

**CHALLENGES FACING ADOLESCENTS WITH TYPE 1
DIABETES MELLITUS IN NAIROBI CITY COUNTY**

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Declaration

This thesis is my original work and has not been presented for an award of a degree in any other University.

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This thesis has been submitted for examination with my approval as the University Supervisor.

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Dr. Salome Atieno Bukachi

Dedication

This thesis is dedicated to my parents Mr. Samuel Bakesia and Mrs. Penina Shikuku. Special dedication to my siblings, and my son Ramsey. Please follow in the same steps.

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Abstract

Diabetes is a silent killer disease because many people live the disease without their knowledge, and for those who know about it, they have challenges managing its complications. Type 1 Diabetes Mellitus (T1DM) is a complex disease to manage. Adolescents with the disease have to deal with developmental challenges, and challenges of managing the disease. They are deemed to suffer the complications of the disease and therefore, not lead normal lives like their counterparts who do not have it. This study aimed at exploring the school-based and home based challenges faced by adolescents with type 1 diabetes mellitus (T1DM) in Nairobi City County. The study adopted a cross-sectional design that used qualitative methods of data collection, with the aim of getting the informants to describe their home based and school based challenges of living with the T1DM. The study was guided by the shifting perspectives model of chronic illness by Paterson (2001). The key informant interviews were conducted with 15 adolescents, aged 14–18 years, with T1DM recruited from a pediatrics outpatient diabetes clinic at the Kenyatta National hospital (KNH). In depth interviews were also conducted with 15 of their teacher/ school care givers at school and five of their healthcare providers at the KNH. Sample selection was through purposive non probability sampling, and a total of thirty five informants were sampled through the same method. Data analysis was done by thematic analysis, through reading of the interview scripts and identification of the emerging themes to gain an understanding of the challenges faced. The data was presented in themes, and verbatim quotes were used to give a clear picture of the challenges of the adolescents with T1DM. The results on the home based challenges showed that adolescents with T1DM had constant conflicts with their parents. These conflicts stemmed from non-adherence to the management regimes, the feeling of too much interference in their freedom to do things on their own, and their parents having to worry too much when they were away from home. The adolescent also conflicted with their parents because they felt that parents did not give them time to make their own independent decisions. The results also pointed out that the adolescents faced stigmatization from their friends and peers and at social events. Inaccessibility of health services was also a challenge because of the distance, and the unavailability of insulin as well as its cost. The adolescents also found the school environment (both day and boarding schools) rather restrictive for the management of their T1DM because of the inappropriate meals for adolescents with diabetes, and poor meal timing which interfered with their diabetes management plan. The inadequate information, education and communication on the part of the school personnel on how to deal with the complications arising out of increased or decreased sugar level was a also challenge. The other school based was on the part of the administration that set strict school rules that affected the management of T1DM. Such rules included not carrying syringes to school, not leaving the examination rooms, not having meals in classrooms, and in boarding schools, food from outside school was prohibited. This study contributed to the understanding of the challenges faced by adolescents T1DM in the Nairobi City County, and it was one to of the few studies to explore the diabetes experience using the shifting perspectives model of chronic illness. It enabled the making of recommendations for school personnel and community at large, based on the participants' interpretations of the needs of diabetic adolescents in the schools. The study therefore recommended that the teachers, parents, peers and the community at large, need more training and awareness on T1DM. Learning institutions in Kenya should formulate a diabetes policy to help the diabetic adolescents with the disease management. Further studies may look into the psychological challenges.

Abbreviations and Acronyms

DM	Diabetes Mellitus
GDM	Gestational Diabetes Mellitus
IDDM	Insulin Dependent Diabetes Mellitus
IDF	International Diabetes Federation
KNH	Kenyatta National Hospital
KII	Key Informant Interview
MDGs	Millennium Development Goals
NCDs	Non-Communicable Diseases
NGOs	Non- Governmental Organizations
NIDDM	Non-Insulin Dependent Diabetes Mellitus
OPDC	Outpatient Diabetes Clinic
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
WHO	World Health Organization

CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 Introduction

Diabetes mellitus is a “metabolic disorder caused by different factors and characterized by a chronic high level of blood sugar with disturbances to carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both. The global prevalence of non-communicable diseases (NCDs) dominated by diabetes, is increasing with the greatest burden being felt in the developing countries. It is projected that by the year 2020, NCDs will surpass the communicable diseases (CDs). For instance, Diabetes is a world silent killer disease that claims more people’s lives than does HIV/AIDS. The World Health Organization (WHO) states that 347 million people worldwide have diabetes. In 2004, an estimated 3.4 million people died from consequences of high blood sugar (WHO, 2009).

More than 80% of the death occurred in the middle-income countries. It is projected that diabetes will be seventh leading cause of death by 2030 (WHO, 2009). A person dies every ten seconds from complications arising from diabetes and in the very ten seconds, two people are diagnosed with diabetes (Baillie, 2008). Scientists have categorized diabetes into three different groups: Type 1 diabetes mellitus/insulin dependent diabetes mellitus (IDDM) is also known as type 1 diabetes. Type 2 diabetes mellitus (noninsulin dependent diabetes mellitus (NIDDM), adult-onset diabetes is found in individuals who are insulin-resistant and who usually have relative insulin deficiency. Gestational diabetes mellitus (GDM) is defined as any degree of glucose intolerance with onset or first recognition during pregnancy (International Diabetes Federation, 2007:30). Type 1 diabetes mellitus (T1DM) which was the focus of this study, is a serious life-long autoimmune condition where a person’s immunity system attacks the beta cells located in the pancreas and are responsible

for the production of the insulin hormone that converts food into energy (Scramuzza *et al.*, 2010: 1237).

At present, scientists do not know exactly what causes the body's immune system to attack the beta cells, but they believe that autoimmune, genetic, and environmental factors, possibly viruses, are involved. The symptoms of type 1 diabetes include frequent urination, increased thirst, dry mouth, increased hunger, fatigue and weight loss (Cooke and Plotnick, 2008:377). Type 1 diabetes accounts for 5 to 10 per cent of all diagnosed cases of diabetes, but is the leading cause of diabetes in children of all ages. In 2007, it was reported that T1DM worldwide affected 437,500 children. Some 78,000 children under 15 years are estimated to develop type 1 diabetes annually in developing countries. In the United States of America, 186,000 young people under the age of 20 years had diabetes in 2007, while Canada which has the sixth highest occurrence of T1DM of 3 - 5% per year in children under 14 years (International Diabetes Federation, 2007:30). .

In Africa, the prevalence and incidences of T1DM remains controversial despite few studies indicating a slight increase (Baillie, 2008). In the developed nations, efforts have been made to document and reduce the complications of diabetes in children and adolescents, while in the developing nations even the incidences and prevalence of the disease in adolescents and children is largely unknown thus making management efforts difficult (Baillie, 2008). Furthermore, information on chronic complications of diabetes in sub-Saharan Africa is scarce. The incidence of the disease goes hand in hand with the growing prevalence of the disease. It therefore becomes necessary to assess the complications of the disease and how to manage the complications (Majaliwa *et al.*, 2008). It is estimated that the prevalence of diabetes in Kenya is at 3.3% and is predicted to rise to 4.5% by 2025. Two thirds of the diabetes cases may be undiagnosed. The

double demand from the CDs and NCDs has hindered the Kenyan government from achieving the millennium development goals (Wamai, 2009).

Being the most common endocrine metabolic disorder in children and adolescents worldwide, incidences of the T1DM are said to be increasing. It is not rare in the African context as was once believed by many (Majaliwa *et al.*, 2008). Data on prevalence of T1DM in adolescents and children in sub-Saharan Africa remains an estimate. The International Diabetes Federation (IDF) 2007 estimates that there are 39000 cases of children with T1DM in Africa. In Kenya the prevalence of T1DM is estimated at 5-10 % (Weru, 2008). At the Kenyatta National Hospital pediatric diabetes clinic, where the adolescents to be included in the study were recruited, 75 % of the children and adolescents face challenges managing their T1DM (Ngwiri, 2008).

Good diabetes management requires a lot of time and effort, especially in the beginning. People with Type 1 diabetes must be constantly vigilant for episodes of extremely high blood sugars (hyperglycemia) and extremely low blood sugars (hypoglycemia), both of which can be life threatening. T1DM may make one feel different from other people, and there may be times one feel resentful that one always has to incorporate diabetes planning in everything one does (Wysocki, 1993). Type 1 diabetes is also influences the relationship between adolescents and their families. Given that diabetes management must be integrated into the family's lifestyle, it is likely to affect every family member. Parents often become involved in aspects of their teenagers' lives that they would otherwise ignore (Wysocki, 1993).

The increased responsibility and demands of diabetic treatment can lead to parent-child conflicts. Furthermore, parental involvement may be in conflict with the adolescent's developing sense of autonomy (Anderson *et al.*, 1990:477). As diabetes control is considered a family enterprise, such parental involvement in the adolescent's life is associated with the development of problems in the

parent–child relationship (Wysocki, 1993). In addition, having diabetes affects school life and vice versa as the presence of diabetes may be associated with poor school performance and poor diabetes management (Faro, 1999). Adolescence is a period of major physiological and psychological changes, and is characterized by an effort in young people to establish their identity and gain independence. Teenagers with T1DM have the additional burden of diabetes management. Blood sugar control usually deteriorates during adolescence. Although this deterioration is partly related to hormonal changes of puberty, and to social and behavioural problems, non-compliance with the treatment regimen is of equal importance, as is knowledge of the illness and its treatment (Pound *et al.*, 1997).

For most adolescents, school is a powerful influence in their lives since they spend up to thirty percent of their time there (Lehmkuhl and Nabors, 2008). Studies done previously showed that better school- based diabetes care for adolescents was related to better diabetes management (Wagner, 2005); while greater satisfaction with diabetes self-management support from their schools was associated with better metabolic levels in adolescents with T1DM (Lehmkuhl and Nabors, 2008). Unfortunately, studies have also shown that many schools do not provide adequate support for students with diabetes. In many cases, knowledge and training of school personnel is inadequate (Amillategui *et al.*, 2007), healthy food options in the school setting are also limited (Nabors *et al.*, 2005) adolescents with diabetes felt stigmatized or experienced discrimination by school personnel (Amillategui *et al.*, 2007), and school rules interfered with students' disease self-management (Hayes-Bohn *et al.*, 2004). While several studies have focused on advancements in the clinical management of diabetes, particularly technological advancements in diabetes care, the risk factors and complications of living with the disease (Majaliwa *et al.*, 2010) a combination of

home-based and school-based challenges are less often documented, more so the qualitative approach and hence the focus of this study.

1.2 Statement of the problem

T1DM is on the rise in Kenya, and the trends are very difficult to predict or prevent (Maina, 2007). The problem is even compounded by the absence of data on the incidences and prevalence among adolescents (Majaliwa *et al.*, 2008). The real number of people living with diabetes in Kenya is unknown: data for most regions, including Nairobi is unknown (Maina *et al.*, 2011). Although data on the prevalence of T1DM is unknown, close to 100 adolescents with T1DM are being followed up at the Kenyatta National Hospital in Nairobi, out of which, 75 % face challenges in managing their T1DM. Furthermore, the control of blood sugar and the general management of T1DM related complications among adolescents has not been reliably evaluated in Kenya. In absence of such reliable data, the effectiveness of the therapies and interventions cannot be determined or foretold (Ngwiri, 2008).

According to the diabetes management plan of 2009, all persons above fourteen years should manage their own diabetes (IDF, 2009). Therefore adolescence is a particularly critical time for young people with diabetes, since the management of the disease rests upon them. Whether diagnosed in childhood or adolescence, during this transitional period young people learn to take responsibility for and manage their own diabetes. As they integrate self-management of diabetes into their emerging lifestyles, adolescents directly experience the relationship between their actions and their blood glucose levels, which influences their management plan (Stewart *et al.*, 2005:239). Adolescence is also a stage at which a young person faces physical, behavioural, and social changes that can be challenging to manage. For a diabetic adolescent, these challenges are doubled, as they have to deal with their normal physical development and the management of type

1 diabetes that is involving. This additional pressure to test blood glucose and administer insulin can mean that the disease may increasingly intrude into other aspects of the adolescent's life such as choice of foods, relationship with parents, choice and relationships with peers, attendance to parties, as well as the academic life of the young person. (Stewart *et al.*, 2005:242).

When these aspects of their life are affected, the adolescents not effectively manage the disease or solve problems. When they fail to effectively manage T1DM, the effects of ketoacidosis, chronic high and low blood sugar can lead to coma and death, and other diabetic complications such as cardiovascular disease, renal disease, diabetic retinopathy and peripheral neuropathy. The complications may hinder the achievement of the social pillar of Kenya's vision 2030 aimed at improving the quality of life of all the citizens, and generally affecting development. The study sought to bring out evidence that adolescents with type 1 diabetes mellitus face several challenges that need to be addressed in order to manage the T1DM so as to prevent and combat its adverse complications. The study sought to answer the following questions:-

- i. What are the home based challenges faced by adolescents with type 1 diabetes mellitus in Nairobi City County?
- ii. What are the school-based challenges faced by adolescents with type 1 diabetes mellitus in Nairobi City County?

1.3 Objectives of the study

1.3.1 The general objective

To explore challenges faced by adolescents living with type 1 diabetes mellitus in Nairobi City County.

1.3.2 Specific objectives

- i. To establish the home based challenges faced by adolescents with type 1 diabetes Mellitus in Nairobi City County.
- ii. To examine the school-based challenges faced by adolescents with type 1 diabetes mellitus in Nairobi City County.

1.4 Assumptions of the study

- i. Adolescents with type 1 diabetes mellitus face home based challenges.
- ii. Adolescents with type 1 diabetes mellitus face challenges while at school.

1.5 Justification of the study

According to the International Diabetes Federation (2007:30), the number of people with diabetes in Africa is expected to double in fifteen years. T1DM is a complex disease that presents challenges to the sick person and the people in their surroundings. The information on the challenges it presents is lacking in most literature. Most studies are on the complications, and risk factors and thus this study (Majaliwa *et al.*, 2010). In cases where information is available, it is quantitative and thus the qualitative approach by this study (Maina *et al.*, 2011). Although data on the prevalence of T1DM is unknown, close to 100 adolescents are being followed up at the Kenyatta National Hospital in Nairobi, and 75 % of the adolescents face challenges managing their T1DM (Ngwiri, 2008). This study brought out some of the challenges faced by the adolescents, because most studies generalize them as children and fail to isolate them as people with different needs from those of children. This study was justified because adolescent specific studies are limited. By using the qualitative data collected from this study, the health care providers will be able to raise awareness on the health needs of the adolescents with T1DM. Public health practitioners will also

benefit from the research, as they will be able to improve the interventions for the adolescents. The education sector in Kenya may benefit from this study if the policy makers' use it to develop a diabetes policy for the learning institutions.

1.6 Scope and limitations of the study

The study included adolescents with type 1 diabetes Mellitus and those who had no other health complications. The adolescents were in the age bracket of 14 to 18 years, had lived with the disease for over a year, attend their diabetic clinic at the Kenyatta National Hospital, and also attend a secondary school. The adolescents were also to be residents of Nairobi City County. This study being an exploratory research, a small sample size was used and, the findings were not generalizable to the population at large. The study therefore provided context based, in-depth information on challenges faced by adolescents with T1DM.

