TRANSITIONING ADOLESCENTS WITH DIABETES MELLITUS FROM PEDIATRIC TO ADULT CLINICAL CARE AT MOI TEACHING AND REFERRAL HOSPITAL, ELDORET, KENYA

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A RESEARCH THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE DEGREE OF MASTER OF MEDICINE IN CHILD HEALTH AND PEDIATRICS, SCHOOL OF MEDICINE, MOI UNIVERSITY

DECLARATION

Declaration by the candidate

This research thesis is my original work and has not been presented for a degree in any other university. No part may be reproduced without prior permission of the author and / or Moi University.

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DEDICATION

This is dedicated to:

My father, Mr. Joseph Karingi, who has always taught me to look on the positive side of every situation,

My mother, Mrs. Sarah Karingi, whose patience and love are unfathomable.

My sisters: Wakina, Njoki and Ruguru Karingi, without whom life would be boring.

My daughter, Wanjiru Karingi,who has made me tenacious.

Adolescents with diabetes mellitus.

ACKNOWLEDGEMENT

I would like to recognize and appreciate the effort and dedication of the following people who have both individually and jointly contributed to the development of this thesis:

My supervisors, Dr. Myra M. Koech, Prof. Winstone M. Nyandiko and Prof. Samuel O. Ayaya for all the critique, advice and guidance.

The consultant pediatricians and my colleagues for providing constructive criticism.

Members of staff at the diabetic clinic who have provided information necessary for the development of the thesis.

The statisticians- quantitative (Prof. Ann Mwangi), qualitative (Mr. Hillary Koros, Ms. Cate Kafu and Ms. Gift Walumbe)- for their guidance in the development of this thesis.

My research assistant- Elly- for helping in the logistics of facilitating the interviews and focus group discussions.

My family for their dedication and support.

ACRONYMS

AAP	American Academy of Pediatrics
ACP	American College of Physicians
CHD	Congenital Heart Disease
CHIVA	Children’s HIV Association
DM	Diabetes Mellitus
FGD	Focus Group Discussion
HCP	Health care providers
HIV	Human Immunodeficiency Virus
IREC	Institutional Research and Ethics Committee
KI	Key Informant
MTRH	Moi Teaching and Referral Hospital
WHO	World Health Organization

OPERATIONAL DEFINITIONS

Adolescent- child aged between 14 and 19 years.

Appropriate transitioning – Transitioning involving any one or more of the following:

i. using written plan to transition or
ii. transitioning adolescents disclosed to their diagnosis of diabetes mellitus or
iii. involving adolescents in preparing the plan or
iv. Following any of the existing guidelines for transitioning of adolescents from pediatric to adult care.

Barriers - impediments to transitioning

Determinants - facilitators and barriers

Facilitators - interventions that would make transitioning easier

Process of transitioning – moving from pediatric care to adult care involving preparation while in the pediatric clinic, handover to adult care and follow up in the adult clinic.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

TRANSITIONING ADOLESCENTS WITH DIABETES MELLITUS FROM PEDIATRIC TO ADULT CLINICAL CARE AT MOI TEACHING AND REFERRAL HOSPITAL, ELDORET, KENYA

ABSTRACT

Background: Advances in medical care have enabled children with chronic diseases to survive into adulthood. Transitioning is a process that involves preparing adolescents with chronic illnesses for follow up in adult care. Transfer is the physical movement from pediatric to adult care. Poor disease control has been reported in adolescents who do not go through transitioning. The extent to which this transitioning process is being followed at MTRH is unknown.

Objectives: To determine the proportion of adolescents who met the elements of appropriate transitioning and to describe the process and possible determinants of transitioning adolescents with diabetes mellitus from pediatric to adult care at Moi Teaching and Referral Hospital.

Methods:

Design: A sequential explanatory mixed methods cross sectional study.

Site: Pediatric and adult diabetic clinics at MTRH.

Population: A census study of adolescents aged between 14 and 19 years on follow up at the adult and pediatric diabetic clinics at MTRH, guardians who accompanied the adolescents and health care providers in the clinics**.**

Exclusion: Adolescents diagnosed after the age of 14 years.

Data Collection: Semi-structured interviewer administered questionnaires collected both quantitative (age, gender, period of follow up) and qualitative data. Convenience sampling was used to select adolescents for the focus group discussions. Four separate FGD’s comprising eight adolescents each, were conducted. Key informant interviews with health care providers were held.

Data analysis: Descriptive statistics for continuous data. Qualitative analysis: Audio-recorded information obtained from the interviews was transcribed verbatim. Reduction was through coding. The data was categorized into themes. Data source triangulation was done.

Results: The study participants included 65 adolescents (25 male, 40 female), 8 health care providers (2 pediatricians, 2 physicians, 2 nurses and 2 clinical officers) and 24 parents/guardians (18 female,6 male). Quantitative findings: All the adolescents met one element of appropriate transitioning-disclosed to their diagnosis of DM. The proportion was 100%. Qualitative findings: The movement from pediatric to adult care was abrupt without a preparation period informing the adolescents about the intended change. Facilitators of transitioning included adolescent clinics and sharing information on transitioning. Different categories of barriers were encountered: Health system factors: payment for services in the adult care clinic and lack of guidelines on transitioning. Individual factors: reluctance to move to a new environment and the feeling of abandonment by the pediatricians. Health care provider factors: unfriendly doctors in the adult care clinic.

Conclusion: All the adolescents met one element of appropriate transitioning but did not go through the process of transitioning. The adolescents were moved from the pediatric to the adult diabetic clinics through an event of transfer rather than the process of transitioning. Facilitators that would make transitioning easier included establishment of adolescent-focused clinics and sharing information on transitioning with the parents and adolescents. The barriers to transitioning included payment for services and delays before seeing the doctors in the adult care clinic.

Recommendation: The adolescents with DM should go through the process of transitioning and MTRH needs to have guidelines on transitioning adolescents with chronic illnesses to adult care. There is need to establish an adolescent friendly diabetic clinic in MTRH.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Advances in medical care, increased specialization and knowledge of illness by the general population have enabled children with chronic illnesses survive into adulthood in good health (Nakano, 2011; Pediatrics, 2011; Viner, 1999; Wijlaars, 2016).

Globally over the last decade there has been interest in transitional care offered to adolescents who have chronic illnesses. The American Association of Pediatrics recommends that health care transition be integrated into routine preventive, primary, specialty and subspecialty health care and there currently are guidelines that support transitioning across different chronic illnesses(American Academy of Pediatrics, 2011). In Africa, transitioning process is a new concept that is yet to take root.

Transitioning is defined as ‘the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-oriented to an adult-centered health care’. (McDonagh, 2006; P. Scal, Evans, T., Blozis, S., Okinow, N. and Blum, R., 1999) Transitioning is multifaceted involving not only physical transfer of the children but also training them on self-care, rational decision making and self-advocacy skills.

It involves three phases which are care in the pediatric clinic with preparation for follow up in adult care, the actual hand-over from pediatric to adult care and finally integration into adult health care. The essence of transitioning is to ensure that good disease control still continues after the children begin self-care (Wedgwood, 2008).

Transitioning is challenging partly due to lack of knowledge of guidelines to guide the process and due to differences in modes Transitioning in instances where it happens has been shown to be generally associated with deterioration in the health of the adolescents (Busse F, 2007; Hepburn, 2015; Kipps, 2002; Lotstein, 2013)hence the need to pay close attention to the process.

1.2 Problem Statement

Transitioning refers to all the steps that are taken in order to ensure continuity of health care services from the pediatric to the adult clinic. There is an increase in number of children and adolescents with chronic illnesses who live into adulthood due to advances in medical care (Buschur, 2017) meaning that at some point they have to be followed up in adult care.

The gap that this study set out to fill was that adolescents with DM at MTRH were not moved from pediatric to adult care in the proper manner. It was noted in MTRH that after the adolescents were moved to adult care, they would come back after a week or two crying asking to be retained in pediatric care for follow up.

Adolescents have expressed dissatisfaction with their health care providers concerning how they conduct continuation of care from pediatric to adult care due to poor planning and execution (Castillo, 2017; Viner, 2001). This is either demonstrated as failure to attend the adult clinics as scheduled or going back to the pediatric care providers and have follow up done there.

Different studies involving adolescents with different chronic illnesses showed that children with special health care needs were not receiving transitioning services(Little, 2017; McManus, 2013).

1.3 Justification

Anecdotally, in MTRH there seem to be no adolescents with chronic illnesses who have been taken through the required steps in order to have been transitioned. A generic (cutting across different chronic illnesses) study on transitioning reported that the prevalence of adolescents with chronic illnesses who experienced transitioning into adult care was 26.6 per 10,000 (Mazzucato, 2018).

As a result of the rise in the numbers of the children who get diagnosed with diabetes, there is need to document the process of transitioning adolescents with diabetes at MTRH. The hospital policy states that when children get to the age of 14 years they ought to be followed up in adult care. This is what is done in most cases with some exceptions based on the patients’ characteristics.

Documentation of the process will lead to determination of the facilitators, challenges and barriers to transitioning and from that solutions will be sought in order to improve the process and make it easier for adolescents to remain actively engaged in care.

1.4 Research Question

What is the process and possible determinants of transitioning adolescents with diabetes mellitus from the pediatric to the adult outpatient clinical care at the MTRH?

1.5 Objectives

1.5.1 Broad Objective

To describe the process and determinants of transitioning adolescents with diabetes mellitus from pediatric to adult outpatient clinical care at the MTRH.

1.5.2 Specific Objectives

1. Determine the proportion of adolescents with diabetes mellitus who met the elements of appropriate transitioning from pediatric to adult outpatient clinical care at MTRH.
2. Describe the process of transitioning adolescents with diabetes mellitus from pediatric to adult outpatient clinical care at MTRH.
3. Identify the facilitators and barriers to transitioning adolescents with diabetes mellitus from pediatric to adult outpatient clinical care at MTRH.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Definition of transitioning

Transitioning is defined as the ‘purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-oriented to an adult-centered health care’(McDonagh, 2006)

It has also been defined as ‘a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-orientated healthcare systems’(Blum RW, 1993)

Transfer is the actual movement of the adolescents from the pediatric to the adult clinic for continuation of medical care (Gray 2018). This should occur after the adolescent has been taken through the steps necessary to ensure that they understand their disease and have done a reconnaissance to the adult clinic. The age at transfer is set by the institution though most studies recommend that it should occur between the ages 18 and 24 years (Pediatrics, 2011; Peters, 2012).

Transitioning refers to all the steps that are taken in order to ensure continuity of health care services from the pediatric to the adult clinic while transfer, which is an aspect of transitioning, refers to the actual event of hand over from the pediatric to the adult clinic.

2.2 Appropriate Transitioning

There is paucity of data on what is generally accepted as the minimum criteria that defines appropriate transitioning (Kızıler, 2018; Mahan, 2017; Nakano, 2011).

Transitioning is a process that is multifaceted in order to ensure that all aspects of an adolescent’s life (medical, psychological and educational) are incorporated into the planning for follow up in the adult clinic (Ishizaki, 2018).

In a study that is currently in press, Ayaya, et al, 2017 after perusing through a number of studies and recommendations on transitioning came up with elements that define appropriate transitioning. Most of the recommendations on transitioning require those to be done in order for transitioning to have occurred. Most guidelines recommend that the guardians, adolescents and health care providers need to work together in setting the objectives. There should either be a written transitioning plan that acts as guide to the team members or the involved parties are involved in formulating an appropriate plan It is important for the adolescent to know the name of the chronic illness that they have and understand aspects around its care (Afzali, 2019; Pinzon, 2006).

2.3 Process of Transitioning

Different authors have different ways of describing the transitioning process. A study on transitioning adolescents in East Africa who have Human Immunodeficiency Virus (HIV), broadly classifies transitioning into six phases(Ayaya, 2017). These are: Phase 1- Preparation for Transitioning. This phase involves setting up of a multidisciplinary team from the pediatric and adult teams. The pediatric team takes lead in facilitating the process. The team identifies adolescents who are aged between 11 to 25 years and are still on follow up in the pediatric clinic. At this point the process of disclosure is initiated.

Phase 2 – Assessment of the readiness of adolescents for transitioning. In this phase, the idea of transitioning is introduced to the adolescent together with their family. A transitioning plan is also crafted at this juncture involving the input of the health care providers, the adolescent and the family.

Phase 3 – Meet the adult team. At this point the health care provider in the adult clinic is introduced and they give the adolescents a chance to get to know them as well as have a reconnaissance to the adult care clinic.

Phase 4: Preparation for the handover. The health care providers go over the prepared transitioning plan and confirm together with the family whether the required competencies have been attained by the adolescent. In case there are some gaps, they are addressed. In case the competencies have been met, the adolescent moves to the next phase. All the above mentioned steps happen while the adolescent is still in the pediatric clinic.

Phase 5- Actual handing over. The necessary documents detailing the summary of the medical and psychosocial history, current and past treatments as well as the completed transitioning plan are handed over to the adult care team. The adolescent and the family get officially handed over by the pediatric team to the adult care team.

Phase 6 - Follow up in the adult clinic. Follow up by the pediatric team happens within the year in order to ensure that the care that had been initiated is still going on in the adult clinic and also gives an opportunity for anonymous evaluation of the transitioning process by the adolescents.

The key areas that ought to be addressed in all phases of transitioning are; self advocacy, independent health care behaviour, sexual health, psycho social support, educational and vocational planning and health and lifestyle (Health, 2018).

Transitioning is multifaceted cutting across all aspects of an adolescent's life - medical, vocational, psychosocial and educational needs. The adolescents are taught on health matters involving substance abuse, sexual health and mental health and the effects each has on their disease control. Medical education should involve discussion about the disease they have, the need for medication, and the adverse effects likely to occur should they miss medication, recognizing complications and what to do in case they require urgent medical attention. (Rauen, 2013; Viner, 2001)

The goal of transitioning care from pediatric to adult health care is to facilitate the uptake and maintenance of successful disease self-management in young people with chronic conditions. (Rauen, 2013; Wedgwood, 2008) Transitioning should be age and developmentally appropriate in order to ensure that the right skills are imparted at the right time (Chiang, 2018). Acquisition of the proper skills will make survival through the adult life more bearable. Teaching about adolescent health and transitioning to the health care providers needs to start at undergraduate level so that they are adequately equipped to facilitate transitioning. (McDonagh, 2006)

Transitioning is a process which is coordinated by the health care providers under instruction from the hospital guidelines and is comprehensive, including all the aspects that need to be addressed in order to prepare the adolescent for follow up in the adult clinic. It involves training the adolescents on communication skills, critical thinking and decision making together with aspects on self-care which should enhance responsibility. (Reid, 2004; P. Scal, 2002; Stam, 2006)

When adolescents reach the age of transfer to the adult clinic, which is dependent on the health care institution or provider, they either directly get followed up in the adult clinic, remain in the pediatric clinic or get discharged from follow up. Adolescents need a clinic that focuses on them as growing people who undergo different phases of development and varied family concerns. (Viner, 1999)

Transfer is an aspect of transitioning that ought to come after the adolescent has been counselled about their disease condition, they have had their concerns addressed, they know about how their health would be financed and they even know the doctors that will be attending to them once they move to the adult clinic . The ideal time for transfer should generally be individualized and agreed on by the adolescent, their guardian and the health care provider (Sabbagh, 2018). It should occur much later in transitioning after the adolescent has been psychologically prepared, aspects of vocational, reproductive and social life discussed, a visit to the new clinic done and a written summary prepared. If these steps are skipped, the adolescent misses out on essential aspects that are necessary in equipping them with the skills they need after moving to the adult clinic.

Transitioning is important because it prepares the adolescent to be followed up in the adult clinic. The process has a number of steps which when followed will form a guideline in terms of the skills and knowledge that need to be imparted to the adolescents in order to enhance their self-care (Buschur, 2017).

Certain factors need to be in place before transitioning can be initiated. These include the developmental readiness of the adolescent to transition and their health status. Transitioning readiness is determined by whether the adolescent can manage their condition independent of their care givers since this is what happens in the adult clinic. The transitioning should be a coordinated process beginning at least a year before the intended day of transfer. (Davis, 2001) It should happen when the adolescent is in good health and not sick.

Recommendations on the process of transitioning include: there should be a policy on when to begin the discussion on transitioning which should be individualized but begins between the ages of 13 to 20 years. Other facilities tally transitioning with events such as transfer to high school or entry into college. A preparation period is adequate to ensure that the adolescents get to know that they will be expected to take care of themselves, understand their disease condition and know how to advocate for their needs. They should have a visit to the intended new health care providers in order to familiarize themselves with the new settings. The adult care system receiving the adolescents ought to be interested in and capable of handling them. The members of staff need to be aware of the challenges that the adolescents go through and hence have an idea on how to handle them. (Mohammed, 2017; Monaghan M, 2016; Viner, 1999; Zhou, 2016)

The hospital administration has a role to play in ensuring that transitioning occurs seamlessly through having checklists that guide on transitioning and ensuring organization of transfer of records. (Viner, 2001)

A committee of experts drawn from the American Association of Pediatrics, the American Association of Family Physicians and the American College of Physicians made recommendations on transitioning of adolescents with chronic illnesses.(Pediatrics, 2011)

The recommendations made were that transitioning care ought to be included in the standards for providing health care for all youth. They recommended that transitioning should involve the health care providers, the parents/caregivers and the youth.

