FAMILY PSYCHOSOCIAL AND FACILITY RELATED DETERMINANTS OF ADHERENCE TO HOME MANAGEMENT OF TYPE 1 DIABETES MELLITUS AMONG CHILDREN AT KENYATTA NATIONAL HOSPITAL

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THIS THESIS IS SUBMITTED IN PARTIAL FULFILMENT OF REQUIREMENT FOR THE CONFERMENT OF MASTER OF SCIENCE IN NURSING (PAEDIATRICS) IN THE DEPARTMENT OF NURSING SCIENCES OF THE UNIVERSITY OF NAIROBI

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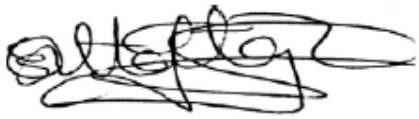
DECLARATION

I, Okello Samuel, hereby declare that this thesis is my own original work and has never been submitted anywhere for any award.

Signature  Date: 28th /11/2022

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APPROVALS

SUPERVISORS' APPROVAL

This thesis has been written by the student through our supervision, mentorship, guidance and support; and is a true account of his own original work. The candidate wrote this thesis diligently.

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DEDICATION

I dedicate this thesis to all family caregivers of children with type 1 diabetes mellitus and to my beloved family, my daughter Forat Samantha and wife Ezatiru Lucy.

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Above all, I am most thankful to the Almighty God for seeing me through this journey.

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LIST OF ABBREVIATIONS

ADA	American Diabetes Association
AIC	Akaike Information Criteria
CHO	Carbohydrates
CI	Confidence Interval
DKA	Diabetes Ketoacidosis
HbA1C	Haemoglobin A1C
HCW	Health Care Workers
KNH - UON ERC	Kenyatta National Hospital- University of Nairobi Ethics and Research Committee
KNH	Kenyatta National Hospital
MoH	Ministry of Health
PRRs	Prevalence Ratios
SDGs	Sustainable Development Goals
SMS	Short Messaging Service
T1DM	Type 1 Diabetes Mellitus
UNICEF	United Nations International Children's Emergency Funds

DEFINITION OF TERMS

Adherence: Is the extent to which a person's behavior, taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider. For this study adherence is demonstrated by the score of 80 and above for the recommendedset of parameters measuredi.e. insulin therapy, nutrition, blood glucose monitoring and exercise

Non adherence: Score of less than 80% for the set of parameters measured i.e. insulin therapy, nutrition, blood glucose monitoring and exercise

Diabetes mellitus: Is a chronic disease that results into hyperglycemia due to failure of the pancreas to produce insulin with or without the loss of action of insulin.

Type 1 diabetes mellitus: Is a chronic metabolic disorder that is characterized by deficient insulin production due to the selective beta cells destruction resulting into hyperglycemia.

Hyperglycemia: A random capillary whole blood glucose equal or above 11.1 mmol/L or a fasting capillary whole blood glucose greater than 6.1 mmol/L or blood glucose greater than 125 mg/dL while fasting and greater than 180 mg/dL 2 hours postprandial or a 75 g oral glucose tolerance test.

Diabetic ketoacidosis: Is a venous pH less than 7.3 or serum bicarbonate concentration less than 15 mmol/L, serum glucose concentration greater than 200 mg/dL (11 mmol/L) together with ketonemia, glucosuria, and ketonuria.

Insulinopenia: Is the deficient secretion of insulin by the pancreas, resulting in hyperglycemia.

Insulinitis: Insulitis is an inflammation of the islets of Langerhans.

Beta cells: Are cells of the pancreas which produce insulin.

Nephropathy: Is the disease or damage of the kidney, which can eventually result in kidney failure.

Neuropathy: Is the damage or dysfunction of one or more nerves that typically results in numbness, tingling, muscle weakness and pain in the affected area.

Retinopathy: Is any damage to the retina of the eyes, which may cause vision impairment.

Home management of type 1 diabetes: Is the use of insulin, dietary regulation, blood glucose monitoring and physical exercises performed for a child with type 1 diabetes at home.

Insulin: Is a hormone which regulates blood glucose levels.

ABSTRACT

Background: Type 1 diabetes mellitus (T1DM) is a chronic disease and is the most common type of endocrine disorder in children with a global incidence of 3%-6.2% yearly. Home management which includes administration of insulin as per the prescription, blood glucose monitoring at least 4 times a day, dietary regulation and physical activity is the recommended care. However, poor adherence to home management of children with T1DM remains a challenge and has contributed to increased mortality in children.

Objective: This study established the adherence and family psychosocial and facility related determinants of adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital (KNH).

Methodology: This was a descriptive cross-sectional study carried out at KNH pediatric diabetes clinic among caregivers of children with type 1 diabetes mellitus. The sample size was 91 caregivers recruited through simple random sampling. Data was collected using a structured interviewer administered questionnaire. Review and approval for the protocol was provided by University of Nairobi-Kenyatta National Hospital (UoN-KNH) research and ethics committee. Permission was sought from the KNH administration to implement the study in the facility. Study participants provided informed consent to participate. Data was analyzed using SPSS V28 and presented in tables, pie charts and graphs. Descriptive and inferential statistics were applied in data analysis. Demographic characteristics were presented as frequencies and percentages while overall adherence was determined through model analyses by combining the individual elements of adherence. Family psychosocial and facility related determinants to adherence were determined using multivariate logistic regression analysis at 95% confidence interval (CI).

Results: From this study results show that only (39.6%) of the children were deemed adherent to T1DM home management. The family psychosocial factors established to have a statistical significant and positive association with adherence to T1DM home management included, perceived helpfulness of the treatment ($p = 0.016$) and affordability of necessary resources and treatment by the family ($p = 0.000$). The facility-related factors established to have a statistical significant and positive association with adherence to T1DM home management included, support from the health care workers ($p = 0.011$), treatment availability in the health facility ($p = 0.000$) and appropriate health education offered to the caregivers ($p = 0.004$).

Conclusion: Based on the findings of the study, the level of adherence to type 1 diabetes mellitus home management among most of the surveyed children attending diabetes clinics at KNH was sub-optimal particularly in domains of diet, physical exercise and blood glucose monitoring. The key determinant factors of adherence in T1DM clients include a mix of both family psychosocial and facility factors

Recommendations: The low level of adherence calls for concerted efforts and sensitization of caretakers and health workers on T1DM management that include individualized health education talks be given to caregivers and children. Strengthening home visits approach for the families of children with T1DM.

1.0 CHAPTER ONE: INTRODUCTION

1.1 Study Background

Type 1 diabetes mellitus (T1DM) is the most common type of endocrine disorder in children. The annual rise among children is about 3% globally, with high incidence to prevalence ratio at 6.2% (Patterson et al., 2019; Statista, 2021; WHO, 2016).

Diabetes mellitus (DM) is a chronic health condition that results into hyperglycemia due to failure of the pancreas to produce insulin with or without the loss of action of insulin. DM can be classified as type 1, type 2, gestational diabetes and diabetes due to other causes such as pancreatectomy, pancreatitis, pancreatic disease among others. Type 1 Diabetes Mellitus (T1DM) is characterized by deficient in insulin production, due to the selective beta cells destruction (WHO, 2016). T1DM is divided into type 1a, which is linked to the immune system and type 1b of which the cause is idiopathic. Type 1a results from the autoimmune destruction of the Beta pancreatic cells causing insulinopenia (Erlich et al., 2008; Kumar et al., 2009a; Paul, 2019).

The clinical presentation of type1 diabetes mellitus in children include: polyphagia, polyuria, polydipsia, loss of weight, change in vision, and tiredness (Erlich et al., 2008; Kumar et al., 2009b; Paul, 2019). In developed world such as Europe and US, 20% to 30% of T1DM new cases diagnosed in children have diabetes ketoacidosis (DKA), one of the major complications of T1DM in children (WHO, 2016, 2021; Wood, 2018). However, in the developing world especially in Africa, almost all cases of newly diagnosed diabetes type 1 in children present with DKA, with many children dying before diagnosis or receiving treatment. This is because of lack of capacity to make diagnosis by the health care workers and lack of diagnostic equipment in most of the lower facilities (Mukama et al., 2012; WHO, 2016). Most complications of type 1 diabetes mellitus include hyperglycemia, DKA, severe cognitive dysfunction, stunted growth and delayed puberty, infections, microvascular, macro-vascular disease, nephropathy, neuropathy and retinopathy. Another complication of T1DM in children and adolescence is diabetes cataracts with the prevalence of 0.7 to 3% in children and adolescence (Mukama et al., 2012; Šimunović et al., 2018).

Currently there are no preventive measures to type 1 diabetes mellitus in children, however, the following are the home management strategies put in place to prevent the complications: blood sugar monitoring, a minimum of 4 times every day; use of insulin therapy as per the prescription. Others include healthy eating in which the child's foods should be rich in nutrients such as whole grains, lean protein, fruits and vegetables, and low in fats and calories. Physical activity (sweating exercise) for at least 60 minutes by children with the guidance of the parents should be performed. Parents should also ensure prompt follow-up of medical care on appointments, this ensures good diabetes management. During follow-up appointment, the HbA1c should be checked and the level be ≤ 7.5 for all children and teens (Ministry of Health, 2010; Smith & Harris, 2018; WHO, 2021; Wood, 2018).

Worldwide, about 3.4 million people die every year owing to high blood glucose, with as high as 80% of these happening in developing nations. Globally in 2019 there were 1.98 billion children age 0-14 years, of these about 601 thousand had type 1 diabetes, with 98,000 children newly-diagnosed per year (Statista, 2021). Within the African region, about 7,600 new cases of type 1 diabetes mellitus among children are reported every year and there were over 166,400 cases in 2015 (Lu et al., 2016). Home management of T1DM is a key solution to the prevention of complications linked to the growing tide of Type 1 diabetes mellitus in children. Recommended home management guidelines include: adherence to insulin therapy, dietary management, physical exercise, and self-blood glucose monitoring. Adherence to home management among children is very low standing at only 21%. (Fernando et al., 2018; Smith & Harris, 2018; WHO, 2021). Complications occurring due to poor adherence to home management stand at 21-52 % (Fernando et al., 2018; Smith & Harris, 2018; WHO, 2021). Studies have reported that only 1/3 (33%) of children adhere to blood glucose monitoring, 52 percent adhere to insulin therapy, and 29.5 percent adhere to dietary management (Boas et al., 2014a; Kyokunzire & Matovu, 2018; Moström et al., 2017; WHO, 2021). DKA is one of the complication of type 1 diabetes mellitus, occurring as a result of poor adherence to home management and it contributes to 3.4% to 13.4% mortality rate in children in developing countries (WHO, 2021). In Kenya, limited information existed regarding adherence to type 1 diabetes mellitus home management among children.

1.2 Problem Statement

The current guidelines for the type 1 diabetes mellitus home management include: monitoring of blood sugar, a minimum of 4 times a day; use of the insulin as per the prescription; taking of foods rich in nutrients and low in fat and calories; getting at least 60 minutes of physical activity daily and follow-up medical care (Ministry of Health, 2010; WHO, 2021; Wood, 2018). Despite the above clear home management guidelines put in place by the Ministry of Health, World Health Organization and America Diabetes Association for children with type 1 Diabetes mellitus, most of the children were still being admitted with type 1 diabetes mellitus complications. With the high number being admitted with diabetes ketoacidosis, contributing to 13.4% death among children (Musoma et al., 2020; WHO, 2021).

Annually about 3.4 million deaths in children are attributed to high blood glucose, of which 80 percent occur in developing countries (Lu et al., 2016; WHO, 2016, 2021). About 41.1% children admitted at KNH have severe DKA while 35.7% have moderate DKA, with a death rate of 6.9% (Musoma et al., 2020). These have contributed negatively to the burden of care, with the cost being levied on the family. Also the cost and time spend in the hospital during the management of these children affect the progress of families.

In Kenya there was limited literature on determinants of adherence to homemanagement of T1DM among children, although, anecdotal data from Kenyatta National Hospital showed a rise in the number of children with T1DM being attended to in KNH's pediatric diabetes clinic. This study therefore aimed at establishing the level of adherence, family psychosocial and facility related determinants of adherence to home management of type 1 diabetes in children at KNH.

1.3 Justification of the Study

Sustainable Development Goal (SDG) number 3, "Good Health & Wellbeing" targets to ensure healthy lives and promotes wellbeing for all, across all ages, children inclusive, with the aim of ensuring that more children survive now than ever (UNICEF, 2022).

As strategies to achieve sustainable development goals (SDGs) by 2030 are being implemented, home management of type 1 diabetes mellitus in children needs to be strengthened. This would be realized when adherence to home care plans were followed to the dot to ensure effective control of blood sugar levels hence control of complications of type 1 diabetes mellitus and its' associated morbidity and mortality. Understanding of determinants that determined adherence would inform the design of specific and appropriate interventions to improve the level of adherence to home management of type 1 diabetes mellitus in children. Kenyatta National Hospital being the national referral centre and having a diabetes clinic therefore provided the population for this study.

1.4 Purpose of the Study

The study sought to establish the family psychosocial and facility related determinants of adherence to type 1 diabetes mellitus home management among children attending diabetes clinics at KNH. The family psychosocial determinants and facility related determinants were assessed using a structured questionnaire.

1.5 Objectives

1.5.1 Broad Objective

To establish the family psychosocial and facility related determinants of adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital.

1.5.2 Specific Objectives

1. To determine the level of adherence to type 1 diabetes mellitus home management for children attending pediatric diabetes clinic at Kenyatta National Hospital.
2. To assess the family psychosocial determinants influencing adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH.

3. To establish the facility-related determinants influencing adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH.

1.5.3 Research questions

1. What is the level of adherence to type 1 diabetes mellitus home management for children attending pediatric diabetes clinic at Kenyatta National Hospital?
2. What are the family psychosocial determinants influencing adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH?
3. What are the facility-related determinants influencing adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH?

1.6 Expected Benefits of the Study

To policy: The findings are anticipated to be used by hospital administrations and the nurse managers to develop new policies, hence ensuring that health care workers (HCW) and facilities improve on the level of adherence, through development of family partnership in care of children with T1DM.

To nursing education: The findings of this study are anticipated to enrich the nursing curriculum with the family psychological aspects, and implementation of the Casey Model of nurse family partnership in care of children with type 1 diabetes mellitus.

To nursing practice: This would contribute to the achievement of the sustainable development goal number 3, specifically of ensuring the wellbeing of children through creating the partnership in care of children and their family.

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 Overview of Diabetes Mellitus

Diabetes mellitus is a chronic disease that results into hyperglycemia, resulting from failure of insulin production by the pancreas, with or without the loss of action of insulin. It's categorized into gestational diabetes, type 2, type 1, and diabetes arising from other causes such as pancreatectomy, pancreatitis, pancreatic disease among others. Deficiency in insulin secretion/production due to the selective beta cells destruction causes type 1 diabetes mellitus (T1DM) (WHO, 2016). T1DM is divided into type 1a - linked to the immune system and type 1b whose cause is idiopathic. The immune system linked Type 1a results from the autoimmune destruction of the Beta pancreatic cells causing insulinopenia which then causes protracted high blood glucose (hyperglycemia). Insulinitis and peri islets cellular infiltration is associated with a reduction in pancreas' beta cells. A wide range of antibodies are linked with T1DM. T1DM is also linked to human-leukocyte-antigen (HLA) gene. About 40% to 50% of the clients with T1DM is link to the HLA gene with specific alleles at the loci of DRB1, DQA1, and DQB1 taking the solid link to T1DM (Erlich et al., 2008; Kumar et al., 2009a; Paul, 2019).

Acute consequences of T1DM in children include diabetic ketoacidosis and severe hypoglycemia, which are caused by insufficient or excessive insulin administration, respectively. Hyperglycemia remains the most important complication. All these complications if not managed result into, diabetes ketoacidosis and death (Rewers, 2002) .

Most of the times, children are admitted with complications occurring due to non-adherence to home management which include administration of insulin, nutritional diet low in fat content, sweating exercises atleast for 60 minutes, blood sugar monitoring atleast four times day (Smith & Harris, 2018). In children adherence is determined by full support and supervision of the family members, and in chronic illnesses such as type 1 diabetes mellitus, the health care support plays a very important role to ensure that adherence is realized (Ministry of Health, 2010). This chapter therefore reviews literature on the level of adherence to type 1 diabetes mellitus home

management in children, including adherence to insulin therapy, nutritional diet, exercises and blood glucose monitoring. It also reviews literature on family psychosocial support and health facility related determinants for adherence to type 1 diabetes mellitus among children.

