

**CHALLENGES FACING PARENTS OF  
DIABETIC CHILDREN**

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**NOVEMBER 2009**

# **CHALLENGES FACING PARENTS OF DIABETIC CHILDREN**

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A dissertation submitted in partial fulfillment of the requirements for the degree of Masters in Social Work (Family Therapy) by the University of Kwa-Zulu Natal, Durban.

November 2009

Submitted with the approval of my supervisor.

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Dr Reshma Sathiparsad

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Date

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## **DECLARATION**

I declare that the Challenges Facing Parents of Diabetic Children is my own work, that all the sources that I have used or quoted have been appropriately indicated and acknowledged by a complete reference list enclosed, and that this work was not submitted before for any other degree at any other institution.

University of Kwa-Zulu Natal, Durban, November 2009

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SIGNATURE

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DATE

NAME: KUMESHINI PILLAY



## **DEDICATION**

This research is a dedication, to my late dad Mr. Nairainsamy (Craig) Naidoo who passed away on 25/02/2007. Words can never explain the loss we feel and your parting has left a void in our lives. We love and miss you dearly. Continue to be my angel from the heavens above.

## **ACKNOWLEDGEMENTS**

I am deeply appreciative of those who have made this study possible.

The following individuals require special mentioning:

- My supervisor, Dr Reshma Sathiparsad. You were my guardian angel throughout this process. Your valuable support, guidance and understanding was heartwarming and greatly appreciated.
- A big thank you to the participants for participating in this research process.
- Miss Lungileni Duma for translating the consent forms into Zulu and for assisting with translating during the interviews.
- To my husband Nithia Pillay, your constant encouragement definitely kept me going on. Thank you for being my pillar of strength through the good days and the bad. I love you.
- To my darling daughter Lyankha, a big thank you for helping me when I had difficulty with the computer packages. Thank you my angel and remember mummy loves you.

## **ACRONYMS**

<b>DM</b>	Diabetes Mellitus
<b>DKA</b>	Diabetic Ketoacidosis
<b>NGO</b>	Non Governmental Organization
<b>IDF</b>	International Diabetes Foundation
<b>HLA</b>	Human Leukocyte
<b>IDDM</b>	Insulin Dependent Diabetes Mellitus
<b>HHNS</b>	Hyperosomolar Hyperglycemic Nonketotic Syndrome
<b>MDT</b>	Multi Disciplinary Team
<b>MMOL</b>	Millimol
<b>ADA</b>	American Diabetes Association
<b>UN</b>	United Nations
<b>GM</b>	Glucose Monitoring

# **CHALLENGES FACING PARENTS OF DIABETIC CHILDREN**

## **ABSTRACT**

The study aimed to explore, describe and interpret the challenges of the parents who care for diabetic children. The study aimed to attempt to highlight relevant issues that may assist the diabetic team in developing guidelines in managing diabetic children. The data were collected by engaging in face to face in depth interviews with parents of diabetic children who attended the outpatient clinic at a hospital in Durban. The interviews were guided by an interview guide, which allowed the researcher to cover all relevant areas of interest in a logical and uniformed way. The sample consisted of 16 participants, which was racially mixed.

The findings of the study revealed that parents who have diabetic children experience many challenges while some are able to incorporate it into their daily lives others continue to experience problems despite the team involvement and education. Diabetes is a life long disease that requires continued management which includes ongoing education, family support, finances and support from the diabetes team. The study also revealed that caring for a diabetic child is expensive and many families struggle to meet their dietary needs due to financial constraints. The finding further revealed that diabetic children are often affected by the diagnosis and many withdraw from family, friends and social activities. Healthy siblings sometimes do not understand the child's diabetes. In some instances, the parents' relationships are affected as couples do not have couple time and the family's lives are altered and most schools have minimal knowledge of diabetes. Based on these findings, recommendations regarding the required information and assistance to be given to the diabetic patients and family members were formulated. Schools have a role to play and the larger communities require diabetes awareness.

# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 BACKGROUND OF THE STUDY**

Diabetes, which historically has been a phenomenon in older people, has now crept into the lives of young children. Some families are able to manage diabetes whilst some find it difficult, too complex to understand and just give up. Diabetes management is a very demanding responsibility that requires both parent and child to work together in order to successfully control it.

This study is about the parents who care for diabetic children and the challenges that they experience and face in managing this disease. The literature available focuses on juvenile diabetes with limited local studies on the said topic. There is an increase in the number of children diagnosed with diabetes and this is becoming a global concern. Recent statistics indicate that one in every three children will develop diabetes in South Africa ([www.diabetes.com](http://www.diabetes.com)).

The high incidence of diabetes in children is evident locally and internationally. Diabetes affects 246 million people globally and is expected to affect 380 million by 2025. The International Diabetes Foundation (IDF) recently released these alarming figures, as 14<sup>th</sup> November 2007 marked the first United Nations (UN) World Diabetes Day. South Africa has dedicated the entire month of November to diabetes awareness and education around the management of diabetes. National Statistics are also of concern because data indicated that 6-8% of the South African population has diabetes (that accounts for 3.3 million from a population of 47 million) and it is estimated that 1-3 million diabetes sufferers remain undiagnosed. Of great concern is the estimate that one in four children in South Africa has diabetes ([www.diabetes.com](http://www.diabetes.com)).

Diabetes is an international phenomenon. In the United States of America, statistics reveal that one in every three children will develop diabetes in the United States of America. There is an annual 3% increase of children between the preschool and toddler age group contracting diabetes. It was projected that 440 000 children will be living with diabetes by 2007 and there is an increase in deaths caused by diabetic ketoacidosis (DKA) ([www.diabetes.org](http://www.diabetes.org)). According to research conducted in Finland by Hekkala et al (2006:98), the findings concluded that the incidence of DKA in Finland is the highest in the world. The findings concluded that DKA is the leading cause of acute morbidity and mortality in children with type 1 diabetes. The findings reported are those children between the ages of 5 to 9 years as having lowest (11.3%) levels of DKA and an assumption is that parents observe their younger children more closely. Boys had a higher risk of DKA than girls did and children over 10 years had a higher risk (23.1%).

It is possible that teenagers are more secretive of their symptoms and therefore run a higher risk of developing DKA. In South Africa, insulin treatment is available to all diabetic children, and parents have a legal and social obligation to ensure the safety of all their children, especially the diabetic children as it is a fully treatable condition. The aim of the treatment of diabetes is to achieve blood glucose levels as close to the non-diabetic state as possible. Parents' and patients must take full responsibility for their own care and should therefore acquire the knowledge and technical skills to monitor urine and blood glucose, recognize and prevent hypoglycemic / hyperglycemic complications (Ragnar, 2004:12).

Therefore, the purpose of my research was to explore the challenges that families face and to look at how best to help them manage this disease thus preventing repeated admissions. Proper management is likely to result in healthier lives for the child and for families.

## **1.2 RATIONALE FOR THE STUDY**

The researcher works in a tertiary medical setting that treats diabetic children requiring specialized endocrine care so therefore they attend the hospital out-patient clinic. The researcher has observed through supervision that many diabetic children are admitted repeatedly due to acute diabetic ketoacidosis because of poor adherence to the treatment regime. Diabetic ketoacidosis is a severe condition, caused by the lack of insulin or an increase of stress hormones in the body. It is recognizable by high blood glucose levels and ketones in the urine, and occurs in those with type one diabetes. This can result in a diabetic coma if not attended to (Ragnar, 2004:7).

Therefore, my interest was stimulated to explore how parents coped in managing their children's diabetes. Diabetes is a chronic but manageable condition and the researcher is of the opinion that no child should die of diabetes. My observations indicated that many parents lack proper guidance and education to manage this condition in the family. The family's difficulty in managing the disease may result in the child presenting with complications related to the diabetes. The researcher is further of the opinion that, if social workers are aware and understand the challenges that the parents face in managing their child's diabetes, then perhaps we, as medical social workers, may be able to provide supportive networks to help families to increase adherence and compliancy. I was not involved in rendering services to diabetic children at the time of the study but observed these concerns during supervision sessions with the respective social worker concerned.

Diabetes is a chronic disorder characterized by high levels of glucose in the blood. Juvenile diabetes is also termed type 1 or insulin dependent diabetes. It is a chronic disease and requires life long management. Zimmerman and Walker (1999:12) define juvenile diabetes as the absence of sufficient insulin in the body, which results in a diabetic diagnosis. Insulin replacement requires careful administration with the use of monitoring tools.

Diabetic ketoacidosis can develop and result in a coma or possible death if no insulin is administered. Type 1 diabetes treatment is a life long condition that one has to accept and live with. It requires ongoing education, management and support from family and relevant role players in order to ensure adherence. Type 1 diabetes occurs when the pancreas loses its ability to produce adequate insulin that is required by the body. It is common in children diagnosed between 2- 16 years of age. Diabetes requires the family to make changes to their daily lifestyle and routines. Parents and children need to take responsibility for their treatment and take charge of their lives.

When a child has diabetes, many reactions and mixed feelings surface in the parent. As a social worker at the hospital, the following have been some responses from parents upon hearing of their child's diagnosis:

*"Oh, no, this cannot be. I cannot believe this.*

*Is this really happening to my child? What can I do to fix it?*

*How is my child going to cope?*

*What wrong did I do and why is God punishing me?*

*No! No! I cannot inject my child. How could I do this"?*

These responses demonstrate the extent to which parents feel overwhelmed at the thought of having to manage the disease in their child. They may start to wonder how they are going to juggle all these added responsibilities into their daily lives. According to Gard et al (1997:126) and Hillson (1996:162) when there is an absence of professional guidance, some parents may become over-protective and this may instill negative feelings or behavior that will inevitably lead to negative clinical outcomes. Many parents go through the bereavement process when their child has a chronic illness. This is more evident when the parent has the same illness and there may be much self-blame. Hillson (1996:162) states that during the first year and at special occasions, parents of diabetic children may experience feelings of grief, sadness, anger and resentment.



The parent may direct anger towards the child for being diagnosed with the illness although the parent may realize that this anger is illogical. The parent may ventilate this anger towards the spouse, another child or any object.

A further rationale for my study is provided by Gard et al (1997:127) who states that parents who have children with a chronic illness have concerns regarding whether they are able to understand the medical terminology and are able to communicate with the health professionals. They are also concerned about their reactions to the diagnosis, the limitations this disease may place on their lives, the effect this diagnosis will have on the other children in the home and the impact it will have on their socialization with family and friends. Davis (2001:87) further illustrates in his study on the impact of the illness on parents which concluded that parental warmth increased adherence while restrictions decreased adherence. They also found that parents of diabetic children use less limit setting with their children than parents who have healthy (non-diabetic) children. This is so because the diabetic child has so many existing rules which pertain to treatment that the parents do not want to further frustrate or burden the child and therefore tend to be very lenient with them.

A further study to support my topic is provided by Daneman et al (1999:159) who concluded that parents who have healthy attitudes towards management of a chronic disease help their children to adjust and accept the diagnosis. Children respond to the cues that they get from their parents and are more likely to comply with the treatment, when their parents are consistent in their approach to managing the diabetes. Families depend largely on their attitudes and beliefs to cope with the diabetes. Both parents should be involved in the management to prevent burnout and this will increase adherence. Both parents and children need ongoing information to keep them motivated to ensure adherence and this will ultimately provide positive clinical outcomes. Diabetes forces the parent and child to learn new skills whether they are ready or not.

Some examples are the ability to do glucose monitoring, locating an injection site, administering the insulin, adjusting meal plans and identifying highs and lows of diabetes. This additional responsibility is likely to affect family relationships. This clearly indicates that diabetes is a life changing experience and it imposes change to a family's routine and sometimes forces them to make changes whether they are ready or not.

The ultimate aim of the study was to gain a better understanding of the challenges that the parents and families face in managing the disease. The research findings will provide some guidelines for the helping professions especially social workers in providing appropriate services to the diabetic patient, parents and family. The findings may provide a framework when structuring individual, family interviews, educational programs and support groups. This study intended to provide participants an opportunity to open up and talk about their experiences, feelings and challenges that they face in managing their diabetic children. This study was conducted with the hope of not only being therapeutic but also to contribute to the existing body of knowledge, may refute or concur with previous findings and authors. Furthermore, it may help guide the hospital professionals in understanding the uniqueness of each patient. This study focused on the challenges facing parents of diabetic children and it is evident that the hospital is rendering professional guidance, support and education to the diabetic children and their parents but this study provided evidence that there are still gaps in the aftercare and the community support services for a continuity of care. Despite the medical team approach, some parent's still continue to struggle with diabetes management.

As indicated previously, diabetes mellitus (Type 1) is a major chronic disease and it affects millions of adults and children worldwide. Pediatric diabetics are dependent on their parents for management and a good quality of life. Poor adherence to the treatment regime results in poor clinical outcomes for the child.

The hospital, in which I am practicing social work, has a paediatric diabetic clinic, which treats children who require specialized endocrine care and continued management. The present number of children attending the clinic range from 150 to 180 per month. They require hands on management because of poor adherence to the treatment program. The diabetic team members, comprising of the endocrine doctor, diabetic nurse, dietician, psychologist and social worker engage with the patients and their families. Despite this engagement, some patients do not adhere to the treatment program.

The repeated admissions of some children are due to acute ketoacidosis and these force the team to suggest a removal of the child to a children's home or alternative care. There appears to be a high percentage in the hospitalization of diabetic children because their conditions tend to deteriorate at home. Health professionals are concerned that if the child is not managed appropriately at home, further complications may arise. According to Ragnar (2004:7) in extreme cases, this could lead to the possible death of the child. It is the parent's responsibility to understand the magnitude of the disease and the importance of adherence to the treatment regime (Ragnar, 2004:7).

The assumption underlying this study is that parents feel overwhelmed by the disease and therefore perceive difficulty in managing the diabetes. The lack of proper education, support and guidance results in poor monitoring of diabetic children and lead to repeated admissions.

This study aimed at exploring the experiences of parents who care for diabetic children with more specifically the challenges, their first reaction to the diagnosis, the factors which hindered or promoted their adherence and if they are able to incorporate diabetes into their lives and their needs.

The researcher was interested in finding out what the challenges are and the impact of diabetes on the families' adherence to the treatment plan. Once these causes are identified, then recommendations can be made which might improve their adherence to the diabetes treatment plan.

### **1.3 RESEARCH OBJECTIVES**

- ❖ *To explore the parents' initial reactions and attitudes to the child's diagnosis.*
- ❖ *To ascertain to what extent parents are able to incorporate diabetes into their lives.*
- ❖ *To gain insight into the challenges that parents face.*
- ❖ *To ascertain factors that hinder / promote the parents' management of the disease.*
- ❖ *To identify the needs of parents to help them effectively manage the disease.*

### **1.4 RESEARCH QUESTIONS**

- ❖ What were the parents' initial reactions / attitudes to the child's diagnosis?
- ❖ To what extent are parents'/families able to make diabetes part of their life?
- ❖ What challenges do parents' face?
- ❖ What factors hinder or promote the parents' management of the disease?
- ❖ What are the parents' further needs to help them effectively manage the disease?

## **1.5 SIGNIFICANCE OF THE STUDY**

This study can be significant in providing information regarding the knowledge the diabetic children and families have on diabetes mellitus, its treatment and the challenges that they face in its treatment. This will also guide the helping professionals to provide the type of information that the families and children need to help them cultivate a positive view of diabetes, the treatment and management with special reference to the individuals who have negative views and attitudes of the disease. This topic was not previously researched at my place of employment and it will provide valuable information to the diabetic team. The findings will help the professionals to develop guidelines to help the parents to become better caregivers and protect the already disadvantaged children to live a healthy and normal life without major disruptions. Furthermore, it will help health personnel to understand the uniqueness of the individuals and understand the difficulties that they experience on a daily basis and to accept the patients as they are. Hopefully parents and the patients realize the importance of adhering to the treatment regimes which will ultimately decrease or prevent complications.

The functions of the social worker have to be involved as broadly as possible in the patient's situation. The intervention starts with prevention followed by assessments for social work services. This can be attained by having the social worker as a member of the team. The social worker undertakes a thorough assessment of the patient's social, psychological and environmental strengths and weaknesses. These findings will enable the team to understand the patients and their families better and hence provide the needed services with sensitivity.

## 1.6 THEORETICAL FRAMEWORKS GUIDING THE STUDY

Two models were used to guide this study, namely the ecological and the biopsychosocial models. I was of the opinion that these approaches best suited the study because the focus was the family system. Furthermore, these models allowed me to understand the impact the individual system and the disease has on the family system. Ecology according to Meyer et al (1996: 71) *“is a science that is concerned with the adaptive fit of organisms and their environment.” It is further concerned with the “The ideas that reflect the transactional patterns or process that exist in nature and how humans relate to these through mutual adaptation”* (Meyer, 1996:19).

