

A QUALITATIVE INVESTIGATION INTO THE
MANAGEMENT OF DIABETIC LEARNERS IN
SOUTH AFRICAN SCHOOLS

by

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Submitted in fulfillment for the requirement of the degree of Master of
Education in the School of Education, Faculty of Humanities,

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3 March 2014

DEDICATION

I would like to dedicate this work to my wonderful family, my wife Dané, my sons Luke and Benjamin and my daughter Hannah, who have stood by me throughout this lengthy process.

ACKNOWLEDGEMENTS

A huge thank you to Dr. Joseph Divala, my supervisor, who has tirelessly guided me from beginning to end. Without his patience and assistance, this would not have been possible.

To Melanie Clark and Dominique Proctor for assisting in putting everything together.

To Lesley Menego, thank you so much for doing the editing for my dissertation. It is much appreciated.

To Ronica Pardesi and Beverley Davey for their valued assistance. Thank you.

Dr. John Thurlow for his valued guidance and advice during the entire process of this work.

And last but not least, to my parents, thank you Mom and Dad for your encouragement and support.

DECLARATION

This work is entirely my own work, except otherwise acknowledged

Signed: _____

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Date: February 2014

ABSTRACT

This research was sparked by a personal encounter with diabetes. My middle child was first diagnosed with type 1 diabetes mellitus (diabetes) four years ago. None of his teachers had any idea of how to assist us as parents in the daily management of this disease. The purpose of this investigation then, began initially with this background in mind in an attempt to discover how the management of diabetes occurs in public schools across South Africa. Literature indicates that there is apparent widespread screening to detect the symptoms and the onset of diabetes in other countries across the world which reveals that both type 1 and type 2 diabetes are on the increase.

The respondents in the research process consisted of principals, teachers, peers of the diabetic learners and the diabetics themselves. The investigative process required the respondents to complete a questionnaire as well as being part of an interview process to determine the major outcomes of the study. These interviews were audiotaped. The outcomes of the investigative process included examining the daily routines of the diabetic.

The results of the investigation revealed that in the context of the South African situation concerning learners suffering from diabetes, basic knowledge about the disease is limited to the extent that teachers and peers of the diabetic learner are ill-informed and this is as a result of a lack of communication in the entirety of the management process of diabetic learners at schools in this country. Diabetes is generally a “mystery” to most people not in contact with it on a daily basis and many people are confused by the glucose monitoring and the insulin injecting process as a “foreign method” of medicine.

The results of the investigative study indicate that diabetic children need to have a management plan for school but significantly more important is the assistance, understanding and communication that is required on a daily basis by a team of caregivers consisting of parents, educators and their peers

if diabetics are to feel and form part of an integrated South African education system. Also, the study reveals that the training of certain individuals to take specific care of diabetics would assist these children.

Camps that diabetics can attend also assist their child in taking most of the responsibility for their own lives and the diabetic groups that parents can join to share similar experiences with other adults also proved effective in the practice of sound management. For diabetics, friendships fostered and the “buddy” system in the classroom where a friend could identify dangerous situations proved invaluable.

Policy makers need also to heed the call of re-visiting policy decisions of the past in order to serve the plight of the diabetic learner and increase the awareness of diabetes in our schools.

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CHAPTER ONE

RESEARCH ORIENTATION

1.0 Introduction

This research is a qualitative study centred on the management of diabetic learners in South African schools. The study seeks to interrogate the relationship between learning, conceptions of self-image and acceptance by peers and teachers in children with diabetes. Academic progress and the effects that negative diabetic “episodes” may have on those diagnosed will be part of the research. Also, physical activity both in the formal and informal sense will be part of the investigative process that unfolds. The associated illnesses that diabetics encounter as a result of diagnosis of diabetes mellitus form part of this researcher’s work.

Although the South African education system embraced an equal and inclusive system of education in 1996 with the adoption of the new constitution, the study seeks to examine if, in real terms, all learners are actually included in the running of schools. I will do this by focusing on the case of learners with diabetes.

Human rights issues and prejudices that diabetic learners in schools encounter will be investigated and reported on in the section devoted to theoretical framework and data analysis. The general day to day management of diabetic children during and after school in terms of self-management as well as assistance received from a myriad of people and/or caregivers and diabetic-management team members form part of my study.

The dietary requirements and the effect that different foods have on the levels of blood glucose in diabetics’ bodies as well as the unique and collective general challenges that these learners may encounter will form part of the investigative process.

I will attempt to establish, through the investigative process, to what extent children who live with this disease are supported during and after school time and how one deals with the monitoring processes of it. Hence the study seeks to interrogate and find better ways of managing diabetic students in South African schools and whether or not some loopholes in the education system can be addressed.

1.2 Background to the Research

Diabetes is a relatively new disease and has become known only within the last two centuries. Hanas (2005, p.12) argues that the first human to be treated with insulin was a 14 year old boy, Leonard Thomson, in Canada in the year 1922.

Most people are ignorant about diabetes. Until five years ago, I knew absolutely nothing about the disease. As a grade head some years ago, I had heard that one of the learners in our grade had ‘sugar diabetes’. The mother of this specific learner had always assured us that the learner had everything under control; that she knew how to manage her condition. My grade head partner had been on Netball tours with our diabetic learner and was more informed about her condition as well as what action to take in the case of an emergency. As a result, I was completely ignorant about every aspect of the disease. This meant that in the event of an emergency the diabetic learner in my grade would either have had to be in control and would deal with it by herself or my colleague would effectively manage the situation. Thus there was no real danger and I saw no problem and no need for me to be educated on the subject of diabetes as other people would deal with it for me.

When the diabetic learner in my grade matriculated, we congratulated her and wished her and her parents everything of the best for her bright future, as she had excelled in every field at school. As there had been no incident relating to her disease, the staff of the school where I teach assumed that her “normal” teenage years would graduate into “normal” adulthood.

Some four years ago my middle child started to exhibit behaviour that was somewhat out of the ordinary. He always seemed to be tired. He had also, during the two previous weeks, wet his bed from time to time and as parents we wondered if there was any psychological problem at school. He played rugby for his school and after being tackled, as he got to his feet, he attacked the unsuspecting lad of the opposing team with flying fists and with such ferocity that we were alarmed.

He was asked to leave the field and, embarrassed, we left the venue wondering what had become of our fun-loving young son. When we arrived home, he took off his shirt to change and it seemed to me that over the past two days he had suddenly become extremely thin. His ribs were showing and we began to worry. We were to get him to an endocrinologist immediately. During the trip to the doctor, thirty (30) km away, he slept most of the way. It was almost loss of consciousness rather than sleep. Medical tests later revealed his diabetic status. His average blood sugar level for the previous six (6) months registered thirty two (32). An average of between (3.2) and eight (8) mmol/l is considered normal.

We later learnt that there are three types of diabetes. Type -1 diabetes- the rarer kind – is primarily caused by the destruction of cells in the pancreas that make the hormone insulin. It is called an autoimmune disease because the body mistakenly makes antibodies that attack the cells in the pancreas. Once the majority of these cells are destroyed, a person cannot function without insulin. It used to be called “insulin-dependent diabetes”. This usually develops in childhood and hence was also called “child-onset diabetes (Holford, 2001, p.4). Type -2 diabetes accounts for over ninety (90) per cent of all diabetes. On the other hand, people with Type-2 diabetes almost always have very high levels of insulin. The third is gestational diabetes and is mostly found in pregnant women (ibid).

The diabetes educator explained to us that our son’s blood contained too much glucose (sugar) and that the food he eats, especially the carbohydrates, are broken down into glucose and stored in his cells for energy. He needs

this energy so that he can perform all his basic daily activities like running, learning, swimming and others.

In Type-1 diabetes, the insulin producing cells of the pancreas are destroyed by a process in the body known as “autoimmunity” (Hanas, 2005, p.12). This “leads eventually to a total loss of insulin production. Without insulin, glucose remains in the bloodstream, so the blood glucose level increases, especially after eating meals. Glucose is then passed out of the body in the urine” (Hanas, 2005, p.12). Type 1 diabetes cannot be prevented. It is also not contracted by eating too much sugar candy or other sugar laden products. The disease is not contagious. Presently there is no cure for diabetes but one can lead a relatively normal life by regular glucose testing, healthy living and the administering of insulin by injection.

One can also argue that when a family member is diagnosed with type -1 or type- 2 diabetes people need to make some adjustments. Lifestyle patterns, as well as food intake, must change. Becoming familiar with administering injections at meal times can be stressful and may lead to anxiety in the family. Support, encouragement and love, together with the re-building of “confidence and self-esteem prove invaluable” (Flynn, 2005, p.126).

In the experience narrated above, I discovered that what doctors take years to study is crammed into a few hours of instruction during the first visit to the doctor after diagnosis. Importantly one has to understand that there is never any “time off” from the disease and that going on trips and outings would never be the same again. As with many cases, there is a “honeymoon period” that lasts for some months in that one’s body can be assisted with the supply of injected insulin and the pancreas is helped in the production of insulin. This means that the pancreas, as a result of this foreign supply of insulin to the body, would produce a little more insulin than at the time of diagnoses and that it does not need to function at optimum level as it is being assisted. Thus it would function better for a few months and then stop producing insulin to the body completely.

While not much is done at the level of schools, today there are four people at my school who have type 1 diabetes and this confirms that “there is a steady increase in the number of cases diagnosed per year in most countries, especially in the younger age group” (Hanas,2005, p.15). I had eventually learnt, albeit the hard way, what had consumed that young girls life while in my care as school. “In the past, no effective treatment was available. Before insulin was discovered, Type-1 diabetes always resulted in death, usually quite quickly” (Hanas, 2005, p.12).

1.3 Rationale for the study

In many countries around the world, schools have nurses who take care of the children’s medical needs. Mostly, this service includes the administration of medicines to children as well as a first aid service for minor injuries, cuts and bee stings. Most children rarely visit the nurse’s room or the “sick bay”, as it has been called in South Africa. The diabetic child, however, would probably need to make regular stops at the nurse’s office to test blood sugar levels as well as administer insulin shots, given the nature of the disease. It can be argued that even in the case of a diabetic child, the nurse’s room is a good place to go to as it provides relative privacy to the child administering insulin to him or herself.

In South African public schools there are no nurses, so diabetic children tend to use the school cloakroom to test blood sugar levels and administer insulin. Unfortunately, there are few people who know what this process entails and children who suffer from diabetes mellitus may unfairly and unfortunately be left “exposed”, with no privacy to care for themselves.

Despite the steady increase in diagnosed cases of children with diabetes mellitus, they have no allocated area in which to administer insulin before meals and in many cases no one ensuring dosages are correct or assisting in this regard. Other children in our schools in South Africa who do not understand the disease, and do not know the implications of receiving insulin shots and why insulin is injected instead of being taken orally, have in the

past ostracised diabetics through a lack of knowledge and understanding and have also excluded children socially.

Since children are now more than before, and on a regular basis, being diagnosed mostly with Type -I but also with Type -2 diabetes mellitus and since the “number of cases of Type -2 diabetes as a proportion of the total number of newly diagnosed diabetes among children is extremely high”, (Hanas, 2005, p.15) it can be assumed that schools are faced with this responsibility. Because your body will not be able to continuously “produce large amounts of insulin necessary to keep your blood sugar level normal”,... (ibid) if you are overweight and are overeating your body will slowly become “more vulnerable to Type -2 diabetes” (Hanas, 2005, p 13,15). Children in most South African schools are exposed to tuck shops that perhaps supply unhealthy food and candy as well as drinks that are sugar laden. This, together with the fact that children may be less active as a result of technological games that they play instead of playing outdoors and taking part in sport, adds to the possible increase in diagnosis of Type -2 diabetes.

The major problem with Type -2 diabetes is that “late complications of diabetes such as eye disease (retinopathy) and kidney disease (nephropathy) develop in children and adolescents with Type -2 diabetes at a similar or faster pace, than in those with Type - 1 diabetes” (Keda, 2003, p.51). Unfortunately this means that children suffer complications from Type -2 diabetes which may be more harmful to them than those suffered by children diagnosed with Type -1 diabetes. Children with type 2 diabetes “go through a long ‘silent period’ during which they do not display any subjective symptoms” (ibid). This is often a problem as “Type- 2 Diabetics may often have established late complications when they first visit a diabetes centre” (ibid).

Life Orientation teachers, School Governing Bodies as well as School Management Teams can possibly be said to have a responsibility to address the previously highlighted issues. Learners need help to manage their diabetes at school as the disease does have an impact on their lives. Are

peers and teachers able to help in this regard, and to what extent is assistance needed?

Teachers, parents, doctors and diabetic educators may need to unite to help diabetic children cope at school. Unfortunately, there is a limited amount of expertise in public schools in South Africa and the diabetic child has often to form an individual diabetes healthcare plan without much help from his or her school. One can only speculate that there needs to be much more attention given to this problem facing diabetics. One wonders whether in our schools one needs to ensure that there is appropriate food available at the school tuck shops and cafeterias as well as “safe zones” where children can administer insulin with or without the help of a teacher or adult supervisor. I will investigate this in my research.

In other countries such as “the United States of America, Federal laws protect children with diabetes” (Hanas, 2005, p.292). This means that in all ways children with diabetes must and should be treated in the same way as all other children in the school and protected, as well as assisted, because “under these laws, diabetes has been determined as a disability, and it is illegal for schools and/or day centres to discriminate against children with diabetes. This could occur by not ensuring that adequate procedures and mechanisms are in place in schools” (Hanas, 2005, p.292).

Keda (2003, p.52) reports that “in Japan, more than 90% of new cases of childhood and adolescent Type -2 diabetics are identified by the school based diabetes screening programme”. In South Africa there is a desperate need for health promotion in our schools and if the country is to combat diabetes successfully and prevent it (Type -2 diabetes at least) from becoming an unmanageable problem, schools may need to implement programmes such as the ones that have helped the Japanese. Furthermore, the South African National policy is actually relatively silent on chronic disease as the document only suggests that diseases such as cerebral palsy, asthma and diabetes “have the potential to cause learning and development barriers” (Republic of South Africa, 2010, p.95). Presently, “in India and

China, free glucose tests and insulin supplies have been made available due to a threat of a diabetic epidemic there.” (Keda, 2003, p.51)

There have been many problems with food intake both in South African schools and throughout the world. As Chopra and Puoane say, “despite two decades of recommendations for fat reduction in the United States, people are not reducing their intake of fat” (2003, p.25). Obesity in the urban black population is becoming a public health problem in South Africa, where it is associated with the emergence of Type -2 diabetes” (Chopra and Puoane, 2003, p.25). The problem with this statistic is that there are many other associated diseases that become apparent, because “57% of urban African women are overweight or obese” (Chopra and Puoane, 2003, p.25). General obesity in South Africa, probably due to “unhealthy food preparation and large portion sizes,” (Chopra and Puoane, 2003, p.25) as well as a lack of physical activity also complicate this issue. Chopra and Puoane (ibid) also comment that in the townships of South Africa there is a shortage of low fat food and fresh fruit and vegetables. In South Africa the staple diet for many people is maize meal which is high in carbohydrates and as a result raises the blood sugar levels. Often then in rural areas of South Africa, diabetes is misdiagnosed or even undetected and this impacts adversely on learning in general terms. Daneman (2010, p.13) considers the magnitude of the problem of massive increases in Type -1 diabetes in children. “China and India alone”, he says, “will contribute to increases at a rate of 2 – 5% per annum”. So what of the future, what are the demands on governments, communities, parents and teachers?

The question on how diabetes is understood and managed in schools is therefore one of the South African schooling system’s challenges.

1.4 Research Questions

1.4.1 Main Research Question

How is diabetes in school- going children managed?

1.4.2 Sub-Research Questions

- (a) How is a child's daily routine concerning glucose testing and insulin injecting managed?
- (b) What factors affect diabetic learners' self-image?
- (c) Are diabetic learners treated differently in schools?
- (d) What knowledge awareness of diabetes do teachers and peers have?
- (e) To what extent does diabetes affect academic progress?
- (f) What role does sport and physical activity play in the life of the diabetic?

1.5 Aims and objectives of the study

The main purpose of this study was to determine how some of the learners at schools in South Africa manage their diabetes. The study also aimed at understanding how the children are assisted, if at all, by their peers and educators. To this end, the study also sought to understand if the education system, and individual schools in particular, are aware of challenges faced by diabetic learners and if this knowledge translates into putting into place sufficient official mechanisms meant to assist learners suffering from diabetes in the schools.

These aims for the study were set on the basis that in society generally, the effects of diabetes on children are relatively unknown. In this case, I also took interest in investigating if children with the disease have (i) an affected self-image, (ii) if they are treated differently to other children, (iii) exactly how they are treated (if differently) and (iv) to what extent any differences exist in this regard.

Linked to this, I also sought to understand the knowledge people in schools have of the disease and if they are willing or able to assist in the management

of diabetes and if so, how? At this level, the study focused on both teachers and peers. Although difficult to prove, the study also tried to ascertain if having diabetes had any perceived effects on academic and what impact, if any, physical activity has on diabetic children.

1.6 A Synopsis of the Research Report

This research report comprises of eight (8) Chapters. In Chapter One (1) I have given an orientation and introduction to the study. In this Chapter, my focus has been on discussing the main reasons and significance of the study as well as outlining the key questions and justification for the study.

In Chapter Two (2), I will outline the key methodological considerations for the study. In a nutshell, this research is a qualitative investigation on the management of diabetic learners in schools. This qualitative framework makes use of interviews with key participants as outlined. In Chapter Three (3), I discuss the literature review for the study. I begin my literature review by examining the nutritional requirements of a diabetic child followed by an exploration of the psychological implications for children and parents coping with diabetes. I also look at the role of physical exercise in a diabetic child's life and how educational practices have a bearing on this.

In chapter Four (4) I focus on support systems available to learners in South African schools as well as certain barriers to learning that diabetics experience on a day-to-day basis. Human Rights is also included in the discussion here. Aspects of general diabetic information during and after school are discussed in this chapter, together with the technical aspects of the disease. A series of interviews and the answering of questionnaires were completed. Diabetics, their peers, teachers and parents were involved.

Chapter Six (6) reveals certain findings of the investigation. The negligible knowledge of peers and teachers alike was discovered. Also, the unique way diabetics need to exercise control over their own specific situation revealed the importance of assistance to them at all times. Self-image and the

confidence, or in some cases the lack thereof shown by diabetics, together with the importance of physical activity, were among highlighted issues in the results of the investigation. In conclusion to this report, in Chapter Seven (7), this researcher highlights the apparent lack of facilities in South African public schools to assist the diabetic learner. Glucose monitoring and insulin administration are often difficult to perform under the present circumstances in which these children have to function. Also, prejudice by peers and ineffective management strategies employed by educators proved challenging. Official policy may also need to be re-visited by the authorities.

CHAPTER TWO

METHODOLOGY

2.1 Introduction

As indicated in the previous chapter, this study aims to investigate the management of diabetic learners in schools. In seeking this goal, the research looks at the following focus areas: the daily management plan of a diabetic learner; the effect that routine diabetic activities (e.g. injecting, eating plan) have on self-image; how, if at all, academic achievement is influenced in any way; the extent to which peers and teachers treat diabetic children differently in a sociological sense and how physical activity impacts on blood glucose levels. In order to satisfy these aims, I will use various research methods and techniques. This research falls under qualitative research. The research techniques which I will use include: document analysis, questionnaires, semi- structured interviews and focus group interviews.

2.2 Qualitative research and its relevance

The research approach best suited to my work will be qualitative in nature. “Qualitative research is an inquiry in which researchers collect data in face-to-face situations by interacting with selected persons in their settings” (McMillan and Schumacher, 2006, p. 315). Qualitative research is best suited for this study because such a study “requires the observation and analysis of people’s individual and collective social actions, beliefs and thoughts (McMillan and Schumacher, 2006, p. 310). Similarly, the characteristics of a qualitative research are also suited to my gathering of data and its analysis.

Merriam (1998, p. 6) states that “qualitative researchers are interested in understanding the meaning people have constructed, [as] that is how they make sense of their world and experiences they have in the world”. In other

words, what people experience and feel is important to them and they shape their lives around what happens to them. The situations they find themselves dealing with in everyday life create the world they live in and this has a direct impact on their future.

On the other hand McMillan and Schumacher (2006, p.119) refer to the qualitative approach to data collection as a “naturalistic inquiry”. This method refers to the evolving of data where the researcher does not interfere but rather observes as the situations unfold naturally. This means that there will be no pre-determined constructs or outcomes as information emerges from my participants. In my research I aim to observe the selected participants in as natural an environment as possible. This allows them to be true to themselves during the process of interview.

This research also falls under the nature of a purposive investigation in the sense that the involvement of my respondents in the research comes in because I have purposely selected them because they “qualify due to certain criteria; that is, they all suffer from a certain disease or have had a particular life experience. They may be actively managing it or associating with friends who have the disease (Given, 2008, p. 697) or that they are teaching children suffering from the disease. Furthermore, in the study, necessary effort was taken to collect data and produce findings that were not previously collected or determined in South Africa. Specifically, this qualitative study uses a purposive sample of six (6) learners mainly because these are the learners accessible to the researcher. The parent, teacher and principal respondents who were interviewed during the study happen to be those involved in the life of the learners with diabetes who are central to this study.

The diabetic learners, their parents and principals of their school can be considered as the sample for the study. McMillan and Schumacher (2006, p.119) note that a sample group is a group of subjects or participants from whom the data will collectively be gathered. These participants supplied me with the data on which my research is based and upon which I arrive at conclusions.

In order to understand the life of a diabetic person and to analyse the data that I had to contend with, I needed to disassociate myself from the “emotion” of the research and try to understand the social dynamics of each situation that I was to be involved in. I also needed to be mindful of the fact that the responses I received from the participants involved were also only from a personal point of view of the respondents and thus I needed to be sensitive when setting the questions to differences that might exist from participant to participant. Each method was used to uncover elements that have not been discovered in other processes other than mere repetition of methods. In this way, I hoped that a form of validation and coherence would be achieved in the research.

The proposed research participants were six (6) diabetic learners, and as stated earlier, this is because they are the ones accessible to me as a researcher. As indicated above, the parents, teachers, and peers were consequently only those who are in direct association with these learners.

2.2.1 The importance of a case study

Case studies “strive to portray what it is like in a particular situation, to catch the close-up reality and thick description of participants’ lived experiences of, thoughts and feelings, for a situation” (Cohen et al, 2000, p.182). McMillan and Schumacher (2001, p.157) also state that case study approaches, examine a “bounded system” (2001, p 157), that is “a case examined in detail over a specific time thereby utilizing various sources of data situated within the specific case”. Weiss (1998, p. 261) further argues that a case study is a thorough investigation of any particular entity.

2.2.2 Document Analysis

Garmen comments that “document analysis is a technique in education evaluation which relies heavily upon a variety of written materials for data, insights and judgements about programmes and events” (1982, p. 2). In

addition to data collected from the respondents, this study also uses insights and policy statements from such sources as: Department of Basic Education Curriculum Statements, White Paper 6 on Inclusive Education as well as a variety of other Policy documents and Diabetes literature.

2.2.3 Questionnaires and Interviews

Questionnaires require participants to answer a set of questions. Cohen et.al defines this technique as a “set of questions on a form that is completed by the respondent in respect of a research project” (2007, p. 263). Different questionnaires were prepared for teachers, parents, learners and peers. This research instrument was advantageous to me in that the questions were standard yet there were many angles of response. The disadvantage of questionnaires is that some participants may not take the work seriously and may leave out certain information (*ibid*).

Interviews were the main source of gathering information. Two different types of interviews were used: semi-structured and focus group interviews. The semi-structured interviews had an element of unstructured interviews since some questions developed dependent on the responses I was getting from the respondents.

Unstructured interviews provide the researcher with great latitude in asking broad questions in whatever order seems appropriate (McMillan and Schumacher, 2001, p. 319). Valenzuela and Shrivastava (2013, p. 4) concur with McMillan and Schumacher when they argue that unstructured interviews are “open and adaptable” and the interviewer can “go with the flow”. This allows the questions asked to be informal and of a conversational nature. The conversation meanders in the way that is determined at that specific time and it is not predetermined. Only if the researcher is presented or he/she identifies a “gap” will it be pursued in order to collect data.

Similarly, “semi-structured interviews are structured in such a way that respondents may have the question rephrased if what is actually being asked

is misunderstood. This process gives the researcher an opportunity to describe the situation, process or response” (McMillan and Schumacher, 2001, p.320). Minichiello et al. (1990, p.93) suggest that semi-structured interviews provide the researcher with the opportunity to “control the conversation” which is geared at adhering to the main interest in the research. Nevertheless both of these sources caution that achieving a balance of control in executing this should not be overlooked.

Different from these interviews is the focus group discussion. A focus group interview comprises of the researcher and a group of participants purposely identified. “A focus group is a general term given to research conducted with a group of people who share a similar type of experience” (Kelly, 1999). Cohen et al (2007, p 299) state that “they (focus groups) create a social environment in which participants share ideas and differing perception”. These insights increase the quality of collected data and they are time saving as they produce a large amount of data in a short amount of time. Due the nature of the research and the sensitivity that goes with health issues, focus group discussions were used in this research.

2.3 Data Analysis Procedure

The moment that I started collecting the data, I had to make sure that I follow the correct procedures. This refers to the moment that I had collected all my written and audio-taped material. From this raw information I produced written (typed) scripts of all my work. Thereafter I studied these scripts and encoded them in order to reveal the key themes with which I would work with. This process ensured that key and common issues from the field data should begin to emerge.