2.2 Management of Type 1 Diabetes Mellitus in Children

There is currently no medication available to treat, slow or stop the progression of type 1 diabetes mellitus disease (Wood, 2018). As a result, the goal is to keep the disease under control through controlling the glucose levels, promoting a happy childhood, and reducing long-term complications. The management of T1DM include insulin therapy, blood glucose monitoring, physical exercise, dietary management, psychological support and health education (Ministry of Health, 2010; WHO, 2021).

2.2.1 Insulin therapy

Insulin therapy is recommended in management of type 1 diabetes. At initial dosage, a little amount is required at 0.4–0.6 IU/kg per 24 hours first. This phase, is recognized as the 'honeymoon period.' The insulin dose must then be adjusted as the child grows. Prepubertal child who have had T1DM for more than 1–2 years often/normally needs 0.5–1 U/kg per 24 hours. At the mid of adolescence there is increased growth hormone levels that lead to higher insulin resistance, this leads to a rise in need for insulin by 40 to 50 percent and doses of 1–2 U/kg per 24 hours are adminstered (Ministry of Health, 2010; WHO, 2016, 2021; Wood, 2018).

The insulin regimen is twice-daily injection of either soluble and isophane insulin or a mixed formulation. The first 2/3s of the dose is taken in the morning, and the remaining dose is given at night during which a meal should be served within 20 minutes of the insulin injection. Cleaning of the injection site which include upper arm, abdomen and thigh with water and subcutaneous injection is done. To avoid lipohypertrophy and lipoatrophy, parents and children should be taught to rotate injection sites. Depending on the glycemic level, the dose must be adjusted (Bilous et al., 2021; Fernando et al., 2018; Ministry of Health, 2010; Smith & Harris, 2018; WHO, 2021; Wood, 2018).

2.2.2 Blood glucose monitoring

With the help of the glucometer, short term control monitoring is done. Thus, parents should monitor the blood glucose daily. Evaluation of glucose control on the long term is done by use of HbA1C and fructosamine markers for three and six-month control respectively. The blood sugars target in infants and children under six years is 5-12mmol/l; age six to twelve years is 4-10mmol/l and in adolescents and adults is 4-8mmol/l. During bed time the blood sugar target is 7-10mmol/l for all children. Blood glucose self-evaluation should be done, with the aim of maintaining pre-prandial blood glucose in the range 4.0-7.0 mmol/l, and post prandial less than 9.00mmol/l (Fernando et al., 2018; Smith & Harris, 2018; WHO, 2021). The HbA1C should be less than 7 in children less than 18 years. Glucose monitoring should be done before meal and during bed time, before physical activity, when one feels weak, with at least 4 times monitoring in a day (Ministry of Health, 2010; Wood, 2018; WHO, 2014).

2.2.3 Dietary management

The 'healthy eating' diet is recommended for a child with diabetes and it is a family meal, there should be no restrictions. The diets should include balance between carbohydrates, protein and fats, with inclusion of essential vitamins and minerals. Diet is grounded on the child's energy requirements, which are determined at the time of presentation and gradually increased to the mean of the current weight and the 50th percentile weight. Carbohydrates (CHO) should account for 55 percent of daily calories and are measured in portions (1 portion = 15g of CHO) with a mix of high and low glycemic index meals. The quantities are divided into three main meals and three snacks, according to the child's daily routine (Fernando et al., 2018; Smith & Harris, 2018; Wood, 2018).

2.2.4 Physical exercise

Exercise is essential for a child with type 1 diabetes mellitus, and physical activity should not be restricted. Physical activity reduces blood glucose levels, which might appear several hours after the activity, and the degree of hypoglycemia varies depending on the intensity of the activity. As a result, parents and children should alter the insulin dose based on activity and modify their diet (Fernando et al., 2018; Wood,

2018). Children 3 years and above should be encouraged to get at least 60 minutes of sweating physical exercise (Fernando et al., 2018; Ministry of Health, 2010; Smith & Harris, 2018; Wood, 2018).

2.2.5 Psychological support and health education

Type 1 diabetes mellitus in children and adolescents can cause stress and distress among children and the family at large. With preexisting problems in the family the situation is likely to be worsen. Psychological support therefore is vital aspect of management, and it should be made available to the entire family as needed. For continued education and support to the family, the services of a diabetes nurse educator and a social worker are critical (Bilous et al., 2021; Fernando et al., 2018; Ministry of Health, 2010). Ongoing type 1 diabetes mellitus education of children and adolescent with type1 diabetes mellitus focuses on insulin therapy, injection, blood monitoring, diet monitoring and acute complication of hypoglycemia, hyperglycemia, and diabetes ketoacidosis. It should also focus on planning the meals, management of physical activities, and insulin therapy (Wood, 2018).

2.2.6 Guidelines and standards on home management of type 1 diabetes mellitus

Four areas of home management were adopted from guidelines from Ministry of Health, American Diabetes Association, World Health Organization; with focus on insulin therapy, blood glucose monitoring, physical activity and nutrition management. The guidelines recommend that children with type 1 diabetes mellitus while at home should follow strictly the recommendations for glycemic levels to be controlled (Ministry of Health, 2010; Wood, 2018; WHO, 2014, WHO, 2021). The following were the guidelines used: The guidelines from the Ministry of Health Kenya: National Clinical Guidelines For Management of Diabetes Mellitus 2010, Chapter 4 which focuses on the management of type 1 diabetes in children at home (Ministry of Health, 2010). The guidelines by American Diabetes Association 2018, titled the type 1 diabetes self-care manual: A complete guide to type 1 diabetes across the lifespan for people with diabetes, parents, and caregivers (Wood, 2018). The World Health organization 2013 guidelines for the management of common childhood illnesses

(WHO, 2014). The WHO, 2021 guidelines on diagnosis and treatment of diabetes in children (WHO, 2021).

The guidelines state that with the use of glucometer, short term control monitoring is done. Thus, parents should monitor the blood glucose daily. Glucose monitoring should be done before meal and during bed time, before physical activity, when one feels weak, with at least 4 times monitoring in a day. Evaluation of glucose control on the long term is done by use of HbA1C for three-month control. Insulin therapy is recommended in management for children having type 1 diabetes. The insulin regimen is twice-daily injection of either soluble and isophane insulin or a mixed formulation. The 'healthy eating' diet is recommended for a child with diabetes and it is a family meal, there should be no restrictions. The diets should include balance between carbohydrates, protein and fats, with inclusion of essential vitamins and minerals. The quantities are divided into three main meals and three snacks, according to the child's daily routine. Exercise is essential for a child with type 1 diabetes mellitus, and physical activity should not be restricted. Physical activity reduces blood glucose levels, which might appear several hours after the activity. Children 3 years and above should be encouraged to get at least 60 minutes of sweating physical exercise.

2.3 Adherence to Type 1 Diabetes Home Management

Adherence to insulin therapy, dietary management, physical exercise and self-blood glucose monitoring among children at home with support from the family remain a key tool to controlling the glycemic levels in children. Only 21% of children with type 1 diabetes mellitus achieve the glycemic target of pre-prandial blood glucose between 4.0-7.0 mmol/l, post prandial of less than 9.00mmol/l and HbA1C of less than 7 recommended by American Diabetes Association (Fernando et al., 2018; Smith & Harris, 2018; WHO, 2021). Another similar study indicated that adherence was at 52 percent with only 1/3 reporting adhering to blood glucose monitoring, most of which reported that environmental interferences including inconveniences, painfulness, lifestyle interference and cost being the issues occasioning non-adherence (Vincze et al., 2004).

In a cross-sectional study conducted to evaluate self-glucose monitoring in Swedish patients with type 1 diabetes, results indicated that adherence was poor with only 43.9 percent undertaking regular personal monitoring of blood glucose more than 4 times in a day (95% confident interval 38.5 percent to 49.4 percent). The main reason for poor adherence were lack of time, forgetfulness, and self-consciousness. With facts being reported in adults who can be able to work, remember, and understand the danger of complications, it can only be thought that this could even be worse in children who are vulnerable in all aspects and without family involvement may even make matters worse (Boas et al., 2014b; Moström et al., 2017).

A similar study conducted in Uganda on adherence to recommended type 1 diabetic care indicated that, overall adherence to recommended care remains low at 37 percent, with 52 percent adhering to insulin therapy, 76.5 percent on blood glucose monitoring, and 29.5 on dietary adherence (Kyokunzire & Matovu, 2018).

A cross sectional study carried out among adults at KNH with type 2 diabetes indicated non-adherence. Results indicated that medication adherence is low standing at 28.3 percent of the population (95 percent confidence interval: 23.1, 33.5). However, there is no local literature that shows the compliance levels to type 1 diabetes mellitus home management in children. With adults having non-adherence, the results could even be worse among children who may not be able to understand fully the consequences of poor adherence and without ability to take care of themselves, adherence may even only be worse (Waari et al., 2018).

Exercise for about 1 hour among diabetic children reduces glucose level by 40%. Assessing the level of blood glucose prior to and following exercise is important among children with type 1 diabetes. With blood glucose of less than 120mg/dl in children, hypoglycemia is likely to occur during exercise. This is because 15 g of oral glucose only causes a 20-mg/dl increase in glucose levels, 30-45 g of oral glucose may be a better choice for treating hypoglycemia during exercise. Although adherence to prescribed exercise of about 1 hour is essential in regulating blood glucose level in children, only 60% of children spend an average of 1 hour performing exercise per day. Only 50% perform blood glucose monitoring prior and after exercise, one third adjust

insulin dose after exercise and two third add carbohydrate to avoid hypoglycemia (Datye et al., 2015; Moström et al., 2017).

2.4 Determinants for Adherence to Type 1 Diabetes Home Management among Children

In one of the cross-sectional studies to assess the relationship of family support and compliance in care among children with type 1 diabetes, the findings indicate that adherence to care is associated to less independence of children to care. More family support leads to better compliance to care among children with type 1 diabetes, this eventually leads to better glycemic controls (Hsin et al., 2010).

Determinants of adherence to home management in children with T1DM include psychological, family support, a well functional family among others. Good relationship between the family members with children is very key in promoting adherence to type 1 diabetes home management in children. Lack of parental support leads to poor home management in children with type 1 diabetes. Close monitoring of children by the parents enable them to adhere (Datye et al., 2015; Mlynarczyk, 2013; Palmer et al., 2011; Waari et al., 2018).

A study conducted among children to assess the barriers to type 1 diabetes mellitus care, indicated that three major barriers contributes immensely to non-adherence including: cost of care at 43.0%, poor communication and lack of necessary information at 43.0% and 48.4% respectively (Valenzuela et al., 2014). The health care workers need to effectively communicate to the clients especially spending adequate amount of time with the family and the children while listening to their concerns and answering their pressing questions and issues. The family centered approach helps in implementing this type of care and promotes good adherence (Boas et al., 2014b; Valenzuela et al., 2014).

The insulin associated factors remain key in determining adherence, the pain caused by injection, its cost, and fear of the risk of side effects contribute to poor adherence among children. Usually children fear the painful situations in life and therefore may not adhere appropriately to care (DeCosta et al., 2020).

Follow-up communications by the health care workers remain a very important tool to improve adherence, messages related to medication, diet, physical activities and glucose monitoring improves the glycemic control among children. Use of text messages, emails and smartphones applications demonstrated improved adherence. In a systematic review conducted among ten studies on use of messages, email and smart phone applications to remind about home management, three studies showed improvement in glycated hemoglobin level indicating improved adherence. Other three studies found that there was increased glucose monitoring adherence, and six studies found a reduction in hypoglycemia episodes (glucose of less than 3.0 mmol/L) out of the ten studies reviewed. In addition, five research looked at a mobile app with a message/response text mechanism. Only one of them showed a substantial decrease in severe hypoglycemia episodes, another solitary trial found a 0.3 percent drop in median glycated hemoglobin levels ($p<0.001$) (Ryan et al., 2017; Sun et al., 2019).

2.5 Gaps in Literature

Generally, there was a gap in the literature related to adherence to diabetes type 1 care in children. Most of the studies were related to adherence in adults leaving limited literature related to type 1 diabetes mellitus in children in Kenya. During literature review there was only 1 article found related to type 2 diabetes adherence done at KNH, and one related literature on type 1 diabetes mellitus done in Uganda. This study therefore contributes in narrowing the gap and recommends a need for further researches related toT1DM in children. This therefore provided an opportunity for the research to add on the body of knowledge of type 1 diabetes mellitus in children.

Most of the common factors hindering adherence to T1DM home management in other countries included lack of familial support, poor communication among health care workers and families. There was clear evidence that most of the health care workers did not use the family friendly models while caring for the children. There was also a clear gap in literature related to determinants locally. This study therefore generates insights relating to family psychosocial and facility related determinants for adherence to type 1 diabetes mellitus home management among children at KNH.

2.6 Conceptual Framework

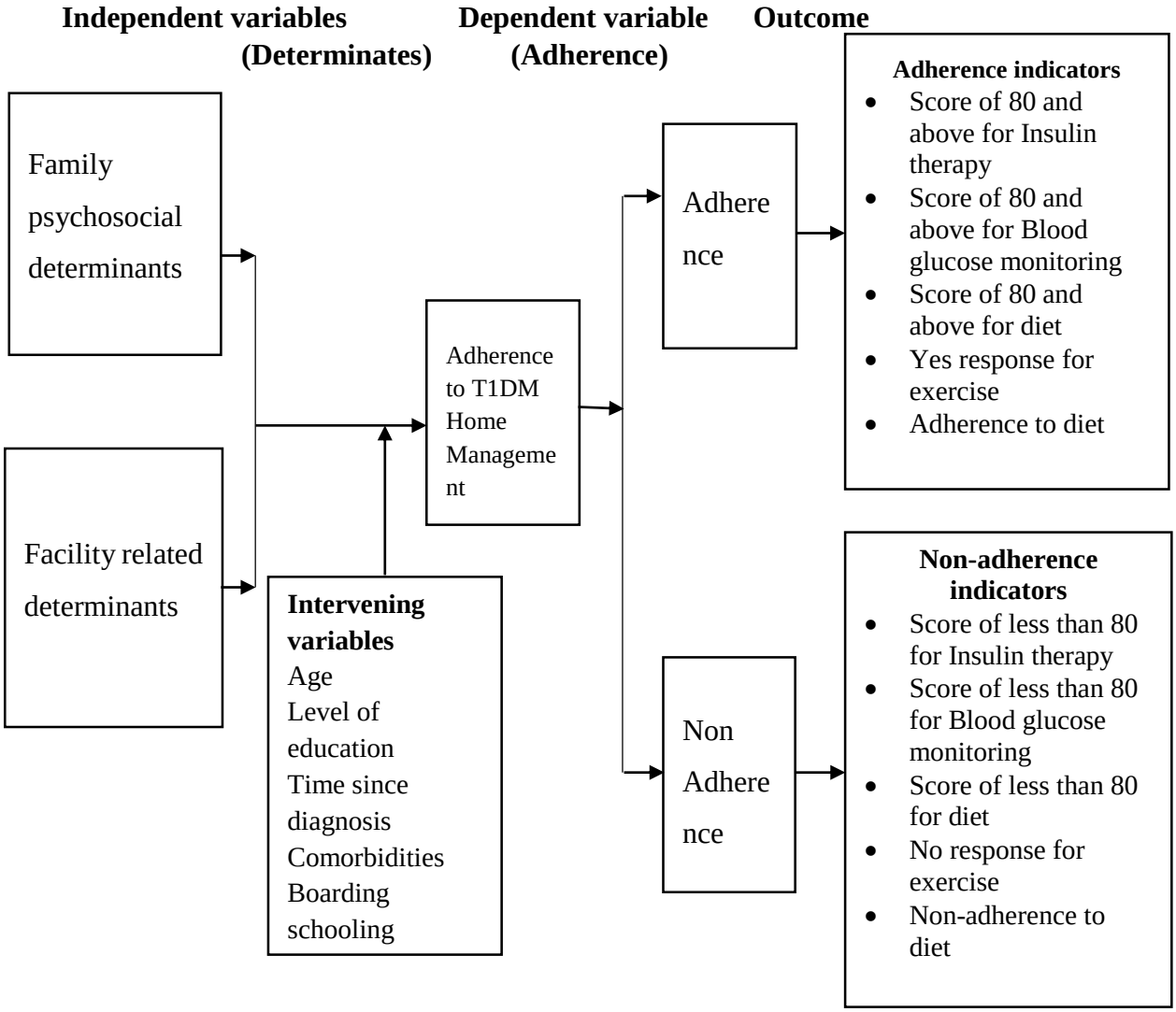

Figure 2.1: Conceptual framework

2.7 Theoretical Framework

This study adopted Casey theory; partnership in care pediatric nursing model. According to Casey theory(1988), childrens' care, whether a healthy or a sick child, is best done by their families as well as with an appriate level of help from competent HCPs where need be. For optimal health and healing to be achieve, the family and parents need to be involved. The model has 5 core concepts: the child, health, environment, family and pediatric nurse.

