers often know when and how to offer their patients the needed treatments. In this regard, caregivers are often given a thorough knowledge pertaining how and when they should respond to either a symptom or complication that may emerge at the very time. Caregivers are time and again being taught by the professional health workers on how

and when to make a treatment to their patients (Dhada and Blackbeard, 2019). Ideally, the blame of mishandling the patients' treatment, may sometimes be levelled against the caregivers (grandparents) due to their continuous forgetfulness.

**Sub-theme 3.3: Lack of knowledge related to diabetic diet**

The issue of diet had been stressed throughout the interview sessions. The knowledge on the suitable diet for children with diabetic was stressed. During the interviews, one caregiver highlighted the statement below:

*"Children are children, and nobody could predict their reactions well. A granddaughter, while still young used to obey the prescribed diet rules, but later ate the forbidden foods and fruits while with friends at school. Hmmm! The re-admission at the hospital is the result thereof." [P.15].*

Van Erk-Koivisto (2017) once commented that: "To make an error is human and to forget is divine." In fact, no-one can truly claim to be perfect in life, except our Holy God in heaven because He does not make an error." Since the beginning of this section of the study, blames after blames have been labelled against the elderly caregivers for some valid reasons. Regarding the T1DM rules, the sick children could also be rightfully blamed. For example, it is only after those sick patients have grown to the ages of 9 to 10 years old that they start to refuse being injected by the grandmothers. To our surprise, those patients would have all along been treated by them correctly. In such an instance, who is to be blamed? On the one hand, one finds that after the caregivers have been taught about the diet rules, they keep on teaching the sick patients at least on a daily basis. On the one hand, one finds that the sick children later ignore or neglect everything they might have been taught. For example, while at school with their friends who are not sick, they start to eat or drink the forbidden foods and fruits. More importantly, it then further compels one to conclude that caregivers are full of knowledge at such an instance, but the sick children are not willing to abide by the doctors and dieticians' rules. In addition to this, some sick children could come back home being carried by their friends from schools or playing places, after having eaten the forbidden foods or fruits in agreement with their peers' compulsion.

**Sub-theme 3.4: Lack of knowledge related to medications and their side effects**

It was realized that many caregivers had limited knowledge relating to the medication and treatment of T1DM. Responses were often however similar in nature. One of the caregivers responded in the following manner:

*"Young T1DM-patients could be hardly controlled with regards to how the prescribed health rules should be used. As I am speaking now, the bigger boys from a neighbouring family do help me when I intend to inject my grandson hence, he keeps on refusing to be injected. He now prefers tablets rather than an injection. However, it remains the same, hence time and again, he is being readmitted at the hospital." [P.13].*

Consequently, it seems to be a fact that whenever any person is sick or feeling some pains somehow, medication or even injection should be used by him or her so that the healthy conditions are revived. Furthermore, with the caring of the T1DM disease-patients, things appear to be somehow as young children can only cry as a form of communication during the administering of the insulin injection period (Deeb, 2017). To one's surprise, at the age of 9 to 10, they might even refuse to start being injected by their caregivers. In such an instance, caregivers would have no other alternatives, but to take those sick sons or daughters to professional health workers, so that they could later inject themselves.. On the other hand, asking for assistance from other people could not be well-recommended, in case those relatives or are absent.

On the contrary, the T1DM patients appear to prefer taking in of tablets rather than injections. By the way, some sick children even go to the extent of asking them tablets instead of injections, because they are used to tablets. In this regard, this usually happens after the caregivers may have forgotten to give them medications on time. Those sick children do usually forget that ignoring or neglecting being injected has some side effects towards their daily health, and could lead to being readmitted at the hospital.

**Sub-theme 3.5: Lack of knowledge related to disease condition and all related factors**

Caregivers have seen that it helps to consult a medical practitioner as an avenue to get information about the disease condition and other related factors pertaining to T1DM in

children. The issue of support coupled with the desire to do more was revealed in the following caregiver's response:

*"Yes, it is true that the T1DM-young patients cannot easily be controlled after they have grown up, in terms of deciding how medications should be used correctly. As I am speaking now, the neighbours bigger boys do help me when I intend to inject my grandson. The reason being that he now keeps on refusing to be injected by me, but he prefers mostly to use tablets rather than to be injected. However, it remains the same thing, hence he is often admitted at the hospital." [P.11].*

Having knowledge pertaining as to how and why one has decided to become a caregiver involves a lot of things. For example, before one may become a caregiver, she must have knowledge of what kind of medication is to be given to a sick child and the type of injection to be applied to such a patient. The issue of attending the check-up programs appears to be of paramount importance, hence they enable the caregivers to gain knowledge of looking after the T1DM patients well. For example, in cases where a sick child could just wake up and cry during night, the caregiver must simply know the type of medication to be given to such a patient. However, it is during such a time when a caregiver must know which medication and how it is administered before taking the patients to either a clinic or hospital.

Besides this, they are taught the physical activities to exercise so that they could use them properly aiming at keeping those sick children well (Lawrence et al., 2015). For example, a T1DM child who keeps on showing signs of weakness could get healthier by undertaking regular physical training. In addition to this, a sick child must be always warned to refrain from eating sweet or fatty foods, including fruits. The main reason behind this being that continuation of either eating or drinking the forbidden fruits and foods, might result in them being admitted to the hospital (Lawrence et al., 2015).

