ASSESSING FEAR OF HYPOGLYCAEMIA AMONG PARENTS OF CHILDREN WITH TYPE 1 DIABETES MELLITUS

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DECLARATION

I, Kitsiso One Madumetse, declare that this research is my own work. It is being submitted in partial fulfilment of the Masters of Science Degree in Nursing at the University of the Witwatersrand, Johannesburg. It has not been submitted previously for any other examinations at this university or any other.

Signature: KMadumetse

Date: 4. 11. 2017

DEDICATION

I dedicate this research report to God Almighty who has been with me through this journey.

I also dedicate this report to my mother Ntebogang Marilyn Wantwa, who has been my source of inspiration; her phone calls which I received just to encourage me kept me going and her prayers helped me not to lose hope but to look up and hold on to the end; when the road seemed dark and uncertain she taught me to hold on and look unto God hence there cometh my strength. Thank you, mom and dad, for your prayers.

My husband who has been my pillar of strength: I left him with our three daughters Gofiwa, Ranewa and Amantle, all under the age of 7 years, 600 km away, to come and pursue my dreams in Johannesburg South Africa; he has been a mother and a father to my daughters. I say thank you; without you it could have been a very lonely journey.

To my three daughters, thank you girls! I become emotional when I think how you managed to pull through without me by your side; you made me a strong woman and I learned to lean on God for all my needs. I pray that as I submit this research report my time will be dedicated to you.

To my family, thank you for encouraging me in all my pursuits and inspiring me to follow my dreams.

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I would like to express my appreciation to the Botswana Government's Ministry of Health for their sponsorship of my further education.

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ABSTRACT

Introduction: Hypoglycaemia is the most widespread acute side effect of insulin therapy in individuals with type 1 diabetes mellitus. Severe hypoglycaemia can cause loss of consciousness, seizures, accidents or physical injuries, and even death. Given these severe consequences, it is almost inevitable for patients or their caregivers not to develop fear of hypoglycaemia. Fear of hypoglycaemia in children and their parents has not, thus far, been measured at diabetic clinics in South Africa.

Fear of hypoglycaemia among paediatric type 1 diabetes mellitus patients and their parents affects quality of life and adherence to diabetes management strategies. However, behavioural workshops can address and decrease such fears and therefore increase compliance with T1DM management programmes. An improved understanding of fear of hypoglycaemia should assist nurses running clinics to develop appropriate programmes to offer support.

Aim of the study: To assess fear of hypoglycaemia among parents whose children have type 1 diabetes mellitus.

Study objectives:

The objectives of the study were:

1. To identify aspects suggestive of worry about hypoglycaemia among parents whose children have type 1 diabetes mellitus, and
2. To determine the behaviours adopted by parents to prevent hypoglycaemia among children with type 1 diabetes mellitus.

Method: A descriptive and cross-sectional survey design was used to identify factors suggesting fear of hypoglycaemia among parents and the actions parents take to prevent hypoglycaemia. In this study the population comprises parents of type 1 diabetes mellitus children attending a specific diabetic outpatient’s clinic (N=140). The total population was used as a sample over a period of three months due to the limited population size. Fifteen (15) patients are pre-booked for clinic services every Monday from 08h00–13h00.

Only parents or guardians of children aged 3 to 18 years, diagnosed with type 1 diabetes mellitus and on insulin therapy, were considered eligible for the study.

Data collection: A self-administered Hypoglycaemia Fear Survey – Parent version (HFS-P) was used to collect data. Besides demographic data, the HFS-P’s data collection tool focuses on worry and avoidant behaviours, with a total of 25 questions scored using Likert Scales ranging from 0 (“never”) to 4 (“always”). The Worry subscale HFS-P (W) measures different anxiety-provoking aspects of hypoglycaemia. The Behaviour subscale HFS-P (B) measures behaviours used to avoid hypoglycaemia and its consequences.

The demographic data collected concerned parents’ ages, genders, marital status, employment status and levels of education.

Data analysis: Data was analysed using STATA version 13.1. Data analysis was divided into descriptive and inferential statistics.

Results: Parents of type 1 diabetes mellitus children are more likely to experience fear of hypoglycaemia and to practise negative behaviours to avoid hypoglycaemia, which eventually impact negatively on glycaemic control. Nurses should be able to intervene and teach such parents how to manage type 1 diabetes mellitus correctly.

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LIST OF ABBREVIATIONS

CHSF	Children Hypoglycaemia Fear Survey
FoH	Fear of hypoglycaemia
HSF	Hypoglycaemia Fear Survey
HFS-P	Hypoglycaemia Fear Survey Parent Version
T1DM	type 1 diabetes mellitus
WHO	World Health Organization

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This chapter provides background information related to a study conducted on fear of hypoglycaemia (FoH) among parents of children with type 1 diabetes mellitus (T1DM). This chapter furthermore presents the rationale for conducting the study, the activities carried out to answer the research question, and a brief outline of the ethical considerations.

1.2 BACKGROUND TO THE STUDY

Type 1 diabetes mellitus (T1DM) is considered the most common metabolic disorder in children (Pate, Rutar & Battelino et al., 2015). According to the World Health Organization (WHO), an estimated 65 000 children below 15 years of age develop type 1 diabetes mellitus each year.

The exact cause of T1DM is not known. However, it is associated with insulin deficiency, which is caused by the autoimmune system erroneously destroying insulin-producing pancreatic beta cells (Pate et al., 2015).

Pate et al. (2015) describe T1DM as a “family condition” as it has an effect not only on the child’s life but on the lives of the whole family. This is because firstly, young children depend on their parents for management and support (Zysberg & Lang, 2015). Secondly, the intensive treatment regimen places greater demands on the person responsible for taking care of the child as well as the rest of the family members living with the child.

Jaser, Linsky and Grey (2014) described the treatment regimen for T1DM as a complex and demanding process requiring regular monitoring of blood glucose levels, control of carbohydrate intake, and frequent insulin administration.

In a study conducted by Whittemore, Jaser and Chao et al. (2012), caring for a child with T1DM was described as a time-consuming, overwhelming and distressing experience, causing family disruption in the sense that whatever is planned must take into consideration the “diabetic child” in the family.

Kratzer (2012) conducted a study to investigate the barriers to coping with diabetes in Ghana, finding that financial burden was one of five key barriers to coping with T1DM, along with issues with primary care facilities, schools, formal support and access to information.

Hypoglycaemia is the most common complication of insulin therapy in individuals with T1DM (Ly, Maahs and Rewers et al., 2014). Hypoglycaemia is defined as an abnormally low plasma glucose concentration that exposes the individual to harm at a blood glucose level of 3.9 mmol/L or less. This cut-off value has been debated, with the score currently hovering at a value of 3.5 mmol/L (Cryer, 2016).

Jaser et al. (2014) explained that parents of young children with T1DM often develop a sense of “constant vigilance” and “continuous responsibility” to maintain metabolic control and prevent episodes of hypoglycaemia.

According to Lohan, Morawska and Mitchell (2015), parents may develop a high level of fear and worry that a child could have a hypoglycaemia episode while unaware, because the child might not recognize and respond to symptoms of hypoglycaemia.

Gonder-Frederick, Nyer and Shepard et al. (2011) stated that in addition to being life-threatening, effects of severe hypoglycaemia include lack of coordination, physical injuries, accidents, fits or convulsions, and bouts of unconsciousness. Given the possible consequences of severe hypoglycaemia, it is likely that people affected develop fear of hypoglycaemia (FoH) at some point.

The concept of fear of hypoglycaemia has been well researched. The interest in FoH research is related to the behaviours adopted due to worry or anxiety, as these behaviours have been associated with poor glycaemic control and parental emotional distress (Haugstvedt, Wentzel-Larsen and Aarflot et al., 2015). Similar findings were reported in a systematic review conducted by Barnard, Thomas and Royle et al. (2010).

The results in Barnard et al. (2010) further showed that fear of hypoglycaemia also affected both parental health and quality of life. They found that parents of T1DM children experience negative consequences to their well-being because of fears that their child could develop severe hypoglycaemia.

In the United States, Gonder-Frederick, Fisher and Ritterband et al. (2006) conducted a study exploring predictors of fear of hypoglycaemia (FoH) in T1DM adolescents and their parents. The results showed that anxiety and frequent episodes of severe hypoglycaemia were significant predictors of FoH. Patton, Dolan and Henry et al. (2008) conducted a study among parents of younger children with T1DM showing that parents of these children reported a higher level of fear of hypoglycaemia.

Research studies related to fear of hypoglycaemia commenced in the late 1980s. The Hypoglycaemia Fear Survey (HFS) was the first questionnaire developed and used among adults with diabetes (Cox, Irvine and Gonder-Frederick et al., 1987). Besides demographic data, the HFS collected data regarding worry and behaviours, scored using Likert Scales. The Worry subscale (HFS-W) measured different anxiety-provoking aspects of hypoglycaemia. The Behaviour subscale (HFS-B) measured behaviours used to avoid hypoglycaemia and its consequences.

The majority of the studies conducted since the 1980s were aimed at developing and testing the psychometric properties of the questionnaire as well as adapting it to different age groups.

The HFS –P was adapted for use among children with diabetes as the CHFS (Green, Wysocki and Reineck, 1990), and also for use among parents with diabetic children, using the Hypoglycaemia Fear Survey – Parent version (HFS-P) (Clarke, Gonder-Frederick and Snyder et al., 1998). Gonder-Frederick et al. (2011) reported that diabetic children as young as six could report their fear of hypoglycaemia reliably.

Shepard, Vajda and Nyer et al. (2014) explored the constructs of fear fundamental to the Hypoglycaemia Fear Survey for both parents and children. The results revealed “four similar factors” in both of the adapted surveys: the Behaviour Subscales measure different behaviours that attempt to “keep blood glucose levels high” to prevent hypoglycaemic episodes, and “other behaviours that attempt to avoid hypoglycaemia”.

The Worry Subscales measure different types of concerns related to hypoglycaemia such as “helplessness” and concerns about its “negative social consequences”.

1.3 PROBLEM STATEMENT

Fear of hypoglycaemia among T1DM patients or their guardians affects quality of life and adherence to the management programme, and can cause potential phobias. Evidence has shown that behavioural programmes can decrease fear of hypoglycaemia and therefore increase compliance with diabetes management programmes in patients at risk of developing, or with existing fear of hypoglycaemia.

Fear of hypoglycaemia among patients and their parents has not thus far been measured at a diabetic clinic in an academic hospital in Johannesburg. An improved understanding of FoH should assist doctors and nurses running the clinics to develop a behavioural programme to support patients and parents with fear of hypoglycaemia.

1.4 RESEARCH QUESTION

What are the features suggestive of fear of hypoglycaemia among parents whose children have type 1 diabetes mellitus and the precautions taken by parents to prevent hypoglycaemia and the effects?

1.5 AIM OF THE STUDY

The aim of the study was to assess fear of hypoglycaemia among parents whose children have type 1 diabetes mellitus and the behaviours they adopt to avoid hypoglycaemia and the effects.

1.6 RESEARCH OBJECTIVES

The objectives of the study were:

1. To identify aspects suggestive of worry about hypoglycaemia among parents whose children have type 1 diabetes mellitus.

2 To determine the behaviours adopted by parents to prevent hypoglycaemia among children with type 1 diabetes mellitus.

1.7 SIGNIFICANCE OF THE STUDY

Fear of hypoglycaemia among patients and their parents has not, thus far, been measured at any diabetic clinics in South Africa. An improved understanding of FoH should assist the nurses managing the clinic to develop a behavioural programme that will give support to patients and parents with fear of hypoglycaemia.

1.8 OPERATIONAL DEFINITIONS

- **Hypoglycaemia** is an abnormally low glucose concentration in one's plasma that can cause harm, specifically between 3.5 mmol/L and 3.9 mmol/L and lower in children (Cryer, 2016; Lehecka, Renukuntla & Heptulla, 2012).
- **type 1 diabetes mellitus (T1DM)** is a “chronic metabolic disorder caused by an absolute or relative deficiency of insulin, an anabolic hormone” (Lamb, 2015). Insulin is made by the beta cells of the islets of Langerhans in the pancreas; any drastic reduction in these cells results in type 1 diabetes (i.e., insulin-dependent diabetes mellitus).
- **A parent** in the context of this study is the biological mother or father or a relative or caregiver in charge of managing a T1DM child at home.
- Only parents of **children between 3 and 18 years old** were considered eligible for this study.
- **Fear** of hypoglycaemia is assessed by measuring aspects suggestive of worry and the behaviour adopted to prevent hypoglycaemia and the effects.
- **Worry** in this context is assessed by measuring the anxiety-provoking aspects related to hypoglycaemia
- **Anxiety-provoking** aspects in this study are all the features suggestive of hypoglycaemia that parents of children with diabetes are concerned with. Anxiety-provoking features could result in or lead to fear of hypoglycaemia.

1.9 OVERVIEW OF THE RESEARCH METHODOLOGY

- **Research design**

A descriptive and cross-sectional survey design was used to identify the aspects suggestive of fear of hypoglycaemia among parents of children with T1DM and the behaviours used to prevent hypoglycaemia and their effects.

- **Research setting**

This study was conducted in an academic hospital in Johannesburg, Gauteng Province, South Africa. For this study the specific setting was the Children's Diabetic Outpatients clinic. Fifteen (15) patients are pre-booked for the clinic every Monday from 08h00–13h00. Patients are typically booked to come in once a month, and if their blood sugar is stable they are booked in once in two months.

- **Population and sampling method**

In this study the population included all parents of T1DM children attending the diabetic clinic (N=140). The total population was used as sample size over a period of three months due to the limited population size.

A non-probability convenience sampling technique was used to select eligible parents for the study.

As the focus of the study was on assessing fear of hypoglycaemia among parents of children with T1DM, only parents of children aged 3–18 years were considered for the study. The child had to have been diagnosed with T1DM and also had to be on insulin therapy. Only one parent per child was sampled.

- **Data collection**

Data was collected through a self-administered Hypoglycaemia Fear Survey – Parent Version (HFS-P) questionnaire (see Appendix E). The HFS-P is a questionnaire that was developed by Cox et al. (1987). It is a modified version of the original HSF survey for adults and is made up of three parts.

The first part of the data collection survey gathers demographic data.

The second part consists of two subscales using a five-point Likert Scale, where 0=never and 4=always. The first subscale has 15 items and explores factors suggestive of parents' worry about a child developing hypoglycaemia. The second 10-item subscale measures specific behaviour carried out to avoid hypoglycaemia.

- **Validity and reliability**

The hypoglycaemia fear survey instrument has been translated into 34 different languages. Adequate reliability of the original hypoglycaemia fear survey for adults by Irvine et al. (1994) indicated internal consistency ranging from .60 to .96 and test–retest reliability ranging from .59 to .76. In a study conducted by Gonder-Frederick et al. (2006), the Cronbach's alpha indicated adequate internal consistency at 0.89 for the total score, 0.76 for the behaviour subscale and 0.91 for the worry subscale. Adequate reliability was also reported for the HFS-P by Haugstvedt et al. with an internal consistency ranging from 0.72 to 0.89 (2015). In the current study the HFS-P questionnaire's internal consistency was checked using Cronbach's alpha coefficients from the pilot study and main study results.

- **Data analysis**

Data was entered on a Microsoft Excel spreadsheet for verification and coding thereafter was imported to "STATA" statistical software 13.1 for data analysis. Descriptive data was used for analysis of demographic data and inferential statistics for analysis of the behaviour and worry subscales.

1.10 ETHICAL CONSIDERATIONS

The following steps were implemented to make sure that this study was conducted based on acceptable and appropriate ethical standards.

1.10.1 Institutional permission to carry out the study

A clearance certificate (M160550) was issued by both the Human Research Ethics Committee of the University of the Witwatersrand (see Appendix A) and the Research and Postgraduate Committee of the Health Sciences Faculty of the Witwatersrand (see Appendix B).

Permission was also sought from and granted by the Chief Executive Officer of the participating institution (see Appendix C) as well as the author of the Hypoglycaemia Fear Survey Parent Version (HFS-P) (see appendices D and E).

1.10.2 Participants

To uphold the principles of voluntarism and anonymity, participants were given an information letter explaining the nature of the study (see Appendix G).

Agreeable parents were asked to complete the consent form (see Appendix H). The researcher observed ethical principles of beneficence, justice and autonomy to promote good and avoid harm for participants.

1.11 ORGANIZATION OF CHAPTERS

Chapter 1 introduces the study with an outline of the problem, research design and methodology.

Chapter 2: Presents the literature review conducted.

Chapter 3: Presents the research methodology.

Chapter 4: Presents the results and the discussion.

Chapter 5: Concludes the study, discussing its limitations and making recommendations for practice.

SUMMARY

This chapter has outlined the study’s background and rationale, including the problem statement and objectives. An overview of the research methodology and the ethical considerations has been presented.

Chapter 2 presents a review of the literature regarding diabetes mellitus in children, the complications thereof, and fear of hypoglycaemia among parents of children with type 1 diabetes mellitus.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter introduces the literature review conducted to explore and describe hypoglycaemia in children, complications thereof and fear of hypoglycaemia among parents of children with T1DM.

2.2 GLOBAL STATE OF DIABETES

The World Health Organization (2016) has reported that the total number of people living with diabetes mellitus increased from 108 million in 1980 to 422 million in 2014. In addition, the global occurrence of diabetes in adults 18 years of age and above increased from 4.7% in 1980 to 8.5% in 2014. Moreover, diabetes occurrence has been increasing very fast in the middle and low income countries.

In 2012, there were about 1.5 million diabetes-related deaths worldwide. A further 2.2 million deaths were caused by high blood glucose levels, nearly half of which claimed victims below the age of 70. The World Health Organization (2016) predicts that diabetes will be the seventh major cause of death by 2030. In sub-Saharan Africa, the prevalence of diabetes has increased according to the American Diabetes Association (2015).

In 2010, about 12.1 million people were suffering from diabetes in Africa; this figure was estimated to grow to 23.9 million by 2030 (Hall, Thomsen and Henriksen et al., 2011). However, it was already 25 million as of 2016 (Chutel, 2016).