Meyer et al (1996:19) and Rothery (1999:129) agree that the ecological perspective adds a new dimension that is the “Goodness of fit” that links clients to their social and physical environment. The goodness of fit can be understood in terms of the demand and resource factors. The environment always places demands on people in that it constantly presents itself with the stressors that require us to adapt. These are often termed stress, problems and / or concerns that require us to adapt. Although this sounds harmful but when we say demand, it is less negative. These demands may be challenging and it helps to re-energize the individual (Rothery, 1999: 129). An example: Diabetes diagnosis- how do I cope. When a child is diagnosed with diabetes, the family system is disrupted and the existing roles need changing. The child and parents take on additional roles thus disrupting the family’s daily routines. Siblings are affected and the child has regular disruption to his / her schooling to attend monthly medical monitoring and sometimes admissions. The environment will provide us with access to resources to help us meet the demands. The diabetes is a demand and if we are lucky, then the hospital has the resources to help us adapt.

In using the ecological model, we can say that the child is part of a number of other micro systems which starts from their immediate families and which then includes the extended family support systems, the school, the neighborhood, the religious organizations and the larger community within which they live. These systems play a part in shaping an individual and what is significant is that when there is a change in one system it has a ripple effect on the individual's interaction with other micro systems. This then highlights the role the hospital system plays in providing medical information, support and guidance, the school plays a role to support the child with the administration of insulin at school and to help understand and identify when the child is ill. Furthermore, the family systems goes through changes and it is important for the hospital micro system to play a role by providing medical support, education and monitoring to assist the family to adapt and adjust to these added responsibilities. Diabetes affects the functioning of the family, their socializing with family and friends and it forces change. Furthermore, it affects the child's functioning at school and his/her interaction with friends.

Rothery (1999:129) supports the above and states that when we access adequate support and it is plentiful, individuals can cope effectively with the demand that the environment places and the "goodness of fit" will compliment the environment. However, if the support and resources are poor, then the individual will not cope well and he/she will become stressed. The ecological model was relevant to this study because the diabetic child is viewed in interaction with their environment as far as us understanding the parent's challenges, come up with recommendations and how the medical professionals can provide resources to benefit the affected child and parents.

The second model that was used was the biopsychosocial model because in a medical setting, it is imperative that the multi-disciplinary team engages with patients because we believe that the actions at the biological, psychological and social level are interrelated and that these relationships can affect both the processes and outcomes of care.

According to Marks et al (2004:56-57) the biopsychosocial model states that disease and illness do not manifest themselves only in terms of patho-physiology (definition in section 1.8), but may also affect the levels of functioning from the organ, to the person, family and society.

Marks et al (2006:17) further elaborate that the biopsychosocial model accepts that people are complex biopsychosocial systems and this in itself states that no single discipline can adequately explain human development and behavior. Therefore, it is important to note that it is necessary to use the information obtained from the psychologist, social worker, dietician, nurse and the endocrine doctor when attempting to manage a diabetic patient. This model claims that health and illness is a product of the combination of biological, behavioral, psychological and social perspectives. A child presenting with diabetes may be experiencing psychological or social problems that may affect their level of understanding and adherence to the treatment (Marks et al, 2006:17).

The biopsychosocial model allows for holistic assessments and it offers professionals the opportunity to work with people from across disciplines in an effort to provide the best possible service thus promoting good clinical outcomes (Marks et al, 2006:17). The social worker engages with the child, family, community and resources to ensure ongoing services and continuation of care in the community. Although diabetes is a medical condition, it requires a multi faceted approach to understand and optimally manage it. Therefore, the researcher is of the opinion that the biopsychosocial model together with the ecological model best suits this study.



## 1.7. RESEARCH METHODOLOGY

### *1.7.1 Research Design*

A brief overview of the research methods used in this study is discussed in this section. Chapter 3 will describe the methodology in detail. The research was a qualitative study and Denzin and Lincoln (1994:2) defines a qualitative research as *“a multiperspective approach to social interaction, aimed at describing, making sense of, interpreting or reconstructing this interaction in terms of the meanings that the subjects attach to it”*.

A combination of the exploratory and the descriptive designs were used to guide this study. These research designs were appropriate to this study because the topic was not investigated previously in my work setting and according to Babbie and Mouton (2001:85) exploratory studies are valuable to social science research because they are necessary when a researcher is finding new information, it satisfies the curiosity and understanding of the researcher's topic of interest. Furthermore, the descriptive design was appropriate because it complemented the study in that it allowed the participants to relate their experiences and describe their daily situations as they experience them. It also allowed the researcher to obtain reliable information by asking individuals that are suitable for inclusion in a study, a set of questions as stated by Pilot and Hungler (1993: 195-200). The interviews were audio recorded and transcribed.

### ***1.7.2 Sampling and Data Collection***

During the period of study, a sample of 16 parents was selected from the population of children who attend the paediatric diabetic clinic at the tertiary state hospital. Polit & Hungler (1993:445) defines a sample as a subset of a population selected to participate in a research study. A convenience sampling method was applied to recruit the participants because they were easily accessible to me. Grbich (1999:70) defines a convenience sampling as a method used where the aim is to locate a group of people as quickly as possible in order to maximize convenience and minimize cost. I met the families at the clinic and informed them of the study, sample size, criteria, and recruited volunteers to participate in the study. I was able to recruit 16 parents whose children ranged from 2 – 13 years of age, diagnosed in the last 3 years and the sample was racially representative. These factors met my target criterias. Individual in depth face-to-face interviews were held with each participant. These appointments coincided with their hospital appointments. An interview guide was used during the interview process. The datum were collected by transcribing the tape recordings.

### ***1.7.3 Data Analysis***

The datum was organized and analyzed using thematic content analysis. The transcripts formed the main datum source. The content analysis method was applied as it suited the study because of the volume of datum obtained. According to Weber (1990: 12–15) content analysis enables a researcher to sift through large volumes of datum with relative ease in a systematic fashion. It is also further useful for examining trends and patterns in documents. The data analysis is explained in detail in Chapter 3.

## 1.8 OPERATIONAL DEFINITIONS

This section provides definitions that are relevant to the study.

- ❖ Diabetes a condition in which the body cannot produce insulin or cannot use insulin properly. Insulin is necessary for the pancreas to be able to work adequately. This helps to keep the glucose at desired levels between and after meals. This condition is characterized by high blood sugar levels.
- ❖ Blood Sugar a common term, used in South Africa to refer to blood glucose.
- ❖ Blood glucose self-monitoring when a diabetic measure his/her own blood glucose levels regularly with the use of home monitoring tools. This is required so that the diabetic can track if the amount of insulin he/she is taking is effective to manage the diabetes. The patient can also monitor the hypoglycemic or hyperglycemic episodes.
- ❖ Blood glucose levels the amount of glucose in the blood, which is measured in millimol (mmol) per liter
- ❖ Glucose a simple form of sugar that acts as the body's fuel.
- ❖ Hyperglycemia a condition in which blood glucose levels are higher than 10 millimol (mmol) per liter. The condition is characterized by frequent urination, thirst, blurred vision
- ❖ Hypoglycemia a condition of extremely low levels of blood glucose. The condition can quickly lead impairment and unconsciousness if not treated.

- ❖ Insulin a hormone that is produced by the pancreas that helps the body use glucose.
- ❖ Diabetic Ketoacidosis (DKA) a severe condition, caused by the lack of insulin or an increase of stress hormones in the body. It is recognizable by high blood glucose levels and ketones in the urine, and occurs in those with type one diabetic. This can result in a diabetic coma if not attended too.
- ❖ A Child according to the South African Constitution, Act 108 of 1996, a child is any person under the age of 18 years.
- ❖ Patho-physiology the study of the detailed malfunctioning of the bodily functions that comes from or alternatively causes diseases. It is the study of the diseases on the body.

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## **1.9 PRESENTATION OF CONTENTS**

The researcher introduced and provided a broad overview of the study in Chapter one. The background of the study, rationale, value of the study, objectives of the study and the research questions has been briefly discussed. The operational definitions used in the study were included and defined. The remainder of this report is divided into the following chapters:

- Chapter two consist of the literature review
- Chapter three details the research methodology
- Chapter four provides an analysis and discussion of the results of the study
- Chapter 5 outlines the main findings, conclusions and recommendations drawn from the study.

## **1.10 CONCLUSION**

This Chapter provided an overview of the study. The background and research problem was put into context and supported by references to the literature. The purpose of the study, the research objectives, significance of the study to the medical setting has been described and the operational definitions pertaining to the study have been provided. A brief outline of the research methodology, method of datum analysis and an outline of the chapters were given. The next chapter contains the literature review on diabetes mellitus and the family is included.

## **CHAPTER TWO**

### **LITERATURE REVIEW – TYPE 1 / JUVENILE DIABETES MELLITUS**

#### **2.1. INTRODUCTION**

This chapter provides an overview of diabetes with a focus on the aspects that are relevant to the families with diabetic children. The literature review focuses on diabetes mellitus with specific reference to type one diabetes. The different insulin types and treatment available, storage of insulin, causes of diabetes, relevant definitions, symptoms, complications, related diseases, the effects of the diabetes on the child and family, parental management and the role of the multidisciplinary team in the management of the disease and challenges faced by the social worker will be included in this chapter.

#### **2.2 WHAT IS DIABETES MELLITUS**

Diabetes is a disease in which blood glucose levels are above normal. People with diabetes have problems converting food to energy. After a meal, food is broken down into a sugar called glucose, which is carried by the blood to cells throughout the body (Ragnar, 2004:2-3). Cells use insulin, a hormone made in the pancreas, to help them convert blood glucose into energy. People develop diabetes because the pancreas does not make enough insulin or because the cells in the muscles, liver, and fat do not use insulin properly, or both. As a result, the amount of glucose in the blood increases while the cells are starved of energy.

According to Ragnar (2004:2-3) over the years hyperglycaemia also commonly known as high blood glucose damages nerves and blood vessels, which can lead to complications such as heart disease and stroke, kidney disease, blindness, nerve problems, gum infections, and amputation.

Juvenile Diabetes Mellitus is known as Type 1 diabetes or insulin dependent diabetes and it is a chronic condition, which requires lifelong management and it is characterized by an elevation of the level of glucose in the blood (Hillson, 1992:9). It requires ongoing education and support from the family and the relevant role players in order to ensure compliancy. Type 1 diabetes, is when the pancreas loses the ability to produce adequate insulin needed by the body and it is commonly found in children who are diagnosed between the ages of 2 – 16 years of age (Hillson, 1992:9).

*“Just twenty years ago, the best information available suggested that 30 million people had diabetes but now a bleaker picture has emerged. Diabetes is fast becoming the epidemic of the 21<sup>st</sup> century”* Diabetes Focus (2007: 54). November 14<sup>th</sup> is dedicated to World Diabetes Day. This started in 2007 and it calls for all United Nations Member States to observe the day and all nations to develop national policies for the prevention, treatment and care of diabetes. Diabetes is responsible for close to four million deaths every year. It is a leading cause of heart attacks, stroke, blindness, kidney failure and amputations. (www.diabetes.com)

Diabetes involves a lifetime of treatment with insulin, but it also requires changes to a family's daily lifestyles and routines (Ragnar, 2004: 4). He is of the opinion that parents and their children need to take responsibility for their treatment and to take charge of their lives. He further elaborated this statement by *“you can control the diabetes rather than the diabetes controlling you”* (Ragnar, 2004: 5). This opinion clearly emphasizes that diabetes is a disease that requires hands on management and support from the parents and the professional team to ensure adherence and compliancy.

In support to this statement Yousef (1993:29) states that apart from the impact of the physical development this condition may have, there are various effects on the psychological and behavioural development of a child.

## **2.3 PREVALENCE OF THE DISEASE**

According to the Diabetes Focus (2007:16-17, 54) more than 70000 children develop diabetes annually with a projected 3% rise of new diagnosis. South East Asia had the highest number of children living with type 1 diabetes with an increase noted in low prevalence areas like Central and Eastern Europe. Among the young, type 2 diabetes accounted for 2-3 % of all types of diabetes. Type 2 is an emerging problem and it has potentially serious outcomes, especially in the ethnic communities. 440 000 children were projected to be living with type 1 diabetes in 2007. It further provided that there is an increase in deaths caused by diabetic ketoacidosis. Statistics reveals that more than 200 children per day develop diabetes globally. It is one of the most chronic disease-affecting children in their childhood and can present in children as early as toddlers or preschool years. There is an annual 3% increase of children diagnosed between the preschool and toddlers age group. The recent data revealed that 1 in every 3 USA children will develop diabetes during their lifetime and children belonging to an ethnic group are 1 to every 2 children. Diabetes, which was once considered a disease for the elderly, has crept into the lives of our young children. This trend is more prevalent in the low to middle - income countries and many of these children die because they are diagnosed late and or misdiagnosed (Diabetes Focus, 2007:16-17, 54).

According to the Diabetes website ([www.diabetes.org](http://www.diabetes.org)), the high incidence of diabetes in children is evident locally and internationally. Diabetes currently affects 246 million people globally and it is expected to affect 380 million by 2025 ([www.diabetes.com](http://www.diabetes.com)).



## 2.4 TYPES OF DIABETES

The most common types of diabetes are type 1, type 2 and gestational diabetes. All the types of diabetes have similar symptoms because all are characterized by too much of glucose/sugar in the blood. Our cells use glucose as a source of energy to stay alive. The body's inability to use glucose from the blood is different for type 1 and type 2 diabetes. The following provides a brief overview of the different types of diabetes:

### 2.4.1 Type 1 Diabetes

Type 1 diabetes is also termed “juvenile diabetes” because majority of the cases of diabetes was reported in children or young teenagers. In this type of diabetes, the body cannot make insulin. Type 1 diabetes is usually due to an autoimmune destruction of the pancreatic beta cells. The immune system by mistake attacks the cells in the pancreas that make and release insulin. As the cells die, the blood sugar levels rise. Type 1 diabetics are treated with insulin. Ragnar (2004:29) defines juvenile diabetes as “*a long error of carbohydrate metabolism resulting from a relative or absolute deficiency of insulin caused by the destruction of the beta cells in the islets of Langerhans*”.

The replacement of the insulin must be combined with careful monitoring of the blood glucose levels by using the monitoring tools. Diabetic ketoacidosis can develop and result in a coma or death without insulin. The medical team, emphasize lifestyle changes namely altering the diet and exercising, but this cannot reverse the loss of insulin production. The average glucose levels for type 1 diabetics are between 4 – 6 millimols per litre (mmol/l) (Ragnar, 2004:29-30).

### ***2.4.2 Type 2 Diabetes***

Davis (2001:39) states that type 2 is the most common form of diabetes and it develops in adulthood. The body does not make enough insulin, or it does not properly use the insulin your body makes. This type of diabetes is characterized by high levels of insulin in the blood, which is referred to as hyperglycemia. This can lead to serious health problems. Lowering blood sugar levels is the main key to managing diabetes. High blood sugar levels can cause harm to one's organs and increases the risk of heart disease. Oral medication and increased physical activity is prescribed, as part of the treatment plan.

The medication can improve the hyperglycemia. He further states that the disease is progressive and sometimes the need for insulin is necessary. The individual with type 2 diabetes may go unnoticed for years because the symptoms are mild and the individual does not present with ketoacidosis. The diabetes may be detected and diagnosed only when one has routine bloods or an examination. Risk factors for type 2 are central obesity, adult and childhood obesity, aging and family history. In the last decade, type 2 diabetes is increasingly affecting children and adolescence because we have a higher prevalence of childhood obesity (Davis, 2001:39-40).

### ***2.4.3 Gestational Diabetes***

Gestational diabetes only appears during pregnancy in woman without any previous history. It occurs in about 2 % – 5% of all pregnancies and may improve but usually resolves itself with the delivery of the child. It is treatable and requires careful medical supervision throughout the pregnancy. About 20% - 50% of woman affected develop type 2 diabetes later on in their lives (Ragnar, 2004:30).

## 2.5 THE DIFFERENT CAUSES OF JUVENILE DIABETES

There has been an alarming increase of incidences of newly diagnosed diabetic children. The reasons for this are uncertain. According to Davis (2001:38), *“Childhood or juvenile diabetes is now recognized as being multifactor etiology, an autoimmune condition with a genetic basis and coupled with unknown environmental triggers.”*

### 2.5.1 Hereditary / Genetics

According to Brewer (2005:8-9) diabetes tends to run in families and this suggests that certain genes are involved. Not everybody with these genes will develop diabetes but statistics reveal that the child has a 1 – 20 chance if the father has diabetes, 1 – 40 if only the mother is diabetic and if both parents are diabetic, the chance of the child developing diabetes at some stage in their life is around 1 in 20. People do not inherit type 2 diabetes mellitus, but they inherit a genetic predisposition towards developing type 1 diabetes. About 10% of children who develop diabetes have a sibling or parent with the disorder, whereas only 1% of non-diabetic children have a diabetic relative.

Two conclusions emerged from Blooms study (1980: 12), in that there is undoubtedly a hereditary component in the transmission of the diabetes, however, since 90% of children developing diabetes have nobody in the immediate family with the disorder, the hereditary factor cannot be the only factor and it is probably not the most important. His research further indicates that it is unlikely that the *“hereditary disposition to diabetes is due to a single recessive gene but rather that there are varying combinations that are responsible”*. According to Eisenbarth (1996:287-288) who supports the allele theory, the natural history of diabetes mellitus begins with genetic susceptibility.