This process was repeated until I was satisfied that I had identified and extracted all the relevant data pertaining to the study. This is referred to as the process of data saturation in research analysis. I also ensured that the central issues and themes that I had identified related fully to the main and

sub-research questions of the investigation. These central themes, as a result, also related to one another.

2.4 Ethical Considerations

The integrity of the researcher is paramount in any study or investigation. While my own personal value system will guide me in the way I proceed in my work, I am aware that all ethical issues need to be sensitively approached. As a researcher my investigative situation presents its own set of values and I will be careful to remain observant of these throughout the work. Efforts will be made to make sure that my value system does not unnecessarily influence the way the research is done or the results that are found. This ensures that I remain objective at all times and I ensure that the participants in my study and even their own values do not influence how information on how they experience the management of diabetes is presented. I take cognisance of a number of factors in relation to the ethical issues. Firstly, the researcher's positionality is crucial in any research. In this case my relationship with my research participants could impact on my data collection. This was taken care of by ensuring that at all times a professional relationship was maintained between me, as a researcher, and my respondents. Before the research, I provided details of the importance of informed consent in the research process and stressed that each participant also had to give consent for his/hers voice to be recorded. I also explained the rules of confidentiality to my research participants and assured them that their views will remain anonymous for anyone accessing the research, apart from the researcher. In this case, data was coded with pseudonyms.

Specifically, the idea of informed consent means that all participants in any research have to choose freely to participate in the processes of the research at any given moment. This also means that those participating have a clear sense of what the research is all about and that they do not see any harm arising from such participation. Similarly, confidentiality is an ethical principle that seeks to hold the knowledge of the participants within the

researcher and the participants. In other words, one's participation in a given research cannot be revealed because this jeopardises the legitimacy of views collected from the research. The consequence of this rule is that the participants remain anonymous when the research results are being discussed and fake names are used wherever possible. I will as part of the confidentiality process and the protection of my participants, keep the data that I have gathered from my notes, data record book, interview transcripts, questionnaires, in a safe place – under lock and key-for the duration of the prescribed time stipulated by the University of the Witwatersrand.

These principles formed the anchor for the ethics application form that I submitted to the Wits Ethics committee. This research was given Ethical approval by the Wits School of Education Ethics Committee in 2013.

CHAPTER THREE

LITERATURE REVIEW

3.0 Introduction

This study is a qualitative investigation into the management of diabetic learners in South African Schools. This review is designed with the main question in focus on how diabetes in school-going children is managed. In proceeding, I present my literature review in six sections.

Importantly, each aspect in the literature review of this work reflects how the aspects are related to what teachers, coaches and other care givers in schools may at some point have to deal with in the complex business of managing a child with diabetes at school. There are many aspects of diabetes that have a knock –on affect and manifest themselves in other associated ways in the body. Awareness of these aspects promotes sound management of the disease and action concerning them may assist in preventing unnecessary complications in the life of the diabetic child.

Specifically, the literature review will proceed by examining the nutritional requirements of a diabetic child. Following on from this, it will explore the psychological implications for children and parents dealing with diabetes. Thereafter, an investigation into the complications that could arise from the associated illness caused by the diabetic condition will be examined. In addition, the importance of the relationship between physical exercise and diabetes, showing how an active lifestyle can assist in controlling blood sugar levels will also be examined. Some focus will be put on the relationship between the child's general progress at school and diabetes, looking at how low and high blood glucose levels can affect teaching and learning. This literature review will conclude by exploring formal physical education offered in the curriculum while placing emphasis on whether the management of diabetes children in schools is aware of the same.

3.1 What does the nutrition of a diabetic child involve?

Often before people, especially children, are diagnosed with diabetes mellitus they are not really concerned about what foods they eat and less so the nutritional value or lack thereof of those foods. Parents and newly diagnosed diabetics are often bombarded by the nutritional information of food at the very first visit to the endocrinologist and the diabetes educationalist. Bits of nutritional information that both parent and patient hardly ever thought of, now become the focal point of this family's life. At the outset it is important to understand that "there are 5 main food groups that make up a balanced healthy diet in order for your child's body to get all the vitamins, minerals and nutrients they require to function at its optimum" (Segal and Balanco, 2009, p.9).

Type -1 diabetes is a lifelong disease and the more prevalent type of diabetes in young people. Children remain children and "to vary one's food intake and indulge in the occasional sweet treat has not been found to worsen blood sugar control", (Hanas, 2005, p.204). However, control is the operative word here and the "treat" should be covered by the appropriate administering of insulin. "In a Finnish study of young children with Type -1 diabetes, all family members increased their consumption of skimmed milk, low fat cheese and low fat cold meats. They also ate more fruit and vegetables" (Hanas, 2005, p.204).

The main everyday concern of a diabetic sufferer is the level of their glucose (sugar) in their blood at any given time. It is the aim of the diabetic to maintain a relatively stable level of glucose in their bloodstream. "The most accurate measure of the total effect a food or a meal has on the blood glucose level is called the glycaemic level or GL" (Holford, 2011, p. 65). This is based on what is called a glycaemic index (G.I.). Carbohydrate foods that release their sugar content into the body more slowly, have a low G.I. (ibid) The G.L. is calculated using the G.I. and a portion size, so that the diabetic can see at a glance what food is best to eat and what size portion to have (Holford, 2011, p.65).

Low G.I. foods that release glucose into the bloodstream more slowly than Intermediate and High G.I. foods, provide sustained energy over a longer period of time as the carbohydrate is released more slowly into the bloodstream and a gradual rise in blood glucose is the result. Foods that are high G.I. foods and “are absorbed quickly into the bloodstream tend to raise the blood glucose levels quickly” (Segal and Balanco, 2009, p.9). Foods that are in the high G.I. category include white bread, white rice, white pasta and French fries. Intermediate or average G.I. foods “are absorbed at a gradual rate and have less of a rise on the blood sugar values” (Segal and Balanco, 2008, p.9). Foods that have an average glycaemic index include “wholemeal rye bread, honey and grapes” (Hanas, 2005, p.213).

How then does the body break down the food that we eat and how are the nutrients of that food used thereafter? The main food groups can be divided into 3 nutrient groups which have individual effects on the body as Segal and Balanco (2008, p. 9) explain below.

Proteins - These nutrients are our bodies' growth foods and have little effect on the blood glucose levels. Half of the protein we eat is converted to glucose over a long period of time so it has a gradual rise on the blood glucose levels. These foods make excellent snacks between meals and will not require extra insulin. Furthermore, proteins can be eaten when blood glucose values are high in order to prevent them from rising further. (ibid)

Fats - These foods are also energy foods in the body; however they have twice the amount of calories than carbohydrates and therefore are to be kept to a minimum in order to protect the heart and other vital organs. Fats are needed for cell growth and protection for organs and play a very important part in children's growth and development. (ibid)

There are different types of fats: - *Unsaturated fats* - Mainly from plants/vegetables and fish oils. These have positive health benefits. The *Saturated fats* – from mainly animal sources have more negative effects on health. (ibid)

Carbohydrates -These nutrients are the body's main supply of energy. They are the foods that have a significant effect on blood glucose values. They raise the blood glucose values and is the food group that needs to be kept under control in order to manage diabetes (ibid). All carbohydrates are broken down into glucose as their final form of energy for the body (Hanas, 2005, p. 205). “Glucose from food can only be absorbed into the bloodstream after it has passed through the intestines, as the food must first pass through the lower opening of the stomach to the intestine below” (Hanas, 2005, p.205).

In order for our bodies to use the food as energy or for it to be stored in our bodies “complex carbohydrates must first be broken down to simple sugars before they can be absorbed into the bloodstream” (Hanas, 2005, p.205 – 206). All foods, whether made up of proteins, fats or carbohydrates will eventually enter the blood stream as glucose, notwithstanding the fact that it may take more time to break down into sugar the variety of foods that have been consumed.

Although most people assume that such knowledge on food nutrition should be readily available in schools, it is not clear if teachers and principals dealing with diabetic learners are aware of the same. In this study I first establish the level of knowledge that my participants have of these issues. I will do this by investigating the nutritional intake of my research participants and how these influence their curricular and non-curricular activities. I plan to show how food types might impact on learning differently in my respective respondents. For this reason, in the section that follows, I provide details of the major food types – with examples – and discuss the effects that the glucose levels have in diabetics.

3.2 What is our food made of?

Diabetics are taught to be aware of the types of food that they consume. The food that we eat is mainly made up of a mixture of carbohydrates, fats and proteins. The table below provides examples of each of these food types.

Carbohydrates	Fat	Protein
Sugar	Butter	Meat
Bread/Flour	Margarine	Fish
Cookies	Cookies	Egg
Potatoes	Oil	Cheese
Pasta	Cream	Milk
Rice	Milk	Yoghurt
Fruit	Cheese	
Cereals		
Sweetcorn, taro		
Milk, yoghurt		

(Hanas, 2005, p. 206).

According to Holford (2011, p.111) “the real villain as far as diabetes is concerned is sugar and starch, not fat, or more specifically a high G.L. diet”. This statement indicates that sugar, when left unattended in our bloodstream, that is, when it is not used as energy is harmful to the body. Hanas (2005, p.210) says that sugar supplies “empty calories”, which means that sugar gives only energy and as such no other nutrients. Also, says Hanas (2005, p.205) from a nutritional point of view, we do not actually need pure sugar at all. The liver is quite capable of producing the 250 – 300 g of glucose that a healthy adult normally needs per day. (ibid)

Professor Tim Noakes's father died from "the complications of adult on-set diabetes" (Noakes, 2012, p.2). Noakes has always led a healthy life and has been at the forefront of sports medicine in South Africa for many years. He has also "actively followed the 'prudent heart healthy' high carbohydrate, low fat diet as advocated by my colleagues with nutritional and cardiological expertise" (Noakes, 2012, p.2). He thought that he was living a healthy life as he does not smoke and rarely, if ever, drinks alcohol. "Imagine my surprise then when I discovered recently that I am pre-diabetic; that my fasting blood levels and glycosylated haemoglobin concentrations are chronically elevated, whereas worryingly, my fasting blood insulin is low" (Noakes, 2012, p.2).

These readings suggested that he had inherited his father's problem of being a possible diabetic and all the exercise and marathons that he has run had meant nothing to his health. He then decided to use himself as an "experimental model" (Noakes, 2012, p. 2) and that there is "only one way" as he puts it "to reduce my risk for developing adult on-set diabetes and that is to minimize my daily carbohydrate intake" (Noakes, 2012, p. 2). The results after 16 months of this experiment show "blood cholesterol parameters now that are much 'healthier' on a high fat diet than they were on a carbohydrate diet" (Noakes, 2012, p.2). Also he has found that "my weight has fallen by 15 kg, I have dropped my running time in 21 km races by more than 40 minutes". He also now only "eats when the thought strikes me" (Noakes, 2012, p.2).

But Noakes adds that "all I can report is that, as a pre-diabetic, I have tried both a high and a low carbohydrate diet" (Noakes, 2012 p 2). He has also stated that he does not advocate that all diabetics "either Type -1 or Type -2 should have this diet prescribed, as well as that he is aware that his colleagues do not agree that a low carbohydrate diet" is acceptable for diabetics (ibid).

Noakes's weight fell considerably when his pre-diabetic 'situation' was eradicated and he had more energy on a low carbohydrate diet, as his times for the marathons he ran improved dramatically. The low carb diabetic

website in the United Kingdom (www.lowcarbdiabetic.co.uk-lowcarblifestyle) states that “when we (diabetics) stopped using what we now call the big five, i.e. potatoes, bread, pasta, rice and baked pastry products, our blood glucose number dropped to non-diabetic within days.” This provides another example of what Noakes had done, i.e. a low carbohydrate lifestyle that resulted in the dramatic drop in blood glucose of diabetics. Holford, (2011, p.113) states that there are good reasons to increase your intake of the right kind of fats, and that “a diet high in omega 3 fats, found in cold water oily fish, as well as certain seeds notably chia, flax and pumpkin, helps reduce one’s risk of diabetes”. This is similar to the dietary foods that Noakes followed in his experiment that took him from being pre-diabetic to having “normal” blood glucose levels and as he puts it “better health”.

“A lack of Vitamin D is known to increase the risk of other autoimmune diseases, so its perhaps no surprise to find that children with Type -1 diabetes have lower Vitamin D levels than those without” (Holford, 2011, p.114).

As diabetes is an autoimmune disease, there is an argument that Vitamin D assists in treating diabetes. Indeed “one small trial involving only 10 people with diabetes found that it both improved insulin production and lessened insulin resistance” (Holford, 2011, p.114).

However, according to Silverstein et al. (2005, p.15) nutrient recommendations are based on requirements for all healthy children and adolescents because there is no research on the nutrient requirements for children and adolescents with diabetes. Children and adolescents should adopt healthy eating habits to ensure adequate intake of essential vitamins and minerals. (ibid)

Given what I have discussed above, it is apparent that the experts do not always agree on what foods and diets should be eaten and followed as Silverstein et.al adds that “consideration of a child’s appetite must be given when determining energy requirements and the nutrition prescription”

(Silverstein et al, 2005, p.15). It is also apparent that the goal of the diabetic child or adolescent is to maintain a stable blood glucose level. Trial and error in terms of what food is eaten together with the correct administering of levels of insulin is a difficult balancing act that is to be constantly monitored and adjusted. The HbA1c levels (3 month average of blood glucose) tell the true story of the success or failure of recent control of blood glucose.. Dieticians, as well as the diabetic educationalists, assist one in reaching optimum levels with their continuous advice and experience.

In the “Guidelines for inclusive teaching and learning” (Republic of South Africa, 2010) the information provided is too limited to effectively guide and equip teachers who are to assist diabetic children in schools. There is a lack of training in inclusivity, both at university and at in-service training level. The teachers seem ill equipped and policy on chronic illnesses, specifically diabetes, may need to be re-visited. The lack of information ensures that teachers remain uninformed and relatively oblivious to the disease.

This study has mainly focused on trying to understand, through investigations in schools with diabetic learners, teachers and learner peers, whether the learners who suffer from chronic illnesses are indeed “able to” or do fulfill what is expected of them in terms of what is outlined in the Curriculum and Assessment Policy Statement of South Africa (Curriculum and Assessment Policy Statement, p.5). The policy in question expects all learners to do the following:

- “Identify and solve problems and make decisions using critical and creative thinking;
- Work effectively as individuals and with others as members of a team;
- Organise and manage themselves and their activities responsibly and effectively;
- Collect, analyse, organise and critically evaluate information;

- Communicate effectively using visual, symbolic and/or language skills in various modes;
- Use science and technology effectively and critically showing responsibility towards the environment and the health of others; and
- Demonstrate an understanding of the world as a set of related systems by recognising that problem solving contexts do not exist in isolation.”

Just as curriculum intentions are different from curriculum practices, even in this case, it is difficult to assume that the policy statement on curriculum and assessment as it stands is implemented in schools. Such being the case, this researcher is further interested in the fulfilment of such a policy in relation to the management of diabetic learners. Of crucial interest in this regard is the consideration of the health of others, the extent to which diabetic learners are considered as part of the whole irrespective of their challenging circumstances, and how a possible feeling of isolation is dealt with by them, among other problems experienced.

3.3 What are the psychological implications for parents and children living with diabetes?

When first diagnosed with diabetes I think the very first question a child, and a parent for that matter, has is “What does this mean for me and for my life”? The second question begins, “Am I going to be alright, can I live with this disease?”

There is so much to know and learn concerning the management of one’s diabetes and the prospect of the unknown seems daunting and it can be overwhelming. One thing is certain, however, and that is that the newly diagnosed diabetic’s life will change and it will never ever be the same again.

Elizabeth Kübler-Ross, (1969, p1) studied terminally ill people and noticed that there was a grief cycle that these people went through. Through further

research, she realised that “all people who received bad news reacted in a similar sort of way” (ibid). This grief cycle of Kübler-Ross begins when a person is in a relatively calm state and then receives bad news. The cycle then begins. According to Kübler-Ross (Kübler-Ross, 1969, p.1) a person can also get stuck in a cycle and as a result he or she will not be able to progress to the next stage of the cycle until each stage has been passed through. She also states that another relatively common problem occurs when “a person moves onto the next phase, but has not completed an earlier phase and so moves backwards in cyclic loops that repeat previous emotions and actions” (ibid).

When a child is diagnosed as diabetic he/she literally has a new partner in life, albeit “an unwelcome one. It is okay to feel angry, sad, resistant and even guilty” (Segal and Balanco, 2008, p.2). These emotions, according to Segal and Balanco, are normal and will ease with time. It is important to learn to live with the diabetes and not to ignore it, although this may be easier said than done initially. For one to be positive, whether it is a parent or the diagnosed child, is a serious challenge that will relate easier in one’s mind for a period of time before the logical stable mind settles again. “A positive outlook and active management bring about good long term results” (Segal and Balanco, 2008, p.2). There are many people who have gone before and they have gone on to live long and extremely productive lives. These people, however, have managed their situation and overall diabetes well and this has led to their success.

There will be many emotional times during a diabetic’s life and “each day will be a learning experience” (Segal and Balanco, 2008, p.2). Because there are emotionally different types of people who are diagnosed daily with Type -1 or Type -2 diabetes “there are different reactions and different ways in which children respond to this news. Many children with diabetes cope well most of the time on a day-to-day basis” (Flynn, 2005, p. 57). However, a study done by Grey et. al (2005, p.1) to determine “the pattern of adjustment over time of a cohort of children with newly diagnosed diabetes compared with a cohort of peer-selected children without diabetes over the first 2 years

of diagnoses” (Grey et. al 2005, p.1) was not as positive. The results reflected that “by 1 year post-diagnosis, there were no significant differences in psychological status between the two groups. By year 2 post-diagnosis, depression and dependencies were significantly higher in children with diabetes” (Grey et.al. 2005, p.1).

This means that while the children coped well initially, after a period of time and the fact that they had to live with this disease 24 hours a day, it took its toll both physically, emotionally and psychologically and their emotional health deteriorated. Grey et.al (2005, p.1) suggests that “because children with insulin dependent diabetes mellitus (IDDM) experienced twice the amount of depression and adjustment problems as their peers, intervention should be aimed at the critical period between 1 and 2 years post diagnosis”.

Encouragement from friends is almost certainly going to lift a child’s spirits. A child’s friends and peers are extremely important, especially to the teenager who needs to feel accepted as he or she begins to feel that people other than family members become as important, if not more so, than one’s own family.

Flynn, (2005, p.5) comments that there are some common emotional problems experienced by children with diabetes, anxiety being the most prevalent. Talking from my own experience, parents are also subject to these feelings of anxiety and oftentimes these feelings are picked up on by the diabetic child and he or she experiences some level of anxiety too. “Children with diabetes can become depressed and even suicidal. They also experience anger and may become aggressive in their behaviour or difficult about managing their diabetes” (Flynn, 2005, p.59). The role of the school counsellor is extremely important. Together with a school nurse or a person designated to execute such duties, (Flynn, 2005, p.59) teachers need to:

- “Be informed of diabetic children that are in their classes.
- Recognise symptoms of hyperglycemia/hypoglycemia.
- Liaise with parents who provide information for emergencies.

- Promote a supportive learning environment for diabetics.
- Know the parent's phone numbers.
- Assist with sugar readings and injecting insulin.
- Treat the child normally and allow the other children to do the same.”

In my study I will investigate whether or not the above is actually happening in schools at present and also whether it would be worthwhile developing a diabetes management plan in these schools. As there is no screening in South African schools at present, teachers do not identify the symptoms of diabetes. It is an “invisible illness” where children seem “normal” most of the time, but depression, diet (like abstaining from birthdays-cakes and sweets), exercise and symptoms of low sugar all play a role in the life of a diabetic child. Whilst White Paper 6 (DBE, 2010) does provide some strategy for dealing with diabetic learners, what may be lacking are management strategies for dealing with the illness at academic, sporting and social levels. This will form part of the investigative process.

According to Flynn (2005, p. 59) concern, worry, fear and stress create tension and the result is anxiety. “The important thing to remember is that anxiety cannot be left unattended, hence unresolved anxiety takes a heavy toll on the individual” (Flynn, 2005, p.59). A child can become over anxious and also create scenarios in his/hers own mind that are farfetched and unfounded. For a normal child this can result in an extremely stressful time, but “research on children with diabetes has found that if too much anxiety is present, children cope by either avoiding management altogether to reduce their anxiety”, (Flynn, 2005, p.60) which can lead to inconsistent blood sugars “or else by becoming too frenetic in their approach in managing (their diabetes) that their stress levels become intolerable. In either case the control of the diabetes is lost” (Flynn 2005, p.60). Children express high anxiety in the following ways. If four to six or more of these types of symptoms have

been present for six months or more, the child is excessively anxious and displays a:

- “Reluctance to go to school.
- Reluctance to go to sleep without being near a parent.
- Fear of being alone-clinging to a parent.
- Fear of sleeping at a friend’s house.
- Repeated nightmares.
- Complaints of physical symptoms such as headaches, stomach aches, nausea, vomiting, excessive sweating and loss of appetite.” (Flynn, 2005, p.60)”

Parents, as previously mentioned, are also susceptible to anxiety, and Flynn, (2005, p.63) highlights three parental issues which play a big part in the amount of anxiety the child will experience. Firstly, “it is not surprising that parents feel highly anxious when their off-spring develops diabetes. The loss of the child’s good health, the loss of the present way of life, the loss of a relaxed approach to life” (Flynn, 2005, p.63) will probably be the cause of much anxiety in the life of the parents of a newly diagnosed child. These scenarios will be investigated during the study. Parents “have feelings of unbelievable sadness, and feelings they cannot cope with at all” (Flynn, 2005, p.63) “but they need to be addressed” (ibid). Being adults it is more likely than not that the parents will be able to confront their fears, and will be able to come to terms with them and do something constructive to overcome them”. (ibid, p.64).

Flynn (2005, p. 64) suggests the following strategies for parents to cope with anxiety related to their child having diabetes:

- (a) Understanding diabetes and all its requirements goes a long way towards reducing anxiety. “Parents should get as much information as they can about all aspects of diabetes” (Flynn, 2005, p.67). This is a massive

task. There is so much information and advice available to parents and caregivers and given the fact that parents have been bombarded with a management plan at the time of diagnoses this could be an information overload if done too early after diagnosis. Although it would probably be in the best interests of the parents to seek out information, initially one should do all the basics of managing the disease first and maintain a routine that works for one's child and then delve in the "unknown" more deeply. "Doctors and diabetes educators are qualified to give information and parents should find a diabetes educator in their area". (ibid), this is an essential part of managing your child's diabetes and allows for information that is urgently needed to be accessed quickly. Schools need to form partnerships with the parents and the teachers need to participate in an individual care plan for the child.

(b) Obviously "necessary adjustments to lifestyle" (Flynn, 2005, p.67) will have to be made by probably every one of the family members. But if proper planning is done to "establish routines to buy the necessary foodstuffs so they are available when needed and times are established for exercise or even free play." (ibid) this prevents crisis management of your child's disease and allows a sense of calm to be the norm rather than the exception. "Making these adjustments allows for more effective management and the feeling of coping well reduces anxiety" (ibid). Teachers should be educating other children in the class to react to the needs of the diabetic child. Also special food packs need to be kept at the school as part of the diabetic's management plan.

(c) "Parents without partners should find someone trustworthy to confide in and need lines of communication open and to talk to each other about their fears" (Flynn, 2005, p.67). It may also be a good idea to "consult a therapist" (ibid) which will allow one to talk about one's concerns and fear as well as re-organising a lot of random thoughts and feelings" (ibid) which may provoke anxious feelings. Parents could assist school personnel by meeting with them to discuss medical information and discuss future planning.

(d) “Diabetes support groups are also helpful. Practical solutions have often been found by others in similar circumstances” (Flynn, 2005, p.67) and one realizes as well that one’s family is not alone and may even feel acceptance through common adversity.

(e) A common cause for worry is low blood sugar levels during the night when your child sleeps. In order to regain (if lost) a more stable pattern of readings taken and levels of glucose in the blood to be more acceptable, dosages may have to be re-calculated and adjusted in order to prevent these low readings. “Parents will be able to sleep more easily” (Flynn, 2005, p.67) once this has been re-established. Parents must be allowed and encouraged by schools to provide medical supplies and/or prescriptions for the children.

(f) “Anxiety about complications is more persistent. Good control definitely slows the onset of complications” (ibid). One may always worry about complications even in times when one’s child’s blood sugar levels are good. “Perhaps it helps to remember that one can rarely do better than one’s best and that many adults with diabetes were diagnosed in their childhood and they have avoided complications by being well controlled most of the time” (Flynn, 2005, p.68).

(g) “Marital conflict, or conflict between any members of the family, creates tension and anxiety for the whole family” (Flynn, 2005, p.69). Children are often exposed to conflict between their two parents and are highly aware of conflict”. They are often victims as they “feel helpless to do anything about it” (ibid). “Unresolved conflict means anxiety for the child” (ibid) which often hampers the progress of the child at school and socially “research has shown that children with diabetes who have families who cannot resolve conflict tend to have more experiences of ketoacidosis (a condition which will be explained later) needing hospitalisation” (ibid).

(h) “Many children have a fear of needles and injections” (Flynn, 2005, p.69). Unfortunately injections are often associated with a painful experience. “The child with diabetes is confronted with two to five injections

a day” (ibid) albeit that these injections are done with 0,05 mm needles, “as well as numerous needle pricks (which is sometimes more painful) on their fingers to test their blood sugars” (ibid).