The American Diabetes Association (2016) has reported that around 1.25 million American children and adults are living with T1DM. Maahs, West and Lawrence et al. (2010) recorded the occurrence of T1DM in children under 14 years of age in 50 different countries worldwide, totalling 19 164 cases, from a population of 75.1 million children (an estimated 4.5% of the world population in this age range).

Reddy, Ganie and Pillay (2013) reported 250 million diabetes patients worldwide, with half being T1DM children under the age of 15. The rate of T1DM is increasing worldwide at the rate of 2 to 5% per year, with roughly 200 more children diagnosed every day. Therefore, type 1 diabetes mellitus is increasing in all age groups worldwide, particularly in young children, and there is no published data on the incidence of T1DM in children in South Africa.

2.3 HYPOGLYCAEMIA

The American Diabetes Association (2015) defined hypoglycaemia as an irregularly low concentration of plasma glucose that can cause harm, occurring when blood glucose levels drop below 70 mg/dL (3.9 mmol/L). According to Ly, Gallego and Davis et al. (2009), hypoglycaemia is a notorious complication of insulin therapy in T1DM children.

The proposed five classifications of a hypoglycaemic episode as stated in Seaquist, Anderson and Childs et al. (2013) are as follows:

- Severe hypoglycaemia occurs when an individual requires the assistance of a second person to administer carbohydrates or glucagon.
- Documented symptomatic hypoglycaemia occurs when symptoms of hypoglycaemia are accompanied by a measured blood glucose level of less than 70 mg/dL (3.9 mmol/L).
- Asymptomatic hypoglycaemia occurs when there are no visible symptoms of hypoglycaemia, but the measured blood glucose level is less than 70mg/dL (3.9 mmol/L).
- Probable symptomatic hypoglycaemia occurs when symptoms are not accompanied by a measured lower blood glucose level, but are likely caused by blood glucose concentration of less than 70 mg/dL (3.9 mmol/L).
- Pseudo-hypoglycaemia is when a diabetes patient reports any symptoms of hypoglycaemia despite a measured level of blood glucose not less than 70 mg/dL (3.9 mmol/L).

Repeated and severe hypoglycaemia causes high anxiety and emotional trauma for patients and their families and lowers the likelihood of tight glycaemic control (Ly, Gallego and Davis et al., 2009). In addition, severe hypoglycaemia has been linked to a reduction in neuro-intellectual performance in T1DM children, especially in those diagnosed below the ages of five to six. Recurring hypoglycaemic seizures in young children can cause structural brain damage. Furthermore, severe hypoglycaemia may have an impact on other family members because of increased anxiety, sleep deprivation, increased hospitalizations and failure to maintain glycaemic control.

Gonder-Frederick et al. (2011) stated that severe hypoglycaemia can have life-threatening effects such as blackouts or fits, and can even cause death. Hypoglycaemia can also indicate severe illness of the organs, such as liver disease (hepatitis) or kidney disease, mostly because of the major role that these organs play in glucose production and maintenance of blood glucose levels.

Studies indicate that the danger of hypoglycaemia is elevated in patients treated with insulin (Kalra, Mukherjee and Venkataraman et al., 2013). Further evidence suggests that severe hypoglycaemia occurs in 35–42% of T1DM patients, and the rate of severe hypoglycaemia is between 90 and 130 episodes per 100 patient years. Kalra et al. (2013) stated that a UK hypoglycaemia study found that patients who had diabetes for longer durations (>15 years) experienced higher rates of severe hypoglycaemia than those with shorter durations (<5 years).

Patients with T1DM have an average of two episodes of symptomatic hypoglycaemia per week and one episode of severe hypoglycaemia per year (Shafiee, Mohajeri-Tehrani and Pajouhi et al., 2012). An estimated 2–4% of deaths of this population have been attributed to hypoglycaemia.

According to the World Health Organization (WHO) (2016), type 1 diabetes mellitus is characterized by deficient insulin production and requires daily administration of insulin. The cause is unknown so it cannot be prevented in current medicine. Scientists know that in most people with T1DM, the body’s own immune system, which is meant to fight harmful bacteria and viruses, mistakenly attacks the insulin-producing cells in the pancreas. Genetics may play a role in this process, and exposure to certain viruses may trigger the disease. If insulin treatment is not given then the individual cannot survive.

Kenny (2013) divided the symptoms of hypoglycaemia in two categories: neurogenic and neuroglycopenic. Neurogenic symptoms are caused by physical bodily responses to low glucose concentrations, e.g. trembling, anxiety, hunger and sweating, whereas neuroglycopenic symptoms indicate glucose deprivation in the brain and central nervous system, with stressful effects such as confusion, loss of consciousness, and even death in severe cases. Kenny (2013) emphasized that hypoglycaemia can have an undesirable impact on a patient’s wellbeing, preventing them from living a fulfilling life,

Shafiee et al. (2012) stated the following as causes of hypoglycaemia (low blood glucose) in diabetic patients: taking too much diabetic medication such as insulin and diabetes tablets; not eating enough food; missing or delaying a meal; exercising without taking necessary precautions; and drinking alcohol, which inhibits gluconeogenesis.

According to the American Diabetes Association (2015) and other sources (such as Vieira, 2012) the ideal treatment for hypoglycaemia is 15–20 grams of a fast-acting carbohydrate, as follows. The best options are glucose gels or tablets or glucagon. If these are unavailable, glucose or simple starches (carbohydrates) should be eaten, such as one of the following, listed in order of effectiveness: sugar, honey or corn syrup (1 tablespoon); a few smarties or squares of hard chocolate; 1/2 a cup of fruit juice or regular (not diet) soda (soft drinks); 2 tablespoons of raisins or other dried fruit, or 7 jellybeans. Chocolate bars with added cereals etc. are less suitable as they take longer to digest.

A study conducted by Seaquist et al. (2013) reported that the way a patient feels hypoglycaemia symptoms depends on how frequently the patient has experienced hypoglycaemia. Patients with recurrent hypoglycaemia often do not recognise the symptoms. The first symptom they experience is confusion, so they require assistance from a second person to identify and treat their low blood glucose. Such individuals are said to have developed “hypoglycaemia unawareness’. The American Diabetes Association (2015) emphasized that individuals must practise good diabetes control and must learn to detect the symptoms of hypoglycaemia and treat it early before it gets worse.

2.3.1 Hypoglycaemia in non-diabetics

In non-diabetics, hypoglycaemia is associated with ingestion of certain medicines such as quinine (used to treat malaria), sulfa drugs (an antibiotic), salicylates (pain relievers), pentamidine (used to treat pneumonia), alcohol, diseases affecting the liver or heart or kidneys, tumour in the pancreas, eating disorders, malnutrition, haemodialysis, and low levels of certain hormones such as cortisol, growth hormone and glucagon. Referred to as fasting hypoglycaemia, too much insulin in the blood can result in low blood glucose levels (Eckert-Norton & Kirk, 2013). Furthermore, hypoglycaemia is common in pre-diabetics, who experience insulin imbalance, as well as in patients who have stomach surgery that causes the food to pass into the small intestines quickly. Hypoglycaemia could also be associated with lack of an enzyme that causes food indigestion. These factors predispose patients to hypoglycaemia, referred to as reactive hypoglycaemia.

2.3.2 The problem of hypoglycaemia in children with T1DM

Whittemore et al. (2012) conducted a study on the "psychological experience of parents of children with T1DM" in which parents reported that having a child with T1DM was shocking and overpowering. Parents described feelings of desperation, guilt, frustration and grief after learning about the diagnosis and treatment needs of T1DM.

During the early stage of T1DM, the symptoms are non-specific; this can make the diagnosis of a child difficult because of symptoms that are similar to minor illnesses (Usher-Smith, Thompson and Zhu et al., 2015). Furthermore, several studies have indicated that children who experience delays in diagnoses usually present with diabetic keto-acidosis at first, which is a life-threatening complication of hypoglycaemia associated with poorly controlled long-term diabetes (Usher-Smith et al., 2015). Children newly diagnosed under the age of 6 years often have more episodes of hypoglycaemia, leading to cognitive dysfunction and brain abnormalities (Shafiee et al., 2012).

Young children depend on their parents daily for guidance and support with complex demands (Zysberg and Lang, 2015). According to Patton et al. (2007), caring for a young child with T1DM is complex because of the limitations of age; younger children are unable to express their feelings and communicate them to parents when they are feeling low. Therefore the burden of care is upon the parents to always be on guard for symptoms suggestive of hypoglycaemia in their children.

Children need to be able to recognise the symptoms of hypoglycaemia to prevent life-threatening health challenges. Common symptoms include unexplained anger, numbness in the arms and hands, sweating and nausea, confusion, and extreme hunger.

According to Levitsky and Misra (2016), a child’s hypoglycaemia must be managed according to the age of the child; infants (younger than one year) are fully dependent on their parents for daily management of their diabetes. They are at high risk for developing undetected hypoglycaemia because infants are unable to communicate their symptoms to parents, and the clinical signs are non-specific “poor feeding, lethargy and hypotonia”; usually infants with severe hypoglycaemia present with seizures or unconsciousness, which may lead to permanent neurological damage.

Lohan et al. (2015) also emphasized that management of T1DM in children depends on the age of a child; the younger the child, the more difficult management is, as children may refuse to eat, change their food preferences, and have irregular physical activity.

Toddlers (1–3 years old), like infants, depend fully on their parents for daily management and monitoring. They need frequent blood glucose checks because of their frequent food intake and high activity level (Levitsky and Misra, 2016). In addition it is difficult to differentiate normal developmental stages of behaviour and temper tantrums from hypoglycaemia-altered behaviour and tantrums, so parents must test blood glucose before ignoring a temper tantrum that may be a sign of hypoglycaemia.

Preschool and early school-aged children (3–7) can learn how to test their own blood glucose with the supervision of a parent, while remembering that they are still young and easily bored by performing the same task every day, so letting them test their blood glucose without supervision could lead to poor glycaemic control (Levitsky and Misra, 2016).

School-aged children (8–11) should be able to test their blood glucose and administer insulin injections themselves, with parent supervision; otherwise poor glycaemic control may occur (Levitsky and Misra, 2016). Unfortunately at this age, when children realize that their diabetes is a lifetime illness that will not go away, they may develop depression and anxiety. Children may feel different from their peers because of their diabetes and withdraw from social interaction. They need to be encouraged to participate in school activities and to develop normal peer relationships. Attending workshops such as “diabetes camps” helps children to adjust to their diagnosis as they are able to meet peers who are also diabetic and share information on how to manage their diabetes better (Levitsky and Misra, 2016).

Finally, adolescents are more independent and should be responsible for monitoring their own blood glucose levels and administering insulin; however they still need some parental supervision, otherwise poor glycaemic control could result. Due to peer pressure, adolescents may engage in risky behaviours such as alcohol intake, which is associated with severe hypoglycaemia, and they may also start smoking, which is a risk factor for long-term diabetic complications (Levitsky and Misra, 2016). In addition, adolescent girls may develop eating disorders as a way to lose weight, whether through fasting or self-induced vomiting, as well as failing to administer insulin, leading to poorer glycaemic control, frequent hospitalization and increased risk of microvascular complications with increased mortality rates.

According to Riddell and Hoppin (2015), regular exercise is important for children with T1DM, as exercise helps to protect against health risks; however, they emphasized that T1DM children must exercise under special supervision to avoid hypoglycaemia.

During and after physical activity, the risk of hypoglycaemia increases by 30 to 50% in children with T1DM. Exercise increases insulin sensitivity, and thus increases the risk of hypoglycaemia even when sleeping (nocturnal hypoglycaemia); this risk is high in children as they are more physically active.

Nocturnal hypoglycaemia usually occurs in the early morning hours from 2 to 3 a.m. It is important to test blood glucose levels at night, especially after vigorous exercise. (Riddell & Hoppin, 2015)

2.4 ASSESSING FEAR OF HYPOGLYCAEMIA

The Hypoglycaemia Fear Survey – Parent Version (HFS-P) is a tool used in most studies assessing fear of hypoglycaemia in parents of T1DM children (Shepard et al., 2014).

In a study by Patton et al. (2008), mothers of young children with T1DM reported more fear of hypoglycaemia than fathers (P=.006) with high scores on behaviour subscales (P=.001), but with no statistically significant difference between mothers and fathers on the worry subscale.

Mitchell, Hilliard and Mednick et al. (2009) reported that fathers had low levels of fear of hypoglycaemia. Again, in Patton et al. (2008) it was reported that parents who experienced greater FoH were more likely to have children that had experienced a hypoglycaemic seizure than the parents whose children had never experienced a seizure.

Furthermore, Clarke et al. (1998) added that mothers whose children had experienced unconsciousness had greater fear than parents whose children never experienced unconsciousness. Monaghan, Hilliard and Cogen et al. (2009) reported that mothers' fears were related to hypoglycaemic episodes that happened when their children were sleeping (p=.005) or at social gatherings. Most common fears reported in Patton et al. (2007) were a *"child having low blood glucose while asleep"* (63% participants) and *"child having low blood glucose when alone"* (46% participants).

2.5 PARENTAL PERCEIVED WORRY, STRESS AND COPING STATEGIES

A majority of articles have indicated depression, family issues, adherence responsibility and management of T1DM as major contributing factors to parents' worry and distress. Whittemore et al. (2012) expressed that having a child diagnosed with T1DM causes parents trauma as they must come to terms with "losing" a healthy child. The diagnosis also comes as a shock to the family, who must learn to understand the diagnosis and the demanding management of diabetes within a short period (Whittemore et al., 2012).

The treatment regimen for T1DM is difficult and demanding, needing frequent monitoring of blood glucose levels (at least 4 times per day), monitoring and control of carbohydrate intake, and frequent insulin administration (at least 3–4 injections per day).

This demanding regimen places great burdens on mothers who are often responsible for the majority of treatment management. Jaser et al. (2014) reported that mothers may have higher levels of worry when their children have a form of "hypoglycaemic unawareness", i.e., they do not have the ability to recognize and respond to symptoms of hypoglycaemia.

As the child gets older and start attending school, they can report their symptoms more clearly and start sharing the responsibility of diabetes management with their parents.

According to Barnard et al. (2010), new routines must be presented and maintained, new information learned, and management practices, time demands, finances, social support, stigma and concern for the future must all be balanced with achieving glycaemic control and quality of life for the child.

Learning to administer complex treatment and checking blood glucose, especially at night, result in more stress and burden (Shepard, Vajda and Nyer et al., 2014). Caring for a child has been described as a devastating experience requiring “constant vigilance” – a term meaning that parents must always be on alert to quickly recognise if their child is feeling low or high and act appropriately to prevent hypoglycaemia.

Several studies have shown higher maternal depression than paternal depression, with maternal depression linked to apprehensions about hypoglycaemia, life expectancy of the child, changes in family routines, and diabetes burnout (Jaser, Whittemore and Ambrosino et al., 2009).

Parents and children learn quickly that hypoglycaemic episodes are possibly dangerous and they participate in adaptive behaviours to treat hypoglycaemia prematurely (Barnard et al., 2010), such as eating large snacks at bedtime. Shepard et al. (2014) also emphasized that fear of hypoglycaemia in parents may be precipitated by previous history of a child being unconscious and having seizures.

Acute complications of hypoglycaemia include unconsciousness and seizures, causing worry and fear and diminished quality of life for the parent responsible for preventing such complications (Herbert, Clary and Owen et al., 2014).

Fear of hypoglycaemia may distract the parent’s ability to learn the significance of adherence to a diabetic regimen (Pate, Klemencic and Battelino et al., 2016) and may lead to poor glycaemic control. Parents may become stressed when their children start day-care/school (Herbert et al., 2014) as teachers are not trained in checking blood glucose levels, administering insulin and recognising emergency signs of hypoglycaemia, and in some schools where nurses are employed, they might only be there on certain days.

In the interests of caring for their child, employed parents may leave jobs that are far from their homes or alter their work schedule by changing work hours, while others may miss work frequently.

Over time, as parents get used to the daily management of T1DM, they adjust, develop schedules and gain confidence in their ability to care for the child (Barnard et al., 2010). Furthermore, literature has indicated that parents have identified family, spouses, friends, parents of other children with type 1 diabetes, and health care professionals treating the diabetic child as their main sources of support and strength. Having access to health care professionals and being able to ask them questions about their concerns, as well as learning to carry out the daily diabetes care required for their child, are both critical aspects for parents to cope.

Pate, Klemencic and Battelino et al. (2016) stated that fear of hypoglycaemia may distract from a parent’s ability to learn the significance of adherence to a diabetic regimen. Lack of adherence to a diabetic regimen as well as increased levels of fear may lead to parents adopting hypoglycaemia avoidance behaviours (Patton et al., 2007). Common hypoglycaemia avoidance strategies adopted by parents identified by Patton et al. (2007) include administering lower doses of insulin and feeding children without administering insulin. In addition Patton et al. (2007) mentioned that some parents may regularly overfeed their children, which over time could lead to obesity and greater insulin resistance. Furthermore, this behaviour may lead to higher blood glucose levels; prolonged high glucose levels can cause neurocognitive compromise in young children, which emphasizes the importance of teaching parents to maintain their children’s blood glucose levels at close to normal range.

2.6 SUMMARY

In this chapter, the literature on fear of hypoglycaemia among parents of children with T1DM was reviewed.

CHAPTER THREE

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

This chapter describes the research strategy adopted to identify aspects that worry parents of children with T1DM, as well as specific behaviours that parents adopt to avoid hypoglycaemia. The research methods are explained with reference to the setting, the sampling framework, the data collection procedures and the analysis processes. The measures taken to ensure reliability and validity, as well as protection of the participants' anonymity, privacy and safety during the research process, are also discussed.

3.2 AIM OF THE STUDY AND THE OBJECTIVES

The aim of the study was to assess fear of hypoglycaemia among parents whose children have T1DM and the behaviours they adopt to avoid hypoglycaemia and the effects.