Essentially everyone who develops type 1 diabetes mellitus has inherited susceptibility alleles, except for individuals with the autoimmune polyendocrine syndrome type 1 where a major portion of this susceptibility is mapped to the human leukocyte (HLA) region of chromosome 6. The risk of developing type 1 diabetes is five times greater in people who have this type of human leukocyte (HLA) (Eisenbarth, 1996:287-288).

### ***2.5.2 Environmental Factors***

It has been said that certain viruses or toxins may precipitate the autoimmune process that leads to the destruction of the beta cells. This is still not fully understood. Viral infections may cause insulin independent diabetes mellitus (IDDM). Evidence indicates that there is an onset of IDDM following a childhood viral infection (Ragnar,2003:30). According to Guthrie & Guthrie (2002: 245) infections and fever also increases blood glucose levels by activating the adrenal medulla and cortex. An elevated blood glucose level supports the infectious process.

### ***2.5.3 Drugs***

A number of prescription drugs are known to increase blood glucose levels including corticosteroids and drugs used to treat high blood pressure (Brewer, 2005: 13).

### ***2.5.4 Age***

According to Brewer (2005:12) type 1 diabetes is essentially a disease that strikes the young. The older one gets the higher the risk of developing type 2 diabetes. However, the epidemic of obesity, unhealthy eating and sedentary lifestyles now gripping the western world that type 2 diabetes has been seen in children as young as 13 years.

### ***2.5.5 Activity Levels / Obesity***

The day-to-day level of activity is a real factor in diabetes. Choosing a sedentary lifestyle instead of walking, playing sport and not exercising significantly increases the risks of developing type 2 diabetes. Exercise increases the sensitivity of muscle cells to insulin. Slim people who exercise regularly are almost 5 times less likely to develop diabetes than overweight people who lead sedentary lives. Obesity is a major risk factor for type 2 diabetes. According to Brewer (2005:13) an obese man is 7 times more likely to develop type 2 while an obese woman is 27 times more likely to do so. The apple shape obesity in which excessive fat is stored around the midriff indicates higher risk of developing diabetes. This pattern of fat storage is seen much more in men but it is now becoming more common in women too.

## **2.6 SYMPTOMS ASSOCIATED WITH JUVENILE DIABETES**

The researcher's understanding of diabetes, somewhat limited, point to an imbalance in the endocrine system. The pancreas does not produce sufficient insulin and there is an increase of sugar in the blood. This sugar blocks the energy system and the body tries to create a balance by excreting it through the kidney, via frequent urination. According to Guthrie & Guthrie (2002:244), the literature confirms that the individual becomes thirsty because of the frequent urination and therefore consumes large amounts of water. All people with diabetes have one thing in common and that is that they have too much glucose or sugar in their blood. The diabetes can be either poorly or well controlled. When blood sugar levels are low, it is referred to as hypoglycemia and when it is high, it is called hyperglycemia. The differences between the two will be discussed:

### ***2.6.1 Low blood sugar levels / Hypoglycemia***

According to Guthrie & Guthrie (2002:63–64) hypoglycemia is caused when there is an overdose of insulin, too little intake of food, or not often enough and when one exercise more than usual. The diabetic patient will present with hunger, nervousness, trembling, shakiness, sleepiness, anxiety, irritability, confusion, fast pulse and palpitations, tingling lips, going pale, trouble speaking and feeling anxious or weak. It is recommended, that when the blood sugar levels are low, one should eat or drink a small amount of something sweet and retest after 15 minutes. Repeated severe hypoglycemic states might cause brain damage and death which is rare but most deaths occur from ketoacidosis (Refer to Section 1.8). This can be prevented with good management, proper education and access to a diabetic team (Guthrie & Guthrie, 2002:239-241).

### ***2.6.2 Extremely high blood sugar levels/ Hyperglycemia***

Extremely high blood sugar levels can lead to two life-threatening conditions:

#### ***2.6.2.1 Hyperosmolar hyperglycemia Nonketotic Syndrome (HHNS)***

According to Guthrie & Guthrie (2002:72, 244 -245) HHNS can happen in both type 1 and type 2 diabetics. HHNS is usually caused by illness, infection or when the diabetic individual misses doses of medication over a period. The blood sugar levels rises and the body tries to get rid of the excess sugar by passing it through the kidney through frequent urination. This may make the individual thirsty but it is recommended that the person should continue to drink water to prevent dehydration. If untreated, it can lead to seizures, coma and eventual death.

The warning signs to look out for include very high glucose levels over 600 mg/dl, extreme thirst, dry mouth, warm dry skin that does not sweat, high fever, loss of vision, sleepiness / confusion, hallucinations and weakness of one side of the body. The best way to avoid HHNS is to monitor the blood sugar levels closely and daily. This means that parents need to conduct daily routine blood glucose monitoring at regular intervals in order to be able to identify if the child is at risk. This requires dedication and commitment on the part of the parents to ensure a safe and healthy diabetic child (Guthrie & Guthrie, 2002: 245 -256).

### ***2.6.2. 2 Diabetic Ketoacidosis (DKA)***

According to Daneman et al (1999:120 - 121) diabetic ketoacidosis is a serious condition that can lead to a diabetic coma or even death. This happens in type 1 diabetics but very rarely in type 2. DKA means dangerously high levels of ketones or acid build up in the blood. They appear in the urine when the blood does not have enough insulin. They are a warning sign that the diabetes is out of control or that one is getting sick. Treatment for this usually takes place in the hospital. The warning signs to look out for include thirst / very dry mouth, frequent urination, high blood glucose levels, high levels of ketones in the blood, constantly feeling tired, dry / flushed skin, nausea, vomiting or abdominal pains, hard time breathing, fruity odor / breath, having a hard time paying attention and confusion (Daneman et al,1999:120 - 121).

## **2.7 COMPLICATIONS OF DIABETES**

Davis (2001:40) states that complications that may arise when an adult or child has uncontrolled / poor diabetes management. These complications are heart disease / stroke. Adults with diabetes are more likely to have heart disease or a stroke and it is the leading cause of deaths in people with diabetes.

High blood pressure is a common feature in diabetic adults and some children. There is a need for medication to control it. Diabetics experience eye problems and are at risk of developing cataracts, glaucoma and retina problems that can reduce vision or cause blindness in adults. Kidney and nerve damage is common in diabetics. Many people with diabetes have some nerve damage e.g. numbness or tingling in the feet or hands with or without any pain. Severe nerve damage in people with diabetes is a major cause of leg and foot amputations. Furthermore, Davis (2001:40) states that people with diabetes have a higher risk of infections and death from these infections. High blood sugar levels make it hard for the body to fight infections and greater risk of getting other illnesses. Once diabetics get an illness, it takes a longer time to get better. Diabetics are prone to gum infections because they pick up infections more easily. Diabetic women experience problems with pregnancies and mismanaged diabetes before or during pregnancy can cause birth defects and miscarriages. This can also lead to one having very large babies, which becomes risky for the mother and child (Davis, 2001: 40).

## **2.8 THE IMPACT OF UNCONTROLLABLE UNDIAGNOSED DIABETES**

Uncontrollable diabetes can interfere and disrupt the normal development of a child and adolescent (Ragnar, 2004:31). Episodes of very low blood sugar levels (hypoglycemia) in young children may result in frequent admissions, disruptions in schooling, brain abnormalities and impaired cognitive functioning. Therefore, it is imperative to provide proper education in diabetes, which will ultimately reduce complications and save lives. Diabetes management is demanding on children and their families but they can succeed in controlling their blood sugar and grow up to be healthy and happy (Ragnar, 2004:31-32).



## **2.9 RESPONSES AND REACTION TO A DIABETIC DIAGNOSIS**

According to Smallwood (1990:133) from the time of diagnosis, diabetes has an immediate impact on the psychological, emotional and social functioning of the young person, as well as the family. It is important to note that once diagnosed the diabetic persons life will never be the same again. As a child or teenager matures, the family faces many emotional challenges. The psychological effects of diabetes in the family will be different at different ages and the developmental age and needs. Parents may feel unsure how to handle specific situations and may seek professional help. Raising children is based on your childhood experiences, as this is the only model that you are aware of but according to Smallwood (1990:133) problems arise because two parents have had two different experiences. This results with conflicts. However, when a child is diagnosed with a chronic illness the parents become insecure because they are constantly contemplating the balance between over protectiveness and independence.

### ***2.9.1 Reactions to the Diagnosis***

According to Ragnar (2004:129), the diagnosis of diabetes brings about many reactions in parents and child. The family may go through a grieving process, which is coupled with a variety of feelings that may include shock, denial, sadness, anxiety, fear, anger and guilt. Families need to adjust and accommodate the changes. This requires them to adapt and readapt to the diabetes and find themselves feeling some of these emotions repeatedly. The initial stage is one of shock or denial. When we experience a crisis for the first time, our first reaction is one of shock or denial. Parents often say that the reality of the diagnosis has not registered or it is like a bad dream. This feeling is short lived. This is followed by sadness in which parents feel shattered when their child is diagnosed with diabetes. They feel sad because they have to inject the child, do blood tests and have to stick to a meal plan.

They realize that this is most likely a permanent change. They feel sad because they have to change their old lives. The child becomes upset because he/she cannot eat whatever and whenever he/she wants to. Children may be sad because the diagnosis will affect their activities and friendships. Ragnar (2004:129) state that once parents and children have time to express their loss and sadness, they then realize that they do not have to change many parts of their old lives. This then will help create hope for their future success.

Fear and anxiety are normal reactions because the parents are consumed with whether they will be able to cope with the understanding and management of the diabetes. The parents become anxious about the child's health. Some worry about low glucose levels, whilst others may stress about injections. Some children fear needles in the beginning and this may distress the parent. The child will ultimately take cues from the parents and if they see the parent distressed, they may think that they are going to die. This very fear sometimes helps the parent to focus on the child's needs. Anger and resentment also surface because the young children may become angry because they have developed diabetes. They may resent the treatment regime and the restrictions to the diet. They may sometimes feel like the whole world is against them. Ragnar (2004: 129) further illustrates that parents may also feel resentment and helplessness to change the situation. Parents may feel angry because of the additional responsibilities, which are placed on them. Sometimes, it is this very anger that will help some parents to relook the child's diagnosis and make the necessary changes.

Lastly, guilt presents itself because parents often blame himself or herself if the child has diabetes because it runs in their family. Some feel guilty if they did not notice the warning signs early. Children may feel like they are a burden to the family whilst some may feel that they have done something wrong or have caused the diabetes (Ragnar, 2004: 130).

According to research on parental concerns about their child's diagnosis, Gard et al (1997:127) states that parents who have children with a chronic illness have concerns regarding whether they are able to understand the medical terminology and are able to communicate with the health professionals. They are also concerned about their reactions to the diagnosis and the limitations this disease will place on their lives. Furthermore, they wonder what effect this diagnosis will have on the other children in the home and the impact it will have on their socialization with family and friends. These concerns can easily be addressed by the treatment team and by the parents being compliant with the treatment regime.

Gard et al(1997:127) further emphasize that during these initial stages, it is vital that the multi disciplinary team support the parents and child to ensure easier transition into these new roles. The team's support is important, as it will help address their immediate medical and psycho - social concerns and provide the education needed to help the family to adjust and adapt to this new way of life. Diabetes forces families to learn new skills and it alters or changes their lifestyle to accommodate the diagnosis. Therefore, the role of the social worker in a medical setting is vital. The supportive counselling encourages families to talk about these feelings and emotions to manage them and help them to adjust and adapt. When the families' concerns are addressed immediately, it will assist them in the management of the diabetes. These new roles and responsibilities will not seem overwhelming to them (Gard et al,1997:127).

Davis (2001:87) in his study on the impact of the illness on parents concluded that parental warmth increased adherence while restrictions decreased adherence. They also found that parents of diabetic children use less limit setting with their children than parents who have healthy (non-diabetic) children. This is so because the diabetic child has so many existing rules which pertain to treatment that the parents do not want to further frustrate or burden the child and therefore tend to be very lenient with them.

Daneman et al (1999:159) concluded that parents who have healthy attitudes towards management of a chronic disease help their children to adjust and accept the diagnosis. Children respond to the cues that they get from their parents and are more likely to comply with the treatment, when their parents are consistent in their approach to managing the diabetes. Families depend largely on their attitudes and beliefs to cope with the diabetes. Both parents should be involved in the management to prevent burnout and this will increase adherence. Both parents and children need ongoing information to keep them motivated to ensure adherence and this will ultimately provide positive clinical outcomes. Diabetes forces the parent and child to learn new skills whether they are ready or not. Some examples are the ability to do glucose monitoring, locating an injection site, administering the insulin, adjusting meal plans and identifying highs and lows of diabetes. This additional responsibility is likely to affect family relationships.

The ultimate aim of the study was to gain a better understanding of the challenges that the parents and families face in managing the disease. The research findings will provide some guidelines for the helping professions especially social workers in providing appropriate services to diabetic patients, parents and families. The findings may provide a framework when structuring individual, family interviews, educational programs and support groups.

## **2.10 TREATMENT AND MANAGEMENT OF DIABETES**

According to Guthrie & Guthrie (2002:125 126), *“the administration of insulin has often been approached with fear, anxiety, self pity and lack of understanding on the part of the patient and family.* Diabetes mellitus is currently a chronic disease, without a cure. Careful control of the diabetes is needed to reduce the risks of long-term complications. A combination of diet, exercise, weight loss and the use of various types of insulin are used in the treatment for type 1 diabetes.

### **2.10.1 Insulin**

Insulin is the only line of treatment available for type 1 diabetes. There are different types of insulin like ultra fast acting, fast acting, and intermediate acting to long acting, biphasic and ultra long acting insulins available. Patients with Type 1 diabetes will require insulin for life.

Brewer (2005:43) describes the different types of insulin as the following:

***Very rapidly acting insulin*** starts to work around 15 minutes after injection and can be given up to 15 minutes before or after a meal. This effect lasts from 2 - 5 hours.

***Short acting insulin*** is fast acting and the effect peaks between 2 – 4 hours after injection but it lasts up to around 8 hours. It is a clear, colorless fluid which, when released into the blood stream through the portal vein, produces an effect upon the blood glucose within minutes.

***Intermediate acting and long acting insulin*** start acting around 1 – 4 hours after injection and can last up to 3 – 5 hours. The suspensions are modified to reduce their solubility and hence prolong their absorption from the insulin injection site.

***Combination or pre – mixed insulin's*** are stable mixtures containing proportions of short acting insulin and isophane (NPH) insulin. These mixtures are inflexible and if the dose is increased both the short acting and isophane insulin dose is increased.

### **2.10.2 Injection devices**

Estridge et al (1999:29-31) describe the different devices used to deliver insulin as follows:

**Syringes** are small, handy and made from disposable plastic. Syringes take all types of insulins. It is the only device that can be used when administering insulin that is free mixed.

**Pens** are made of hardened plastic and some are fashionably colourful and look more like a fun stationery gadget than a clinical implement. The end of the device hides the needle and the device is placed next to the skin and with the press of the button, the insulin is automatically delivered.

**Insulin Pump Therapy** is an external device that delivers insulin the whole day through. It replicates the function of the pancreas. It delivers a constant rate of insulin (basal rate) to keep the glucose at a desired level. It is a tiny disposable tube, which is inserted under the skin and is changed every 2 or 3 days. The patient takes 12 infusion sets changes per month as apposed to 120 multiple injections. Parents need familiarization and to be assessed for suitability of insulin pump therapy (Brewer, 2005:44). The main advantage of this therapy is that it improves the quality of life for the patient and his or her family. According to Estridge et al (1999:31) the disadvantage of this therapy is that the needle can become dislodged and then no insulin is delivered which can be dangerous and they need to be worn constantly.

### ***2.10.3 Parental Involvement in Treatment, Management and Administration of insulin***

According to Guthrie & Guthrie (2002:125 -126) parental involvement in the treatment, management and administration of insulin is a vital and important function of parents of diabetic children. It is essential for them to understand and familiarize themselves with insulin procedures.

They should be educated that insulin keeps better in the refrigerator, and not in the freezer. If a refrigerator is not available then store it in a cool place away from the direct sunlight. Always keep extra bottles of insulin in the refrigerator.

It is essential that parents have an understanding and familiarize themselves with procedures, as it is essential before recommending insulin treatment. The parent and child should receive counselling and be reassured. Seedat (1998: 15-20) reiterate this as it will ease their concerns about the insulin regime before commencing treatment. This will help to increase motivation in patients and it will help to ensure better home care, self - care and management. The diabetics and the family is informed of the importance of three big meals and three snacks, counseled on the signs and importance of hypoglycemia and hyperglycemia monitoring and they are instructed to have sugar / glucose sweet at hand at all times. The nursing sister discusses the sites of injections, uses of insulin, and proper injection techniques with the use the home glucose monitoring devices and sticks.

According to Seedat (1998:15-20) parents need to monitor the child's glucose levels at home. This is a procedure, requiring knowledge, patience and understanding. Some guidelines are cleanliness in that a parent needs to wash their hands, know how to puncture the finger with a monojector, read and record the results accurately in a diary and parents may also need home glucose monitoring equipment examples test strips, cotton wool balls, diabetic diary and a glucometer when he/she is monitoring the glucose at home.