Even if literature indicates that there are strategies for parents to cope with anxiety related to their child having diabetes as indicated by Flynn (2005, p.69) very little is known in the South African context on whether parents are aware of these cross-cutting strategies or if indeed they have other coping strategies and how these relate or contribute to the management of diabetic children. The strategies employed at home may have some influence in the school depending on the level of interaction between the teachers and the concerned parents. Hence I will investigate in my research whether or not the parents/guardians of diabetic children are involved with the teachers by informing them of the plan of care for their children so as to form a team to deal with the plight of the diabetic child. “Children who are anxious often have difficulty doing their own injections. Helping them to overcome their anxiety is essential to their adapting successfully to their diabetes” (Flynn, 2005, p.67).

During their teenage stage, “the adolescent years are clearly a period of rapid change and development” (Skinner et.al, 2005, p.27). It is during this time “that adolescents spend increasing amounts of time away from home, and their leisure activities become less structured with ever diminishing adult supervision or involvement” (Skinner et.al, 2005, p.28). It is also during this time that the move away from parents and the more constant time spent with peers occurs. The omission of regular blood-sugar readings and the possible occasional skipping of insulin injections could happen. As a result, anxiety may begin to be prevalent in the young adolescent’s life as time goes by over blood sugar levels becoming inconsistent. The problem is that “these will be formative years, which once freely integrated and accepted by the young person, may prove difficult to change” (Skinner et.al, 2005, p.28).

Given the nature of the adolescent stage, one may expect that peers be educated through a programme at schools, possibly through Life Orientation, about the different types of diabetes and how it affects those with the

disease. By assisting with blood monitoring, being part of the training for emergencies, informing other learners of high and low blood sugar levels and their dangers, peers would become involved in their friend's lives and make meaningful differences.

“Social support from parents and other family members is especially important for children with Type -1 diabetes. Research has shown that family members who provide high levels of support for diabetes care have youngsters who adhere better to their diabetes regimen” (Delamater, 2009, p.175 – 176). If this is the case, then surely the child who has grown up in an environment where he or she has taken responsibility for the management of his/hers own diabetes will not stray from the manner in which it has been correctly handled and in turn during those difficult formative years these actions will stand him/her in good stead.

Parents, siblings and extended family and friends have an extremely important role to play in the psyche of the diabetic child. With the support, help, care and love that every child needs, it is a pre-requisite for diabetic children to receive the emotional security and assistance from all stakeholders.

I will therefore investigate whether schools are providing the appropriate care for diabetics and ensuring the immediate safety for diabetic children. Also are the schools in South Africa receiving any assistance from the government where chronic diseases are concerned? The training received , if any, will be examined and the ability and skills required by teachers to aid diabetics to successfully take part at school, in all activities, will also form part of my research.

3.4 What are the associated diseases and complications that affect diabetic children and schooling?

3.4.1 Growth Assessment

As stated earlier in the Guidelines for inclusive teaching and learning, Education white paper 6, (DBE, 2010, p.95-97) there are only four chronic diseases that are listed in the document and it does not mention the dire consequences of the incorrect management of diabetes or what the symptoms of the disease are and how to recognise it. For “normal” growth to occur, continual monitoring of the diabetic child must be done. “Normal linear growth and appropriate weight gain throughout childhood and adolescence are excellent indexes of health in general” (Silverstein et.al, 2005, p.18). Children should grow proportionally in height and weight with “reasonable markers of metabolic control. One of the main goals of treating children and youth with diabetes is to maintain normal physical growth ... especially, during the pubertal growth spurt” (ibid). Normal growth is essential to any child as it indicates good health. This is especially important to the diabetic child and adolescent as the possibility of contracting associated diseases and experiencing acute complications is far higher (as will be highlighted later) than in normally growing children and teenagers.

In the case of the diabetic, “chronic under treatment with insulin with resultant long standing poor diabetes control often leads to poor growth and weight loss and a delay in pubertal and skeletal maturation” (Silverstein et.al, 2005, p.18). Thus the effect of too little insulin administered at appropriate times could result in a child not reaching his or her predicted height and weight. Also, “overtreatment with insulin can lead to excessive weight gain. In addition, this should raise suspicion of the co-existence or development of a comorbidity, including hypothyroidism (thyroid problems) or celiac disease” (ibid).

The height and weight of diabetic and non-diabetic children should be plotted and monitored as this “will allow for early recognition of any

deviations from normal which can then be evaluated and treated” (Silverstein et.al, 2005, p.18).

3.4.2 Celiac disease

“Celiac disease (intolerance to gluten in wheat, oats, rye and barley) is up to 10 times more common in children and adults with diabetes” (Hanas, 2005, p.310). As oats and rye are low G.I. foods that suit the diabetic this further restricts the diabetic’s food variety. Tuck shop policies need to be reviewed and parents together with nutritionists should be involved in tuck shop menus. Planning for birthdays at school requires that thought be put into the types of cakes and sweets parents supply. This assumes that it is only when parents are vigilant concerning the foods that their diabetic children eat, that school tuckshop policies are brought in line with the requirements for diabetic children.

Literature also shows that “patients with Type -1 diabetes are at an increased risk for celiac disease, with a prevalence of 1 – 16%, compared with 0,3 – 1% in the general population (Silverstein et.al, 2005, p.30). Put simply, “if you have celiac disease you will have damaged bowel lining” (Hanas, 2005, p.310). This implies that if one contracts this disease one will refrain from eating any type of food that contains gluten because this may lead to “abdominal complaints, constipation or diarrhea and some people are anemic” (ibid). While the above is the case, little is known on the diabetic’s level of knowledge regarding these issues or even if parents and teachers managing these children are aware of this.

3.4.3 Thyroid Disease

Thyroid diseases occur when there is a “decreased production of thyroid hormones -called hypothyroidism” (Hanas, 2005 p.311). In diabetics, their bodies will try to compensate for this by increasing the size of the thyroid

gland. This can cause younger diabetics to suffer more frequently from hypoglycemia (low blood sugar) than when hypothyroidism is contracted. (ibid)

3.4.4 Skin Diseases

Skin irritations and itchiness often occur in the life of the diabetic. This normally occurs when the blood glucose level is high or “there is fluid loss via the urine and a degree of dehydration takes place” (Hanas, 2005, p.311). Diabetic children will often complain about dry skin and skin irritations, especially during the winter months.

In more severe cases, serious problems with the skin can occur. These might include irregular reddish-brown skin lesions that are 2 – 10 mm in size. “These usually appear on the lower part of the leg and are called shin spots” (Hanas, 2005, p. 311).

3.4.5 Large blood vessels

The large blood vessels in the body include those that service the heart. “Diseases of the heart and blood vessels, or cardio-vascular diseases, are more common among people with diabetes. The blood vessels of diabetics may harden, narrow and sometimes even become blocked” (Hanas, 2005, p.315). When this happens, heart attacks are inevitable and can have catastrophic consequences. “Studies done in Canada show that the life expectancy of people with diabetes (both Type -1 and Type -2) was 64.7 and 70.7 years for men and women respectively” (Hanas, 2005, p.315). This is lower than the life expectancy of people without diabetes, who can expect to live to 82.5 for men and 84.6 years for women. (ibid)

When blood glucose levels are stable, the body, in most circumstances, will function and react “normally”. This implies that with good weight control, regular exercise, no smoking and a very limited alcohol intake, diabetics can

live relatively free of complications or diseases and the reward for “good living” brings quality of life.

3.4.6 Small blood vessels

If blood glucose levels are high over a sustained period of time, diabetics will experience health problems. “The eyes, kidneys and nerves, amongst others can become more brittle. “If a person has diabetes, glucose binds to a protein in the wall of the red blood cells” (Hanas, 2005, p.316). This means that the “red blood cells stiffen and have difficulty in passing through the first blood vessels.” Fortunately for the diabetic person “normal blood glucose levels for 24 hours restore the normal texture of the blood cell walls, remedying the problem (Hanas, 2005, p.317).

3.4.7 Retinopathy

The treatment of diabetes in general has progressed in leaps and bounds over the past twenty (20) years. “The risk of eye damage has decreased considerably. If diagnosed diabetic, and treated early so as to maintain a good A1C (average blood glucose level) over a period of time, there will be little risk that eye- sight will be permanently affected” (Hanas, 2005, p.316 - 317).

In the past, blindness was a common for diabetics but in these times “of one thousand individuals with diabetes, one will sustain serious visual impairment” (Hanas, 2005, p.317). For the diabetic, “smoking also increases the risk of damage to your vision” (ibid).

Retinopathy is persistent or acute damage to the retina of the eye. This is a condition to which diabetics are susceptible. In an Australian retinopathy study, some degree of retinopathy was present in 28% of a group of 178 children and adolescents aged 10 – 14 years with a diabetes duration of 4 -10 years. In a group of 193 older adolescents aged 15 – 22, retinopathy was

present in 52%. In a Swedish study, 14.5% of participants aged 8 – 25 years had retinopathy (*ibid*).

3.4.8 Nephropathy

Nephropathy is a disease associated with the “blood vessels of the kidneys which are formed into small clusters where waste products in the blood are filtered into the urine”. The kidney function is disturbed when “damage to these blood vessels occurs, causing an increased leakage of protein in the urine” (Hanas, 2005, p.319).

After many years of living with diabetes, “(10 – 30) the person is at risk of developing high blood pressure and continuous leakage of protein into the urine (proteinuria)” (Hanas, 2005, p.319). As always, good control of blood sugar levels and of diabetes in general will minimize the risk of contracting this disease. “It is still not known why more than half of all individuals with diabetes are not at all susceptible to kidney damage” (Hanas, 2005, p.320). The body’s nerve fibres, which are made of very long and thin cells, can be affected after many years of diabetes. Sensation decreases and there can be accompanying numbing or tingling (Hanas, 2005, p.321). You will not feel mild pain as the nerves have lost some of the sensation. “Problems arise primarily in the feet, fingers or lower parts of the legs” (*ibid*).

3.4.9 Hypoglycemia

Hypoglycemia implies low blood glucose levels. According to Segal and Balanco (2008, p.2) “any blood glucose level below 4 mmol/l is considered a low blood glucose level”. There are different times of the day that this could happen but “it is most likely that it will happen before meals, during peak action of insulin, (i.e 2 hours after rapid acting insulin or 4 – 6 hours after long acting insulin is administered) or during or after exercising” (Segal and Balanco, 2008, p.20). “All parents are worried about night time

hypoglycemia and wonder if their child might die from this” (Hanas, 2005, p.56). It often happens that during the night one will wake up and test the diabetic child’s blood sugar level as a precautionary measure, to combat the possibility of a “sugar low” as it is commonly named. “Parents try to prevent night time hypoglycemia by administering an evening or bed-time snack” (*ibid*). This is most likely to be a snack that contains carbohydrates.

A person with diabetes hardly ever dies during the night but it has been known to happen on the very rare occasion. This uncommon phenomenon has been called the “dead in bed” syndrome. “It is believed to be caused by a disturbed cardiac rhythm and can also happen to people without diabetes, although this is ever more infrequent” (Hanas, 2005, p.56).

3.4.10 Hyperglycemia

Hyperglycemia occurs when there is too much sugar in the blood (high blood sugar). High blood sugar “over many years can lead to complications associated with diabetes. Areas that can be damaged from high blood glucose levels are the eyes, kidneys, heart and feet” (Segal and Balanco, 2008, p.23) “The high blood glucose levels damage all the small nerves and arteries to the organs mentioned above” (*ibid*). Occasionally a diabetic child will have a high blood sugar reading This will not cause damage and probably, if it is a rare occurrence, will not affect the child’s HBA1C (the three month blood glucose level average).

3.4.11 Ketoacidosis

“Keytones are produced when fat is broken down in the body for any reason. In diabetics, ketones are produced in excess when there is a lack of insulin in the body” (Hanas, 2005, p.29). This often happens in instances where a diabetic has a cold or influenza. “The body tries to get rid of the keytones by excreting them either in the urine or in the form of acetone which is breathed

out through the lungs” (ibid). Hanas reveals that “too many keytones make the blood acidic, causing ketoacidosis. Ketoacidoses is a life threatening condition that must be treated with intravenous fluid and insulin in hospital” (2005, p.29). A diabetic’s life, especially for a child is a tough balancing act. Most of the time one has to try and maintain blood glucose levels, and even be fully aware of what one consumes and what is happening around one. Careful control of blood sugar levels, as well as heeding warning signs may indicate a problem or complication in a diabetic’s make up. General day to day living makes for a stressful life for the diabetic person.

3.5 Physical exercise and diabetes

All people need to do some sort of exercise to keep healthy. Some people don’t enjoy exercise, mostly adults but most children enjoy being active and love to play games. This exercise and physical activity is especially beneficial for the diabetic child and adolescent who for some reason “tend to be more physically active than their friends without diabetes” (Hanas, 2005, p.247). Although diabetics may not be professional athletes, they can reach their full potential when the physical education teacher as well as the sports coach learn about diabetes in order to be effective when complications occur. The coach must be aware of the child’s normal level of activity and any deviation thereof. It is essential that the coach participates in the development of the care plan of the diabetic child.

For people who are sedentary, it is especially important to start off slowly when beginning an exercise regimen. It is difficult to become active after exercise has been missing from one’s life, so small changes must be made to one’s lifestyle in order to accommodate and sustain physical activity in one’s life. “Riding a bicycle to and from school or playing ball are ideal activities to begin doing after diabetes diagnoses” (Hanas, 2005, p.247). “Regular physical exercise lowers cardiovascular risk factors (overweight, hypertension, high blood lipids) in adults and adolescents with Type -1 diabetes” (ibid).

When there is an avoidance of exercise “in some teenagers’ lives, this inactivity seems to contribute to increased insulin resistance” (Hanas, 2005, p.247). As a result of “exercise 3 to 4 times a week” the body will “increase insulin sensitivity even between the training sessions, and the total insulin dose can probably be lowered” (Hanas, 2005, p.248).

The question that most young people ask is “can physical exercise be a substitute for insulin? No it doesn’t work like this” (Hanas, 2005 p.249). Some children and adults, it seems, would like to believe that as they are very active they don’t have to take insulin anymore as the effect of exercise on the body does tend to lower the overall blood sugar in the body.

Hanas, (ibid) explains that despite the fact that exercise and insulin both lower the blood glucose level, without insulin there will be a lack of glucose inside the cells of the body. “Since there is an insulin deficiency, the glucose will remain in the bloodstream, resulting in an increased blood glucose level”. One should not, as a result of this, “exercise when your insulin levels are low” (Hanas, 2005, p.349).

The “rise in blood glucose is usually transient, lasting typically 30 – 60 minutes, and can be followed by hypoglycemia, in the hours after finishing the exercise” (providing insulin is present during the exercise) (Hanas, 2005, p.249). It thus becomes obvious that one should test blood sugar levels during exercise so that hypoglycemia is avoided. It also depends on the type of exercise that is being performed.

Anaerobic activities are characterized by higher intensities of muscular work (for example sprinting, power lifting, hockey). Aerobic activities involve lower intensities of muscular work (for example running, cycling, rowing, swimming and other endurance sports). Many aerobic activities include short bursts of anaerobic activity (like soccer and baseball). “Anaerobic efforts last only a short time (sometimes only seconds) but may increase the blood glucose level dramatically due to the release of the hormones adrenaline and glucagon” (Hanas, 2005, p.249).

Diabetic children will benefit more from aerobic activity which increases the heart rate and strengthens both the heart and the lungs. When the heart rate is increased, the body uses energy and glucose levels are likely to be reduced (ibid). Teachers and sports coaches should therefore encourage diabetic children to participate in frequent aerobic activities such as running and swimming.

Diabetics need to drink a lot of fluids that do not contain sugar. It is important that they remain hydrated throughout the duration of exercise as this will reduce the possibility of skin irritations as well as aiding the functions of vital organs. All people, children and adults alike, whether diabetic or not, will feel the effects of dehydration during exercise. For a diabetic it is more severe than for non-diabetics. “Even a 1% decrease in body mass due to dehydration may impair performance. Fluid intake should closely match the loss of fluids during exercise” (Hanas, 2005, p.245).

3.5.1 The place of Physical Education in the routines of a diabetic learner

As stated earlier, there are three (3) types of diabetes-Diabetes type 1, Diabetes type 2 and Gestational diabetes. Children almost always have type 1 diabetes and can forget to eat and/ or administer insulin .The physical education teacher must always be aware of the potential dangers of hypoglycemia and fluid intake while monitoring the child during Physical Education classes. The diabetic child may feel that all is well and perhaps “take on too much” activity with undesirable consequences. The teacher must ensure moderate exercise is used as a general rule of thumb to ensure the wellbeing of the diabetic child.

Life Orientation lessons in schools in South Africa now have a compulsory physical education evaluation component. All children need to be assessed and physical education marks are an important facet of the overall final mark for Life Orientation. “Children and teenagers with diabetes can and should take part in physical education at school” (Hanas, 2005, p.254). “The risk for

hypoglycemia will be lower if physical education activities can be timetabled for the second or third class following a meal if the child is using rapid acting insulin (Novolog/Novorapid or Humalog)” (ibid). When children know their timetables and are aware of the P.E. times and days, it is easier to plan meals around these times in order to be prepared for P.E. lessons (ibid). Enough food can be eaten and insulin administered to compensate for the exercise done at physical education lessons.

As hypoglycemia is the largest concern to the diabetic, the teacher and the child’s peers must be suitably informed to monitor the diabetic’s physical signs of hypoglycemia. Also the physical needs of the child need to be known by the physical education teacher, as well as the nurse (if the school has one) and “both should have glucose tablets and know when and how they should be used” (Hanas, 2005, p.254).

It may also be advisable to “eat something extra during the session (lesson) if it last longer than thirty (30) minutes. Find out what suits you best” (Hanas, 2005, p 257) through trial and error. The diabetic may want to “eat a large meal afterwards, preferably something with high carbohydrate content, like sandwiches” (Hanas, 2005, p.257). Another “major benefit for all young people with diabetes is that regular daily exercise of one sort or another helps to keep the weight down and also in the long term improves heart and blood vessel fitness” (Hanas, 2005, p. 258).

“The lack of physical education in some schools means that children do not exercise at school anymore, and the rise of the techno-generation results in children doing very little physical activity in general” (Davey, 2012, p.18). Davey’s sentiments are echoed by parents whose children are consumed by television and computer screens and the lack of physical activity during weekends and vacations is astounding.

A concern is that “recent estimates make South Africa the third “fattest” country in the world. With this, we are seeing Type -2 diabetes on the increase. “Recently one of the youngest children with Type -2 diabetes in South Africa was only 6 years old” (Davey, 2012, p.18).

There is thus a good argument to eat healthily and exercise, especially in the school environment. It has become critical for young South Africans to take part in some type of physical activity both during formal lessons at school and in their free time.

While teachers must strive to ensure that the children in their classes are all catered for, special attention must be given to the diabetic child to ensure adherence to the diabetic plan. All adults, peers and other staff at schools can play some positive role to ensure general good health to the diabetic child.

One can argue that physical education is beneficial to the life of a diabetic learner since it has the capacity to control the blood sugar levels. The dangers that physical education can face could be when teachers are not actually aware of the benefits and overlook it due to curriculum constraints. The amount of physical exercise matters if it has to be used as a regulator for blood glucose level. In cases where teachers are ill-advised, this benefit is eroded. How much teachers know and how correct their knowledge is, is something that is not clearly established.

3.6 Conclusion of the Literature Review

In this section I have highlighted the composition of food in terms of nutritional value and the effect it has on the body as well as the bodies' physiological responses to food. The implications for children whose bodies do not have the ability to produce insulin and the resultant possible associated diseases that can arise have highlighted further possible management challenges for teachers of the disease at schools.

Also, to add to this, physical issues with diabetics can have a bearing on the psychological aspects of the child's life, so the implications for parents and siblings are highlighted as important issues in this section although not much research is done on parents and siblings in this regard. The associated diseases and complications that affect the diabetic child are important in that the method and variance of managing diabetic children at school is adjusted

from individual to individual depending to the extent to which each person is affected by these added illnesses. More than one associated disease or illness in an individual demands high levels of attention and being ill informed may lead to further mis-management of this disease. This research seeks to understand the level of information that such key players have in the management of diabetes, which is not as obvious as it may look.

In addition, a diabetic child with hypoglycemia (low blood glucose) will be treated differently to a child with hyperglycemia (high blood sugar). The importance of being familiar with the causes and effects of afore mentioned associated diseases and illnesses is important information for the staff of schools to know in order to successfully manage the diabetic child in his or her care. Similarly, the effects of exercise and human movement in the life of the diabetic have also been included in this section and specific issues concerning exercise have been highlighted.

The literature in this section has revealed much of what potential complications and associated difficulties can occur in the life of the diabetic child's life. Also, it remains to be seen if schools take seriously or if they consider at all the wellbeing of diabetic learners who have to more conscientiously manage their personal diabetic situation, as the literature reviewed in here indicates.

CHAPTER FOUR

THEORETICAL FRAMEWORK

4.0 Introduction

In public schools in South Africa, little attention is given to nutrition, vitamins and minerals within the make up of food or in fact psychological implications of children living with diabetes. The many associated diseases and complications that diabetics face through food management are not, as a rule, taken into account by teachers. Physical exercise is, as stated, an important aspect in the life of any diabetic.

Teachers need to be aware of the reasons why Physical Education has a bearing on the life of a diabetic child. Also important are issues such as the extent to which the diabetic learner is supported physically, (testing and injecting) and how educators are able to assist during this process. Equally important is the basic human right of the diabetic learner to be able to do all of the above as well as have the right to choose food from the “tuck shop” that would be within the realms of acceptable for the diet of the diabetic.

Including the diabetic learner in all facets of school life will both encourage these learners to be part of all activities during and after school hours and negative emotional effect on them should be minimal. Psychological long term damage will be limited but this will only occur when the teachers, coaches and other care givers at public schools become familiar with the correct handling of all aspects of the disease concerning these children. The proactive and reactive actions of people in authority in schools will determine the quality of school life diabetics’ experience. The importance of having at least one person in authority with the basic knowledge of how to handle diabetic children and diabetic issues at schools will be advantageous to the life of a diabetic.

The repositioning of the issues and their focus as elucidated above requires that the theoretical framework makes a preferential option for key ideas such as inclusivity, learner support, barriers to learning, human rights and equal educational opportunities. Most of these key ideas are essentially linked to each other as much as they are associated with the management of diabetic learners in schools.

In the first section I explore inclusivity in education and identify some key elements that appear as barriers to learning and what support is extended to children who suffer from chronic illness. I will try to determine and understand what rights are enjoyed by children who attend mainstream schools as well as children who attend schools for special needs. Following on from this, I explore learner support systems in schools, with a specific focus on how the schools – and education policy at large – provide for the needs of children with diabetes. The discussion on school support leads me to an exploration of the barriers to learning created by diabetes and experienced by children with diabetes. My discussion then moves to focus on human rights in relation to the diabetic child. I conclude this section with a discussion on how educational opportunities are affected by the management of this chronic disease.

4.1 Inclusivity in Schools

Inclusivity is concerned with ensuring that no person is excluded from participating or benefiting from any situation. In the educational context, inclusivity is concerned with ensuring that every person participating in a learning programme is not disadvantaged in any kind of way. In this section I explore the notion of inclusivity and investigate how policy and practice lend themselves to ensuring that the diabetic child is treated inclusively.

Although some study has been done in South Africa concerning the perceptions, views, attitudes and general feelings towards inclusive education, other scholars feel differently. For instance, in one study it was concluded that “teachers in South Africa have a definite lack of knowledge

about issues relating to inclusive education” (Swart et al., 2002, p.183). This lack of knowledge relates to teachers’ own professional practice.

According to Swart, et al. (2002, p.183) it is argued that one of the contributing factors could be the fear of not being able to cope with the children in their classes because of a lack of training, limited time, lack of experience as well as the management of large classes which has become a demanding task. These are some of the challenges which influence the attitudes of teachers towards their classes. As a result, desperation begins to emanate which leads to some avoidance of the issues that need to be dealt with.

On the level of management systems, Swart et al. (2002, p.185) identify a lack of “educational and teacher support, insufficient facilities and infrastructure” as some of the negative aspects that teachers experienced. In general, ‘negative attitudes and labelling’ surfaced because of the view that the outside world sometimes has of learners with special educational needs.

Similar to the above study, Engelbrecht, et al. (2000, p.1) reveals that “administrative issues, the behaviour of the learner, the competence of the learner and the parents of the learner with specific educational needs” are the four most stressful areas that have to be contended with when implementing inclusive education in schools.

The result is that oftentimes one’s attitude and training, or lack thereof, has an influence on the quality of education delivered in inclusive education classrooms in South Africa. This study will attempt to explore the extent to which learners are equipped at school to manage their diabetes and how their management impacts on their self-image and academic progress, as well as the attitudes of their peers.

4.2 Learner support systems in Schools

Support systems or structures are processes that assist with achieving the best possible outcomes. Support systems in schools focus on the wellbeing of the learner. These include an array of support structures from the role of the class teacher, the grade head, support staff (like sports instructors, counsellors and first aiders), to school management structures and communication between parents and guardians. In my study, I will focus on the support structures that impact the learning and functioning of a diabetic child in the school environment.