**THEME 4: Challenges experienced by caregivers during the provision of care to Type1-Diabetic children**

Caring for a child with diabetes mellitus-disease often has a negative effect on the mental health of caregivers and other family members. Furthermore, this is the other issue that differentiates this pandemic disease (T1DM) from the other type of diseases, because

besides the diabetic-sick children, it also affects those who are taking care of them (caregivers). For example, if a diabetic child can be readmitted for some couple days at the hospital, an elder grandparent could also end up being admitted to the hospital due to either stress or depression caused by the absence of the grandson or daughter' (Yaqoob, Khan, Khemani, Ul-Haq, Rafiq & Iftikhar, 2018). On the other hand, other caregivers who have received either family support or social support are found to experience mild depression and more than half of them have no anxiety at all. The views or suggestions that have been given already clearly influence one to take a decision that the T1DM children, besides the caregivers, should in normality be supported by the other family members. For example, in cases where a small boy thought of refusing to be injected by an elderly grandparent, other members while at home, should warn him not to do such actions. The reason being that it could further lead to him being readmitted to the hospital for several times unnecessarily. The other challenge might even come up, in cases where an elderly caregiver can then forget where and when to inject the very patient. Nevertheless, the same sick child may not be injected for a few days. On the other hand, the same might apply to a point when a sick child might eat the forbidden foods and fruits. Such an action might without any further doubt also be admitted due to stress or traumatic conditions she could have been involved in.

After the analysis of the main theme, sub-themes emerged as followed:

1. Lack of adherence to scheduled clinic and medication instructions.
2. Poor understanding of medication and health instructions.
3. Low level of caregivers' literacy.
4. Poor care performance from caregivers.
5. Factors leading to primary caregivers releasing roles to secondary caregivers.
6. Lack of adherence to diabetic diet, medication instructions and health education.
7. Fear of administering insulin injection to children.

**Sub-theme 4.1: Lack of adherence to scheduled clinic and medication instructions**

The participants indicated that they rely on clinics and hospitals to collect medication. However, failure to adhere to the prescribed medication may result in the readmission of some T1DM children. Similarly, other caregivers wait until the development of complications rather than adhering to their scheduled dates for routine check-ups. During

the interviews, one participant said*: "Ok! Yes, I have been looking after my daughter's sick child since birth, she has been quite adherent to the prescribed foods and fruits to eat but started to ignore them at the age of 10 years. By the way, this leads her to be always being readmitted at the hospital."*

Time and again, Type 1-Dabetic children are often being readmitted to the hospitals due to a failure to adhere to the scheduled foods and medication instructions. Furthermore, who should be blamed for such a failure? This is to say that, both caregivers and the so-called sick children (DM-patients) should also be blamed. The reason being that both somehow or somewhere fail to abide by the prescribed instructions as taught by the doctors and dieticians. For example, in cases where the caregiver is an elder grandmother, she might also forget to inject the sick child or even give the T1DM patient the wrong medication. On the same note, this may also lead to the very child becoming sick or sometimes be readmitted to the hospital. However, this serious action might occur after an elderly caregiver has failed to adhere to the rules taught to her by the professional health workers.

On the one hand, a sick child could be taught or even warned by the caregiver how to follow the eating or drinking rules but eats and even drinks while with friends (Sparapani et al., 2012). Over and above, Sparapani et al. (2012) suggested that such serious mistakes of not abiding by the prescribed instructions provided by the professional health workers are ignored or neglected by the sick children while in the presence of their peers. Moreover, this may result in such a sick child resorting to sweet and fatty foods or fruits (Patrick and Nicklas, 2005). By the way, a sick child can also be taught how to inject himself or herself but starts to ignore it while reaching the other ages (from 9 to 10 years old). In such a way, that type of a sick child may also ignore the right time for applying an injection or could even last for some days without doing it.

Consequently, that could lead the caregiver grandmother to become more and even stressed. For that matter, if such a situation is not taken care of, it might drive a caregiver to be admitted at the hospital for no apparent reasons. In short, both a sick child and the caregiver may, of course, be blamed for being the cause of some readmission cases. The only cause of such actions might be that both would have failed to adhere to the prescribed instructions from the professional health workers.

**Sub-theme 4.2: Poor understanding of medication and health instructions**

Caregivers of children with T1DM may find it challenging to adhere to the medication and instructions prescribed by health care professionals. Similarly, confusion with the prescribed medical and health care practices may arise to the lack of understanding. This was evident as one caregiver highlighted the following remarks:

*"Hmmm! I think the whole blame should be put on me. Yes, I did not go any far educationally, because I left schooling at the very lower standards. Furthermore, I stayed at a family of people who were not even properly educated. Truly-speaking, I can now not even write my name, because I did not get a chance to make practice in terms of writing. I always attend the check-up programs where the professional healthcare workers teach us how to apply medications and follow the health rules. However, immediately thereafter, I would have forgotten everything but my relatives helped me many times. I sometimes also forget to offer my patient the right medications. Eish! Eish! Things are bad but there is nothing that I can personally do. The issue is lack of knowledge in relation to the use of medications and remembering the health rules."*

From the afore-mentioned statements**,** still concentrating on this section of the study, most caregivers do have a poor understanding of medication and health instructions as posed by the professional health workers from hospitals. Furthermore, the reason behind this being that many of them belong to the past ages, where they were not forced to continue with education but compelled to engage into earlier marriages before they could reach the real ages. For instance, amongst those caregiver grandmothers, some of them fall under the old age category. In the light of the above-mentioned statements, the idea that some of them are illiterate is true, because they have left schooling at their early ages. Nonetheless, some of them not being able to even read or write their names is an undeniable truth. Alright, one may find at least all of them attending the check-up programs regularly and also being taught by the professional health workers seriously. At the end of the day, those caregivers usually end up not being able to use the given medications properly. Having been taught that physical activities should be done at least one day in a week, one would find the caregivers not even following those rules. This, in fact, means that such ignorant actions may lead to some detrimental effects in the future of the sick child as time goes on. The main reason behind that, being that physical exercise, which enables a sick child to be healthy, was not done.

Furthermore, some caregivers may offer their undivided attention to a sick child due to being used almost every day only once per week. Who knows, such a bad practice could have a serious impact on the very child's health conditions. In some instances, caregivers do offer the sick children some wrong foods or fruits to use, after having experienced a confusion of knowing which one to give to them (Dhada and Blackbeard, 2017). Additionally, Dhada and Blackbeard (2017) suggested that the reason could be nothing-else but lack of adequate knowledge on the side of the caregivers per se. Still on the same note, adopted while taking care of the T1DM children, the request of the neighbours, relatives or even the professional workers to help the caregivers while looking after the sick children might be of vital importance, if regularly used.