The environment under which the discussion on the transitioning planning should occur ought to be free and accommodative of the parents' and the adolescents' wishes and beliefs. Each of the members has a specific role to play. The role of the parents is to be involved in decision making as well as to give the adolescents space to be themselves. The adolescents are supposed to capitalize on their independence and make informed decisions as well as start adjusting to taking care of themselves. The health care providers fall under the auspices of the institution. The institution is charged with the process of facilitating a process that is well coordinated and family centered. The receiving adult clinic is expected to provide developmentally appropriate support for the family and the adolescent (Monaghan M, 2016).

The American Diabetes Association and a panel of specialists in 2011 proposed recommendations for transitioning from pediatric to adult clinical care. (Peters, 2012)

The recommendations made were that preparation for transitioning should begin at least 1 year prior to the transfer date. Some of the skills that ought to be taught, within that year, to the adolescents should enable them to survive on their own in the adult clinic. These include glucose self-monitoring, insulin administration and scheduling clinic appointments. The adolescents need to be educated on the differences between the pediatric and adult providers. The adolescents also need to be aware of the interaction of issues faced during adolescence – birth control, safe sex, alcohol, drugs and smoking- with diabetes mellitus.

The pediatric health care provider should have a written summary containing the adolescent's details and should provide it to both the adolescent and the future adult health care provider.

It is important that the health care providers get to familiarize themselves with the challenges that the adolescents go through and should have an idea or be in a position to help them. The adolescents, with help from the pediatric care providers, should have a visit to their future adult health care providers at least 4 months before the date of transfer.

The care given to the adolescents needs to be individualized and developmentally appropriate to the individual's needs. This means that the level of discussion that will take place is determined by the HCP's assessment of the growth and readiness of the adolescent to handle some aspects of their health.

Follow up clinic visits should take place every 3 months and the guidelines for screening for micro-and macrovascular complications should be followed. The follow up visits also give the adolescents a chance to give feedback to the pediatric team on issues that may or may not need to be corrected (Peters, 2012). The health care providers need to ensure that the adolescents continue to receive primary and preventive health care.

A study done in South Africa on transitioning in children with spina bifida recommended that transitioning needed to be planned for right from the time that the diagnosis is made. It also recommended that the caregivers and the adolescents both need support from the institution in order to make transitioning successful and smooth.

Different transitioning models exist depending on the specific disease conditions and their unique requirements(Westwood, 2014). Adolescent clinics cater to the adolescents and handle their health issues after they leave the pediatric clinic and before they move to the adult clinic. The World Health Organization in 2012 stated that in order to be considered adolescent friendly, health services should be accessible, acceptable, equitable, appropriate and effective. There are two different transitioning models that have been proposed, the first one involves the change of the health care providers from pediatric to adult and the second one adopts the transition clinics/adolescent clinics that incorporate health care providers from both the pediatric and adult clinic then later on hand them over to the adult care providers (Davis, 2001).They have members of staff who have been trained on how to handle adolescents. Attendance to the clinics is easy because the adolescents are likely to meet their peers and interact as well as share experiences with each other compared to instances where they get attended to together with children and adults. (Archibald, 2018)

This is important because they are able to address the issues of concern in the adolescents’ lives without being judgmental (Crowley, 2011). Other adolescent clinics have members of staff who have been trained specifically on transitioning and so they offer routine care in preparation for the move to the adult clinic (Zhou, 2016). They also have members of staff from both the pediatric and adult clinics hence will help in making the transitioning from pediatric to adult care easier (Berens, 2017). Adolescents identify more as groups and having an adolescent clinic will allow them to meet with their peers and enhance clinic attendance as compared to moving to the adult clinic alone without any preparation beforehand (Mbalinda, 2020).

2.3.1 Advantages and Disadvantages of Transitioning

Advantages of transitioning

Direct benefits of transitioning to the patient include improved disease control, decreased hospital admissions, better quality of life, and increased patient satisfaction. (Mohammed, 2017).

Other benefits include increased sense of autonomy and responsibility which make the adolescent more independent in handling their health condition (Ayuk, 2020; Goralski, 2017)

Disadvantages of transitioning

Disadvantages to the patient are a change in the health care provider and a move away from a familiar pediatric setting. Disadvantages to the system include high costs of development and implementation of care with insufficient reimbursement and loss of revenue for children's hospitals. (Suris, 2009)

2.4 Barriers and facilitators of transitioning

2.4.1 Barriers to transitioning

2.4.1.1 Adolescents

Adolescents with chronic diseases like DM may view transitioning as a tier closer to disease complications and death due to the natural history of the disease. This may present reluctance from the adolescents to be followed up in the adult clinic. (Davis, 2001; Wedgwood, 2008; Zhou, 2016)

There is at times reluctance from the adolescents to change health care providers since they have gotten accustomed to a particular pediatric health care provider. The whole process of learning to trust new providers and establish relationships is seen as tedious hence the preference to remain in the pediatric clinic. As part of the development of adolescents is the need to identify with their peers and feel normal. Some may view the medication they are on and the hospital visits as different from their peers and in an effort to fit in may end up getting lost to follow up and stop taking medication. (Wedgwood, 2008)

2.4.1.2 Parents/Guardians

In the pediatric clinic, the parents are involved in decision making concerning the care of the adolescents. The setting in the adult clinic is slightly different with the adolescents expected to make decisions for themselves. This may not go well with the parents who may still feel the need to be actively involved in decision making hence preference for the pediatric clinic. (Viner, 2001; Wedgwood, 2008)

2.4.1.3 Health Care Providers

i) Pediatricians

Some pediatricians may be reluctant to have the adolescents take care of themselves. They feel that the adolescents are not mature enough to handle their health condition while in the adult clinic.

There is trust that had been built between the adolescents, their care givers and the pediatricians while on follow up at the pediatric clinic. There is the element of a feeling of loss when the adolescents have to be followed up by different health care providers in the adult clinic. This may manifest as pediatricians who may not want to let go (Mohammed, 2017).

Other pediatricians may not have confidence in the skills or the flexibility that the adult providers may provide to the adolescents and would prefer to continue monitoring them.

There is fear of loss of long term follow up and in some instances loss of income for the pediatricians when the adolescents transfer. (Viner, 2001)

ii) Adult Health Care Providers

The adult health care services may present barriers to the process of transitioning. Some adult health care providers may not know how to handle adolescents. They expect them to behave like adults while failing to understand that they are not yet mature and need more tolerance.

Other provider clinics have elderly patients who make the adolescents feel out of place. (Viner, 2001)

2.4.1.4 Structural

Most adult and pediatric health care providers do not have information on transitioning care and what is required of them. They are not adequately trained on transitioning care. This creates confusion when the time for transitioning comes due to lack of knowledge on what to do in order to facilitate proper transitioning. (Wedgwood, 2008)

Lack of proper communication between the pediatric and adult health care providers due to lack of guidelines on how to proceed has been found to affect transitioning. This causes delays in the actual transfer of the adolescents. Some adolescents reported that they did not know the name of the adult providers that they were to be followed up by (K. C. Garvey, Markowitz, J.T. , Laffel, L.M., 2012).

Lack of infrastructure having adolescent friendly services and facilities has been cited to be a barrier. The adolescents will feel that their needs are not adequately met. In the United Kingdom, the lack of adolescent friendly facilities like adolescent wards and the lack of health care providers skilled in meeting the specific needs of adolescents have been noted as obstacles to transitioning. (Davis, 2001)

The hospital administration has at times been faulted with failure to provide information to the clients concerning transitioning. This creates a knowledge gap on the side of the patients and their care givers because they do not know what is expected of them. (Wedgwood, 2008)

2.4.2 Facilitators of Transitioning

Facilitators of transitioning have been described as structures which when put in place would help overcome any challenges that may be present in the process of transitioning. Sharing with the adolescents and their parents information about transitioning and constant communication on the progress made so far have been reported as being facilitators towards easing transitioning (Havlicek, 2016; Heath, 2017).

Giving the information before-hand will help in preparing the adolescents psychologically and help them anticipate the transfer and new life in the adult clinic. The parents/guardians are taught what is expected of them as part of preparing for the transitioning so in a way prepare the adolescents under their care.

2.5 Diabetes Mellitus in Adolescents

Type 1 diabetes mellitus results from auto-immune destruction of pancreatic beta cells causing interference with insulin production. This occurs in all age groups in children. The affected children usually require insulin for survival.

The incidence of chronic illnesses which get diagnosed in childhood is increasing (Michaud, 2007). Type 1 Diabetes mellitus has become prevalent in the childhood period (Maahs DM, 2010; WHO, 2018; Ziegler, 2018). Type 1 DM is the most common endocrine-metabolic disorder in children and adolescents worldwide.(Wherett, 2018) There is an increasing prevalence of chronic illnesses in adolescents with the prevalence of diabetes mellitus in adolescents being 22.9 new cases per year per 100 000 persons up to age 15 (WHO, 2018).

Lifestyle changes involving sedentary lifestyles have increased the prevalence of diabetes mellitus. The increase in the prevalence of diabetes mellitus in children will translate to more children transitioning into adult care. Advances in the medical field have increased the survival rate of children with chronic diseases into adulthood.

In 2009, the highest prevalence of type 1 diabetes mellitus was 2.55 per 1000 among white youth (95% CI, 2.48-2.62) and the lowest was 0.35 per 1000 in American Indian youth (95% CI, 0.26-0.47) and type 1 diabetes mellitus increased between 2001 and 2009 in all sex, age, and race/ethnic subgroups except for those with the lowest prevalence age 0-4 years and American Indians (Dabelea, 2014).

There is a paucity of published articles on the incidence of type 1 diabetes mellitus among children in Africa. A study in Nigeria showed the prevalence rate of 0.3 per 1,000 and 1.5 per 100,000 per year in Tanzania. A survey done in Sudan among 43,000 school children aged 7 to 11 years found a prevalence rate of 0.95 per 1,000 (Ramiaya., 2006).

Adolescents often want independence from their caretakers (Nakano, 2011).This is a period that is characterized by rapid physical changes, cognitive development, a new discovery of self and lots of pressure to conform with peers. Those with chronic illnesses may be shy to inform their peers and this is likely to put their health at risk because of other competing interests associated with adolescence and this increases their risk of metabolic complications. Adolescence is a preparation period for life as an adult independent of their parent/guardians. Adolescents with chronic illnesses need special attention so that they get to take care of themselves. Metabolic control has been reported to get deranged in adolescents with diabetes mellitus. This is due to increased secretion of hormones which promote insulin resistance, irregular feeding times and exercise and poor adherence to treatment as well as engaging in risky behavior(alcohol ingestion, tobacco and cannabis smoking) (Jin, 2017).

Studies on transitioning adolescents with diabetes mellitus have shown better glycemic control in adolescents who still remain with the same providers compared to those who change providers. The variables that have been looked at include post-transition diabetes mellitus related admissions, clinic attendance and glycemic control using glycated hemoglobin. (Coyne., *et al* 2017)

The other features that have been considered are hypoglycemia, hyperglycemia and diabetic ketoacidosis during the period of transitioning. Factors that were found to be contributing to poor glycemic control included less supervision from the parents resulting in missed clinic appointments, poor diabetic control as a result of increased pressures at school and irregular mealtimes, adoption of sedentary lifestyles which lead to decreased physical activity and the exposure to influences like alcohol. (Lee, 2013)

Adolescents with type 1 diabetes mellitus usually experience derangements in glycemic control which is attributed to irregularities in feeding and exercise patterns, poor compliance with medication and exposure to alcohol, illicit drugs and tobacco smoking. Eating disorders also characterize adolescence as well as metabolic changes which are hormonal and contribute to greater insulin resistance. Changes in growth especially weight gain in girls can be as a result of diabetes mellitus treatment which results in skipping insulin as a way of losing weight eventually altering the glycemic control (Court, 2009).

When these are incorporated into the life of the adolescent with diabetes mellitus, they result in poor glycemic control which when persistent results in acute diabetic and chronic microvascular and macrovascular complications. (Lee, 2013)

The adolescents need to be aware of the triggers of hypoglycemia such as alcohol, symptoms of hypoglycemia and how to correct it. They also need to know the impact that hypoglycemia has on their activities of daily living such as academics, sports, driving and work performance. In case they cannot abstain from the alcohol, tobacco and illicit drugs, a realistic advisory approach needs to be in place to regulate consumption (Cox, 1994; Gonder-Frederick L, 1997).

Alcohol consumption inhibits gluconeogenesis in the liver resulting in severe hypoglycemia. Cigarette smoking is a risk factor for cardiovascular disease and microalbuminuria. Illicit drug use increases the risk for acute and chronic complications of diabetes mellitus. (Jin, 2017)

Pregnancy in females with diabetes mellitus needs to be carefully planned for in order to ensure as little maternal and fetal risk as possible. Preconception glycemic control needs to be accurate in order to prevent congenital malformations and spontaneous abortions ensuring the delivery of a healthy infant. (Ray, 2001)

Good glycemic control is important to ensure that later on males do not become impotent due to autonomic neuropathy.

Adolescents who seek employment need to inform their employers about diabetes mellitus and its management. A medical report adds credibility to the claims especially in cases where there is doubt on the adequacy of glycemic control.

Sexual health is discussed focusing on preventing sexually transmitted illnesses and unplanned pregnancies together with avoidance of hypoglycemia during or after coitus. (Court, 2009; Jin, 2017). All this information is imparted to the adolescents with diabetes mellitus in preparation for transfer to the adult clinics.

It is therefore imperative that the health care workers involved in care of adolescents understand the physiological and psychological development of adolescence and handle them appropriately-communication skills, confidentiality, patience and understanding.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study Design

A sequential explanatory mixed methods cross sectional study design involving both quantitative and qualitative research methods was employed.

3.2 Study Site

The study site was Moi Teaching and Referral Hospital (MTRH) which is located along Nandi Road in Eldoret town. Eldoret is in the North Western side of Kenya, about 350 km from Nairobi.

Moi Teaching and Referral Hospital is the second largest referral hospital in Kenya after Kenyatta National Hospital. It has a bed capacity of 1000 The services offered include outpatient and inpatient medical services, surgical, mental health and comprehensive care services. The outpatient clinics offer follow up services for chronic diseases such as diabetes mellitus, where the study was carried out. Its catchment area is Nyanza province, North Rift and Western Provinces. The estimated population is 19 million out of the country's total population of 50 million. Adolescents are about 4 million out of the 19 million in the western region.

Adolescents with HIV and mental health conditions in MTRH are attended to at Rafiki Adolescent Clinic that is located with the MTRH grounds. It has health care workers who have undergone special training on how to handle adolescents. Specifically the study took place in the pediatric and adult diabetic specialist clinics of MTRH. The clinics are located on the ground floor of the Chandaria Cancer and Chronic Diseases Centre. The diabetic clinics run between 0800 hours and 1300 hours. The members of stuff include nurses, clinical officers nutritionist, counselors and consultant pediatrician and physicians. The pediatric clinic runs on Tuesday and

Thursday, approximately 15 patients are seen on weekly basis. The adolescents in the diabetic clinic were 96 in number at the time of the study. The adult diabetic clinic runs on Monday, Wednesday and Friday. An average of 150 patients are seen weekly with adolescents seen being 30. The distance between the two clinics is about 20 meters.

3.3 Study Population

3.3.1 Target Population

This study targeted three categories of research populations; adolescents with diabetes mellitus on follow up at the outpatient adult and pediatric specialist clinics, Health Care Providers at the adult and pediatric specialist diabetic clinics and guardians/parents involved in care of the adolescents with diabetes mellitus

3.3.2 Study Population

Specifically, this study included adolescents with diabetes mellitus on follow up at the adult and pediatric specialist clinics at the Moi and Teaching Referral Hospital. Additionally, the study targeted nurses, clinical officers, medical officers and consultants who were working at the adult and pediatric specialist diabetic clinics during the study period. Finally, the study also included guardians/parents who had accompanied the adolescents with diabetes mellitus to the clinic.

3.4 Selection Criteria

3.4.1 Inclusion Criteria

Adolescents between the age of 14 and 19 years who were on follow up at the pediatric and adult diabetic specialist clinics. (In MTRH, adolescents are seen at the adult clinic at the age of 14 years and above)

3.4.2 Exclusion Criteria

Adolescents on follow up at the adult diabetic clinics who were diagnosed at the age of 14 years and above.

3.5 Study Period

The study was carried out over a period of 6 months between July 2017 and December 2017.

3.6 Population Size Calculation

The study aimed to collect data from all the adolescents who had met the inclusion criteria. It was a census study. Diabetes mellitus in children is an uncommon condition and a look at the previous records over a three-year period showed the average number of adolescents with diabetes mellitus per year to be 60 so it would be possible to interview all the adolescents with diabetes mellitus within the time frame of the study hence the census.