The objectives of the study were:

1. To identify aspects suggestive of worry about hypoglycaemia among parents whose children have T1DM.
2. To determine the behaviours adopted by parents to prevent hypoglycaemia among children with T1DM.

3.3 RESEARCH SETTING

Brink, van der Walt and van Rensburg (2016) describe the research setting as a specific place or places where data collection is conducted.

The specific research setting for this study was the Children's Diabetic Outpatients Clinic (CDOC) at one of the academic hospitals in Johannesburg, Gauteng Province, South Africa. The children's diabetic clinic service is offered once a week on a Monday from

08h00–13h00. Fifteen (15) patients are pre-booked, either for their first time or for follow-up visits.

The Children’s Diabetic Outpatients clinic is managed by specialist doctors who consult with the patients, as well as by registered nurses who are responsible for managing the service and for caring for patients.

3.4 RESEARCH DESIGN

Once the research problem has been identified and the research question is formulated, the researcher adopts a research design. Brink et al. (2016) describe a research design as “a set of logical steps” that is used to guide the researcher in terms of accessing the population and information to be collected, analysed and interpreted.

This study made use of a descriptive and cross-sectional survey design to identify the features suggestive of fear of hypoglycaemia among parents of children with T1DM, as well as the activities adopted to prevent hypoglycaemia, and their effects.

3.4.1 Descriptive design

Brink et al. (2016) state that a descriptive design is not intended to establish a cause and effect relationship. However, descriptive studies are used for describing variables in order to answer a research question. Furthermore, descriptive designs are more appropriate for investigating concepts where no studies have been conducted on the phenomenon or where there is insufficient literature available.

Fear of hypoglycaemia is a concept that has been extensively researched and published. However, no studies have been conducted in the South African context on fear of hypoglycaemia in adults, children or parents of children with T1DM. For this reason a descriptive design was chosen for this study. Through a descriptive study, the researcher was able to identify factors that provoke worry, as well as the behaviours adopted by parents of T1DM children to prevent hypoglycaemia.

3.4.2 Cross-sectional study

A cross-sectional design is described as an approach wherein data is collected at one point in time or at a specific time. In contrast, a longitudinal design collects data from one group at different times (LoBiondo-Wood and Haber, 2006).

In the current study, data was collected only once, from parents who had brought their children to the Children's Diabetic Outpatient Clinic either for a first visit or for a follow-up visit.

3.5 RESEARCH METHODS

3.5.1 Population and sample

The population is the entire set of people who meet the characteristics required to be part of a study. On the other hand, a sample refers to a selected group of people who meet the specific requirements for inclusion in a study (Grove, Burns and Gray, 2013).

In the current study, the population comprised all the parents of children diagnosed with T1DM on insulin therapy who were attending the Children's Diabetic Outpatients Clinic (N=140). The total population was used as the sample size over a period of three months due to the limited population size.

A non-probability convenience sampling method was used to select parents eligible for the study. The selected participants were parents accompanying their children to the diabetic clinic during the period of the study. Selection of participants continued until the desired sample size was reached (Polit and Beck, 2012).

Since the focus of the study was on assessing fear of hypoglycaemia among parents of children with T1DM, only parents of children aged 3–18 years attending the diabetic clinic were considered for the study.

The first criterion used for selecting the participants was that the parents should be at least 18 years old. Secondly, they should be able to read and write in English, and thirdly, the child must have been diagnosed with T1DM and be on insulin therapy.

3.5.2 Data collection

3.5.2.1 Data collection instrument

Data collection is a systematic strategy for gathering information relevant to the research purpose and question of the study (Grove et al., 2013).

The Hypoglycaemia Fear Survey (HFS-P) questionnaire was initially developed for use on adults by Cox, Irvine and Gonder-Frederick et al. (1987). It is a three-part survey consisting of demographic aspects and two subscales.

The CHFS was adapted and tested for use on children by Green, Wysocki and Reineck (1990); Marrero, Guare and Vandagriff et al. (1997) and Clarke et al. (1998).

The HSF-P, for parents of children with T1DM, was adapted from the original version created for adult patients. It has three parts: the demographic section, a worry subscale comprising 15 questions with a score ranging from 0–60, and a behaviour subscale comprising 10 questions with a score ranging from 0–40. The HFS-P has been used and tested for validity and reliability in a number of studies (Irvine, Cox and Gonder-Frederick, 1994; Gonder-Frederick, Fisher and Ritterband et al., 2006; and Haugstvedt, Wentzel-Larsen and Aarflot et al., 2015).

A self-administered HFS-P (see Appendix E) was used for this study. The first part of the questionnaire requests demographic data including the caregiver's age, gender, marital status, education level, employment status and their relationship with the T1DM child, as well as the child's data, including age, gender, incidence of severe hypoglycaemia, presence of T1DM complications, and whether the child carries fast-acting carbohydrates.

The second part of the questionnaire consists of two subscales with a total of 25 questions. The worry subscale (HFS-P(W), which measures different anxiety-provoking aspects of hypoglycaemia and negative consequences, has 15 questions, while the behaviour subscale (HFS-P(B), which measures different types of behaviours used to avoid hypoglycaemia and the negative effects, has 10 questions.

The scores for each scale differ depending on the number of item questions. In a study conducted by Haugstvedt, Wentzel-Larsen and Aarflot et al. (2015), the researchers used a scale presented by Clarke et al. (1998), where the items were rated on a five-point Likert scale ranging from 1 (never) to 5 (always). The behaviour (HFS-P (B) and worry (HFS-P (W) subscale scores were computed by adding the items in the subscales. The total HFS-P score was obtained by adding the HFS-P (B) and HFS-P (W) subscale scores. The maximum was 50 score for the behaviour subscale, 75 score for the worry subscale, and 125 for the total score.

However, for the purpose of this study, a Norwegian version of the HFS-P questionnaire was used, with the administration and scoring sheet (Cox et al., 1987; Clarke et al., 1998) supplied by Dr Gonder-Frederick (see Appendix F). The Likert scale used had a range of 0 (never) to 4 (always). The behaviour and worry item scores were entered on the computer and scores added. The maximum was 40 for the behaviour subscale (HFS-P (B) and 60 for the worry subscale (HFS-P (W), with maximum 100 for the total score.

The scoring used in this study is based on the scoring below:

	Rating scale	**Number of items**	**Score range**
HFS-B	0–4	10	0–40
HFS-W	0–4	15	0–60

Mean scores were calculated and the sum scores were compared to the possible range of scores for each scale/subscale. Higher scores reflect greater fear of hypoglycaemia. A higher score on the behaviour subscale (HFS-P (B) reflects a greater tendency to avoid hypoglycaemia and/or its negative consequences. A higher score on the worry subscale (HFS-P (W) indicates more concern about episodes of hypoglycaemia and its consequences.

Subscale	**Low**	**Moderate**	**High**
Worry	0–20	21–40	41–60
Behaviour	0–13	14–26	27–40

3.5.2.2 Reliability and validity of the instrument

The significance of the outcome of the quantitative study results using an ordinal scale such as a Likert scale is dependent on the reliability and validity test results. Pietersen and Maree (in Maree, 2010) describe reliability as the ability of a tool to produce the same results each time it is used. On the other hand, validity refers to the extent the tool measures what it is intended for.

The instrument (HFS-P) has been translated into 34 different languages for use in different countries.

Adequate reliability of the original hypoglycaemia fear survey for adults by Irvine et al. (1994) indicated internal consistency ranging from .60 to .96 and test-retest reliability ranging from .59 to .76.

In a study conducted by Gonder–Frederick et al. (2006), the Cronbach's alpha indicated adequate internal consistency at 0.89 for the total score, 0.76 for the behaviour subscale, and 0.91 for the worry subscale.

Adequate reliability was also reported for the HFS-P with the internal consistency ranging from 0.72 to 0.89 (Haugstvedt et al., 2015).

In the current study, the HFS-P questionnaire's internal consistency was checked using Cronbach's alpha coefficients from the pilot study and the main study results.

3.5.3 Data collection procedure

The pilot study and main study data collection process commenced after permission was obtained from the Human Research Ethics Committee and the relevant hospital authorities as discussed in Section 3.7.

The researcher attended the Paediatric Outpatient Department on Mondays for data collection as the service is offered once a week. Upon arrival at the Diabetic Outpatient Clinic, permission was obtained from the sister in charge to speak to the parents.

All the parents of children with T1DM who were present in the Children's Diabetic Clinic were approached individually and given a separate information sheet, which explained the purpose and objectives of the study as well as eligibility for participation in the study (see Appendix G).

The participants were given time to read and understand the information letter before giving consent to participate in the study. In addition, further information was given related to how anonymity and confidentiality would be achieved and maintained.

On agreeing to participate, a separate consent form sheet was distributed (see Appendix H) to confirm their willingness to participate in the study.

The questionnaire was administered by the researcher to the parents during their waiting period. Participants were expected to complete the questionnaire and the researcher was available to clarify any areas that were not clear to participants.

Participants were reminded not to write individual identification information on the questionnaire (see appendix E) and were requested to return the filled in questionnaire in a sealed envelope to the researcher. The envelopes were kept in a sealed box.

A pilot study was conducted prior to the commencement of the main study on 18 July 2016. The pilot study aimed to simulate the main study.

The data collection questionnaire was used on five (5) participants, who met the inclusion criteria and were included in the study. Ethical considerations were followed.

Participants indicated that the language was understandable and no recommendations were made to change the language of the instrument. Each participant took an average of 10–15 minutes to complete the questionnaire.

The purpose of the pilot study was to determine the effectiveness of the instructions and the ability of the parents to comprehend and answer questions, as well as to assess how much time was needed to complete the questionnaire. Results of the pilot study were not included in the main study.

3.6 DATA ANALYSIS

Grove et al. (2013) described data analysis as a process implemented to reduce and organise data to make it meaningful.

The returned questionnaires were carefully checked for completeness before the data. Errors were verified and corrected. The data was coded and input into a Microsoft Excel spread sheet using a password-secured personal computer.

After coding and data capture, the data was imported into STATA version 13.1 for data analysis. The data analysis was divided into descriptive and inferential statistics.

Descriptive analysis was computed to describe the symptoms suggestive of worry of hypoglycaemia and behaviour adopted to prevent hypoglycaemia among parents of children with T1DM using central tendency measures.

The Shapiro Wilk test was used to determine the distribution of the overall satisfaction variable, to establish the appropriate central tendency measure.

The Wilcoxon rank sum test (for comparison between two medians) and Kruskal Wallis (for comparison between more than two medians) was computed to test for difference between the medians.

Independent t-test (for comparison between two means) and Kruskal Wallis (for comparison between more than two means) was computed to test for difference between the means.

For the inferential statistics, factors associated with fear (using the worry subscale score and the behaviour subscale score) of hypoglycaemia among parents of T1DM children were determined through computing a univariate and multivariate linear regression model. The reason for fitting a linear regression model was that the outcomes “worry subscale score” and “behaviour subscale score” are continuous variables.

3.7 ETHICAL CONSIDERATIONS

Ethical research is important to generate sound knowledge for practice, while protecting the rights of human subjects (Grove et al., 2013). Polit and Beck (2012) explained that when human subjects participate in a study, considerations must be implemented to ensure that their rights are protected. The following ethical issues were considered in this study:

3.7.1 Institutional approval

A clearance certificate (M160550) was granted by the Human Research Ethics Committee of the University of the Witwatersrand (Appendix A) and the Research and Postgraduate Committee of the Health Sciences Faculty of the Witwatersrand (Appendix B). Permission was also sought and granted by the Chief Executive Officer of the participating institution (Appendix C) as well as the author of the Hypoglycaemia Fear Survey – Parent Version (PHSF) (Appendix D &E).

3.7.2 Participants

- A participant information letter was given to each participant explaining the nature and objectives of the study (see Appendix G).
- Participation in the study was voluntary.
- Participants were allowed to withdraw from the study at any time without penalty.
- Confidentiality and anonymity of the participants was guaranteed with no direct personal identification information being collected.
- Code numbers instead of names were used.
- Participants signed consent forms to confirm their desire to take part in the study. Their signatures indicated informed consent (see Appendix H).

3.8 SUMMARY

This chapter outlined the study's research methodology, and the ethical considerations were presented.

CHAPTER FOUR

RESULTS AND DISCUSSION

4.1 INTRODUCTION

The previous chapter presented the research methodology used in the study. This chapter describes the method that was used for data analysis and interpretation of the results. Data was collected from parents of children with T1DM attending the diabetic clinic (n=140).

4.2 DATA ANALYSIS PROCESS

The data collection process was facilitated using the Hypoglycaemia Fear Survey – Parent Version (HSF-P) questionnaire (Clarke, Gonder-Frederick and Snyder et al., (1998) (see Appendix E).

The returned copies were checked for completeness, verified, corrected, coded, entered into a Microsoft Excel spreadsheet and then taken across into STATA version 13.1 for data analysis.

Descriptive and inferential statistics were used to answer the research questions. For the descriptive and inferential statistical analysis, a continuous “worry subscale score” and “behaviour subscale score” was generated in accordance with the HSF-P questionnaire administration and scoring instructions (Appendix F).

For the worry subscale score, the score range was 0–60, and a higher score on the worry subscale indicated more worry concerning episodes of hypoglycaemia and its consequences (see Appendix F).

For the behaviour subscale score, the score range was 0–40, and a higher score on the behaviour subscale indicated more fear-induced behavioural patterns to avoid episodes of hypoglycaemia and its consequences.

Descriptive analysis was conducted using the following included statistical tests: Shapiro Wilk test, Wilcoxon rank sum test, independent t-test and the Cronbach's reliability coefficient. Testing was done at the 0.5 level of significance ($p<0.05$) and insured a power of at least 95% accuracy in findings.

The descriptive tests were computed to:

- describe the demographic profiles of parents and children (Table 4.1)
- describe symptoms suggestive of worry (Table 4.2 and Figure 4.1 indicating distribution of the worry score)
- analyse symptoms suggestive of worry (Table 4.3)
- describe avoidant behaviours adopted (Table 4.4 and Figure 4.3)
- analyse avoidant behaviours adopted to prevent hypoglycaemia (Table 4.5).

Inferential statistics were conducted to establish factors associated with fear (using the worry and the behaviour subscale scores).

Univariate and multivariate linear regression models were created, firstly to determine the relationship between demographic factors and worry subscale scores, and secondly to check the association between each demographic factor and worry about hypoglycaemia, when adjusting for all other demographic factors (Table 4.6).

The same linear regression approach (univariate and multivariate) regression model was applied to determine factors associated with the behaviours adopted, as well as the association between each demographic factor and behaviours adopted to prevent hypoglycaemia when adjusting for all other demographic factors (Table 4.7).

A linear regression model was chosen because the outcomes "worry subscale score" and "behaviour subscale score" are continuous variables.

4.3 PRESENTATION OF THE FINDINGS

The Hypoglycaemia Fear Survey – Parent version (HFS-P) (Clarke et al., 1998) was used for data collection (see Appendix E). The first section requests demographic data. The second section concerns the worry and behaviour subscales.

The worry subscale findings were interpreted using the mean scores, as well as the Inter-quintile range scores, classed as low (0–20), moderate (21–40), or high (41–60), based on the 15 questions with a score range of 0 to 60. Higher scores indicated more worry concerning episodes of hypoglycaemia and its consequences.

The behaviour subscale Inter-quintile range scores were classed as low (1–13), moderate (14–26) or high (27–40), based on the 10 questions with a score range of 0 to 40, with a higher score indicating more hypoglycaemia avoidance behaviour.

4.3.1 Section A: Demographic data

This set of data describes the demographic variables of the sample, and was analysed to assess any effect on the subscales. Parents and caregivers were asked about their own age and gender, marital status, relationship to the child, education level, and employment status. They were also asked about the child's age and gender, incidence of severe hypoglycaemia (with unconsciousness), whether the child usually carried emergency glucose, and the presence of T1DM complications (Table 4.1).

Analysis of the demographic data showed that the parents' ages were not normally distributed (p=0.0318). The median age for the participants was 38 (IQR=10). Most were between the ages of 18 and 49 years (91.4%; n=128). There were more female participants (75%; n=105) than male participants (25%; n=35). Almost half of the participants (48%; n=68) were married, followed by 44% who were single parents (n=62). More than half of the participants were mothers of a T1DM child (70%; n=98).

Most of the participants (47%; n=66) had attained some high school education only (i.e. grade 8–12), whereas a total of 35.7% (n=50) had a certificate, diploma or university degree. A small percentage (3.57%; n=5) had never been to school.

The number of employed participants (44.3%; n=62) was almost the same as the number of unemployed (43.6%; n=61). However, the results showed that 10.7% (n=15) of the participants were stay-at-home parents and 1.4% (n=2) were pensioners.

Table 4.1: Demographic characteristics of study participants

Characteristic		Frequency	Percentage (%)
Gender	Male	35	25
	Female	105	75
Participant age	18–29 years	24	17.14
	30–39 years	59	42.14
	40–49 years	45	32.14
	50–59 years	10	7.14
	60–69 years	2	1.43
Marital status	Married	68	48
	Single	62	44
	Divorced	2	1.43
	Widowed	5	3.57
	Separated	1	0.71
	Cohabitation	2	1.43
Relationship to child	Mother	98	70
	Father	25	17.9
	Guardian	17	12.1
Employment status	Employed	62	44.3
	Unemployed	61	43.6
	Pension	2	1.4
	Stay at home parent	15	10.7
Highest level of education	Never attended school	5	3.57
	Grade 1–3	4	2.86
	Grade 4–7	15	10.71
	Grade 8–12	66	47.14
	Certificate or Diploma	36	25.71
	University degree	14	10
Gender of child	Male	55	39.29
	Female	85	60.71
Child's age	<5 years	18	12.86
	5–9 years	37	26.43
	10–14 years	66	47.14
	15–18 years	19	13.57
"Child has experienced hypoglycaemia with unconsciousness"	Never	65	46.43
	Rarely	25	17.86
	Sometimes	46	32.86
	Often	3	2.14
	Always	1	0.71
"Child carries emergency glucose"	Never	38	27.14
	Rarely	16	11.43
	Sometimes	30	21.43
	Often	5	3.57
	Always	51	36.43
"Child has complication of T1DM"	Yes	19	13.77
	No	119	86.23

The distribution of children’s ages was found to be normal (p=0.1242). The mean age of children was 10 years (SD=3.86 years). Most of the children were between 5 and 14 years old (73.6%; n=103) and most were female (60.7%; n=85). Most participants reported their child to never have experienced severe hypoglycaemia (46.4%; n=65), to always carry emergency glucose (36.4%; n=51), and to not have any T1DM complications (86.2%; n=119).