**Sub-theme 4.3: Low level of caregivers' literacy**

Caregivers have realized that health education was beneficial to their experience with caring for children with T1DM. Low levels of literacy were revealed as one of the challenges leading to poor health care being provided to the children under care. This was evidence as the following statement was mentioned by another participant during the interviews:

*"Hey! My granddaughter, I also agree with the fact that the blame of whatever happens during the caring of the sick children should not be solely put on the shoulders of the very sick patients but simply on us, hence we are, of course, old and mostly suffer from forgetfulness."*

Suffice it to say that there are also other factors that could lead the caregivers not to do their work well, while looking after their sick children at their homes. Despite all the other types of poor performances that caregivers might be involved in, some other factors that also occur, are forgetfulness and the fear of injections which seemed to be the main effect during the caring of the T1DM children by the caregivers.

Over and above, the lower levels of education from the caregivers' side, including the forgetfulness syndrome, are some of the real factors that hinder the caregivers from doing their caring of the sick children well. Some caregivers may offer their undivided attention to a sick child due to being used almost every day only once per week. Who knows, such

a bad practice could have a serious impact on the very child's health conditions. In some instances, caregivers do offer the sick children some wrong foods or fruits to use, after having experienced a confusion of knowing which one to give to them. Additionally, the reason could be nothing-else but lack of adequate knowledge on the side of the caregivers per se (Stallwood, 2006). Still on the same note, adopted while taking care of the T1DM children, the request of the neighbours, relatives or even the professional workers to help the caregivers while looking after the sick children might be of vital importance, if regularly used. Thus, the issue of the lower levels of education on the side of the caregivers indeed have a serious impact on the way they look after the sick children under their care (Stallwood, 2006).

**Sub-theme 4.4: Poor care performance from caregivers**

It is still a challenge for many caregivers to provide the necessary health care practices and habits in the caring of children with diabetes. These challenges often create a compromising situation to both the caregiver and the child when caring and treating diabetes. The below statement is evidence on the need for proper care-taking of children with T1DM:

*"Yes, Ok! I am going to defend myself, but the truth is that we both make mistakes. For example, a caregiver does sometimes give a patient the wrong medicine. On the other hand, the patient also eats the forbidden foods or fruits after being forced by the other peers. Hmmm! We all do whatever we can to help each other so that the patients stay healthier."*

Mistakes after mistakes are being made not only by one person, but by both caregivers and the sick children per se. By the way, this pertains as to how the Type 1-Diabetc children must be taken care of by the caregivers in different homes. For example, one may discover that some caregivers may give a sick child wrong medication due to forgetfulness. Due to this reason, the sick son or daughter may wrongly be offered a medicine to heal a certain pain, but ends up not successfully healing them, hence wrong medicine will have been offered. Furthermore, an instance does also happen where an illiterate grandparent could inject the sick patient on the wrong part, using such as a compromise of yielding a sick remedy for his or her illness now. On the other hand, a grown-up sick child may take in a wrong medicine as a compromise for having done the

right thing in relation to his or her caregiver. From mthe researcher's perceptive, it simply leads one to an opinion that some mistakes are committed by both the caregivers and sick children, as a compromise to getting rid of the sick child's remedy. However, it could also be a reminder that those mistakes are not intentionally done, but only as a compromise to even try and abide by the T1DM-patients' speedy recovery perceptions. Suppose a caregiver sees a sick child just crying, she could take any kind of medicine at her disposal and offers it to the sick child as a fact of taking care of the patient concerned. One could be forced to ask a question, like: "Is this the right form of taking care of the sick child? The answer to this posed question, could be correctly to truly-given, by a big "'Yes ', hence she may have that as a compromise to let the sick child finally cool up. Regardless of all the examples or suggestions so far about the topic under study, it means mistakes after mistakes are usually made, by both caregivers and the sick children as a compromise to let the patients stay ever healthier (Streisand and Monaghan, 2014).

**Sub-theme 4:5: Factors leading to primary caregivers releasing roles to secondary caregivers**

Caregivers do not understand that they can manage and care for children with diabetes by simply following the prescribed caregiving responsibilities. Since many children rely on the medication that is provided by the hospital, it becomes a problem when they experience complications at home due to caregivers not fulfilling their roles. This was confirmed by a caregiver who mentioned that: "*Yes, when looking after the T1DM-patients, both the primary and secondary caregivers should work together (caregivers and professional health caregivers). We regularly attend check-up programs where professional caregivers teach us rules for diet and making exercises. I think we should respect each other's roles while looking after the T1DM-patients. Ok! We should then work together as a solution towards securing the lives of those patients*."

Looking after the T1DM patients is not an easier task, but a very difficult one, which also needs more hands (more people) while doing it. The reason being that this adage simply literally means that unity is strength, and many people can ever work well, rather than only naturally. To be more precise and sticking to the topic under study, it further includes the fact that caregivers might do their caring duty properly well, if they could work together with the other professional health workers. On the other hand, it only means it could be possible, if the caregivers visit the check-up sessions regularly where they could be

assisted through the gaining of adequate knowledge concerning the caring of the sick children (Kobus and Imiela, 2015). From my own perception, it seems caregivers do not intend to do this in time as they only waited until a T1DM illness problem surfaced. Yes, it is, of course, a reality that the secondary caregivers (health professional workers) are indeed helping them in terms of solving the T1DM patients' ailing conditions. Ideally, it should often be realized that problems will keep on happening to an extent that caregivers could start looking for other help from the health professional workers (Dhada and Blackbeard, 2019). For example, after a caregiver can keep on fearing to inject her T1DM patient as explained by the health professional worker during the check-up programs. In this instance, it means that the service of another co-worker is, in reality, always needed. The reason being that nothing could sound possible, unless a person who does not suffer from forgetfulness and is a professional health worker, can be used.