It was only recently, in 1994, that South Africa has become committed to “the development of a single, inclusive system (of schooling) which has the capacity to provide for the appropriate ways and means to facilitate learning and meet the needs of all learners, including those with disabilities” (Engelbrecht et al., 2001, p.1). Within this framework, it is generally recognised that the support of learners and teachers is not only the responsibility of schools, but also of the district in which these schools are situated. In the Draft Policy Document *White Paper 5: Special Needs* (DoE, 2001, p.5) it is clearly stated “that schools need to be supported and will require appropriate district as well as school-based support services” (Engelbrecht et al. 2001, p.2). In view of this, Engelbrecht et al. (2001, p.4) propose that if schools have to implement the changes outlined in Draft Paper 5, appropriate frameworks for meeting the needs of schools need to be implemented. These include “a team approach, professional in-service training and behaviour management” (Engelbrecht et al., 2001, p.5).

The team approach involves all stakeholders (parents, teachers and caregivers) and “planning then takes place and professional in-service training seeks help and resources to sustain active learning” (Engelbrecht et al., 2001, p.5). The behaviour management area of the framework involves discussion and “strategies to address behaviour problems” (Engelbrecht et al., 2001 p.5) with all the stakeholders.

Although the concept of learner support is relatively new in the South African educational management system, I will, through my study try to determine if learners in this country are given the assistance, in the management of this disease. The involvement of all stakeholders also takes into account how the learners' peers are willing to avail themselves in some way and in so doing learn more about the disabilities of others.

4.3 Barriers to Learning

Barriers to learning implies an obstacle that may prevent a learner from gaining the best possible outcomes. In other educational systems, barriers to learning may be called learning impediments, handicaps or disabilities. The term "barriers to learning" is the preferred term used in South Africa to explain why some learners do not experience learning success (Walton et al., 2009, p.1f.). White Paper 6 (DBE, 2010) outlines a national strategy for systematically addressing and removing barriers to learning through establishing full service schools, converting special schools into resource centres and training managers and teachers (Walton, et al., 2009, p.1).

In order to address the many different health barriers to learning that are presently being experienced in South African schools, some research based information on inclusive education is beginning to emerge in South Africa. This research is "congruent with international trends in research in this field" (Walton et al., 2009, p. 2). For instance, the World Health Organisation (WHO) defines health as "a state of complete physical, mental and social wellbeing" (World Health Organisation, 1948, p.3). In other words, "health relates to the whole person".

Different barriers to learning, however, can range from not having the basic materials for learning, to the barriers society places on children, which restricts them. This is in addition to the medical barriers that children have to contend with. These barriers to learning may be more restrictive than initially thought as a learner may experience more than one barrier at any given time.

In order to be of any assistance to learners, one can argue that teachers need firstly to be equipped to do their work. Their environment, teaching aids and general working conditions will be examined to establish the extent to which teaching is conducive. I will also try to determine if the children involved in the study perceive as having been disadvantaged in any way due to their disability and the conditions within which they survive as diabetic children in schools.

4.4 Human Rights and diversity in education

In the Universal Declaration of Human Rights article 26 it states that “everyone has the right to education”; and that “education shall be compulsory”. This serves to inform that everyone is included in the education systems of the world, without exception. The mandate to widen access to education also goes with the mandate to direct all education “to the full development of the human personality”. This further implies that education should “promote understanding, friendship among all nations, racial or religious groups” (see The Universal Declaration of Human rights). (<http://www.un.org/en/documents/udhr>). This means that all children have the right to be educated, at least at primary school level, and that “special needs education is a type of education that merges ‘inclusive education’ and social inclusion, within broader epistemological principles” (Knight 1999, p.1). On a practical level, Knight (1999, p.1) suggests that a classroom needs to be democratic and socially inclusive to the extent to which it involves all students as equally valued members of the school community. Nevertheless, in many cases, in and out of school, the “denial of rights seems to gain momentum” (Knight 1999, p.12). This may be an indication of the extent to which learners in all schools are able or not able to voice opinions, express themselves and learn from experience.

In view of the above, the South African education scenario seems to have very little comment on the law and how it is applied to children who suffer from chronic disease. One would then ask: to what extent does this hinder

the progress of such children? In addition, the government expenditure on health services in South Africa counts for 40% of the total budget but unfortunately this has to accommodate 80% of its people so there is a large proportion of South Africans who have no access to proper health care. (ibid).

4.5 Equal Educational opportunity and the management of chronic diseases in schools

Equal opportunity in education means providing equal education access to all learners, regardless of all of the equal access considerations laid out in the South African Constitution. Equal access means ‘that all children should be granted a fair opportunity to reach their maximum potential and support should be provided wherever possible to overcome any barriers or obstacles that might prevent equality of opportunity’ (Brighthouse, 2010). In my study, I will particularly look at how equality may be achieved by learners with diabetes. Migdal (2008, p.1) argues that our schools are supposed to prepare us to enter the real world. The equality of human beings as enshrined in the UDHR (The United Nations General Assembly, 1948), further requires that all learners, whether those with limitations or not, are prepared equally to live fulfilling lives. Although the notion of equal educational opportunity mainly comes up in the discussion about boys and girls ‘being wired’ differently; that the two genders react and behave differently, equal educational opportunity can also involve how schools manage learners with difficulties.

In the case of inclusive education it appears that while many countries seek to achieve equality for all children, learners who are diabetic may be further marginalised despite believing in equal educational opportunities. Their marginalisation could be due to limited medical supplies, violence, lack of understanding of their special circumstances and many more. I will investigate all these possibilities.

CHAPTER FIVE

RESEARCH FINDINGS

5.0 Introduction to research findings

The findings of this research are mainly from my interviews with my respondents. The procedures and techniques that were used in collecting and analyzing the data have already been discussed in the methodology chapter earlier on. These respondents were: learners with diabetes, parents whose children have diabetes and are selected to participate in the research, and educators whose learners are diabetic and are also participating in the research. In the research interviews, three types of issues were covered with all the respondents. The first type of questions, Section (A), deals with general information. The second type, Section (B), deals with the technical aspects of diabetes mellitus, and the last type, Section (C) relates to the management of diabetes in general terms.

5.1 Responses from Diabetic learners

In this section, I will report on information received from the diabetic learners regarding the three different question dimensions of the research. These are: general information, technical information and their practices and perceptions of the general management of the disease.

5.1.1 Diabetic learners' general knowledge relating to diabetes

In commencing with the responses of the learners themselves, this section will report on the knowledge of the general aspects of blood glucose levels, different foods and dietary requirements as well as the effect that diabetes can have on one's body and the relationship diabetic children have with their peers.

General knowledge questions	0	1	2	3	4
Are you able to concentrate when your blood sugar levels are high?	0	0	6	0	0
Do you ever feel frustrated because your diet is limited?	2	0	2	1	1
Do you feel/think that your parents treat you differently to your brothers and sisters?	2	0	2	1	1
Are you worried that your Diabetes will affect other parts of your body?	1	0	1	2	2
In sport, are you able to compete equally with your peers?	0	0	0	2	4

Key: 0 = Never; 1 = Seldom; 2 = Sometimes; 3 = Often; 4 = Always

The table above has captured the number of respondents who have given a specific response. In this regard, all six (6) of the diabetic respondents indicated that they were sometimes able to concentrate when their glucose readings were above normal or acceptable levels. Two (2) out of the six (6) respondents never feel frustrated due to diet limitations while a further two (2) felt frustrated sometimes because of it. One (1) respondent often felt that diet limitations frustrated her and (one) 1 always felt frustrated due to having a restricted diet.

Two (2) out of the six (6) respondents never felt that their parents treat them differently to their siblings. Two (2) felt that they were sometimes treated

differently while one (1) felt treated differently often and one (1) always felt as if he is treated differently from his siblings.

One (1) respondent never felt that diabetes would affect other organs of the body, while one (1) person felt worried that sometimes it may affect your other body parts. Two (2) often felt worried that diabetes would affect your organs and two (2) always worried about diabetes affecting other parts of the body in some way.

In sport, two (2) respondents often felt that they could compete equally with their peers and four (4) respondents always felt that they could compete equally with their peers on a competitive level during sport.

As a result of being a diabetic, sacrifices have to be made. The most troublesome seemed to be the restriction of eating at will (any foods) and the process of testing of blood sugar and injecting insulin is laborious. Also, a strict regimen of continually watching one's diet and having to choose healthy foods over less healthy food takes the fun out of eating. Only one (1) person out of the six (6) felt no sacrifice had been made as a result of being diagnosed a type 1 diabetic, as healthy food appealed to her anyway.

Academically, the general feeling of the respondents is that they are often tired during school teaching time and they also struggled to maintain high levels of concentration.

5.1.2 Diabetic learners' knowledge of technical information on diabetes

In this this section I aim to ascertain certain technical aspects of the disease. Testing of blood glucose levels at school, and the inquiry of specific supply of services offered by the school to diabetic learners during lunch breaks will be covered. The support available to these learners by teachers or the labelling of the same will be investigated. Also, I enquire about areas of blood glucose testing and future concerns of how diabetes may impact on the life of a diabetic.

Technical knowledge Questions	0	1	2	3	4
Do you feel that you get extra support at school from your teachers?	Number of Respondents				
	3	2	1	0	0
Does the school tuck shop cater to your needs?	2	4	0	0	0
Have you ever felt that your parents or teachers have singled you out for being different?	1	1	2	2	0
At school, is there a safe place where you can test your blood sugar levels?	5	0	1	0	0
During physical education, are you allowed to stop during the activity when you want to?	1	4	1	0	0

Key: 0 = Never; 1 = Seldom; 2 = Sometimes; 3 = Often; 4 = Always

Three (3) respondents said that no extra support was given by the teachers at school, while two (2) respondents felt that they seldom received extra support from teachers at school. Only one (1) child responded that he received support from a teacher at school. Two (2) respondents indicated that the tuck shop never catered for their mealtime needs, while the other four (4) respondents felt that their mealtime needs were seldom catered for. One (1) respondent never felt that parents or teachers singled them out for being different. One (1) other person said that she seldom felt like that while two (2) others sometimes felt treated differently and the last two (2) diabetic

learners claimed that they often felt as if they were singled out for being different.

Four (4) respondents expressed that there was never a safe place to do glucose testing and injecting at school, while one (1) of the respondents said that he sometimes had a safe place to test and inject. One (1) respondent was never allowed to stop during physical activity when he chose to, while four (4) others expressed that they were seldom allowed to stop for the same thing and one (1) was sometimes allowed to stop.

The playground, toilets or sometimes in a classroom are the areas that the diabetics felt are available for them to test glucose levels and to inject insulin.

Generally the diabetic respondents are concerned with their eyesight and the girls about “being able to” fall pregnant one day. No other real concerns came to the fore.

5.1.3 Learners’ management of diabetes

The central theme of this section is to ascertain the general daily self-management and assistance diabetic learners have during school time. Also, I aim to discover to what extent the peers of diabetic learners in schools across South Africa are aware of the dangers of hypo/hyperglycemia and if they have any knowledge concerning these conditions.

Everyday management during and after school	0	1	2	3	4
When your blood sugar levels are too high, are your test marks affected?	Number of respondents				
	0	0	1	3	2

If necessary, do your teachers allow you to eat during class?	3	1	1	0	1
Do you think that your teachers and friends help you enough with your diabetes management?	2	3	1	0	0
Are your teachers and friends aware of the consequences if your blood sugar drops too low?	3	2	1	0	0
Do your friends and teachers know that you should eat before you do physical activities?	3	3	0	0	0

Key: 0 = Never; 1 = Seldom; 2 = Sometimes; 3 = Often; 4 = Always

One (1) respondent said that when his blood sugar levels (glucose) are too high, his marks are sometimes affected, three (3) respondents were often affected by the same and two (2) respondents indicated that their test marks are always affected when the glucose level in the blood is high.

Three (3) of the six (6) respondents are never allowed to eat during teaching time while one (1) was seldom allowed, one (1) other was sometimes allowed, and only one (1) respondent is always allowed to eat during class time if necessary. Three (3) respondents said that friends and teachers never help enough with their diabetes management, while three (3) expressed that their friends and teachers seldom help enough.

Three (3) respondents claim that teachers and friends are not aware at all of the consequences of a low blood sugar reading. Two (2) of them say that the

same people seldom know what the consequences are and only one (1) respondent feels that sometimes teachers and friends are aware of the consequences of a diabetic whose glucose level falls dangerously low. Three (3) respondents indicated that friends and teachers do not know that the diabetic learner should eat before doing some physical exercise and three (3) respondents feel that the same people seldom know that this should happen.

Half of the respondents claimed that they had a “hidden” treat without anyone knowing of such and when glucose levels in the respondents fell, they ate it quietly. All respondents felt feelings and emotions of anger, sadness, irritability, grumpiness and mood swings.

5.2 Parent and Teacher Responses

This section attempts to investigate the knowledge and practices that teachers and parents have with regard to diabetes. More specifically, I will attempt to ascertain to what extent the fluctuation of different blood glucose levels (if any) have on a diabetic learner’s life. I will also try to determine if these same learners are treated differently by their teachers and/ or parents and to what extent these adults accept the role of assisting the child.

Together with this I will also enquire if the adults who take care of the diabetic children in my study are fearful as a result of this responsibility that they have acquired and if the children are treated as equals in the areas of formal and informal physical activity.

5.2.1 Parent and Teacher general Information

The table below indicates the questions parents and teachers were asked regarding their general knowledge of diabetes

	0	1	2	3	4
To what extent have you noticed a lapse in concentration when the reading of the blood sugar level is too high?	Number of respondents				
	0	0	2	4	1
Do you feel you have to constantly manage and monitor the diet of the diabetic child in your care?	2	1	1	1	2
Do you ever find yourself treating the diabetic child differently to his/her peers?	3	2	0	0	2
Is there a fear that high blood sugar levels will adversely affect other areas of the child's health?	2	0	2	1	1
Is the diabetic child disadvantaged on the sports field?	1	3	3	0	0

Key: 0 = Never; 1 = Seldom; 2 = Sometimes; 3 = Often; 4 = Always

Parents / teachers in two (2) instances noticed a lapse in concentration when the reading of the blood sugar level is too high. Four (4) parents / teachers often noticed for the same and one (1) parent / teacher respondent said that she always noticed a lapse in concentration when the blood sugar level is too high.

As far as the constant management and monitoring of diet goes, two (2) parents / teachers expressed never having to do this, one (1) parent / teacher seldom did managing or monitoring of diet, one (1) sometimes had to do this and two (2) parents / teachers felt that they always had to manage and monitor the diet of the diabetic child in his their care.

Two (2) respondents say that they have no fear that high blood sugar levels will adversely affect the other areas of the diabetic child's health. Two (2) say that sometimes this is a fear for them. One (1) respondent sometimes feels the same will affect the child's health and one (1) respondent expressed that he /she always fears that the diabetic child's health will be adversely affected by high sugar readings.

Three (3) of the parent / teacher respondents never find themselves treating the diabetic child differently to their peers. Two (2) respondents seldom find themselves doing the same, and two (2) parent / teacher respondents say that they always treat the diabetic child differently to their peers. Parent / teacher respondents always try to keep the options at mealtimes healthy and control the intake of sugar to a minimum as well as injecting more insulin before a treat.

One (1) child never feels disadvantaged on the sports field, while three (3) seldom do and three (3) sometimes experience the same.

All the teachers say that their role is passive and they assist only when asked to do so by the parents or the diabetic child in their care. The teachers feel that, when properly informed, they do know enough to care properly for a diabetic child in their class.

5.2.2 Parents' and teachers' technical knowledge on diabetes

In order for the teacher/parent of the diabetic child to be of assistance, technical information available to them would be helpful in the day to day care of these children. This section sought to discover how glucose monitoring and testing, care and assistance offered by adults as well the

monitoring of eating habits or foods consumed by diabetic children takes place at school and at home.

Technical Knowledge questions	0	1	2	3	4
Do you need to consistently offer the diabetic child in your care additional academic support?	Number of respondents				
	2	2	1	0	2
Are the eating habits of the diabetic child in your care strictly monitored?	2	1	0	1	2
Do you find the responsibility of caring for a diabetic child overwhelming?	0	2	2	0	3
Have you been vigilant about measuring the child's blood sugar levels?	3	0	0	1	3
Can the diabetic child compete equally with his/her peers in sport?	0	0	2	3	2

Key: 0 = Never; 1 = Seldom; 2 = Sometimes; 3 = Often; 4 = Always

The majority of parents and teachers do not vigilantly offer support to the diabetic children in their care. This could be during the monitoring and testing of blood glucose levels but also during mealtimes and times of physical activity.

Two (2) parent / teacher respondents say that they never have to consistently offer the diabetic child in their care academic support. Two (2) seldom have to do the same, one (1) sometimes has to do so and two (2) always have to consistently offer him / her support.

Two (2) parent / teacher respondents never monitor the diabetic child's eating habits, one (1) seldom does the same, one (1) often monitors eating habits while two (2) parent / teacher respondents indicated that they always monitor the eating habits of the diabetic child in their care.

In caring for a diabetic child, two (2) parent / teacher respondents seldom find the task overwhelming , two (2) sometimes find it overwhelming and three (3) parent / teacher respondents are always overwhelmed by doing their task.

Three (3) parent / teacher respondents are never vigilant when measuring / testing the child's blood sugar levels, one (1) parent / teacher respondent is often vigilant for the same and three (3) are always vigilant where measuring / testing blood sugar levels is concerned. In sport, two (2) parent / teacher respondents feel that the diabetic child in his / her care can sometimes compete equally in sports, three (3) say that this is often the case and two (2) say that they can always do so as diabetics. Four (4) parent / teacher respondents are concerned that the diabetic's sugar level may fall so low that convulsions and even a comatose situation may occur. Three (3) out of the seven (7) parent / teacher respondents do not know the meaning of "hypo" as far as a diabetic is concerned. The other four (4) suggested that some type of sugar laden product be administered to a diabetic child experiencing low blood sugar until it rises.

5.2.3 Teachers' and parents' management of diabetes

The subtle management of diabetes by the responsible adult (in a classroom for example) requires a certain amount of monitoring. In this section I aim to discover to what extent academic achievements are affected (if at all) in the diabetic child as well any other causal affects in the fluctuation of blood glucose readings and how food could possibly affect the results of the glucose readings of the diabetic child.

Questions on the Management of diabetes	0	1	2	3	4
When the diabetic child's blood sugar levels are too high or too low, are their academic achievements affected?	Number of respondents				
	2	2	0	1	2
Are you flexible when dealing with the eating habits of the diabetic child?	0	0	3	2	2
Have you been vigilant about the management of the diabetic child's blood sugar levels?	2	0	0	2	3
Do you understand the risks and casual effects of fluctuating blood sugar readings?	4	0	0	3	0
Are you aware that physical exercise may cause a reduction in blood sugar?	3	0	0	1	3

Key: 0 = Never; 1 = Seldom; 2 = Sometimes; 3 = Often; 4 = Always

Due to too high or low blood sugar levels (inconsistent readings), two (2) parent / teacher respondents say that the academic achievements of that child are never affected, two (2) parent / teacher respondents say that this is seldom the case, one (1) parent / teacher respondent indicates that the diabetic child's academic results are often adversely affected by high / low blood sugar levels and two (2) other parent / teacher respondent says that this is always so.

When dealing with the eating habits of the diabetic child, three (3) parent teacher respondents are sometimes flexible in this regard. Two (2) are sometimes flexible and two (2) parent / teacher respondents are always flexible.

Two (2) parent / teacher respondents have never been vigilant about the management of the diabetic child's blood sugar levels, two (2) others are often vigilant concerning this while three (3) other parent / teacher respondents are always vigilant about managing the child's blood sugar levels. Four (4) parent / teacher respondents never understand the risks and causal effects of fluctuating blood sugar readings. Three (3) parent / teacher respondents have never been aware that physical exercise can help reduce high glucose readings, while one (1) parent / teacher respondent says this is often the case and three (3) other respondents declare that this is always the case. Two (2) respondents are never vigilant about the glucose management levels of their children, while two (2) others are often concerned about it and a further three (3) are always concerned.

Generally four (4) of the seven (7) parent / teacher respondents say that the diabetic child needs the following when on a tour or spending a night away from home: a phone, a cold drink (sugar laden), snacks, glucose testing equipment, correct insulin dosages and injections. Six (6) also say that they need to have prior instructions to deal with the diabetic. One (1) parent / teacher respondent felt that because there is never a day off from diabetes, these diabetic children do not live "normal" lives. Six (6) parent / teacher respondents say that diabetic children are able to live "normally" under controlled conditions.

The results above indicate that there are some teachers and parents, who are familiar with the disease and who manage the life and all that is connected with the lot of a diabetic child better than others do. There are also varying degrees of success that these adults enjoy in terms of the monitoring of the management of blood sugar readings, academic prowess and physical activity.

CHAPTER SIX

ANALYSIS OF RESEARCH FINDINGS

6.1 Introduction

The semi-structured interview involved the diabetic children while the focus group interview was done with the parents.

During the semi-structured interview, the children were addressed with questions relating to the following areas of their lives: Academics, Self-image, Teachers and peers, being treated differently, Management of diabetes and Sport. Each of these mentioned areas of concern were chosen specifically so that one could get an idea of how the diabetic children live their lives as well as how the parents and teachers assist them in their daily routines, especially during school hours and sports practices.

Diabetes Mellitus Type 1 or Type 2 in children specifically, has a profound alteration on the life of any child. In fact the entire family is affected because a whole lifestyle change is involved for the diabetic child. Such changes also affect meals, outings, schooldays and other routines that need to be followed by the child.

Despite the above demands on the child and the system as a whole, very little is known about the disease itself generally in schools by teachers, peers, admin staff and other parents. This apparent lack of knowledge impacts heavily on the general school and academic life of the diabetic learner. Furthermore, general information about the management of diabetes is almost “hidden” from anyone who is not directly involved with or close to someone who is associated with the disease. According to statistics, Chopra and Puoane (2003, p.25) comment that there is an increase in diagnosis of type 1 and type 2 diabetes in children of a school going age.

The management of diabetes during and after school by learners, parents and teachers involves glucose level testing and the administering of insulin by small injection (in the case of type 1 diabetics). Much of the management is the responsibility of the learner which can be daunting for all parties concerned.

The findings of this research are manifest mainly in how the diabetic learner sees him or herself and how others respond to these children. While there is evidence of discrimination and prejudice towards the diabetic learner in public schools in South Africa, there are also those who assist in the general life and education of said children.

This researcher has also explored the impact on the self-image of the diabetic learner with varying results. As is the case with academic performance, or the lack thereof, the two aforementioned aspects in the life of the diabetic vary according to the personality and D.N.A. wiring from individual to individual. As much as two diabetic learners can differ in makeup, physical or otherwise, their bodies' responses to different foods, climates and weather patterns are also unique to themselves.

The management of the diabetic child is thus personal and needs to be adapted to the needs of the individual specifically, with the administering of insulin to cover food as well as other dietary requirements such as the consumption of additional vitamins and minerals. Also, the analysis of my data revealed the positive impact sport and physical activity has on an individual who suffers from diabetes. In all cases the presence of physical activity or sport 3 to 4 times a week "increased insulin sensitivity" as Hanas (2005, p.258) describes, "and the total insulin sensitivity even between the training sessions, increased and as a result, the insulin dosages could be lowered."

In analysing my data, the literature reviewed served as a benchmark from which I made comparisons, tested the literature, identified gaps, looked for differences and recognised similarities. It is important to note that during my analysis, it was clear that the literature often related to other sections of the

analysis and findings – in many instances, the data was not mutually exclusive. In this chapter discussions are presented in relation to the critical questions posed for this study.

These include diabetes management by diabetics, certain adults, as well as peers, during and after school hours. In my discussion I will include general diabetic knowledge of various parties and the self-image of diabetic learners. The negative possibilities of peer pressure, prejudice and discrimination of diabetic children at school will be discussed as will the positive influences of friends and helpful educators. Knowledge and general diabetic awareness, academic performance and the general impact of exercise as well as the rights of all humans, form areas for discussion.

6.2 Management of diabetes

The management of diabetes in school going children concerns a number of people, but the parents of a diabetic child are probably the people who will take charge of the bulk of the management process. It is imperative for these parents to allow their children to learn to take care of themselves from as early an age as possible. Managing diabetes means, among other things, keeping blood glucose levels as near to normal as is physically possible without pumping the body unnecessarily full of insulin. Managing diabetes at school, at home and on the sports field is a challenging task, especially, one would think, for the newly diagnosed diabetic child. Monitoring the balance of food intake at school and allowing the diabetic child freedom to experience life but also monitoring eating habits is difficult for parents to cope with in general terms, and for the teachers at school it becomes a massive challenge.

6.2.1 Management of diabetes by diabetic children during and after school hours

Segal and Davey (2009, p. 9) state that it is important that

...some diabetics do not have a specific diet, but eat most foods, all however, in moderation and covered by insulin. Primary school children are susceptible to high readings of blood glucose because at public schools they are the primary source of managing their diabetes and they often make mistakes.

Flynn (2005, p. 57) states that during bouts of anxiety and the increased levels of stress in trying to manage the disease post diagnosis, the home situation can become unbearable. As a result “control of the disease is lost, either way”.

Children are influenced by one another and it becomes very difficult for the young primary school child to abstain from eating (food and sweets) when in a group. As one respondent said, “I probably do cheat” (eat food not covered by insulin). No other diabetic respondent admitted to eating foods or snacks without first being covered by insulin. ‘Cheating’ in diabetic children can compromise their glucose levels because they are consuming foods for which insulin has not been administered. Nevertheless Hanas (2005, p.13) stresses that it is important for children to remain children first and foremost. As such, for diabetic children to “indulge in the occasional sweet treat has not been found to worsen overall blood sugar control” Hanas (2005, p. 13).