4.3.2 Section B: Worry subscale

The worry subscale assessed the anxiety-provoking aspects of hypoglycaemia with a score range of 0–60 where a higher score indicated more worry about hypoglycaemia.

Table 4.2: Symptoms suggestive of worry

	Worry subscale	**0** **Never** n (%)	**1** **Rarely** n (%)	**2** **Sometimes** n (%)	**3** **Often** n (%)	**4** **Always** n (%)
1	“Child not recognising that he/she is having a reaction”	28(20)	11(7.86)	35(25)	13(9.29)	**53(37.86)**
2	“Child not having food, fruit or juice with him/her”	33(23.57)	9(6.43)	30(21.43)	20(14.29)	**48(34.29)**
3	“Child feeling dizzy or passing out in public”	58(41.43)	12(8.57)	37(26.43)	15(10.71)	18(12.86)
4	“Child having a reaction while asleep”	51(36.43)	13(9.29)	43(30.71)	14(10)	19(13.57)
5	“Child embarrassing self or friends/family in a social situation”	**92(65.71**)	13(9.29)	19(13.57)	7(5.00)	9(6.43)
6	“Child having a reaction while alone”	61(43.57)	10(7.86)	38(27.14)	8(5.71)	22(15.71)
7	“Child appearing to be ‘stupid’ or clumsy”	**86(61.43**)	10(7.14)	27(19.29)	4(2.86)	13(9.29)
8	“Child losing control”	60(42.86)	20(14.29)	41(29.29)	7(5.00)	12(8.57)
9	“No one being around to help child during a reaction”	57(41.01)	11(7.91)	19(13.67)	9(6.47)	**43(30.94)**
10	“Child making a mistake or having an accident at school”	**70(50)**	18(12,86)	32(22.86)	5(3.57)	15(10.71)
11	“Child getting a bad evaluation at school because of something that happens when his/her sugar is low”	64(45.71)	17(12.14)	39(27.86)	4(2.86)	16(11.43)
12	“Child having seizures or convulsions”	67(47.86)	14(10)	28(20)	9(6.43)	22(15.71)
13	“Child developing long term complications from frequent low blood sugar”	55(39.29)	8(5.71)	24(17.14)	9(6.43)	**44(31.43)**
14	“Child feeling light-headed or faint”	43(30.71)	22(15.71)	49(35)	8(5.71)	18(12.86)
15	“Child having an insulin reaction”	**100(71.43)**	11(7.86)	13(9.29)	3(2.14)	13(9.29)

4.3.2.1 Symptoms suggestive of worry

In this section a description of parent's responses to the worry subscale questions is given. Frequency tables were computed to determine the proportions for each response and the results are presented in Table 4.2.

The findings from Table 4.2 show that the top four symptoms suggestive of worry that parents **always** worry about with regards to hypoglycaemia in this study were: *"worrying about the child not recognizing that he/she is having a reaction"; "child does not have food, fruit or juice with him/her"*; "*child might develop long term complications from frequent low blood sugar"* and *"if there is no one around to help the child during a reaction"*. However, fewer than half of the sample size of parents in this study (30–38%) rated these items as "always".

The highest-rated worry was about the *"child not recognizing that he/she is having a reaction",* rated as "always" by 37.86% (n=53) of participants. The second-highest rated item results was *"the child not having anything to eat or to drink"* rated as "always" by 34% (n=48) of the parents.

The third-highest rated item pertains to parents worrying about the potential *"development of long-term complications from frequent low blood sugar"*. The fourth-highest worry was regarding the *"child having hypoglycaemia with no one around to help the child during a reaction",* rated as "always" by 31.4% (n=44) of parents.

The four aspects that parents were least worried about (rated "never") were *"child having an insulin reaction"* (71%; n=100); *"child embarrassing self or family in a social situation"* (66%; n=92); *"child appearing to be stupid or clumsy"* (61.4%; n=86); and *"child having seizures or convulsions"* (Item 2) (47.9%; n=67).

4.3.2.2 Distribution of the worry score

The probability distribution of the worry score shown in Figure 4.1 below shows that the worry score was not normally distributed (p=0.0001). The median worry score for all the study participants was 20 (IQR=20). The inter-quintile range of 20 lies between 0 and 20, which indicates low worry concerning episodes of hypoglycaemia and its consequences.

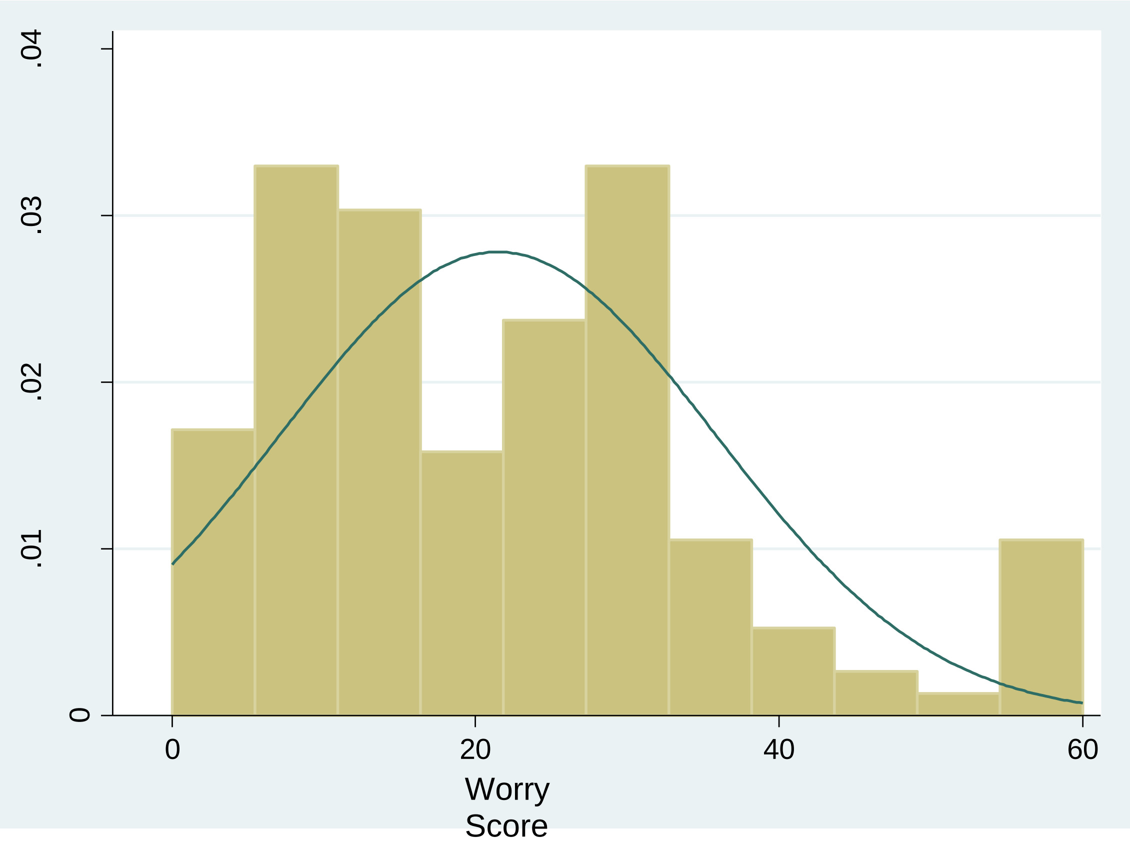

Figure 4.1: Distribution of the worry score (Shapiro Wilk p=0.001)

4.3.2.3 Descriptive analysis of aspects suggestive of worry of hypoglycaemia

The focus in this section is on the results of the description of symptoms suggestive of worry based on the participants' demographic features. In addition, aspects related to a history of hypoglycaemia, carrying emergency glucose and the presence of T1DM complications were presented. A comprehensive description of the median worry subscale scores for each demographic characteristic of the participants is detailed in Table 4.3.

Table 4.3: Descriptive analysis of aspects suggestive of worry of hypoglycaemia among parents of children with T1DM

Characteristic	Median	IQR (interquartile range)
Gender of parent (Wilcoxon rank sum test, p=0.0251)		
Male	13	24
Female	**22**	18
Marital status (Kruskal Wallis, p=0.8080)		
Married	20.5	21.5
Single	20	20
Divorced	**30**	6
Widowed	17	12
Separated	10	0
Cohabitation	20	34
Relationship to child (Kruskal Wallis, p=0.1070)		
Mother	**22**	18
Father	14	24
Guardian	12	15
Highest level of education (Kruskal Wallis, p=0.2815)		
Never attended school	**40**	11
Grade 1–3	16.5	16.5
Grade 4-7	16	16
Grade 8–12	22	22
Certificate or diploma	21	21
University degree	21	11
Employment status (Kruskal Wallis, p=0.1680)		
Employed	20	20
Unemployed	**21**	19
Pension	5	2
Stay at home parent or guardian	27	26
Gender of child (Wilcoxon rank sum test, p=0.7580)		
Male	18	21
Female	**21.5**	20.5
History of severe hypoglycaemia in child (Kruskal Wallis, p=0.0108)		
Never	14	21
Rarely	13	19
Sometimes	28	14
Often	**29**	26
Always	19	0
Child carries emergency glucose (Kruskal Wallis, p=0.3098)		
Never	18	20
Rarely	19.5	31
sometimes	**23**	19
Often	8	8
Always	22	21
Child has complications of T1DM (Wilcoxon rank sum test, p=0.4453)		
Yes	**24**	16
No	18.5	22

4.3.2.3.1 Gender of parents

Of the total sample size of 140 participants in this study, the median worry subscale score for women (22) was more than that for men (13). The Wilcoxon rank sum test of comparison between the medians indicated a statistically important difference between the female parents' median worry subscale score and that of the male parents (p=0.0251). This result implies that female parents were more likely to worry than male parents (see Figure 4.2).

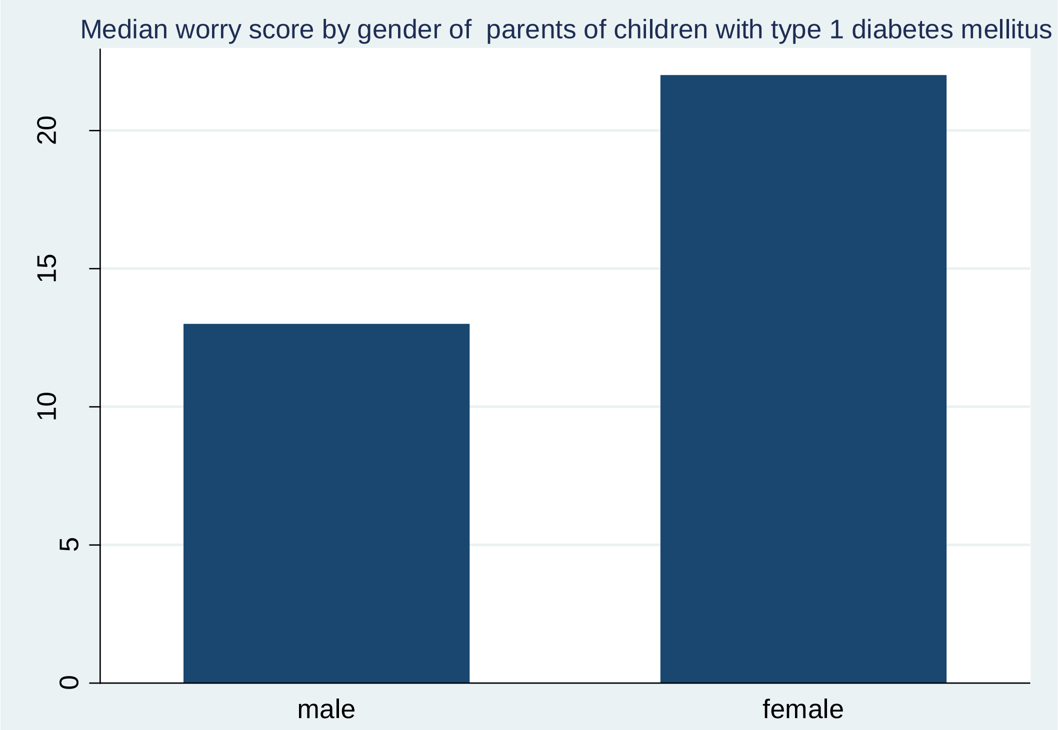

Figure 4.2 Median worry score of hypoglycaemia among parents of T1DM children by gender of parents

4.3.2.3.2 Marital status

Data on marital status of the participants showed that married participants were more likely to worry than participants of other marital status categories. However, the Kruskal Wallis statistical test indicated that the difference in the median worry subscale scores was not statistically significant (p=0.8080).

4.3.2.3.3 Relationship to the child

For the data on relationship to child, mothers (median score=22) had the highest median worry subscale score in comparison to fathers (median score=14) and guardians (median score=12); however, these differences in the medians were not significant at the 5% statistical significance level (p=0.1070).

4.2.3.3.4 Employment status

The data on employment status indicates that “stay at home parents” had the highest median worry subscale score (27) while parents on pensions had the lowest median worry subscale score (5). These results imply that stay-at-home parents were more likely to worry than other parents in the employment category. However there was no statistical significance in the different median worry subscale scores based on employment status of parents of children with T1DM (p=0.1680).

4.3.2.3.5 Child characteristics

The data on the child’s characteristics indicate that parents of female children (median score = 21.5), children who “often” had *“history of severe hypoglycaemia”* (median score = 29), as well children who “sometimes” *“carried emergency glucose”* (median score = 23), and children with *“complications of diabetes type 1”* (median score = 24) had the highest median score in comparison to other characteristics of the children listed.

“Child having a history of convulsions” was the only variable with a statistically significant median (p=0.0108). The other variables’ mean scores were not statistically significant (p>0.05).

4.3.3 Aspects associated with worry of hypoglycaemia among parents of children with T1DM

For the multivariate linear regression, the following variables were considered as covariates: gender, marital status, relationship to child, highest level of education, employment status, gender of child, history of severe hypoglycaemia in child, whether child carries emergency glucose and whether child has complications of T1DM. The PHFS worry subscale score was considered as the dependent variable. The coefficient estimates along with 95% CI and associated p-values of each of the predictors listed as covariates and their relationship to worry subscale were computed and outlined in Table 4.4. For the univariate analysis, only parent gender was significantly associated with the worry subscale score. The univariate model shows a statistical significance (p=0.000) in the findings indicating that female parents or guardians were likely to have a worry subscale score 0.11 higher than the worry subscale score of male parents or guardians.

Table 4.4: Demographic aspects associated with worry of hypoglycaemia among parents of children with T1DM

	Univariate analysis			**Multivariate analysis**		
Characteristic	**coef**	**p-value**	**CI**	**coef**	**p-value**	**CI**
Gender (base=male)						
Female	0.11	0.000	0.05-0.16	0.10	0.608	–0.47–0.28
Marital status (base=married)						
Single	0.71	0.782	–4.35–5.78	–0.73	0.809	–6.74–5.27
Divorced	8.81	0.399	–11.80–29.42	12.05	0.271	–9.55–33.66
Widowed	–1.59	0.813	–14.90–11.72	–1.74	0.819	–16.78–13.29
Separated	–11.19	0.446	–40.12–17.74	13.88	0.361	–43.89–16.13
Cohabitation	–1.19	0.909	–21.80–0.47	7.87	0.488	–14.56–30.29
Relationship to child (base=mother)						
Father	–4.29	0.180	–10.59–2.01	–6.38	0.358	–20.07–7.32
Guardian	–6.92	0.066	–14.30 –0.47	–9.31	0.065	–19.20–0.58
Education (base=never attended school)						
Grade (1–3)	–16.45	0.088	–35.36–2.46	–17.70	0.083	–37.77–2.37
Grade 4–7	–14.2	0.056	–28.75–0.35	–15.67	0.064	–32.25–0.90
Grade 8–12	–14.67	0.028	–27.74–1.60	–12.05	0.108	–26.79–2.69
Certificate of diploma	–10.74	0.117	–24.22–2.73	–9.55	0.207	–24.48–5.37
University degree	–10.41	0.163	–25.10–4.27	–7.35	0.378	–23.81–9.11
Employment status (base=employed)						
Unemployed	–2.33	0.370	–7.44–2.79	–1.15	0.703	–7.11–4.81
Pension	–17.56	0.089	–37.85–2.74	–13.54	0.239	–36.24–9.15
Stay at home parent/guardian	1.78	0.667	–6.36–9.92	0.37	0.935	–8.54–9.27
Childs age	0.09	0.780	–0.54–0.71	0.18	0.675	–0.68–1.04
Childs gender (base=male)						
Female	0.03	0.989	–4.90–4.97	–0.25	0.675	–5.77–5.27
History of severe hypoglycaemia (base=never)						
Rarely	2.72	0.410	–3.78–9.23	6.62	0.113	–1.60–14.83
Sometimes	7.92	0.004	2.56–13.29	7.90	0.015	1.59–14.21
Often	15.59	0.061	–0.75–31.93	18.08	0.058	–0.59–36.74
Always	0.92	0.948	–26.95–28.80			
Child carries emergency glucose (base=never)						
Rarely	4.48	0.295	–3.94–12.91	4.72	0.309	–4.44–13.90
Sometimes	3.63	0.305	–3.34–10.60	3.32	0.394	–4.38–11.02
Often	–9.18	0.179	–22.63–4.27	–10.58	0.171	–25.80–4.63
Always	2.60	0.398	–3.46–8.66	2.14	0.549	–4.92–9.21
Child has complications with type1 diabetes (base=yes)						
No	–0.78	0.827	–7.86–6.29	1.44	0.715	–6.33–9.21

The univariate models of marital status, relationship to child, employment status, gender of child, child carries emergency glucose and child has complications of T1DM were all found to not be statistically associated with worry subscale score (p>0.05).