Moreover, it also appears that if the professional health workers have been used at such a pace, many unnecessary deaths of our young generation would have been avoided. Bearing in mind that the secondary caregivers (doctors, nurses and dieticians) are the best stakeholders to be easily used by the caregivers during the looking after of the T1DM –patients, wherever they are, hence they appear to be always in a position of the required knowledge (Helgeson et al., 2008). In a nutshell, taking care of the different ideas and suggestions of how the caregivers should use their secondary caregiver's further shows one that such a practice could play a vital role in letting the T1DM-patients be healthier.

**Sub-theme 4.6: Lack of adherence to diabetic diet, medication instructions and health education**

Non-adherence to prescribed medication regimens is common in patients with caregivers of diabetic children due to the dietary and medication instructions which are taken lightly by caregivers. The following caregiver reiterated the importance of adhering to medical instruction which prevents further complications and hospital readmission. In answering the posed question, the interviewed participant replied that: "*A large group of the T1DM children do not usually adhere to the diabetic diet, medication instructions and health education, which could actually lead them to some terrible complications while looking after the sick children at their homes. Some sick children even end up being readmitted at the hospitals for no apparent reasons for several days"*.

For that matter**,** it lets the innocent sick children be admitted to the hospitals or clinics for a long time, which also consumes their schooling hours unnecessarily (Lawrence et al., 2015). Furthermore, the T1DM-patients may adhere to diabetic diet rules while still young but started to ignore them while at their adolescent ages (Seckold, 2019).

Despite that, the sick children are the ones who will stay healthier or be cured after the use of whatever medication. After experiencing the problems with the application of an injection to the reluctant sick child, a caregiver could request assistance from the professional health workers, who could teach him or her how to apply an injection by himself. As we all know, children are children and will stay the same at whatever place they are found. Still on the same note, such a sick child could not intentionally skip some days without using the recommended instructions while trying to hide the caregiver in whatever way. In some days to come, who will be the sufferer in such an event? In honest fact, the reason being that such a sick child might even come back home being carried by his friends and in an unconscious state. That such an unconscious sick child could result in being readmitted at the hospital after pleasing his peers by eating or drinking the forbidden foods. After being discharged from the hospital, the very sick child would try to adhere to the prescribed diet for some couple of days, but later changes while in the presence of his or her peers.

All in all, primary caregivers could only realise that the sick child is not obeying the diet instructions after looking at the conditions the child would come back displaying. Nevertheless, some do not even mind about the incident of being brought home in an unconscious atmosphere or being carried by friends. What would have happened if those friends were not there, is none of their business. By so doing, this could also lead to grandparents becoming traumatized or even depressed to an extent of being admitted to the hospitals due to the worries about the lovely sons and daughters' conditions. However, such an incident may happen after the misuse of the wrong medicines and the sick children' refusal of taking in the recommended injections as recommended by the professional health workers. What is the use of such an action? Who is to suffer most at the end of the day? The correct answer is that the sick children themselves, will at the end of the day be readmitted at the different hospitals for no apparent reasons.

**Sub-theme 4.7: Fear of administering insulin injection to children**

Some caregivers mentioned that it is not easy to apply the prescribed medication with emphasis on the injection type of medication. The fear of hurting the child receiving the injection often creates reluctance in following the prescribed medication. Hence one caregiver mentioned that: *"Yes, honestly-speaking, I am looking after my daughter's son since his birth. I did not go far away with schooling, but I am always afraid to inject my patient. I am usually assisted by my neighbours or relatives. On the other hand, my patient is afraid of the injection but only prefers mostly the taking in of tablets. Hmmm! It is indeed a problem, but there is presently nothing I could do".*

More significantly, the action of fearing the giving or receiving injections is itself shaped in a dual structure which leads to either a problem or challenge (Dhada and Blackbeard, 2019). The main reason being that it is not only the sick children who fear being injected but also their caregivers, hence they are not sure whether what they are doing is right or not. To sum this up, it seems the caregivers do not know the application of the injections well, because they grew up without experiencing such an event (Dhada and Blackbeard, 2019). In this regard, the point that they are of lower levels of education in terms of using either medications or the application of injections to their patients with T1DM-disease could be the main cause. On the other hand, those sick children appear to be fearing the application of injections since their births. In addition to this, when every care is conducted, be it in a hospital or clinic, if the injections are applied; one would always hear the sick children crying at the top of their voices. In this regard, it then indeed forces one to simply conclude that any right-thinking person should never further argue why the sick children do always cry while they are being injected (Howe et al., 2011).

The other reason is that children are indeed afraid of the injections, whether the bigger ones or smaller ones. On the other hand, caregivers are also afraid to inject their patients. This further appears to be a great challenge; hence caregivers are to inject or give medications to the sick children at least all the time (Barnard, et al., 2010). Additionally, the caregivers are compelled to carry out all the treatments to their patients, despite whether they have enough knowledge or not. Nonetheless, the researcher observed that some sick children are readmitted to the hospitals after their caregivers have given them the wrong medications or applied the injections on the wrong parts of their patient's bodies. Arising from their fore-going examples, it clearly reveals that the fear of using

either the injections or lacking enough knowledge of which and how certain medications must be used remains a traumatic challenge specifically to the caregivers(Howe et al., 2011; Dhada and Blackbeard, 2019). By the way, it also drives one to also realise that fearing of giving or receiving the treatment by both sides appears to be a serious challenge to both caregivers and the sick children.

## 4.4. CONCLUSION

Over and above, this section of the study had presented the collected data using the interviews (face-to-face) and an observation from the 14 sampled participants, so that the readers might understand it well. Therefore, the other important point was that the participants have been composed of either elderly-grandmothers and young mothers selected from the caregivers of the T1DM-patients, who are getting treatment from Tshilidzini Referral hospital, within Vhembe District, Limpopo Province. Similarly, the data analysis and interpretation strategies were discussed including the data analysis instrument to be used before the interpretation process could take place. Prior findings will also have been developed before being discussed in detail as to be done in the following section. In the next section of this study, the findings that would have emerged from this part should be identified and discussed. Additionally, the collected data will be properly linked to the findings, recommendations and a conclusion with other related studies, including the theoretical framework that underpins this study.