Convenience sampling based on the availability of the adolescents was used to select participants for the focus group discussions.

3.7 Data Collection Tools

Quantitative data: The questionnaires had demographic details of the adolescents-current age, age at diagnosis, sex, period of follow up at the clinic, marital status and level of education.

The questionnaires to the guardians in the pediatric clinic asked about the age of the child at diagnosis and period of follow up in the current clinic as well as whether the HCP had informed them about follow up in the adult clinic and what exactly had been discussed.

The questionnaires to the guardians in the adult clinic enquired about what happened when the time came for their children to move to adult care, whether there had been a discussion prior to that, any barriers they had encountered and whether there were recommendations that they would make to ease the process.

The health care providers involved in running the diabetic specialist clinics had a different set of questionnaires as well. The questionnaires had information on the cadre of health care that the respondent was in, their ages, the gender and the period of time they had worked at the diabetic clinic.

Qualitative data: Focus group discussions to the adolescents and key informant interviews to the health care providers were used in collecting qualitative data.

The adolescents in the pediatric clinics had sets of questions that probed on what their understanding of transitioning was. The questions sought to find out whether there had been any discussions with the health care providers that would help the adolescents prepare for the anticipated change in care from pediatric to adult care and also asked their hopes on what would happen when the time came for them to move to adult care.

The questions to the adolescents in the adult clinics focused on the participants' understanding and description of the experiences that they had gone through when they moved from pediatric to adult care. They were asked about whether there had been any discussions that had happened informing them about the intended change of care, their perceptions on how the process was conducted, any differences noted between the pediatric and adult care models and whether there were aspects that they felt could have been done in a different or better way.

The questionnaires to the key informants probed on the understanding of the health care providers on what transitioning was,how it was conducted at MTRH and also sought clarification for some of the responses that had been given by the adolescents. The questions sought to find out how come the adolescents only knew their diagnosis but not the other elements of appropriate transitioning and also explained why some of the barriers that were reported by the adolescents existed.

3.8 Study Procedure

The principal investigator (PI) went to the pediatric and adult diabetic clinics in order to inform the members of staff about the intended study and what would be required. The PI selected one of the members of staff to be the research assistant (RA). The research assistant was chosen based on his experience working in the diabetic clinic for the last 7 years. He is a laboratory technician by profession. The data was collected by the PI with the aid of the RA. The PI informed the RA about the criteria that would be used to select the participants in the study. The diabetic clinic usually had a predetermined list of the expected clients on the specific days. The RA identified the names of the adolescents who met the inclusion criteria and when they came to the clinic, after being seen by the doctors were asked to wait a bit. The PI was then informed about the adolescents who had arrived. The PI met them in a separate room adjacent to the clinic, introduced herself to the adolescents and their guardians (those who had accompanied their children),informed them about the study and asked whether they would agree to take part in it and informed them about the focus group discussion that was to take place sometime later. Those who agreed to take part in the study had the process of informed consent administered to them. The interviewer administered questionnaires were administered to the adolescents and their guardians by the PI. The RA observed the process and later on was able to carry out the interviews in instances when the PI would not make it. The whole process of identifying the study participants and recruiting them was repeated until all the 65 adolescents were included in the study.

Quantitative methods: Interviewer-administered questionnaires administered by either the PI and RA were used to collect quantitative data from the adolescents and their parents. There were different questionnaires for the different respondents in the pediatric and the adult clinics. Those who agreed to take part in the study were interviewed in the room adjacent to the clinic.

Qualitative methods: Information received from the open ended questionnaires was analyzed and used to formulate questions for the focus group discussions (FGD). The moderator of the focus group discussions used a structured list of questions in guiding the discussion. The moderator had a master’s degree in public health and was picked on basis of having trained in qualitative data collection and had at least 5 years’ experience in conducting focus group discussions for other research projects within MTRH. The adolescents who were to take part in the focus group discussions (FGD) were selected on basis of whether they were in the pediatric or adult clinics and also on basis of their ages. The adolescents were stratified into mid (14-16 years) and late (17- 19 years) adolescents. Both clinics had the two age groups. They were called on phone and invited for the planned focus group discussions. They were informed about the expected day, time and place where the discussions were to be held. For each FGD, a total of 15 respondents were invited to take part. There were separate FGD's for the adolescents in the pediatric and adult diabetic clinics. Each of the groups had both male and female participants. The participants in the FGD were picked based on their availability to attend the discussion after being invited. Out of the 65 adolescents who were interviewed, 44 took part in the FGD's. The participants in the first and second FGD's in the pediatric clinic were 10 and 8 respectively. Those in the adult clinic FGD's were 12 in the first one and 8 in the second. Each discussion took an average of thirty minutes. Two different FGDs were done for the mid adolescents and two different FGDs were done for the late adolescents.

The discussions were conducted by the moderator in English and Kiswahili with the PI in attendance. Responses were noted on paper and on an audio recorder. The discussions were held in one of the conference rooms in the second floor of the Chandaria Cancer and Chronic Diseases Centre in MTRH.

Saturation was reached after conducting two interviews in each of the groups and no new responses were obtained.

The key informants were selected on basis of being health professionals who worked in the pediatric and diabetic clinics. The PI met them individually, introduced herself to them as well as the study and the purpose of the study. They all agreed to take part in the study hence the process of informed consent was administered to them. The interviews took place in one of the rooms adjacent to the clinics. The key informant interviews were conducted in English. The questions that were asked were based on the responses that had been obtained from the FGD's with the adolescents and sought to get a deeper understanding and explanation of the responses that had been given by the adolescents and their guardians. Each cadre of the health care providers had 2 members who were interviewed. The responses they gave were recorded on paper and on an audio recorder.

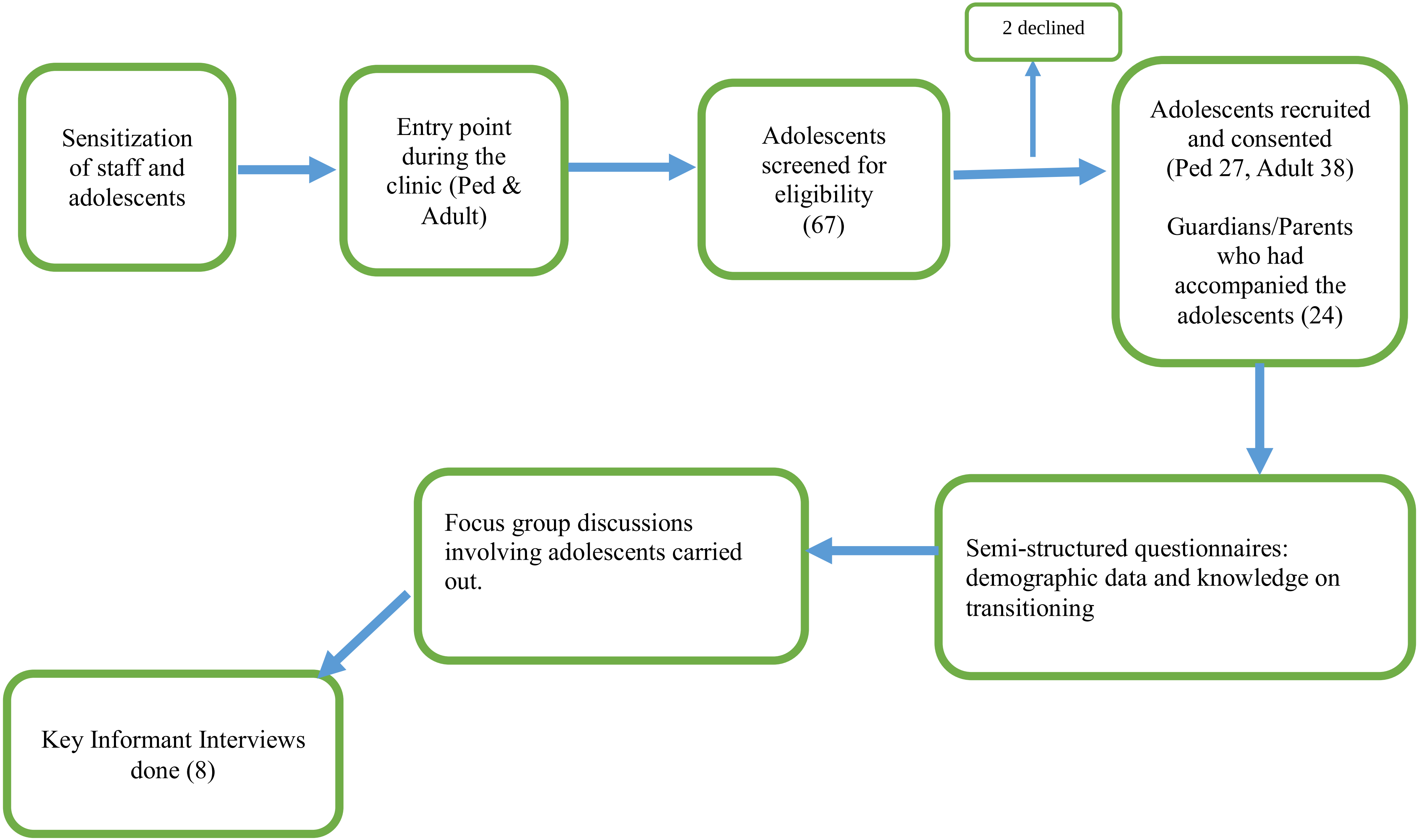

Figure 1: Flow of the respondents

3.8 Data Analysis

Quantitative data was double entered in the computer program Microsoft excel and checked for completeness before being exported to SPSS for descriptive analysis. Descriptive analyses were performed to characterize the population using percentage frequencies. These analyses gave demographic breakdown of the population such as male: female ratio and mean ages.

Qualitative data was transcribed verbatim from the audio recordings. Responses that had been given in Swahili were then translated into English. Qualitative data analysis involved coding which involved organizing the information into categories and themes. Thematic analysis was done in line with the objectives: process of transitioning, facilitators of transitioning, and barriers and facilitators faced during transitioning. The information obtained was entered into Nvivo12 software.

3.9 Ethical Consideration

Ethical consideration involved seeking approval from the MTRH Institution Research and Ethics Committee (IREC) which was granted. The approval letter was presented to the management of the MTRH in order to be allowed to carry out the study. Permission was sought and granted from the various people in charge of the clinics where the study was carried out. A brief description of the study process and its aims was given to the study population. They were not coerced in any way to take part in the study. Those who agreed signed consent and assent forms.

The process of informed consent was administered to the parents/guardians of the adolescents with diabetes mellitus, the adolescents with diabetes mellitus who were above 18 years and the health care providers in the diabetic clinics. This was evidenced by signing of the consent forms in order to participate in the study.

The process of informed assent was administered to the children less than 18 years, consent was also obtained from their care givers. This was evidenced by the signing of the assent and consent forms.

The adolescents who were minors and had come to the clinic unaccompanied by their guardians, a doctor at the clinic (not the researcher) played the role of the guardian and gave consent for the adolescent to take part in the study while the adolescents signed assent forms.

Reimbursement for transport to the adolescent participants was done and lunch for the FGD participants was given.

The questionnaires did not have any personal details that could be linked to the respondents. A code known only to the investigators was used to identify each member and also to avoid sampling an individual twice.

The information obtained was anonymized and kept confidential. Access was restricted to only the investigators and the supervisors.

The information on hard copy was kept under lock and key in a safe cabinet. The information in the computer was stored in a password protected computer.

CHAPTER FOUR

4.0 RESULTS

4.1 QUANTITATIVE COMPONENT

4.1.1 Demographic Data

A total of 97 participants comprising of 65 adolescents, 8 health care providers and 24 guardians/parents took part in the study (Table 1). Among the adolescents, majority of the respondents were in the adult clinic 38 (58%) with the mean age of 17 years while at the pediatric clinic, the mean age was 14 years. Two (2) of the adolescents had chronic heart disease and were on follow up in the cardiology clinic. In addition, four (4) of the guardians had diabetes mellitus and were on follow up at MTRH.

Table 1: Demographic and clinical characteristics of Adolescents with DM at MTRH

Variable	Frequency (%)
Adolescents N=65	
Gender	
Male	25 (38.4)
Female	40 (61.5)
Age	
14 - 16 years	39 (60)
17 -19 years	26 (40)
Clinic Attending	
Pediatric	27(42%)
Adult	38(58%)
Education Level	
Primary School	25 (38.4)
Secondary School	37 (56.9)
Tertiary	3 (4.6)
Period of Follow Up	
6 - 12 months	2 (3)
13 - 24 months	8 (12.3)
25 - 59 months	19 (29.2)
60 or more months	36 (55.4)
County of residence	
Uasin Gishu	61 (94)
Other (TransNzoia, Kisumu)	4 (6)
Diabetes Medication Usage	
70/30 Insulin	52 (80)
NPH Insulin/Humalog Insulin	9 (15)
Lantus Insulin	4 (5)
Person accompanying adolescent to the clinic	
Parent/Guardian	24 (40)
Sibling	11 (17)

Self	30 (43)

Table 2: Demographic and clinical characteristics of Guardians accompanying the adolescents with DM in MTRH

Variable	*Frequency (%)*
Parents/Guardians N=24	
Gender	
Male	6 (25)
Female	18 (75)
Clinic Attending	
Pediatric	15 (63)
Adult	9 (37)
Age	
30- 40 years	3 (12)
41- 50 years	15 (63)
51- 60 years	6 (25)
Highest Level of education	
Primary School	10 (42)
Secondary School	6 (25)
Rtiary	8 (33)
Marital Status	
Single	10 (42)
Married	14 (58)
Mode of employment	
Formal	9 (37)
Informal	15 (63)

Table 3: Demographic characteristics of the Health Care Providers at the diabetic clinics in MTRH

Variable	*Frequency (%)*
Health Care Providers N=8	
Cadre	
Pediatricians	2 (25)
Physicians	2 (25)
Clinical Officers	2 (25)
Nurses	2 (25)
Age	
25-35 years	1 (13)
36- 50 years	7 (87)
Work Experience at the clinic	
0-18 months	1 (13)
19- 36 months	5 (61)
37 or more months	2 (26)

4.1.2 Proportion of adolescents who met the elements of appropriate transitioning

The 65 adolescents interviewed were in both the pediatric and adult clinics. A total of 38 (58%) had transferred to the adult clinic. Transitioning was deemed to be appropriate when the adolescents met any one or more elements of appropriate transitioning. One element of transitioning(disclosure of diagnosis) was met by all the 65(100%) adolescents but none of the other elements were met vy ant of the adolescents. (Table 2). Although all the adolescents met one element of appropriate transitioning, they did not go through the process of transitioning hence they were transferred.

Table 4: Elements of appropriate transitioning and the responses

Criteria	**Respondents (n=65)**
Disclosed to their diagnosis of diabetes mellitus	65 (100%)
Using written plan to transition	0
Involved in preparing transitioning plan	0
Using any other existing guideline	0

4.1.3 Process, facilitators and barriers to transitioning adolescents with DM from pediatric to adult outpatient clinical care

Table 3 indicates the responses to the structured questionnaires on the description of the process of transitioning.

Table 5: Description of the process of transitioning

Variable	Frequency (%)
Awareness about diagnosis (N=65)	
Yes	65 (100)
No	0 (0)
Accompanied to the clinic (N=65)	
Yes	35 (53)
No	30 (47)
Adolescent preparedness to be followed up in the adult clinic (N=27)	18 (67)
Yes	9 (33)
No	
Noted changes in the transitioning (N=38)	
Changes in the day of clinic	12 (32)
Change in physical location of the clinic	8 (24)
Different doctors	18(44)
Preparation for transitioning (N=65)	
Yes	0
No	65 (100)
Perception towards moving to the adult clinic (N=65)	
Ready to move	20 (31)
Fear of breaking close ties already formed	29 (45)
Fear of a new environment	16 (25)
Actual movement from pediatric to adult care (N=38)	
Requested to move to the new clinic	20 (53)
Moved to the clinic despite raising objections	5 (13)
Short discussion then move to the clinic	13 (38)

Table 4 illustrates the facilitators of transitioning based on the responses obtained from the adolescents who were already in adult care. The pre-existing factors were those that were already in place when they were moving to adult care while the suggestions were what if installed would make the process better.

Table 6: Facilitators of transitioning

Variable	Frequency (%)
Preexisting (N=38)	
Moving with their peers	30 (80)
Clinics within the same facility	4 (10)
Suggestions (N=38)	
Establishment of the adolescent clinics	32 (84)
Inform adolescent in advance about transitioning	10 (26)

The various barriers that were encountered by the adolescents during the move from pediatric to adult care are summarized below in table 5.

Table 7: Barriers to transitioning

Variable (N=38)	Frequency (%)
Health care facility factors	21 (53)
Health care provider factors	13 (34)
Adolescent factors	4 (12)

The parents'/guardians' involvement in the care of their children and as part of preparation for transitioning is summarized in the table below.