However, higher levels of worry were associated with parents who had obtained grade 8–12 level of education (p=0.028) as well as parents of children who “sometimes” had severe hypoglycaemia (p=0.004).

For the multivariate analysis, when adjusting for all other predictors of demographic characteristics of parents of T1DM children, none of the predictors were found to have a statistically significant relationship with the worry subscale score (p>0.05) as indicated in Table 4.4.

4.3.4 Section C: Behaviour subscale

The behaviour subscale assessed behaviours used to avoid episodes of hypoglycaemia. The score range of the 10 items is 0–40 with a higher score indicating more fear-induced behavioural patterns to prevent hypoglycaemia and its consequences. The behaviour subscale Inter-quintile range scores were classed as low (1–13), moderate (14–26) or high (27–40).

To determine the appropriate central tendency measure, behaviour subscale scores were tested for normality using the Shapiro Wilk normality test. For comparisons between two medians, the Wilcoxon rank sum test was used, whereas the Kruskal Wallis was used for more than two medians.

4.3.4.1 Item descriptions of behaviours adopted

In this section, a description of parents’ responses to the behaviour subscale questions is given. Frequency tables were computed to determine the incidence of each response and the results are presented in Table 4.5.

Out of the 10 items indicated in Table 4.5, the top four behaviours adopted to prevent hypoglycaemia and its consequences, indicated by the “always” score, were: *“checking child’s blood sugar often when the child plans to go out”* with an always score of 62.9% (n=88); *“feeding the child at the first sign of low blood sugar”* (59.3%; n=83); *“avoiding* *leaving the child alone when blood sugar is likely to be low"* (37.2%; n=52); and *"having the child carry fast-sugar"* (30.7%; n=43).

The results further showed that items with higher behaviour scores parents said they "sometimes" do were: *"having my child eat a large snack at bedtime"* (40%; n=56) and *"allowing child's blood sugar to be a little high to be on the safe side"* (40.7%; n=57). However, the results further showed that 62.9% (n=88) "never" *"keep child blood sugar higher when the child plans to be away from the parent"* for a while and 55.7% (n=78) "never" *"keep the blood sugar higher if the child will be left alone for a while"*. In addition, 32.1% (n=45) reported that they "never" *"reduce the child's insulin when they think the blood sugar is too low"*.

Table 4.5: Item description of behaviours adopted

	Behaviour subscale	**0 Never** n (%)	**1 Rarely** n (%)	**2 Sometimes** n (%)	**3 Often** n (%)	**4 Always** n (%)
1	"Have my child eat large snacks at bedtime."	51(36.43)	16(11.43)	56(40)	10(7.14)	7(5.00)
2	"Avoid having my child being alone when his/her sugar is likely to be low."	36(25.71)	11(7.86)	22(15.71)	19(13.57)	**52(37.14)**
3	"Allow my child's blood sugar to be a little high to be on the safe side."	47(33.57)	11(7.86)	57(40.71)	14(10)	11(7.80)
4	"Keep my child's sugar higher when he/she will be alone for a while."	78(55.71)	11(7.86)	33(23.57)	6(4.29)	12(8.57)
5	"Have my child eat something as soon as he/she feels the first sign of low blood sugar."	7(5.00)	8(5.71)	23(16.43)	19(13.57)	**83(59.29)**
6	"Reduce my child's insulin when I think his/her sugar is too low."	45(32.14)	12(8.57)	38(27.14)	21(15)	24(17.14)
7	"Keep my child's blood sugar higher when he/she plans to be away from me for a while."	88(62.86)	10(7.14)	28(20)	6(4.29)	8(5.71)
8	"Have my child carry fast-sugar."	38(27.14)	10(7.14)	40(28.57)	9(6.43)	**43(30.71)**
9	"Have my child avoid a lot of exercise when I think his/her sugar is low."	37(26.43)	11(7.86)	48(34.29)	19(13.57)	25(17.86)
10	"Check my child's sugar often when he/she plans to go on an outing."	12(8.57)	8(5.71)	17(12.14)	15(10.71)	**88(62.86)**

4.3.4.2 Distribution of the behaviour score

The probability distribution of the behaviour score shown in Figure 4.3 shows that the behaviour is normally distributed (p=0.0001). The median behaviour score for all study participants was 20 (IQR=20).

The inter-quintile range of 20 in this study lies between IQR 14 and 26. This result indicates moderate behaviours adopted to prevent hypoglycaemia and its consequences. However, the Shapiro Wilk test showed the results were not significant (p=0.14192).

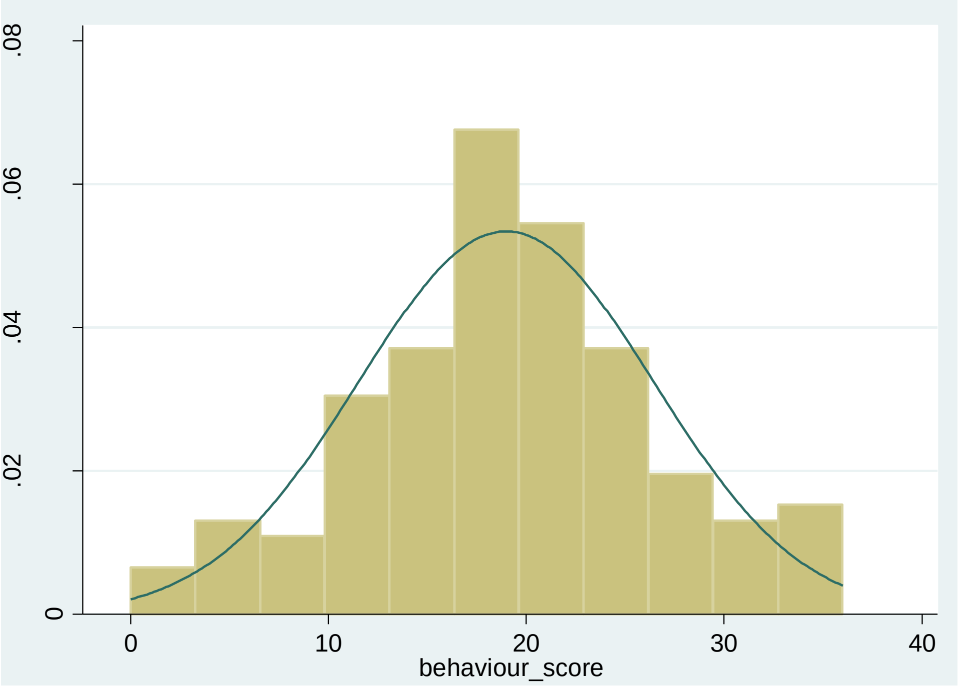

Figure 4.3: Distribution of the behaviour score (Shapiro Wilk p=0.14192)

4.3.4.3 Behaviour adopted to prevent hypoglycaemia among parents of children with T1DM

The focus in this section is on the behaviour adopted to prevent hypoglycaemia in relation to parents' demographic features. In addition, aspects such as a history of hypoglycaemia, carrying emergency glucose, or the presence of T1DM complications is presented. A comprehensive description of the median score of behaviour adopted for each demographic characteristic of the participants is detailed in Table 4.6.

4.3.4.3.1 Parent’s gender

Out of the 140 participants in the study, the mean behaviour subscale score for male parents (19.14) was slightly more than the mean behaviour subscale score for female parents (18.93). The Independent t-test to compare the mean male and female parents’ subscale scores indicated no statistically significant distinction (p=0.8836). This implies that, in this study, male parents having fear or worry about hypoglycaemia were more likely to do something to prevent it.

4.3.4.3.2 Marital status

When assessing the data on marital status of the participants, it was found that there were more divorced participants with a higher mean behaviour subscale score than participants of other marital status categories, as indicated in Table 4.6.

However, the one-way analysis of variance parametric test indicated that the difference in the mean behaviour subscale scores between the different marital status categories of the participants was not statistically significant (p=0.5414).

4.3.4.3.3 Relationship to child

For the data on relationship to child, carers who are guardians (median score=20.51) had the highest median behaviour subscale score in comparison to fathers (median score=18.48) and mothers (median score=18.85). However, this difference in the medians was not significant at the 5% statistical significance level (p=0.6488).

4.3.4.3.4 Employment status

The results on employment status indicated that parents who were employed had the highest mean behaviour score (20.27) while unemployed parents had the lowest mean behaviour score (17.74). However, there was no statistical significance in the different mean behaviour scores based on employment status (p=0.3117).

4.3.4.3.5 Child characteristics

The data on the children’s characteristics indicated that parents of male children (median score=19.61), children who “often” had history of severe hypoglycaemia (mean score=29.27), children who “always” carried emergency glucose (mean score=20.47), and children with complications of diabetes type 1 (mean score=20.63), had the highest mean score for parents' avoidant behaviours in comparison to other characteristics of the children listed in Table 4.6; however the difference in each of the median scores was not statistically significant (p>0.05).

Table 4.6: Descriptive analysis of behaviour adopted to prevent hypoglycaemia

Characteristic		Mean	SD (standard deviation)
Gender (t-test, p=0.8863)	Male	**19.14**	7.61
	Female	18.93	7.45
Marital status (One-way anova, p=0.5414)	Married	18.38	7.59
	Single	19.73	7.62
	Divorced	**25.5**	3.54
	Widowed	15	4.80
	Separated	18	7.29
	Cohabitation	20.5	3.54
Relationship to child (One-way anova, p=0.6488)	Mother	18.85	7.62
	Father	18.48	7.54
	Guardian	**20.51**	6.64
Highest level of education (One-way anova, p=0.4445)	Never attended school	**22.6**	9.58
	Grade 1–3	13	6.22
	Grade 4–7	20.2	7.66
	Grade 8–12	18.39	7.29
	Certificate or diploma	19.53	7.97
	University degree	19.5	6.94
Employment status (One-way anova, p=0.3117)	Employed	**20.27**	6.40
	Unemployed	17.74	8.66
	Pension	18	5.66
	Stay at home parent/guardian	18.87	6.08
Gender of child (t-test, p=0.4221)	Male	**19.61**	7.74
	Female	18.58	7.30
History of severe hypoglycaemia (One-way anova, p=0.0656)	Never	17.94	7.63
	Rarely	18.76	7.55
	Sometimes	20	6.66
	Often	**29.67**	9.29
	Always	14	.
Child carries emergency glucose (One-way anova, p=0.2386)	Never	16.87	7.05
	Rarely	18.31	8.95
	Sometimes	19.2	6.61
	Often	**20.8**	6.91
	Always	20.47	7.67
Child has complications of T1DM (t-test, p=0.3223)	Yes	**20.63**	7.48
	No	18.78	7.51

4.3.4.4 Factors associated with behaviour adopted to prevent hypoglycaemia among parents of T1DM children

For the multivariate linear regression: the predictors listed in section 4.3.4 were regarded as covariates, while the behaviour subscale score was considered as the dependent variable.

The coefficient estimates along with 95% CI and associated p-values of each of the predictors listed as covariates and their relationship to behaviour scores were computed and outlined in Table 4.7 (see below). No results are presented for the “always” level of association with “*history of severe hypoglycaemia”* as there was only one such respondent for this question.

For the univariate analysis, all the predictors with the exception of the *“history of severe hypoglycaemia in child”* and *“child always carrying emergency glucose”* variables were found to not be statistically associated with the behaviour score.

For the history of severe hypoglycaemia, the univariate model indicated that parents who reported children to “often” have had severe hypoglycaemia were likely to have a behaviour subscale score 1.78 times higher than the score of parents who reported their children to “never” have had severe hypoglycaemia, at the 5% significant level (p=0.008).

For the *“child carries emergency glucose”* variable, parents who reported their child to “always” carry emergency glucose were likely to have a behaviour subscale score of 3.60 times higher than that of parents who reported their child to “never” carry emergency glucose, at the 5% significance level (p=0.025).

For the multivariate analysis, when adjusting for all other factors, parents who reported children to “often” have had severe hypoglycaemia were likely to have a behaviour subscale score 13.36 times higher than that of parents who reported their children to “never” have had severe hypoglycaemia, at the 5% significant level (p=0.007). Parents who reported their child to “always” carry emergency glucose were likely to have a behaviour subscale score of 4.51 times higher than that of parents who reported their child to “never” carry emergency glucose, at the 5% significance level (p=0.016).

Table 4.7: Demographic factors associated with behaviour adopted to prevent hypoglycaemia among parents of children with T1DM

	Univariate analysis			Multivariate analysis		
Characteristic	**coef**	**p-value**	**CI**	**coef**	**p-value**	**CI**
Gender (base=male)						
Female	0.21	0.886	–3.10–2.68	–2.13	0.500	–8.36–4.11
Marital status (base=married)						
Single	1.34	0.309	–1.26–3.95	–0.17	0.910	–2.89–3.24
Divorced	7.11	0.188	–3.51–17.75	8.35	0.141	–2.81–19.51
Widowed	–3.38	0.332	–10.25–3.48	–1.14	0.771	–8.92–6.64
Separated	–0.38	0.960	–15.31–14.54	–1.78	0.821	–17.27–13.72
Cohabitation	2.12	0.694	–8.51–12.75	2.04	0.729	–9.58–13.66
Relationship to child (base=mother)						
Father	–0.37	0.827	–3.69–2.95	–3.94	0.929	–11.02–3.14
Guardian	1.68	0.395	–2.21–5.58	–1.86	0.272	–6.98–3.25
Education (base=never attended school)						
Grade (1–3)	–9.6	0.058	–19.51–0.31	–10.06	0.058	–20.45–0.34
Grade 4–7	–2.4	0.535	–10.03–5.23	–2.04	0.640	–10.64–6.57
Grade 8–12	–4.21	0.227	–11.06–2.65	–2.74	0.478	–10.36–4.89
Certificate of diploma	–3.07	0.391	–10.12–3.98	–3.35	0.392	–11.10–0.39
University degree	–3.1	0.427	–10.80–4.60	–2.92	0.497	–11.41–5.57
Employment status (base=employed)						
Unemployed	–2.53	0.061	–5.19–0.12	–3.26	0.038	–6.34–0.18
Pension	–2.27	0.672	–12.86–8.31	0.82	0.889	–10.87–12.52
Stay at home parent/guardian	–1.41	0.513	–5.65–2.83	–1.00	0.666	–5.62–3.60
Child’s age	–0.17	0.310	–0.49–0.15	–0.22	0.322	–0.66–0.22
Child’s gender (base=male)						
Female	–1.04	0.422	–3.60–1.52	–1.12	0.436	–3.95–1.12
History of severe hypoglycaemia (base=never)						
Rarely	0.82	0.635	–2.59–4.24	0.98	0.650	–3.27–5.22
Sometimes	2.06	0.147	–0.73–4.86	0.60	0.715	–3.64–3.83
Often	1.78	0.008	3.16–20.29	13.36	0.007	3.70–23.02
Always						
Child carries emergency glucose (base=never)						
Rarely	1.44	0.515	–2.93–5.82	0.88	0.715	–3.87–5.63
Sometimes	2.33	0.201	–1.25–5.92	2.99	0.138	–0.97–6.95
Often	3.93	0.268	–3.05–1092	3.17	0.426	–4.69–11.04
Always	3.60	0.025	0.46–6.74	4.51	0.016	0.84–8.17
Child has complications with type1 diabetes (base=yes)						
No	–1.84	0.322	–5.51–1.82	–1.90	0.351	–5.92–2.12

4.4 DISCUSSION

4.4.1 Worry and behaviour subscales

The Cronbach's reliability test was conducted on both the HFS-P worry and HFS-P behaviour subscales to check for internal consistency. Values ≥ .70 are regarded as satisfactory (Fayers and Machin, 2007).

In the current study, the Cronbach's alpha coefficient results were 0.90 for the HFS-P worry subscale and 0.73 for the HFS-P behaviour subscale respectively. Both subscales' results showed adequate reliability. The results from the current study compare well with the findings from Haugstvedt et al. (2015) where the worry subscale had a Cronbach's alpha of 0.89 and the behaviour subscale had 0.72.

The behaviour subscale Cronbach's alpha in the current study and in Haugstvedt et al. (2015) are slightly above the acceptable ≥.70 reliability score. The results from the current study confirmed Haugstvedt et al.'s (2015) conclusion that the worry subscale might be a more suitable subscale for assessing FoH. However, there is a need for further research studies to be conducted to check the validity of the HFS-P behaviour subscale.

The probability distributions of both of the HFS-P worry subscales and the HFS-P behaviour subscale were not normal. However, the results of the HFS-P worry subscales had a significant value (p=0.0001) as compared to the HFS-P behaviour subscale (p=0.14192). The insignificant result of the HFS-P behaviour subscale indicates the need for further research on the psychometric properties of this subscale, as recommended by Haugstvedt et al. (2015).

The median score in both HFS-P worry subscales and HFS-P behaviour for all the participants was 20 (IQR=20). The results revealed that HFS-P worry subscales' median score of 20 (IQR=20) indicate low scores of fear. In contrast, the same median score of 20 in the HFS-P behaviour subscale indicate moderate hypoglycaemia avoidance behaviour adopted as the median rate lies between 14 and 26 IQR ranges.

4.4.2 Demographics

4.4.2.1 Age and gender

Most of the parents' ages were between 18 and 49 with a mean age of 38. Females made up 75% whereas 25% were males.

With regards to gender, the median HFS-P (W) score for women (median score=22) was more than for men (median score=13). The results indicate that female parents were more likely to worry than male parents (p=0.0251).

Interestingly, whereas the female parents worried more about hypoglycaemia, the mean HFS-P (B) score for male parents was slightly higher than that of females. This indicates that the male parents were more likely to take action to avoid hypoglycaemia. Oddly, no similar findings have been described in the literature about fathers adopting behaviours to avoid hypoglycaemia.