Due to the few number of adolescents within the age bracket that was selected for this study, the researcher had to visit the pediatric OPDC at KNH many times to attain the desired number. The study was also limited by the fact that the researcher was dealing with people who were terminally ill. The researcher therefore excluded the very sick and hospital admitted cases. Some of the informants expected immediate financial gains from the study. The issue of studying a young population was a limitation to the study because the researcher had to rely on parental consent. The study was limited to the home based challenges such as conflicts with parents, stigma from friends and peers and, stigma at social events as well as the inaccessibility of health services. The school-based challenges faced by adolescents with T1DM included the inadequate information, education and communication on the part of the school personnel, administrative factors, scheduling of functions and the inappropriate school environment.

1.7 Definitions of key terms

Adolescents- these are individual who are in the age bracket of 14 to 18 years of age and are in a secondary school.

Diabetes- is a “metabolic disorder caused by different factors characterized by a chronic high level of blood sugar with disturbances to carbohydrate, fat, and protein metabolism resulting from defects in insulin secretion, insulin action, or both.

Type 1 diabetes mellitus- is a metabolic disorder characterized by the loss of insulin-producing beta cells of the pancreas, resulting in a deficiency of insulin.

Home based challenges- these challenges refer to problems that adolescents have interacting with parents, peers, while at home, or have problems engaging in normal social behaviors as well as the inaccessibility of health services.

School-based challenges- refer to the administrative factors such as strict school rules, inappropriate school environment, scheduling of school functions such as meals, and the inadequate information, education and communication among the school personnel and students that hinder diabetic adolescents from managing T1DM.

Shifting perspectives model- the model that states that adolescents with T1DM continually shift from an illness in the foreground perspective to the wellness in the foreground perspective depending on the circumstances they find themselves.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This section presents the literature related to the study, focusing on the nature of T1DM, home based challenges of adolescents living with T1DM as well as the school based challenges. This section also discusses the theoretical and conceptual framework that was adopted for the study.

2.2 Nature of Type 1 Diabetes Mellitus

Type 1 diabetes mellitus (T1DM), also termed juvenile-onset or insulin-dependent diabetes, is an autoimmune disease and a metabolic disorder characterized by T-cell-mediated destruction of pancreatic β cells, resulting in insulin deficiency and high blood sugar. In 2007, it was reported that 437,500 children were affected by T1DM worldwide. About 70,000 children aged less than 14 years are developing T1DM per year, (200 children daily) with a reported annual global increase of about 3%, particularly in younger children. Diabetes is a world silent killer that claims more people's lives than does HIV/AIDS (IDF, 2007:30).

Further statistics indicate that person dies every ten seconds from complications arising from diabetes and in the very ten seconds, two people are diagnosed with diabetes (Baillie, 2008). In the United States of America, 186,000 young people under the age of 20 years had diabetes in 2007, while Canada which has the sixth highest occurrence of T1DM of 3 -5% per year in children under 14 years (Baillie, 2008). In Africa, the prevalence and incidences of T1DM remains controversial despite few studies indicating a slight increase. Its burden is huge in developing countries due to lack of basic means for reaching a reasonable glycaemic control. Due to

unavailability of reliable epidemiological data, the natural history of type 1 diabetes, including its complications is largely unknown (Majaliwa *et al.*, 2008).

The few data available on Sub-Saharan African children estimated an incidence of 1.5/100,000 in Tanzania (Majaliwa *et al.*, 2007), and an increase in incidence from 9.5/100,000 in 1991 to 10.3/100,000 in 1995 in Sudan, has been reported (Elamin *et al.*, 1997). In a Sudanese study it was reported that 10% of children were not admitted at the time of diagnosis, being admitted only after they develop diabetic ketoacidosis (DKA) or hypoglycemia. Most studies have shown a high prevalence among the Sudanese (Elamin *et al.*, 1992). There are 10.1 cases in every 100,000 Sudanese children who are under 15 years on age, with a major peak of 12 years in girls and 14 years in boys (Elamin *et al.*, 1992).

In Kenya, the prevalence of diabetes is estimated to be 5-10% (Weru 2008). This figure is based on regional projections and is likely to be an underestimation as over 60% of people diagnosed to have diabetes in Kenya, usually present to the health care facility with seemingly unrelated complaints. The estimated diabetes prevalence in Kenya ranges between 2.7% (rural) and 10.7% (urban). The prevalence of impaired glucose tolerance is 8.8% (rural) and 14.4% (urban). The real numbers of people living with diabetes is unknown: data for most of the regions is not available. In 2003, non-communicable diseases (diabetes, cardiovascular diseases, chronic lung diseases and cancer) contributed 53% of hospital admissions in Kenya. Diabetes accounted for 27% of these hospital admissions (Maina *et al.*, 2011).

The cause of T1DM is largely unknown, but it is thought that a genetic predisposition, environmental factors, and distinctive metabolic changes are involved in the initiation, development, and progression of the disease. Insulin deficiency in T1DM leads to increased glucose in the blood, elevated metabolism of free fatty acids, and the generation of ketone bodies,

resulting in diabetic ketoacidosis. The primary clinical signs of T1DM are ketoacidosis—, which can lead to coma and death — and chronic high blood sugar. Chronic high blood sugar is the primary cause of several macro vascular and micro vascular diabetic complications, including cardiovascular disease, renal disease, diabetic retinopathy and peripheral neuropathy (Baillie, 2008). Other symptoms include frequent urination, increased thirst, increased hunger, and fatigue and weight loss.

Insulin-replacement therapy is the life-saving first-line treatment for T1DM. However, although intensive insulin therapy for T1DM is lifesaving, it is not a cure. Drug compliance among diabetes patients, like in many other chronic diseases is poor, and this results in long time complications and subsequently poor quality of life. This is even more a problem among patients of T1DM who are insulin-dependent and have to cope with multiple daily insulin injections. The T1DM patients may at times omit insulin doses out of carelessness and this could lead to an increase in ketones in the blood and this could be life threatening. Management of the disease and prevention of the complications requires constant checks of the blood sugar levels, proper insulin administration, proper diet and appropriate physical exercises (Peyrot *et al.*, 2005: 1382). The adherence to these management practices was affected by several factors that are discussed in the subsequent sections.

2.3 The challenges faced by adolescents living with T1DM

2.3.1 Home based challenges

Lifestyle diseases such as diabetes require a different yardstick for management, unlike other communicable diseases (Jacobson *et al.*, 1996:511). Patient participation is crucial in the management of diabetes and these may appear very challenging to the patient as well as affect negatively on the overall feeling of wellbeing (Peyrot *et al.*, 2005:1379). Diabetes puts many

demands on lifestyle and poses debilitating and life-threatening complications which overall have a negative impact on a person's well-being and social life. A lack of understanding of the disease by their peers, family members and teachers also makes it difficult for them to adjust to their new situation. (Peyrot *et al.*, 2005:1381).

Adolescents begin to spend more time in the presence of their peers as they seek to gain insight into the normal rules of behaviour, and the process for identity formation (Cheung *et al.*, 2006:53). The guidance, emotional support and understanding that were once bestowed upon the individual by parents are now sought out from peers (Cheung *et al.*, 2006:54). Although social relationships are important in determining the quality of life of most individuals, these relationships with friends are particularly influential for adolescents with diabetes, affecting not only their quality of life, but also their overall state of health (Faro, 1999:301). Despite an increased need for support among adolescents with chronic illness, several researchers have found that chronically ill adolescents spend more time in isolation, and have fewer friendships than healthy individuals (Cheung *et al.*, 2006:55).

Fears of appearing different from peers and feelings of self-consciousness often overwhelm the chronically ill individual, leading to decreased efforts and motivation to initiate friendships with healthy individuals (Cheung *et al.*, 2006:55). Social interactions may be further limited by the unwillingness of the adolescent to test blood glucose in a public setting for fear of blood-borne disease, and the possibility of contracting an illness (Cheung *et al.*, 2006:55). When adolescents do choose to engage in social activities, they often decide not to check blood glucose levels, administer insulin, or eat foods that are different than their peers in an attempt to appear normal (Hanson *et al.*, 2008:34). The restrictive nature of the diabetes regimen might also interfere with

the teenager's participation in a variety of social activities, including sports, driving, and dining out with friends.

Type 1 diabetes is a demanding chronic illness that influences patients' everyday life, and has particular implications on adolescents and their families. Given that diabetes management must be integrated into the family's lifestyle, it is likely to affect every family member. Parents often become involved in aspects of their teenagers' lives that they would otherwise ignore. The increased responsibility and demands of diabetic treatment can lead to parent-child conflicts. Furthermore, parental involvement may be in conflict with the adolescent's developing sense of autonomy (Wysocki, 1993). The growing autonomy and creation of a personal identity are important developmental tasks of adolescence. These tasks may be more complicated for adolescents with T1DM because, at this time in their lives, both metabolic control and treatment compliance are likely to deteriorate.

It has been found that less parental involvement in diabetes care is associated with poorer diabetes outcomes (Wysocki, 1993). In contrast, adolescents whose parents remain involved in their self-care activities have better compliance and more effective blood sugar control. However, increased parental involvement in diabetes management is also reported to create diabetes-related family conflicts. Indeed, high levels of family conflict, and low levels of family cohesion and support, are associated with poorer metabolic control and poorer compliance with treatment among adolescents, (Wysocki, 1993). Another effect of diabetes on parental behaviour is the high burden of stress that parents carry for the wellbeing of the affected child. Parents often express excessive worry over diabetes and its treatment, especially concerning high and low blood sugar levels and long-term diabetes complications, in addition to the usual adolescent activities such as driving. This worry is often expressed by intrusive behaviours such as nagging, scolding, asking too many

questions and giving orders, (Davis *et al.*, 1996:455). Sometimes, parents will question their adolescents' management decisions, resulting in disrupted communication and resentment.

Another reason for child–parent conflict is the lack of understanding in the parents, leading to intrusive and blaming behaviours. Thus, although these parents are attempting to help, they are, in fact, suggesting that their child or adolescent is incapable of managing the diabetes rather than truly helping their child to learn how to manage the illness, (Davis *et al.*, 1996:455). Adolescents, on the other hand, consider their parents' behaviour as “annoying” and, at times, accuse them of “losing sight of them as people” and of seeing them solely as “having diabetes”, (Davis *et al.*, 1996:455). They may also feel frustration and guilt over the effect of diabetes on their parents, and the stress it can cause to the family. Nevertheless, many families are able to raise their adolescents with T1DM without excessive trouble. These families approach problems with warmth and empathy, rather than hostility and anger, and have clearly defined goals and expectations. By anticipating imperfection in self- management, they encourage the appropriate level of autonomy, using social support systems and effective communication to solve the problems together (Wysocki, 1993). In middle childhood, as children spend increasing amounts of time outside of the family, they become affiliated with peer groups, spending more time with them and deriving significant support from such friendships (Bearman *et al.*, 2002:417). The support of friends for an adolescent with diabetes is mostly orientated towards companionship (such as during exercise) and emotional support, and less frequently towards helping with insulin injections and blood glucose testing.

Also, girls have more support than boys for diabetes control and emotional problems, which may be attributed to the more intimate nature of female compared with male friendships (Bearman *et al.*, 2002:420). There is some indication that friends' support for blood glucose testing is predictive

of compliance in diabetes and may be related to the adolescent's disease adaptation and quality of life. Nevertheless, peers may sometimes lack sufficient knowledge of diabetes and of the importance of daily care management, so they may not support the diabetic friends in a regular and consistent manner, and may even have an influence that is either neutral or detrimental to the daily care regimen (Bearman *et al.*, 2002:421).

Adolescents with diabetes are no different from their non-diabetic peers as regards dating attitudes, as they have similar psychosocial maturity (Pacaud *et al.*, 2007). However, they tend not to focus as much on intimacy in their relationships as their non-diabetic peers, and look for romantic partners who can offer them security, support and assistance in a stable relationship (Krenke, 2000) addition, adolescents with T1DM are reported to experience less trust and less of a sense of intimate friendship in their love relationships than their non-diabetic peers (Jacobson *et al.*, 1997) which suggests specific feelings of lower self-worth and self-esteem in social relationships. Access to healthcare while at home is also an aspect that needs attention. Studies have shown that there are obstacles that hinder the adolescents from accessing insulin, hospitals and health professionals (Mcfaren, 2008).

2.3.3 School-based challenges

School-aged adolescents with diabetes must contend with a range of issues and feelings that vary with developmental stage contrary to their counterparts who do not have the disease. Feeling different from their peers is the most common challenge they must face both socially and while at school (Faro, 1995). Separating from parents when starting or returning to school also causes school adolescents with diabetes to fear for their safety. This is because they are not sure whether the teachers, school nurses and other staff are adequately educated and informed to deal with the

high blood or low blood sugar levels (Gray *et al.*, 1991). Furthermore, most schools meals are at a specific time and yet diabetic adolescents have a meal plan drawn to them by a nutritionist (Brenner *et al.*, 2000). Some learning institutions may refuse to admit students who are diabetic, and to those who are admitted, schools may not provide the adequate and necessary assistance in the testing and monitoring of blood glucose and insulin administration. The schools may also prohibit the adolescents from having the snacks, especially in classrooms (Brenner *et al.*, 2000).

In Kenya, it is the responsibility of the parents to explain the condition of their children to the school so that they can allow the adolescents to access the snacks when signs of low blood sugar present. The parents may also ask the schools to provide an appropriate diet to the adolescents. Despite this, efforts by the parents to make the schools take responsibility of the adolescents, school nurses do not take responsibility for administering medication. Some schools even lack nurses. Adolescents on the other hand face a problem of having to let their peers learn about their diabetic condition. This simply means that they are ‘different’, something that is naturally difficult to face and live with (Faro, 205). In addition, the cultural myths and the ‘labelling’ associated with the also a challenge. Some teachers are too harsh and become too loose in treating the adolescent as ‘different from others’ when they learn about the condition (Tolbert, 2009: 51).

There is stress and stigma associated with the school meals and the timing of the school functions. Given that most schools in Nairobi rarely offer healthy snacks, incidences of low blood sugar or high blood sugar are bound to occur. Exogenous insulin administration at social events also makes the adolescents feel different. Over and about, adolescents need flexibility, if they have to manage the disease, whether at home or at school. to facilitate the appropriate care of students with diabetes the school personnel must have an understanding of diabetes and its complications, and how it is supposed to be managed (Gray *et al.*, 1991:34). When dealing with the condition at school, it is

often unclear whether teachers have the legal responsibility to administer medication or provide medical assistance to a student with a chronic medical condition (Thomas, 2006). This is because the treatment of diabetes often involves handling of blood, and could therefore place at risk the teacher and the student.

The proper management of diabetes is a complex process that requires a proper collaboration between the adolescent with diabetes, the school care provider and staff, peers and the medical practitioners. For instance, teachers should have proper knowledge of the signs and symptoms of T1DM, and how to deal with the medical emergencies such as high blood and low blood sugar. Failure to recognize the early symptoms could lead to losing consciousness, diabetic coma, and in extreme cases, death (Gould, 2002). It is unfortunate that teachers do not have an adequate understanding of diabetes and are therefore unable to recognize the medical and educational needs of these students (Mukherjee *et al.*, 2000; Nabors *et al.*, 2003 and Wagner *et al.*, 2005). A survey of 463 elementary school teachers in Arkansas showed that 90% of the teachers had never received training on diabetes, and only a few could identify the symptoms or appropriate treatment of low blood sugar. These results are frightening considering that this is a life-threatening condition (Gormanous *et al.*, 2002).