The child has needs that are met by the parents or other family members, as they grow they learn to be independent. The child's needs is related to need for "adherence to type 1 diabetes home management" including adherence to blood glucose monitoring, insuline therapy, nutrition and exercise/ physical activity.

Health is when one is in an optimal state of wellbeing, physically and mentally. Ill health leads to compromise in physical, psychological, intellectual, social and spiritual development. Health is related to the "outcome of adherence to T1DM home management" demonstrated by "adherence or non-adherence". Adherence leads to maintainance of normal glycemic levels and therefore the child being free from complications of T1DM like diabetes ketoacidosis, nephropathy, neuropathy, retinopathy. On the other hand nonadhernce leads to hyperglycemia resulting into complications of T1DM above.

Environment has variety of environmental stimuli that have impact on a child's growth, therefore environment must be safe, caring and loving. Environment is related to the "Intervening variables" like home environment, boarding schooling, peer groups, commobities or infections and "Facility environment"

Family is a group of people who share primary responsibility for the child's care and have a significant impact on his or her development. Parents execute a crucial task in the care of the child through adequate support and performance of the tasks that leads to optimal health. Family is related to the "family psychosocial determinants" of adherence to T1DM home management including family support, good communication and reminder to the child, provision of resources to the child like drugs, transport, food, glucometer, and food.

Pediatric nurse, offers skilled care, which can not be done by the family, support the family to perform skilled task, teach the family and the child and make referral of the child for appropraite care. The concept of Pediatric nurse is related to "facility related variables" which determines adherence to T1DM home management. This include technical support to the family, provision of treatment/insuline, health education of the child and family, and followup through messages, calls, and emails. All these impact

on the level of adherence and eventually to the control of glycemic levels.

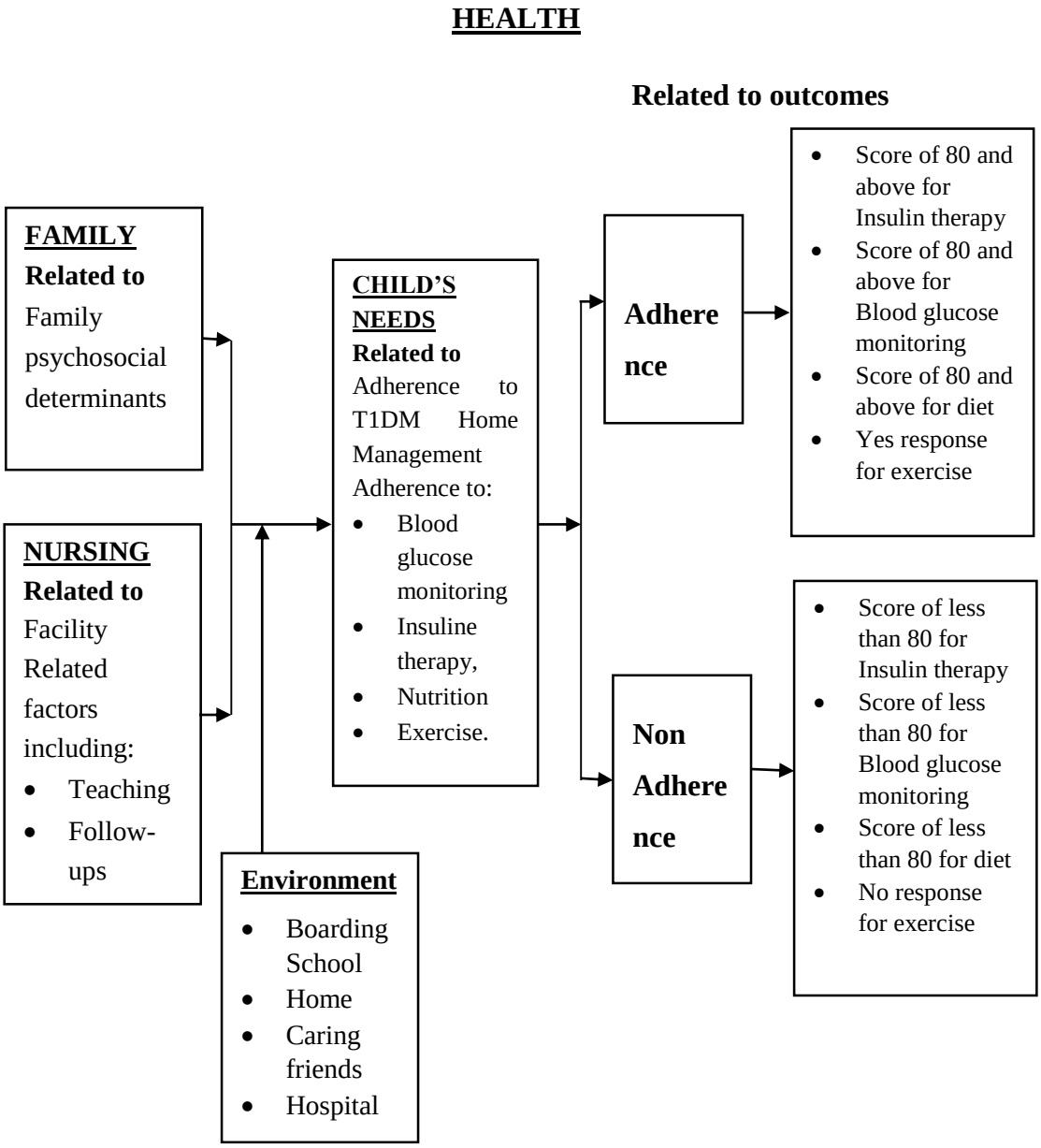

Figure 2.2: Partnership in care model concepts related to conceptual framework (Casey 1988)

3.0 CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter describes the following; study design, where the study was done, who participated in the study and how they were selected, how data was gathered and with which tools, how the data was managed and analysed, ethical principles that guided the study's conduct, study limitations and dissemination of study findings.

3.2 Study Design

The study employed descriptive cross sectional study design, which according to (Kesmodel, 2018) is recommended in description of a phenomenon (adherence and its' determinants to adherence to type 1 diabetes home management) required and collects data at a single moment without the necessity of follow-up. The study employed quantitative data collection methods for determination of adherence level, family psychosocial and facility related determinants of adherence to type 1 diabetes mellitus home management among children attending pediatric diabetes clinic at KNH. This was chosen because the problem of complication of diabetes in children remained the main issue and directly caused by non-adherence to home management (Khunti et al., 2019; Wood, 2018). This therefore may form a future basis for interventional studies on how to improve on adherence to diabetes type 1 mellitus home management in children.

3.3 Study Setting

The study was carried out at Kenyatta National Hospital pediatric diabetes clinic. KNH is the largest teaching and referral public hospital in the country and region. It's situated about 3.5km from the country's capital central business district, off Ngong road. It can accommodate over 1,800 inpatients with different clinics that run on different days of the week (Kenyatta National Hospital, 2021). It is also a training hospital for UoN's medical students from Faculty of Health Sciences and other training institutions. KNH is a specialized hospital and therefore receives patients as referrals from all over the other lower facilities in Kenya and the entire Sub-Saharan Africa. Being the referral center therefore cares for children with complications of type 1 diabetes mellitus and

other conditions. Pediatric diabetes clinic attends to pediatric clients with diabetes every Tuesday of the week and currently receives about 120 clients on a monthly basis. The staff who attended to the clients included doctors on fellowship program, the resident doctors, pediatric endocrinologist, nurses, counselor and dieticians.

3.4 Study Population

The study population were all caregivers of children with type 1 diabetes mellitus followed up at KNH's pediatric diabetes clinic. These caregivers administer/supervise care of children with type 1 diabetes at home. They were assumed to be having adequate knowledge in relation to type 1 diabetes mellitus home management in children and were therefore adequately adhering to the recommended care. It was also assumed that these caregivers were actually a key factor in determining adherence of children to type 1 diabetes home management.

3.5 Inclusion and Exclusion Criteria

3.5.1 Basis for Inclusion

The study considered the following as being eligible to participate in the study:

i. Must be 18 years and above
ii. Should have consented to participate in the study
iii. Should have cared for the child with T1DM for at least 1 month prior to date of data collection

3.5.2 Exclusion Criteria

The study excluded:

I. Participants with mental impairment and not able to give informed consent.
II. Participants with sick children who needed immediate attention.

3.6 Sample Size Determination

The Kish and Leslie formula (1965) illustrated below was applied in determining the size of this study's sample;

$$N = \frac{t^2 p (1-p)}{d^2}$$

Explained as;

N = sample size

t= the standard confidence-interval as depicted on the log-book at 95% CI equating to 1.96.

p= population-proportion assumed to be knowledgeable of the issue under study, in this case set as 0.5

d= margin of error allowed, herein set as 0.5%

Therefore, $N=\frac{1.96\times1.96\times0.5\ (1-0.5)}{0.005^2}$

N=384

However, modifying of the sample size was done as follows;

$$nf = \frac{n}{1+ n/N}$$

Explained as;

nf= appropriate sample size with a population < 10,000

n= size of sample for populations ≥ 10,000, in this case 384

N=estimated number of care takers within two months since data collection took a period of two months and this was 120

nf = 384 / [1+ (384/120)]

nf = 91.4

Hence, the investigator selected 91 participants as the sample from these computations.

3.7 Sampling Procedure

The investigator used simple random sampling procedure to select participants who had given their consent of being part of the study on every Tuesday, which was the day of the paediatric diabetes clinic. Numbers ranging from 1 to 100 were written on pieces of papers that were folded and mixed in a box. Every caregiver of a child with the condition under study attending the clinic on the day of data collection and had consented to the study was requested to pick one paper on a random basis. Those who picked odd numbers participated in the study. This technique of participants' selection was appropriate because it provided an equal opportunity to caregivers of children with type 1 diabetes mellitus to participate in the study without any bias.

3.8 Recruitment and Consenting Procedures

The targeted participants in this study were the caregivers of children with T1DM who had brought their children to the pediatric diabetic clinic for review. The researcher approached them during waiting time at 8:00 am, where brief information about the study before review was done. The session did not last for more than 6 minutes. During this brief session, the researcher offered important points about the study; emphasized on the selection criteria and disclosed where he could be found for further details within the diabetic clinic. The caregivers who met the inclusion criteria were requested to meet with the researcher and research assistants in a separate room after review, where detailed information and procedures of the research were explained.

Upon understanding and accepting to participate, voluntary informed consent was sought from caregivers of children with type 1 diabetes mellitus. Assent was also sought from the children to allow their caregivers to participate in the study. This entailed caregivers signing the study's informed consent document and children giving verbal assent. The considerations of the consenting included voluntary participation, respect for the dignity and autonomy of the participants, ensuring confidentiality of any information provided and ensuring that the study participants felt at ease during the data collection exercise. Those who declined to participate in the study were allowed to do so without victimization and were still accorded the standard care of treatment.

3.9 Research Tool

The researcher used a structured interviewer-administered questionnaire to collect data from participants sampled. Part of the questionnaire on adherence was adopted from modified Morisky medication adherence assessment scale, comprising of 8 questions and had been used by previous researchers in related adherence studies (Arnet et al., 2015; Boas et al., 2014a). The other part of the questionnaire was developed based on the recommendations of type 1 diabetes mellitus home management from the standard guidelines from WHO, American Diabetes Association (ADA), and Ministry of Health (Ministry of Health, 2010; WHO, 2021; Wood, 2018). Questions on family psychosocial and facility related determinants to adherence for type 1 diabetes mellitus in children were developed based on other related researches done in other places (Boas et al., 2014b; Khunti et al., 2019; Kyokunzire & Matovu, 2018; Mlynarczyk, 2013; Moström et al., 2017; Waari et al., 2018). The questionnaire was used because it enabled the researcher to collect standardised data from the participants and it was cheaper for collecting needed data from the 91 participants within the short period of 2 months. The questionaire consisted of structured closed ended questions with structured responses written in English and translated to Kiswahili for easy understanding by the study participants. The interviewer read the questions to the participants and the responses were ticked accordingly (responses from participants were ticked from the questionnaire).

3.10 Research Assistants

Data collection was done by two research assistants who were trained by the principal researcher on how to interview the participants using the questionnaire. The research assistants were engaged because the principal investigator had language barrier and was not conversant with Kiswahili. The research assistants were nurses from different departments with a minimum of bachelor's degree in nursing and with valid practising licence. This was because they had knowledge related to data collection and were licenced to work in clinical and research areas.

3.11 Pre-Testing

The questionnaire was pretested among 9 caregivers of children with T1DM admitted at Kenyatta National Hospital Pediatric Endocrinology and Gastrointestinal Unit (Ward 3B), for its validity and reliability. Necessary adjustments were made to the questionnaire after the pre testing to enhance its validity and reliability.

3.12 Ethical Considerations

The researcher submitted the proporsal to the KNH-UON ERC for review and approval. Upon approval, an approval letter was presented to KNH administration to allow the researcher collect data. The study participants were educated on the purpose and study objectives of the study and what was expected of them. Informed consent was sought from the study participants. Confidentiality was ensured by use of codes in the questionnaires and not names. Privacy was maintained during the process of data collection by conducting the interviews in a private room, complete questionnaires were kept under lock and key, and data was kept in a password locked computer.

Justice: was observed through ensuring that all the participants were treated equally without bias, and in a manner that was consistent with the laws governing research. The researcher complied with all the university and the ethics and research committee guidelines.

Beneficence: was observed by ensuring that at all times the intention of the study was doing good to the participants. The findings of this study are meant to benefit children with Type 1 diabetes mellitus by making appropriate recommendations on improvement of adherence to home management of type 1 diabetes in children hence improving on the glycemic controls and reductions of complications of non-adherence.

Non-maleficence: was observed by ensuring that the research did not cause harm to the participants. In this research there were no risks which were associated with this study. However, if should there would be any emotional consequence as a result of the research, participants would be counseled and also referred for further appropriate counselling.

Autonomy: was observed by ensuring that participants made their own choices about their own thoughts, intentions, and actions. In this study only willing participants were recruited to participate in the study. The identity of all participants was kept anonymous by ensuring the use of codes and not names or any identifier.

3.13 Data Collection

Data was collected every day of the clinic (Tuesday) from 8 am to 2 pm for 2 months using an interviewer-administered questionnaire. Two months was chosen because participants are usually given return dates within 3 months and therefore no chance of repetition of sampling the same participant again and also enabled the researcher to sample adequate number of study participants. The researcher together with two research assistants sampled 12 care takers every clinic day for the first 7 weeks of data collection making a total of 84, then in the last week sampled 7 participants. This gave a total of 91 participants at the end of the period of data collection. Filling of the questionnaire took approximately 15 minutes after receiving services. The researcher and the research assistants introduced themselves to the participants, and explained the objectives of the study. All participants that met inclusion criteria were given a chance to consent to the study without any bias. Those who consented to participate were then interviewed. The principal researcher oversaw the process of data collection to ensure that the research assistants provided correct information and adhered to ethical principles.

3.14 Data Storage

The questionnaires and informed consent were serialized and participants did not use their names or any identifier. The filled questionnaires and signed informed consent form were received from the data collecting team. The principal investigator scrutinized them to ensure they were complete before sorting, arranging and storing them in a secure location that only he could access. The responded to study tools and informed consent were safely locked in a cupboard accessed only by the researcher. The data entered was stored in a flash disk coded with the password only known to the researcher. All these were done to ensure confidentiality.

The filled questionnaires and signed informed consent shall then be stored safely for a period of five years after which they will be destroyed by burning completely into ashes.