However, a number of studies published have shown that female parents were more likely to worry than the male parents, as well as do something to avoid hypoglycaemia, as reported in Patton et al. (2008) and Jaser et al. (2014).

Patton et al.'s results (2008) showed that mothers of young children with T1DM who indicated a higher level of fear also had higher scores on the behavioural subscale than the fathers of young children. Similar results were reported by Haugstvedt, Wentzel-Larsen and Graue et al. (2010) in a comparative study conducted on fear among mothers and fathers. The latter authors' results showed that mothers had higher scores than fathers in both the worry and behaviour subscales.

Similar results were reported in Jaser et al. (2014) wherein high levels of fear among mothers was associated with their being in charge of most of the child's treatment and care. Hence, they experienced more stress than fathers related to having "constant vigilance" around the child. Furthermore, mothers usually were responsible for the blood glucose monitoring, insulin administration and food management.

Managing a child with T1DM is described as a complex and demanding task requiring parents to always be on the lookout for symptoms of hypoglycaemia in their children, as younger children cannot recognise and communicate their symptoms. Other factors that make it difficult to manage a T1DM child include their erratic eating patterns or loss of appetite, leading to uncontrolled blood glucose. This may add to FoH. The parent may decide to wake up frequently at night to monitor nocturnal hypoglycaemia, and administer tiny doses of insulin to adjust the blood glucose level.

Oskouie, Mehrdad and Ebrahimi (2013) explained why mothers' roles are often more significant than fathers in taking care of a T1DM child. Firstly, in some instances the male parent spends less time at home and more time at work. Secondly, they might fear potential problems during their intervention. On the other hand, it should be stated that in some cultures, men take more responsibility than women. However, the findings of Oskouie et al. (2013) are understandable due to the mother-child bond that develops during pregnancy, and mothers instinctively tending to worry more and become more vigilant than fathers.

4.4.2.2 Marital status

The marital status results in the current study showed that there were more divorced parents in comparison to other categories. The results further showed that marital status was not statistically significant in either the HFS-P (W) score ($p=0.8080$) or the HFS-P (B) score ($p=0.5414$). However, divorced parents had higher mean scores of 30 for worry and 25.5 for behaviour.

There were no similar results in the literature regarding divorced parents being more likely than other marital status categories to worry and adopt avoidant behaviour. However, studies have shown that a T1DM child living with both parents is more likely to have better glycaemic control (Haugstvedt et al., 2011). In addition, Whittemore et al. (2012) reported that shared responsibility between spouses was a source of support in dealing with decision-making, while single parents found it difficult to manage a diabetic child alone.

A similar study on predictors of glucose control in T1DM children and adolescents (Urbach, LaFranchi and Lambert, 2005) showed that children of married parents had better glycaemic control than children whose parents had another marital status. Findings from Thompson, Auslander and White (2001) confirmed the possible importance of both parents being present for glycaemic control of T1DM children.

Thompson et al. (2001) conducted a study among adolescent children of single parents, finding significantly poor glycaemic control when compared with children from married-parent families. In conclusion, Lord's findings (2015) revealed that single parents had more negative behaviours when parenting T1DM children.

4.4.2.3 Education level and employment

The majority of the participants in this study (47.1%) had a grade 8–12 level of education whereas 3.57% had never attended school. With regards to descriptive analysis of fear-provoking factors and the behaviour adopted, the results showed that the parents that had never attended school had a higher mean score of 40 for worry and 22.6 for the behavioural subscale. Although both median scores were not significant (p=0.2815 and p=04445 respectively), there is some correlation or consistency in the results, indicating that those who had never attended school were more likely to worry about hypoglycaemia as well as do something to prevent it.

Although both the worry and behaviour results were not significant in this study, findings from a study conducted by Majidi, Wadwa and Bishop et al. (2014) showed that the level of a parent's education does have an impact on a child with T1DM. Children of parents who had not attained high school education were reported to have poor health compared to other children. The results further showed that lower socio-economic status has been associated with poor glycaemic control, and has been reported to increase the risks of complications in children with T1DM.

With regards to employment status, the results in this study showed a less than 1% difference between the employed and the unemployed (44.3; n=62 & 43.6; n=61) respectively. The results further showed that almost 11% of the sample were stay-at-home parents. Pensioners accounted for 1.4% of the sample size.

Stay-at-home parents had the highest median worry subscale score (median 27) with no statistical significance in the different median subscale score (p=0.1680). However, on the behaviour subscale score, parents who were employed had the highest mean behaviour subscale score (p=20.27). Although the results showed that there was no statistical significance in the different mean of worry and behaviours subscale score (p=0.1680 and p=0.3117 respectively), the literature has shown the relevance of employment status in having a child with T1DM in a family.

In a study by Whittemore et al. (2012), employed mothers who were the primary care givers to their children with T1DM had to re-arrange their work schedule to accommodate caring for their diabetic child. Some mothers had to quit their jobs to care for their children full-time at home. Whittemore (2012) stated that they had to leave work because it was difficult to find suitable caregivers to be responsible for care of the diabetic child .

Similarly, studies by Jaser et al. (2009) and Kratzer (2012) have highlighted the financial implications or burdens related to the complex treatment management of a child with T1DM.

In Jaser (2009) the results showed that parents with lower earnings found it difficult to cope with diabetes management and this situation contributed to increased anxiety and fear.

Similarly, Kratzer (2012 found that financial burden was one of the 5 key barriers to coping with T1DM in Ghana where insulin therapy is covered by the National Health Insurance Scheme. Therefore, accessing insulin is a challenge for unemployed parents without medical insurance. This results in difficulty in caring for a child with T1DM because of the financial restrictions on insulin access.

4.4.3 Child characteristics

The results in this study showed that most of the children (60.7%) children attending the Children’s Diabetic Clinic in this study sample were female.

4.4.3.1 Gender of child

Interestingly, the study results revealed that parents of female children had a higher mean worry score of 21.5 compared to parents of male children, with a mean score of 18. In contrast, the mean score for behaviours adopted was higher for parents of male children at 19.61. The results in this study imply increased fear of symptoms of hypoglycaemia in female children compared to male children. Although not statistically significant, the results showed a greater likelihood of avoidant behaviour adopted by parents of male children.

4.4.3.2 History of severe hypoglycaemia

History of severe hypoglycaemia is classified as one of the fear-provoking factors in parents of children with T1DM. An incidence of severe hypoglycaemia, apart from increasing the level of fear, could also contribute to psychological distress (Paton et al., 2008).

Forty six percent of the parents stated that their children had “never” had an episode of hypoglycaemia with unconsciousness. Only one parent indicated that their child had “always” had episode of severe hypoglycaemia.

Concerning the worry factors associated with severity of hypoglycaemia with unconsciousness; only “sometimes” was found to be significantly associated with *“history of severe hypoglycaemia in a child”.* Parents of a child with severe hypoglycaemia were 7.92 times likely to worry than those with no history of severe hypoglycaemia (refer to Table 4.4).

On the other hand, with regards to behaviour, the univariate regression analysis results showed that parents who reported children to “often” have had *“history of severe hypoglycaemia”* were likely to have a behaviour subscale score that was 1.78 times higher than behaviour subscale score of parents who reported their children to “never” have had history of severe hypoglycaemia at the 5% significant level (p=0.008). Whilst, the multivariate analysis on adjusting for all other factors, parents who reported children to “often” have had history of severe hypoglycaemia were likely to have a behaviour subscale score that was 13.36 times than the higher behaviour subscale score of parents who reported their children to “never” have had history of severe hypoglycaemia at the 5% significant level (p=0.007). The current results showed that parents who reported severe hypoglycaemia occurring on a frequent basis had high behaviour subscale scores (Table 4.7).

Patton et al. (2007) and (2008) highlighted the significance of history of severe hypoglycaemia as one of the fear-aggravating factors in parents of children with T1DM.

The results in a study conducted by Patton et al. (2008) showed that most of the parents reported an incidence of hypoglycaemia occurring 3–5 times a week. However, Patton et al. (2008) stated that the severity of hypoglycaemia plays a major role in causing fear, compared to the number of hypoglycaemic episodes. Clarke et al. (1998) support Patton et al.'s views that the level of fear is related less to the number of episodes than to their severity. Findings from a study by Patton et al. (2007) that explored fear of hypoglycaemia among adolescents and their parents confirmed this sentiment. The results showed that an episode of severe hypoglycaemia had the potential to aggravate fear in both adolescent children and their parents. In the same study, the results showed that parents of young children who had had a seizure worried more than parents whose children had not had a seizure.

Interestingly, the results in the current study showed that almost half of the parents (47.9%) stated that they "never" worry about the "*child having seizures or convulsions"*. Only 15.7% stated that they "always" worry about "*child developing seizures*". Nonetheless, no study has been found so far reporting significant correlation between parents' increased worry and their child developing seizures.

4.4.3.3 Child carries emergency glucose

Administration of glucagon subcutaneously or intramuscularly is a simple and effective strategy to treat mild hypoglycaemia (Kedia, 2011). It can used at home and elsewhere, and is reportedly effective in allaying parents' fear of hypoglycaemia (Chung and Haymond, 2014).

In this study, over a third of the parents (36.4%) stated that their child "always" carried emergency glucose. An equal number of parents' responses ranged between "rarely", "sometimes" and "often" while 27% stated that the child "never" carried emergency glucose.

Both the univariate and the multivariate regression results showed statistically significant results, with p=0.025 and p=0.016 respectively. Parents whose child "always" carried emergency glucose were likely to have a behaviour subscale score 3.60 times higher than that of parents whose child "never" carried emergency glucose. The multivariate analysis showed a behaviour subscale score 4.51 times higher for those who selected "always" compared to selectors of "never".

The results from a study by Patton et al. (2007) showed that carrying emergency glucose was a specific strategy endorsed by 100% of the parents. Yet in the current study, less than 40% of the parents stated that their child always carries emergency blood sugar.

4.4.3.4 History of complications of T1DM

Ammari's Saudi Arabian study (2004) about "Long term complications of type 1 diabetes" commented that diabetes remains a constant fear in individuals with T1DM and their families.

In the current study, Table 4.2 shows that 86% of the parents reported their children not having diabetic-related complications, and 39.3 % reported that they "never" worried about "*child developing long term complications from frequent low blood sugar".*

In contrast, in Whittemore et al. (2012), parents expressed concerns and worries about their children developing long-term complications and about not coping adequately with managing their diabetic children's needs. One of the parents reported that she "never stopped worrying".

Nonetheless, in the current study, there was no statistically significant association between worry and coping behaviours adopted or between worry and the child having complications of diabetes.

4.4.4 Fear of hypoglycaemia

The focus in this section is to discuss some of the factors associated with fear of hypoglycaemia.

Item analysis of the fear-aggravating factors on the HFS-P worry subscale showed that the two aspects most highly ranked by parents (i.e. as "always") were *"child not recognising that she is having a low"* and *"child having no food, fruit or juice".*

"Child not recognising that she is having a low", i.e. an insulin reaction, was one of the common sources of fear among the parents in this study. The study results showed that among the 15 items on the HFS-P subscale, this was the only aspect that almost 40% of the parents were "always" worried about.

Hypoglycaemia unawareness can be potentially dangerous. Martín-Timón and Del Canizo-Gomez (2015) reported that hypoglycaemia unawareness can lead to complications such as seizures, coma and cognitive deficits, or even death. In younger children, repeated severe episodes of hypoglycaemia may cause brain abnormalities, structural brain changes, decreased mental abilities as well as behavioural problems characterised by confusion, temper tantrums (in younger children) as well as aggressive behaviour. It is in this context that some parents worry about *“child embarrassing self or family in a social situation”* or *“child appearing to be stupid or clumsy”* as well as *“child getting a bad evaluation at school because of what happened when their sugar was low”*.

However, the results in this study showed that the fear aggravating factors were some of the aspects that parents did not worry about. A high percentage of parents are not worried at all about these aspects. More than 60% of the parents stated that they “never” worry about a *“child embarrassing self or family in a social situation”* or *“child appearing to be stupid or clumsy”* and slightly over 41% “never” *“worry about child losing control or getting a bad evaluation at school”* because of a reaction to their sugar being low.

It is interesting to note that *“child not having food, fruit or juice with him/her”* had the second highest fear response at 34.3% in the current study. So far no other studies have found this aspect to be one of the highest ranked sources of fear or worry.

Another surprise from the current study is that 71.4% of the parents stated that they are “never” worried about a child *“having an insulin reaction”*. It is interesting and unexpected that these parents were not worried about insulin reactions to low blood sugar. Insulin reaction has been described as the most common complication of T1DM according to Levitsky et al. (2016), and worry or fear related to *“child having an insulin reaction”* is generally a common issue.

Parents have also raised fears related to *“child having an insulin reaction while asleep”*, *“while alone”* or *“when no one is around to help the child”.* In Patton et al. (2007), 63% of the parents were worried about the *“child having low blood glucose while asleep”* and 46% were worried about the *“child having low blood glucose when the parent was away”*.

In this study, most parents were not very worried about *“child having a reaction while asleep”.* Less than fifteen percent (13.6%) selected “always”, while 30.7% said they “sometimes” worried about it and 36.4% “never” worried about this factor.

Literature has shown that most parents reported considerable concern over hypoglycaemia occurring while asleep (Whittemore et al., 2012; Brunton, 2007). Brunton (2007) explained that nocturnal hypoglycaemia is challenging for patients because they are unable to recognise and report warning symptoms of hypoglycaemia while asleep, and therefore they don't wake up to treat themselves.

Buckingham (2008) reported that hypoglycaemia is common at night, because during sleep the counter-regulatory hormone (epinephrine) that responds to hypoglycaemia is decreased, and therefore patients are at risk of developing complications of hypoglycaemia if their symptoms are not recognized early.

The Juvenile Diabetes Research Continuous Glucose Monitoring Study Group (2010) reported that of all patients with T1DM, 6% are at risk of being found "dead in bed" as a result of unrecognized severe nocturnal hypoglycaemia.

It is not surprising that parents develop fear of nocturnal hypoglycaemia given the possible consequences, especially when their children are asleep and unable to recognise the symptoms, and given that night time is the longest time that children are not directly observed. Shepard et al. (2014) emphasized that FoH in parents of T1DM children increases at night, resulting in stress and disturbed sleep patterns. Constant worrying and fear of hypoglycaemia, coupled with the burden of treatment of daily glucose monitoring and administration of insulin, could predispose parents to psychological distress.

Jaser et al. (2014) explored the association between mothers' diabetic-related stress and their coping strategies. The results showed that mothers exhibited signs of anxiety and depression and needed programmes to help them cope with managing T1DM children.

4.4.5 Hypoglycaemic avoidance behaviour

Occurrence of hypoglycaemia in T1DM is associated with unpleasant physical symptoms (Gonder-Frederick et al., 2006) such as confusion, poor coordination, mental stupor, unconsciousness and seizures; death can also result. Due to these negative consequences it is not surprising that individuals develop FoH. Fear of hypoglycaemia may motivate individuals to adopt management behaviours aimed at avoiding hypoglycaemia (Gonder-Frederick et al., 2006).

In the current study, the HFS-P behaviour subscale had higher “always” scores for avoidance behaviour such as *“avoiding leaving the child alone when their sugar is likely to be low”* (37.1%); *“having my child eat something at the first sign of low blood sugar”*, *“having my child carry fast-sugar”*, and *“checking my child’s blood sugar often before he/she leaves for an outing”.*

Literature has shown that coping behaviour, such as avoiding leaving the child alone, can have a major impact on family lifestyles. In Martín-Timón (2015), family members reported limiting their lifestyles to be with their diabetic child in order to care for them, to help detect symptoms of hypoglycaemia and to ensure their safety. Whittemore et al. (2012) found that parents had to redesign their lifestyles to avoid leaving children alone. With their routines and lives revolving around the child, some parents experienced social isolation.

In the current study, almost 60% of the parents stated that they “always” “*have the child eat something at the first sign of low blood sugar”*, as well as *“check the child’s blood sugar when the child is about to leave for an outing”.*

Fear of hypoglycaemia may increase anxiety in parents and lead to continuous checking of blood glucose when their child is going out; this may lead to premature treatment of hypoglycaemia. Patton (2007) noted that fearful parents may over-feed their children, which could cause insulin resistance and increase the child’s weight. Also, parents may feed their children without administering insulin, in an attempt to prevent a hypoglycaemic episode. This behaviour may cause increased blood glucose levels above the required target range, possibly leading to neuro-cognitive impairment in young children.

4.4.6 Coping strategies

Section 4.4 has highlighted some of the most common or preferred behaviours adopted mainly because of underlying fears as part of a strategy to avoid or prevent hypoglycaemia. Barnard (2010) reported that the hypoglycaemia avoidance behaviour in parents results in poor glycaemic control in children and increases the chance of long-term complications.

Frequently elevated blood glucose may lead to compromised intelligence in children. In view of this, it is alarming that parents of T1DM children with high levels of FoH may practise or adopt negative behaviours in order to manage their fear, such as giving low doses of insulin, providing food without giving insulin, and treating hypoglycaemia prematurely. These behaviours may increase the level of blood glucose to above the required targets, with far-reaching consequences. They are thus poor coping strategies. (Patton, 2007)

Whittemore et al. (2012) conducted a systematic review exploring the psychological experiences of parents of children with T1DM and derived themes from the study results. Parents expressed that developing schedules, being patient, communicating with others, living with hope, having good self-esteem and being positive were some of the most effective coping strategies. In addition, as time went on, they tended to become more proficient at managing their diabetic children and were more confident after working hard to make sure their child would have a normal life. The parents identified sources of support such as health workers, family, friends, and other parents of children with T1DM.

It is in this context that Pate et al. (2015) advocated for intervention strategies for parents of T1DM children, such as support groups, which parents reported benefiting from. Groups were described as their source of support (as the name implies) as well as a safe space where parents could meet, talk, and have their frustrations heard. In addition, families reported that support groups improved family dynamics and functioning, leading to improved glycaemic control.