Once the children get to know their own bodies and how low or high blood sugar levels affect them, it does seem to get easier and the adaptation of food and insulin administering is easier to handle. This was a view shared by one of my parent respondents who noted that her child had become quite disciplined about monitoring his food intake while he is at school. This is a fairly long process and it takes time for the diabetic child to learn to and adapt to the responses of the body. The parents acknowledge that through a process of trial and error, certain personal patterns emerge and new eating habits are established. For example, one parent respondent explained that beef biltong seemed to push his child’s glucose levels higher than biltong made from game meat. There are still times when there is a fluctuation of glucose and one child respondent explained that she “still can’t do it” to the precise point where her sugar level management is completely controlled.

The main controlling factor for children is to ensure that they are covered by enough insulin when they eat meals or snack on something and remember to do this because if they forget about or ignore their diabetes, they will experience *hyperglycemia* (high blood glucose levels) and this leads to drowsiness, tiredness and in extreme cases convulsions and coma.

As noted by a child respondent, the main problem with the management of diabetes is not having to administer insulin, but rather to balance the insulin intake with the levels of your blood glucose. She went on to explain that:

“... when a person has a headache or a sore tummy for example, you take a Panado or whatever else you need to, to get rid of it. But when you have diabetes, you can't just take insulin to get rid of high blood sugar or cover your food. You have to take only a certain amount so as not to go low and not too little, or your glucose becomes high.”

This then is a balancing act, one that children find very difficult to master, control or maintain, because, as this child respondent further noted, “how much is enough and how much (insulin) is too much?” This is one of the dilemmas facing a diabetic child. She further explained that too much insulin can place a diabetic in danger, and too little insulin can do the same. On this issue, all but one of my child respondents made mention of insulin intake being difficult to manage.

All of my research respondents, the diabetic children, are unique in the management of their diabetes and responded differently to the foods they eat and the levels of administering insulin dosages varied from person-to-person. Generally though, it was a commonality amongst all my diabetic respondents that carbohydrates increased the glucose levels in their blood. This supports Noakes' (2012, p.2) view that on a low carbohydrate high fat diet he lost weight and his cholesterol levels were much healthier. He was pre-diabetic and does not recommend this way of living to a diabetic child. He further suggests that he is merely stating the personal results of his diet. What he did was to lower his carbohydrate intake and this was responsible for lower

glucose levels in his blood. Noakes (2012, p.2) further notes that by increasing his dietary fat intake, his blood sugar levels were not affected – in fact he noted a general improvement in blood sugar levels.

The investigation showed that it is important that all of my child respondents “maintain a stable blood glucose level”. Silverstein et.al (2005, p.15) notes that this is important so that “high and low glucose level fluctuations are kept to a minimum”. Silverstein (et.al, 2005, p.15) is supported by Davey and Segal (2009, p. 9) who also contend that the inclusion of carbohydrates and “balancing the diabetics’ plate”, must not “deprive them (diabetics) totally of carbohydrates.”

6.2.2 Management support of the diabetic child by their peers

Generally the classmates that diabetic children have do not know much about diabetes. It is apparent that only one or two friends who are very close to the diabetic know something about controlling diabetes and the processes that the diabetic has to follow. This is because the diabetic children spend time with their friends when they eat, play and socialise. One of the parent respondents explained that since her child had started school, she requested that she have a friend who acts as a “back up” for her should her blood glucose levels rise or drop excessively. This involves the friend calling for help or to organise a sugar laden snack or drink on the request of the diabetic.

Peer respondents noted that peers and friends lack certain skills and the basic knowledge to assist diabetics with their glucose level management – this is not their own fault or doing. For a number of reasons, when diabetics routinely check blood glucose levels and administer insulin, they are also not prepared or taught how to help their diabetic friends carb-count or recognise foods that would influence the levels of blood glucose.

In my literature review, I highlighted that Flynn (2005, p.60) suggests that “teachers should be educating other children in the class of the diabetic child

to react to the needs of this child”. This would encourage the other children to get more involved in assisting the diabetic child as knowledge is shared and more understanding emerges from the process. Establishing routines and being able to recognise a problematic situation will possibly encourage the peers of the diabetic and acceptance and inclusion may result.

According to Flynn (2005), peers need to be educated through a programme at schools, and in South Africa this could be done during Life Orientation classes. This would assist the diabetic and help in the inclusion of “being part of the training for emergencies and informing other learners (not in their class) of high and low blood sugars and their dangers” (2006, p.60). Unfortunately policy in South Africa (white paper 6 and the relatively new Curriculum Assessment Policy Statement (C.A.P.S.) document do not make sufficient provision for children in South African schools as far as assistance in managing chronic diseases is concerned.

Chopra and Puoane (2003, p.25) have stated that diabetes mellitus is on the rise and spiraling out of control as more and more people are diagnosed everyday (usually type 2). They argue that people in the United States of America refuse to “reduce their intake of fat” and that in South Africa people are subject to “unhealthy food preparation and large portion sizes.” These dietary practices may contribute to the increase of obesity in people and in turn more diagnosis of diabetes cases.

There is still so little information that the general public are exposed to or taught concerning this chronic disease. In my research sample, of the peers who participated, only one seemed to have any in-depth knowledge of the disease. I established that this child had a family member who is diabetic. It is therefore evident that diabetic children cannot rely heavily on their peers for diabetic management assistance. As a researcher, I was surprised at how little the peer respondents knew about the disease. This raises concerns about how they might respond in an emergency.

6.2.3 Management of diabetes by the teachers and the knowledge they have which affects the diabetic child's everyday well-being at school

From the research findings, it is evident that teachers often feel overwhelmed about diabetes and the management of it. One teacher respondent explained that she often felt anxious about the “sugar levels” and “consequences of these” of the type 1 diabetic child in her class. At least 60% of the teacher respondents demonstrated concern about assisting diabetic children placed in their care. Nevertheless, half of the teachers interviewed suggested that they are afraid of assisting diabetics with injecting because they are afraid of what the personal consequences might be should they make an error in insulin administration or any other management issue concerning the disease.

Compounding the fear in managing a diabetic child at school, it was also revealed that some teachers lack the appropriate skills in handling diabetic children there. This is confirmed by a girl respondent who had had many unhappy incidences at her previous schools and said that “unfortunately teachers do not have the skills to deal with the disease”. She has since left that school and is now in a home schooling centre.

Generally teachers are unable to assist children in an emergency. As the learner respondent expressed, “even the qualified first aid teacher panicked and did not know what to do in the event of an emergency that I experienced one day ... teachers have no idea about my diabetes and definitely do not understand my diabetic needs”.

The lack of skills and knowledge in managing a diabetic child at school may be compounded by the fact that teachers, as most adults do one suspects, refer to diabetes mellitus as a “sugar problem” and do not realise that carbohydrates are as much of a problem when broken down by the body to form glucose to be used for work and play. Few teachers know the negative effects that high glycemic index (G.I.) foods produce and the benefits of low G.I. foods for the diabetic, according to Segal and Davey (2009, p.9) in my literature review. They further state that in their experience teachers may

even avoid the diabetic child at school for fear of “getting the needs of the diabetic wrong” and making mistakes in management assistance for the child. Hanas (2005, p. 210) states that “all carbohydrates are broken down into glucose as their final form by the body in order to be used for energy.” The teachers appear to be “afraid” of getting involved in helping the diabetic children at school.

The problem that diabetic children experience is that teachers are reluctant to involve themselves with the personal diseases and problems of the children in their schools. The fear of accusation and lawsuits against a teacher who is *in loco parentis* of a child when problems arise is not a situation any teacher wants to find him or herself confronted with. The diabetic child is then left to fend for him/herself or with the basic help of friends in order to deal with these challenging situations.

Given the perceptions that were revealed by the diabetic learners, one can conclude that very little is known about the dilemma in which the diabetic child is placed. For reasons mentioned above, as well as other factors such as the lack of exposure to chronic disease and the resultant lack of confidence and knowledge that the teachers experience at their level, this leaves them exposed and prone to failing the child in their time of need. According to the respondents, teachers at their different schools either did not know enough about diabetes mellitus or did not want to become involved with their disease. According to all the learner respondents, the management of diabetics by their teachers, is mostly limited and the diabetic children at schools cannot rely on the educators for assistance.

6.2.4 Parents’ knowledge and management of diabetic children

From the time that a child is diagnosed with diabetes, his or her life “is never the same” one respondent declared. Some parents learn as much as possible about the disease in order to be well equipped to deal with the management of the diabetic. Others, the less anxious ones, gathered information and “found their way” by trial and error. According to one parent respondent

“being in and remaining in a positive frame of mind is extremely taxing on the parents especially”. Segal and Davey (2009, p.9), however, indicate that in this tough situation now suddenly being faced by the parents of the diabetic child “a positive outlook and active management will bring about good long-term results”. Flynn (2005, p.60) concurs with this sentiment and she states that “many children cope well on a day to day basis.” However Grey et al (2005, p.1) state that by year 2 post diagnosis depression and dependencies (on parents and others) were significantly higher in children with diabetes, a study shows. It is noteworthy then that children may regress academically and socially as this disease begins to take its toll on the entire family and the realisation of a life- long management of a medical condition becomes a permanent fixture in their lives.

None of the diabetic respondents, teachers or parents stated that they had at any stage received therapy or professional school counselling. Flynn (2005, p.59) suggests that school counsellors form a vital part of the progress and stability of the diabetic child’s life. My research participants indicated that this kind of support is not readily offered in schools. The data therefore implies that the psychological well-being of the entire family might, in certain cases, need to be monitored.

100% of the parent respondents noted that they had to change their lifestyles in order to accommodate their diabetic children. “It is almost impossible”, declared a respondent “for your life, and the lives of the entire family not to change drastically. At first, it is a major shock, but you learn to adapt and as time goes on you learn to live with it (diabetes)”. In my literature review, Hanas (2005, p. 206) explains that “in a Finnish study, all family members increased their consumption of skimmed milk, low fat cheese and low fat cold meats”. This adaptation to the family menu, to a greater or lesser extent, occurred in all of my respondents’ lives and eating habits. These new habits altered mealtime experiences, especially for the diabetic respondents at school.

The data suggests that parents try to “protect” their children and attempt to allow them to function in as normal environment as possible. Two parent

respondents actually used the word 'protect', with others using synonyms or phrases to suggest concern and protection. Children, the parent respondents declared, were all, without exception totally reliant on their parents at the time of diagnosis.

Testing blood sugar levels and administering insulin become the parents' job and they all took responsibility as the child's life is literally in their hands. The early stages of the disease, according to the parents are the "most difficult weeks or months of one's life. Your life changes inexplicably, "especially my child" retorted one respondent. "At 21 months she could not tell us whether she was hungry or thirsty or tired. We "felt our way for the first two years". "Unfortunately your other children, if you have any, suffer the consequences the most, you neglect them and the diabetic becomes your 'only' child". She becomes your "whole life", reported one respondent. As mentioned previously, professional counselling for siblings, says Flynn (2005, p. 12) in my literature, is an important source of assistance for them, a statement that this parent respondent concurs with. Also, it is helpful to make "dates" with your other children says one respondent. This keeps that personal contact between you and the other siblings and they are continually made to feel special. Furthermore, marital conflict due to the new felt tension and adaptation of the new found situation, says Flynn (2005, p.69) can cause new conflict within the family. Despite Flynn's views, none of the respondents alluded to conflict between the parents as being caused by the pressures of managing a diabetic child in the home.

Communication with the child and control of the disease is a critical issue. When a strict management plan is adhered to, generally weeks can go by without a negative diabetic-related incident. This was supported by one respondent who stated that "diabetes is a fickle disease and the slightest cold and your blood glucose levels go haywire. Even before any symptoms of a cold, there are major sugar level fluctuations". Another parent respondent noted that anxiety and stress levels rise because you "do exactly the same routine and dose the same, but there is no correlation between the two actions".

The child's weight and growth also has an effect. During a growth spurt, the food and insulin intake changes. The child eats more and the "normal" dosages are no longer good enough to maintain decent blood glucose levels. Dieticians and health management teams at clinics may be consulted to regain an "acceptable balance and normal readings", as one respondent puts it.

Respondents also comment on the weather and climate being a factor that influences blood glucose levels which may have physical reactions by the child. One parent respondent was of the opinion that on the West Rand, in the Free State and at coastal areas, his child's sugar levels were good and remained quite stable. However, in areas like the "bushveld" and on the East Rand, his daughter's sugar is erratic. Also, he states that when having been on the East Rand, her skin will definitely and without doubt itch on their return to the West Rand. Hanas (2005, p.311) states that there are times when skin irritations and dehydration takes place, "itchiness as well as dehydration often occurs in the life of a diabetic" (*ibid*).

Summer and winter conditions also interfere with the child's levels of blood sugar and this becomes problematic and produces irritability. All the parents are concerned with the effects of low glucose levels in the blood and the dangers of long term effects and what that would mean for their children.

Different foods, including proteins, which are meant to have little effect on the blood glucose levels may also present a problem. For instance, one parent respondent stated that if he gave his daughter "beef, liver or viennas" she would be fine, but that "after one Russian sausage" her blood sugar, even though she is eating a protein, "goes through the roof". Only this one respondent reacted to a protein, albeit only this protein (which does contain a high fat content) so negatively. As has been discussed before, Noakes' (2012, p.2) high fat low carbohydrate diet might not suit this diabetics' meal needs and high blood sugar levels may be the result if this diet were followed by this specific respondent. One parent respondent noted that not all proteins then are "equal" in terms of their effect and one needs to find out for oneself how one's child will react to the different foods he or she eats.

Given the work and effort that goes into the management of a diabetic child, one parent respondent conceded that the disease can consume one's life: "You think of nothing else-when you wake up, you manage it, when you go to bed at night, it's the last thing you think about. But if you manage diabetes correctly", he continues, "through trial and error, you can eventually get a good balance (of blood glucose levels) that are in an acceptable ranges". Another parent respondent agrees with this sentiment. "To manage diabetes one just needs to govern and monitor food and insulin correctly. If this is done then your child can live a relatively normal life without complications." No wonder that the same respondent also commented that the parent of the diabetic child has quite a "tough time because her child always relies on her to have a plan to ensure that her child is properly cared for."

A general perception one gets in interacting with parents who have diabetic children is that the parents of diabetic children always need to be in control of the disease which includes testing and injecting regularly and which ensures "one stays one step ahead of it (diabetes) at all times". The parents also need to be prepared for high or low sugars and planning ahead for meals.

6.2.5 Summary of general findings in managing diabetes

To a large extent, the findings presented in this section indicate that all the parents and diabetic children needed to be involved in the management of the disease. An indication was the idea that good management practices by both these groups of people assisted in good blood glucose level control. From the data this researcher has analysed, it appears that the peers and teachers of the diabetic respondents do not have the relevant knowledge to meaningfully assist diabetic children during and after school.

This section of the research has also shown that most foods can be eaten in moderation by diabetic children and different foods affect the children in different ways. This corresponds with a common sentiment that a child must still be able to be just that, a child, and control diabetes as a secondary factor

to his or her life, although planning is essential if proper control of blood glucose levels is to be maintained.

In addition, all the learner diabetic respondents commented that communication and control was key to their success at school, as well as help from parents and other adults. There is never a day off or free time from this disease, only that it can be managed successfully when responsibility is taken and help is at hand at school and during sports activities.

6.3 Diabetes and its effects on learners' self-image

The self-image of children in general in schools across South Africa today is an important aspect in the process of growth and growing up amongst children. In this section, I will analyse the different areas of self-image that may affect the diabetic child and the respondents' perceptions of these areas. Self-image in the school environment is discussed while being mindful of the fact that diabetes mellitus is a chronic disease.

6.3.1 How diabetics view themselves

One female respondent commented that developing diabetes and dealing with it is much more difficult for a female than it is for a male. Firstly, she says, "girls are far more self-conscious than boys are, and girls want to look pretty. If you use an insulin pump, it is almost impossible to hide it and it sticks out like a sore thumb". This is especially difficult she says "if you happen to be a big girl". Similar to this view, Silverstein et. al (2005,p.18) comment that as a result of "poor diabetes control a delay in pubertal and skeletal maturation" can occur. This means that the diabetics' normal growth functions may be interrupted or worse, affected permanently. None of the respondents, diabetic or other, commented that this had become a problem as yet.

“Boys”, says one parent respondent, “are not as worried about their appearance and testing and injecting”. For this parents’ son, it has never ever been a problem. She said: “My son has a lot of confidence and his friends all know about his diabetes. They don’t quite understand it though, and after he tests and injects, he becomes one of them again (the friends) and is unrestricted in all activities”.

One child respondent, a female learner, did not exhibit as much confidence, and refused to use a pump because it “sticks out under your clothes and makes you look funny”, she said. Her mother exclaimed that “boys thought she was a freak and wouldn’t have anything to do with her or her ‘machine’”. In this case, it looks like either way, you can’t win. If you inject or if you use a pump, you are not seen as a normal looking person to others who do not understand the disease,” she concluded.

“Girls want to diet, well, my daughter does”, says one parent respondent, “because she is a big girl, she wants to be thin. The media also plays a part in the way a girl should look. There are many expectations”. One respondent commented that one, especially females, cannot ever wear what is advertised by clothing and fashion gurus. This parent respondent argued that girls “want to improve on their looks more than boys”, and having diabetes with all its “issues” (injecting, etc.) restricts a female. Of the above issues mentioned, only the females were affected. None of the male diabetic child respondents had experienced these issues that I have highlighted above. Silverstein, et. al (2005, p.18) however, comment that nutrient recommendations are based on requirements for all healthy children. Such nutrition recommendations are meant to guide both sexes of children and adolescents to eat more healthily.

6.3.2 The effects of Peer pressure and social norms on the diabetic child.

Having diabetes is definitely not the norm and makes one feel “different”, according to most of the respondents. Difficulties occur when it comes to

food. At parties, the diabetic child respondents all said, is when life is most difficult. When everybody is having a good time and eating and drinking, the diabetic child has to monitor the intake of food and drink that could spike blood glucose levels. Especially, as one diabetic respondent says, when “you hate testing your glucose levels and injecting insulin because of what others will think and say. The choice we as diabetics have then is to risk having higher blood sugar levels and eating as everyone else does or not eat and miss out on one aspect of the party”.

The everyday norms that people take for granted as being the “done thing” are not the same for a diabetic child, there is no “day off” so to speak, but there is a place for a “treat here and there so long as you don’t overdo it”, comments one diabetic child. The diabetic respondent who had admitted to cheating (not covering food with insulin administration) said that he did so because he never felt the effects of high blood sugar levels. Another diabetic respondent did so because she did not inject in front of others and did not eat at a party. Both had completely different reasons for not testing and injecting and both know that acceptable blood sugar levels need to be maintained for optimum health, yet both are either unperturbed by this fact or need to be assisted in a new management process. As Silverstein et.al (2005, p.18) earlier commented in my theory review, the idea for diabetics is “to maintain a stable blood glucose level.” If this is the case, one can argue that the diabetic respondents need to recognise the need for maintaining acceptable blood glucose levels and applying effective management programmes for their own specific lifestyles in order to remain healthy.

6.3.3 Teacher support and/or prejudice on diabetic children

From the analysis of data in my research, the diabetic children respondents have made it clear that they do not receive much teacher support due to the fact they say that their knowledge concerning the disease is exceptionally limited. Engelbrecht et. al (2001, p.1) argue that “an appropriate schooling system has the capacity to provide appropriate ways and means to facilitate

learning and meets the needs of all learners, including those with disabilities.” (2001, p.1)

“Teachers never really know when I’m low and don’t understand that carbohydrates will make my blood glucose levels rise, not only sugar and chocolate”, reports one child respondent. “It would really help if teachers went on a course. Not all, but some teachers do not understand my needs” he explains. “When I, as a diabetic person attend a school disco for example, then there is nothing available on sale for me to drink or eat in terms of what is acceptable for us as diabetics.”

Another diabetic learner responded that “teachers, if they know anything about diabetes, only have very basic and limited knowledge. Basically, teachers do not know how to support diabetic children and would never be able to cope in an emergency situation”. This finding resonates with Swart et. al (2002, p.183) who indicated that in one study done in South Africa, “it was concluded that South African teachers have a definite lack of knowledge about issues relating to barriers to learning.”

Children with diabetes need to have a strong support network at schools across South Africa. Swart et. al identify, on the level of management systems, due to “a lack of educational and teacher support, insufficient facilities and infrastructure” (2002, p.183) this affects the well-being of children in our schools that suffer from all types of chronic disease in South Africa.

6.3.4 Physical activity and the body of a diabetic child

Hanas, (2005, p.247) states that exercise and diabetes go well together. It is one of the key components in the life of the diabetic child. Diabetics can and should take part in all the physical education classes at school (so long as there are no emergencies with blood glucose levels) and they should also be encouraged to do sport whether at clubs or at school. It (sport and exercise) is a great leveler, as 80% of the children respondents felt most at home when

doing sporting or exercise routine activities. Hanas (2005, p.247) comments that being active is “especially beneficial for the diabetic child and adolescent, who for some reason tend to be more physically active than their friends without diabetes.”

The level and intensity of the physical activity being performed will influence glucose levels as the more heavily one exercises, the more energy is needed to perform. To prevent de-hydration and hypoglycemia, water and a snack should be easily accessed for the diabetic.

It is always better, says one parent respondent, to have a little higher glucose level before physical activity or sport as a precaution. Blood glucose levels need to be checked before and after exercise and coaches, parents and teachers should be a little lenient to food and drink intake during sports / physical activity.

“During sports is when I feel most normal. I just need to remember that if I feel low, to replenish my energy levels with a bit of sugar or a snack,” says one child respondent. When doing sport, this respondent felt completely in control of his life because he competes on equal terms. “No one sees him as different, especially if he excels. It makes him feel good about himself,” reported one parent respondent. According to Hanas (2005, p.247), an hour or so of sport is sufficient and all the diabetic respondents feel that all diabetic children should be encouraged to take part in Physical Education and sports at school.

According to a child respondent, exercise lowers his sugar and as a result may even mean that a snack can be consumed without the extra need for insulin. Hanas (2005, p.254) comments that “when dehydration occurs during this time of physical activity, the skin will begin to itch and become really flushed”. It is a signal that blood sugar is low and the coach / teacher must be on hand to be able to remedy that occurrence with an energy drink of sorts to prevent hypoglycemia. Also, another benefit to doing sport and exercise, says Hanas (2005, p.254) is that “exercise will tend to lower the

overall blood glucose levels in the body” but he also warns that “exercise cannot and must not be substituted for insulin at mealtimes.”

In terms of control, the balance of the blood glucose levels must be closely monitored by the coach / teacher in charge to prevent the child from passing out. “Exercise can never ever however, replace insulin just because it may keep your blood glucose levels lower,” commented one parent respondent.

6.3.5 Summary of general findings associated with Self Image

A child’s self-image is a delicate balance between self-confidence, how they perceive themselves in a group and fitting in with the other children. “Being different” physically need not impact on how these children function and develop at school, socially or emotionally. Their attitude as a diabetic to this disease goes a long way in determining their own self-image as well as what others think about them.

Peer pressures that diabetics have experienced are often subtle, such as the problem of food consumption at social events or parties which has not been covered by insulin and the child forgets to administer insulin or simply chooses not to. This leads to high blood glucose levels. The needs of the diabetic learner are sensitive and appear to be neglected by others quite regularly.

The above statement suggests that teacher and peer support is extremely limited for the diabetic child. The children’s protection and safety concerning this disease may not be in great supply for him or her, in the sense that teachers, coaches, peers, friends and caregivers cannot cater for the children’s needs in or outside of the classroom.

As discussed, during physical education lessons and various sporting activities after school, diabetic children tend to hold their own so to speak and the everyday concerns and management practices needed to control their diabetes are not foremost in their mind, albeit for a short while, as they enjoy these activities with peers, teachers and coaches.

6.4 Prejudice and support of diabetic children

In this section I will examine how diabetic children are “treated” by others in general. During curriculum activities, the practices that a diabetic child would need to expedite in terms of checking blood glucose levels throughout the day and the access to other management processes at school will be analysed. The diabetic child’s ability successfully and independently to control his or her situation in a classroom may be influenced either directly or indirectly by the treatment he or she gets in the classroom by various people. Support or the lack thereof will either help or hinder this process.

6.4.1 Discrimination of diabetics by peers, and the effect it has on their emotional well-being

The initial thought that one learner respondent alluded to was the cruelty of children in general. “There are some children who blatantly call me a freak and tell me that I am different to them or not normal”. Knight (1999, p.1) argues that “special needs education is a type of education that merges inclusive education and social inclusion, within broader epistemological principles.” The Universal Declaration of Human Rights declares “that education should promote understanding, friendship among all racial and religious groups.”

In South Africa, reluctance to attend school by diabetic children appears to be on the increase as anxiety manifests itself in the form of “excessive worry about their own competence and future events.” Flynn (2005, p. 62). Flynn continues that children (diabetics) who are “highly anxious or angry will tend to feel more humiliated when things go wrong.” She adds “that poor bladder or bowel control is one of the most humiliating experiences children with diabetes can experience when they accidentally wet or soil their pants.” The future humiliation through teasing may adversely affect the diabetic child’s life indefinitely.