Hayes-Bohn *et al.* (2004) conducted a study with 30 adolescent females (13-20) years old who had T1DM. Through semi-structured interviews, the researchers learned about the girls' perceptions of the barriers and resources for diabetes management that existed in their schools. One of the issues brought up by several participants was the lack of healthy food choices available in the cafeteria. According to the girls, there was a high prevalence of junk food in the cafeteria and in the vending machines. Cafeterias often did not provide the nutritional information about the food they prepared, which made it more difficult for participants to accurately monitor their

carbohydrates intake. Other studies that have examined meals offered in cafeterias throughout the United States have called similar attention to the fact that very few cafeterias provide healthy food options (Hayes-Bohn *et al.*, 2004).

Although the participants were mainly concerned with the lack of healthy food choices offered by the cafeterias, several girls also commented on the difficulty of adhering to the diabetic regimen when friends or teachers offered them treats (Hayes-Bohn *et al.*, 2004). According to several of these individuals, teachers often brought in candy or other sweets as a reward for their class. This practice made the girls feel excluded and singled out, as their classmates noticed when the girls refused to eat the treats. For participants who preferred to keep their diabetes a secret, the teacher's act of generosity resulted in feelings of discomfort and humiliation.

When schools are inflexible with their rules, students with diabetes may be placed at a disadvantage. Rules that prohibit the presence of syringes at school mean that students with diabetes must go to the nurse's office where they can be supervised administering their insulin. For individuals who prefer to keep their condition hidden from their peers, this process of leaving the classroom so that they can be supervised by an adult is embarrassing. Studies by Hayes-Bohn *et al.* (2004), and Wagner *et al.* (2005) indicate that many students are required to leave the classroom before checking their blood glucose levels or administering doses of insulin.

According to Wagner *et al.* (2005), 56% of children who participated in their study had to go to the nurse's office, main office, or their locker when giving an injection during school hours. The children who were required to leave the classroom had poorer metabolic control than those who were allowed to monitor their condition in the classroom. Leaving the room to manage their diabetes meant that the students would miss class time, a fact that many students described as being an inconvenience (Wagner *et al.*, 2005). Some teachers also refused to allow students to eat or

drink in the class, or to go to the bathroom as needed, because they did not believe it was fair to the other students in the class who had to follow rules established by the school (Hayes-Bohn *et al.*, 2004).

As such, many individuals with type 1 diabetes experienced difficulties maintaining a consistent level of metabolic control while at school (Hayes-Bohn *et al.*, 2004; Nabors *et al.*, 2003). By refusing the students their rights to fulfill diabetes-related needs, schools were unnecessarily placing students with T1DM at risk. Because of the general lack of diabetes knowledge among school staff, children with diabetes are often unnecessarily denied the opportunity to participate in extra-curricular activities (Mukherjee *et al.*, 2000; Nabors *et al.*, 2003; Wagner *et al.*, 2005).

2.4 Theoretical model

2.4.1 Shifting perspectives model

Following a metasynthesis of 292 qualitative studies of chronic illness, Paterson (2001) developed the Shifting Perspectives Model of Illness. Unlike previous models that depicted the adaptation to life with an incurable disease as being a phased process in which a person follows a predictable path, the shifting perspectives model assumes that the experience of living with a chronic illness is an ever-changing process. According to this model, a person with a chronic illness assumed one of two perspectives, the illness in the foreground perspective, or the wellness in the foreground perspective. Although individuals may have a preferred outlook, they were likely to shift between the two several times over the course of their illness experience (Paterson, 2001:21).

While assuming an illness in the foreground perspective, an adolescent with T1DM focused on his or her sickness, and the burdens, suffering, and loss associated with it. The chronic illness was viewed as destructive to the self, and to others in their lives. People assuming this perspective

become absorbed in their illness experience, and may have difficulties attending to the needs of significant others. While this perspective was typically assumed by individuals who had been newly diagnosed, individuals who had previously assumed a wellness in the foreground perspective could assume an illness perspective when there was a threat to control such as signs of disease progression, an inability to manage the disease, or interactions with others that emphasize dependence and hopelessness (Paterson, 2003:987). For a disease such as diabetes where many of the underlying symptoms and pathologies such as presence of ketones, an increase/ decrease in blood sugar were invisible to a lay person, a focus on the illness and symptoms may allow the individual with diabetes to provide evidence to others that the illness is real. Focusing on the illness also helped the adolescent with T1DM to seek required attention from family members, healthcare professionals, and school officials (Paterson, 2001:21).

The second perspective that individuals may assume was the wellness in the foreground perspective. In this perspective, chronically ill people viewed their illness as being meaningful, and as serving a purpose in changing their relationship with the environment and with others. To achieve this perspective, individuals created a consonance between their self-identity and who they have become because of their disease. In doing so, individuals are able to accept the limitations that may exist, and view themselves as healthy beings (Paterson, 2001:23). They believed that in viewing themselves as healthy, chronically ill individuals were not distorting reality, but re-examining what is possible and normal. At this point the self, and not the diseased body, becomes the source of identity and this is important for the diabetic adolescents who are forming an identity. Individuals assumed a wellness in the foreground perspective by learning as much as possible about the illness, identifying the body's unique patterns of responses, and sharing their knowledge with others.

2.4.2 Relevance of the model to the study

The shifting perspectives model was relevant to this study because diabetes is also a chronic disease that individuals not only followed a single trajectory in its management, but also took various channels depending on the situation they were in. When the adolescents faced challenges such as conflicts with parents, stigmatization, inaccessibility of health services, and the inappropriate school environment, they focused on the illness in the foreground perspective. The illness in the foreground perspective could result into increased/decreased blood sugar levels which could be disastrous. When the adolescents face the challenges but adopted the wellness in the foreground perspective, they only focused on the identity they had acquired by having T1DM and thus despite the challenges, they practiced the diabetes management to achieve a normal blood sugar level. Using this model helped the researcher to provide an explanation as to why adolescents with diabetes had varied attention their disease. Sometimes they attended to the symptoms in ways that seemed ill advised by their peers or self, or even harmful to their health. The model also helped the health professionals to know what perspectives the patient had about their condition and thus knew what support to offer to the diabetic adolescents. This was because they faced different challenges that required specialized attention for them to achieve a wellness in the foreground perspective. This can be conceptualized as shown in figure 2.1.

2.5 Conceptual Framework

This conceptual framework has been formulated from the shifting perspectives model of Paterson (2001).

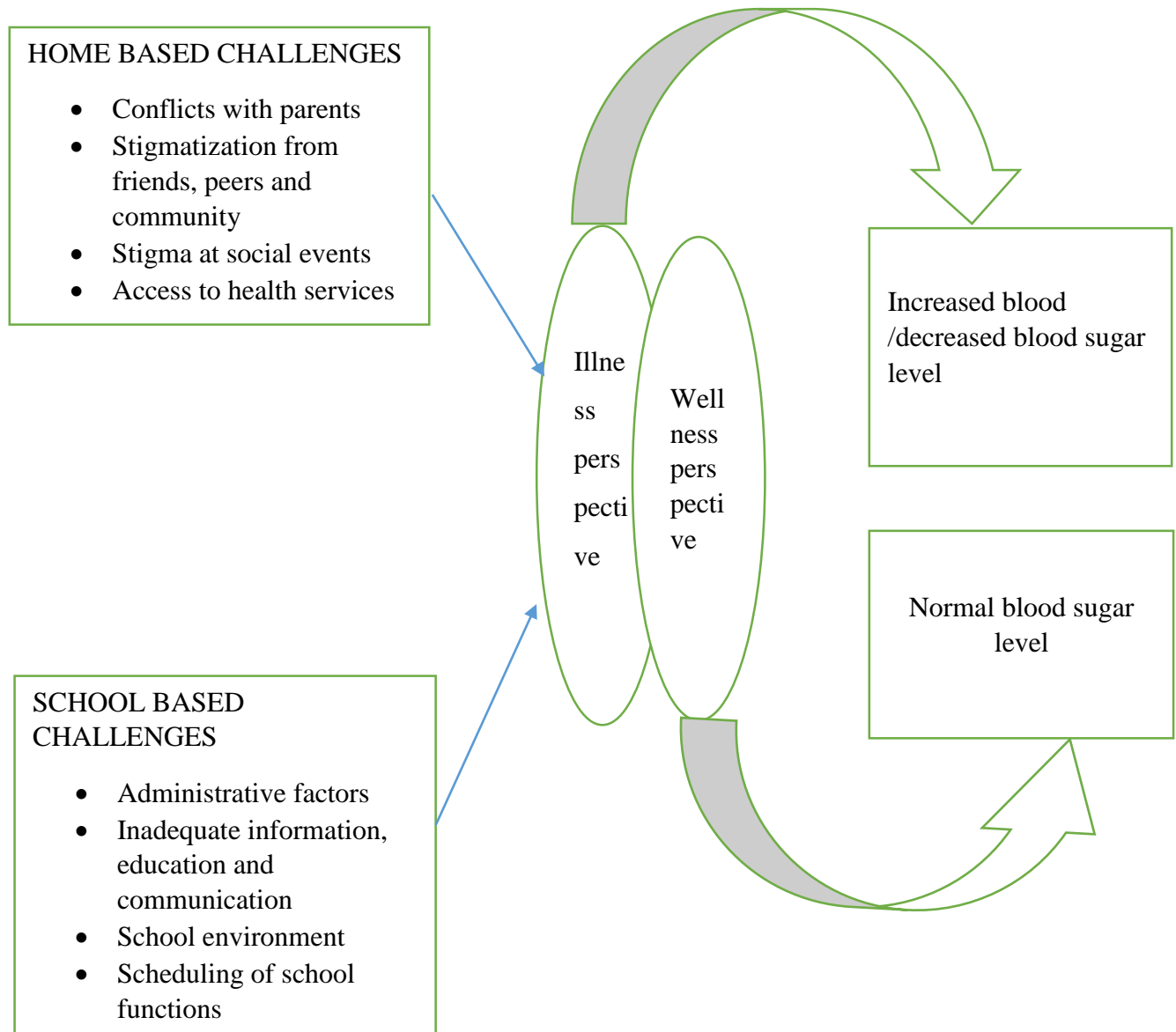


Figure 2.1 Conceptual model (Source: Author's study, 2014).

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This part presents the methodology of the study. It describes the research site, research design, the study population, the sample population and sampling procedure, the data collection methods and the methods that were used for data processing and analysis. It ends by describing the ethical considerations that that taken were into consideration during the study.

3.2 Study site

The study site was the pediatric outpatient diabetic clinic at the Kenyatta National Hospital (KNH) in Nairobi City County, Kenya. Kenyatta National Hospital is located in Dagoretti constituency, Nairobi City County. Studies have shown that, diabetic patients occupy 58 per cent of the total bed capacities in the hospital. Of the adolescents who visit the hospital 75% of them are unable to manage their blood glucose (Maina *et al.*, 2011). The recruitment of the adolescents was done at the KNH and then the researcher followed them up to their home in Nairobi City County where the interviews were conducted. During adolescent recruitment, they also identified the teacher, /school care giver/ nurse that attended to them while at school. For the school care givers, they were interviewed at the school during break time. The five health care providers from the hospital were selected from the pediatric diabetes clinic and interviewed from there. Figure 3.1 shows the location of the study site.

accompanied by a parent/caregiver to ensure that oral consent was sought. The researcher visited the hospital on Tuesdays, when the hospital held its consultations and clinics for the children and the adolescents with diabetes for their recruitment. The health care providers and teachers were also recruited during this phase.

The adolescents who were the main study subjects were then followed up to their homes for the key informants to be conducted. The second stage involved collection of data using an in depth interview guides and key informant guides. Data collection took three months. Key informant interview guides were used to collect data on the adolescents with T1DM in their homes, while in-depth interviews were used to collect data from the health care professionals at the hospital and the teachers school/care givers at school.

3.4 Study population

The target population consisted of all adolescents aged 14-18 years with type 1 diabetes mellitus at the Kenyatta National Hospital. A participant inclusion criterion was adopted, where adolescents between the ages of 14 and 18 years, who had been diagnosed with T1DM for at least one year. The adolescents were also to no other significant health problems were selected to ensure that only challenges resulting from T1DM are documented. The adolescents were also to be studying at public or a private secondary school in Nairobi County, Kenya.

3.5 Sampling procedure and Sampled size

A purposive non-probability sampling method was used to recruit the fifteen adolescents who were accompanied by their parent through the solicitation of volunteers from Kenyatta National Hospital. The adolescents also identified fifteen teachers/school caregivers during their recruitment. The school care givers and the five health care providers were also selected by the

same sampling method. The sample size of the adolescents comprised of 15 adolescents with T1DM in the age bracket of 14-18 and 15 teachers/ school care providers. For the in depth interviews included five health care providers. This was based on the works of Hardon (2001) on the rule of thumbs for qualitative data collection. A total sample size of thirty five people were selected for this study.

3.6 Data collection methods

The data collection methods used in this study were in-depth interviews and key informant interviews. Secondary methods of data collection were also used in this study.

3.6.1 Key informant interviews

These were conducted with fifteen adolescents with type 1 diabetes mellitus using an in-depth interview guide (Appendix 2). This being the main tool of study, its aim of was to obtain information on the home based and school based challenges faced by adolescents with T1DM. The interview sessions were tape recorded on a digital wave model of a tape recorder after consent forms were signed. The interview session were conducted at the adolescents' home, and they last for forty five minutes to about an hour.

3.6.2 In-depth interviews

These were conducted with the five health care professionals at the pediatric OPDC (Appendix 3) who attended to the adolescents and fifteen school caregivers (Appendix 4) who has knowledge of their health condition. The interviews with the school caregivers conducted at school and they lasted for thirty minutes. They were be face-to-face interviews aimed at generating knowledge on

the challenges facing adolescents with T1DM to help build on the information that was collected from the adolescents.

3.6.3 Secondary sources

Information on the home based and school based challenges faced by adolescents with T1DM was obtained from journal articles, the internet, books and theses. The information obtained from such literature sources helped to build discussions for the primary data collected from the adolescents.

3.7 Data processing and analysis

Data obtained from this study was purely qualitative and thus the researcher first transcribed all the notes from all the interview sessions. Data analysis was done through thematic analysis. Field notes and interview transcripts were read and re-read to gain a general impression of the emerging themes. The themes were categorized depending on the basis of the informant and interviewee, and the frequencies of how they appeared were tallied. The researcher sought for common themes among the informants, as well as identification of differences. Verbatim quotes were used to build up the cases of the challenges being faced.

3.8 Challenges encountered during data collection and their solution

Due to the few number of adolescents within the age bracket that was selected for this study, the researcher had to visit the pediatric OPDC at KNH many times to attain the desired number. The researcher also returned to the clinic to recruit other informants, after two of initial recruits gave very little information and even after several trials of convincing, they never opened up. It was also a big task to convince the key informants at the pediatric OPDC that this study was equally important since they thought that the solution of low blood sugar was in insulin taking. At some

point, the researcher had to stop the recruitment because the nurses would call the patients and tell them that their work was important than what the researcher was doing.