Table 8: Parental roles

Variable (N=24)	Frequency (%)
Accompanied their children to the clinic	15 (62)
Child was aware of diagnosis	24 (100)
Never had discussions concerning follow up in the adult clinic	17 (71)
Suggestion: Informing the adolescent about the intended transitioning	20 (83)

4.2 QUALITATIVE COMPONENT

The topics of interest to the study were 1) process of transitioning adolescents 2) facilitators of transitioning and 3) barriers to transitioning. The responses obtained were coded into themes and categorized into the different topics that formed the objectives of the study.

4.2.1 Focus Group Discussions

4.2.1.1 Process of Transitioning Adolescents

The process of transitioning in the study was divided into three phases, preparation for transitioning while still in the pediatric clinic, the actual movement to the adult clinic and follow up in the adult clinic.

a) Preparation for transitioning

Discussion concerning the intended move

The adolescents in both the pediatric and adult clinics were asked whether there had been a discussion between them and the health care providers concerning follow up in the adult clinic. Those in the adult clinics noted that the health care providers had informed them about the plan to move to the adult clinic then they were moved. They had been asked questions and requested to fill in some details such as name, age and gender in a form.

"They just asked some questions and then I filled a form…Okay, as for me they took the book and then they called us to get in then informed us that we need to move the children's clinic to the adult clinic. Ever since we filled those [Forms], we have not been told anything" (Adolescent, 14-16 years, pediatric clinic)

The adolescents also had discussions with the parent about the transitioning process. This is well illustrated as follows:

"My mum… She advised me that I am now a big girl whom I can manage myself, I know how to control my sugars, I can be left on my own and that she will no longer be bringing me to the clinic anymore and that I should go to the adult's so that I will be going alone. She said that I am ready and I am a big girl now. She told me that I am ready to go to the adult clinic" (Adolescent, 17-19 years, pediatric clinic).

Others mentioned that they were not involved in any discussion with the health care provider about their transitioning to the adult clinic:

"No, there hasn't been any mention by the doctor that I will be moving to the adult clinic." (Adolescent, 14-16 years, pediatric clinic)

"I don't remember there being a discussion with the doctors while in the child clinic about follow up in the adult clinic. I just found myself in the adult clinic one day" (Adolescent, 17-19 years, adult clinic)

Readiness for follow up in the adult clinic

When asked about their feelings about preparedness to change into an adult health care provider, the adolescents mentioned that they feared meeting older patients, feared separation from their peers and fear of what to expect at the adult clinic. They also felt bad, scared and not ready or prepared for the transitioning.

"I was not prepared because what made me know that I was with the adults is that my classmates whom I was with them, I could not see them anymore. Then it was like I was asking myself a lot of questions; why am I with these people? Why am I not with the rest? Or is it because our dates are no longer the same? So I felt like maybe there

were changes at Referral (Hospital) and so let us move on because life must go on" (Adolescent, 17-19 years, adult clinic)

However, some of the adolescents mentioned that they were ready for the transitioning process. They mentioned that they were able to monitor the sugar levels, they were grown up and now were adults, needed some change, ready to be independent in the management and monitoring of the blood glucose levels and ready to learn more about the condition. This is well illustrated below:

"I am ready to change from childhood to adult clinic so that I can manage myself well and I can monitor my blood sugar" (Adolescent, 14-16 years, pediatric clinic) *"Because I have grown up… Because I have reached adolescent age. I am fourteen, I am no longer a child and I need to start a new life at this age of mine"* (Adolescent, 14-16 years, pediatric clinic)

b) Movement of the adolescent from pediatric to adult care

Age

When asked about their thoughts about the best time for crossing over to adult care, some adolescents mentioned that they did not have a specific age rather attainment of certain competencies like , the ability to manage the blood sugar levels. Others noted at the beginning of the year, during the next clinic visit, at one's birthday and any time:

"The best time is at seventeen. When someone sees himself/ herself that he/she is big enough and can stand on their own and manage himself/herself. That is the time that he/she should be transitioned. At that time when you and manage your sugars, maybe when you are fourteen years. I think you can be able to know everything at that time. So long as you can manage yourself, you understand yourself that you have this, you

need to use this, and you need to leave this and those many other things" (Adolescent, 17-19 years, adult clinic)

Fear of change

The fears of transitioning into the adult diabetic clinic included the likely assumption that the health care providers might make that the adolescents have adequate information on the disease condition. They feared the changes that would come as a result of transitioning, they felt shy about having to relate with older people and wondered how they would ask for some help especially during the initial times in the adult clinic. In addition, they feared having to meet and start interacting with unfamiliar health care providers and different clients from the ones they were used to interacting and relating with. Moreover, they wondered what was taught at the adult clinic as compared to the pediatric clinic:

"There is fear. Let's say it is your first time, you are on your own and you still need some help. You fear that you are still young, maybe you don't much, you want to be like other people but you still look young. So you are afraid of adulthood because it is new to you. You can't talk sometimes because maybe you are used to pediatric where you could go with your mother but at this time you are going there alone…Maybe they don't teach a lot of things at the adult clinic like they do at the children's clinic" (Adolescent, 17-19 years, adult clinic)

Transfer

The adolescents in the adult clinic were asked on what happened when the time came for one to be followed up in the adult clinic. The adolescents reported that a short discussion was held facilitated by the health care provider in the pediatric clinic where the adolescent was informed that they had reached an age which qualified them to be in the adult clinic. The expectation was that on the next visit they would attend the adult clinic.

"I was told that I have grown up and I need to move to the adult side". (Adolescent, 14-16 years, Adult clinic)

Other adolescents said that they were told to move to the adult clinic with no explanation being given as to why the decision had been made.

"I came to the pediatric clinic and was told that from next month I will be attending the adult clinic". (Adolescent, 17-19 years, Adult Clinic).

Some adolescents said that they were asked by the health care providers whether they were ready to move to the adult clinic and they responded in the affirmative. Transitioning for them had happened.

"The doctor in the clinic asked me whether I was ready to move to the adult clinic and I said yes". (Adolescent, 14-16 years, Adult clinic)

Another response was that they had been compelled to move to the adult clinic despite voicing their objection to the idea. The decision had been made by the clinician and the adolescent had to comply.

"I was told that I would move to the adult clinic, I told them I was not ready. I did not feel like moving. The next time that I came, I don't know what happened but I was just told that I had to go." (Adolescent, 14-16 years, Adult clinic)

c) Follow up in the adult clinic

It was observed that there was follow up on the adherence to treatment and management. The health care providers did not however enquire whether there were any noted differences in care.

"Okay, just the normal process like when they are checking on the sugars, they ask how much insulin you inject. Sometimes he asks to know how I am doing…Yes. But it was once." (Adolescent, 17-19 years, adult clinic)

4.2.1.2 Facilitators of Transitioning

Facilitators were viewed as the structures/facilities which when put in place would ease the movement from pediatric to adult clinic. The responses were categorized into two themes: supply side factors (facility and health care providers) and the demand side factors (patient factors).

d) Supply side factors

The question that was posed to the adolescents in the adult clinic was whether there was anything that they felt had it been in place would have made the movement from pediatric to adult care easier.

Preparation for transitioning

The adolescents also noted the need for increased sensitization of the adolescents on the whole process of transitioning. They mentioned the need for increased support for the diabetic services in terms of ease of access to equipment and supplies, the need to set a fixed age limit for one to transition to the adult clinic and reduced prices for the services, supplies and equipment:

“I think you should tell the person how the other side is, the differences too. I mean he/she should know everything before he/she goes to the other side” (Adolescent, 14-16 years, adult clinic).

“They should be prepared psychologically. Let’s say they should prepare you psychologically that you will be moving from the child clinic to the adult clinic. They have to tell you that the doctors are different and that you are moving from the child clinic to the adult clinic. Also, they should be filling forms like she said that when she was moving from the child clinic to the adult clinic, they gave her some forms to fill unlike us who we were not given any forms to fill. (Adolescent, 17-19 years, adult clinic).

“*I think you should tell the person how the other side is, the differences too. I mean he/she should know everything before he/she goes to the other side.”* (Adolescent, 17-19 years, adult clinic).

“*If at some point the doctors decide that we have to move to the adult side, they should tell us and give us some time to digest that information then wait for us to tell them that ‘yes, we are ready to move’ not just having us move on short notice, you know*” (Adolescent, 17-19 years, adult clinic)

Adolescent Clinics

It was noted that there was need for scheduling of clinics specifically for the teenagers or in the event of clinics comprising both pediatric and adult clients priority ought to be given to the adolescents, as well as having proper attention and focus on the needs of the adolescents by providing services tailored to their needs., They also emphasized on the need for provision of adolescent friendly services and creation of support groups and sessions targeting the adolescents. Most of the adolescents suggested that it would be better if there was a central place where the adolescents would be seen on a specific day, by doctors who understood them and were preferably trained in adolescent care. . Adolescents identify more with their peers and this cuts across all aspects of their lives.

"One suggestion is that when they are fixing those checkups, at least they should consider [More teens on same day]. You find that you are alone and personally if I don't know you, I will not talk to you. I have that problem. You are queuing with old people and you get so bored until you leave. I rather go to Edu's office until they come and look for me. Just like that. So they should consider. "(Adolescent, 14-16 years, adult clinic)

"It should be more like the children's just a little bit because we have not yet become fully adults. So we should not be treated so much like adults" (Adolescent, 14-16 years, adult clinic)

Structures to support continuity of care

The adolescents suggested the need of continuous and adequate health education on diabetes mellitus. They mentioned the need for frequent encouragement to the adolescents with the condition. They suggested the need for frequent seminars and group sessions for the adolescents to discuss what affects them. It was noted that sustenance of good communication, rapport and friendliness of the health care providers with the adolescents would also be important.

In addition, provision of timely services without delays, health education and awareness creation on diabetes mellitus to the family and community as well as increased follow up of the patients were recommended.

"What we can do is being open, talking to them freely and helping them where there is a problem in understanding. Whenever they have any problem, you understand them…Maybe the officer should be open to the patient and should not take it like the

patient understands everything. I mean that they should not make it like the patient understands everything. They should give them full information" (Adolescent, 17-19 years, Pediatric clinic)

e) Demand side factors

The main benefits of transitioning to adult clinic included: creation of a sense of adulthood, feeling happy about the transitioning and provision of the opportunity for more interactions and to learn more.

"*That at least you are in the adult category [Laughing]. Then again you know they stopped treating you like a kid. At least they are giving you the reality of life that you are now an adult, you are now able to take care of yourself, you are not supposed to be so dependent that the parent will now be the one to be telling you; "You have to eat this". You are being told to understand yourself, what you are supposed to eat and such like things"* (Adolescent, 17-19 years, Adult clinic)

4.2.1.3 Barriers faced during transitioning

Barriers in this study were defined as any difficulties that the adolescents and their guardians had experienced during the move from pediatric to adult care.

f) Supply side factors:

The adolescents in the adult clinic were asked whether there had been any difficulties that they had encountered when they moved from the pediatric to the adult clinic. Some of the responses they gave are outlined as follows:

Increased cost of care in the adult clinic

There was increased cost of transport due to change of the checkup clinics from the one used to attend the pediatric clinics.

“I have to come to Eldoret for my clinic appointments in the adult clinic from Kitale which is expensive for my parents.” (Adolescent,17-19 years, adult clinic).

In addition there was a need to pay for some of the services such as testing at the adult clinic. For instance, equipment in the pediatric clinic was offered to the adolescents at no cost while in the adult clinic they had to pay for them.

“Like paying for strips is Ksh. 1500, it should be Ksh. 900 and so if you don’t have money, you are disadvantaged. Sometimes you might be called and the last time you did a test is weeks ago.” (Adolescent, 17-19 years, adult clinic)

“We are now paying for HbA1c which we did not pay for while at the child clinic…Okay, for me I heard that when you hit eighteen, you have to pay for those strips and then sometimes that money is not there. You have to pay for the strips and then like Gladys had talked of the syringes, we used to be given the big box which we are no longer given nowadays” (Adolescent, 17-19 years, Adult clinic).

Longer waiting times in the queue

There was delayed and increased waiting time before seeing a care provider at the adult clinic compared to the pediatric clinic. They mentioned that there were more clients in the adult clinic.

“Yeah, like my last week’s checkup which I came at eight and I left at one just because I am queuing with a lot of people. So you see the disadvantage.” (Adolescent, 14-16 years, adult clinic).

“Okay, in the child section, I was not used to waiting to go and see the doctor. I would come and see the doctor and during that time that you are in there, you feel like you have been helped but for that adult section, you will come and wait and you would ask yourself; “Why did I come?” Such kind of stuff.” (Adolescent, 17-19 years, adult clinic)

Model of care in the adult clinic

The adolescents noted that the health care providers in the pediatric clinic were more engaging compared to those in the adult clinic. Both body and verbal language were used to gauge the level of friendliness. This was reported to be a barrier to successful transitioning in that there was poor communication and rapport between the health care provider and the client coupled with poor health education from the health care providers in the adult clinic due to the assumption that the adolescents were already aware of the topics, reduced follow up in terms of a lower frequency of the number of phone calls made to the adolescents in order to assess their glycemic control and discourteous language used by the care providers to the patients.

“In the pediatric clinic they used to call twice or thrice a week but for the adults, it is once in two weeks.” (Adolescent, 14-16 years, Adult clinic).

“When the doctor sees you he/she should not be chatting on the phone. You know it is very irritating. One day, I came to the clinic and then another doctor was called on phone. He talked for like twenty or thirty minutes and you are a patient sitting there, you are supposed to take a snack. That is not fair! [Laughs]” (Adolescent, 17-19 years adult clinic)

*"Okay, the doctors should be advised to talk nicely with the patients. Like there is a time I was with someone and he told me; "We are tired with you". You know that will make you feel bad. It is not good by the way. "(*Adolescent, 14-16 years, Adult Clinic)

g) Demand side factors

Different doctors in the adult clinic

One of the barriers was change from the familiar doctors in the pediatric clinic and meeting different care providers in the adult clinic. The pediatricians at the clinic were few unlike the adult clinic which had many different doctors. Different doctors had different management plans which were at times confusing to the patient. The adolescents had had a bond with the pediatricians because they had spent a lot of time with them. Asking them to move and meet new doctors made them feel like they were losing close ties.

"The changing of doctors. You go and meet another doctor and you cannot talk much. Another challenge is that in the past, you would stick to one doctor but now, this month you are with this doctor, the next month you are with another doctor. So you see that is another challenge. A big one because this one is saying this today, the other one is saying that tomorrow." (Adolescent, 17-19 years, adult clinic)

"Yeah, because you meet this doctor and he/she tells you to inject yourself with this drug say for example Humalog, but you go to another and he/she tells you to use Humulin, the next time you go, the doctor tells you to use Mixtard." (Adolescent,14-16 years, adult clinic)

"There is a day that I came for checkup, that doctor changed the drugs that I was taking and then when I came again, the drugs were changed. So you see you get bored." (Adolescent, 17-19 years, adult clinic)

"In the child section, there was a very close follow up but if you go to the adult section, it is like you have been thrown away." (Adolescent, 14-16 years, adult clinic)

Uncertainty about the new clinic

There was fear and shyness about the issues to be discussed at the adult clinic. The adolescents faced challenges with the loss of and separation from their age mates at the pediatric clinic.

"Shyness… It can be a big problem in that the person who is going to adult clinic will think that the questions that he/she is being asked will be hard. Maybe it will not be like when he/she was in pediatric. I mean he/she will think that the questions there belong to the adults and it will be hard for him. So he/she will think that it will be a problem for him if he/she will go there. Maybe he/she will fear many things over there that they will be talking about adult issues" (Adolescent, 17-19 years, Pediatric clinic).

In addition they also faced difficulties when meeting older patients and making new friends. Change from the familiar pediatric setting with fellow adolescents known to them to that with adults some who are the age of their parents and grandparents was unsettling for some.

"I felt that I am missing a lot. It was difficult. Before, I could meet with people, laugh with them not like now where you are queuing with people who are older than you, someone who is like a grandmother to you." (Adolescent, 17-19 years, adult clinic)

"It is like you are being separated from your age mates and so you are facing new people who are older than you, you cannot share your ideas, and you cannot laugh with that person." (Adolescent, 14-16 years, adult clinic)

Some of the observed differences in the care provided at the adult clinic as compared to the pediatric clinic included: more congestion at the adult clinic as compared to the pediatric clinic, friendlier care providers at the pediatric clinic as compared to those at the adult clinic, payment of services at the adult clinic unlike at the pediatric clinics where the services were free, reduced follow ups in the adult clinics, few number of care providers attending to the patients at the adult clinics and reduced social support groups and activities in the adult clinics.

"When you are at the children's clinic, the doctor is freer than when he/she is at the adults. He/she talks freely with you. I mean you will be more jovial with him/her but when at the adult's clinic, he/she will be jovial a little bit and then ends it quickly" (Adolescent, 17-19 years, Pediatric clinic).