3.15 Data Analysis

Data was analyzed using *SPSS V28.* The children's and caregivers' demographic information were evaluated descriptively using means and standard deviation for continuous variable while categorical ones were presented using frequencies and percentages. Participants' gender constituted the basis for stratifying the findings on their demographic attributes. Comparison of the categorical variables was done utilizing the Fisher's exact test. Adherence to T1DM home management was determined by model analyses by combining the individual adherence to monitoring of blood sugars, dietary prescriptions, insulin treatment and physical exercise. This was because adherence to home managment of type 1 diabetes required adherence to insulin therapy, diet, blood glucose monitoring and physical exercise. Family psychosocial and facility related determinants of adherence were determined with the use of altered and unaltered prevalence ratios (PRRs) at 95% Confidence Interval with robust standard errors applying a generalized linear model. The researcher used PRR and not odds ratio because odds ratios tended to overestimate how strong an association was in cases where a given result was more evident. The study utilized a multivariable logistic regression analysis model at a significance level of 5% for identifying the predictors of adherence to type 1 diabetes home management in the studypopulation.

3.16 Data Dissemination

Original printed copies of this research thesis are submitted to the following bodies; University of Nairobi, department of nursing for academic award of the program being studied, copy to the University of Nairobi Library, KNH-UON ERC, KNH administration, supervisors and a personal copy for future reference.

Results shall also be shared in scientific conferences and also published in a peer reviewed journal which can be referred to by researchers and viewers.

Dissemination shall also be done through health education talks to caregivers and children with T1DM in the diabetes clinic of KNH.

3.17 Limitations and Delimitations of the Study

Language barrier as the researcher did not understand Kiswahili. However, the principal investigator used the translated questionnaire and research assistants. These assistants did not understand the research like the way the researcher understood it. This could have led to missing of important information from the participants as far as the study was concerned. However, the researcher still believes that the use of research assistants helped greatly in overcoming this limitation of language barrier and more so the researcher adequately trained them prior to data collection and worked closely with them.

Fear of deceiving since this study was conducted among caregivers, who possibly feared that they could be blamed for not adhering to the home management recommendations. Nevertheless, through explaining the study's aims as well as adherence to the informed consent helped in this limitation.

Some participants who wished to share with the researcher individually the challenges related to what they faced may be opted not to do so, because the research instrument the investigator had chosen did not allow individual narrative. This could not however be solved unless during the point of data dissemination such participants were allowed to listen to the findings and be given a chance to discuss such issues.

The study was chiefly conducted among care givers. This could leave out very vital information among children themselves and their feelings about being and living with T1DM, however through findings and recommendations the researcher has recommended such studies be conducted. Also it forms a foundation for the researcher to further conduct such studies related to the feelings of children with T1DM, the challenges they faced and coping strategies.

4.0 CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter presents the study results as per the study objectives. The results were presented on family psychosocial and facility related determinants of adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital. The contents of the chapter include the study's response rate, demographic characteristics of the children and caregivers, adherence to type 1 diabetes mellitus home management and determinants of adherence to type 1 diabetes home management.

4.2 Demographic Characteristics of the Children

The study sought to establish the demographic profile of the children with type 1 diabetes mellitus at KNH. The demographic attributes considered were gender, age, education level and duration that the child had lived with the T1DM.

Results showed that almost an equal number of male and female children with T1DM, all aged 18 years and below, in basic education level and who had lived with T1DM mostly for ≤ 5 years formed the focus of the study. The findings are as summarized in table 4.1;

Table 4.1: Demographic characteristics of the children (n = 91)

		Frequency	Percent
Gender	Male	46	50.5
	Female	45	49.5
	Total	**91**	**100.0**
Age	0 - 5 years	20	22.0
	6 - 10 years	33	36.3
	11 - 18 years	38	41.8
	Total	**91**	**100.0**
Education level	Pre-primary	20	22.0
	Primary	47	51.6
	Secondary	15	16.5
	Not yet started	9	9.9
	Total	**91**	**100.0**
Duration lived with T1DM	0-1 year	23	25.3
	2-3 years	22	24.2
	4-5 years	24	26.4
	More than 5 years	22	24.2
	Total	**91**	**100.0**

4.3 Demographic Characteristics of the Caregivers

The study also sought to establish the demographic profile of the caregivers of the children with T1DM. The demographic attributes considered included their age, marital status, employment status, education level and religion.

From the findings shown in Table 4.2, (58.2%, n = 53) of the caregivers were aged 36 years and above while the remaining were aged 35 years and below. Most (68.1%, n = 62) of the care givers were married. Only (31.9%, n = 29) of the caregivers had formal employment while (40.7%, n = 37) were self-employed. A significant number (40.7%, n = 37) had Tertiary education while only Secondary education (37.4%, n = 34). Majority (92.3%, n = 84) of caregivers were Christians.

Table 4.2: Demographic characteristics of the caregivers (n = 91)

		Frequency	Percent
Age	18 - 23 years	3	3.3
	24 - 29 years	18	19.8
	30 - 35 years	17	18.7
	36 years & above	53	58.2
	Total	**91**	**100.0**
Marital status	Married	62	68.1
	Single	19	20.9
	Separated	10	11.0
	Total	**91**	**100.0**
Employment status	Formal employment	29	31.9
	Self-employed	37	40.7
	Not employed	25	27.5
	Total	**91**	**100.0**
Education level	Primary	17	18.7
	Secondary	34	37.4
	Tertiary	37	40.7
	Never attended	3	3.3
	Total	**91**	**100.0**
Religion	Christian	84	92.3
	Muslim	6	6.6
	Others	1	1.1
	Total	**91**	**100.0**

4.4 Adherence to Type 1 Diabetes Mellitus Home Management

The first objective of the study sought to determine the level of adherence to type 1 diabetes mellitus home management for children attending pediatric diabetes clinic at Kenyatta National Hospital. Results are as described in the subsequent sub-sections.

4.4.1 Adherence to Insulin Therapy

The caregivers were requested to respond to a number of statements denoting their children's adherence to insulin therapy.

From the findings, majority (87.9%, n = 80) of the caregivers administered insulin to the children without fail, as is illustrated in Figure 4.1.

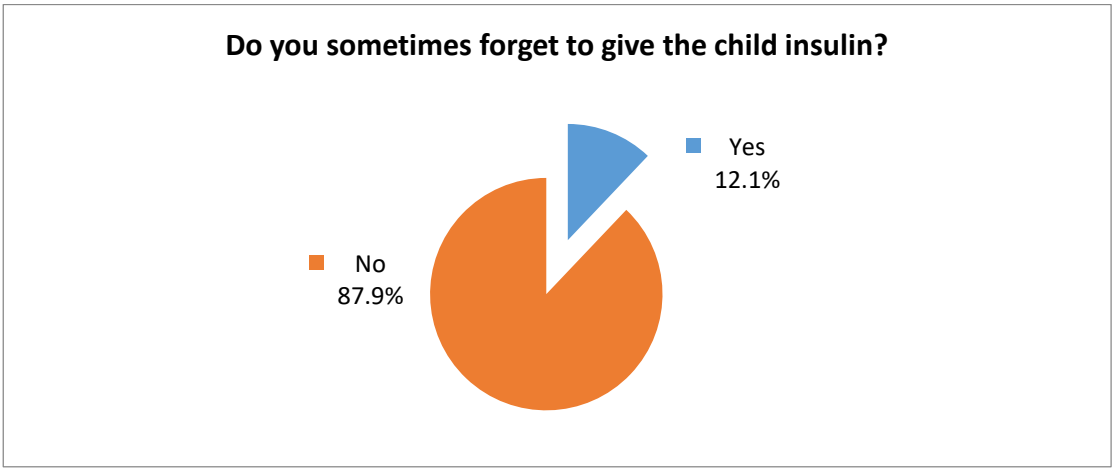

Figure 4.1: Whether the caregivers forgot to give the child insulin

As to whether there were days, in the past 2 weeks, that the child did not receive insulin, majority (87.9%, n = 80) of the caregivers indicated that the child had not failed to receive insulin over the past two weeks. Figure 4.2 presents the findings.

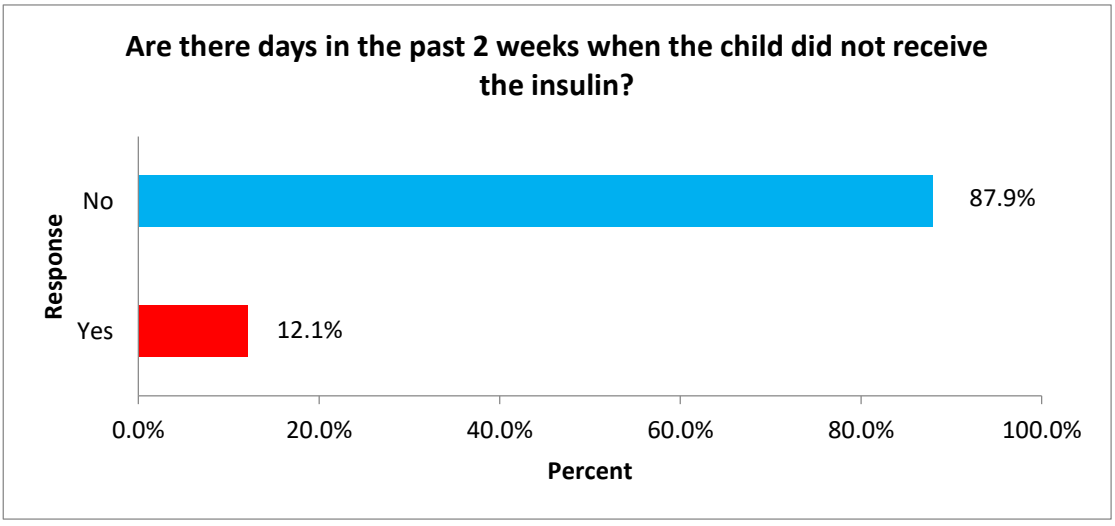

Figure 4.2: Whether the child had missed insulin over the past 2 weeks

The caregivers were also asked whether the child had ever been stopped from receiving insulin without telling the doctor or a health care provider because he/she felt worse after receiving it. From the findings, majority (86.8%, n = 79) of the caregivers indicated that the child had never been stopped from receiving insulin without notifying

the doctor or a health care provider (HCP) because of feeling worse after receiving it. Figure 4.3 illustrates the findings.

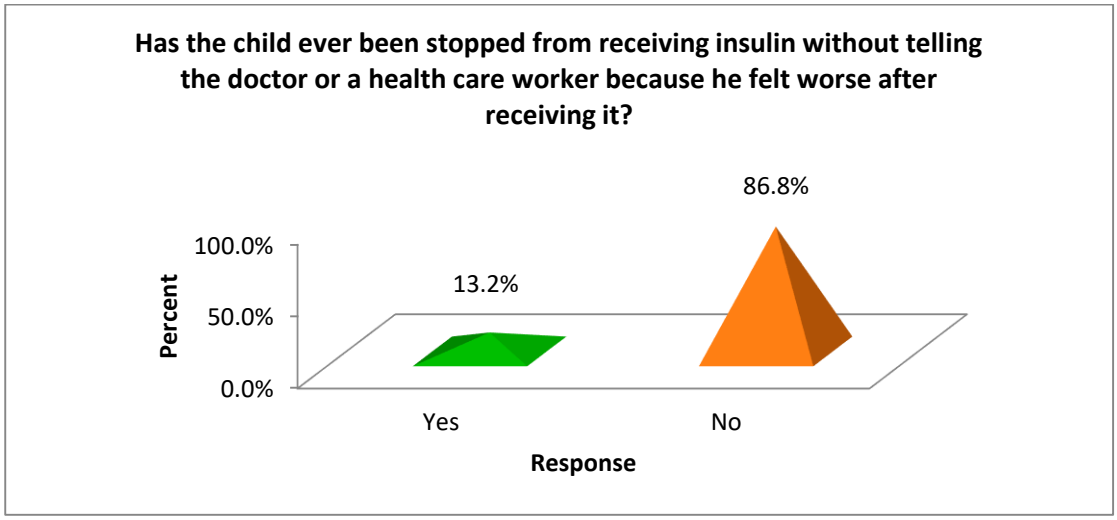

Figure 4.3: Whether the child had ever been stopped from receiving insulin without informing the health care providers

Regarding the child having the insulin with him or her whenever away from home, most (93.4%, n = 85) of the caregivers indicated that the child never forgot to go along with insulin when he or she travelled or left home. Figure 4.4 shows the findings.

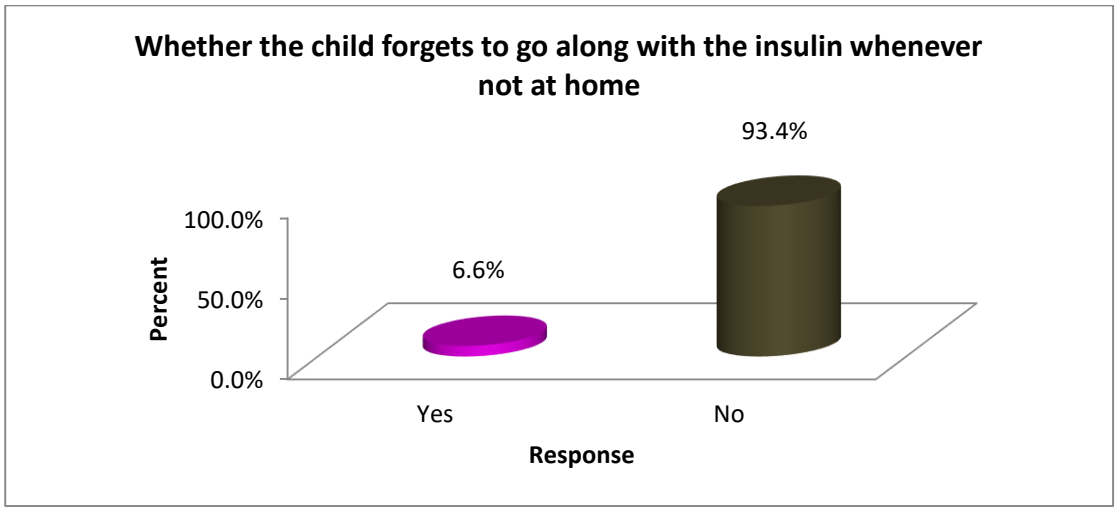

Figure 4.4: Whether the child forgets to carry insulin whenever out of home

Regarding other aspects of adherence to insulin therapy, results indicated that most (83.5%, n = 76) of the caregivers indicated that the child had received insulin the

previous day; most (83.5%, n = 76) of the caregivers indicated that they never stopped giving the child insulin, even when they felt that the child's condition was under control; morethan half (58.2%, n = 53) of the caregivers indicated that they did not sometimes feel hassled sticking to the child's treatment plan and majority (92.3%, n = 84) of the caregivers indicated that they did not have difficulty in remembering to give the child insulin. This denotes that most of the caregivers ensured that their children adhered well to the insulin therapy. The findings are as shown in Table 4.3.

Table 4.3: Adherence to insulin therapy among the children (n = 91)

	Yes		No	
Statements	**Freq. (n)**	**%**	**Freq. (n)**	**%**
The child received insulin yesterday	76	83.5	15	16.5
When I feel the child condition is under control sometimes, I stop giving the child insulin	15	16.5	76	83.5
Sometimes I feel hassled sticking to the child's treatment plan	38	41.8	53	58.2
I have difficulty in remembering to give the child insulin	7	7.7	84	92.3

4.4.2 Adherence to Diet

The caregivers were requested to respond to a number of statements denoting their children's adherence to diet.

As to whether the caregivers participated in monitoring the foods that the child ate, majority (81.3%, n = 74) of the caregivers indicated that they were actively involved in monitoring the foods that the child ate. This is as shown in Figure 4.5.