Children who suffer from diabetes may need to test their blood glucose levels urgently throughout the day at any place or at any time. This exposes the diabetic child, and “opens them up to ridicule”, comments one parent respondent as the accusations “one has to endure are often drug related, with snide remarks and hurtful words like ‘abnormal’ and ‘druggie’ describing you.” Flynn, (2005, p.22) states that if children with diabetes meet with such social disappointment “they become depressed and lose interest in living. They may even feel suicidal.”

Many children, after witnessing a diabetic respondent ‘test and inject’, for the first time, did not want to associate themselves with her, commented one learner respondent. She then decided that at school she will simply not “have diabetes”. She eventually changed schools and is now at a home schooling centre as a result of the children “picking” on her and telling her that she was “different”. Migdal (2008, p.1) argues in my theory that “our schools are supposed to prepare us to enter the real world.” The reactions of this respondents’ peers are inconsistent with what Migdal (2008, p.1) states is acceptable in the treatment of our fellow humans.

“It’s different at the school where I am at now because I don’t check sugar, I don’t eat at school,” reports one learner respondent. This attitude could have severe consequences for the diabetic child if her blood sugar levels fall and she has no energy or too little sugar in her blood to remain conscious. She continues that she “tries not to let anyone know that she has diabetes” unless she has no option because her glucose levels are so low that it becomes dangerous. Only her best friend knows and is the only one capable of helping her if there is an emergency.

The behaviour and attitude of the diabetic child displayed above is a direct result of what happened at her previous school. “If I have to check, then I will go to the bathroom or something”. She says there is not much that the diabetic children can do. “I have to inject something at school that everyone else’s body manufactures. It’s only a small thing, but the problem is that I need to be able to keep up to date with my work so that I don’t fall behind. The other children are cruel”. One diabetic child responded that she had been

reported to the deputy principal as well as the principal by the leaders because when she had to inject herself with insulin, they thought that she was “doing drugs” as she puts it.

One female learner recalls that when rumours of her “drug addiction” started doing the rounds, she was kicked out of class for doing drugs as she was injecting one day. She indicated that “people have no clue”, that they don’t understand she needs to function in class and she should be able to test and inject anywhere and at any time so that she does not miss out on any teaching being done.

Another learner respondent says that many rumours about him started one day when he injected insulin to “cover” his school lunch. “People came up to me and asked me if I was doing illegal substances at school”. Only my friends know the truth and I feel it is impossible to clear your name once the rumours start”.

Possible misinformation from other learners and the pre-judging of peers who have diabetes mellitus is a problem that these diabetic children live with and experience every day. Testing blood glucose levels for them is a problem and an emotional experience for some children as they are continually ridiculed and accused of wrongdoing at school. Kübler-Ross (1969, p.1) in her study of the grief cycle states that a “person has to complete the entire grief cycle so that acceptance can be obtained”. However, the pre-judgement of peers with diabetes may prevent the completion of this cycle and as a result the diabetic may be “stuck in the cycle and not be able to progress until a specific stage has been passed through.” Kübler-Ross (1969, p.1). This is extremely harmful and the diabetic may now even be affected physically as testing blood glucose and injecting stops due to the ridicule of other learners.

Correcting misconceptions about diabetic children is possible for the teacher and the peer (friend) to do in the classroom. The child must be told that he or she had done nothing to “deserve” contracting the disease. The child must be reassured as often as possible and the feelings of guilt must be allayed.

Dealing with the feelings of the diabetic child is imperative as the child then feels secure and loved.

6.4.2 Discrimination against the diabetic child by teachers due to insufficient / lack of diabetes knowledge

During class time, it is extremely frustrating for them (the diabetics) when teachers ask diabetic children to leave their classroom during teaching time because a child has to have a snack to ensure sugar levels remain constant. Also, misbehavior has been misinterpreted due to a low blood glucose level when children need to react to it and action is taken (eating). “Insubordination” is a word used by a teacher when a child was injecting during an explanation of work by a teacher during a lesson.

In the Draft Policy of White Paper 5, it clearly states “that schools need to be supported and will require appropriate district as well as school-based support services” (DoE, 2001, p.4). The lack of knowledge presently experienced in public schools needs to be addressed by both the district offices and the schools themselves. A needs analysis must be done and the specific areas of lack in this regard must be identified and then combined with information supplied by the counsellors at schools. A team effort needs to be made with the schools and the districts and programmes set up to assist in this regard.

Because of a lack of knowledge, and as one respondent described it, ignorance, teachers who struggle to keep control during lessons are more prone to complain about the justified actions of a diabetic child in their class during teaching time. “Not enough is known by teachers who lack the basic knowledge of assisting us diabetic children during an emergency. Even during routine testing and injecting, teachers do not know what I am doing”, responded one learner. When diabetics (who often need a toilet break, more than other children) ask to be excused, teachers often do not permit them to go to the bathroom. This causes unnecessary discomfort for the child and levels of anxiety are raised.

6.4.3 Needs of the diabetic that are met by teachers and peers

“Only a few friends, usually two (2) at the most, are able and willing to help with my diabetic needs”, says one learner. “If your child is confident”, said one parent respondent, “then you have no problems. My child tests and injects at any place and at any time and his friends all know about his diabetes”. This child has no problem with his routine and his actions taken during class time or anywhere else as he “tests, injects and goes on with his work or play”, explained one respondent teacher. This teacher further revealed that she has “had the experience of four (4) diabetic learners in her care previously and all have been very different.” She gauges each one and responds accordingly with any assistance required by the learner.

Some teachers know the basics about being diabetic. This obviously helps the child. They (the teachers) who do have this knowledge are able to recognise unusual behavior. (By this I mean a low blood sugar reading as well as high blood sugar dangers). All diabetics at some point probably need some assistance, even those who independently perform blood glucose monitoring, especially when experiencing low blood sugar glucose. Engelbrecht et al.(2001, p.5) suggests that the “team approach involves all stakeholders (parents, teachers and caregivers) and planning then takes place and professional in-service training seeks help and resources to sustain active learning.”

One learner respondent commented that “a teacher or a classmate who knows how to assist me when I have a low blood glucose reading after testing helps me in preventing me from a possible seizure which has happened to me before.” This can be complemented by teachers who allow (and assist) diabetics to test and inject in the classroom, thus providing the child with a safer environment in which to do so, as well as preventing time spent out of class. “I honestly wouldn’t mind testing if I was supported by the people around me at the time,” reported the diabetic learner. Possible improvement of levels of blood glucose control can be attained as well as a decrease in the risk of long-term complications. When this is done, the diabetic child feels that he or she is being treated as any one of the other

children in the class which allows for less time spent out of the learning environment.

There is a definite advantage for this child as recognising and preventing hypoglycemia is increased. Also, “when I test I like having my best friend near me, and I cannot have her close if she has to stay in class when I go to the bathrooms to test,” commented a diabetic child. “What happens if I lose consciousness in the bathrooms? I am helpless if this happens,” she concluded.

Another respondent held true that he thought “that teachers can assist me by providing easy access to my insulin as well as allowing me to test during class time.” Also, as one respondent teacher added “the permission granted to diabetic children to drink water and have a snack to ensure they manage their diabetes correctly, ensures good diabetes management practice, which is something these children strive for.”

One learner respondent suggested allowing diabetic learners extra time, when affected by blood sugar variables, “to make up on missed homework or tests, which happens to be law in the United States of America”, she concludes.

6.4.4 Summary on the discrimination of diabetic learners and the effect it has on their well-being

Diabetic children at school need to be allowed free and unrestricted access to the restroom and to liquids and snacks when necessary, according to a parent respondent. The more knowledge one has of the disease as a friend or a teacher, the more assistance can be applied to help the diabetic learner. Diabetic children often become frustrated at school because of the following reasons quoted by a learner respondent:

- “I am often ridiculed at school when I test
- Some people call me an addict

- If I need a snack or a drink I am often ignored and have to wait till later
- Bathroom breaks are not always allowed to be taken
- I don't feel comfortable testing and injecting in class"

Children and teachers who do not understand the disease and lack the fundamental knowledge, tend to ridicule and label diabetic children. Communication and knowledge are key to educating the other learners so as to provide enough information so that the diabetic child is protected. The circumstances under which the diabetic has to manage and control his or her diabetes and the actions that are taken by them to determine acceptable / non-acceptable diabetes "control" in the classroom is already challenging, without added unnecessary stress.

Acceptance of diabetic children by teachers and peers is key to the confidence the diabetic child has in the classroom and the barriers that are broken down as a result can only have a positive influence on all concerned and assist in the process of education.

6.5 Knowledge and awareness of diabetes

Generally there is a limited amount of knowledge that is shared and known by the general learner at most schools. In fact, according to diabetic children, if one of your classmates has not been exposed to someone with the disease, the chances are that he or she will have no knowledge of the disease at all.

It is a chronic disease not referred to in the curriculum and a silent killer that people ignore. As it is not a "visible" disease, the diabetic children are basically isolated by it. A teacher respondent commented that what is most important for the diabetic child in and outside of the classroom is the support that he/she receives. Assistance for the diabetics in many different forms in their management processes produced the desired results.

6.5.1 Knowledge and general awareness of diabetes by the diabetic child's teachers

Teachers are the most important part of the link between other children in the classroom and the diabetic child. The teacher deals with most of the trouble shooting and helps with assisting the child with diabetes deal with coping mechanisms which includes “bullying” of the diabetic children. In confirmation of this position, one learner responded by saying: “Allowing me to talk to the rest of the class about my diabetes helped me relate my story to others. Not that they felt sorry for me, but that they began to understand what was happening when I tested and injected”.

Flynn (2005, p.68) states “that the responsibility of the teacher after being informed about a diabetic is to have good sound communication with the diabetics’ parents and liaise often with them and also, most importantly, to provide a supportive learning environment for these diabetic children.” This action requires knowledge and insight as well as sound planning. It would also spread the workload throughout the grade. By treating the child normally and allowing others to do the same Flynn’s suggestion (2005, p.68) allowed the scenario below to occur.

“I felt that some of the bullying I had experienced stopped. The other children were not embarrassed (and neither was I) when the time came to “test”, commented one learner respondent. The opportunity afforded the child by this insightful teacher broke down some of the barriers that the diabetic had experienced in the past. It helped the child find new confidence to “walk tall”, with his head held up high and also informed others that his condition was manageable and under control. This indicates that all the diabetic learner needed was some understanding from his classmates.

6.5.2 Knowledge and general awareness of diabetes by the diabetic child's peers

Children need to be encouraged to have friends, and to have fun with friends. The diabetic children at a school often felt excluded and “left out” as a result of the other children claiming that they are “abnormal”. In the literature review I indicated that “a classroom needs to be democratic and socially inclusive to the extent to which it involves all students as equally valued members of the school community” Knight (1999, p.2). The lack of understanding and tolerance that this respondent experienced at school exhibits clearly how the lack of knowledge influenced the actions of the other non-diabetic learners to their “friend.”

Another diabetic learner further reported: “Connecting with other children at school who have diabetes helped me realise that there are others out there that experience what I do and that we are not alone.” This means that at schools a buddy system helped diabetics make contact with each other and help one another share some of their ideas. They had the opportunity to try different methods of managing their diabetes. “To share knowledge and ask other kids with diabetes about it really helped me realise that this disease could be controlled in class during lessons as well as on the sports field,” commented one diabetic learner. Another learner respondent commented that, “I could eventually share some of that anger and frustration with someone else and they would know what I was talking about.”

Often though, friends who helped the diabetic children the most were non-diabetics themselves. Feelings of sadness and hopelessness are common for the diabetic child and feelings of guilt when “cheating” on an eating plan can take its toll. These feelings are real for the diabetic, yet when they have a dependable friend it helps during a classroom session or on the social front. “My friend is the only one who I can trust and who supports me. Without her I would be lost,” claimed one learner respondent.

6.5.3 The impact diabetes has on the diabetic child's academic performance, school outings and tours

“Hypoglycemia can impair a student's cognitive abilities and adversely affect academic performance. Sometimes its symptoms are mistaken for misbehavior” (<http://ndep.nih.gov/publications/PublicationDetail.aspx>).

“There were times”, commented one teacher respondent, “that I believed the diabetic child in my class was genuinely misbehaving. I soon realised, albeit erroneously, that his blood sugar was low. Now when this happens he tests himself and manages the glucose reading accordingly. It always solves the problem.”

According to one respondent her child's sugar levels, “if monitored and are kept stable and at acceptable levels, should pose no problem to academic and educational growth. My daughter actually copes better in the classroom and in different learning situations when her sugar is slightly higher than normal,” expressed a parent respondent. This researcher discovered that different individuals react differently to high or low blood glucose levels. There are learners who perform better on a higher blood glucose level and vice versa. The individual determines, over a period of time, which scenario suits him or her best.

Another respondent had a different view. “When my son learns for a spelling test and is low that night, then he cannot remember his words the next morning”. In the Curriculum and Assessment Policy Statement (CAPS) all children who suffer from a chronic disease should be able to, among other requirements, “work effectively as an individual or in a team and demonstrate an understanding of the world as a set of related systems and that problem solving contexts do not exist in isolation” (Pretoria, 2012 p.5). Ultimately then the diabetic children in South African schools need to be catered for because no two diabetic children behave the same way under the exact same set of circumstances.

One learner respondent has a better academic record on a higher glucose level and then could not concentrate when too low (blood sugar level), while

the other respondent struggles to keep concentration levels up when his blood glucose levels are too high. Low and high sugars affect different people in different ways and have different results. Concentration however is affected when doing the academic classwork or homework. “When my son’s blood glucose levels are high, he cannot remember doing that specific academic work. When he does a test, he cannot remember it and forgets to do two or three sums and when he gets his paper back has no recollection of it,” reported one parent respondent. She continues that “this affects his marks and his academic progress of retaining content when in the classroom, as well as when learning for tests and exams. When checking my son’s progress and then relating it back to the memory on the blood testing machine, there is always a correlation between that reading and poor academic achievement in the classroom.”

Children on school tours also have a problem controlling their blood sugar levels, especially if they are young. “When my child went on a tour, she just ate and ate. She had sugars of twenty (20) every time she tested. The teachers never had a clue how to help her,” retorted one respondent.

When in the classroom, diabetic children are marginalised. “My son, when low in class, is not allowed to eat a snack. He is also sometimes prevented from going to the toilet,” claimed one respondent. This practice is in heavy contrast to the fact that a diabetic person can urinate more often than a non-diabetic.

Teachers ignore children with diabetes and also seem to forget that they have the disease. Parent respondents claim that this is completely unfair and unacceptable as these children need to be “accommodated so as not to live under stressful and anxious conditions,” says one parent respondent. The only way to communicate and control diabetes in schools is to form partnerships with the teachers, parents and diabetic children. If the communication with parents and tolerance of children with chronic disease is not addressed, Knight (1999, p. 1) comments that as “the denial of rights seems to gain momentum these children will continue to be marginalised.”

There are other medical issues that affect the diabetic learner in the classroom. One is the fact that diabetics miss school due to their condition. Hanas (2005, p.315) comments in my literature that there “are many associated medical issues and problems that diabetics may experience as well as problems arising in the feet, fingers or lower parts of the legs.” Many diabetics have blood circulation problems, but probably the most common problem for children is when the normal childhood diseases strike or even the common cold or a bout of influenza. Keytones develop (as explained in my theory) and these have to be addressed first and foremost, together with the diagnosis of the illness contracted. “I have missed about a month’s worth of school days. When I was younger, my mom would keep me at home whenever I had keytones and was vomiting,” one respondent commented. He continues, “I can’t concentrate when I am too high or too low (blood glucose levels) and this affects my work in the classroom and my academics in general.”

Children with diabetes do tend to tire more easily and “can’t work properly” as one female respondent said. “Teachers moan at me that I am not concentrating and then I get in trouble,” reported another male respondent. This is a typical response to the depletion of insulin in a diabetic’s make up and the physiological results of the body manifesting itself in this way.

On a later tour in grade seven (7) “her sugar levels were much better and more regulated, she had matured a bit” said one parent respondent. Oftentimes when the child takes control of the management of his / her diabetes, there are better management results.

Parents and teachers (in class) differ and some are more rigid and stringent in their control than others. The important thing is to find a way to manage and control blood glucose levels and in so doing, create a good balance in one’s life as a diabetic child. “I have found that once my child had been on a camp for diabetic children, she become accountable for her diabetic management and this has allowed me as a parent to recede into the background and she is in control,” reported one parent respondent.

6.5.4 The impact sporting activities have on the diabetic child's daily performance

When one considers the reaction of the diabetic's teachers to the questions posed about the problem in the research, one can conclude that this is one aspect of the diabetics' life that is positive. All diabetic educators as well as doctors advocate that sport / P.E. is definitely a part of a diabetic's life that must be included as it assists in keeping blood glucose levels lower. Hanas states that "playing ball and riding a bicycle to school are ideal activities after diagnosis of diabetes." (2005, p.249)

Sport or physical activity must be managed, however, one needs to "ensure a little bit of extra food is packed for the day, as well as insulin and some Super C's" reports one parent respondent. Also, Hanas (2005, p.249) comments, that the diabetic child must not take on too much exercise. Moderate exercise is the best way of ensuring exercise can be enjoyed without any "catastrophic consequence". The child's peers must also be suitably informed to help monitor the diabetic's physical signs of hypoglycemia.

"Diabetes does not run my life. I ensure that I go into a game with a little bit of a higher blood sugar (glucose) level so that if I do drop a bit due to the exercise then I don't pass out or something," reports a learner respondent. He continues that "my coach looks out for me, because he knows about my condition. Not many people are able to assist me." Because there is no school nurse in most public schools in South Africa, the diabetic children need to be able to rely on the physical education teacher or the sports coach to monitor and recognise symptoms of hypoglycemia. Hanas (2005, p.311) states that one must "always remain hydrated during exercise" and furthermore "fluid intake should closely match exercise."

Children need to ensure that they remain hydrated and that the exercise is not to the point of over exertion. "Exercise does lower my sugar levels, but I must still take insulin. It is not a replacement for insulin," commented one learner respondent.

“My skin itches when I become dehydrated,” commented a learner respondent, “so I must remember to drink water at regular intervals during the exercise at physical education lessons at school or during a game”. Hanas (2005, p.311) also states that there are other major benefits to doing exercise for the diabetic child and daily exercise “ helps to keep weight down and also in the long term improves heart and blood vessel fitness.” As one learner respondent commented, she also wanted to be “thin like her friends” and this allowed her to and encouraged her to do exercise to control her weight rather than use fad diets that would affect her health now and possibly in the long term. As a result this learner respondent felt compelled to do some sort of exercise which, according to Hanas (2005, p.247), has many physical positive results for the diabetic child.

6.5.5 Summary of the impact of sport and physical exercise

Sport and physical exercise is an important regimen for the diabetic child, but the coaches and physical educators must have knowledge and closely monitor the exercise being done by the diabetic child. Ensuring that the blood glucose levels are controlled as well as allowing a snack and keeping the child hydrated are important aspects that the teacher or coach must keep in mind. Testing and injecting insulin is also important and the prevention of hypoglycemia is of the essence.

6.6 Reflections on diabetic management in schools in relation to Human Rights

An organisation for the control and management of diabetes has been vocal of late in relation to the management of diabetes and human rights. This organisation argues that “Children are vulnerable and, as such, require and are entitled to a specific set of Human rights guaranteeing special care and assistance in protection...in all actions concerning the child the best interests of the child shall be a primary concern” ([Non Communicable Alliance, 2013](#))

[p.1-2\)\(NCD Alliance\)](#). This provision for the rights of the child does not end when the child enters school. It is a provision that is supposed to apply in all circumstances and all areas of everyday life for everyone. This is so because the very nature of human rights is such that they are a lifetime entitlement. In the case of diabetic learners, the right implies that diabetic children in public schools are equally protected by the same. Furthermore, there are specific requirements and certain procedures that the diabetic child must include in his or her daily management of diabetes at school. In the data analysis of this work which I have just given above, it is clear that the treatment of diabetic children in South African schools is not consistent with the expectation contained in the Universal Declaration of Human Rights (UDHR) (The United Nations General Assembly, 1948). I explain some of these issues below.

The South African White Paper 6 on Guidelines for Inclusive Teaching and Learning (DBE, 2010, p.9) epitomises the situation most common in schools at present with the fact that “no two children are alike and all children can learn...this approach also provides information as to how specific barriers to learning present themselves... and how educators should integrate the learning experience.” This means that teachers need to create an environment where they assist learners in overcoming certain barriers to learning in the classroom. In this instance, diabetes is the barrier and the teacher needs to accommodate the diabetic learner by improvising and strategising with different teaching techniques so as to include the learner in all academic activities during class-time. This will ensure the full integration of this learner despite suffering from a chronic disease.

The document referred to in the preceding paragraph also provides suggested strategies for teachers involved in educating children suffering from diabetes. One strategy of significance to this researcher, is to “educate the class about the condition to reduce teasing” (Pretoria, p.98). This statement serves to confirm that teasing does in fact take place in the classroom. The reference to “reduce” teasing is one of concern to this researcher as this is a definite infringement on the rights of the diabetic learner in a classroom at a

public school in this country. The analysis of my data did indeed confirm that there were instances of diabetic children being the targets of marginalisation in the classroom and the document referred to above, at best, suggests that to simply attempt to reduce teasing is sufficient enough practice to assist these learners. Teasing, as it stands in the document appears to be advocated and almost allowed to take place but at a reduced occurrence.

The basic human rights of the child at school are not being protected and the teachers in *loco parentis* have not been properly trained or sufficiently informed in order to be effective in protecting the diabetic children in their care. One of the learner respondents in my research declared that she simply chose to ignore her diabetes at school to protect herself from possible abuse. This could have begun to affect her health in general because as a result she would not eat or drink anything at school, literally starving herself to avoid possible comments or ridicule from the other learners. My research also reveals other examples where teasing is evident to the extent where one of my sample respondents left her school of choice to attend a home school.

The view of this researcher is that positive and decisive action must be taken by the educators to prevent teasing and bullying if they are going to meaningfully assist the diabetic learners in public schools in South Africa at present. As such the basic human rights of children suffering from chronic diseases as stated in article 26 of the Universal Declaration of Human Rights are being infringed upon. (The United Nations General Assembly, 1948)

The World Health organisation promulgates that “people with diabetes have the right to education and information that can improve the quality of their lives...for example, because it is injected many people believe that insulin is a drug of addiction.” (World Health Organisation press release WHO/85 1998.) In my research, there is a specific instance of a female respondent being accused by classmates of narcotic activity and the consequences of this event adversely affected her at school. The lack of understanding and empathy by these friends of hers, according to this learner respondent, eroded her self- confidence and her self- image and her reputation never recovered. The reality is that the administration of the “medicine” diabetics

need to receive exposes them to ridicule due to the injections that diabetics need to give themselves to survive.

The documents that I have examined that are provided by the Department of Basic Education in order to supply the educators in schools across the country with skills and effective knowledge do not appear to provide that for which they were meant to serve. Children, according to the data analysed by this researcher are not protected from their human rights being infringed upon. As I have previously expressed with reference to article 26 in the Universal Declaration of Human Rights “everyone has the right to education,” (The United Nations General Assembly, 1948) which implies that understanding, friendship, loyalty and general goodwill to all persons should be readily accessible to all human beings.

6.7 Conclusion of data analysis findings

Diabetes Mellitus Type 1 or Type 2 in children specifically, has a profound alteration on the life of any child. In fact the entire family is affected because a whole lifestyle change is involved for the diabetic with regard to meals, outings, schooldays and other routines that need to be followed.

Despite the challenges that diabetes brings to oneself and family members, it is apparent that very little is known about the disease itself in general and also in schools by teachers, peers, admin staff and other parents. Just like with any human disease, the apparent lack of knowledge impacts heavily on the general school and academic life of the diabetic learner.

If one is not exposed to a diabetic in one’s daily life, that is, if a diabetic family member or a close friend is not in one’s midst, one does not have any contact or reason to be concerned with the management of diabetes, as it is “hidden” from anyone who is not directly involved. In other words, if one is not exposed to something the chances are that one is not aware of it and even that one may not actively take an interest in it. With regard to parents, teachers and peers directly connected to someone with diabetes at school,

this researcher has found that these people rarely realise the impact associated with this disease. In many instances life carries on as normal for a “healthy” diabetic learner but the consequences of ill management to restrictions of eating plans as well as the elements and certain areas of the country where blood sugar readings may be adversely affected, can detrimentally affect the life of a diabetic learner.

Academic results as well as self-image concerns can affect the healthy learning environment of the diabetic learner and the social environment at school can become volatile. As it was revealed in my findings, continuous low blood glucose readings can have a negative effect on levels of concentration and academic results. Sport and physical activity is the one area where the diabetic can excel and fit naturally into the environment.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

7.1 Research concluding remarks

This research focused on the management of diabetes in school going children. How children manage their own diabetes from a young age and into the teenage years is a delicate process as different aspects of the disease impact on the life of a diabetic. Added to this, as children grow up, there are stages of childhood and adolescence that must be passed through which hold different challenges for children at different ages. This researcher will briefly outline the main aspects of these management challenges experienced by diabetics and how lifestyle changes were experienced in the process of growing up.

Managing one's diabetes as a child does not mean doing so on one's own. It requires much planning by one's parents, teachers and other school personnel in order to obtain the desired results. It is argued that the "control of diabetes requires ongoing balance between nutrition, physical activity and medications in order to monitor blood glucose levels" ([National Diabetes Education Program](#), 2006, p.12.).