However, a clear explanation of the purpose of the study resolved this. The diabetic adolescents also kept referring to the researcher as ‘doctor’ and would even ask medical related questions on diabetes this was addressed by explaining to them the scope of the study. The researcher also referred them to their respective nurses and doctors for further clarifications. Some of the patients thought that there were some financial gains since they got free insulin from the NGOs in case they were called for interactions. This was addressed by informing that this was an academic research that was based on voluntary participation and that there were no immediate financial benefits but the study would be of benefit to them in the future.

3.9 Ethical Considerations

Before commencement of this study, a proposal was submitted for ethical review at the Kenyatta National Hospital/ University of Nairobi Ethical Review Committee. The approval was granted and the reference number is KNH-ERC/A/246. Protection of the participants’ rights and the need for confidentiality and anonymity was taken as central to the research process. The study informants were selected on the basis that they are accompanied by their parent so that the purpose and objectives of the study are explained to them in presence of the participants before the study. This was for the purpose of oral consent of the parent and adolescents. Before commencement of the study, the purpose of the study was explained to the adolescents and then informed consent forms were signed before the interview sessions.

After the study, the information collected on tapes was deleted and the interview notes were burnt. The researcher made available the findings at the KNH library, and upon request by the adolescents the data will be shared with them. The study also sought ethical clearance from NACOSTI

(National Commission of Science, Technology and Innovation), reference number NACOSTI/P/14/1760/1010 and, an introductory letter from the University of Nairobi was obtained. The results of the study were availed at the University of Nairobi Library and the NACOSTI's library.

CHAPTER FOUR

HOME BASED CHALLENGES FACED BY ADOLESCENTS WITH TYPE 1 DIABETES

4.1 Introduction

This chapter begins by highlighting the socio-demographic characteristics of the adolescents. This chapter also presents their experience prior to the diagnosis with T1DM. The findings on the home based challenges faced by the adolescents living with T1DM are also presented in this chapter.

4.2 socio-demographic characteristics (n=15)

As indicated in Table 4.1, a majority (60%) of the informants in this study were females, were 15 years of age, and were in form one (53%). A majority (60%) of the informants had also stayed with the disease for a period of one to four years.

Table 4.1 Socio-demographic characteristics of the adolescents

Variable	Number of informants and the percentage
Age (years)	
14	2 (13)
15	9 (60)
16	2 (13)
17	1 (7)
18	1 (7)
Gender	
Male	6 (40)
Female	9 (60)
Level of education	
Form 1	8 (53)
Form 2	3 (20)
Form 3	3 (20)
Form 4	1 (7)
Duration with the disease (years)	
1-4	9 (60)
5-9	4 (27)
Above 10	2 (13)

(Source survey results 2014)

The findings of this study showed that there were more females than males with T1DM. A study by Majaliwa et al. (2007) found out that T1DM is more prevalent in girls than in boys. In studies from Ethiopia, Sudan, Nigeria and Libya, T1DM is more prevalent in girls than in boys (Majaliwa *et al.*, 2007; Elamin *et al.*, 1997). A study conducted in Kenya by Maina et al. (2011) also showed that there were many women with diabetes than the males. Of the targeted 2000 respondents, 1982 (99.1%) were interviewed in this study. There were more females 1151 (58.1%) than males 831 (41.9%) interviewed (Maina *et al.*, 2011).

According to the IDF (2009) the prevalence of T1DM is higher females than in males. For females who do not currently have diabetes, pregnancy may put them at risk of getting gestational diabetes (IDF, 2009). Although both sexes were equally affected in childhood, females were more commonly affected in early adult life than in teenage. There were many fifteen year olds in this study relating to the fact that this was the age when most of them had just moved away from home to boarding school, and that they were solely responsible for their condition. The duration one had stayed with the disease was important in the management of T1DM. This is because adolescents who have stayed with the disease knew how to deal with the disease more than those who were newly diagnosed. Studies also showed that prevalence of T2DM was higher in women than in men and that pregnancy presented them a risk of gestational diabetes. Gestational diabetes develops in 2% to 5% of all pregnancies but disappears when a pregnancy is over (IDF, 2009).

4.3 Pre-diabetes experience and understanding of T1DM

A majority of the informants (75% n=15) reported to have heard about diabetes but did not understand the meaning of the disease until they were hospitalized, and doctors had to explain to them what it was. Most of the adolescents were unaware of the symptoms and management of the disease prior to the doctor's explanations. The adolescents reported a smooth life of not having to

worry about what they ate and how to behave around their peers, before they were told that they had T1DM. The adolescents also noted a drastic change in their lifestyle, ranging from the kind of diet they have had to maintain, the type of friends they kept and even the interactions with their siblings. The diabetic adolescents indicated a great performance at school before they were told that they had T1DM. They reported being shocked that they had diabetes the very first time they were diagnosed with it. This is expressed in the one incident where a female adolescent explained her experience before...

'Life was sweet, interesting...it was a free world... I would eat anything and in whatever amount I wished. I would eat sweets, cakes (black forest was my favourite) but now I have to check the amount of carbohydrates I consume. I never liked vegetables especially the traditional vegetables. I now have to eat plenty of them and fruits too. We cooked and shared meals as a family but that is not the case now as my mum has had to prepare my food separately. This is my foods are not to be salted. My menstrual cycle was very regular and predictable, contrary to the case today where I can go for a year without the monthly periods. I never used to wear spectacles before I was told I had diabetes, but now things have changed. My school performance used to be very good. At one point I scored an A-grade in school. That has since changed as my last grade last term was just grade C... since I have had admissions going beyond a month when my blood sugar goes low (KII 001 16 years, Umoja).'

Another male adolescent gave his understanding and experience before T1DM. This echoed the sentiments of many other adolescents...

'I was shocked when I was told that I had T1DM and what I was supposed to do to maintain a normal life. This is because my life before was very interesting and very easy unlike today. The doctor told me that my body cannot produce insulin and that is why I have diabetes. I don't know how to explain to someone who does not know anything this not about this disease, because personally, I had not heard about it. I would easily mingle with every person of my age. I would do many things for my peers such as organizing our football tournament. I would not have to check the food I consumed. I would eat any amount of carbohydrates such as chips. I would attend birthdays freely: I would go shopping and even play in the field with my friends without having to care about my blood sugar level. This is not the case today (KII 002 15years, Dagoretti).'

Another diabetic adolescent also gave their experience before diagnosis with diabetes as follows...

'I couldn't pay attention in class, and I wasn't studying either. When I would try to read the required book for class, it didn't really work, because I would start sleeping even before I would complete any of them. I lacked motivation to go to school, and while I was at school, I was literally sleeping on the desks even during class time. If I was sleeping and was woken up, I would find my classmates laughing at me and when I would ask somebody what was going on, I would get into trouble for making noise during preps time. I had many punishments, and I would accept them, because one is not supposed to sleep or make noise in class. I think I got used to the punishments. It was just a normal thing to me. I just thought that I was overworking myself and it was my own fault for not studying. I did not care. But maybe I should have been keen enough to know this were signs of a looming problem (KII 003 14years, Savanna).

Although the above informant was not studying, she managed to pass her end of term examinations and thus even her teachers were not alarmed. The following term she went back to her old habits. Although she noticed that she had lost some weight and felt tired all the time, these symptoms never made her think of an underlying serious problem. Her teachers thought she was lazy and continued to punish her. Even if her teachers would have asked her, why she was so tired all the time, she would have mistakenly assumed it was because of overworking herself at home. When another adolescent was asked how diabetes had changed her life, she quickly made the following remarks...

'Diabetes has become a pretty big part of my life since I was diagnosed. You are always bothered about the level of your blood sugar, whether it is too high or too low. Being a diabetic means that my planning should always be more than what other adolescents plan for. I have to plan to always carry juice and a snack with me every time I step out. I have to think when next I have to attend my clinic, and when I should have my blood sugar tested. You have to consider when your insulin should be changed and the effects... and for us diabetics, it is really important to get a flu shot, so I have to think where and when I am going to get the shot. It is just a few extra things to think about all of the time and all of your life; things other people don't have to always think about (KII 004 15years, Githurai).'

Despite the many challenges that the informant from Githurai has of living with T1DM she is able to identify some of the benefits of living with this chronic condition. She focuses on diabetes not only as an illness but something that has helped her interact and form friendships...

'I think life is a lot easier without this diabetes. Although I guess I wouldn't be so aware of how important it is to be eating properly and even exercising and keeping my weight and blood pressure under check. I wouldn't have the friends from the diabetes management Centre who even aside from our shared diabetes, are some of my best friends. After being on media with diabetes educators from all over the Nairobi, I have realized that I am pretty lucky. Were it not for the diabetes I would not have been on the television (KII 004 15years, Githurai)'.

A nurse from the KNH stated that most of the time parents and adolescents were not prepared or even aware of what diabetes is, and that they always had a tough time explaining to them. The nurse said that it is usually shocking to the parents...

'Most adolescents are shocked when we diagnose them with type 1 diabetes. They do not even know what it is. You have to do a lot of explanation to them but they still do not understand what diabetes is. (They are young to understand anyway). Parents are equally shocked, and we have to do a lot of counselling for them to accept. Most parents think diabetes is a disease of the adults, only to be shocked at the diagnosis. Life changes a great deal for the newly diagnosed diabetics. They have to come for clinics every month, miss school and at times episodes of low and high blood sugar cause them long hospital admissions (Nurse 4, KNH)'.

Adolescents were stressed by the limitations they faced after being diagnosed. For example, previously enjoyed activities were no longer possible due to the challenges of the danger of severe low blood sugar levels or of carrying medical essentials and also the worries of parents that adolescents may be unable to take care of themselves outside their parents' homes. Many adolescents began to have challenges managing their sugar levels and experience side effects of low or high sugar levels. As one of the male adolescent noted:

'I feel really stressed when my blood sugar level is high. I begin to feel very sick and weak. Sometimes I vomit and become tired. I grow very slim that people begin to look at me as though I am infected with the HIV virus (KII 008 16 years, Kangemi)'.

In a study done in Kenya by Maina et al. in 2011, only 575 (29%) of respondents had good knowledge of signs and symptoms of diabetes while 1407 (71%) of respondents had poor knowledge on what diabetes is. 518 (26.1%) could correctly identify the probable causes of

diabetes mellitus while 1464 (73.9%) could not. Only 523 (26.4%) of the respondents could identify complications of diabetes they knew while 1459(73.4%) had very little or no knowledge of complications of diabetes. The findings of this study reveal a serious deficiency in knowledge of diabetes among community members in Kenya. Only 27.2% of the people interviewed had good knowledge of diabetes (Maina *et al.*, 2011).

There is a low level (perhaps under 30%) of public awareness and knowledge about diabetes in Kenya. Knowledge differs according to education and region. Most respondents have poor behaviours towards diabetes: 41% show an unwillingness to adopt healthier lifestyles. Although an increased level of knowledge is associated with good practice for diabetes prevention, 49% with adequate knowledge failed to put this into practice (Maina *et al.*, 2011). Puepet et al (2007) found a similar level of knowledge of diabetes, 30.2%, among patients with diabetes in Jos State, Nigeria (Puepet *et al.*, 2007). Dinesh and others, in a study in western Nepal, noted a lack of awareness of diabetes even in patients who had had the disease for a long time (Dinesh *et al.*, 2008).

4.4 Home based challenges faced by adolescents with type 1 diabetes

This section presents the findings and discussions in relation to the home based challenges. The challenges included the conflicts with parents, stigmatization from peers and friends, stigmatization at social events and inaccessibility of the health services. This led to an understanding of how the challenges affected the adolescents' management of T1DM.

4.4.1 Conflicts between adolescents and parents

While most parents were able to handle their children's post diagnosis, the feeling at the time of diagnosis was overwhelming to both the child and the parent. One female adolescent from a single parent family explained her problems with her parents as follows ...

'When I was diagnosed, with type 1 diabetes, it was difficult for me and my mum to handle it. I think it was the first thing that my mum couldn't teach me. For her, it was always like 'I have gone through that. Don't worry. You will sail through'. That was her first time she was like 'I haven't been through it. There is nothing I can do and I don't know what to do to change the situation'. It has been hard for her since I am her only child, and no one else in our family has had diabetes before. She was like 'why my daughter?' this disease has greatly affected our relationship, since she stopped looking at me as the normal child I was and instead looks at me as sick always. She annoys me by saying 'you know you are sick, you have to take care of yourself' (KII 005 15years, Umoja)'.

As was the case with many other parents, the mother to the informant from Umoja spent a lot of her time worrying about her especially when she was away from home, while in the informant's case, she felt that there was nothing to worry about.

'My mummy worries a lot about me when I am away from home, just like any parent would do, but I think her worry is ten times worse. This is because I go to a boarding school and be away from home and from her care. I therefore have to take care of myself. I remember one time she came to school panicking when one of the teachers (whose son is diabetic) informed her that I was not feeling well, yet it was just that my sugar levels were low because I had not taken any food. I could see the worry on her face. Although she tried to be calm, she later on quarreled me for not taking food and causing trouble on myself. She fails to understand the school meals are very boring at times that even if you are hungry, you just can't take it (KII 005 15years, Umoja)'.

Another male adolescent also expressed his worries, in that although he knew the impact of not testing the sugar levels, he would not test the levels and even when he did so, he would never say the exact level. This is because he felt that his parents were not allowing him to do his own independent things despite the fact that he felt he was of the right age...

'When I got to standard seven, I became a very cheeky boy. I would never tell the truth to my parents because they were just all over my case. When it was not my mother, it was my father. I would test my blood sugar level only when I felt like. I would test my blood sugar level that would show that I am near comatose but I would tell them the opposite. This is because my mum would shout at me as if it was my mistake that the sugar level was that high. I resorted to telling lies so as to prevent the quarrels from my parent. Sometimes I just chose not to test my sugar level so that mum shouts as was her norm (KII 006 18years, Embakasi)'.

One nurse at the KNH also expressed her disappointment in parents for the misunderstandings between the adolescents and their parents, but later stated that it out of the fear that their children would be hospitalized because of the low or high blood sugars.

'You know we get cases where children are brought here for their clinics and yet they haven't tested the blood sugar level for even a whole day. We even hear parents ask the children in our presence and even quarrel them in our presence because they say that the children are not taking charge. This tells us as professionals that the parents are not fully involved. In such situations we take the charge by testing the blood sugar level for we know that the teenager may not tell the right thing for fear of being quarreled again. We understand the fears of the parents but sometimes it is also the lack of knowledge on the part of the parents that the disease is really involving for the teenager. It is difficult (Nurse 3, KNH).'

The adolescents' frustration were often expressed in form of criticism or complaint. The frustration of the participants in this study was centered on them not meeting their diabetes management plan and parent's feeling of hopelessness in effecting change in the adolescent's behavior. The frustration on the part of the adolescents was outlined in such statements as... *'Mummy doesn't understand my situation at times and yet she wants to make all the decisions. Am a grown up'. I just do the wrong things at times just to annoy her.* Yet a different female adolescent from Kayole had this to say...

'Mummy never notices when you do the right thing like testing sugars on time. She seems to think that I forget that I am diabetic, something I can't forget even for a second in my life. She keeps on reminding me 'do you know your sugars will go up' just in case I want to test something sweet. You know it is not a taboo but she thinks so. I once told her that I will leave it to her to do everything for me even when am at school. At times she just becomes annoying (KII 007 17years, Kayole).'