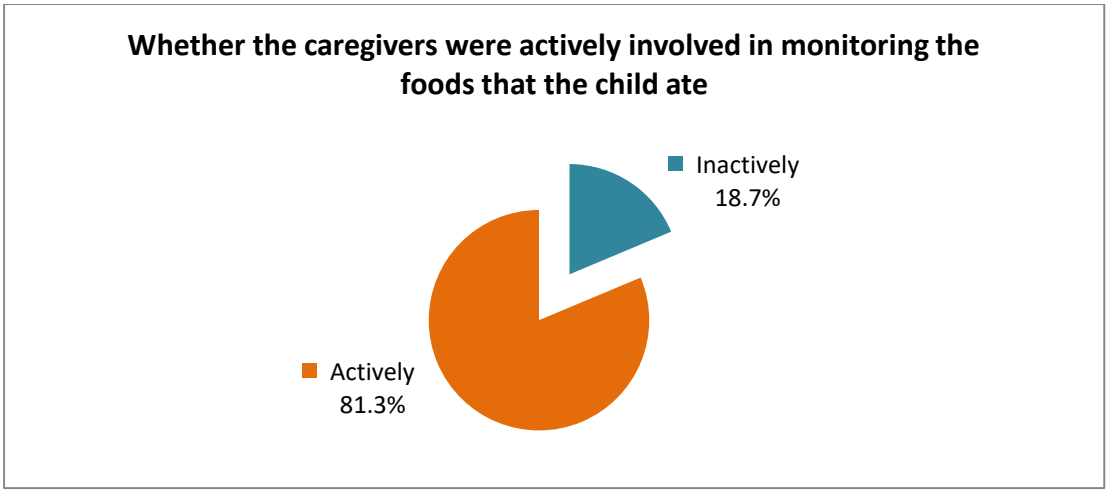

Figure 4.5: Whether the caregivers participated in monitoring the foods that the child ate

Further, most (92.3%, n = 84) of the caregivers indicated that the child ate the same food with the family members; most (64.8%, n = 59) of the caregivers indicated that the child fed on highly nutritious protein foods; majority (91.2%, n = 83) of the caregivers indicated that they gave snacks and food in between exercise and that most (86.8%, n = 79) of the caregivers indicated that they gave the child food within 20 minutes of insulin administration. The findings are as presented in Table 4.4.

Table 4.4: Adherence to diet among the children (n = 91)

Statements	Yes		No	
	Freq. (n)	%	Freq. (n)	%
The child eats the same food with the family members	84	92.3	7	7.7
The child feeds on highly nutritious proteins food	59	64.8	32	35.2
I give snacks and food in between exercise	83	91.2	8	8.8
I give the child food within 20 minutes of insulin administration	79	86.8	12	13.2

Further, 38.5% (n = 35) of the caregivers indicated that the child fed on food more than 4 times while 31.9% (n = 29) said that the child fed on food 4 times with the remaining

indicating that the child fed on food either 3 times or twice. Results are as shown in Figure 4.6.

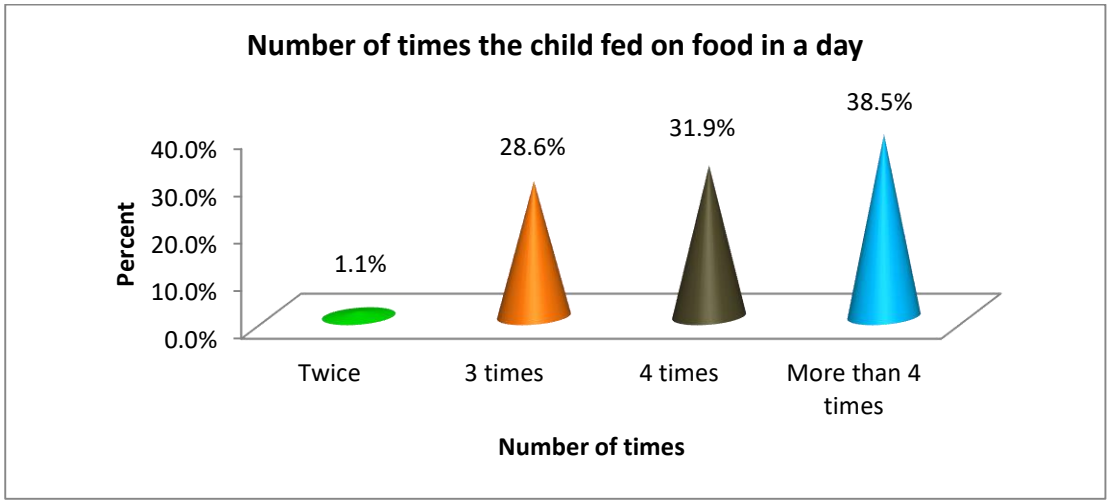

Figure 4.6: Frequency of child feeding in a day

4.4.3 Adherence to Exercise

The caregivers were requested to respond to a number of statements denoting their children's adherence to exercise.

From the findings, most (90.1%, n = 82) of the caregivers indicated that their child was above 3 years old. Of this whose children were older than 3 years, only (32.9%, n = 27) indicated that their child participated in sweating exercise daily for at least 60 minutes, denoting non-adherence to the recommended exercise level among the surveyed children. Table 4.5 illustrates the findings.

Table 4.5: Adherence to exercise among the children

Statements		Frequency (n)	Percent (%)
Child is above 3 years	Yes	82	90.1
	No	9	9.9
	Total	**91**	**100.0**
Child participates in sweating exercise on daily for at least 60 minutes (n = 82)	Not daily	55	67.1
	Yes	27	32.9
	Total	**82**	**100.0**

4.4.4 Blood Glucose Monitoring

The caregivers were requested to respond to a number of statements denoting their monitoring of the children's blood glucose.

From the findings, all (100%, n = 91) of the caregivers agreed that they monitored the blood glucose of the child daily, with 41.8% (n = 38) indicating that they monitored it 3 times every day while 34.1% (n = 31) monitored it 4 times every day. This is as presented in Figure 4.7.

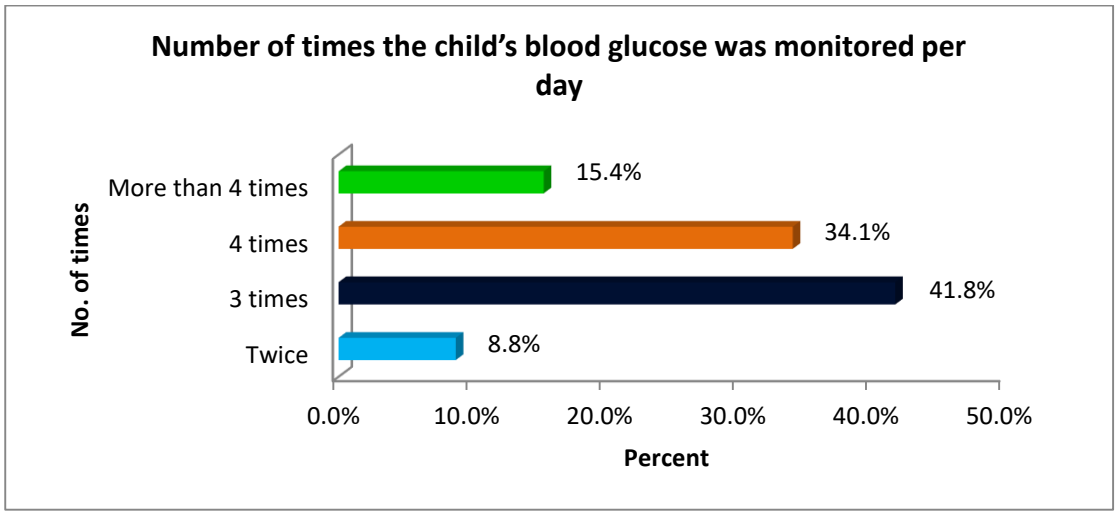

Figure 4.7: Number of times the child's blood glucose was monitored per day

Further, most (91.2%, n = 83) of the caregivers indicated that they monitored the child's blood glucose before meals; 41.8% (n = 38) of the caregivers indicated that they monitored the child's blood glucose before exercise while 30.8% (n = 28) indicating that they monitored the child's blood glucose after exercise.

In addition, majority (98.9%, n = 90) of the caregivers indicated that they monitored the child's blood glucose before the child went to bed while majority (97.8%, n = 89) of the caregivers also indicated that they monitored the child's HBA1c every 3 months. This denotes that most of the caregivers were keen on close monitoring of their child's blood glucose as is required. Table 4.6 contains the findings.

Table 4.6: Adherence to monitoring of the children's blood glucose (n = 91)

Statements		Freq. (n)	Percent (%)
I monitor the child's blood glucose for meals	Before meals	83	91.2
	After meals	6	6.6
	Don't monitor	2	2.2
	Total	**91**	**100.0**
I monitor the child's blood glucose for exercise	Before exercise	38	41.8
	After exercise	28	30.8
	Don't Monitor	25	27.5
	Total	**91**	**100.0**
I monitor the child's blood glucose before going to bed	Yes	90	98.9
	No	1	1.1
	Total	**91**	**100.0**
I monitor the child HBA1c every 3 month	Yes	89	97.8
	No	2	2.2
	Total	**91**	**100.0**

4.5 Family Psychosocial Determinants of Adherence to Home Management of Type 1 Diabetes Mellitus among Children

The second objective of the study sought to assess the family psychosocial determinants influencing adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH.

The participants were asked to identify which family psychosocial factors could influence the child's adherence to the recommended type 1 diabetes mellitus home management.

From the findings, the family psychosocial factors identified by the caregivers as influencing adherence to Type 1 Diabetes home management care among the children included: support from the family members and the siblings as cited by 87.9% (n = 80) of the participants; good communication always and reminders to the child as cited by 93.4% (n = 85) of the participants; holding/perceiving the disease as being very serious

as cited by 52.7% (n = 48) of the participants; the treatment given to the child being perceived as helpful as cited by 96.7% (n = 88) of the participants; family being together without any conflict as cited by 72.5% (n = 66) of the participants and the family being able to afford the necessary resources, treatment and food as cited by 76.9% (n = 70) of the participants. However, 58.2% (n = 53) of the caregivers did not hold the view that the child was vulnerable to complications of the disease. The findings are as depicted in Table 4.7.

Table 4.7: Participants' view of family psychosocial determinants of adherence to home management of type 1 diabetes mellitus among children (n = 91)

	Yes		No		Not sure	
Statements	**F (n)**	**%**	**F (n)**	**%**	**F (n)**	
Support from the family members and the siblings	80	87.9	7	7.7	4	4.4
Always good communication and reminder to the child	85	93.4	6	6.6	0	0.0
We think the disease is very serious	48	52.7	38	41.8	5	5.5
The child is vulnerable to complications of the disease	27	29.7	53	58.2	11	12.1
The treatment we are given helps the child	88	96.7	1	1.1	2	2.2
Family being together without any conflict	66	72.5	5	5.5	20	22
The family is able to afford the necessary resources, treatment and food	70	76.9	20	22.0	1	1.1

4.6 Facility-Related Determinants of Adherence to Home Management of Type 1 Diabetes Mellitus among Children

The third objective of the study sought to establish the facility-related determinants influencing adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH.

The participants were asked to identify the health facility related factors that could influence the child's adherence to the recommended type 1 diabetes mellitus home

management. From the findings, the factors identified included support from the health care workers as cited by 96.7% (n = 88) of the participants; follow-up calls, text messages or emails by health care workers and use of apps on phones as cited by 58.2% (n = 53) of the participants; treatment availability in the facility as cited by (100%, n = 91) of the participants; health care workers having positive attitude and willingness to help as cited by 98.8% (n = 90) of the participants; being offered sufficient health education regarding the treatment, food, blood sugar monitoring and exercise as cited by 97.8% (n = 89) of the participants and being accorded adequate time by the health care workers at all times as cited by (100%, n = 91) of the participants. The summary of the findings are shown in table 4.8.

Table 4.8: Participants' views on health facility related determinants of adherence to home management of type 1 diabetes mellitus among children (n = 91)

	Yes		No		Not sure	
Statements	**F (n)**	**%**	**F (n)**	**%**	**F (n)**	
Support from the health care workers	88	96.7	2	2.2	1	1.1
Follow-up with calls, text messages or emails by health care workers and use of apps on phones	53	58.2	37	40.7	1	1.1
Treatment availability in the facility	91	100.0	0	0.0	0	0.0
Health care workers have positive attitude and willing to help	90	98.8	0	0.0	1	1.1
Health education given to us about the treatment, food, blood sugar monitoring and exercise was sufficient	89	97.8	2	2.2	0	0.0
Health care workers always give us adequate time	91	100.0	0	0.0	0	0.0

4.7 Adherence to Type 1 Diabetes Mellitus Home Management

Summary of the aggregate adherence to type 1 DM home management among the children with type 1 diabtes mellitus at KNH was computed.

In this study, those achieved a score of 80% and above in relation to observance of recommended guidelines in the four T1DM home management components namely insulin therapy, diet, exercise and blood glucose monitoring were deemed as adherent while those who achieved a score of less than 80% were deemed to be non-adherent.

Based on this criterion, while most (75.8%, n = 69) of the children with type 1 DM were found to be adherent to insulin therapy, there were notable gaps in the children's adherence to diet, physical exercise and blood glucose monitoring. The results indicated that those adherent to prescribed diet recommendations were 37.4% (n = 34); those adherent to recommended physical exercise level were 32.9% (n = 27) and those adherent to prescribed blood glucose monitoring recommendations were only 27.5% (n = 25). On the aggregate, only 39.6% (n = 36) of the children were deemed adherent to T1DM home management while 60.4% (n = 55) were deemed to be non-adherent to home management of T1DM. Results are as shown in Table 4.9.

Table 4.9: Adherence to type 1 DM home management among the children

T1DM care components	Adherent		Non-adherent	
	Freq. (n)	Percent (%)	Freq. (n)	Percent (%)
Insulin therapy	69	75.8	22	24.2
Diet	34	37.4	57	62.6
Physical exercise [for only ≥ 3 years olds, n = 82]	27	32.9	55	67.1
Blood glucose monitoring	25	27.5	66	72.5
Aggregate rates	**36**	**39.6**	**55**	**60.4**

4.8 Bivariate and Multivariate Analysis of Associations between Selected Independent and Dependent Factors

This section describes the association between family psychosocial and facility related factors and adherence to type 1 diabetes home management among the caregivers of children with type 1 diabetes mellitus. Evaluation of the association was done using both bivariate and multivariate logistic regression analysis models.

4.8.1 Association of Family Psychosocial Factors with Adherence to Home Management of T1DM among Children

The study conducted both bivariate and multivariate logistic regression to analyze the association of the various family psychosocial and facility related factors and adherence to type 1 DM home management among the children with type 1 diabtes mellitus at KNH. Both logistic regression analyses were performed at 95% confidence interval.

The dependent variable was adherence to type 1 DM home management among the children, measured on a dichotomous scale -adherent or non-adherent.

The independent variables under the family psychosocial determinants category included support from the family members and siblings (x1), good communication always and reminders to the child (x2), perceived helpfulness of the treatment (x3), living together in family without conflict (x4), perceiving the disease as serious (x5) and affordability of necessary resources and treatment by the family (x6).

From the bivariate logistic regression analysis findings, the family psychosocial factors found to have a statistically significant and positive association with adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital included support from the family members and siblings ($\beta = .488$, $p = 0.023$); good communication always and reminders to the child ($\beta = .632$, $p = 0.012$); perceived helpfulness of the treatment ($\beta = .681$, $p = 0.009$); living together in family without conflict($\beta = .417$, $p = 0.034$) and affordability of necessary resources and treatment by the family ($\beta = .779$, $p = 0.000$).

Table 4.10: Bivariate analysis results for the association of family psychosocial factors with adherence to type 1 DM home management

						95% CI for PR(β)		Decision
		β	S.E	Sig.	PR(β)	Lower	Upper	
Step 1[a]	x1	.488	.166	0.023	1.31	.642	2.768	Reject the null hypothesis (H_o)
	x2	.632	.108	0.012	1.49	.435	2.420	
	x3	.681	.034	0.009	1.65	.271	2.963	
	x4	.417	.572	0.034	1.14	.307	1.774	
	x5	.218	.262	0.275	1.03	.494	1.306	
	x6	.779	.081	0.000	1.74	.753	3.014	
	Constant	4.076	1.593	0.000				

a. Variable(s) entered on step 1: x1, x2, x3, x4, x5, x6.

x1 - support from the family members and siblings; x2 - good communication always and reminders to the child; x3 - perceived helpfulness of the treatment; x4 - living together in family without conflict; x5- perceiving the disease as serious; x6 - affordability of necessary resources and treatment by the family

Multivariate logistic regression analysis was utilized to remove the effects of confounding. From the multivariate logistic regression analysis, the family psychosocial factors established to have a statistically significant and positive association with adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital, after controlling for confounding factors, included perceived helpfulness of the treatment ($\beta = .619$, $p = 0.016$) and affordability of necessary resources and treatment by the family ($\beta = .728$, $p = 0.000$), as depicted in Table 4.11. This implied that perceived helpfulness of the treatment; x6 - affordability of necessary resources and treatment by the family were the family psychosocial factors with the most significant influence on adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital.