Although this is an ongoing demanding process, it has advantages. The parents are confident and have better control over hypoglycemia because he/she can alter the insulin doses as he / she gets more comfortable and understand the diabetes management. Furthermore, they may feel better equipped to handle emergencies because they have more control over their child's diabetes and understand how to manage either hypoglycemic or hyperglycemic episodes.

#### ***2.10.4 Exercises***

According to Horton (1996:395), there are two forms of exercises and these are aerobic and anaerobic. The body needs both forms of exercises. Aerobic exercises such as brisk walking, running and swimming helps to keep the heart healthy and with glucose control. Anaerobic exercises like rugby, soccer and squash helps to build muscle tone / mass, which will help to increase the metabolic rate. Both the exercises are important to ensure effective diabetes care and management.

According to Horton (1996:395) the benefits of exercise is that it is said to lower blood glucose concentration during and after exercise, improve insulin sensitivity and decrease insulin requirement, improve lipid control, increase energy levels, improvement in mild to moderate hypertension, assist with cardiovascular conditioning, increase strength and flexibility, improve sense of well being and enhanced quality of life (Horton,1996: 395). Parents are encouraged to motivate children to participate in some exercise but they should be aware that there are risks to consider when children are diabetic. Parents need to plan carefully. Horton (1996:396) states that exercise can bring on hypoglycemia and or hyperglycemia after strenuous exercises and parents need to look out for these symptoms when children participate in exercise. Children should eat healthy snacks prior to participating in vigorous exercises.



### ***2.10.5 Managing the child's diabetes – Food***

Blood glucose levels is controlled by sticking to sensible eating habits and choosing the best foods for our body's system, together with following a healthy lifestyle that involves exercise, not over eating and over indulging in chocolates, sweets and chips. These together with the insulin administration will help to protect against long term complications of diabetes.

## **2.11 EDUCATION AND SUPPORT**

Smallwood (1990: 144 – 145) states that education is one of the most important processes in the treatment of diabetes. Parents must have good understanding of the diabetes, its nature and the management before they will have sufficient motivation to undertake the responsibility of managing their children at home.

Diabetes is a condition that relies greatly on family support and it is exceptionally important for patients to receive diabetes education, encouragement and support towards a sensible exercise regime, self-glucose monitoring and motivation towards keeping their glucose levels under control.

For insulin dependent children, the parents will accept the initial responsibilities for management but it will eventually be handed over to the child when it is obvious that he / she will be able to cope independently with minimal supervision (Smallwood, 1990: 145). According to the American Diabetes Association (ADA) Diabetes Care (2002: Volume25, Nr 1: Supplement 1) the patient and family education and counselling on their nutritional intake is vital in effective diabetes management. The universal diabetes management encourages lifestyle changes, ongoing educational training, individual counselling, family counselling, restrictions to ones dietary intake and increased physical activity levels as this can produce better management of the diabetes.

## **2.12 DISEASES RELATED TO DIABETES MELLITUS**

According to Zaida (2007:170) diabetes is a disease of complications, affecting almost every part of the body. A discussion on the diseases related to diabetes is included in this section because if parents do not manage the child's diabetes appropriately then the child has a higher risk of developing complications. These diseases are present in adult and children with diabetes. In chapter 1 section 4, one of my stated objectives was to ascertain if families are able to incorporate diabetes into their lives. The reason for this is that if families fail to incorporate the diabetes into their daily living then the child is at risk of developing complications as the diabetes progresses.

### ***2.12.1 Complications of Diabetes***

A list of the frequent diabetes complications is included:

#### ***2.12.1.1 Vascular Disease***

Chronic elevations of blood glucose levels can lead to damage of the blood vessels (angiopathy). The damage of the small vessels leads to microangiopathy, which can cause severe vision loss or blindness and abnormal or decreased sensation in the hands and feet.

***2.12.1.2 Diabetic retinopathy-*** growth of poor quality new blood vessels in the retina and swelling of the macula, which can lead to severe vision loss or blindness. Retinal damage is the most common cause of blindness among non-elderly adults in the USA.

***2.12.1.3 Diabetes neuropathy*** - This is the abnormal and decreased sensation in the hands and feet, present frequently in diabetic individuals.

**2.12.1.4 Diabetes nephropathy** - which is the damage to the kidney which can lead to chronic renal failure, which the patient may eventually need dialysis. Diabetes is the most common cause of kidney failure worldwide in the developed countries.

**2.12.1.5 Macro vascular disease leads to cardiovascular disease:**

Coronary artery disease, which leads to angina or myocardial infarction (heart attack), stroke, peripheral vascular disease (which relates to leg and foot pain) and muscle wasting (diabetic myonecrosis) are common concerns faced by diabetic individuals.

**2.12.1.6 The Feet**

Diabetic foot – may cause skin ulcer and infection, which in serious cases causes necrosis and gangrene. This is why diabetics are prone to leg and foot infections and why it takes them longer to heal from leg and foot wounds. It is the most common cause of adult amputation, usually of the toes and feet in the developed countries.  
([www.diabetes.com](http://www.diabetes.com))

## **2.13 DIABETES AT DIFFERENT DEVELOPMENTAL STAGES IN CHILDREN**

According to Davis (2001:37-38) the psychological effects of diabetes on the family will be different at different developmental age and needs. Parents may feel unsure how to handle specific situations and may seek professional help. Raising children is based on how you were raised. This is the only model that you are aware of but problems arise because two parents have had two different experiences. This may result in conflicts. However, when a child is diagnosed with a chronic illness, the parents become insecure. The parent is constantly trying to strike the balance between over protectiveness and independence.

The researcher is of the opinion that this area is important so that we are able to get a clearer understanding of the concerns that present when managing diabetic children. The sample group will be drawn of the diabetic children within these developmental ages therefore this information was included.

### ***2.13.1 Challenges Facing Parents in Managing the Child's Diabetes at the Different Developmental Ages are:***

According to Davis (2001:37 – 38) the following are some of the challenges that parents may experience:

#### **Infants (0 – 3 years)**

The first relationships exist between the mother and child. When a child is diagnosed during this age, the family will undoubtedly become stressed. The parents may find it difficult to communicate security and confidence to the diabetic child. The children do not understand why they need to eat if they are not hungry and why not when they are. Feeding problems present at this time. Children will attempt to test the boundaries and limits during the ages of 2 – 3 years. The children will show different levels of anger and frustration. The parents may have trouble to distinguish whether the bad temper is due to a hypoglycemic or hyperglycemic episode. The child may be difficult when it is time for injecting or testing the blood glucose levels. The parents may become confused. Parents may want to over compensate for the illness and therefore have poor limit setting in the home. The child may then become disruptive and may continuously test the limits to provoke the parents to react. Parents need to remember that a diabetic child needs a normal upbringing just as much as any other child.

### **Pre school children (3-6 years)**

The child in this age begins to understand more about the outside world. Children may believe that they have developed diabetes as a punishment for doing something wrong or that the blood glucose test is a punishment. Children will be restricted to freedom because the parent fears that he/she will become hypoglycemic. It may be difficult to give insulin and take tests when the child is uncooperative.

### **Primary school children**

Starting school is stressful for any child, and he/she may find it difficult to adjust in the beginning. The start of school coincides with the child's need to distance himself from his/ her family. During primary school years, children learn to master impulse control and understand acceptable behavior, limits and guidelines. Normalize and acknowledge the child's feeling regarding the glucose monitoring and insulin injections. Concerns about the food and whether the child is eating appropriately are predominant during these years so tracking insulin administration and monitoring the glucose levels becomes difficult. The parent may fear that the child may experience hypoglycemic episode and must therefore be easily contactable. Teachers need to be informed of the child's diagnosis to assist in supervision at school (Davis, 2001:37-38).

## **2.14 DIABETES MANAGEMENT: THE CHILD AND FAMILY**

A discussion will follow in this section regarding the impact the diabetes has on the child, parents, siblings, school, friends and lifestyle.

De Villiers (1995:24) emphasizes the importance of the emotional nurturance of the diabetic child. She recommends that group therapy and individual therapy is vital for diabetic children.

She emphasized the importance for diabetic children to meet other diabetic children so that they do know that they are not alone. They will see that other children also experience similar problems in managing the diagnosis.

#### ***2.14.1 The Diabetic Child and the Family System***

The researcher is of the opinion that diabetes is an added stressor for an already overburdened family. Not only will the physical care be poor but also the emotional care may be unreliable and thus relationships within the family may be distorted. Therefore, it is important to have a social worker / counselor on the diabetes team to help address the social concerns with the family. Children may present with problematic behavior because they do not understand their diagnosis and each child may have his/her own perceptions of diabetes. The child may be afraid of the diabetes and he / she need to be encouraged to talk about it so that he/ she can obtain a better understanding of diabetes. Cleaver (1994:272) in her study states that” *over-protective families do not promote independent children and these children withdraw from friends and family. She further states that families who do not encourage children to be independent and are over-protective make children anxious, afraid and worried*”.

According to a study on the impact of the illness on parents, which was conducted by Davis (2001:87), parental warmth increased adherence while restrictions decreased adherence. He also found that parents of diabetic children use less limit setting with their children than parents who have healthy (non-diabetic) children. This is so because the diabetic child has so many existing rules which pertain to treatment that the parents do not want to further frustrate or burden the child and therefore tend to be very lenient with them.

### ***2.14.2 The Diabetic Child***

Young diabetic children often fear needles and find this the hardest part of diabetes acceptance and management. The child may adjust to the treatment or rebel. He or she may eat too many sweets and manipulate the situation. During the early school years, children learn new skills across a wide range of areas. The child may take on diabetes care and responsibilities because he/she believe that they can do it.

However, current research indicates that parents should still monitor and oversee these tasks throughout this period. Parental involvement will help to create higher compliancy levels and ensure good glucose control. Parents should not hand over responsibilities too early (Ragnar, 2004:342-343).

Many children with diabetes have experienced the hurt of not receiving invitations to a friend's party or other social event (especially sleepovers) because the friend's parents did not want the responsibility of a child with diabetes. If this happens, talk to the parents about diabetes and how it could be handled at the social event. For example, you may offer to come to the friend's house the morning after the sleepover to give your child her injection. Just offering to be available by phone at all times during the event may be enough to reassure the parents.

### ***2.14.3 The Parents of the Diabetic Child***

When a child has diabetes, many reactions and mixed feelings surface in the parent. During supervision with the junior staff member the parents' responses to the children's diagnosis were discussed. The following are some responses from parents upon hearing their child's diagnosis:

*"Oh, no, this cannot be. I cannot believe this.*

*Is this really happening to my child? What can I do to fix it?*

*How is my child going to cope?*

*What wrong did I do and why is God punishing me?*

*No! No! I cannot inject my child. How could I do this"?*

These responses demonstrate the extent to which parents feel overwhelmed at the thought of having to manage the disease in their child. The parents feel like it is the end of the world and they fear injecting their little ones with insulin. They become consumed with overwhelming thoughts and wonder if they are going to accept and cope with this new diagnosis. They become consumed with thoughts of how are they are going to juggle all these added responsibilities into their daily lives. According to Gard et al (1997:126) and Hillson (1996:162) when there is an absence of professional guidance, some parents may become over-protective and this may instill negative feelings or behavior that will inevitably lead to negative clinical outcomes. Parents may become overprotective and the child may react to want too much control or rebel against the treatment. The diagnosis of a chronic illness triggers the bereavement process in parents. The parent may blame him/ herself if he /she have the illness. The feelings of grief, anger, sadness and regret may surface intermittently, especially during the first year. The parent may be angry with the child for being diagnosed with the illness, although the parent may realize that this anger is illogical. The parent may displace the anger on the spouse or other children as his/her way of ventilating.

#### ***2.14.4 The healthy (non diabetic) sibling's attitude towards the diabetic child and the role of the parent in managing these appropriately***

According to Daneman et al (1999:111) brothers and sisters of children with diabetes may have a variety of reactions to the diagnosis. Some may fear that they will get diabetes. Reassure them that they cannot catch it from their sibling. Many siblings become jealous or feel left out because the child with diabetes suddenly begins to get more attention. Let them express their feelings. If it is true that you have been giving more attention to the sibling with diabetes, admit it and explain why? Many parents find that siblings of a child with diabetes appreciate "special time" with one or both parents. Set aside some time for each sibling to do something with you that he or she enjoys. It could be a special outing, or something as simple as playing a video game together.



You may find that these special times reduce the number of complaints from siblings about their brother or sister with diabetes. Being a brother or sister of a diabetic sibling can be difficult sometimes.

Daneman et al (1999:111) further emphasizes that parents should take it serious when the healthy (non-diabetic) child complains and remember to give the healthy (non-diabetic) child some extra attention. The parent should allow the healthy (non-diabetic) child to make decisions for example, to plan his /her own party. The diabetic child can be given extra insulin on that day so that he/she can partake in the party. Siblings are support networks for the diabetic child and the older siblings may take over the diabetes management from their parents.

## **2.15 ADDITIONAL INFORMATION TO ASSIST PARENTS IN MANAGING THE DIABETIC CHILD**

According to the diabetes website ([www.diabetes.com](http://www.diabetes.com)), many parents take complete responsibility for the child's diabetes management without requesting assistance from family members or friends. This is dangerous as it can lead to burnout and may result in poor adherence and negative clinical outcomes. The following are some recommendations for parents to consider:

### ***2.15.1 Lifestyle***

One of the main areas of concern to adjusting to diabetes is to keep the family routine, as close to normal as possible and the diabetes care should fit into the daily lifestyle. It is natural for parents to be focused on diabetes for the first weeks and months after diagnosis, but parents need to remember to focus on incorporating the diabetes into their family routines and traditions ([www.diabetes.com](http://www.diabetes.com)).

### ***2.15.2 Support Systems***

According to Ragnar (2004:218) because type 2 is far more common than type 1 diabetes, you may find that adults have misconceptions about your child's condition based on their experiences with people with type 2 diabetes. They may not realize the importance of adhering to the insulin and eating schedule. Parents must impart diabetes knowledge to the significant others and dispel myths by explaining the facts. The adults in your child's life may fear making mistakes in caring for diabetic child and more information may be needed to allay fears for many. Encourage them to observe how you and your child deal with diabetes. Parents should point out that your child's diabetes is under control and that he / she is healthy and active. People who are especially close to your family, like grandparents or close family friends should be encouraged to learn about the diabetes and management to render support to the parents as this can help to prevent caregiver burnout. The grandparents may go through a grieving process which according to Ragnar (2004:218) is completely normal, and a sign of how much the person cares about the child.

## **2.16 THE IMPORTANCE OF THE MULTI DISCIPLINARY TEAM IN DELIVERING DIABETES CARE**

Ragnar (2004: 33 – 34) emphasizes that diabetes is a controllable disease and the team approach can help to identify concerns early and assist with therapeutic intervention and education. The multi disciplinary team should provide hands on diabetes care to the diabetic individual and family at a clinic setup. Paediatric specialists and diabetic nurses play a vital role in improving diabetes care to children and young people. The team usually includes a diabetic specialist (Doctor), nurse, social worker, dietician, physiotherapist and psychologist. These professionals come together, complement each other's skills and work together with a common goal of managing the diabetic patients' and their families.

Ragnar (2004:33-34) further elaborates that the combination of these skills reinforces that type 1 diabetes is a lifelong disease and requires commitment and dedication on the part of the individual and the family. They reinforce that compliancy and adherence to the treatment regime is of paramount importance. The family should have regular contact with the paramedical staff to provide support, education and guidance to help address the concerns and pitfalls that the family experiences in their daily management of diabetes. The parent's perceptions, coping skills and concerns can be addressed appropriately and timeously to avoid families using maladaptive coping skills (Ragnar, 2004:33-34).

### ***2.16.1 The Role of the Team Members***

This section focuses on the members of the treatment team with a specific focus on the social worker's role. The endocrine doctors, nurses, psychologist, dietician, physiotherapist and the social worker make up the treatment team. The doctors and nurses provide the medical care and support, education and training regarding diabetes care and insulin management. According to McDowell et al (2007:50) the role of the educator is to “*teach the facts and skills of diabetes management through a respectful balanced collaborative partnership between the educator and the diabetic patient and family*”. This partnership acknowledges the clinician's expertise in terms of the knowledge and experience of working with others who have diabetes.

According to Clark (2006:578), the dietician plays a vital role in educating the child and family on the importance of adhering to a diet when a child is diabetic. Dietary intervention is fundamental in the management of diabetes mellitus. These guidelines should be individualized according to the patient's age, weight, physical activities, culture and it must be affordable. The reason for this is that if the diet is rigid the patients find it difficult to follow and it often leads to non - adherence. The importance of main meals and healthy snacks are highlighted with the focus being on maintaining good glucose control.

The physiotherapist guides the child and family with encouraging regular aerobic exercises because this is an important component of the management of diabetes. The physical activity should be distributed over the week with a minimum of 30 minutes per day.