The diabetic must have an individualised management plan which is an integral part of diabetic management for the individual. No two diabetics respond to different food groups in the same way. Proteins, carbohydrates and fats make up the food intake of the diabetic and meal planning is essential. A human being reacts differently to different foodstuffs with more or less insulin needed to react with balancing the blood glucose levels as is appropriate for the body.

Monitoring of blood glucose describes the test done to measure the amount of glucose at a specific time. This is done four (4) or more times a day, usually before meals, sport and bedtime. Diabetics should be allowed to test

where they feel most comfortable and no restrictions should be placed on the individual. There should be minimal disruption in the academic and sporting life of the diabetic when this need arises. Many diabetics have felt marginalised as a result of the monitoring actions required and the self-confidence and self-image of the individual is affected to the detriment of the diabetic child. Children with diabetes should never be left alone during this process of glucose monitoring and the danger of hypoglycemia and the damage done to the child's self-esteem becomes a delicate issue for classmates as well as the diabetic learner. In South African public schools there is a lack of facilities for diabetic children to manage their diabetes and their actions need to be executed in the bathrooms or on the playgrounds of schools.

Thus there appears to be a definite lack of privacy for diabetic children to control the disease. The apparent lack of awareness of the disease by fellow learners and professional staff at schools in South Africa has resulted in the attempted masking of diabetes by these children and in some cases, even the blatant ignoring of the disease by those affected by it for the fear of being ostracised by fellow learners. The self-image of certain diabetic learners can be so low that the resultant effects of the lack of control so adversely harm these children that in some cases immediate action to restore optimum health is required.

The blood glucose levels of the learner respondents that I interacted with exhibited fluctuations in blood glucose levels during different seasons of the year as well as in different areas of South Africa. The blood glucose levels of these learners appeared to be more stable in coastal regions and other areas that are surrounded by large bodies of water like the ocean, lakes and dams.

When a family goes on a vacation or a school tour is planned, scenarios of blood glucose fluctuation levels need to be taken into consideration and planned for accordingly. A child with diabetes impacts on outings and family vacations. The diabetes of one child affects the entire family and sacrifices

for everyone are inevitable. Siblings and parents have to accommodate the diabetic person concerned and resentment may result.

The diabetic child, as well as other family members, may feel isolated, guilty, fearful, anxious, depressed and perhaps even embarrassed when dealing with the diabetic learner's disease. Feelings of resentment may surface from siblings and the diabetic child may even feel responsible for "causing concern or problems" within the family unit.

In South Africa there are no laws to protect diabetic children although diabetes is considered a chronic disease. In the United States diabetic children are considered "disabled and it is illegal for schools or daycare centres to discriminate against children with disabilities" (American Diabetes Association, 2003, p.1). As a result, learners in South Africa are not given extra time to compensate for lost time in the event of a learner going for a self injection in the process of writing an exam and academic results are final.

The above is made worse by the fact that diabetic care centres at school for learners who suffer from the disease in across South Africa are yet to be established and implemented. As a result "the child's immediate safety, long term well-being and academic performance" is adversely affected (American Diabetes Association, 2003, p.1).

Children with diabetes may feel frustration and become emotional as a result of their condition. It is a continual cycle of blood sugar monitoring, insulin injecting and diet control with no time off from the disease to enjoy a "break". This, together with bullying and teasing experienced at school, left at least 80% of my respondents with feelings of anger, frustration and resentment. Unfortunately the lack of understanding, communication and information concerning the disease renders the diabetic child exposed to harmful emotional and psychological attacks on them.

The combination of the problem described above, together with being emotionally misunderstood, often leaves the diabetic learner at schools in

South Africa unable to properly and effectively deal with this chronic disease at all levels.

Policy documents in official governmental department publications simply mention strategies for teachers and caregivers to follow in order to take care of diabetic children at schools in this country. The challenge remains that no training for this disease is provided for by the Health or Education departments in South Africa, no monitoring mechanisms are in place and as a result teachers continue to be ill equipped and/or uninformed about diabetes.

There are no private areas where a diabetic can monitor blood sugar readings in public schools in South Africa and no professionally trained personnel (nurses) to assist diabetic learners. The result is that these children are often labelled as “drug addicts” (due to the process of injecting) or the total avoidance of diabetics to treating their condition due to teasing and or bullying. Emergency situations due to a lack of insulin administration (hypoglycemia) could result in seizures, diabetic comas or even the death of a diabetic child.

Concentration levels wane as mismanagement of the disease occurs and academic work then suffers. This adversely affects ongoing academic progress and in certain cases loss of contact time with teachers due to sick days or hospitalisation. Furthermore, a lack of insulin aggravates the child’s ability to execute academic work which leads to irritability and fidgety behavior. This can be perceived as a lack of respect for teachers or as acts of misbehaviour. Intervention with understanding must be practiced by a person in authority.

Simply stated, there is no appropriate area for diabetic learners to exercise correct and effective management of this disease. Official Education Department policy documents state that knowledge acquisition must occur and understanding with compassion and empathy must be realised by teachers, sports coaches, counsellors and classmates. However, no direction

or courses are provided for by the Education department for diabetes education to occur.

The gap between documentation and reality are far removed from one another. This results in diabetic children mistakenly blaming themselves for their present situation with a lack of management of the disease as an outcome. Routine blood glucose monitoring and insulin injecting is affected and serious fluctuations of spikes and troughs result in the blood glucose readings. The diabetic learner often feels alone and marginalised as he/she does not feel “normal” and then begins to isolate himself/herself from the other children. The resultant psychological stress adversely affects the body and derails correct management of the disease. To assist in the management process, healthy low carbohydrate, low G.I. foods have to be included in the diet of the learner to help control blood glucose. Sufficient vitamins, minerals and nutrients must always be part of the nutritional make-up of the diabetic’s diet.

Long term, continuous negative diabetic management results in the degeneration of cells in the body with associated diseases connected to diabetes further negatively influencing the health of the learners. The reality of this situation spirals into further mismanagement and in some cases a total breakdown in the control of the disease. The burden then becomes too great for the individual to bear. This scenario may play itself out during the pubescent years while changes of body shape and hormone surges are present.

As children become teenagers, their metabolic rates alter. The technological age has reduced the amount of exercise both in children and adolescents. This produces a further challenge for the diabetic individual who is inactive. Active children appear to have fewer high blood glucose readings and thus are able to reduce their insulin intake.

This work is significant because this area of study is under researched. Although there are new diagnoses every day, there is poor policy focus on the subject. There also appears to be little support in schools for Senior

Management Teams especially. There appear to be no safe places to test and inject as well as minimal support emotionally or psychologically for children who need this type of support. Knowledge concerning diabetes and the management thereof at schools is also limited.

With this in mind I have the following to recommend:

7.2 Significance of the research and Recommendations

This work and the results it has generated are very important for the management of diabetic learners in schools because other than simply considering the problems from the side of school managers, teachers and district officials, this study has revealed what it means to live the life of a diabetic learner in current school environments. This area is largely under-researched despite the increasing number of diabetes cases in schools. With this understanding the recommendations below apply.

One of the most important factors influencing one's diabetes is that of self-management. Following on from this, the knowledge one extracts from life's trials and errors of diabetes is ensuring that one learns as much as possible about this chronic disease. This way, the diabetic sufferer leads a relatively normal life with minimal disruption of school attendance. Also, the more knowledge a diabetic has of this disease, the more understanding and control he or she acquires as time goes by.

There are several important advantages of this newly acquired knowledge concerning diabetes mellitus. Firstly, the role of the diabetic is to follow a healthy eating plan in order to gain control of his or her weight while introducing or continuing with an exercise regimen. The role of the diabetic learner includes a diabetic management plan. Monitoring blood glucose and injecting insulin should be done in any environment in which the child feels safe. A "safe zone" for those specific purposes consisting of an equipped room including refrigerated facilities for insulin and in privacy should be provided for the diabetic learner at public schools in South Africa.

Specific roles for teachers, physical educationists, sports coaches, counsellors and school management should be procedural to assist diabetic learners. Courses on this chronic disease with levels of knowledge appropriately supplied on a need to know basis must be available for all to attend. For example assisting with basic management of the disease and recognising symptoms of hypo- and hyperglycemia are essential for classmates. Knowledge of administration of glucose testing and insulin injecting are applicable for teachers, classmates, coaches and school management teams.

Large scale testing and screening of blood glucose levels typical of those in other countries around the world should be done in South African public schools to determine the extent of children living with diabetes who are at present unaware of their predicament. To assist in post diagnosis, mobile diabetes clinics, especially in rural areas where doctors and nurses are unavailable need to be in operation to assist newly diagnosed learners.

Diabetic learners should be given the opportunity at school to share information formally and informally with their peers. This information will provide understanding for non-diabetics and perhaps relieve the stress and anxiety of the continuous management of the disease for the diabetic child. The liaison of teachers and parents with regard to general management of their diabetic children will provide dialogue between the two parties and provide information for emergencies. If school personnel have an understanding of the requirements of the diabetic learner, risks of hypoglycemia diminish and the control of stable blood glucose levels are established.

For the peace of mind of the diabetic child at school, the more “normally” he or she is treated at school, the less pressure there seems to be on the diabetic child. Acceptance by peers affords these diabetics the opportunity to form and maintain friendships that are necessary for socialisation in their lives.

Diabetic children’s camps, where everyone is monitoring blood glucose and injecting insulin as part of their diabetic management programme levels the

playing field and is necessary for the diabetic learner to understand and feel that he or she is not alone. These camps enable these children to be part of and share valued information with others in a similar predicament to their own and involve others who can positively assist them and who are non-judgmental.

This action helps the diabetic child develop confidence in a lifelong journey and the assistance the individual receives and the exposure to people who have specific expertise is invaluable to these learners. Joining a website for diabetic parents and learners is another valuable opportunity for people who have some connection to the disease to share and receive information.

At public schools in South Africa, the detailed information sheets supplied to the parents of diabetic children should include the specific management plan of the diabetic learner as well as detailed contact information of the parents, the child's professional diabetic management team consisting of the child's endocrinologist, the diabetic educationalist and emergency action details for hyper/hypoglycemic episodes.

The actions of the school should include the provision of supportive and capable learners to assist the diabetic, quick access to diabetic supplies, and the immediate availability of at least one member of staff in times of emergency. The diabetic must ensure that snacks to combat low blood glucose are readily available and easily accessible in their school bags.

Reasonable timeframes to catch up on missed schoolwork, assignments and tests should be afforded to the diabetic learner. The awarding of extra time and the opportunity to re-write tests and exams must be explored if the diabetic child has had a hypoglycemic episode during same.

The dignity and preservation of the basic human rights of diabetic children should be a mandatory given in order to preserve and uphold article 26 of the universal declaration of human rights. One of the major findings that this research has revealed is that diabetic children are not protected by the policy statements that are meant for that very end. Specifically, learners in schools across South Africa have not been properly catered for due to the lack of

adequate inclusive methods related to the management of diabetes in schools.

7.3 Reflections and challenges on the research process

During school hours the academic teachers are the most important “care-givers” to the diabetic child. There are few nurses in public schools in South Africa so the role of the class teacher as a substitute for a nursing sister is of paramount importance to the diabetic in terms of assistance.

His or her role is determined by many factors in the supportive role and it was an aim of this researcher to discover, during the investigation, what specific roles people played, as well as what the contribution to the everyday life of the diabetic child was during and after school hours. There were many challenges experienced in this research while applying the methods of discovery and investigative processes.

The breakdown of communication due to a lack of knowledge and understanding concerning diabetes and the management thereof in a classroom proved to be a major hindrance to the qualitative investigation. At times, respondents, due to the lack of exposure to the disease, along with a limited amount of diabetic management knowledge, proved to be challenging. I was left to guide some educator respondents while carefully ensuring not to lead or direct anyone when responses were sought.

The challenge was to extract information from limited responses which restricted the scope of the investigation to a certain extent. The quality of responses became a concern which was overcome. However, the lack of understanding of diabetes by some educator respondents did prove to assist the research as a whole and satisfied to answer a myriad of unanswered questions. At the same time, due to the inabilities of educators to recognise and act on certain tell-tale diabetic signs of warning when dangerous situations arise in the life of a diabetic, some detail in the investigative process may not have been included in the study.

In some cases the diabetic learner was the most helpful to the teacher when included in the discussions in the classroom. These discussions were based on the real life experiences of the child in the form of the special needs a diabetic learner has. As a result, certain knowledge was shared with the other learners in the classroom and this resulted in a better understanding of diabetics with regards to lifestyle, diet, exercise, and associated illnesses and diseases one may experience as a diabetic. These classroom “sessions” proved invaluable to the research investigation.

This encouraged teachers to delve into previously untapped areas such as self-image, academics and blood glucose levels and readings. The chasm between those educators who did experience these discussions and those who were unable to do so was revealed. The majority of the educator respondents who did not participate in said discussions also had less to offer in terms of substance in the investigation that was conducted.

This became evident during times when investigating the role of the teacher in the learning environment and what actions needed to be taken in the event of a diabetic emergency. Also, another restriction to the process of data collection was the little sharing amongst teachers themselves of diabetic management processes that all teachers should be acutely aware of. There is a lack of shared knowledge which hindered the progress of research. A further restriction which exacerbates the situation is that substitute teachers, bus drivers and outside sports coaches are excluded from first- hand information due to the temporary nature of their work with the diabetic learners.

The end result was an emergence of the fact that learning about the disease from all quarters was hindered due to the lack of shared knowledge and other limitations already mentioned.

The principal respondent also proved to limit the investigation and this proved to be a challenge in that the role of the headmaster was not clear to him as leader of the school. Policy documents provided by the Department of Basic Education, although limited as a manual in strategy for functional

everyday purposes, had not been consulted and impeded the participative progress of my investigative work. The daily management plans of diabetic learners were not discussed at this level of the school and thus the coordination and filtering of vital information to other role players was neglected.

Although the qualitative investigative methods were somewhat restricted, relevant information of the management of diabetes by principals was discovered and added to the quality of the investigation.

The parent respondents of the diabetic children who are always actively involved in the lives of their children and the management of their diabetes revealed much in the study and results were forthcoming yet also not without restrictions. Their challenge emanated from, at times, inadvertently withholding information, which was vital for educators to have and understand and this broke the link of continuity in terms of sound diabetic management.

The result is an ineffective educator who does not assist in the diabetic management process of eating plans, blood glucose monitoring, insulin dosages, emergency procedures, school outing requirements, snack times, fluid intake, and many other procedures that a diabetic child relies on. Without this information going out from the parents to the educators, this investigation proved to be limiting again.

The physical educationalist is required to be well informed and understand, as well as be able to be pro-active concerning the possible drawbacks and situations that a diabetic child may experience. This teacher needs to have direct access to the parents of a diabetic child and also needs to be especially sensitive to specific needs of the diabetic learner. The recognition and symptoms of hypoglycemia (low blood glucose) together with food and fluid intake is a basic knowledge requirement for someone in this position.

Irrespective of having attended a basic first aid course, this respondent was more informed than most, but insufficient knowledge of the more technical

aspects of the diabetic child, restricted the process of investigation to a degree. A fair amount of work was however able to take place.

The role of the counsellor who is also an educator revealed that she was well equipped in the measure of support offered to the diabetic children in her “care”. Support for the entire family was evident and assisted the process of the investigation. Although technically the teacher was challenged as far as daily management plans were concerned, genuine care was shown to the diabetic children and their siblings alike.

To conclude, the diabetic learners themselves appeared to be the most communicative respondents. This appeared to be contradictory as investigative results lack a certain sharing with others for fear of prejudice and discrimination in the classroom. In their role as respondents however, and as a “team,” the investigation was propelled forward with much of the valuable information needed received from the diabetics themselves. The relaxed, less threatening atmosphere in a comfortable environment may have contributed to their positive participation in the investigative process.

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ANNEXURE A

Semi-structured interview for the diabetic child

Participant A: Male adult (P1A)

Participant B: Male adolescent (P2A)

Participant C: Female adolescent (P3A)

Teachers and Parents Group (A)

Mr Moore (MM)

Format: Question asked by Mr Moore followed by the participant's answers.

Key:
• Academic
• Self-image
• Teachers & peers
• Treated differently
• Management
• Sport

Q: Tell me about how you manage your diabetes?

P1A: Uhm, it's not a big thing actually. Healthy eating as far as possible, and ja, I eat anything but within moderation. I don't have a specific diet or anything that I have to stick to. So ja my sugar levels are pretty good, every time I see a specialist I see a dietician who helps actually more than the specialist does because they work on a ratio on how much insulin you need to inject per how many grams of carbs and it works. So that's about it for me.

MM: Alright and yourself?

P2A: I'm not too sure.

MM: Well how do you manage you insulin, for instance what do you do? What is the thing you do, what do you mean you not to sure? What are you allowed to eat, what are you allowed to...how do you inject, when do you test? What are you allowed to do, what are you not allowed to do. There

could be sometimes you do other things, some more than others...or what how do you do it?

P2A: I take insulin three times a day and well

MM: And what are the amounts you take? Any amount you want?

P2A: Well it depends on how much sugar you need

MM: Ok carry on...

P2A: Well, you not supposed to cheat.

MM: What does that mean?

P1A: No bar-ones!

P2A: No extra carbs

MM: And do you cheat?

P2A: Probably.

MM: Ok and what does your management look like of your diabetes?

P3A: Uhm, it's kind of the same, uhm like when I was little my mom used to do it a lot for me so it was definitely harder but now that I'm older I can look after it a lot more on my own. I'm basically on my own when I need my mom's help. But for me it's not really about carb counting, it's kind of like most of the time I also just estimate how much sugar is in it, how much carbs is in it and work it based on that. Uhm...

MM: And adjust your insulin?

P3A: Ja, I do it like for instance one slice of bread I inject 3 units, but that's what my body requires, but it may be different for other diabetics.

MM: Alright now tell me, thanks very much for that, are you able to or have you been able to participate in sporting activities or does this disease hamper your progress?

P2A: I take part in lots of sports, lots of sports yes and no not really, it doesn't really affect me

MM: So it doesn't really affect you?

P2A: No not really

P1A: Well in school I wasn't really diabetic but I did have hypoglycemia to a certain extent, so I suffered a lot of low blood sugars. But uhmja, half time or whatever I test sugars in if needed but it only happened once during a rugby game where my sugar levels went low because they weren't sure what happened, and tested my sugars the paramedics. Other than that it doesn't really, I mean if I was a diabetic at school, you test before you play and you try go into your game with slightly higher sugar, but if it does drop that it doesn't drop to a level where you pass out or something.

MM: And you?

P3A: For me, I don't really see it as a disease, I see it as a health condition, so it doesn't really run my life. Like sometimes, yes, I feel like I can kill something because I do feel sometimes like it is controlling my life, but it's not. So sports and gyming or anything like that I do one hour once and just...I can't like for instance if I want to go to gym I go and make sure that my sugar levels are above a certain point because if I go and gym on an 8 sugar it's going to go low. But, other than that not really no.

MM: So you can take part in sports is what you are telling me. Right how often do you miss school, or did you, because of your diabetes?

P3A: I don't miss school, it's just...I'm young but not anymore. When I was younger I would wake up or if I woke up with a really high sugar and I had key-tones then...my mom would keep me home because then in would feel very sick and would be throwing up.

MM: And yourself?

P2A: Uhm, this one time I went to school with key-tones, and...no not really I go to school. Uhm, sometimes if I have key-tones I stay at home.

MM: Ok. How many days do you think you have missed school because of diabetes?

P3A: Honestly not that many, I had to put them all together I would say maybe a month, maybe a month's worth of school. But that was honestly a whole bunch of primary school, but that wasn't really the diabetes, that was when you woke up with stomach bugs.

MM: Ok that's fine, and you?

P2A: Uhm, I think about a month as well. Or even more. Probably more.

MM: We not talking ...ok. Alright so you saying because of sugar you have missed a month of school?

P2A: Yes, if I put them all together.

MM: Ok but don't take your appendix into the problem! Alright, do you think your teachers understand your diabetic needs?

P3A: Honestly, to be very very honest no!

MM: Out of ten, ten being the most and one being the least, how much do they understand it?

P3A: 2 if I'm lucky. They have no idea

MM: No idea? Ok and you?

P2A: Uhm...

MM: Same experience or do you find it different?

P2A: No, I think about 6 out of 10.

MM: Do you?

P2A: Yes

MM: Why do you say that?

P2A: Because they actually know what diabetes is

MM: Do they! That's quite interesting. So what do they know?

P2A: That I'm not allowed to eat specific foods.

MM: Ok so if you went into a coma they would know...a low glycaemic coma they would know what to do? Is that what you are saying?

P2A: No

MM: So are you changing your mind a little bit or what do you say?

P2A: Yes, but they know what I'm not allowed to eat.

MM: And do you think that because maybe you have a parent at the school as a teacher or has that got nothing to do with it?

P2A: Uhm, yes.

MM: Is it? Ok so if I can ask you, another child in another grade that doesn't have the same teachers, how do they know about diabetes? Or don't they?

P2A: Uhm, no.

MM: They don't? Ok so you think you might be in a bit of a preferred area?

P2A: Yes.

MM: Ok, at school when do you test and inject?

P2A: At breaks, at break time.

MM: Ok, and then what do you do?

P2A: Well first test myself to see my blood sugar level and then if I'm high I give myself insulin, and if I'm low then I just eat more carbs.

MM: Alright, and yourself?

P3A: Preferably I, at school it's basically like I don't have diabetes. Uhm because of the past I've had with teachers being...how can I put this...

MM: Ignorant?

P3A: Yes! Towards me, they don't treat me differently. Although I know it will be different at the school that I'm at now, I don't check sugar, I don't eat at school. When I do eat at school I make sure its protein so I don't have to give insulin. But I try not let people know that I have diabetes. Unless I'm low or I feel that something is not right then I don't do anything about it, but if I know that I have to check then I'll go the bathroom and check there or something.

MM: Do you have any one specific teacher or friend that knows about your diabetes and knows what to do if you go into a low?

P3A: My best friend, but that is only for in case, I'm not reliant on her.

MM: And you?

P2A: Yes

MM: Ok who? Teachers? Are the teachers or...don't say names, just say teachers or...

P2A: No, my friends.

MM: And do the teachers know what to do if you go into a low?

P2A: No.

MM: They don't know? So basically just now you said that they do know what you not allowed to eat, is that basically where it stops?

P2A: Yes

MM: So they only know that you shouldn't eat chips and all of that, that's it. Ok alright so we need to educate them. Uhm, anything you would like to say on that?

P1A: Yes. Just to cut in, I think the biggest problem is a lot of people refer to diabetes as sugar diabetes, and it can be quite confusing for people that don't know because a lot of people that I've spoken to about it don't know that carbs count. You know you not allowed chocolate or you not allowed coke because it's full of sugar, they don't worry about carb counting. They don't know you need to inject for bread and mash potato and things like that. A lot of the teachers they have just just the basics, the ones that do know a little bit about it and they know that you not allowed to have chocolate or you not allowed to have coke, but when it comes to the carb counting and that kind of thing they have no clue, they have absolutely no clue.

MM: Do you think that it would help in general for teachers to know and to go on a bit of a course in terms of knowing about diabetes or not, or would that be wasting time?

P1A: Absolutely, it is very necessary. Especially in today's life where diabetes is growing at a very fast rate, and there are more and more kids getting it so I think it is very important. Maybe not all of them, but the more the better I think it's very necessary.

MM: And you guys? What do you have to say? Would you like more teachers to know or not?

P2A: Yes, I think so.

P3A: Honestly, yes it would help to a certain degree because like helping, even if they go on a course they will understand more of it or they might understand everything. The way I feel, unless you have diabetes, you don't know. Like I get very frustrated even my doctors, I recently changed doctors, even my doctors sometimes like I get so frustrated with them because they think ok because they have knowledge behind them they can tell you how to narrow and although they are a doctor, they don't know your background,

they don't know how you dealt with it, they don't know your life, they don't know your lifestyle...so yes. They could say ok well if you are high inject, but with me lately I'm battling so much if I'm high and I inject I go higher, I inject more and then I drop as fast as anything and then what they going to do? Oh drink coke! And you not going to lift, you going to take a while to lift and anything could happen. So yes to a certain degree it would help, but after that no.

P1A: And there are a lot of factors that come into play as well and I think also what...it would be beneficial for people to go on courses and learn about it because say for instance one day I have a low you know and the teacher or whoever is helping me does one thing and it works, it doesn't necessarily mean that that is going to work the next time. Things as small as temperature play a role in your sugar levels, you know what might work in winter might not work on an extremely hot day. You are sweating and you exerting more energy. Things differ...its small little things that can change the outcome of something, so I think it's really important and the basics aren't enough, they need to get taught in more depth of what diabetes is and how to handle it especially when a scholar or whoever has a low or a high...especially lows I think.

P3A: Not only that, it's also different people react to different things differently. You know one person can take a certain amount of insulin and that's fine, perfect, he will have a perfect sugar. Another person can have the sugar intake, the same amount of insulin but could react completely different. So it varies from person to person and although, like I said, although a course would help you have to get to know your body, yes, you have to know what works for you. That's why honestly I just think it's better yes it's good to have some help, somebody to know what they are doing, but it's basically up to you and the people close to you to know because unless you know you not going to get anywhere.

P1A: As an example, my sister there have been a couple of times where she's been at home and her sugars have gone as low as 1.1 and she's sitting watching T.V., but another diabetic at 3 will start almost falling over and

that's why you can't have your teachers waiting for you to pass out and then they realise you've gone low. You know they need to know the warning signs and in particular her scholar, they need to get to know their scholars that have diabetes, that's a big thing as well.