Table 4.11: Multivariate analysis results for the association of family psychosocial factors with adherence to type 1 DM home management

						95% CI for PR(β)		Decision
		β	S.E	Sig.	PR(β)	Lower	Upper	
Step 1[a]	x3	.619	.173	0.016	1.86	.548	2.750	Reject the H_o
	x6	.728	.115	0.000	2.11	1.107	3.627	
	Constant	5.382	1.707	0.000				

a. Variable(s) entered on step 1: x1, x2, x3, x4, x6.

x3 - perceived helpfulness of the treatment; x6 - affordability of necessary resources and treatment by the family

4.8.2 Association of Facility Related Factors with Adherence to Home Management of T1DM among Children

The independent variables under the facility-related determinants category included support from the health care workers, necessary follow-up by the health care workers, treatment availability in the health facility, HCPs positive attitude and willingness to help, appropriate health education offered to the caregivers, being offered adequate time by the HCPs.

From the bivariate logistic regression analysis findings, the facility-related factors found to have a statistically significant and positive association with adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital included support from the health care workers (β = .677, p = 0.005); necessary follow-up by the health care workers (β = .509, p = 0.036); treatment availability in the health facility (β = .894, p = 0.000); HCPs positive attitude and willingness to help (β = .572, p = 0.024); appropriate health education offered to the caregivers (β = .731, p = 0.000) and being offered adequate time by the HCPs (β = .623, p = 0.017).

Table 4.12: Bivariate analysis results for the association of facility-related factors with adherence to type 1 DM home management

						95% CI for PR(β)		Decision
		β	S.E	Sig.	PR(β)	Lower	Upper	
Step 1[a]	x1	.677	.207	0.005	1.56	.570	2.606	Reject the null hypothesis (H_o)
	x2	.509	.082	0.036	1.11	.294	1.979	
	x3	.894	.155	0.000	2.71	.813	4.761	
	x4	.572	.219	0.024	1.24	.536	2.518	
	x5	.731	.097	0.000	2.07	.681	4.115	
	x6	.623	.126	0.017	1.30	.421	2.229	
	Constant	3.718	.667	0.000				

a. Variable(s) entered on step 1: x1, x2, x3, x4, x5, x6.

x1 - support from the health care workers; x2 - necessary follow-up by the health care workers; x3 - treatment availability in the health facility; x4 - HCPs positive attitude and willingness to help; x5 - appropriate health education offered to the caregivers; x6 - being offered adequate time by the HCPs

Multivariate logistic regression analysis was utilized to remove the effects of confounding. From the multivariate logistic regression analysis, the facility-related factors established to have a statistically significant and positive association with adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital, after controlling for confounding factors, included support from the health care workers (β = .641, p = 0.011), treatment availability in the health facility (β = .822, p = 0.000) and appropriate health education offered to the caregivers (β = .714, p = 0.004), as depicted in Table 4.13. This implied that support from the health care workers, treatment availability in the health facility and appropriate health education offered to the caregivers were the facility-related factors with the most significant influence on adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital.

Table 4.13: Multivariate analysis results for the association of facility-related factors with adherence to type 1 DM home management

						95% CI for PR(β)		Decision
		β	S.E	Sig.	PR(β)	Lower	Upper	
Step	x1	.641	.188	0.011	1.72	.856	2.917	
1[a]	x3	.822	.173	0.000	2.30	.689	4.085	Reject
	x5	.714	.162	0.004	2.27	1.174	3.206	the H_o
	Constant	4.903	1.158	0.000				

a. Variable(s) entered on step 1: x1, x2, x3, x4, x5, x6.

x1 - support from the healthcare workers; x3 - treatment availability in the health facility; x5 - appropriate health education offered to the caregivers

5.0 CHAPTER FIVE: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter presents discussion of findings, conclusions and recommendations of the study in line with the study objectives. The study evaluated the family psychosocial and facility related determinants of adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital.

5.2 Discussion

The findings were discussed under the following sub-headings: adherence to type 1 diabetes mellitus home management, family psychosocial determinants of adherence to home management of type 1 diabetes mellitus among children and facility-related determinants of adherence to home management of type 1 diabetes mellitus amongchildren.

5.2.1 Adherence to Type 1 Diabetes Mellitus Home Management

5.2.1.1 Adherence to Insulin Therapy

According to this study, most (75.8%, n = 69) of the caregivers ensured that their children adhered well to the insulin therapy with most of the surveyed children found to be adherent to the insulin therapy. This agreed with findings by Mukama et al. (2012) who in a study conducted among among children with type 1 diabetes mellitus in Tanzania reported fairly good adherence level to insulin therapy among most of the surveyed children. In studies by Datye et al. (2015) and Mukama et al. (2012), most of the children with type 1 diabetes mellitus were also found to be well adherent to insulin therapy. The findings were however in contrast to those of Kyokunzire and Matovu (2018) who conducted a study in Uganda exploring adherence to recommended type 1 diabetic care showed low adherence to insulin therapy among surveyed children. Similarly, studies by Datye, et al (2015) and Fernando et al. (2018) also reported poor adherence to insulin therapy among children with type 1 diabetes mellitus within their study populations. From the study finding adherence to insulin is associated to perceived helpfulness of the insulin and its affordability by the caregivers. This could

also be related to support from health care worker, its availability in the health facility and the adequate education talks given to caregivers and children as found in this study to be the determinants of adherence to care. Parents being key in home management could also be a factor through actual admistration of insulin, and close monitoring of the children's level of adherence to insulin could be also the contributing factor.

5.2.1.2 Adherence to Diet

The study established that most of the caregivers were actively involved in monitoring the foods that the children living with diabetes ate. Further, most of the caregivers indicated that the children ate the same food with the family members; the children fed on highly nutritious protein foods; they gave snacks and food in between exercise and that they also gave the child food within 20 minutes of insulin administration. This denoted fair attempt on the part of the caregivers of the children with T1DM to adhere with some of the prescribed guidelines relating to diet in the care of their children. This concurred with the observations of Rewers (2002) and Mukama et al. (2012), where though adherence to prescribed diet among children with T1DM was sub-optimal, a significant proportion of these children's caregivers were found to make efforts to observe recommended practices in their children's feeding. Similarly, in studies by Mlynarczyk (2013), Fernando et al. (2018) and Musoma et al. (2020), most of the caregivers were found to be committed to doing all they could to feed their children diagnosed with type 1 diabetes mellitus as was recommended by the health care teams.

However, though, most of the caregivers made efforts to adhere to prescribed diet for their children, this study established that the level of adherence to prescribed dietary recommendations among children with type 1 diabetes mellitus at KNH was low as only 37.4% of the caregivers were deemed to be adherent to prescribed dietary recommendations for children with T1DM. This showed that there were notable gaps in adherence to diet requirements among T1DM children at KNH. The researcher would attribute this low adherence to recommended diet among the study participants to possible socio-economic attributes such as low household income status which would imply that the caregivers have limited financial means to afford the prescribed diets. It could also be due to possible lack of or low knowledge of recommended dietary requirements for children with type 1 diabetes mellitus among the children's caregivers.

Similar findings on low adherence to recommended diet among children diagnosed with type 1 diabetes mellitus were reported by Valenzuela et al. (2014) and Šimunović et al. (2018) who noted that sub-optimal adherence to recommended dietary regimen for children with T1DM remained a key challenge in home management of these patients and significantly contributed to reported complications in this patient group. Similar sentiments were also shared by Palmer et al. (2011) and Mukama et al. (2012) who also reported low adherence to issued diet recommendations among children with T1DM.

5.2.1.3 Adherence to Physical Exercise

The study also established that only (32.9%, n = 27) of the children with type 1 diabetes mellitus at KNH were adherent to the recommended physical exercise level of participating in sweating exercise every day for at least 60 minutes. According to the study findings, most (67.1%, n = 55) of the caregivers indicated that though their children participated in sweating exercises, they did not do it for at least 60 minutes every day, as is recommended. This showed that there was low adherence to recommended physical exercise level among the children with type 1 diabetes mellitus at KNH. This low physical activity level among the children with T1DM is attributed to possible lack of or low awareness among their caregivers of the significance of engaging in physical exercises for their children. It could also be due to unwarranted fears and misconceptions among the caregivers that active participation in physical exercise could be detrimental to their child's medical condition status.

This collaborated with the findings of Kyokunzire and Matovu (2018) who did also observe sub-optimal adherence to recommended physical exercise level among children with type 1 diabetes mellitus in Uganda. Similar findings were also reported by Datye et al. (2015) who also noted that dismal adherence to recommended physical exercise level remained one of the leading challenges affecting home management among children and adolescents diagnosed with type 1 diabetes mellitus across numerous settings. WHO (2014) observes that moderate to active physical exercises of at leats 60 minutes every day are helpful in care management of type 1 diabetes mellitus patients. Unfortunately, in most of the contexts, this recommendation is barely implemented to the detriment of this vulnerable patient population. These sentiments are also shared by Wood (2018) and Valenzuela et al. (2014) which also identify poor

adherence to recommended physical activity level as one of the barriers to effective care among children and adolescents diagnosed with type 1 diabetes mellitus in many settings.

5.2.1.4 Adherence to Blood Glucose Monitoring

The study established that only 27.5% (n = 25) of the children with type 1 diabetes mellitus at KNH were adherent to the recommended blood glucose monitoring level. This denoted low adherence to blood glucose monitoring among the children with T1DM at KNH. This was also evidenced by the observations that only about half (49.5%, n = 45) of the children had their blood glucose levels measured at least 4 times daily; most (93.4%, n = 85) of the children did not have their blood glucose levels measured after meals as is recommended and most of the children had their blood glucose levels monitored either before (41.8%, n = 38) or after (30.8%, n = 28) exercise and not both before and after exercise as is recommended. It was therefore evident that there were gaps in adherence to blood glucose monitoring recommendations among children with T1DM at KNH. The researcher attributes this observation to inadequate knowledge of the blood glucose monitoring guidelines among these children's caregivers or potential conflicts in the daily schedules of these children from those of their caregivers. It could also be attributed to the fact that caregivers feel "they do not want to waste the glucose monitoring stripes".

This collaborated with Sun et al (2019) who also identified poor adherence to blood glucose monitoring as one of the leading factors that impeded effective home management care for children and young adults diagnosed with type 1 diabetes mellitus. Similar results were also reported by Ryan et al. (2017) and Palmer et al. (2011) who also reported sub-optimal adherence level to blood glucose monitoring among children with type 1 diabetes mellitus. Similarly, in an empirical study evaluating adherence to self-monitoring of blood glucose in persons diagnosed with type 1 diabetes mellitus in Sweden, Moström et al. (2017) also observed low adherence rates in relation to blood glucose monitoring levels among the surveyed patients with T1DM. similarly, in a review on adherence to treatment for diabetes mellitus, deficiencies in adherence to blood glucose monitoring in a regular basis as is recommended for patients with type 1 diabetes mellitus were also noted by Boas et al. (2014). Gaps in observing

recommended intervals for the monitoring of blood glucose were also reported in studies by Fernando et al. (2018) and Bilous et al. (2021), where most of the children with type 1 diabetes mellitus were found not to be assessed for blood glucose levels at all the different intervals as is recommended. These studies therefore affirm to the current study's finding of low adherence to recommended blood glucose monitoring guidelines among children with T1DM in the local context.

5.2.2 Family Psychosocial Determinants of Adherence to Home Management of Type 1 Diabetes Mellitus among Children

From the findings, the family psychosocial factors found to have a statistically significant and positive association with adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital included support from the family members and siblings ($\beta = .488$, $p = 0.023$); good communication always and reminders to the child ($\beta = .632$, $p = 0.012$); perceived helpfulness of the treatment ($\beta = .681$, $p = 0.009$); living together in family without conflict ($\beta = .417$, $p = 0.034$) and affordability of necessary resources and treatment by the family ($\beta = .779$, $p = 0.000$). This denotes that various family psychosocial determinants did influence adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH.

This collaborated with the findings of Hsin et al. (2010) who observed that adherence to home management among children diagnosed with type 1 diabetes mellitus was strongly associated with the level of family support that the children received. Similar views were also expressed by Datye et al. (2015) and Palmer et al. (2011) who opined that some of the determinants of adherence to home management in children with T1DM included receiving adequate family support, living in a well functional family and a family's ability to afford treatment and other care necessities. They also noted that good relationships between or among the family members with the sick children were critical in promoting adherence to type 1 diabetes home management among the affected children. On their part, Mlynarczyk (2013) and Waari et al. (2018) averred that lack of parental support led to poor home management in children with type 1 diabetes while close monitoring of the T1DM children by their parents enabled them to better adhere to prescribed home management recommendations.

5.2.3 Facility-Related Determinants of Adherence to Home Management of Type 1 Diabetes Mellitus among Children

From the findings, the facility-related factors found to have a statistically significant and positive association with adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital included support from the healthcare workers ($\beta = .677$, $p = 0.005$); necessary follow-up by the healthcare workers ($\beta = .509$, $p = 0.036$); treatment availability in the health facility ($\beta = .894$, $p = 0.000$); HCPs positive attitude and willingness to help ($\beta = .572$, $p = 0.024$); appropriate health education offered to the caregivers ($\beta = .731$, $p = 0.000$) and being offered adequate time by the HCPs ($\beta = .623$, $p = 0.017$). This denotes that various facility related psychosocial determinants did influence adherence to Type 1 Diabetes home management for children attending pediatric diabetes clinic at KNH.

This agreed with Valenzuela et al. (2014) who also observed that support from the healthcare workers and necessary follow-up by the healthcare workers were instrumental in helping children with T1DM and their families to be able to adhere with the various prescribed recommendations for home management of these children. The findings were also in line with those of Boas et al. (2014) and DeCosta et al. (2020) who also argued that various health facility related factors such as availability of necessary treatment in the health facilities and HCPs positive attitude and willingness to help were positive predictors for adherence to treatment among children diagnosed with T1DM. On their part, Ryan et al. (2017) and Sun et al., 2019) also shared the view that follow-up communications by the health care workers, appropriate health education offered to the caregivers and being accorded adequate time by the health care workers were leading positive predictors in adherence to recommended home management care among hildren with T1DM.

5.3 Conclusions

Based on the findings of the study, the following conclusions were drawn:

1. The level of adherence to type 1 diabetes mellitus home management among most of the surveyed children attending diabetes clinics at KNH was low particularly in domains of diet, physical exercise and blood glucose monitoring. Although the level of adherence to insulin therapy was found to be high compared to other similar studies, this measure is below the recommendation set by this study, other similar studies and standard guidelines on adherence.
   This study therefore concluded that there was non-adherence to home management of type 1 diabetes mellitus and therefore standard measures should be implemented to improve on adherence to home management of type 1 diabetes mellitus among children.
2. The key determinant factors of adherence to T1DM home management among children comprise a mix of both family psychosocial and facility factors including: perceived helpfulness of the treatment, affordability of necessary resources and treatment by the family, support from the health care workers, treatment availability in the health facility and appropriate health education offered to the caregivers.

5.4 Recommendations

- The low level of adherence calls for concerted efforts and sensitization of caretakers and health workers on T1DM management that include individualized health education talks be given to caregivers and children particularly in the areas of the seriousness of type 1 diabetes mellitus with its associated complications which the child can get if the adherence to management is not strictly followed.
- Strengthening home visits approach for the families of children with T1DM, this would lead to improvement of family partnership in care of children with type 1 diabetes mellitus among the three key players: the child, the family and the health care system.

- Follow-up calls, text messages to constantly act as a reminder to the four basic principles of home management including: insulin therapy, diet, blood glucose monitoring and physical activities when implemented can lead to improvement of adherence as found in other similar studies on use of follow-up messages.

5.5 Suggestions for Further Studies

- Interventional studies could also be carried out on the impact of home visits, health education of the entire family and the use of follwup text messages on adherence to home managmenet of children with T1DM in Kenya as such studies have not been conducted locally.

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APPENDICES

Appendix 1: KNH-UON ERC Approval Letter

UNIVERSITY OF NAIROBI
FACULTY OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/260

6th July, 2022

KENYATTA NATIONAL HOSPITAL APPROVED 06 JUL 2022 QUALITY HEALTH CARE KNH/UoN-ERC P.O. Box 20723 - 00202, NAIROBI

Samuel Okello
Reg. No. H56/38451/2020
Dept. of Nursing Science
Faculty of Health Sciences
University of Nairobi

Dear Samuel,

RESEARCH PROPOSAL: FAMILY PSYCHOSOCIAL AND FACILITY RELATED DETERMINANTS OF ADHERENCE TO HOME MANAGEMENT OF TYPE 1 DIABETES MELLITUS AMONG CHILDREN AT KENYATTA NATIONAL HOSPITAL (P211/03/2022)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P211/03/2022.** The approval period is 6th July 2022 – 5th July 2023.