# CHAPTER 5

# LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

## 5.1 INTRODUCTION

This section in its innermost presents a summary of the findings based on the responses and findings of the study. The chapter presents a summary of the research project together with the limitations, recommendations and conclusions of the findings. Similarly, the recommendations and conclusions are drawn from the findings, which were presented as main themes and sub-themes detailed in the previous chapter.

## 5.2 LIMITATIONS OF THE STUDY

Gibson and Brown (2012) also defined the term 'limitations' as referring to the act of preventing something from happening in the way it should have occurred. Furthermore, this also refers that such a thing should have happened in the way that the doer has been expecting it. In the context of the study, the research is limited to the Vhembe District of the Limpopo Province. Therefore, the results cannot be generalised to other districts hospitals in the Limpopo province. The primary reason for conducting the study in the Vhembe District was linked to a higher referral rate to Tshilidzini referral Hospital recorded from the other six district hospitals. The researcher explored the knowledge and experiences of the caregivers of children with T1DM. The study was also limited to the number of respondents who were willing and available to be interviewed. Recruiting the participants was limited in the caregivers living at faraway places were faced with transportation challenges.

## 5.3 RECOMMENDATIONS

The following suggestions were recommended based on the developed themes of the findings:

### 5.3.1 Nursing education and training

- The current nursing curriculum should be developed to incorporate home-visits in order to understand the current challenges faced by caregivers and to assist caregivers with their challenges relating to diabetes mellitus, especially in the

context of T1DM in children. This approach will assist caregivers to cope and equip themselves with appropriate skills to maintain a good quality of life for the children under their care.

- The nursing module content could be modified to include a practical element were training nurses are given an opportunity to educate caregivers of children with T1DM on the proper caring requirements and techniques.
- Professional development objectives for professional nurses can incorporate short courses to further develop their knowledge and skills to deliver more health education to caregivers of children with T1DM when they come for their regular check-up appointments.

### 5.3.2 Nursing practice

- The other 6 district hospitals that refer children with T1DM to the Tshilidzini Referral Hospital should at least have one health care professional at the facility specifically focusing on non-communicable diseases.
- Nursing staff should be granted routine access to public facilities and institutions within the Vhembe district to disseminate information about T1DM education, prevention, and care to the youth and elderly citizen who are likely to be caregivers of children with diabetes mellitus.
- Awareness campaigns on diabetes should be conducted in the various hospitals in the Vhembe district in a form of pamphlets which are distributed to caregivers. These pamphlets could include posters drawings of food that should be consumed, as many caregivers of children with T1DM are not well literate. The pamphlets could also incorporate other caring practices like ‘to do’ activities that could assist caregivers with their experience in caring for these children.
- More professional training needs to be provided to Home-based carers in relation to the symptoms of T1DM and how to monitor blood glucose, so they can do home visits regularly and effectively. The additional training can include information on the nature of the disease, the various diabetes self-management behaviours and positive and negative consequences of not adopting health recommendations. This educational training may take place individually or in a group setting.
- Dieticians could be present during the regular check-up attendances, so that they could continue teaching carers about the diet rules, with the aim of assisting them somehow against the T1DM.

### 5.3.3 Nursing research

- The provision of a research budget from the Provisional Department of Health for more research to be conducted at all levels could assist in finding more methods and solutions to the challenges posed by diabetes provincially and nationally.
- Generalisation and benchmarking from other developing and developed countries needs to be realised in order to mitigate the re-admission and increase of new T1DM cases.

### 5.3.4 Areas of further research

- Future research should focus on exploring the challenges faced by caregivers of diabetes patients, in the context of both type 1 and type 2 diabetes mellitus in order to draw a meaningful case study.
- Other studies can focus on predisposing factors that influence the rate of diabetes mellitus cases from a rural and urban setting.
- Researchers could also conduct a similar study in different districts, cultural contexts and age group in order to comprehensive findings

## 5.4 CONCLUSIONS

In a nutshell, the relationship between the caregivers and their T1DM-patients could be easily revived if they could follow the prescribed rules well. Furthermore, it then also means that the T1DM-patients must properly listen to the caregivers' advice. The reason being that they (rules) are coming from either their doctors or dieticians not from the caregivers as they might suspect. In addition to this, the patients should never refuse to obey the diet rules, hence it is for their own benefits. For that matter, refusing to be injected by the patients should also not be done, because it is important for their own bodies, and not for that of the caregivers. Additionally, the Department of Health should also come with the other strategy of forcing the patients to follow given rules when either eating or drinking. Finally, the T1DM-patients must refrain from causing troubles for their caregivers or doctors hence they still have the other diseases to attend to (Malaria and the pandemic COVID-19).

## 5.5 SUMMARY

This chapter presented a summary of the findings (results) gathered using the face-to-face interviews and an observation. All in all, this had enabled them to be simply analysed by using Tesch's (8-steps) data analysis method which best- suited the study, hence the researcher had chosen a qualitative approach for data collection. In this context, the developed findings had discovered that the caregivers for the T1DM-patients usually run short of transport money in order to attend the regular check-up programs which are conducted at Tshilidzini Referral hospital within Vhembe District, Limpopo Province. Another matter of great concern which emerged during the findings, was that caregivers do regard T1DM-disease as an epidemic disease. The reason being that it usually led to the patients running short of glucose in the blood (insulin), which results in the patients experiencing the higher sugar-diabetes rate. At the end of the day, such patients would be admitted to the hospitals. By the way, when caregivers are left alone, they become stressed, depressed or even traumatized which results in them also being admitted. On the other hand, when those patients are not admitted they would also keep on worrying about their admitted grandsons or daughters, which later led them to being admitted. However, if the T1DM-patients had known this, they would have stopped troubling the caregivers while looking after them, hence are also 'moving patients' in disguise. In fact, old people are prone to suffering from the other types of diseases, because some of their body systems are no longer having power.