"At the children's' clinic, you get attended to quickly unlike with the adult's where you have to follow some process…Being taken round and round. You may come and then you are told that the file is on the other end and then again when you go back there you are returned back. At times you could keep waiting when you have not been attended to and yet the doctor could have already left" (Adolescent, 17-19 years, Pediatric clinic)

Other adolescents said that they had not encountered any barriers during the transitioning process.

"I have not had difficulties. I have been with my friend for this period. We are in the same school and most of the things we are doing together. I have not experienced any difficulty." (Adolescent,17 - 19 years. adult clinic)

4.2.2 Key Informant Interviews

i) Preparation for transitioning

When asked whether there was any consideration that they had before moving the adolescents from the pediatric to the adult clinic, the health care providers reported the following :

Age

The clinicians considered the adolescent's age before moving them.

"*Once they turn 14 years, I consider them old enough to be followed up in the adult clinic"* (Clinical Officer, Diabetic clinic)

Glycemic control

The other factor was glycemic control for those who were 14 years and above. Those whose blood sugars were well controlled were moved to the adult clinic while those who were struggling with poor glycemic control were counselled and closely followed up in the pediatric clinic.

"We consider how the glycemic control has been and if it is good, they become candidates to be followed up in the adult clinic" (Pediatrician, Diabetic Clinic)

Knowledge of diagnosis

The health care providers mentioned that the adolescents knew their diagnosis of diabetes mellitus and had been taught about how to maintain blood sugars within the expected range and as well as how to administer insulin to themselves before moving to the adult clinic.

"*We teach the children how to administer the insulin to themselves and give them some education on how to detect hypoglycemia and what to do to control it*" (Nurse, Diabetic Clinic)

"Yes, once the diagnosis is made, we try to explain it to the child in the simplest terms possible what the disease is and how it is managed" (Pediatrician, Diabetic clinic)

Guidelines on transitioning

The health care providers reported that they were not aware of any guidelines on transitioning and they were not aware about preparing any transitioning plans. They also reported that there was no written policy that guided transitioning. They were not aware of what was expected of them when it came to preparing the adolescents for follow up in the adult clinic. They also mentioned that they had not received any training on transitioning :

"I am not aware about any policy that is used as a guide during transfer to the adult clinic" (Physician, Adult clinic)

"*We do not have any guidelines on transitioning that we use in the clinic. The adolescents move to the adult clinic after turning 14 years old*" (Pediatrician, Pediatric clinic)

ii) Movement of the adolescent from pediatric to adult care

The health care providers were asked to describe what had happened when it was time to physically move the adolescents from the pediatric to the adult clinic. Their responses are outlined as follows: The patient's file was moved to the adult clinic and it served as the reference. It was noted that there was no summary written during the transitioning*:*

"We do not prepare any summary. The adolescents move with their files to the adult clinic" (Nurse, Diabetic Clinic).

They reported that they would only inform the adolescents that they were old enough and it was time to move to the adult clinic.

"We inform the adolescents that they are old enough to be seen in the adult clinics and that further visits will be on the adult side" (Pediatrician, Diabetic Clinic)

j) Follow up in the adult clinic

The health care providers were asked whether there was any follow up that was done by the team in the pediatric clinic in order to establish that the adolescents who had been moved to the adult clinic had maintained follow up. The health care workers reported that they did not do follow up visits to check on how the adolescents were progressing in the adult clinic after transfer.

"I haven't come across an incident where the pediatric team has called to see whether the patients, they sent over are keeping clinic appointments" (Physician, Diabetic clinic)

CHAPTER FIVE

5.0 DISCUSSION

5.1 PROPORTION OF ADOLESCENTS WHO MET THE ELEMENTS OF APPROPRIATE TRANSITIONING

All the adolescents in this study knew their diagnosis as had been explained to them by the parents/guardians and the health care providers concerned with their care. The transitioning guidelines that were used by Viner et al (Viner, 2001) in a study on transitioning adolescents with diabetes mellitus emphasized that the competencies that needed to be attained included knowledge of the diagnosis, insulin administration and detection of glycemic derangement.

While there are many guidelines that mention several aspects that need to be considered before transitioning is deemed complete there is paucity of guidelines that define what appropriate transitioning is (Kızıler, 2018; Mahan, 2017; Nakano, 2011). The guidelines that were reviewed mentioned the elements adapted for appropriate transitioning independent of each other and brought out their importance. The definition of appropriate transitioning that was used in this study was adapted from a study on HIV positive adolescents that is in press that summarized the recommendations from different transitioning guidelines(Ayaya, 2017).

Understanding of their diagnosis is important because one is able to know how aspects like taking alcohol, engaging in sexual activities, uptake of contraceptives and pregnancy integrate into the management of the illness (Burström, 2017). These are aspects that all adolescents face as they grow and the presence of a chronic illness is likely to complicate the integration of illness into these phases.

The HCP’s in this study did not know about the existence or use of any written plans to guide them during transitioning of the adolescents. The HCP’s were not aware of what is expected in the crafting of a transitioning plan. There lacks information in the medical school curriculum on transitioning (Castillo, 2017). This study set out to establish whether or not there was transitioning taking place, monitoring disease control was however beyond the scope of this study. The studies that reported the use of transitioning guidelines involving written plans reported that the HCP's had had training on transitioning hence were familiar with what was expected of them (Buschur, 2017; Reiss, 2012; Sable, 2011; Weissberg-Benchell, 2007)The adolescents that were interviewed had missed out on the ideal guidelines and the steps that make transitioning easy.

In MTRH, the hospital policy states that at 14 years, children in pediatric care ought to move to adult care. Details on the contents of the policy document were beyond the scope of the study hence were not looked into. The existing guidelines on transitioning adolescents with HIV are in Kenya and Uganda. (Katusiime, 2013; NASCOP, 2018). Guidelines are developed after extensive research and evidence have been put into consideration in order to inform policy(WHO, 2013). Transitioning guidelines are usually disease specific and allow some modification to be made in order to suit the needs of the adolescents who are being transitioned. They outline the steps that need to be followed and can be followed by HCP's who have received basic training. The adolescents were not taken through the steps outlined in the guidelines hence were not well prepared for follow up in adult care.

5.2 PROCESS OF TRANSITIONING

5.2.1 Preparation for transitioning

The health care providers in this study reported that they considered a combination of the age of the adolescent, at least 14 years old, the adequacy of glycemic control and knowledge of the diagnosis together with the ability of the adolescents to administer insulin by themselves as determinants of whether or not they were ready to move to the adult clinic. A combination of these factors demonstrates responsibility of the adolescents and the ability to manage the disease relatively independent of their caregivers. Other guidelines recommend that chronological age together with the ability of the adolescents to manage their condition should be determinants of transitioning (Schwartz, 2014).

The average age at which the adolescents were transferred to the adult clinics in this study was 14 years. The reason for this age was due to the hospital policy which sets the cut off age at 14 years. Different authors have different cut off ages that are considered ideal for transfer to the adult clinic to occur (Njuguna, 2019). The age of 14 years was at a lower age compared to what other guidelines state where the recommended age of transfer was between 18 and 25 years (Fernandes, 2014; Katusiime, 2013; Pediatrics, 2013; Weissberg-Benchell, 2007). These guidelines recommended tallying the transfer with moving from high school to college where the adolescents were more mature and able to take an active role in managing their health.

The adolescents in this study knew their diagnosis and had also in the same setting been taught how to administer insulin to themselves, how to detect glycemic derangements and also informed about the chronicity of the disease. This is similar to other transitioning guidelines in children with congenital heart disease and HIV where by at the time of disclosure the adolescent was also taught about basic concepts of its transmission and aspects of its care including the need for medication and the chronicity of the condition before getting to transition which all eventually translate to better disease management (Burström, 2017; Masese, 2018; Sable, 2011).

In this study, there was no reconnaissance of the adult clinic that was done. A reconnaissance should be done at least 4 months before the actual date of moving to adult care and helps the adolescents familiarize themselves with the new settings and also gives them a chance to ask any queries they may have concerning any differences in care between the pediatric and adult teams(Monaghan, 2016). It also helps in reinforcing the message that at some point they have to leave pediatric care and be followed up in the adult care hence facilitating easier movement. A reconnaissance also gives the adult care providers an opportunity to assess the level of knowledge of the basic skills on disease management that the adolescent has before moving to adult care (Iyengar, 2019).

5.2.2 Movement from pediatric to adult care

Transfer is one of the components of transitioning and it refers to the hand over from the pediatric to the adult clinic (Gray 2018). Movement from the pediatric to the adult care without following the laid-out steps and having the time aspect incorporated is essentially transfer. This was because the HCP's did not have adequate knowledge concerning what needed to be done in order to prepare the adolescents for follow up in the adult clinic.

Adolescents in this study reported that they were transferred to adult care without any preparation while in the pediatric clinic. Interestingly, this finding has also been reported in other parts of the world where by transfer was done without following the recommended steps in transitioning. This resulted in dissatisfaction from the adolescents and their caretakers about moving to the adult clinic (Weissberg-Benchell, 2007).

Garvey, et al, 2014, reported similar cases of transfer where the adolescents stated that they were transferred to the adult clinic without any preparation being done and by (Iversen, 2019) in a study on transitioning adolescents with diabetes mellitus where they reported that the movement was abrupt. The reason for the transfer was due to lack of structured transition programs.

The venue of the clinics, the nurses and the clinical officers did not change in this study. The changes that were encountered were the health care providers from pediatricians to physicians, the consultation rooms and the day of the visits from Tuesday and Thursday in the pediatric clinics to either Monday, Wednesday or Friday in the adult clinics. These changes happened as part of the hospital recommended guidelines on what ought to happen when the children move from pediatric to adult care.

In this study, the same file that was used in the pediatrics clinic was the same one that was used in the adult clinic. It contained information on the management of the disease and the instructions by the pediatrician to have the child followed up in the adult clinic. There were no other details pertaining to preparation for follow up in the adult clinic since the discussion did not happen due to lack of knowledge on transitioning by the health care providers. Having the file with the details it had was commendable because a different health care provider would be able to follow up and see how management has been. Coordination between the pediatric and adult health care providers is important to ensure sustainability and reduce the cases of loss to follow up after transitioning to the adult clinic (Suris JC, 2015). Centers that have existing transitioning guidelines ought to use transfer checklists that come with the guidelines. In the absence of the transfer checklist, it is recommended that a summary be written by the pediatric team detailing what has been happening in terms of management of the health condition and the gains made so far in attaining the steps towards completing the process of transitioning and forwarded to the adult health care providers. This is important especially in cases where the health care providers are in different hospitals (Peters, 2012; Sabbagh, 2018).

5.2.3 Follow up in the adult clinic

In the findings from this study, after moving to the adult clinic no further follow up was done by the pediatric team. Our adolescents missed out an opportunity to give feedback to the health care providers on what can be altered in order to make the transitioning easier. After moving to the adult clinic, it is recommended that within 3 months, a follow up visit is done by the pediatric team in order to find out how the adjustment is going on (Peters, 2012). This helps in giving feedback to both the pediatric and adult teams on areas that may need modification or further attention. A study on transitioning adolescents with HIV in a number of countries in sub-Saharan Africa also reported that there was no follow up done after the adolescents moved to adult care. This is attributed to lack of knowledge on transitioning by the health care providers (Dahourou, 2017).

5.3 FACILITATORS OF AND BARRIERS TO TRANSITIONING ADOLESCENTS

5.3.1 Facilitators of Transitioning

5.3.1.1 Supply side factors

The adolescents reported that incorporation of adolescent clinics into their care would help ease the movement to the adult clinic. In MTRH there is an adolescent clinic that currently caters to HIV positive adolescents with the long-term plan of eventually catering to all other chronic illnesses in adolescence. Adolescent clinics have been reported as a good avenue to identify peer support groups and mentors that would encourage those who may be anxious about their condition (Archibald, 2018). Other adolescents reported that adolescent clinics were a bridge between pediatric and adult services hence a welcome idea (DeSouza, 2019). Adolescent clinics are an excellent opportunity give the adolescents a chance to be catered for in an environment where they have the freedom to behave and be treated like the adolescents they are and not as children or as adults.

The model of transitioning that was used at MTRH involved change of health care providers from those in the pediatric to the adult clinic and came along with other changes. This is slightly different from other set ups where the clinics are in most cases in different hospitals or even different buildings within the same hospital and the members of staff are totally different creating a new atmosphere for the adolescent.

Katusiime et al., 2013 in her study on transitioning HIV positive youth had the second model that incorporated adolescent clinics which cater to the needs of the adolescents by having health care providers from both the pediatric and adult clinics who are trained in adolescent medicine. This makes handling of their health care issues better because of the availability of appropriately trained health workers who know how to handle them based on their level of maturity.

The adolescents in this study reported that the doctors in the adult clinic were not as friendly and as engaging as those in the pediatric clinic. Similar sentiments have been echoed by adolescents in Tanzania (Masese, 2018) who reported that the doctors in the adult clinic were not friendly. Having friendlier members of staff would help the adolescents feel at ease in the new setting of the adult clinic considering they would have to leave their friends and the other previously familiar settings in the pediatric clinic. They are more likely to keep the clinic appointments if they feel welcome to the new setting (Mbalinda, 2020).

Some of the recommendations that were put forth by the adolescents and their guardians were that the health care providers in the pediatric clinics should inform the adolescents and their parents about moving to the adult clinics before it actually happens. This can either be done verbally during the clinic visits or put in the form of notices which can be read. The importance of giving them the information cannot be overstated because it forms the basis of transitioning. Guidelines and studies on adolescents with diabetes mellitus emphasized the need for sharing information as a way of easing the movement (Archibald, 2018; Iversen, 2019). It would be better to inform them during the clinic visits because this would allow room to ask questions and seek clarification on issues that may not have been clear. They will also be informed about possible differences that they would expect in the adult clinic (Mbalinda, 2020). The communication lines ought to be open in order for the adolescents and their parents to know that they should be free to seek clarification on issues from the HCP's at any time(K. Garvey, Beste, M. , Luff, D. , Atakov-Castillo, A. , Wolpert ,H . and Ritholz, M., 2014; van Staa, 2011; Wong, 2010). It is a continuous process that gets revisited at every clinic visit. Preparation for transitioning should involve the adolescent, their guardians and the HCP where the HCP informs the other parties what the long term goal is and the steps that would be taken to meet the stated goal- transitioning (Zhou, 2016).

5.3.2 Barriers to transitioning

5.3.2.1 Supply side Factors

The parents and adolescents in this study reported that there was payment for services in the adult clinic specifically the glucometers and glucose strips compared to the pediatric clinic where they did not pay. There was a donor funded program that supported the provision of glucometers and glucose strips in the pediatric clinic. Had there been a discussion about the differences between the pediatric and adult care the adolescents and their parents would have been better prepared for the change unlike in the current situation where they were suddenly confronted with this change that they had to comply with. Interestingly, similar findings were reported by Masese et al., 2018 where by payment for services in the adult clinic was brought forth as a barrier to transitioning. This was because of donor funded programs that supported pediatric services hence making the services available at no charge to the patients.

There were longer waiting times in the adult clinics compared to the pediatric clinics. Epidemiological trends of diabetes mellitus have shown that it is more prevalent in adults compared to children (Forouhi, 2014) which explains why there was a larger number of patients in the adult clinic hence longer waiting times before getting to see the doctor. This is similar to studies done in Tanzania and Uganda where the adolescents who had transitioned said that they had to wait for longer periods before seeing the health care providers in the adult clinic (Katusiime, 2013; Masese, 2018).

This was attributed to more people on follow up in the adult clinics compared to the pediatric clinic.

The adolescents in this study reported that the doctors in the adult clinic are not as friendly and as patient as the doctors in the pediatric clinic. This is similar to what Iversen in her study on adolescents with diabetes mellitus reported where by the pediatricians are ‘more comprehensive in their history’ compared to physicians who are ‘less personal’ (Iversen, 2019). Other studies on transitioning in HIV and diabetes mellitus also reported that the doctors in the pediatric clinic are more friendly and understanding compared to those in the adult clinic (Archibald, 2018; Katusiime, 2013; Masese, 2018)

The adolescents in this study reported that they were better handled at the pediatric clinic than at the adult clinic. Health care in the pediatric setting is more family focused involving the input of the parents and is driven by the developmental readiness of the individual. This is different from care in the adult clinic where it is patient focused and autonomy is required (Society, 2007). Pediatrics as a model of care involves the social aspect which gets incorporated into the medical treatment of the child. The pediatricians will enquire about education and the home environment while the physicians would not ask about the home setting. This may be interpreted by the children as being less caring. This change would not in most cases be a welcome idea to the clients receiving care. The health care providers in the adult clinic did not know how to handle adolescents and expected them to behave like adults (Shaw, 2010; Viner, 2001; Wagner, 2015). Establishment of adolescent clinics having health care providers who are trained in handling adolescents would help reduce this barrier   (Crowley, 2011; Kapellen, 2007).