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used.
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Protect to discover

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://research-portal.nacosti.go.ke and also obtain other clearances needed.

Yours sincerely,

DR. BEATRICE K.M. AMUGUNE
SECRETARY, KNH-UoN ERC

c.c. The Dean, Faculty of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information Dept., KNH
The Chair, Dept. of Nursing Sciences, UoN
Supervisors: Dr. Angeline Chepchirchir, Dept. of Nursing Sciences, UoN
Dr. Joyce Cheptum Jebet, Dept. of Nursing Sciences, UoN

Appendix 2: Authorization Letter For Data Collection From KNH

KENYATTA NATIONAL HOSPITAL
P.O. BOX 20723, 00202 Nairobi

Tel.: 2726300/2726450/2726550
Fax: 2725272
Email: knhadmin@knh.or.ke

Ref: KNH/PAEDS-HOD/48 Vol.II

Date: 14th July 2022

Samuel Okello
Department of Nursing Science
Faculty of Health Sciences
University of Nairobi

Dear Samuel

RE: AUTHORITY TO COLLECT DATA IN PAEDIATRICS DEPARTMENT

Following approval of your Research proposal by the KNH/UON-Ethics & Research Committee and subsequent filing of the Study Registration Certificate, this is to inform you that authority has been granted to collect data in ***Paediatrics Department***, *on* your study titled ***"Family psychosocial and facility related determinants of adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital"***.

Kindly liaise with the Senior Assistant Chief Nurse, paediatrics specialized wards/clinics for facilitation.

You will also be required to submit a report of your study findings to the office of the HOD, Paediatrics - KNH after completion of your study.

Dr. Juiana Muiva-Gitobu
Head of Department, Paediatrics

Cc. SACN, Paediatric Specialized wards/clinic
ACN Incharge, Paediatric Outpatient Clinic - POPC 23

Appendix 3: Participants' Information and Consent Form

Title of Study: Family psychosocial and Facility Related Determinants of Adherence to Home Management of Type 1 Diabetes Mellitus among Children at Kenyatta National Hospital.

Principal Investigator and institutional affiliation:

Okello Samuel

Masters of Science in Pediatric Nursing Student

University of Nairobi

Introduction:

I kindly want to share with you about the study being conducted. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research: i) Your decision to participate is entirely voluntary ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

May I continue? YES [ ] NO [ ]

This study has approval by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No. _____

WHAT IS THIS STUDY ABOUT?

The researcher listed above is interviewing individuals who are caregivers of children with type 1 diabetes mellitus attending diabetes clinic at KNH.

The purpose of the interview is to **establish the family psychosocial and facility related determinants for adherence to type 1 diabetes mellitus home management among children attending diabetes clinics at KNH.**

Participants in this research study will be asked questions about demographic data of the child and parents, use of insulin, blood glucose monitoring, performance of exercise, nutrition, family psychosocial and facility-related determinants influencing adherence to Type 1 Diabetes Mellitus home management for children.

There will be approximately 91 participants in this study randomly chosen. We are asking for your consent to consider participating in this study.

WHAT WILL HAPPEN IF YOU DECIDE TO BE IN THIS RESEARCH STUDY?

If you agree to participate in this study, the following things will happen:

You will be interviewed by a trained interviewer in a private area where you feel comfortable answering questions. The interview will last approximately 15 minutes.

The interview will cover topics such as demographic data of the child and parents, use of insulin, blood glucose monitoring, performance of exercise, nutrition, family psychosocial and facility-related determinants influencing adherence to Type 1 Diabetes Mellitus home management for children.

After the interview has finished, participants will be educated on the home management of Type 1 diabetes mellitus among children.

ARE THERE ANY RISKS, HARMS DISCOMFORTS ASSOCIATED WITH THIS STUDY?

There are no known direct risks, harm involved in this research. However, there could be some discomfort in answering questions. We will keep everything you tell us as confidential as possible. We will use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview.

All study staff and interviewers are professionals with special training in these examinations/interviews.

ARE THERE ANY BENEFITS BEING IN THIS STUDY?

You may benefit by receiving free health education on type 1 diabetes mellitus home management in children. Also, the information you provide will help us better understand the family psychosocial and facility related determinants for adherence to type 1 diabetes mellitus home management among children. This information will enable the research to make appropriate recommendation on the ways forward inorder to improve on the level of adherence to type 1 diabetes home management among children

WILL BEING IN THIS STUDY COST YOU ANYTHING?

Being in this study will not cost you anything.

WILL YOU GET REFUND FOR ANY MONEY SPENT AS PART OF THIS STUDY?

There will be no financial refund or financial benefits given during the time of this study.

WHAT IF YOU HAVE QUESTIONS IN FUTURE?

If you have further questions or concerns about participating in this study, please call or send a text message to the study staff at the number provided at the bottom of this page.

For more information about your rights as a research participant you may contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No. 2726300 Ext. 44102 email uonknh_erc@uonbi.ac.ke.

WHAT ARE YOUR OTHER CHOICES?

Your decision to participate in research is voluntary. You are free to decline participation in the study and you can withdraw from the study at any time without injustice or loss of any benefits.

CONSENT FORM (STATEMENT OF CONSENT)

Participant's statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counselor. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my personal identity confidential.

By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study: Yes [ ] **No** [ ]

Participant printed name (Use code):

_____

Participant signature / Thumb stamp _____ **Date**

_____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher's Name: _____ **Date**: _____

Signature

_____

Role in the study:_____

For more information, contact Okello Samuel Tel: +256788820403 from 8: 00 am to 4:00pm

Appendix 4: Maelezo ya Kushiriki na Fomu ya Idhini

Kichwa cha Utafiti:Viashiria vya kisaikolojia vya familia na hospitali vinavyohusiana na usimamizi wa nyumbani wa kisukari cha aina 1 kati ya watoto walio na kisukari cha aina 1 katika hospitali ya kitaifa ya Kenyatta

Mtafiti mkuuna chuo shiriki:

Okello Samuel

Mwanafunzi wa Shahada ya Uzamili ya Sayansi katika Uuguzi wa Watoto

Chuo Kikuu cha Nairobi

Utangulizi:

Ningependa kujadiliana nawe kuhusu utafiti unaofanywa. Madhumuni ya fomu hii ya idhini ni kukupa taarifa utakayohitaji ili kukusaidia kuamua kama utakuwa mshiriki au la katika utafiti huu. Jisikie huru kuuliza maswali yoyote kuhusu madhumuni ya utafiti huu, nini kitatokea ukishiriki katika utafiti, hatari na manufaa yanayoweza kutokea, haki zako kama mtu wa kujitolea, na jambo lingine lolote kuhusu utafiti au fomu hii ambalo haliko wazi. Wakati tumejibu maswali yako yote kwa kuridhika kwako, unaweza kuamua kuwa katika utafiti au la. Utaratibu huu unaitwa 'kibali cha taarifa'. Ukishaelewa na kukubali kuwa katika utafiti, nitakuomba utie sahihi jina lako kwenye fomu hii. Unapaswa kuelewa kanuni za jumla zinazotumika kwa washiriki wote katika utafiti wa kimatibabu: i) Uamuzi wako wa kushiriki ni wa hiari kabisa ii) Unaweza kujiondoa kwenye utafiti wakati wowote bila ya kueleza sababu ya kujiondoa iii) Kukataa kushiriki katika utafiti huu. utafiti hautaathiri huduma unazostahiki katika kituo hiki cha afya au vituo vingine. Tutakupa nakala ya fomu hii kwa rekodi zako.

Je, naweza kuendelea? NDIO [ ] LA [ ]

Utafiti huu umeidhinishwa na Kamati ya Maadili na Utafiti ya Hospitali ya Kitaifa ya Kenyatta na Chuo Kikuu cha NairobiNambari ya Itifaki

_____

UTAFITI HUU UNAHUSUNINI?

Mtafiti aliyeorodheshwa hapo juu anahoji watu ambao ni walezi wa watoto wenye ugonjwa wa kisukari cha aina ya 1 wanaohudhuria kliniki ya kisukari katika KNH.

Madhumuni ya mahojiano ni **kubainisha viashiria vya kisaikolojia vya familia na hospitali vinavyohusiana na usimamizi wa nyumbani wa ugonjwa wa kisukari cha aina 1 miongoni mwa watoto wanaohudhuria kliniki za ugonjwa wa kisukari katika KNH**.

Washiriki katika utafiti huu wataulizwa maswali kuhusu data ya kidemografia ya mtoto na wazazi, matumizi ya insulini, ufuatiliaji wa glukosi kwenye damu, utendaji wa mazoezi, lishe, kisaikolojia ya kifamilia na viambishi vinavyohusiana na kituo vinavyoathiri ufuasi wa usimamizi wa nyumbani wa Aina ya 1 ya Kisukari kwa watoto.

Utafitiu huu utakuwa na washiriki takribani 91 watakao chaguliwa bila mpangilio fulani. Tunaomba idhini yako ili kuzingatia kushiriki katika utafiti huu.

KITACHOFANYIKA UKIAMUA KUSHIRIKI KATIKA UTAFITI HUU?

Ukikubali kushiriki katika utafiti huu, mambo yafuatayo yatafanyika:

Utahojiwa na mhojiwa aliyefunzwa katika eneo la faragha ambapo unahisi vizuri kujibu maswali. Mahojiano yatadumu takriban dakika 15.

Mahojiano hayo yatashughulikia mada kama vile taarifa ya idadi ya watu ya mtoto na wazazi, matumizi ya insulini, ufuatiliaji wa glukosi katika damu, utendaji wa mazoezi, lishe, kisaikolojia ya kifamilia na viashiria vinavyohusiana na kituo vinavyoathiri ufuasi wa aina ya 1 ya ugonjwa wa kisukari kwa watoto..

Baada ya mahojiano kukamilika, washiriki wataelimishwa juu ya usimamizi/utunzaji wa nyumbani wa ugonjwa wa kisukari cha aina ya 1 miongoni mwa watoto..

JE, KUNA HATARI YOYOTE AU ATHARI MBAYA ZOZOTE ZINAZOHUSIANA NA UTAFITI HUU?

Hakuna hatari za moja kwa moja zinazojulikana, madhara yanayohusika katika utafiti huu. Walakini, kunaweza kuwa na usumbufu katika kujibu maswali. Tutaweka kila kitu unachotuambia kama siri iwezekanavyo. Tutatumia nambari ya msimbo kukutambua katika hifadhidata ya kompyuta iliyolindwa na nenosiri na tutaweka rekodi zetu zote za karatasi kwenye kabati ya faili iliyofungwa. Hata hivyo, hakuna mfumo wa kulinda usiri wako unaoweza kuwa salama kabisa, kwa hivyo bado kuna uwezekano kwamba mtu anaweza kujua ulikuwa kwenye utafiti huu na kupata taarifa kukuhusu.

Pia, kujibu maswali katika mahojiano kunaweza kuwa na wasiwasi kwako. Ikiwa kuna maswali yoyote ambayo hutaki kujibu, unaweza kuyaruka. Una haki ya kukataa mahojiano au maswali yoyote yaliyoulizwa wakati wa mahojiano.

Wafanyakazi wote wa utafiti na wahojaji ni wataalamu walio na mafunzo maalum katika mitihani/mahojiano haya.

JE, KUNA FAIDA ZOZOTE KUWA KATIKA UTAFITI HUU?

Unaweza kufaidika kwa kupokea elimu ya afya bila malipo kuhusu usimamizi wa nyumbani wa kisukari cha aina 1 kwa watoto. Pia, maelezo utakayotupatia yatatusaidia kuelewa vyema viashirio vya familia vya kisaikolojia na kijamii na kituo vinavyohusiana na usimamizi wa nyumbani wa ugonjwa wa kisukari cha aina 1 miongoni mwa watoto. Habari hii itawezesha utafiti kutoa mapendekezo sahihi juu ya njia za kusonga mbele ili kuboresha kiwango cha ufuasi wa usimamizi wa nyumbani wa kisukari cha aina ya 1 miongoni mwa watoto.

JE, KUSHIRIKI KATIKA UTAFITI HUU ITAKUGHARIMU CHOCHOTE?

La hasha. Kuwa katika utafiti huu hakutakugharimu chochote.

JE, UTAREJESHEWA FEDHA ZOZOTE ULIZOZITUMIA KAMA SEHEMU YA UTAFITI HUU?

Hakutakuwa na malipo yoyote au faida ya kifedha itakayotolewa kwa kushiriki katika utafiti huu.

JE, NA UKIWA NA MASWALI BAADAYE?

Ikiwa una maswali zaidi au wasiwasi kuhusu kushiriki katika utafiti huu, tafadhali piga simu au tuma ujumbe mfupi wa maandishi kwa wafanyikazi wa utafiti kwa nambari iliyotolewa chini ya ukurasa huu.

Kwa habari zaidi kuhusu haki zako kama mshiriki wa utafiti huu unaweza kuwasiliana na Katibu au Mwenyekiti wa Kamati ya Maadili na Utafiti ya Hospitali ya Kitaifa ya Kenyatta na Chuo Kikuu cha Nairobi, kupitia nambari ya simu. 2726300 Ext. 44102 barua pepe uonknh_erc@uonbi.ac.ke.

MAAMUZI MENGINE UNAYOWEZA FANYA NI YEPI?

Uamuzi wako wa kushiriki katika utafiti ni wa hiari. Uko huru kukataa kushiriki katika utafiti na unaweza kujiondoa kwenye utafiti wakati wowote bila dhuluma au hasara ya manufaa yoyote.

FOMU YA IDHINI (TAARIFA YA RIDHAA)

Usemi wa mshiriki

Nimesoma fomu hii ya idhini au nimesomewa maelezo. Nimepata nafasi ya kujadili utafiti huu na mshauri wa utafiti. Nimejibiwa maswali yangu kwa lugha ninayoielewa. Hatari na faida zimeelezewa kwangu. Ninaelewa kuwa ushiriki wangu katika utafiti huu ni wa hiari na kwamba ninaweza kuchagua kujiondoa wakati wowote. Ninakubali kwa uhuru kushiriki katika utafiti huu wa utafiti.

Ninaelewa kuwa juhudi zote zitafanywa ili kuweka taarifa kuhusu utambulisho wangu wa kibinafsi kuwa siri.

Kwa kutia saini fomu hii ya idhini, sijaachana na haki zozote za kisheria nilizo nazo kama mshiriki katika utafiti wa utafiti..

Nakubali kushiriki katika utafiti huu: **Ndio**[ ] **La** [ ]

Code ya mshiriki: _____

Sahihi ya mshiriki / Muhuri wa kidole gumba_____

Tarehe_____

Usemi wa mtafiti

Mimi, niliyetia sahihi hapa, nimeeleza kikamilifu maelezo muhimu ya utafiti huu kwa mshiriki aliyetajwa hapo juu na ninaamini kuwa mshiriki ameelewa na ametoa ridhaa yake kwa hiari na kwa uhuru..

Jina laMtafiti mkuu: _____ **Tarehe**: _____

Sahihi_____

__

Jukumu katika utafiti:_____

Kwa habari zaidi, wasiliana na Okello Samuel Simu: +256788820403 kati ya 8:00 am - 4:00pm

Appendix 5:Child Assent

Project Title: **Family Psychosocial and Facility RelatedDeterminants of Adherence to Home Management of Type 1 Diabetes Mellitus among Children at Kenyatta National Hospital.**

Investigator:

Okello Samuel

Masters of Science in Pediatric Nursing Student

University of Nairobi

We are doing a research study about **what makes children to follow home management of type 1 diabetes.**

Permission has been granted to undertake this study by the Kenyatta National Hospital-University of Nairobi Ethics and Research Committee (KNH-UoN ERC Protocol No. _____

This research study is a way to learn more about people. At least 91 parents of children will be participating in this research study with your parents.

If you decide that you want to be part of this study, your parents will be asked to tell us about yourself, how you use insulin, monitor blood glucose, exercise and how you feed. They will also be asked about how the family and health facility helps you in the management of diabetes at home.

Not everyone who takes part in this study will benefit. A benefit means that something good happens to you. We think these benefits might be that the information we shall get will enable us to make improvement in home management of type 1 diabetes in children.