More importantly, in this very chapter, the serious issue of the T1DM-patients becoming reluctant or even ignorant in following the diet rules was also addressed. The reason being that the majority of them do not want to obey the diet rules, and they intend to eat whatever they are interested in eating as patients. However, the caregivers advise them no to eat sweet or fatty foods, but while they are with their peers they start eating or drinking the forbidden foods. Essentially, the issue of staying in isolation will also be seriously discussed, as it lets the very person continue worrying or even deciding to commit some bad actions unnecessarily. For example, most people who commit suicide are known for staying alone while at their homes. Consequently, this study's main aim is to get rid of the consequences that result in the relationship between the caregivers and T1DM-patients becoming sour.

From the researcher's point of view, after the good findings (results) would have been developed, recommendations would then follow. The reason being that findings always come first before the recommendations. If a researcher could speak of making recommendations prior to the findings (results), what will he or she be making those recommendations from? The problem in this very study, seemed to be concerning many stakeholders, and not only the caregivers. For example, after the T1DM-patients had been discharged from the hospitals, doctors and dieticians teach them how to follow the instructions in terms of eating or drinking as 'patients'. While they are at their homes, caregivers also advised them about the important instructions, but they kept on ignoring or even neglecting such warnings. To effectively succeed in tackling the issue of ignoring or neglecting the rules pertaining to either eating or drinking by the young T1DM-patients, working in unity seems to solve this serious problem. This literally means that people must work in unity, hence where there is unity, success always prevails. Moreover, to put into context, if doctors, dieticians, the caregivers and the Department can start working together, the acute problem concerning the young T1DM-patients' unbecoming behaviours may be solved.

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# ANNEXURES

## Annexure A: Letter to Request Permission to the Provincial Department of Health

P.O. Box 6380
Thohoyandou
0950
05 June 2019

Limpopo Province
Department of Health
Private Bag x 9302
Polokwane
0700

Dear Sir/Madam

**LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH.**

**I, Margaren Ndou**, a postgraduate student doing a master's degree in nursing at University of Venda hereby request permission to conduct research in Vhembe District Limpopo Province, South Africa. The topic of the study is “Experiences of Caregivers regarding homecare of children with Type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa”.

The purpose of this study is to investigate experiences of Caregivers regarding homecare of children with Type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa. Complete anonymity and confidentiality was guaranteed to the participants. No names will be required. No rewards will be given to respondents as a result of

participating in the research. For more information, feel free to contact the researcher at +27 79 487 3071, email address: margerenn@gmail.com.

I hope that my request will be taken into consideration

Yours faithfully

_____

Ms Margaren Ndou

**Annexure B: Letter to Request Permission to the Vhembe District Department of Health**

P.O. Box 6380
Thohoyandou
0950
05 June 2019

Vhembe District
Department of Health
Private Bag x 5009
Thohoyandou
0950

Dear Sir/Madam

**LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH.**

**I, Margaren Ndou**, a postgraduate student doing a master's degree in nursing at University of Venda hereby request permission to conduct research in Vhembe District Limpopo Province, South Africa. The topic of the study is “Experiences of Caregivers regarding homecare of children with Type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa”.

The purpose of this study is to investigate the experiences of Caregivers regarding homecare of children with Type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa. Complete anonymity and confidentiality was guaranteed to the participants. No names will be required. No rewards will be given to respondents as a result of participating in the research. For more information, feel free to contact the researcher at +27 79 487 3071, email address: margerenn@gmail.com.

I hope that my request will be taken into consideration

Yours faithfully

_____

Ms Margaren Ndou

**Annexure C: Letter to Request Permission to the Hospital**

P.O. Box 6380
Thohoyandou
0950
05 June 2019

Vhembe District
Department of Health
Private Bag x 924
Shayandima
0945

Dear Sir/Madam

**LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH.**

**I, Margaren Ndou**, a postgraduate student doing a master's degree in nursing at University of Venda hereby request permission to conduct research in Vhembe District Limpopo Province, South Africa. The topic of the study is “Experiences of Caregivers regarding homecare of children with Type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa”.

The purpose of this study is to investigate experiences of Caregivers regarding homecare of children with Type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa. The Researcher will obtain the records and schedule appointments of the caregivers from Tshilidzini Referral Hospital, and make appointments to visit the caregivers at the homes with the aim of data collection.

The main purpose of collecting data at home is to observe how T1DM management or home caring is being conducted. Complete anonymity and confidentiality is guaranteed to the participants. No names will be required. No rewards will be given to respondents as a result of participating in the research. For more information, feel free to contact the researcher at +27 79 487 3071, email address: margerenn@gmail.com.

I hope that my request will be taken into consideration

Yours faithfully

_____

Ms Margaren Ndou

**Annexure D: Letter of Information and Informed Consent**

**RESEARCH ETHICS COMMITTEE**

**UNIVEN Informed Consent**

**Appendix D**

## LETTER OF INFORMATION

**Title of the Research Study**: Challenges faced by caregivers regarding homecare of children with type 1 diabetes mellitus within Vhembe District of Limpopo Province, South Africa.

**Principal Investigator/s/ researcher** : Ms Ndou M

**Co-Investigator/s/supervisor/s** : Supervisor: Dr. R. Tshililo
Co-Supervisor: Dr. S.N. Raliphaswa

**Brief Introduction and Purpose of the Study**:
Worldwide, Diabetes Mellitus Type 1 is a devastating condition for both the diagnosed and the caregiver. These changes drastically affect caregivers in rendering the required homecare. Vhembe District in particular has been experiencing a rise in the number of children who are readmitted with T1DM.
The purpose of this study is to investigate experiences of caregivers regarding homecare of children with type 1 diabetes mellitus within Vhembe District of the Limpopo Province.

**Outline of the Procedures**: (*Responsibilities of the participant, consultation /interview /survey details, venue details, inclusion/ exclusion criteria, explanation of tools and measurement outcomes, any follow-ups, any placebo or no treatment, how much time is required of participant, what is expected of participants, randomization/ group allocation*).