5.3.2.2 Demand side factors

Adolescents reported that they were reluctant to move to the adult clinic because they would end up being separated from their peers and would be in a clinic with clients old enough to be their parents or grandparents. Others were sad that they would have to leave the doctors they had gotten accustomed to and start new relationships with the doctors in the adult clinic. Archibald et al 2018 in a study on transitioning in adolescents with diabetes mellitus brought out the fear of separation from age mates as a barrier to transitioning. HIV positive youth also reported that they were unhappy about leaving their friends after moving to the adult clinic and also having to break links with the doctors in the youth clinic and start new ties with the doctors in the adult clinic (Katusiime, 2013). Adolescents identify more in groups than as individuals and are likely to follow instructions when doing so as a group than as individuals.

The barrier from the adolescents and their guardians was reluctance to move to the adult clinic where they would meet new health care providers that they had not gotten acquainted with. This was also reported by different authors where they reported a feeling of abandonment by the adolescents on changing to the adult clinic. (Rauen, 2013; Wagner, 2015; Wedgwood, 2008)

An interestingly different report was found in Norway where the parents were anxious about their children moving to the adult clinic while the adolescents were excited about the transfer (van Staa, 2011). This could be due to the parents being the ones making the decisions on behalf of the children while in the pediatric clinic so the children were looking forward to being autonomous.

5.4 Study Limitations

Description of how transitioning took place for the adolescents in the adult clinic was based on recollection of previous events so there may have been some recall bias.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

1. All the adolescents met one element of appropriate transitioning making the proportion 100%. However, none of them met the other elements of appropriate transitioning.
2. The adolescents were moved from the pediatric to the adult diabetic clinics through an event of transfer rather than the process of transitioning.
3. The main facilitators of transitioning to the adult clinic was introduction of adolescent-focused clinics and sharing information on transitioning with both the parents and adolescents.
4. The main barriers encountered during transitioning were health facility factors including payment for services in the adult clinic and prolonged waiting times in the adult clinics. In addition, the provider factors included unfriendly HCP's in the adult clinics while the patient factors included feeling of abandonment by the adolescents when transitioning to the adult clinic.

6.2 Recommendation

1. The adolescents with diabetes mellitus should go through the process of transitioning from pediatric to adult care.
2. MTRH needs to formulate a policy document on transitioning of children with chronic illnesses to adult care and there is need to create an institutional "Guideline on transitioning adolescents with diabetes to adult care".
3. There is need to establish an "Adolescent Friendly Diabetic Clinic" in MTRH.
4. The health care providers in the adult diabetic clinic need sensitization/retraining on the special and specific needs of adolescents with diabetes being transitioned to adult care.

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APPENDICES

Appendix I: Time Frame

TIME	SEPTEMBER 2015- DECEMBER 2015	JAN 2016-FEB 2016	MARCH –AUG 2016	SEP –DEC 2016	JUNE –DEC 2017	JUNE –DEC 2017	SEP -DEC 2018	JAN – SEP 2019
ACTIVITY								
Proposal Concept Development	🟨							
Proposal Writing		🟨						
Proposal submission to IREC for approval			🟨					
Preparation for Data Collection				🟨				
Data Collection					🟨			
Data Analysis					🟨	🟨		
Thesis Writing							🟨	🟨
Thesis Defense								🟨

Appendix II: Budget

Item	**Unit Cost (Ksh)**	**Number Required**	**Total Cost (Ksh)**
Stationery(Pens, Paper)	200	20	4,000
Questionnaires	-	-	15,000
Flash Drive 8 GB	2000	1	2,000
Laptop	30,000	1	30,000
Internet(Modem and monthly internet)	3000	6	18,000
Biostatistician	30,000	1	30,000
Research Assistant	30,000	2	60,000
Focus Group Discussion Sessions	-	-	12,000
Miscellaneous			17,500
Total	-	-	192,500

Appendix III: IREC Continuing Approval Letter

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET
Tel: 33471/2/3

Reference: IREC/2016/129
Approval Number: 0001705

1st September, 2017

INSTITUTIONAL RESEARCH & ETHICS COMMITTEE
01 SEP 2017
APPROVED
P. O. Box 4606-30100 ELDORET

Dr. Wariimi Karingi,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

Dear Dr. Wariimi,

RE: CONTINUING APPROVAL

The Institutional Research and Ethics Committee has reviewed your request for continuing approval to your study titled:-

"Process of Transitioning Adolescents with Diabetes from Pediatric to Adult Outpatient Clinic Care at Moi Teaching and Referral Hospital, Eldoret, Kenya".

Your proposal has been granted a Continuing Approval with effect from 1st September, 2017. You are therefore permitted to continue with your study.

Note that this approval is for 1 year; it will thus expire on 31st August, 2018. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

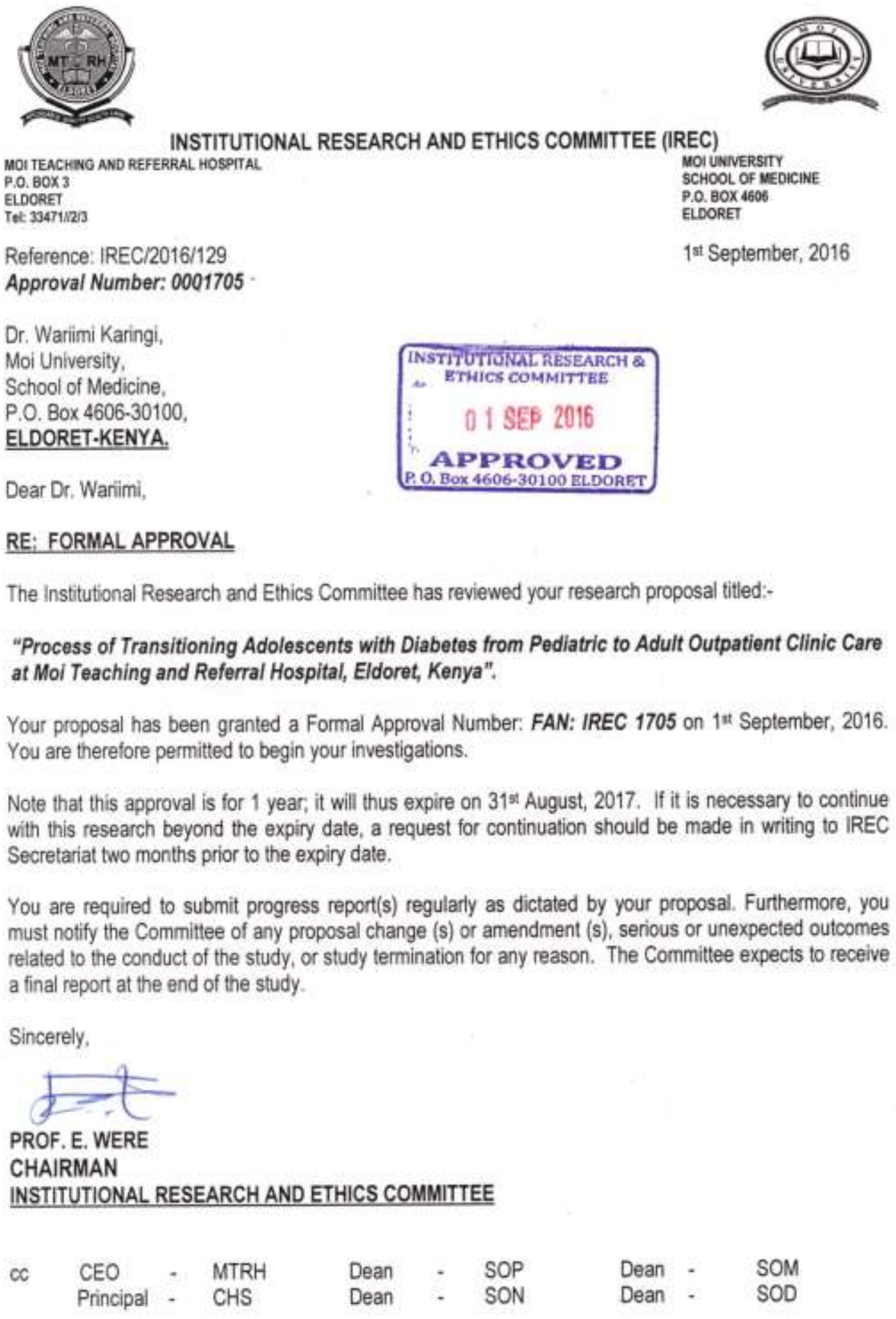
You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc: C.E.O - MTRH
Principal - CHS
Dean - SOM
Dean - SPH
Dean - SOD

IREC Formal Approval



INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET

Reference: IREC/2016/129
Approval Number: 0001705

1st September, 2016

Dr. Wariimi Karingi,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

INSTITUTIONAL RESEARCH &
ETHICS COMMITTEE
01 SEP 2016
APPROVED
P. O. Box 4606-30100 ELDORET

Dear Dr. Wariimi,

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee has reviewed your research proposal titled:-

"Process of Transitioning Adolescents with Diabetes from Pediatric to Adult Outpatient Clinic Care at Moi Teaching and Referral Hospital, Eldoret, Kenya".

Your proposal has been granted a Formal Approval Number: ***FAN: IREC 1705*** on 1st September, 2016. You are therefore permitted to begin your investigations.

Note that this approval is for 1 year; it will thus expire on 31st August, 2017. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

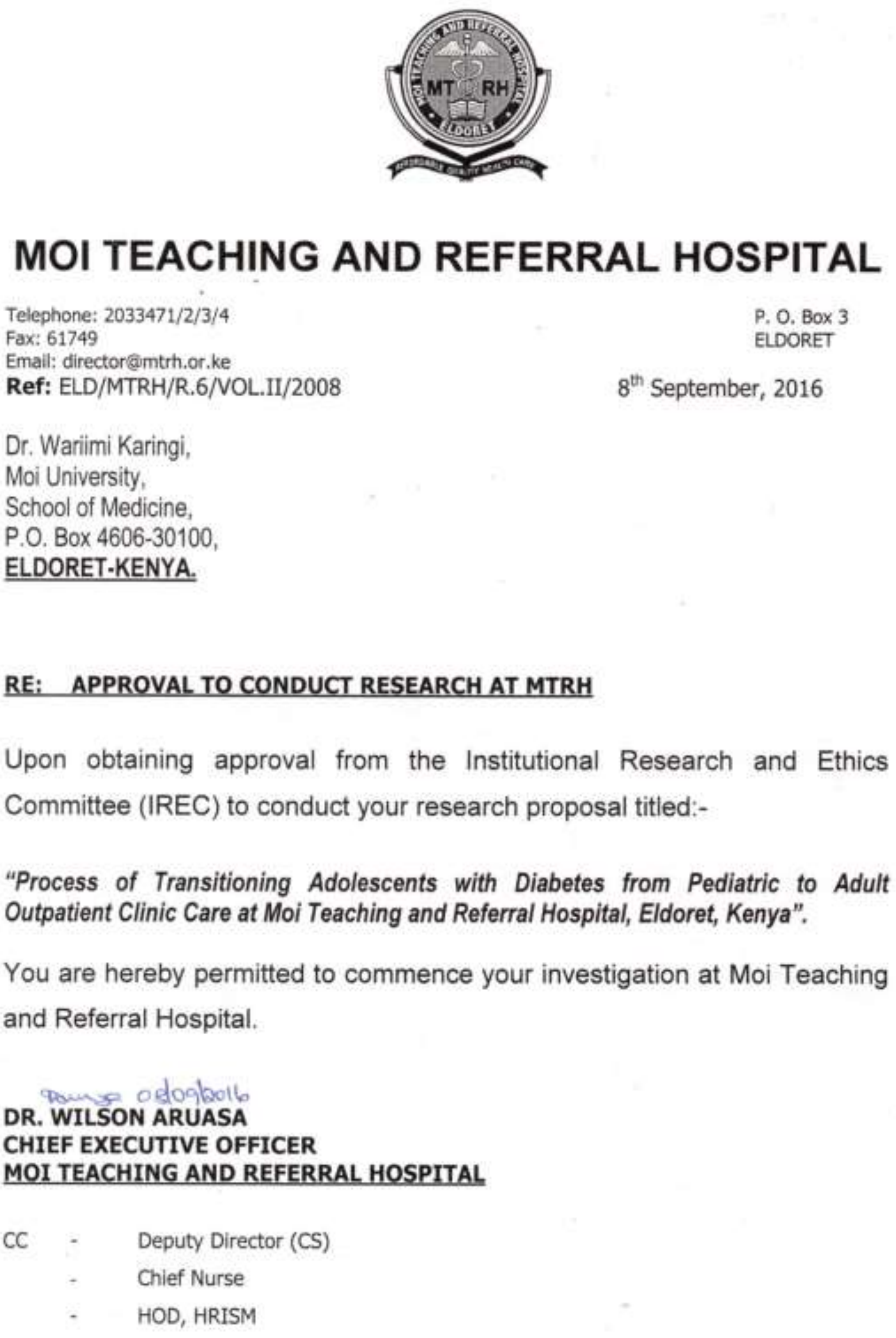
You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc CEO - MTRH Dean - SOP Dean - SOM
Principal - CHS Dean - SON Dean - SOD

Appendix IV: MTRH Approval



MOI TEACHING AND REFERRAL HOSPITAL

Telephone: 2033471/2/3/4
Fax: 61749
Email: director@mtrh.or.ke

P. O. Box 3
ELDORET

Ref: ELD/MTRH/R.6/VOL.II/2008

8th September, 2016

Dr. Wariimi Karingi,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

RE: APPROVAL TO CONDUCT RESEARCH AT MTRH

Upon obtaining approval from the Institutional Research and Ethics Committee (IREC) to conduct your research proposal titled:-

"Process of Transitioning Adolescents with Diabetes from Pediatric to Adult Outpatient Clinic Care at Moi Teaching and Referral Hospital, Eldoret, Kenya".

You are hereby permitted to commence your investigation at Moi Teaching and Referral Hospital.

08/09/2016
DR. WILSON ARUASA
CHIEF EXECUTIVE OFFICER
MOI TEACHING AND REFERRAL HOSPITAL

CC - Deputy Director (CS)
- Chief Nurse
- HOD, HRISM

Appendix V: Assent Form

A. Information Sheet

This informed assent form is for adolescents aged between 14 and 17 years who attend the diabetic clinic and who we are inviting to participate in the research on transitioning adolescents with diabetes.

My name is Dr. Wariimi Karingi, I am a resident in Pediatrics Department, Moi University. I am carrying out a research to find out how adolescents with diabetes are transitioned from the pediatric to the adult clinic at Moi Teaching and Referral Hospital. We want to know whether the process is carried out according to the guidelines and if not, find out from you what can be done to improve the process.

I will invite you to be part of this research study. You can choose whether you will want to participate in the study or not. This will not affect the care that you receive at the clinic. We have discussed this with your parent/guardian and they are aware that we are asking you for your permission to participate in the study.

If you agree to take part in the study, your parents will also have to give permission. Should you not want to take part in the research, you will not be forced, even if your parents have agreed.

If there are any aspects that are not clear, please feel free to ask for clarification, I will be happy to assist.

Your participation will involve asking of questions in interviews and group discussions using a questionnaire guide. The process will be recorded on tape for further use. Your personal information will not be used.

A. CERTIFICATE OF ASSENT

I understand that the research is about evaluating the process of transitioning adolescents with diabetes from pediatric to adult clinical care. I understand that I will take part in an interview and/or a group discussion I order to share my views on the process.

I have read and understood this information (or had the information read to me). Any questions I had have been answered and I know that I can ask other questions if I have any.

I agree to take part in the study.

OR

I do not wish to take part in the study and I have not signed the assent below.___________ (initialed by child/minor)

Only if child assents:

Print name of child ___________________

Signature of child: ____________________

Date: ________________

Day/month/year

If illiterate:

I have witnessed the accurate reading of the assent form to the child, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness (not a parent) _________________

Signature of witness ______________________

Date ________________________

Day/month/year

CHILD'S THUMB PRINT

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the child understands that they will take part in an interview which may be followed by a focus group discussion

I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this assent form has been provided to the participant.

Print Name of Researcher/person taking the assent________________________

Signature of Researcher /person taking the assent __________________________

Date ___________________________

Day/month/year

Copy provided to the participant ________ (initialed by researcher/assistant)

Parent/Guardian has signed an informed consent ___Yes ___No _____ (initialed by researcher/assistant)

Fomu ya Uradhi

A. Ukurasa wa ujumbe

Hii fomu ni ya vijana kati ya miaka 14 na 17 ambao wanahudhuria kliniki ya kisukari na ambao wanaalikwa kushiriki katika utafiti juu ya kipindi cha mpito wa vijana wenye ugonjwa wa kisukari.

Jina langu ni Dkt, Wariimi Karingi, mwanafunzi katika idara ya Watoto ya Moi University. Mimi ninafanya utafiti kuhusu utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto wenye ugonjwa wa kisukari hadi kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

Katika utafiti wetu, tutawauliza vijana wenye ugonjwa wa kisukari maswali. Kabla ya kuuliza maswali, inatupasa kupata ruhusa kutoka kwa washiriki.