### ***2.16.2 The Role of the Social Worker***

The social worker is part of the diabetic team and for the purpose of this dissertation, the role of the social worker will be highlighted. The medical practitioner will first attend to the child and then refer to the social worker for home circumstances investigations and counselling. According to McDowell et al (2007:53) “*counselling is a process through which one person helps another by purposeful conversation in an understanding atmosphere. It aims to establish a helping relationship in which one is counselled can express his/her thoughts / feelings to clarify his/her own situation. To assist the individual to make his /her own decisions from the choices available to him/her*” (McDowell et al,2007:53).

The social worker will undertake psychosocial investigations to ascertain the families’ level of understanding of the diagnosis and to assess their family’s coping skills. The social worker further assesses the impact the diagnosis has on the family and explores the support systems available to the family, assess if the families are able to integrate the diabetes into their lives and identify the maladaptive coping skills that the families may be using to help them cope with the diabetes management. According to McDowell et al(2007:53 – 54) often people are confused about problems they are experiencing and counseling skills can help them make sense of what is happening.

The social worker assesses the patient and family based on the ecosystems approach and focuses on the factors that contribute to the psycho - social problems that presents in the home of a diabetic child.

The ecosystems theory as stated by Compton (2005:23 -24) is identified as the appropriate model when assessing the family because the child is a subsystem within the family system. The social worker has to assess the factors that hinder or promote compliancy and some of these may include poor understanding of diabetes, low socio economic status, family conflict, communication difficulties, burn out of one caregiver, increased responsibilities that the young child is faced with, parental involvement in the management of the disease and the role of family members. This theory emphasizes the whole is more than the sum of its parts. As social workers, we cannot adequately understand a problem with separate assessments of the individual and the environment. Therefore, this model strives to understand the complex interactions between the client and the other systems.

The holistic approach is vital when working with families. The social worker will engage in all methods of social work practice. The methods of social work intervention include casework, group work, community work and case conferencing with the multi disciplinary team. These interventions are ongoing and the social worker is an active member of the team. According to McDowell et al (2007:43 - 46) when patients are assessed and feedback is provided to the team then decisions are made accordingly. Each child experiencing concerns with adherence is referred to the social worker for counselling and to investigate the reasons for non-adherence. The screening for these specific psycho-social problems is vital, as it will help the therapist identify the maladaptive coping skills that the family is utilizing. These coping skills may indicate that the family is of the opinion that they are coping but it does not solve the problems that are facing on a daily basis. The main aim of the counselling is to identify the concerns, which affects / hinders the family's ability to adhere to the treatment regime and to assist them towards adequate maintenance.

### ***2.16.3 Challenges faced by the social worker***

In a medical setting, the social worker experiences challenges in meeting these goals. The social worker needs to keep abreast of all relevant information, policies governing the work practice and diabetes care and management. This area of operation is sensitive and the fact that the families are referred due to poor adherence can sometimes pose as a challenge. Some families resist change and the social worker needs to be conscious that diabetes care is hard work, which some parents are not ready to accept. Some parents do not feel the need to adhere because the child may appear well so educating and altering of their mind set can be difficult. Therefore, the social worker needs to identify the areas of need and counsell accordingly.

### ***2.16.4 The Advantages of a Multi Disciplinary Team (MDT)***

According to Boulton (2006:[www.diabetes.org](http://www.diabetes.org)) the MDT brings together the particular skills and experience of several health professionals to work towards a common goal. This coordinated MDT care provides a high quality, cost effective method, which assists and encourages diabetic individuals to achieve their goals and maintain sick free over a long period. Diabetic support, counselling and ongoing education is part of the team's approach to encourage adherence. The type 1 diabetics have a lower risk for micro vascular complications for eye disease, kidney disease, strokes and diabetes related deaths when a MDT approach is utilized. The short-term benefits are better glucose control; increases follow up appointments with patients, higher patient satisfaction, lower risks of complications, and improved quality of life for the patients and a decrease in cost to the health sector. Shorter hospital stays and readmissions are noted as a short-term benefit. Elizabeth Warren Boulton (2006:[www.diabetes.org](http://www.diabetes.org) ) states that “*properly implemented diabetes team care is cost effective and the preferred methods of care delivery, particularly when services include health promotion and disease prevention in addition to intensive clinical management*”.

## **CHAPTER THREE**

### **3. RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

In this Chapter, the research methodology used in this study is described. The main purpose of this study is to highlight the experiences and challenges facing parents of diabetic children. The intention is to contribute to the existing research but also to provide valuable information to the diabetic team and hospital social workers at the said research site to acknowledge the participants' needs, to develop and implement the necessary services to assist them in making their management easier.

The research design, the sampling, datum collection, datum analysis, ethical issues, validity and reliability raised by this study, study site and the challenges presented while conducting the study is included. I will also include how I overcame the limitations.

#### **3.2 THE SETTING OF THE STUDY**

The study was conducted at a tertiary state hospital in KwaZulu - Natal that provides medical care for patient residing in the Durban and surrounding areas extending from the borders of the Transkei and to the far North Coast. The said hospital has a specialized Paediatric Diabetic Clinic that attends to diabetic children who are state patients and those who are unable to access private medical care. The clinic provides services to a racially mixed population from all different financial backgrounds and religious affiliations.

### 3.3 THE APPROACH AND DESIGN USED

#### 3.3.1 *The Approach Used*

The study explored the challenges facing parents of diabetic children. The qualitative approach was applied while conducting this study. As a social worker in a medical setting, I became aware of the large number of diabetic children being admitted due to diabetic ketoacidosis. The interest was stimulated and I explored this further in this study. Babbie and Mouton (2001:270) describe qualitative research “*as a paradigm that allows the researcher to get an “insider perspective on social action with the goal of describing and then understanding the social action”*”.

Gribich (1999:8) further states that qualitative approaches are complex and varied and it allows the researcher to study a situation from a range of positions and perspectives to find out how people interact and define contexts. The investigations allow researchers to investigate and describe patterns of behaviour, processes of interaction and to reveal the meanings, values and intentions of people’s life experiences. According to Marks et al (2004:55) this method allows the researcher “*to explore how people actively make sense of their lived experiences, interpretation of these experiences through language, cultural and historical expressions in the subjects own written or spoken words*”. This approach was appropriate because it allowed the researcher to obtain rich datum, which was used to provide recommendations to develop guidelines for appropriate interventions. The advantage of the qualitative method is that it allows the researcher to gain more depth and understanding of the one phenomenon under investigation with the focus of understanding the social life and the meaning that people attach to their daily lives with the aid of a semi structured interview guide.



### ***3.3.2 The design***

A research design is defined as a plan or blueprint of how the researcher intends to conduct his/ her research (Babbie and Mouton, 2001:74). The research design is therefore a full proof of how the research was conducted and how the researcher arrived at the findings and conclusions. A research design comprises of the research questions, what data to collect, data collection methods and the data analysis. An exploratory, descriptive design was used to collect the datum from the participants. This research design was appropriate because this study was not done previously in the researcher's work setting. Babbie and Mouton (2001:85) states that exploratory studies are valuable to social science research because they are necessary when a researcher is finding new information; it satisfies the curiosity and understanding of the researcher's topic of interest, has a desire to test the feasibility of undertaking a more extensive study and to develop the methods to be employed in any subsequent study.

Furthermore, the descriptive design was selected because it provides an accurate portrayal or account of behaviour, opinions, beliefs and knowledge of individuals. According to Creswell (2002:141) descriptive research design is used when data are collected to describe persons, organizations, settings and phenomena. This design was chosen to meet the objectives of the study, namely to explore the challenges facing parents of diabetic children. The descriptive design was appropriate because it allowed the participants to describe their daily lives as they occur naturally.

### **3.4 THE RESEARCH PROCESS**

The research process consisted of several stages, which is discussed in this section:

#### ***3.4.1 Negotiating Permission to Conduct the Study***

In conducting this research, I had to seek permission from the management of the hospital to conduct the said study. A letter of request explaining the study, the copy of the proposal, interview guide and the letter from the UKZN higher degrees committee was handed to the Senior Management at the study site. Permission was granted to undertake the study. I then met with the Head of the Paediatric Diabetic Clinic to inform her of the study and to get permission to address the parents at the clinic site and to recruit participants.

#### ***3.4.2 Sampling***

Sampling is defined as a process of selecting a sample that represents a target population who answers the questions asked by a researcher during an interview. According to Burns and Grove (1993:779), a population is defined as all elements (individuals, objects, events) that meet the sample criteria for inclusion into a study. The study population consisted of the parents who are caring for diabetic children between the ages of 2 – 13 years and who attend the paediatric clinic at the said study site. Polit et al (1993:445) defines a sample as a subset of a population selected to participate in a research study. A convenience sampling procedure was applied in this research because the participants happened to be in the right place and the right time and was easily accessible to the researcher. Convenience sampling is in use in exploratory research when the researcher is interested in getting an inexpensive approximation of the truth (Cohen et al, 2000:270). The researcher is aware that the children are the patients but had decided to undertake this study with the parents because they are responsible for the child's diabetes management and care.

#### ***3.4.2.1 Process in selecting participants***

As a social worker within the medical setting, I was able to approach the clinic staff without hesitation. I was aware of how the clinic operated and I knew the clinic dates and times. This familiarity helped me to enter the clinic without any obstacles. The attending doctors and staff welcomed the study and were eager about the results. I addressed the families at the clinic and introduced myself to them. I then informed them of the purpose and process of the study, the sample size and then recruited volunteers to participate in the study. I also informed them that the target sample was to be parents of children between the ages of 2 – 13 years and those diagnosed in the last 3 years. The criteria used to select the participants were that the parent must have a child who is a patient at the Paediatric Diabetic Clinic at the said study site. The child had to be between 2 – 13 years of age and diagnosed in the last three years. Furthermore, the parent must be willing to participate, be of either sex or any race, mentally sound and who is living with a diabetic child.

The researcher selected this timeframe because the first year of the diagnosis brings concerns, adjustment problems and acceptance. In the second year, the family may have settled and will then know if they are coping or not. It is likely that they will have greater insight into diabetes management and understand their challenges in managing the diabetic child. Diabetes is like any other chronic illness that takes time to accept the diagnosis and the families have to alter lifestyle in attempting to manage it effectively. This diagnosis has a direct effect of the present functioning of a family and that they may have to readjust their routines to include these additional responsibilities.

#### ***3.4.2.2 Preparatory Interviews with the Participants***

After I selected the prospective participants from the clinic, I introduced myself and the study to them, stressed that it was voluntary participation, I obtained signed consent forms (see Appendix A attached) to participate and requested permission to record the session. I also informed the non English-speaking participants, that an interpreter was available to ensure that they were comfortable during the interview to converse in their language of choice. I also informed them that there was no monetary gain and they had a right to opt out of the study without any penalty. I also informed the participants that the datum will be used for my thesis write up and that recommendations will be made to the relevant stakeholders depending on the outcome of the study. Confidentiality was stressed and an approximate length of the interview time was discussed. I also informed them that their names would not be used but rather pseudonyms to protect their identities. I ensured that the participants were prepared before the main interview commenced.

#### ***3.4.2.3 Data Collection***

##### ***The Research Instrument***

I compiled an interview guide, which was used to collect datum from the participants (see attached Annexure B). Kvale (1996:6) defines a semi structured interview guide as “an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomenon”. The structure of the research interview is similar to everyday conversation and it is the basic mode of human interaction to share experiences, feelings and concerns. The research interview is a systematic way of talking and listening to people with the aim of collecting datum from participants through professional conversation about their daily lives.

The interview guide focused on themes related to the study. It covered the demographic details, the parent's response to the diagnosis, the parent's education about diabetes, their experiences with the diabetic team, the influence of the disease on the child and family, their challenges, difficulties, whether they are able to incorporate diabetes into their lives and their present needs. An interview guide with semi structured and open-ended questions were used to allow participants to give answers that are more specific and for them to give as much information as possible with them feeling comfortable and free to elaborate on issues as the need arises. The interview guide ensured that all the intended areas were covered and it gave direction to the interview with keeping the research purpose in mind. Grbich (1999: 93 – 96) states that the interviewer controls the session and has to ensure that there are no deviations from the topic and to make sure that no leading questions are asked. This helped to ensure that no time was lost in issues unrelated to the study purpose.

### ***3.4.3 Data Collection Process***

Most of the interested participants who met the criteria were interviewed on the day of recruitment, whilst some requested appointments and two participants were interviewed at their home because they were unable to come to the hospital due to financial constraints, until the target sample of 16 was obtained. The office interviews were held in the privacy of a counselling room during working hours to accommodate the needs of the patient. I had to conduct the two home interviews due to the participant's financial constraints and prior arrangements about the date and time were negotiated prior to the interview. The advantage of the office interviews was that I was able to interview the participants on availability and if I had to interview them at their homes, it would have been difficult to locate some of them who live in rural or informal settlements. Interviewing the participants on the day of their clinic appointment suited them as they did not need to make unnecessary trips to hospital and furthermore most did not incur additional financial expenses.

Cohen et al (2000:267) are of the opinion that interviews are not only concerned with collecting datum about life but it is part of life itself. The interview process consisted of one interview session, which took approximately 60 – 90 minutes per session. It involved a face-to-face interview after the preliminaries and demographic details and consent was obtained. Most of the interviews were conducted in English with only two participants needing an interpreter. The session was tape recorded to ensure accuracy of the information and to prevent any distortion of information. The interpreter was given clear and guided instructions prior to the session on her role and that she needed to ask the said question in the manner in which it was asked without adding any additional information. She was also instructed to relay the message in the said words of the participants to avoid distortions and ensure reliability.

I was able to establish rapport with the participants because I was polite, friendly and professional during the interview. My experience as a practicing social worker helped me to engage with the participants in a non – judgmental and non-threatening manner. My interviewing skills benefited this study, as I was able to engage with participants with the use of careful questioning and utilizing my listening skills with the focus of obtaining rich datum pertaining to the purpose of the study. I was able to lead them into different themes without influencing their opinions. As suggested by Kvale (1997:14, 28 -34) I followed an interview guide and focused on topics related to the purpose of the study. I used probes to follow up on the participant's answers to my questions. Interviews are a non- threatening approach to collect datum and it suited the study because the topic under investigation is sensitive and it allowed participants to express and share personal information without feeling threatened. It also allowed illiterate participants to be part of this study.

The main data collection instrument used was interviews with the aim of understanding themes of the daily life experiences from the participants own perspective. The structure of the interview is similar to the everyday conversation and it is the basic mode of human interaction to share experiences, feelings and concerns. The research interview is a systematic way of talking and listening to people with the aim of collecting datum from the participants through professional conversations about their daily lives. I used a semi structured interview guide for the said research. Kvale (1996:6) defines the semi-structured interview as “*an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomenon*”.

#### **3.4.4 The Interview Process**

The researcher established rapport by introducing herself, being polite, friendly and professional when conducting the interview. I described the purpose of the study, the interview process and the approximate length of the interview. I obtained written consent from the participants prior to the interview and informed them of confidentiality and that anonymity will be maintained. The participants were asked for permission to tape record the interviews and participants were also informed that the interviews will be transcribed, and that the findings may be published. I also informed the participants that while the information obtained from the interviews is very valuable, there would be no reward for participation.

The interviews took place in the privacy of the counselling room in the diabetic clinic and the Social Work Department with the use of an interview guide. I engaged with participants with the use of careful questioning, probes and listening with the focus of obtaining datum pertaining to the purpose of my study. Interviews are a non- threatening approach to collect datum and it suited the study because the topic under investigation is sensitive.

The interview allowed the participants to be able to express and share personal information without feeling threatened (Kvale, 1997:14, 28-34). It further allowed the participants who were illiterate to be able to participate in the study. The researcher anticipated that language may be a barrier to communication and made use of an interpreter to assist with translations. The interview was tape recorded and transcribed. The transcribed text and the tape recordings were used for the purpose of analysis and for interpretation of meaning in respect of the intended study.

#### ***3.4.5 Techniques Used During the Interview***

The interview entailed listening, displaying a non - judgmental approach, clarification, reflection, empathy, encouragement, commenting, paraphrasing and summarizing to help the participants to express him or herself fully in his / her own words. I always remembered that the focus of the interview is research and not therapy. I made brief notes of comments or impressions during the interviews (Marks et al, 2006:101). According to Cohen et al (2000:266) conducting interviews requires a great level of skill, knowledge about the interview topic and understanding of the phenomenon under investigation for the interview to be successful. My knowledge and understanding of diabetes prior to the interviews assisted in facilitating the interview process.

#### ***3.4.6 Method of Analysis***

The researcher used thematic content analysis to analyze the datum received. The transcripts of the interviews formed the main datum source. According to Silverman (2001:305) *content analysis involves establishing categories and systematic linkages between them, and then counting the number of instances when those categories are used in a particular item of text.* Content analysis involves the general procedures of document collection with the aim of developing codes.



The interviews formed an integral part of the datum collection and I made use of Kvale's (1996:88) seven-step process namely, thematising, designing, interviewing, transcribing, analyzing, verifying and reporting.