If you do not want to be in this research study, we will tell you what other kinds of treatments there are for you.

When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too.

If you decide you and your parents want to be in this study, please sign your name.

I, _____(code), want to be in this research study.

_____ _____

(Signature/Thumb stamp) Date

Appendix 6: Idhini ya Mtoto

Kichwa cha utafiti: **Viashiria vya kisaikolojia vya familia na hospitali vinavyohusiana na usimamizi wa nyumbani wa kisukari cha aina 1 kati ya watoto walio na kisukari cha aina 1 katika hospitali ya kitaifa ya Kenyatta**

Mtafiti:

Okello Samuel

Mwanafunzi wa Shahada ya Uzamili ya Sayansi katika Uuguzi wa Watoto

Chuo Kikuu cha Nairobi

Tunafanya utafiti kuhusu **ni nini huwafanya watoto kufuata udhibiti wa nyumbani wa kisukari cha aina ya 1**.

Utafiti huu umeidhinishwa na Kamati ya Maadili na Utafiti ya Hospitali ya Kitaifa ya Kenyatta na Chuo Kikuu cha Nairobi Nambari ya Itifaki _____

Utafiti huu ni njia ya kujifunza zaidi kuhusu watu. Takriban wazazi 91 wa watoto watashiriki katika utafiti huu.

Ukiamua kuwa ungependa kuwa sehemu ya utafiti huu, wazazi wako wataulizwa kutueleza kukuhusu wewe, jinsi unavyotumia insulini, kufuatilia glukosi kwenye damu, mazoezi na jinsi unavyolisha. Pia wataulizwa jinsi familia na kituo cha afya kinavyokusaidia katika kudhibiti ugonjwa wa kisukari nyumbani.

Sio kila mtu atakayeshiriki katika utafiti huu atafaidika. Faida inamaanisha kuwa kitu kizuri kinatokea kwako. Tunafikiri faida hizi zinaweza kuwa kwamba taarifa tutakayopata itatuwezesha kuboresha udhibiti wa nyumbani wa ugonjwa wa kisukari cha aina ya 1 kwa watoto.

Iwapo hutaki kuwa katika utafiti huu, tutakuambia ni aina gani nyingine za matibabu ambazo ziko kwa ajili yako.

Tukimaliza na utafiti huu tutaandika ripoti kuhusu kile tulichojifunza. Ripoti hii haitajumuisha jina lako au kwamba ulikuwa kwenye utafiti.

Si lazima uwe katika utafiti huu ikiwa hutaki kuwa. Ukiamua kuacha baada ya sisi kuanza, hiyo ni sawa pia.

Ukiamua wewe na wazazi wako mnataka kuwa katika utafiti huu, tafadhali saini jina lako.

Mimi, _____(code), nataka kuwa katika utafiti huu.

_____ _____

(Sahihi/ Muhuri wa kidole gumba) Tarehe

Appendix 7: Questionnaire in English

Part of adherence to insuline adopted from Morisky Medication Adherence Scale and modified

QUESTIONNAIRE (ENGLISH): SERIAL NO……..

Research Topic: Family psychosocial and facility related determinants of adherence to home management of type 1 diabetes mellitus among children at Kenyatta National Hospital.

Instruction

1. Tick in the correct boxes the client's responses. Do not add any other information apart from what the participant gives you.

Section A: Demographic Characteristic of the Child

1. What is gender of your child?

a) Male [ ] b) Female [ ] others [ ]

2. How old is your child?

a) 0-5 years [ ] b) 6-10 years [ ] c) 11-18 years [ ]

4. What is the level of your child's education?

a) Preprimary [ ] Primary [ ] b) Secondary [ ] c) Tertiary [ ] d) Never attended [ ] Not yet began [ ]

How long has the child lived with the type 1 diabetes Mellitus since the time of diagnosis?

a. 0-1 year [ ] 2-3 years [ ] 4-5 years [ ] more than 5 years [ ]

Section B: Demographic Characteristic of the Caregiver

1. How old are you?

a) 18-23 years [ ] b) 24-29 years [ ] 30-35 years [ ] c) 36 and above [ ]

2. What is your marital status?

a) Married [ ] b) Single [ ] c) Separated [ ] d) Widowed [ ]

3. What is the nature of your employment?

a) Formal employment [ ] b) Self-employed [ ] c) Not employed [ ]

4. What is your level of education?

a) Primary [ ] b) Secondary [ ] c) Tertiary [ ] d) Never attended [ ]

5. Which religion do you belong to?

a) Anglican [ ] b) Catholic [ ] c) Muslim [ ] d) SDA [ ] d) others [ ]

Adherence to Type 1 Diabetes Mellitus Home management.

Section C: Adherence to insulin therapy

	Items to assess	Yes	no	Don't know
1	Sometimes forget to give the child insulin			
2	Thinking over the past two weeks, there are some day(s) when the child did not receive the insulin			
3	The child has ever been stopped from receiving insulin without telling the doctor or a health care worker because he felt worse after receiving it			
4	When the child travels or leaves home, he/she forgets to go along with the insulin			

5	The child receive insulin yesterday			
6	When I feel the child condition is under control sometimes I stop giving the child insulin			
7	Sometimes I feels hassled sticking to the child's treatment plan			
8	I have difficulty in remembering to give the child insulin			

Section D: Adherence to diet

1. I am involved in monitoring the child's foods that the child eats a) Inactively [ ] b) Actively [ ]

2. The child eat the same food with the family members a) Yes [ ] b) No [ ]

3. The child feeds on highly nutritious proteins food a) Yes [ ] b) No [ ]

4. I give snacks and food in between exercise a) Yes [ ] b) No [ ]

5. I give the child food within 20 minutes of insulin administration a) Yes [ ] b) No [ ]

6. The child feed on food

a) Once [ ] b) Twice [ ] c) three times [ ] d) four times [ ] e) more than four times

Section E: Adherence to Exercise

1. My child is above 3 years a.) Yes [ ] b) no [ ]

2. If yes, the child participates in sweating exercise on daily for 60 minutes? a) Yes [ ] b) Not daily [ ]

Section F: Blood Glucose Monitoring

1. I monitor the blood glucose of the child daily a) Yes [ ] b) Not daily [ ]

2. If yes how many times per day

a) One [ ] b) Two [ ] c) Three [ ] d) Four [ ] d) More than four [ ]

3. I monitor the child's blood glucose for meals

a) Before meals [ ] b) after meals [ ] c) Don't Monitor [ ]

3. I monitor the child's blood glucose for exercise

c) Before exercise [ ] d) After exercise c) Don't Monitor [ ]

4. I monitor the child's blood glucose before going to bed

a) Yes [ ] b) No [ ]

5. I monitor the child HBA1c every 3 month

a) Yes [ ] b) No [ ]

Section G: Determinants of adherence to type 1 diabetes home management

Which of the following may influence the child to adhere to the recommend T1D care?				
A. Family pyscho-social factors				
		a) Yes	**b) No**	**c) Not sure**
	Support from the family members and the siblings			
	Always good communication and reminder to the child			
	We think the disease is very serious			
	The child is vulnerable to complications of the disease			

	The treatment we are given helps the child			
	Family being together without any conflict			
	The family is able to afford the necessary resources, treatment and food			
B. Health care provider related factors				
	Support from the health care workers			
	Follow-up with calls, text messages or emails by health care workers and use of apps on phones			
	Treatment availability in the facility			
	Health care workers have positive attitude and willing to help			
	Health education given to us about the treatment, food, blood sugar monitoring and exercise was sufficient			
	Health care workers always give us adequate time			

Thank you for your participation

Appendix 8: Questionnaire in Kiswahili

Questionnaire (Kiswahili): Serial No……..

Mada ya utafiti: Viashiria vya kisaikolojia vya familia na hospitali vinavyohusiana na usimamizi wa nyumbani wa kisukari cha aina 1 kati ya Watoto walio na kisukari cha aina 1 katika hosipitali ya kitaifa ya Kenyatta

Instruction

2. Weka tiki kwenye visanduku hahihi, majibu ya mteja. Usiongeze taarifa nyingine yoyote mabli na ile mshiriki anayokupa

Section A: Sifa za idadi za watu, za mtoto

1. Mtoto wako niwa jinsia gani?

a) Kiume [ ] b) Kike [ ] c) Na nyigine [ ]

2. Mtoto ana umri gani (Miaka ya mutoto)?

a) Miaka 0-5 [ ] b) Miaka 6-10 [ ] c) Miaka 11-18 [ ]

4. Mtoto yuko shule, kiwango gani?

a) Chekechea [ ] b) Shule ya msingi [ ] c) Elimu ya juu [ ] d) Apo shule ya ufundi [ ]

e) hajawahi hudhuria [ ] f) Hajaanza [ ]

5. Kwa muda gani mtoto ameishi na ugonjwa wa kisukari?

a. Miaka 0-1 [ ] Miaka 2-3 [ ] Miaka 4-5 [ ] Miaka zaidi 5 [ ]

Section B: Sifa za idadi za watu, za mlezi

1. Uko na umri gani?

a) Miaka 18-23 [ ] b) Miaka 24-29 [ ] Miaka 30-35 [ ] c) 36 Na zaidi [ ]

2. Hali yako ya ndoa ni nini?

a) Umeolewa [ ] b) Haijaolewa [ ] c) Umetalikiwa [ ] d) Mjane [ ]

3. Nini chanzo cha ajira yako?

a) Ajira rasmi [ ] b) Kujiajiri [ ] c) Haujaajiriwa [ ]

4. Ulisoma hadi kiwango gani?

a) Shule ya msingi [ ] b) Shule ya upili [ ] c) Elimu ya juu [ ] d) Hujawahi hudhuria [ ]

5. Wewe ni wa dini gani?

a) Anglikana [ ] b) Katoliki [ ] c) muisilamu [ ] d) Adiventista [ ] d) nyingenezo [ ]

Kuzingatia matibabu ya nyumbani ya kisukari

Section C: Kuzingatia tiba ya insulini

	Vipengee vya kutathmini	Ndio	La	Sijui
1	Saa zingine husahau kumdunga mtoto insulin			
2	Ukizingatia wiki mbili zilizopita, kunazo siku ambazo mtoto amekosa kupata insulini			
3	Mtoto hajawahi sitishwa kudungwa insulin bila idhini ya daktari au muuguzi kwa sabau ya kuzidiwa baada ya kupokea insulini			
4	Mtoto anaposafiri, yeye husahau kubeba insulini			
5	Mtoto alidungwa insulin jana			

6	Ninapohisi kuwa hali ya mtoto ipo tabithi, ninasita kumdunga insulini			
7	Saa zingine mimi huhisi kusononeka kwa kuzingatia matibabu ya mtoto			
8	Ninapata ugumu kukumbuka kumpa mtoto insulin			

Section D: Kuzingatia mlo

1.Ninahisika katika kutathmini chakula anazokula mtoto a) Saa zingine [ ] b) Kikamilifu [ ]

2. Mtoto hukula chakula sawa na familia a) Ndio [ ] b) La [ ]

3. Najua aina ya chakula ambacho mtoto anapaswa kulisha a) Ndio [ ] b) La [ ]

4. Nampa mtoto vitafunio na vyakula katikati ya mazoezi a) ndio [ ] b) La [ ]

5.Nampa mtoto chakula ndani ya dakika ishirini za kumdunga insulin a) Ndio [ ] b) La [ ]

6. Mtoto hula chakula a) Mara moja [ ] b) Mara mbili [ ] c) Mara tatu [ ] d) Mara nne [ ]

e) Zaidi ya mara nne [ ]

Section E: Kuzingatia mazoezi.

1. Umri wa mtoto Zaidi ya miaka tatu a) Ndio [ ] b) La [ ]

2. kama ni Zaidi, anashiriki kaitka mazoezi ya kuchosha kila siku kwa dakika sitini (60).

a) Ndio [ ] b) La [ ]

Section F: Kupima sukari ya damu

1. Humpima mtoto sukari ya damu kila siku a) ndio [ ] b) la [ ]

2. Iwapo unapima, mara ngapi kwa siku.

a) Moja [ ] b) Mbili [ ] c) Tatu [ ] d) Nne [ ] e) Zaidi ya nne [ ]

3.Mimi hupima sukari ya damu ya mtoto

a) Kabla ya mlo [ ] b) Baada ya mlo [ ] c) Kabla ya zoezi [ ] d) Baada ya zoezi [ ]

Section G: Vigezo vya kuzingatia usimamizi wa nyumbani wa kisukari cha aina 1

Ni lipi kati ya haya yafuatayo yatashawishi mtoto kuzingatia matibabu yanayohitajika ya kisukari aina ya 1?				
a. Sababu za kisaikolojia za familia				
		a) Ndio	**b) La**	**c) Sina uhakika**
8.	Msaada kutoka kwa wanafamilia na ndugu			
9.	Daima mawasiliano mazuri na ukumbusho kwa mtoto			
10.	Tunadhani ugonjwa ni mbaya sana			
11.	Mtoto yuko kwa hatari ya matatizo ya ugonjwa huu			
12.	Tiba tunayoipata inamsaidia mtoto			

13.	Familia ina umoja bila ugomvi wowote			
14.	Familia ina uwezo wa kumudu mahitaji ya tiba na chakula			
	b. Mambo yanayohusiana na watoa huduma za afya			
7.	Msaada kutoka watoa huduma za afya			
8.	Watoa huduma za afya kukufuatilia kwa kupiga simu, ujumbe mfupi, au barua au program zinginezo			
9.	Upatikanaji wa matibabu katika kituo hiki cha afya			
10.	Watoa huduma za afya wana mtazamo mwema na wako tayari kusaidia			
11.	Mafunzo tunayopata kuhusiana tiba, chakula, kupima sukari ya damu, na zoezi ni ya kutosha			
12.	Watoa huduma ya afya hutupatia muda wa kutosha			

Asante kwa kushiriki

Appendix 9: Work Plan

Activity	Oct -21	Nov -21	Dec -21	Jan -22	Feb -22	Mar -22	Apr -22	May -22	Jun -22	Jul-22	Aug -22	Sept -22	Oct -22
Development of the concept													
Proposal development and presentation													
Submission of proposal to Ethics and Research Committee													
Pretesting													
Data Collection													
Data Analysis													
Report writing and presentation													
Dissemination of results													

Appendix 10: Study Budget

ACTIVITY	ITEM	QUANTITY	UNIT COST (KSH)	TOTAL Cost (Ksh)
Research Proposal development	Stationery	1 ream of photocopy papers	800 per ream	800
	Internet bundles	---	10,000	10,000
Tool pre-testing	Printing questionnaires for pretesting	25 questionnaire	60	1,500
	Allowance for 2 Research assistants and principal investigator during pretesting for 5 days	Daily allowances	2000*3*5	30,000
	Transport during for 2 Research assistants and principal investigator during pretesting for 5 days	Transport allowance by public means	600*3*5	9,000
	Lunch allowance during pretesting	Lunch allowance	500*3*5	7,500
	Airtime for communication during pretesting	Airtime for 3 people	500*3*5	7,500
Data collection	Allowance for 2 Research assistants and principal investigator during Data collection	Allowance for every 2 days in a week for 1 month (8 days)	2,000*3*8	48,000

	Transport during for 2 Research assistants and principal investigator during Data collection	Transport allowance by public means	600*3*8	14,400
	Lunch allowance during Data collection	Lunch allowance	500*3*8	12,000
	Airtime for communication during data collection	Air time for 3 people	500*3*8	12,000
	Printing 90 questionnaire for data collection	100 questionnaire	60	600
	Pens	1 dozen	250	250
	Stapler and staples	3 staplers and 3 packets of staples	300 *3	900
	Folders	3 folders	200*3	600
	Flash disks	1	1500	1500
	Hand books	3 pieces	60*3	1800
	Ethics and Research committee fee	2000	2000	2000
Consultancy	Data statistician	20,000	20,000	20,000
Printing proposal for submission to ethics	Printing	6 copies of 80 pages	800*6	4,800
	Binding	6 copies	100	600
Thesis and Reports	Printing	6 copies of 250 pages	2500*6	15,000
	Binding	6 copies	1000	6000

	Dissemination (publication in peer reviewed journal)	20,000	20,000	20,000
	Subtotal for proposed budget			**226,750**
	Contingencies (10% equivalent of proposed budget)			22,675
GRAND TOTAL				**249,425**

Appendix 11: Google Map Showing the Location of Kenyatta National Hospital