Before data is collected, the researcher will provide information to the caregivers regarding the purpose of the study, so that they can willingly sign the informed consent forms. All willing caregivers who wish to share their experience regarding homecare of children with T1DM will be awarded an opportunity to do so through an interview session. The interview will be conducted in English or the language the participant feels free to express themselves to assure comfort during the interview. The interviews will last for approximately 45-60 minutes and will be held in an arranged private room. An unstructured interview will be conducted. One broad opening question will be asked, namely, ''What are your experiences regarding homecare of children with T1DM?"

**Inclusion of criteria**

- Caregivers whose children have been re-admitted with T1DM.
- Caregivers who are willing to participate in the study.

**Risks or Discomforts to the Participant**: (*Description of foreseeable risks or discomforts for participants if applicable e.g. Transient muscle pain, VBAI, post-needle soreness, other adverse reactions, etc..) No risk of discomfort is expected as the study only involves interviews.*

**Benefits**: (*To the participant and to the researcher/s e.g. Publications*)
The caregiver will gain knowledge on how to care for children with T1DM at home. In relation to the participant, the caregiver will benefit on how to improve their home caring for children with T1DM. Similarly, the researcher can share and recommend other home caring guides that will improve the caregiver's experience based on the literature reviewed and researcher's medical experience with T1DM. Also, the Department of Heath will also benefit because the hospital costs of managing complications associated with T1DM might be reduced.

**Reason/s why the Participant May Be Withdrawn from the Study**: (*Non-compliance, illness, adverse reactions, etc. Need to state that there will be no adverse consequences for the participant should they choose to withdraw.)*

*They will also be informed of their right to withdraw from the study if they are not satisfied with the proceeding. The researcher also has the right to inform all the caregivers that*

*participation in the research study is not compulsory, but each caregiver participates in her free-will.*

**Remuneration**: No remuneration

**Costs of the Study**: None

**Confidentiality**: Confidentiality and privacy of any personal information that may relate to the participants during the data collection will not be shared. Only the researcher investigators and the institution will have access to the data collected.

Prior to the administering of interviews, the participants will be assured that their confidential and private information will be ethically upheld before or after investigation. The information provided by the participants, and all forms of documentation received from them will be secured from the public domain. The reason behind this being that the dignity and integrity of the participants should still be sustained even after the investigation

**Research-related Injury:** No injury is expected to occur during the data collection sessions.

Persons to Contact in the Event of Any Problems or Queries:

(Supervisor and details) Please contact the researcher, NDOU M (telephone 0794873071), my supervisor, Raliphaswa, N.S (tell no 0646808947.) or the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

**CONSENT**

Statement of Agreement to Participate in the Research Study:

- I ……..hereby confirm that I have been informed by the researcher, Ms Margaren Ndou about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: SHS/20/PDC/32/3107.
- I have also received, read and understood the above written information (*Participant Letter of Information*) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant Date Time Signature

**I, …… …… ……. ……**

Ms Margaren Ndou herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher

**……** Date**……** Signature**……**

Full Name of Witness (If applicable)

…… Date …… Signature……..

Full Name of Legal Guardian (If applicable)

…… Date…… Signature……..

**ANNEXURE E: The Recorded Responses of The Caregivers Pertaining to Their Experiences Regarding the Homecare of The T1DM-Patients**

**The posed question to each participant:**

What are your experiences regarding homecare of children with Type 1-diabetes mellitus?

Below are the responses that have been gathered and recorded from the interviewees per interview:

**Key:**

**Researcher: R**

**Participant: P**

The main question that all the participants answered was: **"What are your experiences regarding homecare of children with Type 1-diabetes mellitus?"**

**PARTICIPANT 3: A young mother looking after a 4 years and 6 months old sick child.**

R: Hi there! Good afternoon. How are you?

P: A real good day and I am feeling fine.

R: Do you still remember me? I am thinking so, because I have told you that I will come in uniform.

P: Yes, you are welcome. Feel free to speak to me. Sorry, let us firstly wash our hands, and there is the sanitizer there!

R: Yes, I have also become free now, hence you have welcomed me. I have only one question to ask you, and it says: "What are your experiences regarding homecare of children with Type 1-diabetes mellitus?"

P: I am looking after a 4 years and 6 months old sick female child, who is my own child. I am an unemployed parent but do sell some goods usually eaten by most young children. By the way, this does not enable me to attend the check-up treatment programs every time. I also can buy things for my child. What troubles me is that my child has become sick while still young. I always suspect old people should stay suffering from different diseases while still living. Mmm… not a young child, like mine. Hallelujah! Amen.

R: I understand your problem, but it can be easily solved

P: Ok, how will it be solved? Hey man! She has been ill for so long, but I have tried everything and failed.

R: Yes, it will be easily solved if you can keep on understanding this chronic disease's conditions well, and follow them, the pending problems will then be solved. Furthermore, understanding the lifestyle conditions of this chronic disease will be of help to you.

P: What lifestyle are you referring to? She then starts to cry.

R: Hmmm… Cool up, do not cry. I will make it a point that I will organise such experts in this disease who will come and help you to understand it better. As from today, keep on saving the little money you get in order to save your child's life. Money does not start being many but even the small amount could become more after being saved.

P: Yes, I understand that you will try to get those experts in terms of this disease to assist me. While my child was admitted, the healthcare workers tried to teach me about my ailing child's conditions.

R: Ok, I understand what you are saying. After saving the little money from the little profit you get, you will then be able to regularly attend the heck-up treatment programs.

P: Yes, as a biological mother, it is not easy to understand such a situation, because it looks like a life sentence condition to either a child or mother.

R: Yes, I see. These conditions need some understanding especially by a parent.

P: Eish! I understand but it needs patience and God's assistance, truly-speaking I am failing to understand these conditions by myself.

R: I can also understand what you are saying, but this condition needs one's understanding.

P: Yes, I also understand it, but…

R: Never mind, the healthcare workers will keep on teaching you about your child's treatment during both admission and check-up time programs. On the other hand, the saved little will soon become alright for attending the check-up treatment programs. By then, the existing problem will become solved bit by bit. Try it sister, it will help you, because it has already saved others like you before.