During the datum analysis process, I read the transcripts, grouped words, sentences and paragraphs to form the focus areas highlighted by the participants during the interview process. For example, the participants used words and sentences talking about their initial reaction to the child's diagnosis, their challenges and future needs. During the analysis process, I looked closely at the sentences, which showed how the participants felt about the diabetes, their situations and I formed themes. According to Boyatzis (1998:215) a theme refers to a specific pattern found in the datum in which one is interested. These codes were determined by the datum gathered in the study. The aim is to understand the latent meaning of the themes observed within the datum, which requires interpretation. This allowed the researcher to replicate, extend or refute prior discoveries.

### **3.5 LIMITATIONS**

- ❖ Some parents may not have been forthcoming or truthful during the interview because they did not want to be reflected in a bad light or to be seen as bad parents therefore I explained the purpose of the study and highlighted anonymity.
- ❖ I anticipated that the participants might not be truthful because they may see me as a threat because I work in the hospital therefore confidentiality and anonymity was stressed.

- ❖ I was aware that I might be biased during the process because I have a preconceived idea of what is expected from a parent who is caring for a diabetic child. I utilized my social work skills and applied a non - judgmental approach during this research process. I had to be constantly aware of maintaining a non - judgmental approach because the topic under study was sensitive.
- ❖ I anticipated that language might have been a challenge so I enlisted assistance from an interpreter. This may have interfered with reporting on the actual interview.
- ❖ The sample size was small so these findings cannot be generalized to the larger community.

### **3.6 ETHICAL CONSIDERATION**

According to the Medical Research Council (2002: Book 1:5-6) conducting research is an ethical enterprise which contains a system of morals, rules and behaviours which need to be followed. I used this to guide me in the research process.

- ❖ Conducting research requires a researcher not only to have expertise and diligence but it requires honesty and integrity. This was followed during the entire research process.
- ❖ All ethical measures were applied consistently throughout the research process.
- ❖ The researcher is aware that the human rights of the participants need to be protected at all times so I allocated pseudonyms to the participants when reporting on the datum to protect their identities.

- ❖ Ethical clearance from the University of KwaZulu - Natal was obtained to conduct this study.
- ❖ Consent from the participants was obtained prior to the interview and confidentiality was maintained during and after the study was completed.
- ❖ The researcher informed the KwaZulu - Natal Department of Health and written permission was obtained. I also received verbal permission from the Head of the paediatric diabetic clinic.
- ❖ The researcher informed the Employer that no interviews would interfere with my work and that each participant would be participating voluntarily.
- ❖ I was aware that the topic under investigation was sensitive, so I was prepared to render supportive counselling to the participants. I also arranged with my colleagues in the Department to assist with rendering supportive counselling should the need arise. Two participants received subsequent counselling and were referred to community-based organizations for ongoing services and marital counselling.
- ❖ The research process involved rapport and trust building in order for the participants to share relevant information but I used the strategy of reflexivity during the datum collection process so as to ensure that extreme over involvement did not occur.
- ❖ The findings will be made available to the authorities and participants on request.

### **3.7 ENSURING RELIABILITY and VALIDITY**

#### ***Reliability***

According to Babbie and Mouton (2001:127) reliability is a matter of whether a particular technique, applied repeatedly to the same object would yield the same results each time. I attempted to ask similar questions to all the 16 respondents as this helped to minimize sources of measurements error like data collector biases. The collector biases was minimized by me being the only one to interview the respondents and by exhibiting similar personal attributes eg friendliness, support, the same physical environment where the data was collected and the respondents were made comfortable by ensuring and practicing confidentiality, openness and transparency.

Furthermore, the receptionist was made aware that the interview was in progress and not to disturb the session. This allowed the respondents to be comfortable and they were able to respond with ease during the interview. Most of the respondents were able to speak English but I enlisted the assistance of an interpreter for two interviews. I gave her strict instructions to follow the line of questioning, not to add any additional information and to translate as is said. This helped to ensure reliability of the data.

#### ***Validity***

Silverman (2001:34) states that “*validity is another word for truth. It refers to the extent to which an account accurately represents the social phenomena to which it refers*”. Validity was ensured because all those parents who showed eagerness to participate were interviewed. No single person refused to be interviewed therefore generalizing these findings to the members of the population is justified.

According to Silverman (2001:233) when people's activities or comments are audio or video recorded and transcribed the reliability of the interpretations of the transcripts may be gravely weakened, by us failing to note the crucial pauses, overlaps or body movements. Therefore, when I was transcribing the interviews I noted all emphasizes yes, no, mm, hey etc. to mark that the participants understood and responded appropriately and this also indicated that I was conscious of ensuring a greater degree of reliability and validity by documenting accordingly.

## **CHAPTER FOUR**

### **ANALYSIS AND DISCUSSION OF RESULTS**

#### **4.1 INTRODUCTION**

As outlined in the previous Chapter, the datum was organized into themes and I will now present and discuss these themes. This Chapter will provide in detail the participants profiles and a discussion of the results obtained from this study. These themes were derived from the process discussed in Chapter three and it relates directly to the objectives of the study as explained in Chapter One.

The following table provides a brief profile of the participants' demographic details.

## 4.2 The Table – Demographic Details

No	Parent	Race	Age Parent	Age Child	School	Area
A	Mother	African	37	11	Grade 6	Mandlazini
B	Mother	Colored	48	12	Grade 6	Newlands
C	Mother	Indian	37	10	Grade 5	Phoenix
D	Mother	Indian	34	8	Grade 2	Chatsworth
E	Mother	Indian	30	3	No	Stanger
F	Mother	Colored	34	10	Grade 5	PMB
G	Mother	Indian	50	10	Grade 5	Overport
H	Mother	African	36	4	No	Umlazi
I	Father	Nigerian	45	11	Grade 5	Durban
J	Mother	African	40	7	Grade 2	Kenville
K	Father	Indian	35	4	No	Chatsworth
L	Mother	Indian	43	8	Grade 2	Chatsworth
M	Mother	Indian	28	5	Grade R	Chatsworth
N	Parents	White	48 & 43	13	Grade 6	Mandini
O	Mother	Indian	29	4	No	Isipingo
P	Mother	Indian	37	10	Grade 6	Overport

## **4.3 DISCUSSIONS OF THE FINDINGS**

### ***4.3.1 Demographic Details***

From the above table it is evident that the participants ranged between the age groups of 28 – 50 years. Three participants fall in the 28 – 30 age category, seven in the 31 – 40 and six in the 41 – 50 age category. They reside in different areas ranging from the lower North, South, Central, Coastal and the Midlands areas. Most of the participants reside in urban areas. Most of the participants have additional children apart from the diabetic child to care for. Fourteen of the participants were females with only two males. Most of the children are school going and the mothers are the main caregivers of the diabetic child. Most mothers bring the child to hospital for medical monitoring and follow up.

### ***4.3.2 General Health of the child***

Most of the participants indicated that the children did not have any other related illnesses apart from diabetes. However, three participants indicated otherwise and two of these children are on additional daily chronic medication together with insulin. This also requires constant supervision and medical follow up besides the diabetic management. This places additional responsibilities on the parents to ensure closer supervision to prevent additional health complications. This may further strain a family who is not coping with the diabetes.

### ***4.3.3 Initial Reaction to the diagnosis***

The participants were asked to describe their initial reaction when they heard that the child had diabetes. As indicated by Ragnar (2004:325) diabetes diagnosis brings about many reactions / emotions in parents and the child. The family may go through a grief process and have feelings of guilt, shock, denial, sadness, anxiety and anger.



Most participants indicated similar feelings together with disbelief worry, lost faith in God and being very upset. Participant F's quote explains this point further *"Lord, give me the diabetes and not him, I lived my life and he hasn't"* Apart from these feelings, 10 parents cried but a few parents explained that their reactions differed based on certain circumstances. Some responses were:

Participant I *"My wife lost her faith in God but I tried to explain to her that sometimes the greatness of God can create something like this but I accepted it"*.

Participant M *"I was scared because once they say you are diabetic it is for life. I just panicked"*.

These quotes indicate how distressing a chronic diagnosis can be to a family and it can leave one feeling helpless and overwhelmed. However, sometimes the total opposite can happen. This was evident in participants O and E's quotes:

Participant O explained *"Well I believe that God gives you something and that there is a reason for everything and I take it as a gift that God has given me. I take extra care of him. I do not hate or blame anyone for it. I have accepted it that's why I have to control him and that is the only reason why he is okay and I keep him going all the time"*.

Participant E explained, *"I lost a baby with the same condition in 2002 and I was a little more prepared and was stronger"*.

For these parents their strong faith and previous experience in a similar situation has helped them with acceptance and the grieving process.

The second aspect stemming from this discussion was the factors that contributed to a shift in attitude or beliefs of the diabetes. Most of the participants identified the support from the team members, family, spouse, extended family members, the child taking over the insulin regime and glucose monitoring as the contributing factors that helped the parent and child to have partial or complete acceptance of the diabetes. Two participants are still struggling, have not moved past the denial, anger phase and have not accepted the diagnosis. What stood out for me was participant J's refusal to change family lifestyles and eating patterns because she felt it was unfair for her child to eat differently from the family.

*She elaborated this, "I have seen them all and they are supportive but I cannot change like what they want because we are human beings and it is not easy to change and the food they ask her to eat is not what I will cook at home".*

Such responses supports Gard et al (1997:126) findings and further illustrates that some parents are overwhelmed by the responsibility of managing a diabetic child and are consumed by thoughts of how are they going to juggle all these new responsibilities into their daily lives. They also state that parents sometimes rebel against the treatment. Ultimately, children take the cues they get from the parents and will either accept or reject the diagnosis and treatment plans.

The third aspect from this was the length of time it took parents to have partial or complete acceptance of the diagnosis. Most indicated 1 year which was in keeping with findings of Daneman et al (1999:159–160) but again this is influenced by factors such as education, spouse support, family support, closer supervision from the multidisciplinary team and a shift in the families attitudes. The above reaffirms the significance of the ecological perspective together with the biopsychosocial model which are the two theoretical frameworks underpinning this research when assessing diabetic children and their families. These models will help the team members to assess the patient's circumstances and understand the uniqueness of each individual and family.

#### ***4.3.4 Parent's education regarding diabetes***

The participants were asked if they received diabetes education /counselling following the child's diagnosis. This question aimed to assess whether parents received diabetes education, understanding of diabetes when the child was diagnosed and how this education was imparted onto them. Furthermore, it was to assess their awareness and the benefits of this information sharing.

Of the 16 participants 14 indicated that they received education through individual counselling by the diabetic doctors and sisters and group talks at the clinic level. They were of the opinion that it is beneficial and that they now have a better understanding of diabetes. Most of the respondents indicated that they received handouts and pamphlets on diabetes with a few indicating otherwise. Most of the participants felt that the information was valuable and they reference the material when to refresh themselves. Participant C described this *aptly* *"It is helpful because when I am at home and something goes wrong, I quickly look at the reading material and then I know what to do. I go back to read the information because you cannot remember the entire information. They educate us on a whole lot of things"*. However, three parents were of the opinion that they understood all the information which was imparted and do not reference the material. What was interesting was that a few of the participants shared this information with the child's school. The ongoing information sharing at the diabetic clinic is valuable to most of the participants.

#### ***4.3.5 The Parents Experiences with the Diabetic Team***

As indicated by Ragnar (2004: 345) it is vital that the multi disciplinary team support the parents and child to ensure easier transition into the diabetes management. When the family's medical and social needs are addressed timeously, families tend to adjust, adapt to the disease and will not feel overwhelmed with these new roles /responsibilities.

Most of the participants indicated that the information that they received was beneficial and their experiences with the team were pleasant and helpful but some participants saw other non-medical staff and the participants verbalized having good experiences with them. The dietician, social worker, psychologist and occupational therapist were accessed and they reported helpful experiences with them.

All of the participants have seen the dietician, as this is a very important part of the diabetes management but continue to experience problems with following a correct diet. Three parents indicated seeing the social worker and that were assisted with a care dependency grant. She also helped them to access services from local child welfares closer to their place of residence for continued social work intervention.

*Participant B explained this further “The social worker played a big role and she tried to help us. She counseled him and had to remove him to a hospital because he had high sugars and many DKAs. She referred us to the social worker in my area for assistance. The social worker from my area is working with him and they give him sandwiches everyday because I do not have money to buy him food”.*

Participant B’s son was removed from her care due to financial constraints, which had a direct effect on the child’s diabetes management and repeated admissions. He has had five DKA admissions, which ranged from 2 weeks to three months stay. He was transferred to a Base Hospital awaiting a decision to be returned or removed from his mother’s care due to poor adherence. The poor home circumstances, their limited finances and lack of support contributed to the poor adherence, which eventually led to the decision to remove him to a place of safety. The mother was upset with the decision of removal but she also understood that she was not able to provide for his dietary needs and to ensure that he was compliant with the treatment plan. His removal resulted in better glucose control and he was returned to the mother’s care but the local child welfare has taken over management of the case and is now providing breakfast and lunch to help him adhere to his treatment plan.

Social workers need to be cognizant of the fact that some of these children come from disadvantaged backgrounds and counselling should focus on preservation of the family with removal of the child being the last resort.

The social worker in the medical setting is vital because diabetes forces families to learn new skills and it alters the family's lifestyle. According to Auslander (1997:28-31), the social worker renders supportive counselling and encourages families and children to talk about their feelings and emotions to help them adjust to these the new roles with the focus being on adherence and compliancy to the treatment plan. The social worker has to employ her/his skills to help the patients to define their needs, understand their limitations/challenges and engage them in problem solving. Furthermore, to address the impact of the illness on the patients/families and prepare them to deal with the reality by addressing their psychosocial needs (Auslander, 1997:28–31).

The occupational therapist and the psychologist intervened with two families because the children experienced adjustment problems at school and had difficulty accepting the diagnosis.

Participant 14 explained, *“Our experiences with them were good. All of them helped us. There was a stage where she had to see a psychologist. She could not accept the fact that she was diabetic. The psychologist helped her to accept her diabetes”*. She received regular counselling sessions to enhance her own coping mechanisms through behaviour modification techniques.

Most of the participants rated the diabetes team favorably and regarded them as being supportive and caring.

Participant B explained, *“The team was supportive and encouraged me to make sure that my child takes his insulin because you know children who are diabetic are aggressive and very cheeky. They were warm towards me and this made me feel important. They understand our children and us as parents. They care well for my child when he gets admitted”*.

Participant L supported this and stated, *“The doctor is wonderful. She is good with the children and she takes time to explain. The clinic staff knows the diabetic children and always welcomes them and is friendly. I am happy with their services and they shouldn’t change anything”*.

The above strongly indicates that the members who make up the diabetic team are passionate about their work and strive to make a difference in the lives of the diabetic child and family. Their comments further illustrates that the team members have positive attitudes and understanding towards the patients, which ultimately benefits them. The above indicates that people are complex individuals and that no single discipline can render all services and this thus therefore highlights the importance of utilizing the biopsychosocial model when working with diabetic children and their families.

The participants comments complements Marks et al (2006:17–18) findings which illustrates that if a family receives support and guidance from a multi disciplinary team it can affect both the processes and outcomes of care. Although diabetes is a medical condition, it requires a multi dimensional approach to understand and optimally manage it. This will assist in positive clinical outcomes as indicated by Marks et al (2006:17–18). The multi disciplinary team has a vital role to play because they support the parents and child to ensure easier transition into the diabetes management. When a family’s medical and social needs are addressed timeously, it helps families to adjust and adapt to the diabetes requirements. These new roles and responsibilities will not make them feel overwhelmed.

#### ***4.3.6 The Influence of the Disease on the Child***

This part of the interview explored how diabetic children are affected by their illness and what emerged very strongly is that most of the diabetic children become isolated from social gatherings and parties because the parent is afraid that the child may not adhere to a proper eating plan when away from the family.

Participant N comment stood out and he explained *“my daughter is 12 years old and she is in charge of her own insulin regime and monitoring but we do not trust her to go out on her own and she has not attended a friends birthday party for the past 3 years”*.

Although a child may be independent with the insulin administration, some parents find it hard to trust the child for fear that he / she may eat incorrectly and become ill. The parents over protectiveness may instill negative feelings or behaviour that will inevitably lead to negative clinical outcomes as indicated by Hillson (1996: 126). Furthermore, Ragnar (2004:324–343) in his study on the impact of diabetes on a child found that many children with diabetes have experienced the hurt of not receiving invitations to a friend’s party or social event because the friend’s parent did not want the responsibility of a child with diabetes. It is important for parents to know that parents who have healthy attitudes towards the management of a chronic disease help their children to adjust and accept the diagnosis.

Three of the participants struggle with the insulin regime because the children cry and do not want to be injected.

Some participants explained that the child’s concentration at school is affected, the grades have dropped, some children are aggressive, refuses to take insulin at school, refuses to eat the food, speech was affected and needed speech therapy, refuses to understand that she cannot eat sugary foods. The diabetes has disrupted most of the children’s lives and schooling because of the regular glucose monitoring and the insulin injections.

Children’s social lives are disrupted and they are said to withdraw from friends because they do not want to disclose their diabetes diagnosis for fear that they may be ridiculed or laughed at. A few of the children did not want to take the insulin at school and eat incorrectly while at school although they take lunch, snacks and the insulin pens to school.