All the informants indicated some incidence of diabetes-related conflict with their parents. The study identified three sources of conflict: parental worry, parental lack of understanding and blaming behaviors. Most of the informants described situations involving their parents' worries about diabetes and its treatment (such as high and low blood sugars), longer-term diabetes complications, as well as some typical adolescent activities like games. These worries often were

manifested in some behaviors such as nagging, scolding, asking too many questions, and giving orders. The adolescents reported that their parents often questioned their management decisions, resulting in disrupted communication and resentment. The adolescents described their parents' behaviors as “annoying” and, at times, as suggestive of their parents' losing sight of them as people and seeing them solely as “having diabetes.” The following statement from a male informant illustrated the theme:

‘The first year I got diagnosed, my parents asked me so many times, whether I was okay. And so, they made a rule that they can ask me whether I am okay more than once a day. When my grandmother asks more than once, and I totally lose it with her. Because I am so sick of everyone asking me if I was all right all the time when I’m fine. It’s not like I’ve changed because of diabetes (KII 012 15years, Zimmerman)’

Parents' concerns about the high and low blood sugars of their children sometimes led to immediate attribution of their adolescent's moods to blood sugar levels. This phenomenon was reported by most females. The girls further described how their parents were not always able to distinguish clearly between them and their diabetes. Parents were reported to have made statements such as, “*You must be high,*” or simply “*You’re low,*” based on the girl's mood. For example, one adolescent described her mother as worrying too much and then stated, “*My mom tends to blame my bad moods on an insulin reaction or a high blood or something.*” While acknowledging the importance of their parents' recognition of the symptoms of high and low blood sugar levels, the adolescents found it “frustrating” that they cannot “just be grouchy” without being reminded of their diabetes. In addition, the female adolescents asserted their need and wish to be seen as “normal,” when they stated that diabetes, “doesn't really change who you are” but rather “it's kind of what you do.” Many of the informants described conflicts with their parents during which the adolescent was blamed for mismanagement of the diabetes. Some of these situations resulted from parents' lack of understanding of the complexities of diabetes management. One-third of the informants recounted situations in which they were made to feel as if they had done something wrong to cause

a high or low blood sugar. Parents were described as reacting in highly emotional ways to high or low blood sugars. They also were reported to look for a single cause, usually involving food, for why high blood sugars occurred. One girl described her dealings with her father about high blood sugars in this way...

'My dad's still a control freak and, I mean, if your sugar level is high he asks you what you ate. He assumes that you broke all the management principles, and assumes that you are sick. Sometimes I could just be stressed out. I could be in my own world. Well, I wish he could be in my shoe but he just can't. Your blood level can get high from different things, but he thinks everything is related to food. My insulin shot could have leaked this morning without my knowledge. It doesn't all relate to food, just as my father thinks. (KII 013 15years, Huruma).

This boy described that he recorded false blood sugar levels in his log book so that his father could not continue to be angry at him. However, he also seemed to understand, that his father was “just scared” and “just looking out” instead of him “taking the time to understand.” Blame in relation to food and snacks was so pronounced that half of the female adolescents reported that their parents often hid sweets and other food from them. Several adolescents mentioned that they had siblings, and that it was a problem integrating their dietary restrictions into family life when siblings without diabetes are present. Parents hiding food generated strong emotional responses from the girls. As one of them described...

'It makes you feel hurt... why me? I wish it could just leave me, even for a day, but it cannot. The things my parents do at times makes me hate myself and my condition. They buy things and then hide it from me. I also do the same sometimes. You ask yourself why the discrimination but you remember it is because of the disease. Even foods are hidden from me. And at the same time, it's also annoying because they keep tons of sweets around the house, and they expect me not to touch any of it. (KII 014 15years, Kayole)'

Particularly interesting in the above statement was that, while noting her hurt feelings upon finding hidden foods, this adolescent also shared her struggle with restraining herself from eating these foods. Another common element in many of the adolescent–parent conflicts was parents' emphasis on avoidance of high blood sugar and its potential complications. This was especially true in

discussions of parental worry, blame for blood sugar levels, and the hiding of foods. Adolescents themselves were less likely to report fear or worry about complications. One adolescent explained his lack of concern about future complications by stating, “*My parents are worrying about me.*” These adolescents reported fear for vision loss, limb amputation, and other complications. Many of the adolescents focused more on low blood sugar reactions, which they had all experienced, rather than the future complications resulting from high blood sugars. They described low blood sugar reactions as “scary,” “embarrassing,” and making them afraid. They were especially afraid of being alone during a reaction or being embarrassed by a reaction. One adolescent contrasted the experiences of high and low blood sugars in this way:

‘I don't worry about the highs as much as the lows because you can take care of high blood sugars faster, and usually you're coherent and you can understand what you're doing and everything. For low blood sugars, things are different. It can just hit you at any time and you'll be unconscious, not knowing from what you are doing, so you won't be able to necessarily take care of it all the time (KII 015 15years, Dagoretti).

The adolescents’ frustration was also centered on their need to make decisions and receive full recognition for the positive aspects of their diabetes management. As such, we recognized that the adolescents at times felt a lot of negative parental involvement that affected their diabetes management. Being able to trust the adolescents to manage their own disease was also a challenge to the parents and it was associated with fear. The parents had fears that the adolescents would not be able to confidently handle the disease while away from their presence while the adolescents felt that they are not getting the autonomy they desired. The results of this study therefore emphasized the importance of teaching parents more effective and less intrusive ways of managing their concerns about their chronically ill adolescent child.

One of the means of assisting parents to cope was to begin the discussion of their concerns at the onset of the child's treatment. Health care providers needed to take a more active role in providing a setting where parents' worries could be easily discussed, and in promoting support groups for

families with T1DM. As the adolescent attempted to establish a sense of individual identity and autonomy, it was common for conflicts to occur, and these conflicts often centered on mundane recurring events. Although usual parent-adolescent conflicts are similar for families of adolescents with T1DM, communication about disease management can bring additional and unique sources of friction or conflicts that can influence such an adolescent's metabolic control (Anderson *et al.*, 1990). The ability of parents to maintain team-oriented partnerships when communicating with their teen about diabetes is important to preventing the acceleration of conflict about disease management and promoting metabolic control.

4.4.2 Social Stigmatization

Although it is important to note that diabetes is a stigma related disease, many people who do not have the disease think otherwise about it. Stigmatization was part of the social experience of living with T1DM for adolescents. Strategies and interventions to deal with and mitigate this diabetes-related stigma needed to be developed and evaluated. Traditionally, T1DM research focused on the biomedical aspects of aetiology and management of the condition (Aikins, 2006). However, recent decades have witnessed the rise of psychosocial research, exploring the emotional, behavioral and social aspects of living with T1DM (Schabert *et al.* 2013). Almost all participants (n=12) indicated that they believed T1DM was a stigmatized condition; with most of them indicating they had experienced stigmatization directly. The remainder described the stigma as a phenomenon they perceived in society more generally. They used words such as stigmatization /stigma/stigmatized to describe the experience of living with T1DM before they interviewer used the words. Others described evidence of T1DM stigmatization, or used similar or related phrases such as 'discrimination', without using the word 'stigma' specifically. As one of them noted...

'People around you just assume that you're young and you look healthy so they can't figure it out in their heads how you are always on insulin and that you can't live without it. They think that you wished the disease on your own. I found that really frustrating... the level of judgment that comes with the disease is out of this world (KII 005 15years, Umoja).'

Participants reported being blamed by others, especially family and peers, when it was perceived that they were not managing their diabetes optimally. Examples of behaviour that prompted others to judge them in this way were eating sweet foods, having a severe very low blood glucose levels, gaining weight, and developing diabetes-related complications. One of them observed that:

'It seems as if when you have low blood sugars, you get blamed as being irresponsible all the time 'Why are you eating sweet things? Why didn't you come with something suitable for to eat? Why didn't you test your sugar levels before you left? Why didn't you do this, why didn't you do that?' ... Sometimes perhaps I forget or I'm ill prepared but it is not intentional. Everyone has a question to ask (KII 007 17years, Kayole).'

Blame was also experienced as the result of other people's perceptions that diabetes is a lifestyle condition caused by poor eating habits, being overweight and inactivity. Informants found this to be frustrating and unfair; they believed it reflected confusion (or a lack of sophistication in the understanding) in society about T1DM and T2DM, or a misconception that diabetes is caused by consuming too much sugar. A study conducted in Kenya by Liani (2014) showed that people did not know the exact causes of diabetes. Informants in that study related the cause of their illness to poor dietary habits - mainly taking tea with sugar, eating a lot of food rich in fats, eating food containing too much salt, and consuming a lot of starch. They seem to have recounted on information received from their health care professional on what foods should be avoided.

The adolescents described being worried about, or having experienced, being mistaken for an illicit drug user while injecting insulin. This was particularly the case for those with a longer duration of T1DM, who recalled having to inject insulin with a vial and a syringe, before insulin pens and

pumps were available. Participants were also worried about being considered rude and aggressive, or being mistaken for being drunk, during low blood sugar. As one of them noted:

'We had gone out to a shopping mall with my family when I was maybe 11 years old. I vividly remember sitting at the shopping mall injecting my daily dose of insulin and a crowd of people come up to me, and some person commented it was such a disgrace that someone was doing drugs at such an age. People usually assume that injecting oneself is only done by drug users. They also think that one should also be injected by a doctor if at all they are ill. They confuse being drunk and with the symptoms of having low blood sugar. The signs are often similar...if you see somebody behaving like they're out of control, it's easy to dismiss them when they really need your help ((KII 005 15years, Umoja).'

Exclusion, rejection and discrimination were perceived by participants to occur across a number of life domains. Adolescents recalled having been excluded from social activities and bullied or teased during play time.

'Sometimes my friends refuse to play with me; like my cousin used to say that we can't play with you because you have a disease and we don't want to catch it. Most of the times, I find myself playing on my own. I opt for computer games because there, you do not need a physical companion because. I don't want to be turned down by my playmates, but sometimes, you just feel like you need to release the energy after long sitting hours (KII 001 16 years, Umoja).'

As one of the nurse at KNH said:

'Sometimes they face discrimination, they let them play alone or let them do things alone because some of them think that it can be gotten through physical contact, and they can get it if they hang out with them (Nurse 1, KNH).'

Another nurse from KNH also went on to further note that:

'Insulin makes the adolescent fat and when you look at adolescents particularly if I narrow it to the girls, they want to be slim so as to attract the opposite sex. This is not possible when one is on insulin daily. So they look at their friends as more advantaged than they are because they do not have the disease (Nurse 5, KNH).'

Most adolescents were frustrated and wondered why they had to do certain things that their peers were not doing, such as carrying insulin and injection kits. Adolescents, especially the girls, were also stressed by the fact that the use of insulin was contributing to their weight gain but they still had to continue using it. In addition, some of the participants mentioned that adolescents experienced social stigmatization from peers and society especially among girls with diabetes who are seemingly not wanted for relationships. Social stigmatization was also common during play with peers. As one of the adolescents noted:

'I inject themselves two times a day some three times a day. So the thing of injecting themselves every time is a stress as well. It brings stress whereby you have to be thinking about that needle and if you don't do that anything can happen. I become depressed because of injecting myself, you see I have been injecting myself for seven years on the same spot but what can I do it's my life. The more you inject yourself, the fatter you become, but you cannot stop the injections (KII 007 17 years, Kayole).'

During the adolescent years, peers play a significant role in the management of T1DM. While having diabetes did not prevent, a seventeen year old from Kayole, from going out with friends, it influenced who she chose to become friends with, particularly while she was in form two. She believed it was important to have friends who have diabetes; however, she did not know many individuals her own age who shared this disease. While at a Diabetes walk organized by the Diabetes Management Centre in Nairobi, she had the opportunity to meet several other people with type I diabetes, and would often engage in conversations with them. She believed it was of help for one to talk about living with the disease.

'You are always thinking whether friends are prepared to deal with you and your issues? You are afraid to let people into your life sometimes because you wonder whether they going to be able to handle you? Are they going to be able to take care of me? You start to pick your friends basing on their stability and you start to choose people who are like you; who are really vulnerable. When it comes to being the friend of a diabetic, it is a lot more take on your side since you know the consequences. I know I take a lot more than I give, because I feel like I go through things more often especially when I am sick. It is nice to

just have someone (who feels the same) around. Despite this being the case, there is no other person in the school who has diabetes and the only one who had diabetes was transferred to a day school because she couldn't cope while in this school (KII 007 17years, Kayole) '.

Studies have shown that the influence of friends continues to increase throughout childhood, reaching a peak during adolescence. Adolescents begin to spend more time in the presence of their peers as they seek to gain insight into the normal rules of behaviour, and the process for identity formation (Cheung *et al.*, 2006). The guidance, support, and understanding that were once bestowed upon the individual by parents are now sought out from peers (Cheung *et al.*, 2006). Although social relationships are important in determining the quality of life of most individuals, these relationships with friends are particularly influential for adolescents with diabetes, affecting not only their quality of life, but also their overall state of health (Faro, 1999).

Studies examining the role of social influences and peers on diabetes management have consistently shown that peers can exert a great amount of influence over the individual with diabetes whether the influence is negative or positive (Cheung *et al.*, 2006). In a qualitative interview study conducted by Bearman and La Greca (2002), participants with type I, diabetes reported that friends were the main source of support during adolescence, and that they provided companionship when the adolescent was experiencing difficulty adhering to the diabetic regimen. Greco *et al.* (2001) echoed this concept of support, finding that peers were more likely than family members to provide adolescents with the support that they required over the course of their disease. In seeking to gain a better understanding of peer support during adolescence, Cheung *et al.* (2006) examined adolescent perceptions of the quality of support obtained from peers. The researchers selected 29 participants between the ages of 13-17 who had attended at least one diabetes camp, and 10 participants who had never attended camp. The adolescents completed a series of questionnaires that included a quality of life survey, and a survey to assess the nature of their

friendships with others. Over half of the participants in the study felt that diabetes limited their social relationships and friendships.

Despite having a close group of friends during high school, a seventeen year old from Kayole feels that having diabetes has made her more selective in whom she chooses to befriend at school and even at home. When choosing to form relationships, she now seeks out individuals who are vulnerable like herself, yet can still provide the emotional support that she yearns for...

I used to be a friend of everyone before I was diagnosed. This is not the case today because I prefer to associate with my friends from the Diabetes management center. They understand me and my needs. They know what to do in an episode of low and high blood sugar. They will not pity me but instead encourage me in my management. This is unlike the other people who will be like 'why are you pricking yourself?' when I want to test my blood sugar. They always sound like they pity me and I don't want that to happen to me, especially from my age mates (KII 007 17years, Kayole).

Sometimes, fear of rejection will cause them to isolate themselves from their peer group. But isolation is even worse for self-esteem. To achieve independence, teenagers often form bonds with their friends. But peer groups require conformity, and conformity creates conflict for teenagers with type 1 diabetes. How can they act just like their friends (for instance, getting behind the wheel of a car without checking their blood sugar first) and still keep control of their type 1 diabetes? Adolescents are expected to become totally self-sufficient in their T1DM routine. While this self-reliance helps build confidence, for some it creates another kind of pressure and anxiety. When their blood sugar levels go out of control—in spite of their best efforts—they may feel frustrated, weak, and inadequate. They may react in one of two ways: *denial of the disease*, or with *aggressive behavior*, which may be acted out through food binges or skipping their insulin.