MM: Ok so individualising.

P3A: For example in my last school that I was, one of the students (she was actually one of my very good friends) she was also diabetic and she went, she actually almost went into a coma. She was sitting in art class and she just started shaking and I wasn't in her class, but then one of my other friends that was in her class came to me and said well listen she's gone low, very very low and she needs your help. By the time I got there I was chased out of the class saying no we don't need your help. The person from the office was force feeding her coke so much she almost went into the complete opposite coma she went so high. So I came home and I told my mom, and my mom was like oh ok. She was shaking so much she couldn't do anything, she was sweating and the teachers didn't know it was her so they immediately thought ok force feed her coke and it went overboard.

MM: Alright, ok sorry what was the last question I asked you? How do you feel about the fact that you live with diabetes? Ok...how do you feel about the fact that you live with diabetes?

P2A: Well it doesn't really affect me

MM: You ok with it?

P2A: Yes

P3A: As a girl honestly it's...I'm not trying to be sexist or anything like that but for a girl I honestly think it's a bit more difficult, not in terms of how to handle it but in terms of the things you can do. Like every girl goes through that stage where she wants to do crash diets and she wants to do everything to improve her body and she wants to wear pretty clothes, and especially if you are on the insulin pump you can't wear whatever you want to wear

because it's always showing, but in terms of how you handle things you can't do all the things that your friends are doing or what the media is advertising and anything like that. So in that sense it's a bit difficult, but other than that it's not really any different than what any other person looks.

MM: And do you feel sometimes frustrated or not about it? Does it frustrate you or do you wish certain things or not?

P2A: Yes

MM: Like not being able to eat, for example, a chocolate whenever you feel like it...does it affect you?

P2A: Kind of. Well yes it's actually frustrates me because I can't eat things that, yes, I want.

MM: Ok and you?

P1A: It doesn't affect me at all, but I think it comes down to your personal outlook on life, and I think age has a lot to do with it as well. You know when people are in school parents take responsibility, it's more the parental thing and less of you taking hold of it yourselves so when it comes to my sister she says she thinks girls have it harder, I don't think it's that I mean I'm fasting at the moment, there are ways and means of getting around everything and if you know your body well enough you can do it. You can't crash diet and things like that because it's not good for you but I think once she becomes older and stops growing and hormones settle out and all of that, she will find a ratio that will work for her and she will in time learn the warning signs – without even testing – I know you shouldn't but there have been times where, you do, you forget your insulin at home or you forget your tester at home, you need to be able to know your body if you thinking you haven't got access to a tester. So ja I think as she gets older or once she gets to the size when she stops growing it will be easier. But for me it has no effect on my life, really I got in it late in life.

MM: Do you sometimes get angry, anxious, sad, frustrated getting over this or whatever when you deal with it or not? That's the same sort of question, does it get to you I times. Give me some examples of how you react.

P3A: It definitely does irritate me a lot, uhm when I want to do something, I'm a very impatient person so when I want to do something I want to do it now and a lot of the things I do are based on what my sugar level is, so if it is too high or too low and I can't get it up or down then I'll throw my toys out the cot and be like ok then I may as well just not do it and things like that. Often it frustrates me to the point where I'm in tears because there is nothing I can do about it and I know there is really nothing I can do to fix it I just have to learn to deal with it. But having dealt with it for the amount of time that I have and still knowing that I still can't do it to a precise point where it is completely in control is very frustrating.

MM: And you?

P2A: Well it's kind of like irritating that you want to do something and you can't do it and you get so frustrated.

MM: Alright. You basically answered that in the previous...no good thank you very much, I appreciate your time. Thank you, anything else you would like to say, just to end off with in terms of your diabetes or anything you would like to add to what you have said?

P1A: I think the biggest problem is people not knowing and uhm I think that's also one of the biggest irritations. People don't balance their sugars out and work with them properly because they too embarrassed to take a test or insulin in front of people especially in school because kids can be cruel and rumours can be spread. I think the biggest thing is people need to be taught about it so that the judging stops and things like that so I think that's the biggest thing.

MM: And you? Have you had a problem at school ever?

P2A: No.

MM: And you?

P3A: Many many! I was kicked out of class for doing drugs apparently when trying to inject, and not out of one class...out of various classes. Kids picked on me, even leaders tried to report me to the headmaster, the deputy headmaster saying that I'm doing illegal substances at school, doing drugs all of those. So it's not a case of being embarrassed, it's more of a case of people treating you differently when as a matter of fact you are no different to them. It's a hard condition...it's not a disease. Honestly a disease to me is like having cancer, it's like having high blood pressure and people need to learn to accept that. Just because you have to inject yourself and it a day to day thing, they think you are different and they treat you differently. There's nothing you can do to change their mind because they are so dead set in their ways that just because you are not exactly the same as they are then you are not a normal person.

MM: Great thank you very much for your input everyone, I appreciate your time. Thank you. This now, the second part of this would be the teachers and the parents that are now being interviewed in a focus group interview. Right thank you very much for your time everyone and the first question I have for you is what technical information do you have about the management of or do you know about the management of diabetes in children? Just technically how you would deal with someone with diabetes. You can just chat amongst eachother.

A: The most important thing that I learnt in these two months that she has had diabetes is just to test and test again. My child has never ever ended up in hospital sugar related. The testing, don't go anywhere without the necessary things: the tester, your insulin, your coke and your cell phone and that type of thing. It's just to be very alert at school and as mothers to know their kids, I picked it up in Sheila when she was little and up until this day she says she can see it but then her sugars are high. And when it goes low it goes bigger and bigger and bigger and my hands it starts to go floppy when it goes too low, and then it goes into the Oswald stage then I know what the problem is. It's just the little things that you have to be very alert of and

don't panic. I sometimes panic, but don't panic, do what you have to do and it will be fine. Test, give the coke, give a snack when it's low and when its high bring it down, but rather instead of just giving one big injection do it gradually. Rather test like every hour and things like that.

Uhmja it was a shock in the beginning and things get better as they get older ok, but in the beginning the responsibility is on the parent to actually manage, uhm not just insulin but the food intake, going to the dietician to see what will work and what won't work, because the younger the child and the less the child weighs uhm insulin reacts differently to each child ok so a lot of it was in a sense trial and error but not trial and error that endangers that person's life in any way. A classic one was with her now where the specialist would say she needs so much of this insulin and so much of that insulin. They use guidelines, they can't say you have to give that child that much insulin, if that child is more sensitive ok and the more we would say to them listen you know my daughter has a sensitivity to this type of insulin ok oh nonsense it works for everybody. It doesn't work for everybody, it doesn't. When the insulin was changed ok uhm then you go through a period of maybe two you have to adjust, you have to adjust your food intake, you have to adjust what time to inject because some of them would work quicker than others. Ok uhm she wasn't as sensitive to certain insulin's as to what she is to other insulin's, but they do have the same job. That was the scary part for us, and it took a lot of input from a parent point of view. Uhm and yes it was made basically if we went away for a weekend or to watch sport you know with her brothers, the first thing where's your insulin, where's this where's that and always take an extra tube of insulin because you don't know, someone can kick the bag and break the insulin or you drop it. So it was always...ja you had to plan. Uhm you know once a person gets to an age, we were in a scenario where we had to manage it, and we had to manage our daughter's insulin until she was at school ok uhm because she was so young at which she got diabetes. What happens when they young or as young as what she was alright, they human faults...why should I do it if I have someone to do it for me? A child, regardless of whose child it is and where the child comes from, which walk of life he comes from, colour, creed or

race they are manipulative and its easier for that child to say you know what mommy and daddy can do it because if something happens...it's your fault. And why I'm saying that is because when we get it so young then they only tend to get to a stage when they want and that's the big thing, they have got to accept and want to do it. So now because they have the freedom now they prepared to take it. But if that child gets it when they are at a school going age, they can talk, they have learnt to understand their body to a degree, and they are prepared to take that responsibility because you can communicate with them so you can say to them you know you are a big boy or a big girl and you need to control what you do and this is an extra means of controlling, whereas when they are small they can't talk, they can't tell you how they feel and you as a parent have to do it all for them. And that was a big problem when she was diagnosed. Because for me as a parent having had the two boys, and wanting a daughter all my life and then getting it 7 years later, she is not even 2 years old and you are told...it was like a death sentence and it was difficult to accept. Who are you to tell me you know, there must be something else wrong here, just do other tests, don't worry about that one. It was difficult...it really was.

MM: Right anything you would like to add? Right, I'll start with you then. Do you think that self-image/esteem of a diabetic child is impacted by their condition?

A: Yes I do. I think if you don't have much confidence as a child, getting diabetes is going to be even worse for you. If you take Benjamin for example, he is a confident little boy, but he is not afraid of having injections or telling other people or other children what he's got. So I do think that if you have more confidence as a person you will be fine, and you get it especially I think as a child because I think if you are older you have that confidence of an older person

MM: Ok anyone else?

A: The Sheila at home, she takes the bread and just does it, but going out she would rather go without food than do it because she feels self-conscience

about it and she also loves and dieting because a young girl can never be skinny enough and she feels because she has to eat regularly and everything that just how she feels. In a way...how can I put it...

Food is a serious business (laughing)

She does feel she is less pretty than the other girls, she's bigger than the other girls, uhm and that...it does it...

MM: Even if you wanted to you couldn't do it. So you have got no choice.

A: It's just not healthy for you, and you might not go into a coma today from doing it but it affects you long term, it does.

MM: Alright, do you find yourself treating the diabetic child in your care differently to other children?

A: I did in the beginning when she was little

MM: Ok and how did you do that?

A: When Sheila was first diagnosed she was in hospital for seven days, I stayed by the hospital, came home in the mornings to shower and then went back. When I came home I couldn't care to be a mother to my other two boys, they needed to cook for themselves and look after themselves, I wouldn't go sleep at night, I sat next to her bed...she was my everything. If Sheila said mommy, you could be busy talking to me I ran to Sheila. So I definitely did my boys a big injustice at that stage. It was so consuming the worry of you know there was times I was so tired from not sleeping not eating properly, just worrying and everything and feeling guilty about the other two but I was so tired but you don't want to sleep because you are scared something is going to happen. I it totally controlled my life. It took about 2/3 years for me to really... I mean

MM: That's a long time. But she's 21 months old and I understand because she can't do anything for herself.

A: It really took me a few years to....

MM: ...work with it...come to terms with it.

A: To work with it and to not panic every time the slightest little paleness or maybe she's been running and her hands are sweaty and I'm out with the tester and going crazy. I mean in a way my boys, I'm sure they felt neglected.

MM: Would you do it differently now, if it happened all over?

A: I would, I would definitely do it differently. I'm also older so I can cope better with it.

Ja but to carry on with that question, would we do it differently, uhm most definitely and the reason that it would be possible as well to do it differently now is because technology has changed and now if a child gets diabetes at the age of 21 months, put them onto the pump. That is 90% of your problem resolved because instead of giving yourself an injection or that child an injection, let me tell you there was a time that I wanted to get into a plane and go to a flippen oil rig when she was first diagnosed. For the simple reason, uhm there was a period where I was responsible for injecting her. Because of how much I wanted a daughter, ok and I get my daughter, now I have to inject my daughter and it got to a stage where if she saw me she started screaming because I was coming to hurt her. You know what, do you know how painful that is as a parent when your child screams because they see you coming. That to me was heart wrenching. Ok so would I do it differently, yes I would because now with the pump it's like giving one injection every three days instead of three injections every day. So now I have to do is instead of injecting her I have to monitor and feed. So yes I would do it differently.

MM: And you do you see any other children in your care differently to the one with diabetes?

A: Uhm, yes I do because I have to watch what he eats, so because I'm watching what the diabetic child is eating in actual fact the other will have to

eat the same things as well. So you can't just maybe let the other children have, we buy things specifically for the child that has diabetes.

MM: The whole family has to fit in.

A: the whole family has to fit in and also we have stuff that is Low GI because of him, we try to this because of him, I put lentils in the spaghetti because they are Low GI, you know things like that. You know other normal families that don't have a diabetic child they would just eat normally and the things that you just feel like eating.

MM: Ok. What academic challenges are experienced by the diabetic child in your opinion?

A: To be very honest, there are no challenges on condition that child has monitored and regulated the sugars. Its only if you go low or high or have your sugars going like rough seas that there is a challenge in your educational growth.

I did find with Sheila that she was, Sheila actually copes better on a slightly higher sugar than a good sugar, but when it goes too high she gets headaches, she gets moody, she can't concentrate, uhm really she can't focus on her work. So if its low sugar she is still fine, it is the higher sugar that affects how she concentrates. But otherwise she's quite bright.

I find sometimes that if he is learning for like his spelling and he has a low late night, then he cannot remember the next morning so well with his words. That's what I feel.

MM: Ok thank you. To what extent do outings and holidays affect your planning and times away?

A: I think you know the holidays revolve around eating isn't it. What we do do we always wondering when are we going to eat, it's getting a bit late now, we need to eat and that type of thing.

MM: And school outings?

A: That was a nightmare. Uhm Sheila and her whole primary school went on outings and the first one she went on and I took her tester and checked afterwards and they were all 20 sugars because she just ate and ate and ate and forget about insulin. The second one she went on uhm grade 7 she really took control well. And now she is not going because she is doing home school from the centre and she hasn't been on an outing with them. She goes on more often you know she's not with mommy the whole time.

MM: And yourself?

A: I found that uhm, I agree with you to a certain agree but also Sheila she really enjoys going out me alone ok and especially when we at the sea because I've bought gap to book, I will always say to her listen the insulin isn't here to govern you, you have a life to live and you govern the intake. I'll give you an example, we will take her down to the beach in Ramsgate and I'll tell her we not going to Margate we going to Ramsgate then check your sugar and it's a little bit high and we will say to her right go swim for 10 minutes and then she comes out and she checks it and its going low and I say right now we having waffles. Or we will be walking around and she will say well I feel funny and we check and its starting to go low and I will give her an ice cream or you know have something that she can't normally have alright uhm and then we get active to pull it down again so ja in that sense I'm a lot more flexible uhm where uhm her mother will be more rigid ok. So ja you know one of the first things that was ever told to me by the specialist ok remember what your child was born a child, diabetes is a secondary factor, it needs to be governed ok and that always stuck.

MM: Ok good thank you. Ok I'm going to start then with the next question. What special arrangements do you need to make during sports activities, or did you make? Like food?

A: Not really because we were lucky in the sense that uhm at least one of us would always be at the sporting activity or at the whatever, uhm whether it was dancing in the evenings, modelling in the evening, weekends it didn't

matter because one of us would always be there, the majority of times we would both be there. So I can't really comment on that one.

It was just a matter of Sheila knew whatever she was going to do, she checked her sugar and if your sugars are slightly low forget about being embarrassed, I need to go, you need to go, you need some insulin you do it.

MM: So there was no real problem when you had sport. Uhm ok I was going to ask that question again and you can think about it on the way here, what special arrangements did you or do you need or need to be made when doing sports activities. When your child has sports activities are there any special arrangements?

A: Well I make sure that I pack in extra food for that day; I make sure that I take out super c's in case of low while playing rugby or something.

MM: Ok and fluid intake? Anything about fluid intake in terms of sport or is it just normal?

A: Uhm that also depends on your sugar before you start. Again I'll come back to the question, three or four questions ago. It's a matter of knowing your body and managing it so you know a normal person would be able to go through 15/20 minutes of a rugby game uhm without having to take a sip of water. It's always good for a diabetic to take in a little bit and be more sensitive to your thirst and type of thing ja.

MM: So in terms of being dehydrated at any stage not just in sport will it affect the condition of the skin or itchininess or anything like that?

A: Yes, most definitely. She becomes very flushed and itchy.

MM: When she's dehydrated?

A: Yes, she feels very dry.

MM: And is that throughout the year or in winter specifically or any time?

A: You know it also depends on climate uhm you referring to climate summer winter uhm coastal, West Rand, East Rand, Free State ok. Uhm if we go to the East Rand where her oldest brother lives now, guaranteed tonight her skin will start here. Guaranteed.

The pollution, clubs...the climate affects her skin but it also affects her sugar. Because in Free State and Natal she has got beautiful sugar, she gets away with so much. And if you go the Kruger Park you have got to keep checking because it's a different type of heat, it may be the same temperature with a different type of heat, where there you have to keep saying to her...check...eat...drink...check...eat. Ja so uhm its different, it's definitely different. The strange thing about it is that it effects, bearing in mind now that we have two children with diabetes ok, your son is older and what he does not comply to your daughter ok, totally different, chalk and cheese ok. What happens with the one in the Kruger Park, the opposite happens to the other. So it is a unique scenario, each person is unique to themselves.

MM: Fine thank you, are there any closing comments that anyone would like to give? Anyone want to say anything about any part of what we have spoken about today, the management, the self-esteem, the curing of it, the academics, sport, the skins problems, eczema anything you want?

A: I think what I would say is that taking or acknowledging that each person is different, it is a life style, it is not a disease and as a parent the sooner you comes to terms with it and say you know what, I can only do so much because it's your life and it's your future ok and just be there as a support system because strictly speaking I think a lot of parents and educators get so stressed out that they stress out the child. It's not our responsibility, it's yours, it is your life and it's your future. You manage it, if you have a problem come and talk to me and the sooner we can get that sorted out with that individual or that diabetic, obviously depending on their, but once you can get that sorted I think 70/80% of your battle is won.

MM: Any other comments? So in terms of just the managing/management of it would you suggest then that a pump is the way to go?

A: Well for young children, even for sports children that play things like hockey uhm people that ride BMX bicycles, you know what we have had the experience with having had both and because of the pump giving you insulin every 15mins ok. Where you have your injection 3 or 4 times a day you have peaks and varies and peaks and varies ok so you give insulin and you come down and then you have to eat and then you give insulin ok. Where with the pump you getting the same amount except the pump cuts your insulin intake by about 30% on a 24 hour cycle ok but you won't be having the peak and the bad, you having more of a like a congregation instead of rough seas ok. So what happens is you can now have your breakfast and you give yourself insulin through the pump ok onus you work out what you eating, so it's the same as an injection but you have a little catheter of a pump. You not getting that peak so the concentration level of that child, it also...if the sugars are going like this up and down the whole time, with the pump it does sort out their concentration levels ok and they become more disciplined, but as they get older they become more of a cheat ok, because they bonus more. Their friend has an ice cream, do you want some, yes and then they eat half the ice cream because they tend to be a little bit more sensitive so that's fine. But if you are going to do it and you are going to cheat, then make sure that you operate the pump because you could become more sensitive.

The pump is good, look uhm when Sheila was on the pump she was definitely much better, she had less highs and less lows as well.

MM: Is she no longer on the pump?

A: No, about 4 years...October will be 4 years

MM: Is it better like that?

A: She prefers it like that. She couldn't really wear a nice dress; the pump is in the way. But what I felt, especially when she was younger is that she was very active and she wanted to jump on the trampoline you had to take the pump off because it would bobble and bobble and then she can go for 2 hours and get no insulin. So if you are a sportsman it does have its pros. I say it could work if you are prepared to take the thing off and put it back on and

every half an hour keep that little bit of insulin, because there is nothing that keeps that box steady against your body.

Ok but you also have to take into consideration, that's why I mentioned technology, where we got the pump ok it was one of the first pumps and she was actually one of the first in South Africa to have the pump, we got a first generation pump. It's the same as anything in technology; anything in the first generation is a trial. So yes you did get it but we are already on the 6th generation ok and the newer pumps are unbelievable because I've seen one of the pumps, the pumps are actually smaller, they are a bit bigger than her tester alright and then that pump has got a little sensor just after where the insulin goes into the actual tube so it picks up volume. What happens is if you end up with a bubble it beeps, uhm if there is a blockage it beeps, if there is a leak it beeps, it's an amazing little apparatus. But like I say, generation 1 vs. generation 6.

The only thing with the pump as well, both the pumps that Sheila was on she could only use Nova Rapids on it. It's the only insulin that is strongest.

MM: Yes long lasting you have to inject still

A: The nice thing and the easiest thing that she goes for insulin there is that you could see that insulin in the pencil and then she knows you just have to inject a little bit now and the rest goes over the next 2 hours, so there it worked beautifully. And she could also, when she was little, when she was half way through the dose she could stop insulin didn't all have to be injected. And also when she got sick, every two hours she just grabbed that extra little bonus, ah what a dream, and she never ever ended up in hospital.

MM: So are you considering going back on the pump later on?

A: I think one day when she is pregnant it may be a wonderful thing to do then.

MM: Don't you like it?

A: She hates it!

MM: Is it because of what it looked like?

P3A: Yes a lot of it was about how it looked but I just prefer injecting, I really do.

ANNEXURE B

Diabetics' questionnaire

INSTRUCTIONS:

Comment if necessary (you don't have to)

1. For each question, rate how you feel on a scale of 0 – 4:

- 0. Never
- 1. Seldom
- 2. Sometimes
- 3. Often
- 4. Always

3. Answer questions 6 & 7 in a full sentence.

<u>Section A:</u>	<u>Comments</u>
1. Are you able to concentrate when your blood sugar level is high?	_____ _____
2. Do you ever feel frustrated because your diet is limited?	_____ _____
3. Do you feel/think that your parents treat you differently to your brothers and sisters?	_____ _____ _____
4. Are you worried that your Diabetes will affect other parts of your body?	_____ _____

<p>5. In sport, are you able to compete equally with your peers?</p>	<p>_____</p>
<p>6. What sacrifices, due to your condition, do you find are the hardest to accept?</p> <p>_____</p>	
<p>7. What effect does your diabetes have on your schoolwork?</p> <p>_____</p>	

<p><u>Section B:</u></p>	<p><u>Comments</u></p>
<p>1. Do you feel that you get extra support at school from your Teachers?</p>	<p>_____</p>
<p>2. Does the school tuck shop cater to your needs?</p>	<p>_____</p>
<p>3. Have you ever felt that your parents or teachers have singled you out for being different?</p>	<p>_____</p>
<p>4. At school, is there a safe place where you can test your blood sugar levels?</p>	<p>_____</p>
<p>5. During physical</p>	<p>_____</p>

<p>education, are you allowed to stop doing the activity when you want to?</p>	<hr/> <hr/>
<p>6. Where, at school, are you when you test sugar levels and inject insulin.</p> <hr/>	
<p>7. Are you worried about future complications concerning you diabetes?</p> <hr/>	

<u>Section C:</u>	<u>Comments</u>
<p>1. When your blood sugar levels are too high, are your test marks affected?</p>	<hr/>
<p>2. If necessary, do your teachers allow you to eat during class?</p>	<hr/>
<p>3. Do you think that your teachers and friends help you enough with your diabetes management?</p>	<hr/> <hr/>
<p>4. Are your teachers and friends aware of the Consequences if your blood sugar drops too low?</p>	<hr/> <hr/>
<p>5. Do your friends and teachers know that you should eat before you do physical activities?</p>	<hr/> <hr/>

6. Do you ever cheat and have a treat without anyone knowing?

7. How are your moods affected by your diabetes management?

Parents and Teachers Questionnaire

INSTRUCTIONS:

Comment if necessary (you don't have to)

1. For each question, rate how you feel on a scale of 0 – 4:

- 0. Never
- 1. Seldom
- 2. Sometimes
- 3. Often
- 4. Always

3. Answer questions 6 & 7 in a full sentence.

<u>Section A:</u>	<u>Comments</u>
1. To what extent have you noticed a lapse in concentration when the reading of the blood sugar level is too high?	<hr/> <hr/>
2. Do you feel you have to constantly manage and monitor the diet of the diabetic child in your care?	<hr/> <hr/> <hr/> <hr/>
3. Do you ever find yourself treating the diabetic child differently to their peers?	<hr/> <hr/>
4. Is there a fear that high blood sugar levels will adversely affect other areas of the child's health?	<hr/> <hr/> <hr/>
5. Is the diabetic child disadvantaged on the sports field?	<hr/> <hr/>

<p>6. For <u>diabetic child's parent</u>: Discuss your diabetic management plan.</p> <p>_____</p>
<p>7. Question for the teacher: Are you involved in the management of the diabetic child's diabetes?</p> <p>_____</p>

<u>Section B:</u>	<u>Comments</u>
<p>1. Do you need to consistently offer the diabetic child in your care additional academic support?</p>	<p>_____</p>
<p>2. Are the eating habits of the diabetic child in your care strictly monitored?</p>	<p>_____</p>
<p>3. Do you find the responsibility of caring for a diabetic child Overwhelming?</p>	<p>_____</p>
<p>4. Have you been vigilant about measuring the child's blood sugar levels?</p>	
<p>5. Can the diabetic child compete equally with his/her peers in sport?</p>	
<p>6. What scares you about having a diabetic child in your class/home? _____</p>	

7. What do you understand by hypo's?

<u>Section C:</u>	<u>Comments</u>
1. When the diabetic child's blood sugar levels are too high or too low, are their academic achievements affected?	_____ _____ _____
2. Are you flexible when dealing with the eating habits of the diabetic child?	_____ _____
3. Have you been vigilant about the management of the diabetic child's blood sugar levels?	_____ _____
4. Do you understand the risks and causal effects of fluctuating blood sugar level readings?	_____ _____
5. Are you aware that physical exercise may cause a reduction in blood sugar?	_____
6. What plan would you have in place when a child sleeps at a friend or goes _____ on tour? _____	
7. Do diabetic children live "normal" social lives? Why / why not? _____	