Participant B. further expanded on this. She stated that the diabetes affected her son's social life in that he withdrew from his friends because he was embarrassed to be diabetic. It took him two years before he disclosed his diabetes to his friends and he was able to disclose after receiving counselling from the social worker.

The datum indicated that a few of the older children are limited with sporting activities because their glucose levels may fluctuate during physical education. One child experienced a low glucose level and had to be rushed for medical attention. This strongly indicates that some children struggle with the management and it requires continuous education and support. More than half of the children are of school going and experience problems with their glucose injections and monitoring whilst at school. Participant F has provided the diabetes materials to the school and experience support from the child's class teacher to monitor the child while he/she is at school. She explained, *"You will never believe it the first day of school he got sick and nobody phoned me and he only told me two weeks later. I went to school to thank her and she said to me oh no Ms \*\*\*\*\* you don't have to worry I know what to do because my mother is diabetic and if there is something I cannot do to help him then I will phone you"*. This indicates that the teacher is well informed and is a support resource for the child while he/she is at school but parents need to be informed accordingly.

Participant F's quote *"I felt that when he was at the primary school I was up and down every week. I was running to school. They were not compassionate to what he was feeling. I think that to have affected him with his school work"*.

From the above it is evident that the school community is a place that requires education about diabetes because the child spends most of his/her time at school. This will help pupils, teachers and the larger community understand diabetes and the treatment so the diabetic children do not feel alienated or ashamed of his/her diabetes. The school can become a support network for diabetic children and furthermore, most of the parents have indicated that they are experiencing problems with monitoring the child at school. The school definitely has a role to play in assisting and supervising the diabetic child whilst in their care.



Four participants indicated that their child is still not comfortable to take the insulin injections in front of family and friends. Participant G's comment was different though because her son was afraid of needles but when he was first admitted to hospital with diabetic ketoacidosis and the sister told him that it is time to prick his finger for glucose monitoring, he said "*Ok I will do it*". This indicates that as much as a diabetic diagnosis has negative effects on most children but this child took responsibility from the onset.

A common response indicated that the diet was the hardest to adapt to and that some children refuse to co-operate. Participant K is the main caregiver and he struggles to ensure that the child eats properly thus resulting in the child being repeatedly admitted with diabetic ketoacidosis. Ragnar (2004:4) explains that both parents and children need to take responsibility for the diabetes and both should be involved in the management to prevent burnout and this will increase adherence. This, therefore highlights the importance that both parents and children need ongoing information to keep them motivated to ensure adherence. The ultimate aim guiding the parent's management is to ensure that the child's glucose levels are controlled to prevent complications arising from diabetes. Three participants responded that the children are not affected because they are young and did not know any better. However, a few participants with older children reported that the children are angry and the parents have difficulty understanding this anger.

The findings revealed that that diabetic children display aggression and anger. Doorgapersad (2001: 81) study on the impact of gestalt play techniques on the aggression level of diabetic children supports the above findings because she found that diabetic children are aggressive and that gestalt techniques allow them to experience feelings that were related to the illness. Her study concluded that gestalt techniques decreases rebelliousness, anger, increases understanding of the illness, decreases situations of conflict and decreases their fear of the illness.

This study found that most of the participant's children were affected by being diabetic. They were ashamed and some refuse for family, friends, teachers etc to know about their diabetes. Some were embarrassed to take the insulin in front of people. Some children have withdrawn from activities and others were limited in their social play because of their fluctuating glucose levels. Children were forced to accept these changes, became aggressive, angry, and used maladaptive skills to cope. As social workers, we need to work closely with these children and identify these signs and intervene early by utilizing the ecological model when assessing families and planning intervention strategies.

#### ***4.3.7 The Influence of the Disease on the Family***

This part of the interview explored the influence of the disease on the family. Most participants' responded that their family life has changed drastically, eating habits, cooking, not attending social gatherings, parties and some participants indicated that the healthy (non diabetic) children in the family felt that more time is spent with the diabetic sibling and feel less loved. Participant F had first hand experience with the healthy (non diabetic) children and she revealed that *"my eldest daughter felt that since the diagnosis I spent more time with her brother and she attempted suicide 4 times before she revealed this and she said to me "You know mummy you got more time for my brother and you love him more than you love us".* The child was admitted to hospital and the social worker rendered initial trauma counselling and family therapy. Participant F stated that she *"So, I sat her down and explained to her and I said you know my daughter I am sorry and apologies.*

*I never knew this was what I was doing. I always felt that I treated you'll equally but anyway I apologise. I said to her that this is something that is not just a joke because it is not just that your brother has the flu and he will be fine but this is a major difference. He can go to bed and his sugars can be high or low now and he can go into a coma. You know I tried my best to explain this to her and I made her understand this".*

The above quote is an indication that parents may not be aware that they are spending more time with the diabetic child but it also indicates that siblings do not truly understand what diabetes is and what the diabetic sibling is going through. This indicates that siblings require education so that they gain an understanding of diabetes. Parents have to make conscious efforts to balance time with the healthy (non-diabetic) children. These findings are congruent with Daneman et al (1999:111) whose study revealed that healthy siblings are affected by the diagnosis. They may display different reactions and feel jealous and left out. It is important for parents to acknowledge and admit that they are spending more time with the diabetic child and must explain why. This indicates that some siblings lack understanding of diabetes.

Participant E had a difficult task in that she had to change the family eating times to accommodate the diabetic child's eating schedule and this has affected the older child. She explained, *"Yes it has affected them. When the younger child gets hungry and wants to eat and it is not her turn to eat, I shout and scold her and tell her to wait. She is being neglected. I feel bad when this happens but I don't know what else to do"*. This ongoing pattern will be a concern and should be addressed appropriately.

Participant D, C, B, A, H and P have indicated that changing the cooking style was the hardest and it took months to master cooking appropriately. They cook separately for the child and are concerned that this may indicate that he/she is less loved in the home. Participant 1 explained this further in her quote *"I buy brown rice, diet food and brown sugar for him. Sometimes he gets upset but he eats his food"*. Diabetic children should not feel different and families should take time too consciously make diabetes part of their daily lives so this can help the child to adjust and adapt accordingly. According to Guthrie & Guthrie (2002:86) the more education a family has in planning meals, the more comfortable and flexible meals can become and furthermore no special meal needs to be prepared for the diabetic person but rather the entire family can benefit from eating the same foods.

The mother's are the main caregivers and take almost full responsibility for managing the child's diabetes with some assistance from the father's and other family members. Participant O however works as a couple and both parents share equal responsibility. This participant also receives dedicated assistance from the older child to monitor and supervise the diabetic sibling.

Most of the participants stated that diabetes management requires constant supervision and there is no time for relaxing. The impact has been great on the families. It has forced them to make changes whether they are ready or not. Diabetes is a life long management with no breaks because it requires day and night monitoring because juvenile diabetics are dependent on their parents for monitoring and support. Participant H's quote illustrate this point, *"There is no life even at night I have to get up and check her sugar levels and also see if she is okay. It is a day and night job"*.

This clearly indicates that diabetes is a chronic condition that requires both parent and child to work together. Furthermore, diabetes is a lifelong management that requires support to prevent parent / caregiver burnout. According to findings by Chen –Yen and Fenske (1996:468), the type of support system that parent has, has an influence on the adherence to the diabetic regime. Attending education programmes may assist diabetic parents and children to cope with diabetes because of the advice and support that they may get.

Participant G had a unique response in that the couple blamed themselves for the child's diabetes because they had him late in the marriage. Their relationship is negatively affected because the mother assumes total control of the diabetes and has changed the family lifestyle to suit the child's diagnosis without considering the needs of her husband. The father was not actively involved in the child's management because of his work commitments. The mother focused on a change in the family lifestyle without consulting with her husband.

Participant G expressed her concern that since the diagnosis, the couple does not have time for each other and participant B, E and K shared this view. Participant E's quote explained it further *"It gets so stressful sometimes that the main thing I need is time for myself and time with my husband. My husband works and he takes over with the children. Maybe some time out for the both of us without the kids"*.

Finance was identified as a concern to most of the parents because diabetic food and traveling to hospital for medical follow up appointments is costly. Several of the participants indicated that they are unable to buy proper diabetic food whereas two responded by saying that it is not a problem because they have financial support. Participant N explained this further, *"We try to have diabetic stuff but it's just not suitable for our pockets"*.

Participant H supported the previous quote by stating that, *"Finances is a problem because I had to leave work and my husband has to work overtime to make up my salary. He is never at home. The child misses his father but he need to work because diabetic food is expensive"*.

Some of the families have indicated that they had to change their lifestyles to accommodate the diabetes. A few families have stopped going out and to social gatherings because of the child's diabetes. Participant I further explained, *"Yeh, it has been with the food because Sister told us that it is not good to go to a restaurant and that we are supposes to do everything at home so this has stopped. My wife as difficulty with this because she likes to eat out"*.

#### ***4.3.8 Diabetic Ketoacidosis Admissions (DKA)***

Of the 16 participants, all reported that their child had a diabetic ketoacidosis (DKA) which is a severe condition, caused by the lack of insulin or an increase of stress hormones in the body. It is recognizable by high blood glucose levels and ketones in the urine, and occurs in those with type one diabetic. This can result in a diabetic coma if not attended too. 9 out of the 16 participants reported 1 DKA admission, 7 had two DKAs, 1 had 3 DKAs and 1 participant reported 5 DKAs. The child with 5 DKA admissions remained in hospital for 3 months until he was removed to a place of safety. The family was unable to control his diabetes because of lack of finances. The local child welfare assisted in rendering reconstruction work and returned him back to his mother's care. The social work agency provides him with daily breakfast, lunch meals and oversees that his basic needs are met. The child welfare has taken over the child's monitoring in the community.

#### ***4.3.9 Challenges in Managing the Diabetes***

The findings indicated that most of the participants experienced difficulties and challenges. The finances and diet were highlighted as the two biggest challenges to most participants. Changing of the child's existing eating habits to healthier food choices were faced with much resistance.

Participant L explained, *"He used to eat white bread and we had to change to brown. He never uses to eat his food. He do not like it uptil today. So I spoke to Doctor and she told me to give him the white bread till he can understand why he needs to eat brown bread"*.

Finance was highlighted as a major challenge because diabetic food is expensive. Presently, the policy of the Department of Social Welfare is that diabetic children do not qualify for a care dependency grant, unless they have any additional health problems. Therefore, most of the diabetic children are unable to access this state assistance.

A few participants identified the insulin administration and glucose monitoring as challenges.

Participant 12 explained that *“Yes, I injected him. At first, it was very hard on me to inject him because I was afraid to hurt him. He used to cry and did not want to be injected”*.

These tasks are sometimes painful and difficult for parents to perform and this fear can leave one feeling disabled or it can force one to adapt to the new roles and responsibilities. This was congruent with Ragnar (2004:129) findings in that the parents may become anxious about the child’s health, stressed about injections, and the fear that some children have regarding needles may distress the parents.

#### ***4.3.10 Incorporation of Diabetes into their Daily Lives***

This question provided varied responses. A few participants are able to incorporate diabetes into their daily lives but they continue to experience problems. The families had to make changes to their eating habits and food choices after the child was diagnosed. However, most of the participants continue to struggle with this.

Some children refuse to eat the diabetic food and the parents are forced to sometimes allow them the unhealthy food choices. The few families whom have been able to incorporate the diabetes into their daily lives have been able to achieve this at the expense of the healthy (non-diabetic) children and parents. The healthy (non-diabetic) children are sometimes not permitted to eat as they wish because of the diabetic child. This places additional challenges on the parents, which need to be addressed before the healthy (non-diabetic) children rebel. Many participants identified the cooking style as a major challenge for many of them.

#### ***4.3.11 Their present needs***

The participants were able to communicate with ease regarding their present needs. The main needs identified were that there is a need to start up support groups for both parents and children. Assistance with accessing a care dependency grant was also identified because this will assist the parents to meet some of the child's dietary requirements. Sibling education and support was also identified because the healthy (non-diabetic) children in some families do not understand diabetes. This supports Daneman et al (1999:111) findings in that some healthy siblings become jealous and do not understand the insulin treatment. The participants also felt that ongoing education and support from the team was required to help them cope with the management of their children's diabetes. This is supported by McDowell et al (2007: 49 -50) and Gard et al (1997:127) in that it highlights the importance of the team support in addressing the parents' and diabetic children's needs to help them adjust and adapt to these additional responsibilities.

A few participants also felt that community education and awareness was important because most people are ignorant of diabetes, the importance of adhering to a diet, the complications, the importance of insulin administration and the glucose monitoring. Most of the participants felt that school teachers and pupils need to be made aware of diabetes because diabetic children feel ashamed, isolated and afraid to disclose their diabetes to friends and teachers.

Two participants requested that the hospital provide transportation from central areas of their residence and back home. The participants identified that there is a need for spouse and family support to manage the diabetes better. Parents require time out to prevent burnout. The participants felt that they need couple time. Some felt that the parents' relationships are affected, as couples do not have couple time. Participants spend most of their time with the diabetic children and need to set time to spend quality time with the healthy (non-diabetic) children.



#### **4.4 SUMMARY**

It is evident from the study that paediatric diabetics are dependent on their parents and families for support and management. Most of the participants expressed that it is difficult to manage diabetic children and they continue to experience problems.

There is a need for continuous education and support to help them to care and manage the children adequately. The participants face daily challenges and try to make diabetes part of their daily lives. They face financial difficulties and sometimes resistance from the diabetic child because of the food choices.

Some face difficulties from the healthy (non-diabetic) children because they are forced to change although they are not sick and parents are sometimes faced with problems because the healthy (non-diabetic) children do not understand why they need to spend more time with the diabetic child. Most participants are unable to provide the child with the recommended foods due to limited income and accessing the state grant will assist them to meet some of the child's needs. The state grant is available but not accessible. The community and schools have a role to play but they need diabetes awareness education. Despite all these challenges, the participants are trying to manage the diabetic child in the best way that he / she can.

## CHAPTER FIVE

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

This Chapter outlines a summary of the main findings, outlines the limitations and makes recommendations according to the research findings.

The objectives of the study were:

- ❖ *To explore the parents initial reactions or attitudes to the child's diagnosis.*
- ❖ *To ascertain to what extent parents are able to incorporate diabetes into their lives*
- ❖ *To gain insight into the challenges that parents face.*
- ❖ *To ascertain what factors hinder / or promote family management of the disease.*
- ❖ *To identify the needs of parents to help them to effectively manage the disease*

This study was based on an exploratory descriptive design in that the study hoped to find out the challenges faced by parents of diabetic children through a face-to-face interview with 16 participants. A convenience sample was used of the parents of children who attend the Paediatric Diabetic Clinic at the said hospital. The datum was collected over a six months period. The datum was coded, analyzed, grouped as themes, and is presented accordingly.

This study dealt with the challenges of parents caring for diabetic children and it is my belief that there is still a need for more research into this topic in South Africa in order to come up with support networks / resources for diabetic children and their parents.

## **5.2 CONCLUSIONS DRAWN FROM THE STUDY**

The findings of the study concluded that parents who care for diabetic children have a number of challenges, which include the following:

### ***5.2.1. The parent's first reaction to the child's diagnosis***

Congruent with studies by Ragnar (2004:129) this study found that most of the parents reacted with shock, denial, anger and disbelief but some had other reactions. Only one participant felt more equipped because of previous exposure to the same diagnosis and felt more prepared to accept the diagnosis. Parents are consumed with many thoughts of the new diagnosis and how are they going manage it. Some felt devastated at the initial diagnosis but with time and assistance, have accepted it. Most participants have partial acceptance but two participants continue to struggle with this management. These fears and concerns complemented the studies by Gard et al (1997:127) in that parents who have children with a chronic illness have concerns about their reactions to the diagnosis and the limitations this disease may place on their lives. This may be indicative of a lack of public knowledge regarding the illness.

### ***5.2.2. Parents' education regarding diabetes***

Most of the participants did not have much knowledge of diabetes prior to the child's diagnosis. They explained that the diabetes education imparted by the hospital was very beneficial and helpful. They continue to refer to this reading material to refresh their memories and to assist them to manage the child better.

This education is ongoing and valuable to the parent's and child. Most of the participants indicated that they were angry and upset at the diagnosis but it took them approximately one year before they were able to understand and manage the diabetes. This is in keeping with Hillson (1996:162) findings in that the first year of the diagnosis and at special occasions the parents and child may experience feelings of anger, sadness, resentment and grief. This still appears to be an area requiring attention.

#### ***5.2.3. The parents' experiences with the diabetic team***

The diabetes team members at the hospital were reported on favorably by the participants. The team was reported to be supportive and helpful to all the diabetic children. The team is effectively functioning and the participants did not recommend any changes. . The above findings indicate that the team members function within the biopsychosocial paradigm when working with the diabetic children and their families.

#### ***5.2.4. The influence of the diabetes on the child and family***

This theme clearly indicated that the diabetic child is affected by the diagnosis and that it affects his/her image of him/herself. The diabetes affects the child's attendance at school, ability to participate in activities and their socialization. The child has to change his/her lifestyle to accommodate the diabetes and it may trigger anger outbursts in children.