Utafiti huu unataka kuchunguza kama masharti hufuatwa wakati watoto wenye ugonjwa wa kisukari wanapotoka kutoka kliniki ya watoto hadi ya watu wazima. Tungependa pia kupata maoni yenu kuhusu njia za kuboresha utaratibu huu.

Iwapo hutakubali kushiriki katika utafiti, hakutakuwa na mabadiliko katika matibabu ambayo utapata katika kliniki

Iwapo utakubali, utashiriki katika mjadiliano na vijana 6 wengine. Mjadala utaongozwa na mtafiti- majadiliano ya vikundi. Unaweza pia kuhojiwa na mtafiti kwa kutumia maswali ambayo yatakuwa yameandikwa kisha majibu yatajazwa na mtafiti.

Faida ya utafiti itakuwa kwa vikundi vijavyo vya vijana wenye ugonjwa wa kisukari. Faida hizi zitapatikana kwa kuzingatia yale maoni yatakayokuwa yametolewa kuhusu kuboresha utaratibu wa mpito kutoka kliniki ya watoto hadi ya watu wazima.

Iwapo kuna swali lolote unaweza uliza sasa ama baadaye. Nambari yangu ya simu 0723847478.

Pendekezo hili limekubaliwa na tume ya chuo kikuu (IREC)ambayo ni kamati ya kuhakikisha kuwa wanaoshiriki katika utafiti wanalindwa kutokana na madhara.

B. **CHETI CHA URADHI**

Mtafiti amenifafanulia kuhusu utafiti na jinsi nitakavyoshiriki- kwa njia ya majadiliano ya kikundi au katika mahojiano. Nimesoma habari / nimesomewa habari. Nimeuliza na kujibiwa maswali yote niliyokuwa nayo. Ninafahamu kwamba nikiwa na maswali yoyote, niko huru kuuliza. Mimi kwa hiari yangu nakubali kutoa idhini ili niweze kushiriki katika utafiti huu.

Andika jina la mtoto ___________________

Saini ya mtoto: ____________________

Tarehe:________________

siku / mwezi / mwaka

Kama hawajui kusoma na kuandika:

Nimeshuhudia kusomwa kwa usahihi fomu ya idhini ya mzazi wa kijana na mzazi amekuwa na nafasi ya kuuliza maswali. Mimi nathibitisha kwamba mzazi ametoa idhini kwa uhuru.

Andika jina la shahidi (si mzazi) _________________

Saini ya shahidi ______________________

Tarehe ________________________

Siku / mwezi / mwaka ALAMA YA KIDOLE

Kauli na mtafiti / mtu kuchukua ridhaa

Nimeshuhudia kusomwa kwa fomu kwa mtoto na amepewa nafasi yakuuliza maswali.

Ninadhibitisha kuwa ridhaa imepewa kwa hiari bila kushurutishwa.

Nakala ya fomu hii ya kupata kibali umetolewa kwa mshiriki.

Andika Jina la Mtafiti _________________________

Saini ya Mtafiti ___________________________

Tarehe ____________________________

Siku / mwezi / mwaka

Nakala zimetolewa kwa mshiriki

Jina la mtafiti _____________________

Sahihi ya mtafiti ___________________

Appendix VI: Consent Form

1a Adolescents 18 Years and above

This informed consent form is for adolescents with diabetes who are above 18 years and are taking part in the study on evaluation of the process of transitioning from pediatric to adult clinical care at the Moi Teaching and Referral Hospital.

A. Information Sheet

I am Dr. Wariimi Karingi, a resident in the department of Pediatrics. I am doing a research to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care in Moi Teaching and Referral Hospital. In our research, we will talk to the adolescents with diabetes and ask them a number of questions. Before asking the questions, we usually get permission from the participants.

In case there are sections that are not clear, please ask me and I will be happy to explain. If you have questions later, you can ask them any time.

The research wants to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care and find out whether guidelines are followed. We also intend to find out whether there are any improvements that can be put in place in order to make the process better.

Your involvement will include taking part in an interviewer administered questionnaire and/or a focus group discussion.

Should you not wish to participate in the study, there will be no change in the treatment that you will receive at the clinic.

Should you accept, you will take part in a discussion with 6 other adolescents? The discussion will be guided by me- focus group discussion. You may also have a questionnaire that will be read aloud and you will give the researcher the answer that you would like to have filled out- interviewer administered questionnaires.

The benefits of the study will be on the incoming groups of adolescents with diabetes who will benefit from the recommendations that will have been made by you together with other care givers in terms of improving the transitioning process.

In case you've got any questions you may ask them now or later. Please find attached my phone number 0723847478 in case you have any queries.

This proposal has been appraised and permitted by IREC which is a committee that ensures that study participants are protected from harm.

Certificate of Consent

The researcher has explained to me what the research entails and how I will take part in it- either through a group discussion or taking part in an interview. I have read the information /it has been read to me. I have asked any questions that I might have heard and they have been clearly answered. I am aware that should I have any other questions, I am free to ask. I voluntarily give consent to participate in this study.

Print Name of Adolescent ___________________
Signature of Adolescent____________________
Date _____________________________
Day/month/year
If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness______________________

Signature of witness _______________________
Date __________________________

Day/month/year

PARTICIPANT'S

THUMB PRINT

FOMU IDHINI

Vijana Wenye Umri Zaidi Ya Miaka 18

Hii fomu ya idhini ni ya vijana wenye ugonjwa wa kisukari waliozaidi ya miaka 18 na watakaoshiriki katika utafiti juu ya utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto hadi kwa kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

A. UKURASA WA UJUMBE

Jina langu ni Dkt, Wariimi Karingi, mwanafunzi katika idara ya Watoto ya Moi University. Mimi ninafanya utafiti kuhusu utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto wenye ugonjwa wa kisukari hadi kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

Katika utafiti wetu, tutawauliza vijana wenye ugonjwa wa kisukari maswali. Kabla ya kuuliza maswali, inatupasa kupata ruhusa kutoka kwa washiriki.

Utafiti huu unataka kuchunguza kama masharti hufuatwa wakati watoto wenye ugonjwa wa kisukari wanapotoka kutoka kliniki ya watoto hadi ya watu wazima. Tungependa pia kupata maoni yenu kuhusu mapendekezo ya kuboresha utaratibu huu.

Iwapo hutakubali kushiriki katika utafiti, hakutakuwa na mabadiliko katika matibabu ambayo unapata katika kliniki

Iwapo utakubali, utashiriki katika mjadiliano na vijana 6 wengine. Mjadala utaongozwa na mtafiti- majadiliano ya vikundi. Unaweza pia kuhojiwa na mtafiti kwa kutumia maswali ambayo yatakuwa yameandikwa kisha majibu yatajazwa na mtafiti.

Faida ya utafiti itakuwa kwa vikundi vijavyo vya vijana wenye ugonjwa wa kisukari. Faida hizi zitapatikana kwa kuzingatia yale maoni yatakayokuwa yametolewa kuhusu kuboresha utaratibu wa mpito kutoka kliniki ya watoto hadi ya watu wazima.

Iwapo kuna swali lolote unaweza uliza kwa wakati huu ama baadaye. Nambari yangu ya simu 0723847478.

Pendekezo hili limekubaliwa na tume ya chuo kikuu (IREC)ambayo ni kamati ya kuhakikisha kuwa wanaoshiriki katika utafiti wanalindwa kutokana na madhara.

B.Cheti Cha Idhini

Mtafiti amenifafanulia kuhusu utafiti na jinsi nitakavyoshiriki- kwa njia ya majadiliano ya kikundi au katika mahojiano. Nimesoma habari / nimesomewa habari. Nimeuliza na kujibiwa maswali yote niliyokuwa nayo. Ninafahamu kwamba nikiwa na maswali yoyote, niko huru kuuliza. Mimi kwa hiari yangu nakubali kutoa idhini ili niweze kushiriki katika utafiti huu.

Andika Jina la Kijana ___________________

Saini ya Kijana ____________________

Tarehe ____________________________

Siku / mwezi / mwaka

Kama hawajui kusoma na kuandika

Nimeshuhudia kusomwa kwa usahihi fomu ya idhini ya kijana na amekuwa na nafasi ya kuuliza maswali. Mimi nathibitisha kwamba mzazi ametoa idhini kwa uhuru.

Andika jina la shahidi______________________

Saini ya shahidi _______________________

Tarehe _________________________

Siku / mwezi / mwaka

ALAMA YA

KIDOLE

CONSENT FORM

2. a Parents of Adolescents

This informed consent form is for parents of adolescents with diabetes taking part in the study on evaluation of the process of transitioning from pediatric to adult clinical care at the Moi Teaching and Referral Hospital.

B. INFORMATION SHEET

I am Dr. Wariimi Karingi, a resident in the department of Pediatrics. I am doing a research to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care in Moi Teaching and Referral Hospital. In our research, we will talk to the adolescents and ask them a number of questions. Before asking the adolescents questions, we usually get permission from their parents/guardians.

In case there are words that are not clear, please ask me and I will be happy to explain. If you have questions later, you can ask them any time.

The research wants to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care and find out whether guidelines are followed. We also intend to find out whether there are any improvements that can be put in place in order to make the process better.

Your child will take part in either an interview and/or focus group discussion.

Should you not wish for your child to participate in the study, there will be no change in the treatment they receive at the clinic.

Should you accept, your child will take part in a discussion with 6 other adolescents. The discussion will be guided by me- focus group discussion. Your child may also have a questionnaire that will be read aloud and they will give the researcher the answer that they would like to have filled out- interviewer administered questionnaires.

The benefits of the study will be on the incoming groups of adolescents with diabetes who will benefit from the recommendations that will have been made by your child in terms of improving the transitioning process.

In case you’ve got any questions you may ask them now or later. Please find attached my phone number 0723847478 in case you have any queries.

This proposal has been appraised and permitted by IREC which is a committee that ensures that study participants are protected from harm.

B.CERTIFICATE OF CONSENT

The researcher has explained to me what the research entails and how my child will take part in it- either through a group discussion or taking part in an interview. I have read the information /it has been read to me. I have asked any questions that I might have heard and they have been clearly answered. I am aware that should I have any other questions, I am free to ask. I voluntarily give consent for my child to participate in this study.

Print Name of Parent or Guardian __________________

Signature of Parent of Guardian___________________

Date ___________________________

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the parent of the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____________________

Signature of witness ______________________

Date ________________________

Day/month/year PARTICIPANT'S THUMB

PRINT

FOMU IDHINI

Wazazi wa Vijana

Hii fomu ya ridhaa ni kwa ajili ya wazazi wa vijana wenye ugonjwa wa kisukari kushiriki katika utafiti juu ya utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto hadi kwa kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

A. UKURASA WA UJUMBE

Jina langu ni Dkt, Wariimi Karingi, mwanafunzi katika idara ya Watoto,Moi Uinversity. Mimi ninafanya utafiti kuhusu utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto wenye ugonjwa wa kisukari hadi kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

Katika utafiti wetu,tutawahoji vijana kuhusu yale wamepitia katika kliniki. Kabla ya kuwauliza maswali kwa kawaida inatupasa kupata ruhusa kutoka kwa wazazi wao / walezi.

Kama kuna sehemu ambazo zitabidi ufafanuzi zaidi kufanywa,tafadhali usisite kuniuliza. Kama pia unalo swali,waweza kuuliza sasa ama hata baadaye.

Utafiti huu unataka kuangalia kama masharti hufuatwa wakati watoto wenye ugonjwa wa kisukari wanapotoka kutoka kliniki ya watoto hadi ya watu wazima. Tungependa pia kupata maoni yenu kuhusu njia za kuboresha utaratibu huu.

Mtoto wako atashiriki katika mahojiano na / au majadiliano ya kundi.

Iwapo hutamkubali mtoto wako kushiriki katika utafiti, hakutakuwa na mabadiliko katika matibabu anayopata katika kliniki.

Iwapo utakubali, mtoto wako atashiriki katika majadiliano na vijana 6 wengine. Mjadala utaongozwa na mimi- majadiliano ya vikundi. Mtoto wako anaweza pia kuhojiwa na mtafiti kwa kutumia maswali ambayo yatakuwa yameandikwa kisha majibu yatajazwa na mtafiti.

Faida ya utafiti itakuwa kwa vikundi vijavyo vya vijana wenye ugonjwa wa kisukari. Faida hizi zitapatikana kwa kuzingatia yale maoni yatakayokuwa yametolewa kuhusu kuboresha utaratibu wa mpito kutoka kliniki ya watoto hadi ya watu wazima.

Iwapo kuna swali lolote unaweza uliza sasa ama baadaye. Nambari yangu ya simu 0723847478.

Pendekezo hili limekubaliwa na tume ya chuo kikuu (IREC)ambayo ni kamati ya kuhakikisha kuwa wanaoshiriki katika utafiti wanalindwa kutokana na madhara.

B.CHETI CHA IDHINI

Mtafiti amenifafanulia kuhusu utafiti na jinsi mtoto wangu atakavyoshiriki- kwa njia ya majadiliano ya kikundi au katika mahojiano. Nimesoma habari / nimesomewa habari. Nimeuliza na kujibiwa maswali yote niliyokuwa nayo. Ninafahamu kwamba nikiwa na maswali yoyote, niko huru kuuliza. Mimi kwa hiari yangu nakubali kutoa idhini ili mtoto wangu aweze kushiriki katika utafiti huu.

Andika Jina la Mzazi au Mlezi __________________

Saini ya Mzazi au Mlezi___________________

Tarehe ___________________________

Siku / mwezi / mwaka

Kama hawajui kusoma na kuandika

Nimeshuhudia kusomwa kwa usahihi fomu ya idhini ya mzazi wa kijana na mzazi amekuwa na nafasi ya kuuliza maswali. Mimi nathibitisha kwamba mzazi ametoa idhini kwa uhuru.

Andika jina la shahidi _____________________

Saini ya shahidi ______________________

Tarehe ________________________

Siku / mwezi / mwaka

KIDOLE

CONSENT FORM

3a Parents/Guardians

This informed consent form is for parents of adolescents with diabetes taking part in the study on evaluation of the process of transitioning from pediatric to adult clinical care at the Moi Teaching and Referral Hospital.

A. INFORMATION SHEET

I am Dr. Wariimi Karingi, a resident in the department of Pediatrics. I am doing a research to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care in Moi Teaching and Referral Hospital. In our research, we will talk to the parents/guardians of adolescents with diabetes and ask them a number of questions. Before asking the questions, we usually get permission from the participants.

In case there are sections that are not clear, please ask me and I will be happy to explain. If you have questions later, you can ask them any time.

The research wants to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care and find out whether guidelines are followed. We also intend to find out whether there are any improvements that can be put in place in order to make the process better.

Your involvement will include taking part in an interviewer administered questionnaire and/or a focus group discussion.

Should you not wish to participate in the study, there will be no change in the treatment that the adolescents receive at the clinic.

Should you accept, you will take part in a discussion with 6 other parents/guardians? The discussion will be guided by me- focus group discussion. You may also have a questionnaire that will be read aloud and you will give the researcher the answer that you would like to have filled out- interviewer administered questionnaires.

The benefits of the study will be on the incoming groups of adolescents with diabetes who will benefit from the recommendations that will have been made by you together with other care givers in terms of improving the transitioning process.

In case you've got any questions you may ask them now or later. Please find attached my phone number 0723847478 in case you have any queries.

This proposal has been appraised and permitted by IREC which is a committee that ensures that study participants are protected from harm.

B.CERTIFICATE OF CONSENT

The researcher has explained to me what the research entails and how I will take part in it- either through a group discussion or taking part in an interview. I have read the information /it has been read to me. I have asked any questions that I might have heard and they have been clearly answered. I am aware that should I have any other questions, I am free to ask. I voluntarily give consent to participate in this study.

Print Name of Parent/Guardian ___________________
Signature of Parent/Guardian____________________
Date ____________________________
Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the parent of the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness______________________
Signature of witness _______________________
Date _________________________
Day/month/year

PARTICIPANT'S THUMB PRINT

FOMU IDHINI

Wazazi / walezi

Hii fomu ya idhini ni ya wazazi wa vijana wenye ugonjwa wa kisukari watakaoshiriki katika utafiti juu ya utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto hadi kwa kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

A. UKURASA WA UJUMBE

Jina langu ni Dkt, Wariimi Karingi, mwanafunzi katika idara ya Watoto ya Moi University. Mimi ninafanya utafiti kuhusu utaratibu unaofuatwa wakati wa kipindi cha mpito kutoka kwa kliniki ya watoto wenye ugonjwa wa kisukari hadi kliniki ya watu wazima katika Moi Teaching and Referral Hospital.

Katika utafiti wetu, tutawauliza wazazi / walezi wa vijana wenye ugonjwa wa kisukari maswali. Kabla ya kuuliza maswali, inatupasa kupata ruhusa kutoka kwa washiriki.