P: Oh! Yes, healthcare workers do the teaching but the pain keeps on troubling me every time, when my child is admitted. As you have advised me, I will save the little I get in order to attend the check-up treatment exercises you are saying have helped others, believing that they definitely also assist me as you have said.

R: Alright! Thank you for allowing me to interview you. Be rest assured that the assistance from the healthcare workers is going to be given to you.

P: Thank you very much. I am also looking forward to receiving your assistance as soon as possible.

R: Many thanks. I will go back well after the welcoming approach I received from you.

## ANNEXURE F: Ethical Clearance Certificate

ETHICS APPROVAL CERTIFICATE

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
**Ms M Ndou**

STUDENT NO:
11514210

PROJECT TITLE: **Experiences of caregivers regarding homecare of children with "Type 1" diabetes mellitus within Vhembe District of Limpopo Province, South Africa.**

PROJECT NO: SHS/20/PDC/32/3107

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

| NAME | INSTITUTION & DEPARTMENT | ROLE |
|---|---|---|
| Dr AR Tshililo | University of Venda | Supervisor |
| Dr NS Raliphaswa | University of Venda | Co - Supervisor |
| Ms M Ndou | University of Venda | Investigator – Student |

Type: Masters Research
Risk: Risk to humans, animals, environment, or a sensitive research area
Approval Period: July 2020 – July 2022

The Human and Clinical Trails Research Ethics Committee (HCTREC) hereby approves your project as indicated above.

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

- The project leader (principal investigator) must report in the prescribed format to the REC:
  - Annually (or as otherwise requested) on the progress of the project, and upon completion of the project
  - Within 48hrs in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
  - Annually a number of projects may be randomly selected for an external audit.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the REC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date; a new application must be made to the REC and new approval received before or on the expiry date.
- In the interest of ethical responsibility, the REC retains the right to:
  - Request access to any information or data at any time during the course or after completion of the project,
  - To ask further questions; Seek additional information; Require further modification or monitor the conduct of your research or the informed consent process.
  - withdraw or postpone approval if:
  - Any unethical principles or practices of the project are revealed or suspected.
  - It becomes apparent that any relevant information was withheld from the REC or that information has been false or misrepresented.
  - The required annual report and reporting of adverse events was not done timely and accurately,
  - New institutional rules, national legislation or international conventions deem it necessary

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE
Date Considered: July 2020

Name of the HCTREC Chairperson of the Committee: Prof MS Maputle

Signature: MSMaputle

Director Research and Innovation

Signature: .....GIEEkosse..... 05 August 2020

UNIVERSITY OF VENDA
OFFICE OF THE DIRECTOR
RESEARCH AND INNOVATION
2020 -08- 0
Private Bag X5050
Thohoyandou 0950

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060
"A quality driven financially sustainable, rural-based Comprehensive University"

## ANNEXURE G: Permission to Conduct Research

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH**

Ref : LP2020-08-012
Enquires: : PF Mahlokwane
Tel : 015-293 6028
Email : Kurhula.Hlomane@dhsd.limpopo.gov.za

Margaren Ndou

**PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES**

Your Study Topic as indicated below;

**Experiences of caregivers regarding homecare of children with "Type 1" diabetes mellitus within Vhembe District of Limpopo Province, South Africa**

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
   a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
   b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
   c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   e. The approval is only valid for a 1-year period.
   f. If the proposal has been amended, a new approval should be sought from the Department of Health
   g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Head of Department

14/09/2020
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

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LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

# DEPARTMENT OFHEALTH
# VHEMBE DISTRICT

Ref: S5/6
Enq: Muvari MME
Date: 17.09.2020

Dear Sir/Madam NDOU M

**Permission to conduct a research on the**
**"EXPERIENCES OF CAREGIVERS REGARDING HOMECARE."**

1. The above matter refers.

2. Your letter received on the 17.09.2020 requesting for permission to conduct a research is hereby acknowledged.

3. The District has no objection to your request.

4. Permission is therefore granted for the study to be conducted within Vhembe District. You are expected to submit the results to the District.

5. You are however advised to make the necessary arrangements with the facilities concerned.

Wishing you success in your endeavors.

..... 18/9/2020
CHIEF DIRECTOR: DISTRICT HEALTH DATE

Private Bag X5009 THOHOYANDOU 0950
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623
Old Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962 2373, (015) 962 227

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# TSHILIDZINI HOSPITAL ETHICS COMMITTEE

## Memorandum of understanding

Tshilidzini Hospital Ethics Committee with Ndou Morgan ..... at their meeting resolved to sign a Memorandum of Understanding after the two parties have agreed on the following information:

1. Reasons for making a research at Tshilidzini hospital.
Tshilidzini Hospital is a referral hospital of Vhembe district. Many patients of Diabetic are referred to Tshilidzini
2. What will be the benefit of the entire hospital community out of your findings?
The hospital will try to do strategies that can make the community to have Health education on radio
3. Who to meet in conducting your research
Mother leaders
4. What do you do with your findings?
To do recommendation so that other research can do a part further role
5. We will require the hard copy of your research
Yes
6. We do not anticipate any information to be divulged to all types of media without the knowledge of the Ethics Committee and Hospital Board.
7. Memorandum of understanding should be signed by both parties.

Signed by: .....

30/9/2020
Date:

Researcher

## ANNEXURE H: Letter from Language Editor

+27 83 215 6445
Rosemarys.pes@gmail.com
1 Richards drive
Midrand, 1684

04 FEBRUARY 2021

To whom it may concern

**RE: LANGUAGE AND TECHNICAL EDITING**

This letter serves as confirmation that the thesis by Margaren Ndou, a master's in nursing candidate titled "**EXPERIENCES OF CAREGIVERS REGARDING HOMECARE OF CHILDREN WITH TYPE 1-DIABETES MELLITUS WITHIN VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA**" was edited by Rosemary's Proofreading & Editing Services.

Kind Regards

R MALULEKE (LANGUAGE EDITOR)