The study concluded that the influence of the disease on the family is enormous. The eating habits, cooking style, making time to accommodate the glucose monitoring, trying to balance time with the healthy (non diabetic) children and spouse, altering family eating times, incorporating the additional responsibilities into the daily lives, financial implications were but a few that the participants disclosed during the interview.

This also indicated that some healthy (non-diabetic) siblings do not understand the diabetes and require diabetes education to help them understand it. The participants also indicated that they do not have couple time since the diagnosis. This is a further area requiring attention.

Most of the participants have reported that the children were admitted to hospital with diabetic ketoacidosis (DKA) on one – five times with a minimum one week with a maximum to four weeks stay. The identified area of need is that the hospital needs to accommodate at least one parent to remain in hospital for a period of two days for education. The above indicate the importance of the ecological perspective when working with families because the child is part of a number of micro systems and when there is change in one system it has a ripple effect on the individuals interaction with the different systems. This ripple effect is evident in the findings of the study as indicated above. The hospital as a micro system has a role to play to render the education and support which families and diabetic children need to help them adjust and manage these additional responsibilities effectively.

#### ***5.2.5. The challenges / difficulties faced and how they were addressed***

The main challenges reported by the participants were that the diet and changing the eating habits was the hardest. They receive continuous dietary counselling to help them manage this. Finance was also rated as a challenge which most of the participants continue to have trouble because diabetic food is expensive. Furthermore, diabetic children do not qualify for a state grant unless they have any other additional health problems. A few parents reported the insulin administration as a challenge but the older children receive education and are encouraged to do the insulin administration and glucose monitoring independently.

A few participants are able to incorporate diabetes into their lives but most of them continue to struggle with this. Conclusion is that some patients find it difficult to change and that there is a need for the team to provide ongoing education, guidance and support to promote them to make diabetes a part of their daily lives.

The participants identified a need to have support groups for parents and children, assistance with accessing a state grant for diabetic children, healthy (non diabetic) siblings to be educated on diabetes, to create diabetes awareness in the communities and schools. Furthermore, both parents should receive diabetes education to increase support and prevent caregiver burnout.

### **5.3 RECOMMENDATIONS**

Based on the findings of this study, the following recommendations are made with reference to the medical setting in which the study was conducted:

#### **❖ *State Grants***

It is evident from the study that diabetes is a chronic condition and it is a life long management. Furthermore, diabetic food is expensive and this can further burden an already financially deprived family. The present policy on state assistance is that diabetic children do not qualify for a care dependency grant, unless there are additional health problems. This study found that meeting the dietary requirements for a diabetic child to maintain proper glucose control, is expensive. Most of the participants are experiencing financial problems and have indicated that finances limit them to provide adequately for their diabetic child's needs. Those lacking finances will certainly benefit from the state grants and it will ease the financial stress that parents experience and may assist in closer glucose monitoring.

There is a need for social workers to mobilize and lobby on behalf of disadvantaged children to motivate diabetic / medically dependent children to be candidates for a state grant. An additional concern was that some schools do not have school feeding schemes. Schools need to be enlightened on the process so diabetic children will receive sandwiches at school and this will / may reduce hypoglycemic episodes at school. I am of the opinion that if the care dependency grant is awarded to all diabetic children this could eventually lead to better clinical outcomes for these children because their glucose levels could be maintained as close as possible to normal levels.

#### ***❖ Need for Support Structures / Groups for Caregivers***

This study found that most diabetic children are affected by their illness. They are ashamed of being diabetic and they refuse for family, friends and teachers to know about their diabetes. Some are embarrassed to take the insulin in front of people, they withdraw from activities and others are limited in their social play because of their fluctuating glucose levels. Children are forced to accept these changes and it may result in them becoming aggressive and angry. As social workers, we need to work more closely with the diabetic children and identify the signs and intervene with individual, family therapy and group sessions. A support group will offer diabetic children to meet other children and they will not feel alone in their diabetes. Parents are the cornerstone of success because children take their cues from their parents. It is the responsibility of the social worker to work closely with these families and through counselling we will be able to identify the signs of poor compliance. These early intervention could help children to accept the diabetes and make it part of their lives.

The majority of the participants strongly indicated the need for support groups for both diabetic children and their parents. These groups will help parents to meet and receive support from other parents and so they will not feel so alone. Furthermore, the parent / caregiver need support to prevent burnout. In addition, a caregiver needs constant education to help them understand the diabetes and reasons for adherence. This support will be to direct the focus towards adherence and proper diabetes management. Caregivers will have a platform to discuss their challenges and to learn coping skills. It is the social workers responsibility to initiate these groups.

### ❖ *Community and school awareness*

The school community has a role to play in assisting and overseeing diabetic children during school hours. There is a need for the school community to be made aware and educated on diabetes. This will help pupils and teachers to understand diabetes and the treatment so that diabetic children do not feel alienated or ashamed of his/her diabetes. The team should have yearly outreach education programmes for the teachers of the children from our clinic list. They could be invited to a day programme to educate them on diabetes and their role in assisting the child while he/she is at school. The teachers may then become a support system to assist the caregiver to monitor the child whilst at school. This ultimately can produce closer glucose control and prevent repeated DKA admissions because parents have identified that they experience problems to monitor the child whilst at school. This recommendation emphasizes the ecological perspective in that all micro / macro systems involved in the care / monitoring of diabetic children require education as this will serve in the children's best interest.



### ❖ *Sibling education*

It is evident from this study that healthy (non diabetic) siblings do not understand diabetes, feel that the parents spend more time with the diabetic child and they feel less loved and sidestepped by the parents. This indicates that siblings lack understanding of diabetes, there is a need for siblings to be educated on this and there is a need to involve and encourage them in the treatment programme. Parents need to encourage the healthy (non-diabetic) children to accompany them for follow up appointments so they could be educated on diabetes. An annual education day for healthy (non-diabetic) siblings should be planned to address this need. This aspect can be focused on during family counselling.

### ❖ *Family support*

What was very evident from this study is that the majority of the mother's are the main caregivers of the diabetic child. They receive minimal support from extended family members but fathers do not support or assist adequately. A number of the participants are single parents with no financial support from the partners. I am of the opinion that if fathers are encouraged to join the education programme this can encourage them to assist in the supervision of the diabetic child. Ultimately, this will assist in preventing burnout of one caregiver. Extended family members can be included in the education programme because parents need time out and couple time to prevent burnout.

#### ❖ *Need for continued research*

There is a lack of local research on the topic. This indicates that there is a need for continued research to contribute to the existing body of knowledge. Research can help medical and non-medical staff to understand patients and identify the gaps to continuously evaluate our effectiveness and implement recommendations accordingly. The significance of this study is that caregivers and diabetic children require ongoing education, support and financial assistance to ensure adherence. This ongoing information sharing will empower parents and children on diabetes and assist in better understanding of the disease and the importance of adherence. The focus is to help children towards independent insulin administration, glucose monitoring (GM) monitoring and to manage themselves in a responsible manner to prevent long-term complication due to the disease.

## **5.4 LIMITATIONS**

- ❖ The findings can only be generalized to the diabetic patients who visit the said hospital.
- ❖ Only the diabetic out patients who were diagnosed in the last three years were involved in the study.
- ❖ The period of collecting datum had to be extended to six months because the participants had to meet specific requirements and some were not readily available.
- ❖ Under reporting or over reporting might have occurred because of the sensitive nature of some of the questions.
- ❖ It was difficult to access local research conducted on juvenile diabetes mellitus.
- ❖ Some participants' could have been restrained in their responses so as not to give me, the social worker a poor impression of the management of their child.

## 5.5 CONCLUSION

The findings of the study revealed that participants and the diabetic children receive adequate education, support and guidance from the hospital team. However, many participants continue to experience problems and the children are sometimes repeatedly admitted with DKA. The parents and children still require counselling and therapy to help mobilize them into closer adherence thus increasing the patient's quality of life. There is a need to assist them in changing attitudes and beliefs to be able to incorporate diabetes into their lives. If they understand the importance of making diabetes part of their daily lives, it may reduce the number of DKA admissions and prevent long - term complications associated with diabetes.

Diabetic patients and their parents need medical, social and psychological support from family members and the professional team to help them manage the diabetes. Diabetes is hard work, which requires daily administration and monitoring without a break. This can sometimes result in burnout. This burnout is a reality that many parents face together with the financial responsibilities that may further burden a financially deprived family.

From the above we can conclude that both the ecological as well as the biopsychosocial models can be utilized by the social workers and /or educators when planning education / awareness programmes for diabetic children and their families.

It is evident from the study that caring for diabetic children is a huge responsibility, it is tiring, their dietary needs are expensive and that they will benefit from receiving a state grant. It will serve in the best interest of the children concerned.

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## LIST OF APPENDICES

Appendix A Consent Form

Appendix B Interview guide

Appendix C Ethical Clearance from UKZN — Howard College

Appendix D Letter from employer granting permission to conduct the  
Research

Appendix E Letter of approval from the Chairperson of the Provincial Health  
Research Committee - KwaZulu Natal Department of Health

## **APPENDIX A**

### **RESEARCH TOPIC: Challenges facing parents of diabetic children**

#### **CONSENT LETTER FOR PARTICIPATION IN THE DIABETIC RESEARCH**

I \_\_\_\_\_, hereby consent to participate in the said research on diabetes conducted by Mrs. Kumeshini Pillay. I am aware that the information from the interview will be used for research purposes and it maybe published. I am aware that my name will remain anonymous to protect my identity. I acknowledge that it is voluntary to participate in the interview. I will abide by the confidentiality clause of the interview.

I have been informed and agree / disagree to the recording of the interview.

I have been informed that an interpreter can be called into the interview should the need arise.

The purpose and the process of the research were explained to me and I fully understand it. I know that I have the right to withdraw from the research at any given time.

Signed: (Parent) \_\_\_\_\_ Date: \_\_\_\_\_

Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

## ISIGAXA A

ISIHLOKO SOCHWANINGO : Izinselelo ababhekene nazo nazo abazli bezingane ezinesifo sikashukela

### INCWADI YESIVUMELWANO SOKUZIMBANDAKANYA OCHWANINGWENT

Mina ..... ngenza isivumelwano sokuzimbandakanya ochwaningweni lwesifo sikashukela oluholwa usonhlakahle u-Kumeshini Pillay. Ngियाqonda ukuthi ulwazi oluvela kowenza inhiolovo luzosetshenziselwa ngenhloso yochwaningo futhi lushicilelwe

Ngियाqonda ukuthi igama lami ngeke lidalulwe ukuvikela ubumina. Ngियाqonda ukuthi ukuzimbandakanya kwami ochwaningweni ukuzinikela akuphogiwe. Ngiyazibophezela. Ngizohambisana ne Ngizohambisa nakho konke okwiyimfihlo kulenhloolovo.

Ngazisiwe futhi ngavuma/ngangavuma ukuqoshwa kwalenhloolovo.

Ngazisiwe ukuthi utolika angase abizwe kunhlolovo uma isidingo,

Ngियाqonda ngenhloso ne nqubo yokufundiswa ukuthi ngachazelwa kahle.

Ngियाqonda ukuthi nginalo iolungelo lokuhoxa kwinhloolovo noma ingasiphi iskhathi enginikwe sona.

Ushicileio (Umzali)\_\_\_\_\_ Usuku\_\_\_\_\_

Umchwaningi \_\_\_\_\_ Usuku\_\_\_\_\_

## **APPENDIX B**

### **INTERVIEW GUIDE**

#### **TOPIC: TO EXPLORE THE CHALLENGES FACING PARENTS OF DIABETIC CHILDREN**

##### **Demographic details**

###### **Parent/ participant**

Relation to child : mother/ father

Age:

Number of children:

Occupation:

Area of residence

###### **Child**

Age of child:

When first diagnosed:

No of years on treatment:

Does child have other health related problems.

Schooling

##### **The parents responses to the diagnosis**

Initial response:

How are you feeling now (about the diagnosis)

What factors contributed to this (either shift or no shift in attitudes/ feelings)

##### **The parent's education**

The nature of diabetic information/ education received.

(Simple, how conveyed, did you understand, who undertook, forms- pamphlets, support groups, doctors, nurses. etc.

Did you find this helpful in managing your child's diabetes? Explain?

##### **Experiences with the diabetic treatment team**

Describe your experiences with the diabetic treatment team? List the professionsls whom you have seen (doctor, social worker, diabetic nurse, other counselor, community. educators?

Did you feel that you received adequate support through this process?

**The influence of the disease on the child**

How has this diagnosis affected the child? ( in terms of functioning — social, diet, activities etc.)

**Family**

How has your child's diagnosis affected the family? ( in terms of functioning — social, diet, activities etc.)

**Their challenges / difficulties**

What were some of the challenges you faced in managing the disease.  
How did you address these?

What were some of the challenges your child faced in managing the disease.  
How were these addressed?

**Incorporation of the diabetes into their lives**

Are you able to incorporate diabetes into your daily life?

If yes, explain how this was facilitated.

If no, explain difficulties/obstacles. What would help to facilitate this process?

**Present needs**

What are your present needs/challenges as a parent who has a diabetic child?

How can the diabetic treatment team help you to cope better in managing the disease?

**Any additional comments ( on how the health sector can help/support families with diabetic children)**

**Please note the following:**

**The purpose of the study will be discussed with the participants before commencing the interview.**

**The researcher will use pseudonyms to protect the participants true identity when analyzing and writing the report.**

**IR**

**4110<sup>11,0111</sup>■00.**  
**UNIVERSITY OF**  
**KWAZULU-NATAL**

RESEARCH OFFICE (GOVANMBEKI CENTRE)  
WESTVILLE CAMPUS  
TELEPHONE NO.: 031 - 2603587  
EMAIL [ximbanaulan.acia](mailto:ximbanaulan.acia)

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13 FEBRUARY 2009

MRS. K PILLAY (9255325)  
SOCIAL WORK AND COMMUNITY DEVELOPMENT

Dear Mrs. Pillay

ETHICAL CLEARANCE APPROVAL NUMBER: HSSI0542108M

I wish to confirm that ethical clearance has been approved for the following project:

*"Challenges facing parents of diabetic children"*

PLEASE NOTE: Research data should be securely stored in the school department for a period of 5 years

Yours faithfully

"krV\DG?"  
.....  
MS. PHUMELELE XIMBA

cc. Supervisor (Dr. R Sathiparsad)  
Cc. Mrs. L Marriott





# DEPARTMENT OF HEALTH

PROVINCE OF KWAZULU-NATAL

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL

## OFFICE OF THE MEDICAL MANAGER

800 Belair Road, Mayville, 4058

Private Bag X03, Mayville, 4058

Tel.: 031 240 1042 Fax. 031 240 1050

[Email. Philisiwemazgalch.co.za](mailto:Philisiwemazgalch.co.za)

15 April 2009

Ms K Pillay  
Dept of Social Work  
IALCH

Dear Ms Pillay

**Re: Ref No: HSS/0542/08M: Challenges facing parents of diabetic children between the ages of 2-13 years.**

As per the policy of the Provincial Health Research Committee (PHRC), you are hereby granted permission to conduct the above mentioned research once all relevant documentation has been submitted to PHRC inclusive of Full Ethical Approval.

Kindly note the following,

1. The research should adhere to all policies, procedures, protocols and guidelines of the KwaZulu-Natal Department of Health.
2. Research will only commence once the PHRC has granted approval to the researcher.
3. The researcher must ensure that the Medical Manager is informed before the commencement of the research by means of the approval letter by the chairperson of the PHRC.
4. The Medical Manager expects to be provided feedback on the findings of the research.
5. Kindly submit your research to:

The Secretariat  
Health Research & Knowledge Management  
330 Langaliballe Street, Pietermaritzburg, 3200  
Private Bag X9501, Pietermaritzburg, 3201  
Tel: 033395-3123, Fax 033394-3782

Yours faithfully

**Dr M E L Joshua**  
**Medical Manager**

*Umnnyango Wozompilo*

*Departement van Gesondheid*



**HEALTH**

KwaZulu-Natal

Health Research & Knowledge Management sub-component  
10 –102 Natalia Building, 330 Langalibalele Street  
Private Bag x9051  
Pietermaritzburg  
3200

Tel: 033 – 395 2805

Fax.: 033 – 394 3782

Email.: [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

**Reference: HRKM052109**

**Enquiries: Mr X. Xaba**

**Telephone: 033-395 2805**

12 May 2009

Dear Ms K. Pillay

**Subject: Approval of Research**

1. The research proposal titled "**Challenges facing parents of diabetic children**" was reviewed by the KwaZulu-Natal Department of Health. The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central Hospital.
2. You are requested to undertake the following:
  - a. Make the necessary arrangement with identified facility before commencing with your research project.
  - b. Provide an interim progress reports and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkmakznhealth.gov.za](mailto:hrkmakznhealth.gov.za).

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr. S.S.S. Buthelezi**

Chairperson: Provincial Health Research Committee  
KwaZulu-Natal Department of Health