In conclusion, literature has shown that fear of hypoglycaemia is a natural occurrence that occurs due to knowledge of the consequences of the impact of hypoglycaemia and the related complications. As a result, individuals who have high levels of fear adopt coping behaviours that could in turn have a negative impact on glycaemia control, as well as family disruption, among other burdens associated with managing a T1DM child.

4.5 SUMMARY

This chapter presented the findings of the study and related discussions along with the demographic data of the participants. The study found that the parents questioned had some different areas of concern than expected when compared to other study findings in the literature. However, South African parents of young children with T1DM also experience fear of hypoglycaemia and resort to certain behaviours to prevent the occurrence of hypoglycaemia in their children. The findings in this study indicate a need for intervention programmes to educate parents about T1DM and hypoglycaemia, address any fear- and worry-provoking factors, as well as helping parents to adopt coping behaviours that have a positive impact on their glycaemia control and quality of life of the family.

CHAPTER FIVE

SUMMARY OF THE FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

This chapter concludes the study with a summary of the research and the significant findings. The chapter also discusses the research limitations and makes recommendations related to treatment of hypoglycaemia and further research.

5. 2 SUMMARY OF THE STUDY

The study set out to assess the anxiety-provoking aspects of hypoglycaemia, and behaviours used to avoid hypoglycaemia and its consequences, among local parents of children with T1DM living in South Africa. The study was conducted at the children's diabetic outpatient clinic in one of the academic hospitals in the Gauteng province.

The objectives of the study were:

1. To identify aspects suggestive of worry about hypoglycaemia among parents whose children have type 1 diabetes mellitus.

2. To determine the behaviours adopted by parents to prevent hypoglycaemia among children with type 1 diabetes mellitus.

A descriptive and cross-sectional survey design was used for this study. Data were collected from a sample (n=140) using a self-administered Hypoglycaemia Fear Survey – Parent Version (HFS-P) questionnaire scale designed by Clarke et al. (1998).

Raw data were analysed with the help of a bio-statistician using STATA version 13.1. Descriptive and comparative statistics were used to accomplish the objectives of the study. The descriptive tests were computed to describe the symptoms suggestive of worry of hypoglycaemia and behaviour adopted to prevent hypoglycaemia among parents of children with T1DM. Inferential statistics were computed to determine demographic factors and the worry and behaviour subscale scores.

5.3 SUMMARY OF THE MAIN FINDINGS

The demographic-related findings showed that most of the study participants (91.4%) were between the ages of 18 and 49 years and females accounted for 75% of the participants. The majority of the participants (48%; n=68) were married, followed by 44% who were single; and more than half of the participants were the mother of the T1DM child (70%; n=98). Forty seven percent (n=66) of the participants had attained a Grade 8-12 level of education. With regards to the employment status, the number of employed participants (44.3%) was almost the same as the number of unemployed (43.6%).

Most participants reported their child to be female (60.7%; n=85), to never have experienced severe hypoglycaemia (46.4%; n=65), and to always carry emergency glucose (36.4%; n=51), while 86.2% reported that their children did not have any T1DM complications.

In the current study, the Cronbach's alpha coefficient results were 0.90 for the HFS-P worry subscale and 0.73 for the HFS-P behaviour subscale respectively. Both subscales results showed adequate reliability.

The median score in both HFS-P worry subscales and HFS-P behaviour for all the participants was 20 (IQR=20). The HFS-P worry subscales median score of 20 (IQR=20) indicate low levels of fear. In contrast, the same median score of 20 in the HFS-P behaviour subscale indicate moderate hypoglycaemia avoidance behaviour adopted as the median rate lies between 14 and 26 IQR ranges.

The results indicate that female parents were more likely to worry than male parents but males were more likely to implement measures to avoid hypoglycaemia.

In this study, the top four symptoms that parents "always" worried about regarding fear of hypoglycaemia included *"child not recognizing that he\she is having a reaction"* (37.86%; (n=53), *"child not having anything to eat or to drink"* (34%, n=48), *"development of long* *term complications from frequent low blood sugar"* (31.4%, n=44), and *"child having hypoglycaemia with no one around to help"* (30.9%, n=43). However, less than half of the parents in this study (30–38%) rated all of these items as "always".

Aspects related to hypoglycaemia that the parents were least worried about included *"child having an insulin reaction"* with 71% (n=100) "never" worrying about it. Additionally, 66% (n=92) were "never" worried about *"child embarrassing self or family in a social situations"* and 61.4% (n=86) felt the same way about *"child appearing to be stupid or clumsy"*. Almost 50% (n=67) of the parents reported that they "never" worry about *"child having seizures or convulsions".*

The most common avoidant behaviours adopted were parents *"checking child blood sugar often when the child plans to go on an outing"; "giving the child something to eat as soon as the child feels the first signs of low blood sugar"*; *"avoiding leaving the child alone when their blood sugar is likely to be low"* and *"having the child carry fast-sugar"*.

The parents who responded "always" regarding their *"child carrying emergency glucose"* were likely to have a behaviour subscale score 3.60 times higher than that of parents who reported that their child "never" carried emergency glucose.

For the multivariate analysis, when adjusting for all other factors, parents who reported a history of severe hypoglycaemia in their children (i.e. "often") were likely to have a behaviour subscale score 13.36 times higher than that of parents who reported no history of severe hypoglycaemia (i.e. "never") at the 5% significant level (p=0.007).

Parents who reported their child to "always" carry emergency glucose were likely to have a behaviour subscale score 4.51 times higher than that of parents who reported their child to "never" carry emergency glucose, at the 5% significance level (p=0.016).

5.4 LIMITATIONS OF THE STUDY

Some limitations of this study were as follows.

- Data was collected from a single population at an academic hospital in Gauteng. Therefore data cannot be generalised to other children's diabetic outpatient clinics in the province.

- Difficulties were experienced in reaching the target sample size as 15 patients were pre-booked for the clinic service every Monday from 08h00 to 13h00. This resulted in a slow turnover of patients as many were missing their appointments, especially when the weather conditions were not favourable.
- In the majority of studies conducted on fear of hypoglycaemia, the HFS-P is administered to parents at the same time as their children complete their own hypoglycaemia fear survey in order to compare the findings. In this study, it was not possible to collect data from both parents and children due to the limited population using the clinic. Secondly, the clinic serves a mixed group where the very young cannot read and write like the older children. Therefore, collection and comparison of child survey findings was not done.

5.5 RECOMMENDATIONS

5.5.1 Nursing practice, education and training

The following recommendations should be considered by nursing management to be incorporated into nursing practice:

- There is a need to screen parents who are at risk of developing depression by assisting them to manage their children's diabetes better, and protocols can be established with appropriate treatment for specific parents.
- Taking into consideration the impact of fear of hypoglycaemia on glycaemic control and in view of this impact, nurses may need to continuously assess fear of hypoglycaemia parents of children with T1DM using the hypoglycaemia fear survey parent version (HFS-P) with parents during clinic services; the questionnaire only takes about 15 minutes to complete. Parents can complete the questionnaire while waiting, and it can be readily scored within the clinical context; this would help the nurse to know the most important things that parents worry about and what behaviours they are using to prevent hypoglycaemia. In addition this could help the nurse to advise patients on how to treat hypoglycaemia, and how they can recognise their own symptoms of hypoglycaemia and act before it get worse.

- Patient education and diabetes education improves patient outcomes. Patient and their parents or caregivers should be taught about the management and prevention of hypoglycaemia, including the possible complications.
- Support groups for parents of children with T1DM and their families exist at the children's diabetic outpatient clinic. However, effectiveness of these support groups should be continuously evaluated and attendance must be promoted, so that attendees can share ideas, understand each other better and encourage each other.
- Parents of children with T1DM should also be educated about cognitive behavioural therapy to help them recognize their concerns and teach them ways to prevent negative thoughts regarding hypoglycaemia, such as "If my child has hypoglycaemia then my child will have a seizure."

5.5.2 Education and training

The following recommendations should be considered:

- Training other family members to manage the child's diabetes if parents are away.
- Holding workshops to discuss the anxiety-provoking aspects of hypoglycaemia.

5.5.3 Further research

- Further research studies as suggested by Haugstvedt et al. (2015) should be conducted on the psychometric properties of the HFS-P behaviour subscale as the Cronbach's alpha results for the current study and other studies was slightly above 0.7.
- The current study results showed a total score suggestive of low levels of worry and most of the HFS-P worry-provoking factors were not significantly associated with fear of hypoglycaemia. Nonetheless, there is a need for further research on interventions aimed at reducing fear of hypoglycaemia. Literature has shown that fear of hypoglycaemia could predispose parents to psychological distress, which in turn could have negative effects on diabetes management.
- Studies aimed at validating the fear of hypoglycaemia survey scales in the South African context should be conducted**.**

5.6 CONCLUSION

This study identified aspects suggestive of worry about hypoglycaemia and the behaviours adopted to prevent hypoglycaemia among parents of children with type 1 diabetes mellitus in South Africa. The total score for HFS-P worry was found to be low whereas the HFS-P behaviour score showed moderate tendencies to take certain precautions to prevent hypoglycaemia.

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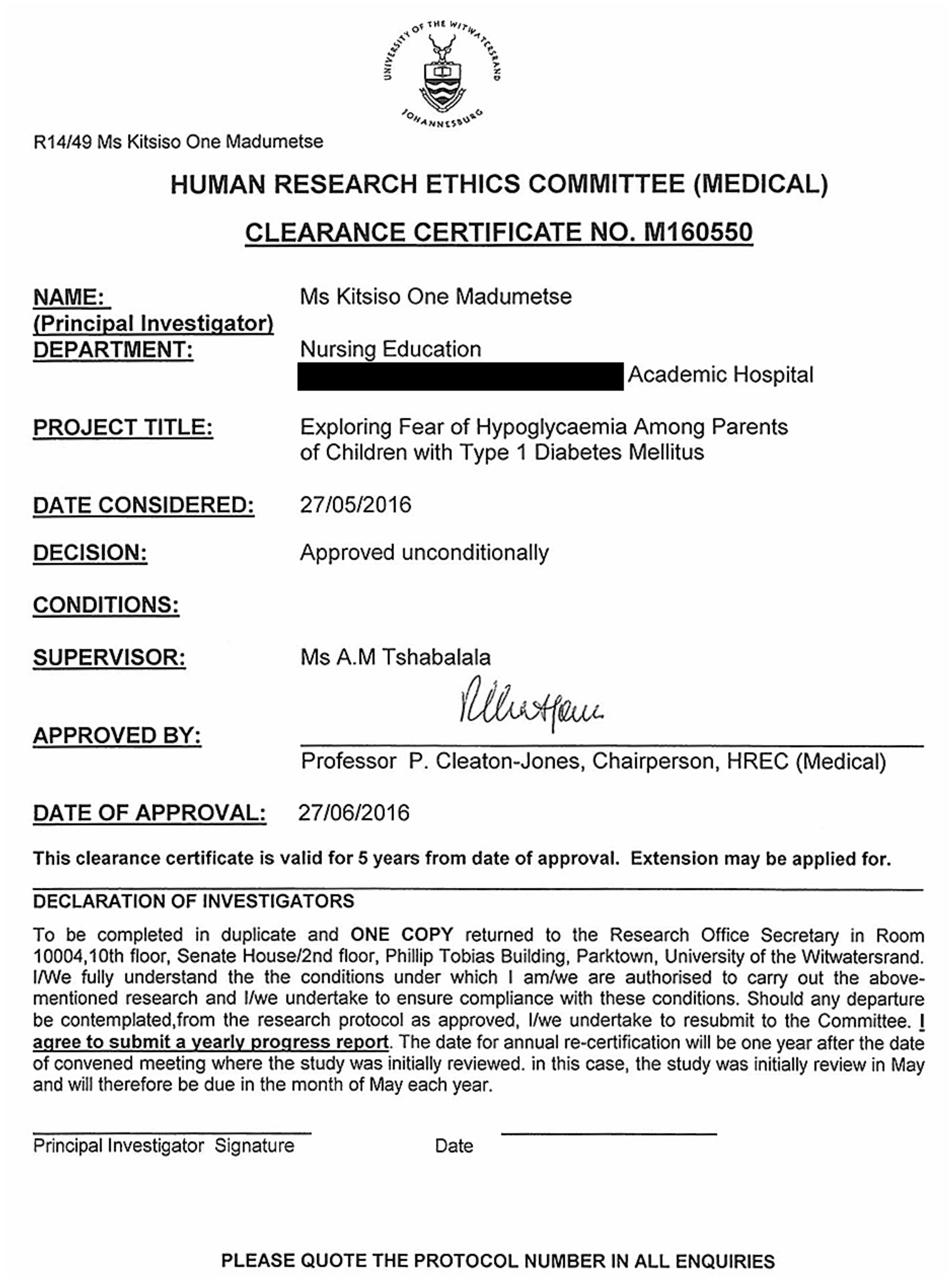
APPENDIX A: ETHICS CLEARANCE CERTIFICATE



R14/49 Ms Kitsiso One Madumetse

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160550

NAME: **(Principal Investigator)**	Ms Kitsiso One Madumetse
DEPARTMENT:	Nursing Education [redacted] Academic Hospital
PROJECT TITLE:	Exploring Fear of Hypoglycaemia Among Parents of Children with Type 1 Diabetes Mellitus
DATE CONSIDERED:	27/05/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms A.M Tshabalala
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	27/06/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

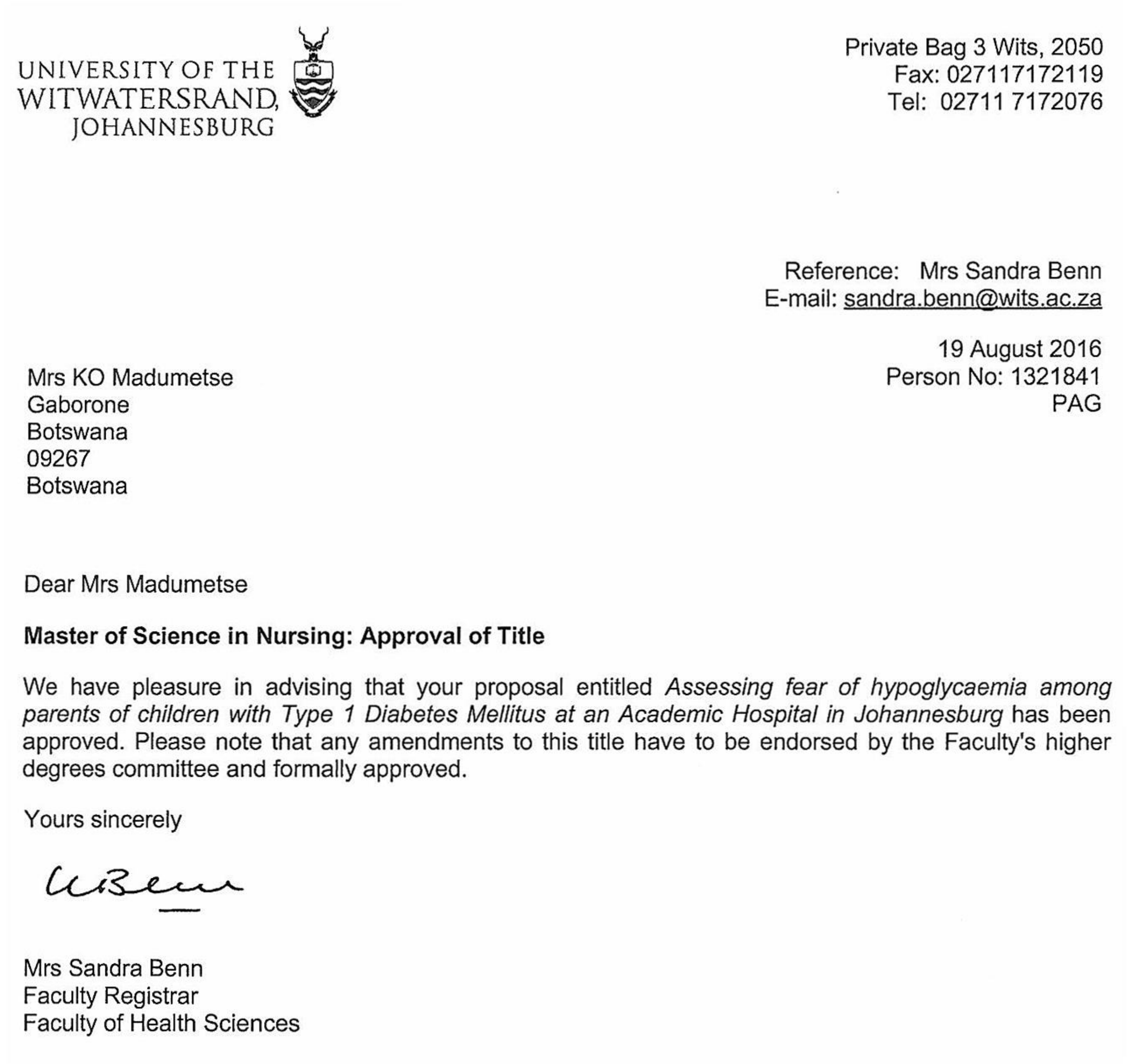
DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated,from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review in May and will therefore be due in the month of May each year.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX B: APPROVAL OF RESEARCH TITLE