This study found stigmatization and discrimination to be common experiences among adolescents, particularly by peers and society at large. Peers often thought diabetes was contagious and thus avoided interacting with the patients while society had beliefs that diabetes patients were not

reproductively fit and had low status value in romantic relationships especially among the girls. Stigma was practiced through restricting adolescents from engaging in most everyday activities, such as sports. The sources and causes of stigma in patients with diabetes differ across cultures. For instance, in our case, stigma was perpetuated by the friends, peers and even relatives who often had a notion that diabetes was a self-inflicted condition and stigmatization often took the form of negative social judgments and exclusions from activities.

4.4.3 Stigma at social events

The participants also experienced not being invited to social occasions where there was likely to be unhealthy or sugary food, experiencing unwarranted restrictions. Participants described their current or past hesitations to disclose the fact that they had T1DM to others. Most common were reservations about disclosing their diabetes condition. Also evident was a reluctance to disclose to new social contacts, especially new romantic partners or potential partners. This was driven largely by not wanting to attract attention, not wanting to be seen as different from others and not wanting to jeopardize the opportunity for friendship. As one of the females from Umoja noted:

'My friends are an interesting lot. They choose where to go with me and where not to. On one occasion when it was a birthday for one of us. I was not told where the party would be. I later saw them with photographs from the event. I felt bad about it. I have decided that from that day, I will form new friends but this time I will not tell them that I am diabetic (KII 001 17years, Umoja).'

Participants described making inconvenient, and sometimes elaborate, plans to ensure they were able to engage in the necessary self-management activities, at the appropriate times, without having to do so in public. Common examples were checking blood glucose and injecting insulin in a toilet cubicle to ensure privacy (which for some resulted in feelings of dirtiness or shame), avoiding swimming or other activities that required that an insulin pump be exposed and planning

meetings or other activities around the time of day when low blood sugar was likely to occur. The adolescents also stated that they did not like social events since being diagnosed with T1DM.

They stated that social events were a threat to them adhering to the diabetes management plan. While a seventeen year old from Kayole learnt how to properly administer insulin and how to follow the diabetic regimen, she reports that she did not always adhere to the treatment protocol prescribed by her doctor. She says that she did that so that she could maintain a semblance of the normal life she had previously led; she frequently refused to take her needles in social events, and engaged in social eating habits that were detrimental to her overall health.

'Before I was 17 years old, I was terrible with my diabetes management plan. I would eat whatever I wanted, because if you count the sugar on the back of the recommended daily allowance, you-can match it with the insulin. I ate as much so that I could be the same as my friends. I would eat chocolate bars and potato chips and all of that while we were out with friends, but I was still very skinny because I wasn't taking enough insulin which I felt ashamed of taking before my friends. When I started gaining weight, the feeling was great. The whole issue of being thin had bothered me, and that is what got me to take care of myself. This was especially when I was out on birthdays and shopping sprees, not the fact that I have diabetes and needed to take care of myself. It was because I had gained a lot of weight and did not want to lose it. So I just ate a lot of carbohydrates, in diets not recommended for me and I felt really good (KII 007 17years, Kayole).'

Going out with friends often reinforced the fact that diabetic adolescents are different from their peers. The above informant describes how most of her friends didn't eat regular meals, and how her friends say she was always eating. For the seventeen year old from Kayole, she stated that she also attempted drinking as an activity to fit into the group.

'Drinking was another one of those things I would do I wanted to fit in my peer group. If I had a really sugary drink, my sugars would go up and I would vomit. I guess it happens a lot. People always assumed that vomiting was because I was drunk, and I wasn't (KII 007 17years, Kayole).'

Another male adolescent reported that he feared attending social events for fear that his blood sugar would go up or down and affect his social image. This is because through experience, the

fifteen year old had learned what it feels like to have high blood sugar, and what it feels like to be low. The feelings are illustrated by the following excerpts...

'The kind of feeling that you feel when you open your eyes first thing in the morning, or in the middle of the night when something wakes you up and you can't even open your eyes. Just so tired, or as if you haven't slept for about three or four days. Your eyes actually physically become too hard to hold open. Moreover, if you can keep them open, everything you see is not clear. I also get really sluggish and lazy. I don't even want to get up or move around (KII 008 16years, Kangemi).'

He describes the low blood sugar as being the exact opposite.

'I feel really jittery, really sweaty, and kind of like your body is rushing. You know, like when something scares you and your heart is beating really fast, that is how you feel. You can literally feel your heart beat really hard. I feel very nervous, very scared, and very panicky because your blood sugar has gone low. I can't imagine that when am out with my friends. Oh no!! They will see me as a coward, especially those who do not know that I am diabetic (KII 008 16years, Kangemi).'

At such times, he wishes he had someone who knows about their condition to talk to about his diabetic troubles and can help manage the high or low blood sugar without having to let the whole event stop because of him...

'You can talk to your doctor about your doses, and you can talk to the dietician about your diet and how to change that, but where are they in a social setting? You want to say "I am really sick of this, and I don't get respite from it. Or I am sick of always having to deal with this. "It is not like it just goes away (KII 008 16years, Kangemi).'

The amount of planning that goes into managing diabetes often meant that he could not partake in certain activities. Unlike his siblings, he could never just go to a friend's house after school.

'Everything has to be pre-thought out. I can't, just up and go to my friend's house for a party. My mum would have to talk to my friends mum. Like even in primary school, I couldn't just go out after school. Or if I did, I had to remember; did I have my dinner insulin? Do I have food with me? Do I have money? Did I tell my mom? What do I do if the plan changes? This is unlike my sisters and brother who would just jet out of the home or school to any event. I just feel like am the odd one out yet we are from the same parents (KII 009 15years, Kasarani).'

On issues related to dating most of the participants (90% n=15) reported that they shy off from having boyfriends and girlfriends. The other few (10% n=15) stated that they had romantic

relationships with the opposite sex but they chose not to tell them that they are diabetic. This is because they did not want to pair up for the wrong reasons and burden others with their condition. They stated that they feared getting into relationships because the people would pity them for having the disease.

'This thing of I am a sick person makes me sicker. You don't want people to only think of diabetes when they see you. You don't want to look weak. At the same 'time, you do want them to know that it is not always easy, and that it requires a lot of attention, and that the 'little things like eating on time and testing your sugars make a big difference. To them it looks easy, and to me I would be like "I am dying here, "At times you want to hit people over the head with it. Yes I am still diabetic. I still have to test, I still have to eat, and I still have to take my insulin. My skin gets infected my fingers get sore. And it is not something that I am going to sit here and whine about. It still happens; I still have to do it every day. As a result I keep of a boyfriend because I know they come with their demands yet I have mine. I just feel like we are bonding over the wrong reason. (KII 009 15years, Kasarani).'

The adolescents stated that (n=15) if one had unsupportive friends, it would negatively affect their management of the disease. Before she was diagnosed, a fifteen year old and her friends participated in the usual teenage activities: going to the movies, throwing birthday parties, going shopping, and going for outings with friends. When she discovered she had type 1 diabetes, she started avoiding her friends, and social situations. She also stated that the group of friends she kept had to change. She explains that it is her fear of having to carry her insulin injections wherever she went with her friends, and not wanting to have to answer several questions about a disease she had also not quiet understood that disturbed her. The girl narrated...

'I stopped going out because I had to have these so called needles wherever I went. If I went out, I didn't carry my needles with me. I would leave them at home; I didn't literally put them in my purse. I didn't want anyone to see me inject myself, because I had lived 15 years not having to do that. I was ashamed of my diabetic condition, so I never hung out with my old friends because they knew that I was diabetic. The few people I tried to make friends with knew nothing about diabetes management. They wouldn't bother reminding me to do the right thing about my diabetes. I also didn't want to have to answer many questions about a disease I also didn't understand and I was still mad that I had diabetes (KII 004 15years, Githurai).'

Having T1DM has thus affected the general social life of the adolescents in terms of the restrictions of forming friendships, relating with parents and those of the opposite sex and even the restrictions in terms of attending social events which are significant events especially to adolescents.

4.4.5 Inaccessibility of health services

Most adolescents mentioned that access to health services while at home was a problem. The problem of access to insulin was also a challenge since it is expensive in most health centers. As one of the adolescents explained:

'It is a problem getting insulin in the nearest public health center. It is available in some private clinics but mum says it is expensive and she can't even afford a dose for me for the whole month from the local clinics. We are only left with the option of coming all the way to Kenyatta National Hospital or go to the diabetes management center in Hurlingham where it is a bit cheap. You see all that cannot help remedy an emergency situation. Mummy only buys insulin from the local clinics when I run out of stock when am in an emergency (KII1004 15years, Githurai).'

As another adolescent explained, it was not only the cost of insulin that was a problem but also the availability. Sometimes, the insulin was not easily available to them. They had to move from one hospital to the other to access the insulin.

'Sometimes we are forced to move from one hospital to another in search of insulin. You could travel all the way from home only to find it also missing at the Kenyatta National Hospital. I remember one time when mum had to squeeze all her savings so that she could buy me insulin to run me the whole term because of the shortage. At times you are forced to make such hard decisions. I have seen mum miss insulin in hospitals twice and you see this is not a disease to take chances with. You must be on insulin come what may (KII 001 16 years, Umoja).'

The study also established that distance was also a challenge they had to deal with if they have to access medical services. They had to traverse the distance if they have to go for the clinics at the KNH that are there every month. They mentioned that even for admissions, they preferred going all the way to KNH because they believed that the doctors and nurses there are aware of their

condition and could handle them well than going to a new hospital where everyone was strange and not familiar with their condition. They presume that services at the KNH are better than anywhere else. As one of the male adolescents put it:

'I like the services at KNH because the nurses there are friendly. When you are admitted there, they come to check on you all the time and even call you by name, when asking you how you feel. I would say that they know my needs more than anyone else. I remember another time when I had been rushed local clinic by the neighbors with an episode of low blood sugar, and the nurses there started testing me of malaria because I was shivering as if I felt cold. I lost consciousness because to the low blood. It took my mother's phone call intervention to remedy my situation. She only told them I am diabetic and a dose of insulin was able to correct my situation. I resolved that I will always be going to KNH for all my health needs (KII 009 15years, Kasarani).'

The utilization of health services by Kenyans in general is increasing but access to quality healthcare remains limited. Poor health service infrastructure and unavailability, shortage of health services, administration and management personnel and financial constraints restrict delivery of an adequate service (Mcfaren, 2008). Kenya cannot fund even the WHO minimal level care package to each citizen (Turin, 2010). Kenya's health facilities are distributed regionally. Widespread disparities in provision, may be attributed to socio-economic, gender and geographical differences, with only 77% of Kenyans who are ill utilizing the healthcare available (Wamai, 2009). Health worker distribution is also uneven, with greater numbers in hospitals and urban areas. Hospitals often have public and private levels co-existing, managed by the same staff. Conditions within public wards are poor compared to the unaffordable private wards.

As in many sub-Saharan African countries, the health system is organized to treat acute rather than chronic conditions such as T1DM, with a lack of primary healthcare to tackle chronic diseases such as diabetes (Wamai, 2009). In Kenya and specifically at KNH which has a high turnover of patients on insulin and which must provide the drug at a highly subsidized price (15% of the price

at private pharmacy outlets), insulin shortages are not uncommon (Wamai 2009). The extent and impact of shortages on the glycemic control in Kenya have not been evaluated. However, only few of the adolescents in the study reported that they had missed their prescribed dose of insulin because they lacked the drug. Those who did so had poorer control than those who reported that they had been compliant throughout the preceding 3 months.

'I prefer to go all the way because the prices is a bit friendly. At times I could come all the way from Kasarani to KNH for the insulin and still miss it. You know everyone goes to Kenyatta because they know it is the only point you are sure to find. There are times when you find that even Kenyatta don't have it. At this point you only use the little you have sparingly (KII 009 15years, Kasarani).'

While these results are in keeping with the scientific fact that insulin is all-important in control of blood sugar, it is still significant that even those who reported good compliance still had a very poor control (Wamai, 2009). Elamin et al. (1992) in Sudan had found that patients faced with scarcity of insulin actually reduced their insulin per dose or the number of doses per day in order to stretch their supply. Tanzanian children with T1DM, in addition to limited supply, reduce spontaneously the prescribed dose of insulin to guaranty a longer period and lower cost of treatment (Majaliwa *et al.*, 2007). It is not clear from our study if the same happens in Kenya.

CHAPTER FIVE

SCHOOL BASED CHALLENGES FACING ADOLESCENTS WITH TYPE

1 DIABETES

5.1 Introduction

This section presents the concerns of adolescents with T1DM at the school setting. Major challenges included inadequate information, education and information among the school personnel, classmates, administrative factors, school environment and scheduling of school functions.

5.2 Inadequate information, education and awareness

The study informants (n=15) stated that the school personnel are not involved in the direct management of their disease, but they are instead supposed to be on the look-out for episodes of low and high blood sugar and other emergencies. They further noted that although this was expected of school personnel, they do not have adequate knowledge on what to do in case of low or high blood sugar. At times, even the school nurses who are perceived as knowledgeable behaved in questionable manner at such occurrences. One adolescent explained her experience at school.

'At one time my blood sugar level went down. I was shivering, I didn't have energy, and I couldn't even eat or bathe. I vomited the whole day. I had skipped my meals that day. I woke only to find myself admitted in the sick bay. To my surprise, one student whose father is diabetic helped me in a better way than the school nurse. She dismissed the case as something minor. I was not shocked since she didn't want the school to admit me, and instead told my parents to take me to a day school. The school nurse has always been very rude to me. I avoid her at all costs, unless it is an emergency and for that day, I couldn't avoid it (KII 001 16years, Umoja).'

According to the adolescent, she expected that the school nurse will act in a professional way since she was trained. This was not the case. She was even shocked that it was the nurse who did not want her to be admitted to the school because she looked at her as an added responsibility. Whether an adolescent had T1DM before attending school or developed it while in school, they were usually concerned about diabetes management at school and expect school personnel, particularly school-administrators and teachers, to help them develop an appropriate management plan. Most of the teachers demonstrated lack of diabetes awareness; one male adolescent knew that he could never rely on them for assistance. One instance which illustrated to him that he could not rely on her teachers occurred in form one.

'I was in an art class, and I knew that my blood sugar was low. I told "Mr. X; I am low. I need to go get something to eat. "So he said that okay. So I went and I drank some juice and had a cookie, but I still wasn't feeling good. When the teacher came in and asked if I was feeling better, I said "No. I am still low." One of the other teachers came in and they had this 10- minute debate over how to treat me. They didn't know how to react to low blood sugar. I told them that I was going to go buy a coke, and the other teacher said "You can't have coke. You need to have orange juice." Mr. X told him that it didn't really matter what the sugar source was, but she kept saying "No. I know diabetics should not have coke. He should have orange juice!" At that point I always felt like it was not going well. (KII 008 16years, Kangemi) '.

In form two, the same adolescent was once again reminded of how limited his teachers' knowledge was on diabetes. His class was on a retreat, and the school was to be providing lunch to the students. Instead of providing a balanced lunch that was originally planned, the school served a late lunch of soda and loaf of bread. The teachers did not have any other plan for him. They expected him to take what other students were taking. The male adolescent was there thinking, how he could have a soda and bread for lunch after he had not taken any meal for all those hours. The student had to go and test his sugar first before he could make a decision...

'I was carrying my insulin pen case with me. It was grey, and it was about the size of a case of glasses. I was looking for a bathroom, and I couldn't find any. I had to check into one of the side rooms of an old house. When I came back carrying the case in my hand, and one

of the teachers asked “Where were you? What is that, a remote control on a school trip? What were you doing watching TV in there? So you have refused to take the soda? I think you will have to sort yourself out (KII 008 16years, Kangemi).’

School nurses and the principal were the contact person between parents and guardians and health care providers with regard to updating children’s individualized diabetes care plans for management of acute problems during the school day. Unfortunately, some school systems did not have enough adequately trained nurses to manage children with type 1 diabetes (Weissberg-Benchell *et al.*, 1995). It was difficult to contact, school personnel who were reluctant to be involved in insulin administration, and teachers who were unwilling to deal with student behavior changes brought on by blood glucose fluctuations. The diabetic students preferred to confide in fellow students as they found them more understanding. The school personnel lacked the knowledge and were unwilling to learn. This was expressed in one interview with a nurse at KNH as illustrated below...

‘We have tried to create awareness on diabetes to the public. We have had diabetic walks to create awareness, and even raise funds. At times, we also do free screening at the hospital, where we try to involve the public but, they just won’t come! We once invited the teachers who take charge of the students while at school but no one turned up. “A parent once told me that they requested a class teacher to accompany them to one of the clinics but the teacher told them that her duty is to teach and not deal with a disease she doesn’t know” (Nurse 2, KNH).’

A teacher from one of the private schools attended by the diabetic adolescents in this study lamented that they have too much to bear and that most of the times, they spend their time at school and in class more than they spend in their homes...

‘I report to school as early as six a ‘clock in the morning, and leave as late as six. I have to teach thirty five lessons in a week and thus my workload is too much. The school administrators are always on our case to improve the school mean grade. A drop in the mean score could cost your job so we work hard to maintain it. We would love to attend the clinics and seminars organized on diabetes but the burden is too much. We even don’t have time for ourselves (Teacher X, School 3).’

Another teacher from a different school also reiterated the sentiments of teacher X...

'While in class we have to do a lot of things like teach, give assignments and mark them. Most of the times, the student to teacher ratio is usually very high. You would want to get the student's attention at once and not having to teach while others are away because this means you have to keep going back and forth. This is usually not the case as diabetic students have to frequently visit the washrooms have a snack and thus are distracted. For me to miss class to attend a seminar means a whole class is missing out (Teacher Y, school 1) '.

A number of schools did not have a diabetes policy and therefore diabetes awareness is non-existent. It was of importance that the parents and diabetic adolescents themselves explained to their classmates and teachers about their T1DM condition and their needs. As one of the adolescent noted...

'My mum would go over everything with them; she needs to eat at noon no matter what; she has to have her snacks or she goes low. I came to a conclusion that people just nod their heads. They say they understand, but they really don't. Or they take in parts of the information. They don't really get it. I think some of my teachers are terrified by it. They definitely see it as another burden; another special needs student in the classroom. So I always felt like it is a bother when teachers found out I was diabetic; because I thought that they would think that I was just going to be some hassle. Some of my teachers were fine but most of them were not happy that responsibility was being bestowed on them (KII 009 15years, Kasarani) '.

Another teacher also stated that they lacked a diabetes policy in school and thus they did not feel objected to help. This teacher explains that she helped the diabetic adolescent because of compassion and not because there are rules that compelled her...

'You see it is only a favour that I am involved in the management of diabetes for the above student. It is only because she is in my class. Nobody compels me to do that. I can choose not to help but you see no one else cares. I pity her parents because if I don't help, it means they have to keep her in a day school where they can monitor her themselves. I am also a parent and I would not want that to be done to my child in case they had a chronic illness like this one (Teacher B, school 15) '.

Most Adolescents (90 % n=15) reported that most parents assumed the responsibility of educating the class themselves, but on occasion the school nurses educated the class. If lack of understanding

on the part of school personnel interferes with providing adolescents with T1DM with a positive and safe school experience, it is paramount that we advocate for these adolescents with diabetes. The level of cooperation the study's participants encountered with school personnel ranged from nonexistent to excellent. Although she was grateful that her teachers allowed her to manage her diabetes in the classroom; however, she did not like when teachers would single her out.

'I had one teacher in high school who always pointed at me "she is diabetic, and her health is so good because she is so careful with what she eats and how much she exercises. "It made me feel kind of embarrassed like really? I am not that special (KII 003 15years, Githurai)'

The findings of this study on inadequate knowledge coincided with other studies done elsewhere. One such study was a survey of 463 elementary school teachers in Arkansas that showed that 90% of the teachers had never received training on diabetes, and only a few could identify the symptoms or appropriate treatment of hypoglycemia. Since acute low blood sugar rapidly deteriorated into a life-threatening condition, those results were frightening. The study also reported inadequate knowledge (Gormanous *et al.*, 2002).

According Wagner *et al.* (2005), very few teachers who were responsible for assisting students in the management of their diabetes at school had actually received formal training from a medical professional. When asked what type of preparation the school personnel had received, most parents indicated that the training varied from informal conversations, to review of educational material, with very few actually receiving training directly from a healthcare provider. The teachers often lacked a clear understanding of T1DM and thus were unable to provide adequate levels of support to diabetic students in the classroom. Many educators were reluctant to seek out medical information from parents, since they did not want to overburden parents, did not want parents to think of them as incapable of caring for their child, and believed that healthcare providers were better able to give medical advice (Wagner *et al.*, 2005).

As evidenced from this study, knowledge was the greatest weapon in the fight against T1DM. Information helped the adolescents to assess the risk of diabetes, motivated them to seek proper treatment and care, and inspired them to take charge of their disease. It is therefore in the interest of the country to design and develop a comprehensive health promotion strategies that ensure information of diabetes is communicated to the relevant persons. For example, Wagner et al. (2006) recommends that schools should implement a ‘diabetes buddy’ program. The program would permit one or few of the classmate to accompany the student diabetes mellitus and its related risk factors. It is equally important to design and implement suitable diagnostic, management and treatment protocols for people with diabetes.

5.3 School environment

School was an important context for adolescents with T1DM. This was because their diabetes self-management behaviours were affected the school environment. Adolescents in this study revealed that the school environment was not adequately supportive of T1DM management tasks. For example, they reported that schools lacked canteens where they could buy snacks or food safe for them to adequately carry out their management. Further still in the boarding schools did not allow any food from outside. A sixteen year old female explained...

'Our school doesn't have a canteen within and therefore, I have to rely on the school meals only. It is hard because sometimes you feel your sugar running low, and all you want is some little sugar to remedy the situation. Although the school allows me to go to the dining hall and request for something to bite when I am low, the inconvenience is just too much to bear. That means I have to leave class and go that far for a snack. At times the sugar level fluctuations are so instant that you do not have the energy to go to the kitchen. The school meals are also prepared at specific times and this might not help me at my time of need. For me to deal with all this challenges I am forced to sneak some sweets to school during opening day so that becomes my only snack. If the school had a canteen, it would be easier (KII 001 16years, Umoja)'.

Another adolescent further explained her challenges in this regards as...

'Having access to food at all times was a big struggle for me. Most of the teachers had a no gum-chewing, no snacking, and no drinking in class rule. I always knew that I could go past that rule, but I always felt like I had to hide it or I had to sneak it in. I never wanted to get up in the middle of class and walk over to my backpack. I wanted to be part of the group; I didn't want to draw any attention to something that is not cool. If you have the attention because you have a new jacket, that is cool. If you are the kid who is always singled out because you need to drink your juice, no. You are just the kid who eats all of the time and this is not the best way to be identified (KII 002 15years, Dagoretti).'

A teacher from one of the public schools attended by a diabetic adolescent when asked on how schools are supportive of the diabetic adolescents, she explained...

'You know our school is public and therefore we treat these students equally in terms of the resources we have. We can't afford to have one student given special meals other than the maize and beans we offer. If a student has to been given any special treatment, they must have a different arrangement with the school cateress and still we do not encourage this. We only have one diabetic student in school because her parents live near the school and can be easily accessed in case of an emergency. At first we even contemplated admitting her because of her condition and not because of her grades. You see no one wants to carry the blame in case of an eventuality (Teacher A, school 10).'

The finding of this study coincide with that of Hayes-Bohn et al. (2004) who conducted a study with 30 adolescent females 13-20 years old who had T1DM. Through semi-structured interviews, the researchers learned about the girls' perceptions of the barriers and resources for diabetes management that existed in their schools. One of the issues brought up by several participants was the lack of healthy food choices available in the cafeteria. According to the girls, there was a high prevalence of junk food in the cafeteria and in the vending machines. Cafeterias often did not provide the nutritional information about the food they prepared, which made it more difficult for participants to accurately monitor their carbohydrate intake.

In another study that examined meals offered in cafeterias throughout the United States, the study called similar attention to the fact that very few cafeterias provide healthy food options (Brener *et al.*, 2001). Although the participants were mainly concerned with the lack of healthy food choices

offered by the cafeteria, several girls also commented on the difficulty of adhering to the diabetic regimen when friends or teachers offered them treats (Hayes-Bohn *et al.*, 2004).

5.4 Administrative factors

Another challenge that was stated by the study participants (n=15) was the stringent school rules that interfere with the management of the blood glucose while in the school. The school rules ranged from not having to carry snacks and syringes to schools, to the stipulated time for breaks, to examinations rules, to school rules regarding school admissions and diet and to the responsibility of the high and low blood sugars. Despite the fact that her school was so small, many of the teachers were aware of her diabetes, and allowed her to treat the illness within the classroom, they at times forgot and had to be reminded. They would forget that she was diabetic and shout out at her for having to take a snack while in class. She had to keep on reminding them of her health condition.

'For most of the teachers, I would be in their classroom a lot of the time, and I would have nothing. So when I did eat they would say "I thought I said no snacking in my class," and I would have to remind them that I was diabetic. It was like "Can't you remember this one little thing about me? I am not doing this to annoy you!" By that time though, I would give it back to them. I had to remind them that it is important for me to snack.' It forced me to be more assertive about my needs (KII 001 16years, Umoja)'.

One other adolescent explained that the school rules made her transfer school. She was not allowed to carry syringes to school and yet her insulin regime had been changed. Others said that even though they were allowed to carry them to school they had to keep them with the school. Despite the importance of diabetes care at school, only two studies have investigated the experiences of children and adolescents negotiating this process. First, in a qualitative study with 30 adolescents and their parents, researchers asked participants to describe their perceptions of the current system of diabetes care in school. Participants expressed concern about school staff's limited knowledge about diabetes, lack of healthy foods available, and inflexible rules that make it difficult to do

necessary self-care tasks. In another study, middle school children attending diabetes summer camp reported a need for increased flexibility and individualized care plans to improve diabetes self-management in school.

When schools were inflexible with their rules, students with diabetes were placed at a disadvantage. Rules that prohibited the presence of syringes at school meant that adolescents with diabetes had to go to the nurse's office where they could be supervised while administering their insulin. For individuals who preferred to keep their condition hidden from their peers, the process of leaving the classroom so that they could be supervised by an adult was embarrassing. Studies by Hayes-Bohn et al. (2004), and Wagner et al. (2005) indicated that many students were required to leave the classroom before checking their blood glucose levels or administering doses of insulin. According to Wagner et al. (2005), 56% of children who participated in their study had to go to the nurse's office, main office, or their locker when giving an injection during school hours.

The children who were required to leave the classroom had poorer metabolic control than those who were allowed to monitor their condition in the classroom. Leaving the room to manage their diabetes meant that the students would miss class time, a fact which many students described to be an inconvenience (Hayes-Bohn *et al.*, 2004). Some teachers also refused to allow students to eat or drink in the class, or to go to the bathroom as needed, because they did not believe it was fair to the other students in the class who had to follow rules established by the school. As such, many individuals with type 1 diabetes experienced difficulties maintaining a consistent level of metabolic control while at school (Hayes-Bohn *et al.*, 2004; Nabors *et al.*, 2003).

By refusing the students their rights to fulfill diabetes-related needs, schools were unnecessarily placing students with diabetes at risk. Despite the ability of children and adolescents with diabetes to participate in extracurricular activities, many rules exist that discourage them from joining after-

school programs. Participants in Nabors' (2003) study told of instances where there was no longer an individual on staff after school hours that could help them manage their disease. They complained that coaches often did not understand their condition, and refused to let them participate in different sports even though they were capable of playing. Other participants noted that their diabetes supplies were often locked in the nurse's office after school, and could not be accessed easily in the case of an emergency. All of these factors impeded the child's ability to participate in extracurricular activities, and may have deprived the student of feelings of support, belonging, and connectedness to the school.

Most schools did not allow absenteeism. Adolescents with diabetes missed schools in most occasions because of episodes of low blood and high blood sugar that could lead to long hospitalizations. Despite the fact that schools required them to ask for permission before absenting themselves, adolescents in this study stated that sometimes the episodes occurred so drastically that they did not have time to ask for permission. They missed out school without any prior notice. The absenteeism was because of hospital admissions or even just a diabetes clinic. As one of the nurses from KNH reported...

'You see we always have one diabetes clinic a week. Unfortunately, it falls on a weekday: Tuesdays. If the teenagers do not come for clinics it becomes difficult to do an evaluation of their condition. We also do diabetes education to parents and their children during this clinic. The topics range from nutrition management, insulin administration and dealing with episodes of low and high blood sugar. Insulin regimens change with age and so this means that the diet to changes constantly. Nonattendance to clinics means they miss out on all this. The adolescents with diabetes re forced to miss out on schools to attend the clinics and the hospital has a long process to follow if at all they have to the day of holding clinics (Nurse 2, KNH).'

A fourteen year old from savanna estate explains that she has been admitted several times due to complications arising from poor diabetes management. She says that she has missed out a lot in school due to these hospitalizations...

'It is rather obvious that my blood sugar will go down or up if I don't eat a well-balanced diet, miss out on meals and not taking my insulin. This can happen because the school situation is different from the home environment. The meals are not adequate and at times I would engage in physical activities without snacking which can be dangerous. The low blood sugar has always been my challenge. I am not able to control them and thus I have been admitted severally due to this. I remember one time I was admitted for over a month. I missed school and even my end of year examination. I am lucky that when I recovered, the teacher gave me another examination and that is how I proceeded to the next level. I had seen myself repeat a whole year because of the disease. Although the teachers gave me the exams, I had to read and catch up with what my classmates had learnt while I was away on my own. My mum has had to organize for my extra coaching severally because I have been in and out of hospital several times. She pays them in addition to the school fees she pays (IDI 015 female 14years, Savanna).

A teacher also explained trouble they went through because of the absenteeism of the diabetic student.

'You know our duty us teachers is to impart knowledge, not for purposes of passing examinations but to change an individual. These students miss school and you have to repeat what you taught in their absence (teacher Z, school 5).'

Having support at school was found to be important for every adolescent's safety and inclusion. Minimizing preventable absences from school was another priority for both children and parents. School absenteeism was significantly higher in adolescents with diabetes compared to others who didn't have the disease (Glaab *et al.*, 2005). Their absence could be because of the regular medical appointments and prolonged hospital admissions. Many of the adolescents in this reported that they had at least an incidence when away from school because of a hospital admission. Schools that use attendance-incentive programs may unintentionally punish or discriminate against students with diabetes (Glaab *et al.*, 2005). Any policy or practice that pressured students to forego medical appointments negatively affected their well-being and unintentionally discouraged them for taking responsibility for their health.