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

19 August 2016
Person No: 1321841
PAG

Mrs KO Madumetse
Gaborone
Botswana
09267
Botswana

Dear Mrs Madumetse

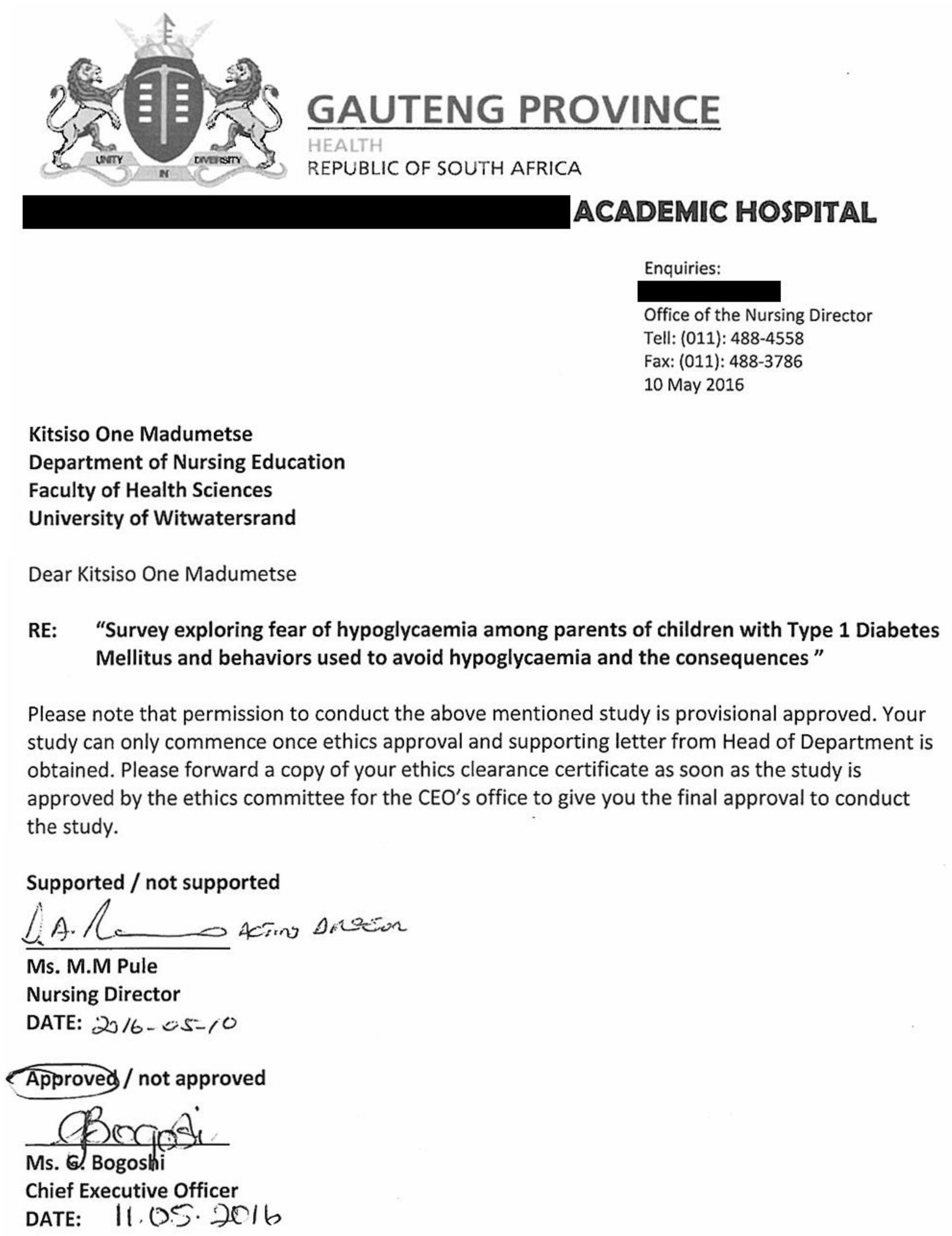
Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Assessing fear of hypoglycaemia among parents of children with Type 1 Diabetes Mellitus at an Academic Hospital in Johannesburg* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX C: PERMISSION TO CONDUCT RESEARCH IN THE HOSPITAL



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

[redacted] ACADEMIC HOSPITAL

Enquiries:
[redacted]
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
10 May 2016

Kitsiso One Madumetse
Department of Nursing Education
Faculty of Health Sciences
University of Witwatersrand

Dear Kitsiso One Madumetse

RE: "Survey exploring fear of hypoglycaemia among parents of children with Type 1 Diabetes Mellitus and behaviors used to avoid hypoglycaemia and the consequences "

Please note that permission to conduct the above mentioned study is provisional approved. Your study can only commence once ethics approval and supporting letter from Head of Department is obtained. Please forward a copy of your ethics clearance certificate as soon as the study is approved by the ethics committee for the CEO's office to give you the final approval to conduct the study.

Supported / not supported

ACTING DIRECTOR

Ms. M.M Pule
Nursing Director
DATE: 2016-05-10

[✓ Approved] / not approved

Bogosi

Ms. G. Bogoshi
Chief Executive Officer
DATE: 11.05.2016

APPENDIX D: PERMISSION TO USE DATA COLLECTION TOOL

From: Gonder-Frederick, Linda *HS [mailto:LAG3G@hscmail.mcc.virginia.edu]
Sent: 14 June 2016 03:04 PM
To: AmmeTshabalala; Lag3g@virginia.edu; Lag3g@hscmail.mcc.viginia.edu
Cc: kitsisowantwa; Grabman, Jesse H *HS
Subject: RE: Request for HSF-P Instrument.

Dear Amme,

Yes, you may use the HFS-P in your research. I am assuming that this is not a study being funded by a pharmaceutical company, which would require a licensing fee. But for research and clinical colleagues, we gladly give permission for the survey to be used.

I am copying this message to my Project Coordinator, Mr. Jesse Grabman, who will send you the survey and a scoring manual. You did not ask for the youth version but if you need this we can send it.

Please let us know if you have any questions and best of luck with your study. We would be very interested in your findings.

Best Regards,

Linda Gonder-Frederick, Ph.D.

APPENDIX E: DATA COLLECTION TOOL

ASSESSING FEAR OF HYPOGLYCAEMIA AMONG PARENTS OF CHILDREN WITH TYPE 1 DIABETES AT CHILDREN'S DIABETIC CLINIC: QUESTIONNAIRE

DEMOGRAPHIC DATA

SECTION A

PARENT/GUARDIAN INFORMATION

1. **Parent's age or Date of birth: ____________________**

2. **Gender of parent/guardian (Please tick the appropriate box)**

Male	**1**
Female	**2**

3. **Marital status**

Married	**1**
Single	**2**
Divorced	**3**
Widowed	**4**

4. **Relationship with child (Please tick the appropriate box)**

Mother	**1**
Father	**2**
Guardian	**3**

5. **Education level (Please tick the appropriate box)**

Never attended school	**1**
Grade 1–3	**2**
Grade 4–7	**3**
Grade 8–12	**4**
Certificate or Diploma	**5**
University Degree	**6**

6. **Employment status (Please tick the appropriate box)**

Employed	**1**
Unemployed	**2**
Pension	**3**
Stay at home parent	**4**

SECTION B: CHILD'S INFORMATION

7. Child's Age OR Date of Birth: ____________________

8. Gender of Child (Please tick the appropriate box)

Male	**1**
Female	**2**

9. Has the child experienced severe hypoglycaemia with unconsciousness? (Please tick the appropriate box)

Never	**1**
Rarely	**2**
Sometimes	**3**
Often	**4**
Always	**5**

10. Does the child carry emergency glucose? (Please tick the appropriate box)

Never	**1**
Rarely	**2**
Sometimes	**3**
Often	**4**
Always	**5**

11. Does the child have any complications of type 1 diabetes? (Please tick the appropriate box)

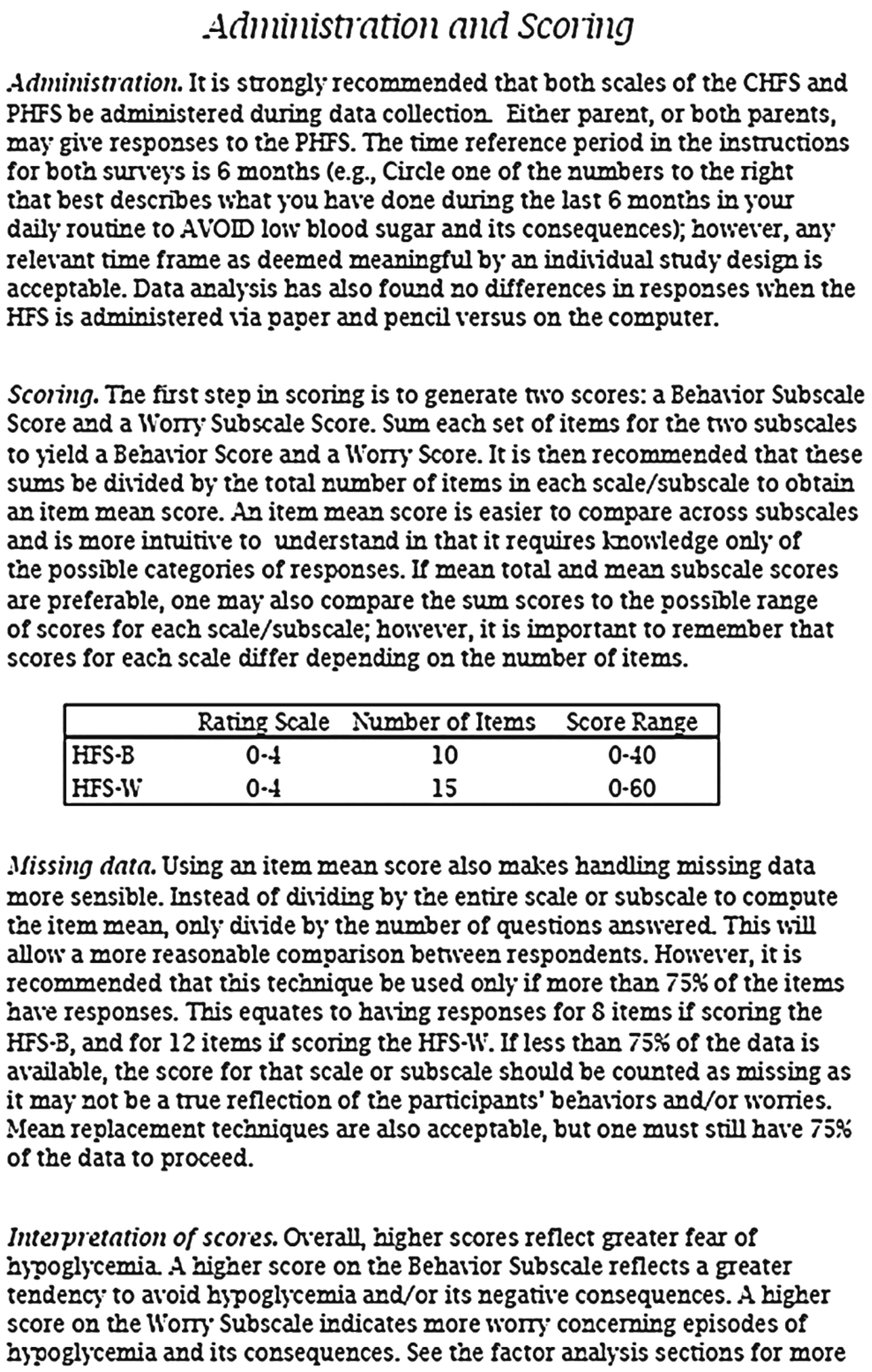
Yes	**1**
No	**2**
Please state	**3**

ASSESSING FEAR OF HYPOGLYCAEMIA AMONGST PARENTS OF CHILDREN WITH TYPE 1 DIABETES AT CHILDREN'S DIABETES CLINIC

Worry subscale	**0** **never**	**1** **rarely**	**2** **sometimes**	**3** **often**	**4** **always**
1. "Child not recognizing that he/she is having a reaction."					
2. "Child not having food, fruit or juice with him/her."					
3. "Child feeling dizzy or passing out in public."					
4. "Child having a reaction while asleep."					
5. "Child embarrassing self or friends/family in a social situation."					
6. "Child having a reaction while alone."					
7. "Child appearing to be 'stupid' or clumsy."					
8. "Child losing control."					
9. "No one being around to help child during a reaction."					
10. "Child making a mistake or having an accident at school."					
11. "Child getting a bad evaluation at school because of something that happens when his/her sugar is low."					
12. "Child having seizures or convulsions."					
13. "Child developing long term complications from frequent low blood sugar."					
14. "Child feeling light-headed or faint."					
15. "Child having an insulin reaction."					
Behaviour subscale					
1. "Have my child eat large snacks at bedtime."					
2. "Avoid having my child being alone when his/her sugar is likely to be low."					
3. "Allow my child's blood sugar to be a little high to be on the safe side."					
4. "Keep my child's sugar higher when he/she will be alone for a while."					
5. "Have my child eat something as soon as he/she feels the first sign of low blood sugar."					
6. "Reduce my child's insulin when I think his/her sugar is too low."					
7. "Keep my child's blood sugar higher when he/she plans to be away from me for a while."					
8. "Have my child carry fast-sugar."					
9. "Have my child avoid a lot of exercise when I think his/her sugar is low."					

10. “Check my child’s sugar often when he/she plans to go on an outing.”					

APPENDIX F: ADMINISTRATION AND SCORING TOOL



Administration and Scoring

Administration. It is strongly recommended that both scales of the CHFS and PHFS be administered during data collection. Either parent, or both parents, may give responses to the PHFS. The time reference period in the instructions for both surveys is 6 months (e.g., Circle one of the numbers to the right that best describes what you have done during the last 6 months in your daily routine to AVOID low blood sugar and its consequences); however, any relevant time frame as deemed meaningful by an individual study design is acceptable. Data analysis has also found no differences in responses when the HFS is administered via paper and pencil versus on the computer.

Scoring. The first step in scoring is to generate two scores: a Behavior Subscale Score and a Worry Subscale Score. Sum each set of items for the two subscales to yield a Behavior Score and a Worry Score. It is then recommended that these sums be divided by the total number of items in each scale/subscale to obtain an item mean score. An item mean score is easier to compare across subscales and is more intuitive to understand in that it requires knowledge only of the possible categories of responses. If mean total and mean subscale scores are preferable, one may also compare the sum scores to the possible range of scores for each scale/subscale; however, it is important to remember that scores for each scale differ depending on the number of items.

	Rating Scale	Number of Items	Score Range
HFS-B	0-4	10	0-40
HFS-W	0-4	15	0-60

Missing data. Using an item mean score also makes handling missing data more sensible. Instead of dividing by the entire scale or subscale to compute the item mean, only divide by the number of questions answered. This will allow a more reasonable comparison between respondents. However, it is recommended that this technique be used only if more than 75% of the items have responses. This equates to having responses for 8 items if scoring the HFS-B, and for 12 items if scoring the HFS-W. If less than 75% of the data is available, the score for that scale or subscale should be counted as missing as it may not be a true reflection of the participants' behaviors and/or worries. Mean replacement techniques are also acceptable, but one must still have 75% of the data to proceed.

Interpretation of scores. Overall, higher scores reflect greater fear of hypoglycemia. A higher score on the Behavior Subscale reflects a greater tendency to avoid hypoglycemia and/or its negative consequences. A higher score on the Worry Subscale indicates more worry concerning episodes of hypoglycemia and its consequences. See the factor analysis sections for more

APPENDIX G: PARTICIPANT INFORMATION SHEET

ASSESSING FEAR OF HYPOGLYCAEMIA AMONG PARENTS OF CHILDREN WITH TYPE 1 DIABETES AT CHILDREN'S DIABETIC CLINIC

Dear Sir or Madam

My name is Kitsiso One Madumetse and I am currently studying for a Master's Degree Student in Child Nursing at the University of the Witwatersrand. As part of the Degree I am required to complete a study under the guidance of a research supervisor. I am conducting a research study assessing fear of hypoglycaemia among parents of children with type 1 diabetes at the Children's Diabetic Clinic at [redacted] Johannesburg Academic Hospital.

Therefore, I would like to invite you to participate in this research study. Your participation in this study is entirely voluntary and there are no risks involved. You have the right to refuse to participate or withdraw from the study at any time without any consequences to you accessing the service in the future. Should you agree to take part in the study, we would like to request that you please sign the attached letter of consent and then fill in the questionnaire. This will take approximately 10–15 minutes to complete. The answers that you will provide to us on the questionnaire will be in our study, however your identity will be protected as neither names nor identifying data will be recorded. Questionnaires are allocated numbers and will be kept separate from the consent letter that you will sign. All completed questionnaires will be kept in a locked desk drawer and the computer analysed data will be password protected and will be accessed by me and my research supervisor only.

Summarized findings of the study will be made available to the CEO of the hospital and the report of the study will be submitted to the University of Witwatersrand for examination purposes.

Thank you for taking your time to read this information sheet. Should you have any queries or need more information please feel free to contact me at: 078 426 4199 or
A.M. Tshabalala, Research Supervisor: Amme.tshabalala@wits.ac.za (011 488 4267/011 488 4272)

If you would like to report any problems or complaints that you have with this research process you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):

Chairperson Prof P. Cleaton-Jones at Tel: 011 717 2301; Email: petercleaton-jones1@wits.ac.za; or Secretariat: Zanele Ndlovu or Langutani Masingi at 011 717 1252/1234 Email: zanele.ndlovu@wits.ac.za or Langutani.Masingi@wits.ac.za

APPENDIX H: PARTICIPANT CONSENT FORM

ASSESSING FEAR OF HYPOGLYCAEMIA AMONG PARENTS OF CHILDREN WITH TYPE 1 DIABETES AT CHILDREN'S DIABETIC CLINIC: PARTICIPANT CONSENT FORM

I ____ (name) have read and understood the information sheet which invites me to take part in the research study: Assessing fear of hypoglycaemia in parents of children with type 1 diabetes.

I understand that:

- Participation will involve me completing a questionnaire.
- Participation is voluntary.
- I may refuse to participate, or withdraw my consent and stop taking part at any time without penalty.
- My identification will not be used when a research report is written.

I hereby freely consent to participate in this research study.

______________________________ ___________________________

Signature of participant Date

If you would like to report any problems or complaints that you have with this research process you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):

Chairperson Prof P. Cleaton-Jones at Tel: 011 717 2301; Email: petercleaton-jones1@wits.ac.za; or Secretariat: Zanele Ndlovu or Langutani Masingi at 011 717 1252/1234 Email: zanele.ndlovu@wits.ac.za or Langutani.Masingi@wits.ac.za