5.5 Scheduling of school functions

The informants described school meals as a major challenge in diabetes management because of the need to monitor blood glucose and administer insulin before eating, the inconsistency of lunch schedules, and high carbohydrate meals. They reported that these challenges are also related to timing of school meals and the difficulties adolescents had regarding the schedule, and the preparation needed before lunch. Most of the adolescents (90% n=15) stated that scheduling difficulties were three-fold: first, the time required for blood glucose monitoring and insulin administration often interfered with students having time to finish eating their lunch; and second, lunch times fluctuated over more than an hour according to schools A or B day schedules and third the adolescents are also concerned about the amount of carbohydrates offered at school: home meals generally included less of carbohydrates, and school meal often had two times more carbohydrates than what they required. Further still, one adolescent who is currently in a day school from a boarding school admitted that he has to carry packed lunch from home since the school meals had too much salt and cooking oil than the recommended. He admitted that the school meal plan often lacked vegetables. He also explained that school meals were the reason he transferred from his previous school.

'The school diet mostly has a mixture of maize and beans for lunch. At times we have rice and beans. We are occasionally given cabbages as vegetable and ugali. This is not good for me as a diabetic as half of my plate should have varieties of vegetables. I used to suffer while I was in a boarding school far away. I would have high and low blood sugar several times in one term and this saw me admitted for long in hospitals. I missed out a lot in school because of those hospital admissions. The lunch break was only thirty minutes. This time was not enough for me to test my blood sugar take my insulin and still have my food. That is why I came to my present school. I can at least carry my packed lunch every day and still take my insulin from home early in the morning in the evening and at night. My health status has changed (KII 002 15years, Dagoretti).'

Low blood resulting from physical activity during physical education classes and school trips was also a concern of the adolescents involved in this study. The teacher's main objective was with preventing low blood sugar episodes in addition to early identification and treatment when episodes occurred. As a result, they tended to prevent the adolescents from participating in games and sports so as to prevent low blood sugar occurrences. The diabetic adolescents felt left out as one of them noted...

'Sometimes I feel left out of everything in school. Like at school parties when I was young, like 5, 6, and 7, I didn't really eat anything. Sometimes I would eat a part of the cake, some of it, or leave the icing and it never feels the same as eating the whole cake with the icing. I guess I did feel left out sometimes, but what can you do about it, right? There is not much I could have done. Field trips are always sort of a landmine, because the teachers would say they were going to give you lunch, and sometimes they wouldn't. Or sometimes they would change the program around and you would eat at 2:00 instead of noon. And that was just treacherous. I remember some time during a school trip when we had late lunch and my sugars went low. That trip came to a standstill. I felt bad for I cost the others entertainment and learning. Sometimes the school offers a soda and a loaf of bread for lunch during school trips; I can't take that as a diabetic (KII 010 15years, Donholm).'

The adolescents also had problems during examinations time due to the examination regulations. Despite the fact that they were not allowed to leave the examination rooms during an examination, they always felt different because they were the only ones exempted from the rules. A sixteen year old from Umoja explained that...

'You know, I have to visit the washrooms several times even when I am not sitting for an exam. During exams time I am the only one allowed to visit the toilets and usually I have to be escorted which gives me a bad feeling of being reminded that I am diabetic. The other students take it that you are being favoured (KII 001 16years, Umoja).'

Such events such as examinations come with their own restrictions that could limit the management of T1DM. Therefore schools need to reexamine the school functions such as examinations, school meals and classroom sessions and make them friendly to the diabetic adolescents.

CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

This chapter presents a summary of the findings of the study together with the conclusions, relating them to the theoretical model that was used in the study in relation to the study objectives. The recommendations of this study are drawn from the main issues arising throughout the study. The specific objectives of the study sought to: find out the home based and school based challenges facing adolescents with type 1 diabetes in the Nairobi City County.

6.2 Summary and conclusions

Adolescence is a challenging time for effective T1DM management because of the difficulties of balancing diabetes self-management and developmental needs. This research is the foundation for other studies, aimed at understanding the meanings of being an adolescent with T1DM. The study aimed at bringing the challenges faced by adolescents with T1DM while at home and at school. The study adopted a Shifting Perspectives Model of chronic illness because T1DM is a chronic disease that individuals did not only follow a single trajectory in its management. They instead followed various channels depending on the circumstances they found themselves. When they experienced challenges such as stigmatization, conflicts with parents and strict rules among others, they are unable to manage their condition and thus an illness in the foreground perspective and thus they could get increased/decreased blood sugar levels that could lead to complication of T1DM. On the other hand when they faced the challenges but adopted a wellness in the foreground perspective, they were able to practice the management regime and thus have a normal blood sugar level that helped them to live a normal life. The management of T1DM thus shifted between these

perspectives depending on the prevailing circumstances. The results from this study revealed that the home based challenges faced by adolescents with T1DM included conflicts with parents, stigmatization and inaccessibility of the health services.

The findings of this study indicated that parents had fears about the adolescent's well-being, while the adolescents felt that parents were not giving them autonomy and as such, the diabetes management plan was affected. The adolescents (n=15) reported that their parents assumed full responsibility for managing their treatment when they were young. They said that they were mature enough to take full charge of their diabetes management especially when they away from home, but parents were not letting this happen without interfering. This led to frequent conflicts between them and their parents.

Almost all participants (n=12) indicated that they believed T1DM was a stigmatized condition; with most of them indicating they had experienced stigmatization directly. The remainder described the stigma as a phenomenon they perceived in society more generally. They used the words 'stigma/stigmatized/stigmatization' to describe the experience of living with T1DM before the interviewer explicitly used this phrase. Others described evidence of T1DM stigmatization, or used similar or related phrases such as 'discrimination', without using the word 'stigma' specifically.

Adolescents in this study were in the process of learning to take responsibility for their diabetes self-management at school, at social events and even while away from home. However, peer derived and school rule-derived social pressures and situational obstacles compromised their effective diabetes self-management. Adolescents did not want to be perceived as different from their peer groups and as a result, they would avoid their diabetes management plan while they were

at social events and even with unfamiliar friends. They also worried about the knowledge of their friends to handle the disease. The adolescents reported that they feared going out with friends to social events as it reinforced the fact that they were different from their friends; they had to test their blood sugar, not eat the same foods as others and even have others worry about their high and low blood sugar episodes. Inaccessibility of the health services was also a challenge faced while at home. T1DM being an insulin dependent disease, issues of cost, storage and accessibility were raised.

The school based challenges involved administration factors, scheduling of school functions, the inappropriate school environment and the inadequate information, education and communication among school personnel. The adolescents reported the lack of knowledge among school personnel affected their management of T1DM while at school. They stated that teacher could not allow them bring snacks to the school and even take them while in the classrooms. They also stated that schools lacked the appropriate meals ranging from the appropriate foods for diabetic people, to the poor timings of the meals. Previous negative experiences with peers also increased their desire to keep their diabetes a secret.

Being the sole health professionals at schools, school nurses were to proactively build up their professional competencies in diabetes care and demonstrate competence in both caring for diabetic students, and educating the school teaching and non-teaching staff, and the student body about T1DM and its management. Because teachers spent so much time with adolescents than their parents, the adolescents believe that the teachers should be more health-conscious in general than their parents should. Not only is it important to be able to notice changes in health, but it is also important to notice changes in a student's behaviour. During an episode of low blood sugar, they may react in an aggressive or violent manner. Because low blood sugar can be a life-threatening

event, teachers must be able to distinguish between signs of low and high blood sugar, and know how to react in both cases. All of the adolescents felt that teachers needed to know more about diabetes. While they believed it is important to know about the medical complications associated with the disease, they felt that teachers should also be aware of the home and school based challenges of diabetes. They also recommended that teachers should do their own research by talking to parents, students, and medical professionals, and by reading memoirs.

At one time or another in their school life, all of these study's participants felt excluded or separated from others in the class. For some of them, it was the inflexibility of classroom rules that caused them most distress. Being the only student in the room who was allowed to eat a snack during class time, they often feel singled-out. For this reason diabetic adolescents suggest that teachers get rid of all of those rules. Not only do teachers need to be more flexible in allowing students to eat in the classroom, but they should also give the student with diabetes time to test their blood sugars during class.

The adolescents also felt excluded when their teacher singled them out in the physical education class, indicating to the whole class that they led a healthy life despite living with diabetes. They all agreed that teachers should not give unnecessary attention to the student, but should instead base the level of attention and accommodations on the individual's personal strengths and needs. As some of them agreed that in some cases individuals with diabetes may need assistance, teachers should be respectful of the student's ability to self-manage his or her illness, and not interfere unless asked for help. Based on the suggestions offered by the participants, it appears that the most important thing that teachers can do for their diabetic students is to remain flexible, sensitive, and aware. Teachers should be sensitive to changes in the students' overall health.

Research suggested that schools found it difficult to provide support for children with diabetes. In many instances, school personnel were not educated regarding diabetes care needs and therefore did not allow children access to the water, restrooms, glucose meters, and medications they need to care for themselves. Availability of school nurses was often limited, and many schools had nurses only once or for few days a week. However, in some schools, only nurses are authorized to provide diabetes care. Concerns about liability could prevent school personnel from participating in blood glucose monitoring, insulin injections, and glucagon administration, leaving children without any competent adult assistance in cases of emergency.

6.3 Recommendations

- Although this study provided a glimpse into the lives of adolescents living with type 1 diabetes in Nairobi City County there are other counties who may experience their illness in different ways. The study therefore recommends that future studies should increase the number of participants and incorporate aspects of observation into a longitudinal study design so as to acquire a clearer understanding of the experiences of adolescents with type 1 diabetes.
- In obtaining an information-rich description of each adolescent's experience with diabetes, this study has brought out several other topics which need further investigation: the issue of insulin and fatness. It is important that future studies look into the effects of insulin on the overall body image. This is because adolescents are so much into issues of appropriate body image and are likely to engage in eating disorders so as that attain the desired body image at the expense of T1DM management.

- The study found out that the community at large needs awareness on the different forms of diabetes, its risks and complications and how to deal with it. This is because most adolescents felt discriminated on the basis of them having the disease. Strategies and interventions to deal with and mitigate this diabetes-related stigma need to be developed and evaluated.
- The policy makers in the education sector in Kenya should endeavor to develop a diabetes policy for students and school personnel because most individuals spend a lot of time in learning institutions and therefore, the school environment should be conducive for T1DM management.

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APPENDICES

APPENDIX 1: CONSENT FORM

Hello informant,

My name is Grace Buluma Bakesia. I am pursuing a Master of Arts degree course at the University of Nairobi, Institute of Anthropology, Gender and African Studies. As required for the award of the Master of Arts degree, I am pursuing a research seeking to understand challenges faced by adolescents with type 1 diabetes in Nairobi City County.

Purpose

You have been selected on the basis that you have T1DM that may be giving you challenges in your daily life. The risk is that you may find some questions to be sensitive.

Methodology

The study is expected to last for three months in which we will have two encounters with fifteen adolescents with T1DM of ages 14-18 years and their school care givers; at home and at school. Recruitment will be at the KNH. Questions on social and school based challenges of living with T1DM will be asked.

Benefits

There are no immediate and direct benefits in for participating in the study but your participation will help in improving interventions.

Risks

There are no risks involved in this study because there are no treatments or experimental procedures in this study. The risk is that you may find some questions quiet sensitive, but you are advised not to respond to any of those you feel uncomfortable.

Voluntary participation

Your participation in this study is voluntary and you may withdraw from this study at any time and any stage. You will be tape recorded.

Confidentiality and anonymity

You have been assured that confidentiality will be maintained, and that your name will not be attached to any form of the data. Disguised extracts from your interview may be quoted in the thesis and any subsequent publications.

Consent form.

If you have any questions, concerns, or complaints about the research ethics of this study about this, I can contact the researcher, Grace Buluma Bakesia 0704539207 (grabuluma@yahoo.com), or I can contact her supervisor, Dr. Salome Bukachi at 0726771808. I have read and understood this consent form and I agree to participate in the study.

Signature _____ Date _____

Signature of person obtaining consent _____ Date _____

In addition to agreeing to participate, I also consent to having the interview tape-recorded.

Signature _____ Date _____

Signature of person obtaining consent _____ Date _____

APPENDIX 2: ADOLESCENTS' KEY INFORMANT GUIDE

Background information

1. Please tell me a bit about yourself, and your background in relation to your diabetes. I am interested in things like your age of diagnosis, and how long you have stayed with type 1 diabetes?

2. When you talk about type 1 diabetes, what is it that you are talking about?

- What does diabetes mean to you?
- How would you describe type 1 diabetes to someone who is not familiar with this condition?

3. Please think back to the years before you were diagnosed with type 1 diabetes. What was your social life, academic life like before you had diabetes?

- What memories do you have from before you had diabetes?
- How was your life different back then?

4. If you were talking to an individual who has been newly diagnosed with type 1 diabetes mellitus, what would you tell him or her to expect?

5. Home-based challenges Questions

Please describe the experience of the diagnosis?

- How are your parents, siblings and peers involved in the management of your condition?
- How difficult has it been for you to go through your teenage years while battling metabolic condition?
- What pressures do you feel as a teenager, and where do they come from?(dietary restrictions, insulin administration, blood glucose monitoring)
- Have you had episodes of high blood sugar while at a social event? Birthday, date? How did the others react? How did they describe the situation to you?
- How does your diabetes affect your social interactions with others?
- How has your diabetes changed the way others look at you?

- How accessible are the health services from home, in terms of availability and cost of insulin, hospitals, distance?

6. School based challenges

- How did your friends and teachers react when you were first diagnosed with diabetes? Do they really understand it?
- Do teachers and students know about your health condition? If so, how do they react? If not, why not? Who told them about your condition? Your parents or yourself?
- Does anyone else in your school have diabetes?
- What are some of the struggles you face while at school?
- How do your friends and teachers support or impede the diabetes management process?
- Have you ever felt that others do not completely understand your condition?
- What is your parents' role in your life at this point?
- Have you missed school because of your health condition?
- How knowledgeable are your teachers/nurses, school staff and peers about diabetes?
- How do your teachers help you? What could they do better to help you?
- What types of things in the school make it harder for you to manage your diabetes?
- How do you manage your diabetes while at school? (Blood glucose monitoring, insulin administration, proper food choices)

7. Do you have any advice for parents, teachers or peers on how they can help others with T1DM?

Thank you for your co-operation

APPENDIX 3: INTERVIEW GUIDE FOR THE HEALTH WORKERS

1. What is your opinion on the understanding of diabetes and its management (adolescents' teachers and friends)?
2. What are some of the challenges that adolescents with T1DM face, home based, school based in terms of relationships with peers, parents and siblings, dietary needs effects on learning, stigmatization, access to health services?
3. What do you think can be done to help T1DM patients improve on their diabetes management?

Thank you for your co-operation

APPENDIX 4: INTERVIEW GUIDE FOR TEACHERS / SCHOOL CAREGIVERS / NURSES?

- 1) How supportive is the school is supportive diabetic students in terms of regulation formulation, school environment, admission, diet and exercise?
- 2) How often do the diabetic students miss school due to their health condition?
- 3) Does diabetes affect a student's social relations with peer, families' teachers?
- 4) Does diabetes pose any challenges known to you that are considered as risky?
- 5) Has the school management placed great responsibility on you when complications arise?
- 6) How supportive is the on diabetes policies such as policies on school trips, meals, identification of students with diabetes?
- 7) What can be done to improve the management of students with T1DM while at school?

Thank you for your co-operation