Utafiti huu unataka kuchunguza kama masharti hufuatwa wakati watoto wenye ugonjwa wa kisukari wanapotoka kutoka kliniki ya watoto hadi ya watu wazima. Tungependa pia kupata maoni yenu kuhusu njia za kuboresha utaratibu huu.

Iwapo hutakubali kushiriki katika utafiti, hakutakuwa na mabadiliko katika matibabu ambayo mtoto anapata katika kliniki

Iwapo utakubali, utashiriki katika mjadiliano na wazazi 6 wengine. Mjadala utaongozwa na mtafiti- majadiliano ya vikundi. Unaweza pia kuhojiwa na mtafiti kwa kutumia maswali ambayo yatakuwa yameandikwa kisha majibu yatajazwa na mtafiti.

Faida ya utafiti itakuwa kwa vikundi vijavyo vya vijana wenye ugonjwa wa kisukari. Faida hizi zitapatikana kwa kuzingatia yale maoni yatakayokuwa yametolewa kuhusu kuboresha utaratibu wa mpito kutoka kliniki ya watoto hadi ya watu wazima.

Iwapo kuna swali lolote unaweza uliza kwa wakati huu ama baadaye. Nambari yangu ya simu 0723847478.

Pendekezo hili limekubaliwa na tume ya chuo kikuu (IREC)ambayo ni kamati ya kuhakikisha kuwa wanaoshiriki katika utafiti wanalindwa kutokana na madhara.

B.CHETI CHA IDHINI

Mtafiti amenifafanulia kuhusu utafiti na jinsi nitakavyoshiriki- kwa njia ya majadiliano ya kikundi au katika mahojiano. Nimesoma habari / nimesomewa habari. Nimeuliza na kujibiwa maswali yote niliyokuwa nayo. Ninafahamu kwamba nikiwa na maswali yoyote, niko huru kuuliza. Mimi kwa hiari yangu nakubali kutoa idhini ili niweze kushiriki katika utafiti huu.

Andika Jina la Mzazi / Mlezi __________________

Saini ya Mzazi / Mlezi ___________________

Tarehe ___________________________

Siku / mwezi / mwaka

Kama hawajui kusoma na kuandika

Nimeshuhudia kusomwa kwa usahihi fomu ya idhini ya mzazi wa kijana na mzazi amekuwa na nafasi ya kuuliza maswali. Mimi nathibitisha kwamba mzazi ametoa idhini kwa uhuru.

Andika jina la shahidi_____________________

Saini ya shahidi ______________________

Tarehe ________________________

Siku / mwezi / mwaka

ALAMA YA KIDOLE

CONSENT FORM

4. Health Care Providers

This informed consent form is for health care providers of adolescents with diabetes taking part in the study on evaluation of the process of transitioning from pediatric to adult clinical care at the Moi Teaching and Referral Hospital.

A. INFORMATION SHEET

I am Dr. Wariimi Karingi, a resident in the department of Pediatrics. I am doing a research to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care in Moi Teaching and Referral Hospital. In our research, we will talk to the health care providers of adolescents with diabetes and ask them a number of questions. Before asking the questions, we usually get permission from the participants.

In case there are sections that are not clear, please ask me and I will be happy to explain. If you have questions later, you can ask them any time.

The research wants to evaluate the process of transitioning adolescents with diabetes from pediatric to adult care and find out whether guidelines are followed. We also intend to find out whether there are any improvements that can be put in place in order to make the process better.

Your involvement will include taking part in an interviewer administered questionnaire and/or a focus group discussion.

Should you not wish to participate in the study, your decision will be respected.

You will have a questionnaire that will be read aloud and you will give the researcher the answer that you would like to have filled out- key informant interviews.

The benefits of the study will be on the incoming groups of adolescents with diabetes who will benefit from the recommendations that will have been made by you together with other care givers in terms of improving the transitioning process.

In case you've got any questions you may ask them now or later. Please find attached my phone number 0723847478 in case you have any queries.

This proposal has been appraised and permitted by IREC which is a committee that ensures that study participants are protected from harm.

B.CERTIFICATE OF CONSENT

The researcher has explained to me what the research entails and how I will take part in it- either through a group discussion or taking part in an interview. I have read the information /it has been read to me. I have asked any questions that I might have heard and they have been clearly answered. I am aware that should I have any other questions,I am free to ask. I voluntarily give consent to participate in this study.

Print Name of Health Care Provider __________________

Signature of Health Care Provider___________________

Cadre____

Date ___________________________

Day/month/year

Appendix VII: Questionnaires

1. A ADOLESCENTS IN THE PEDIATRIC CLINIC

Date: ____________ Dd/mm/yy

1. Date of birth: ______________

Dd/mm/yy

2. Sex:

☐Male

☐Female

3. Date of Diagnosis: _______________________________________

Dd/mm/yy

4. Period of follow up at the clinic:

----------------------months

5. Education Level:

☐None

☐Primary

☐Secondary

☐Tertiary

6. Are you aware of your diagnosis?

☐Yes

☐No

7. Current Diabetes Medication:

☐70/30 Insulin
☐NPH Insulin/Humalog Insulin
☐Lantus Insulin
Others:
____

8. Any other nondiabetic medication:-

____

9. Has any health worker at the pediatric clinic discussed with you about follow up at the adult diabetic clinic?

☐Yes

☐No

If yes, what has been discussed?

☐Change in the day to attend the clinic

☐Change in the health care provider

☐Change in the patient encounter form from pediatric to adult

☐Change in the consultation room

Others:

____
____
____
____
____

10. Is there a written plan for your transitioning?

☐Yes

☐No

11. Have you been involved in preparing the transitioning plan?

☐Yes

☐No

12. Who usually brings you to the clinic?
☐Parents/Guardian

☐Sibling

☐Myself

Others:

____

13. Do you feel prepared to change to an adult health care provider?

☐Yes

Please explain:

____
____
____
____
____
____

☐No

Please explain:

____
____
____
____
____
____

Dodoso
VIJANA KATIKA KLINIKI YA WATOTO
Tarehe:___________

1. Tarehe ya kuzaliwa: ____

2. Jinsia:

☐Mvulana

☐Msichana

3. Tarehe ya kugunduliwa kwa ugonjwa wa kisukari:
____
____

4. Muda wa kufuatiliwa kwa kliniki:

Miezi ____

5. Kiwango cha elimu:

☐Hakuna

☐Shule ya msingi

☐Shule ya upili

☐Chuo kikuu

6. Dawa ya ugonjwa wa kisukari unayotumia:

☐70/30 Insulin
☐NPH Insulin/Humalog Insulin
☐Lantus Insulin
Zingine:
____
____

7. Dawa zingine zozote unazotumia:-
____

8. Madaktari kwenye kliniki ya watoto walijadiliana nawe kuhusu kuvuka kwenda upande wa watu wazima kabla haujaenda huko?

☐Ndio.

☐La

Kama ndio, mlijadiliana nini?

☐Kubadilika kwa siku ya kuonekana kwenye kliniki

☐Kubadilika kwa mhudumu wa afya

☐Kubadilika kwa fomu kutoka kwa ile ya watoto hadi ya watu wazima

☐ Kubadilika kwa chumba cha kuonekana

☐Zingine: ____

9. Ulikuwa unajua kuhusu ugonjwa wa kisukari ulio nao kabla ya kupita kwenda upande wa watu wazima?

☐Ndio

☐La

10. Kulikuwa na mpangilio uliokuwa umeandikwa ili utumiwe wakati wa mpito?

☐Ndio

☐La

11. Ulihusika katika kuandaa mpangilio uliokuwa umendikwa ili kutumiwa wakati wa mpito?

☐Ndio

☐La

12. Kuna mpangilio wowote uliotumika wakati wa mpito?

☐Ndio

☐La

13. Unaona kwamba uko tayari kuvuka kwenda kliniki ya upande wa watu wazima?

☐Ndio

Tafadhali fafanua:
____
____
____
____
____

☐La

Tafadhali fafanua:____
____
____
____
____

14. Nani kwa kawaida hukuleta kwa kliniki?

☐Mzazi/Mlezi

☐Ndugu yangu mkubwa

☐Mimi mwenyewe

Wengineo:____
____
____
____

15. Kuna shida zozote ambazo umekumbana nazo katika kliniki uliyoko?
____
____
____
____

2a. ADOLESCENTS IN THE ADULT CLINICS **Date: __________**

Dd/mm/yy

1. Date of birth: _______________________________________

Dd/mm/yy

2. Sex:

☐Male

☐Female

3. Date of Diagnosis: _______________________________________

Dd/mm/yy

4. Period of follow up at the clinic:

__________________________ months

5. Education Level:

☐None

☐Primary

☐Secondary

☐Tertiary

6. Current Diabetes Medication:

☐70/30 Insulin
☐NPH Insulin/Humalog Insulin
☐Lantus Insulin
Others:
____

7. Any other nondiabetic medication:-
____

8. Who usually brings you to the clinic?

☐Parent/Guardian

☐Sibling

☐Myself

☐Others

____

____

____

9. What happened when the time came for you to be followed up at the adult clinic? What was the process like?

____

____

____

____

____

____

____

10. Did any health worker at the pediatric clinic discuss with you about follow up at the adult diabetic clinic?

☐Yes

☐No

If yes, was any of the following discussed?

Change involving any one or all of the following:

☐Clinic

☐Day of visit to the clinic

☐The health care provider

☐Dosage of the insulin that you are using

☐The patient encounter form from the pediatric to the adult form

☐Consultation room

☐Other____

11. Was there a written plan for your transitioning?

☐Yes

☐No

☐Not sure

12. Were you informed of your diagnosis before transitioning to the adult side?

☐Yes

☐No

☐Not sure

13. Were you involved in preparing the transitioning plan?

☐Yes

☐No

☐Not sure

14. Was there any existing guideline used for your transitioning?

☐Yes

☐No

☐Not sure

15. Did you feel prepared to change to an adult health care provider?

☐Yes

Please explain:
____
____
____
____

☐No

Please explain:
____
____
____
____

16. Were there any difficulties that you faced during the transitioning period?

☐Yes

☐No

If yes, were they any of the following?

☐Difficulties from the parents____
____
____

☐Difficulties from the pediatricians____
____
____
____

☐Difficulties from the adult care providers____

☐Lack of guidelines on how the transitioning should occur ____

17. What do you feel made the transitioning process easy for you?____

18. What, in your opinion, do you feel could be put in place in order to make transitioning easier?____

19. What differences are there, if any, in terms of care between the pediatric and adult clinics?

☐Providers ____

☐Decision making____

☐Others: ____

Dodoso

VIJANA KATIKA KLINIKI YA WATU WAZIMA Tarehe: _______________

1. Tarehe ya kuzaliwa: ____

2. Jinsia:

☐Mvulana

☐Msichana

3. Tarehe ya kugunduliwa kwa ugonjwa wa kisukari: ____

4. Muda wa kufuatiliwa kwa kliniki:

Miezi ____

5. Kiwango cha elimu:

☐Hakuna

☐Shule ya msingi

☐Shule ya upili

☐Chuo kikuu

6. Dawa ya ugonjwa wa kisukari unayotumia:

☐70/30 Insulin
☐NPH Insulin/Humalog Insulin
☐Lantus Insulin
Zingine: ____
____
____

7. Dawa zingine zozote:- ____

8.Nani kawaida hukuleta kwenye kliniki?

☐Mzazi/Mlezi
☐Ndugu yangu mkubwa
☐Mimi mwenyewe

Wengineo:____

9. Madaktari kwenye kliniki ya watoto walijadiliana nawe kuhusu kuvuka kwenda upande wa watu wazima kabla haujaenda huko?

☐Ndio.

☐La

Kama ndio, mlijadiliana nini?

☐Kubadilika kwa siku ya kuonekana kwenye kliniki

☐Kubadilika kwa mhudumu wa afya

☐Kubadilika kwa fomu kutoka kwa ile ya watoto hadi ya watu wazima

☐ Kubadilika kwa chumba cha kuonekana

☐Mengine:

____

10. Ulikuwa unajua kuhusu ugonjwa wa kisukari ulio nao kabla ya kupita kwenda upande wa watu wazima?

☐Ndio

☐La

11. Kulikuwa na mpangilio uliokuwa umeandikwa ili utumiwe wakati wa mpito?

☐Ndio

☐La

12. Ulihusika katika kuandaa mpangilio uliokuwa umendikwa ili kutumiwa wakati wa mpito?

☐Ndio

☐La

13. Kuna mpangilio wowote uliotumika wakati wa mpito?

☐Ndio

☐La

14. Unaona kama ulikuwa tayari kuvuka kwenda upande wa watu wazima?

☐Ndio

Tafadhali fafanua:

☐La

Tafadhali fafanua:

15. Ulipata shida zozote wakati wa kuvuka kutoka upande wa watoto hadi wa watu wazima?

☐Ndio.

Zipi?

☐La

16. Kuna mambo yoyote yaliyofanya mpito uwe rahisi kuliko vile mlitarajia?

17. Ni mapendekezo yapi ungetoa ili kuboresha mpito kutoka upande wa watoto hadi wa watu wazima?____

____

____

____

____

14 Kuna tofauti gani kati ya kliniki ya watoto na ya watu wazima?

☐Wahudumu

☐Uamuzi

Mengine:____

____

____

____

3a.GUARDIANS/PARENTS IN THE PEDIATRIC CLINIC

Date: ________________________

1. How old is your child?
____
____

2. At what age was your child diagnosed with diabetes?
____
____

3. How long has your child been on follow up at the clinic?
____
____
____

4. Is your child informed of his/her diagnosis ?

☐Yes

☐No

5. Have the HCP's discussed with either you or your child about follow up in the adult side?

☐Yes

☐No

If yes, what specifically has been discussed?____
____
____
____
____

6. Has there been change in any one or all of the following:

☐Clinic

☐Day of visit to the clinic

☐The health care provider

☐Dosage of the insulin being used

☐The patient encounter form from the pediatric to the adult form

☐Consultation room

☐Other

7. Is there any existing guideline used for your child's transitioning?

☐Yes

☐No

☐Not sure

Dodoso **Tarehe:____________________**

WAZAZI WA WATOTO KATIKA KLINIKI YA WATOTO

1. Mtoto wako ana umri wa miaka ngapi?

____

2. Ugonjwa wa kisukari ulipatikana mtoto akiwa miaka mingapi?

____

3. Mtoto wako amekuwa kwenye kliniki ya watoto kwa muda gani sasa?

____

4. Madaktari kwenye kliniki ya watoto walijadiliana nanyi kuhusu kuvuka kwenda upande wa watu wazima kabla hamjaenda huko?

☐Ndio.

☐La

Kama ndio, mlijadiliana nini?

☐Kubadilika kwa siku ya kuonekana kwenye kliniki

☐Kubadilika kwa mhudumu wa afya

☐Kubadilika kwa fomu kutoka kwa ile ya watoto hadi ya watu wazima

☐ Kubadilika kwa chumba cha kuonekana

☐Mengine:

____

5. Mtoto wako anajua kuhusu ugonjwa wa kisukari alio nao?

☐Ndio

☐La

6. Kunao mpangilio uliokuwa umeandikwa ili utumiwe wakati wa mpito?

☐Ndio

☐La

☐Sina uhakika

7. Ulihusika katika kuandaa mpangilio uliokuwa umendikwa ili kutumiwa wakati wa mpito?
☐Ndio

☐La

4a. PARENTS/GUARDIANS IN THE ADULT CLINIC

Date: ___________________

Dd/mm/yy

1. How old is your child?

____

2. At what age was your child diagnosed with diabetes?

____

____

3. At what age did your child transfer to the adult clinic?

____

____

4. How long has your child been on follow up at the adult clinic?

____

____

5. Did the health care providers at the pediatric clinic discuss with you about the move to the adult clinic before it happened?

☐Yes.

Please explain.

____

____

____

____

☐No

6. How did the transfer process to the adult clinic happen? Please explain.____

____

____

____

____

____

____

____

7. Did any health worker at the pediatric clinic discuss with you about follow up at the adult diabetic clinic?

☐Yes

☐No

If yes, was any of the following discussed?

Change involving any one or all of the following:
☐Clinic
☐Day of visit to the clinic
☐The health care provider
☐Dosage of the insulin that you are using
☐The patient encounter form from the pediatric to the adult form
☐Consultation room
☐Other

8. Was there a written plan for your child's transitioning?

☐Yes
☐No

9. Was your child informed of his/her diagnosis before transitioning to the adult side?

☐Yes
☐No

10. Were you involved in preparing the transitioning plan?

☐Yes
☐No

11. Was there any existing guideline used for your child's transitioning?
☐Yes

☐No

12. Did your child feel prepared to change to an adult health care provider?
☐Yes
Please explain:
____
____
____
____
____
____
____

☐No

Please explain: ____

13. Were there any difficulties that your child faced during the transitioning period?

☐Yes

☐No

If yes, were they any of the following?

☐Difficulties from the adolescents____

☐Difficulties from the pediatricians____

☐Difficulties from the adult care providers____

☐Lack of guidelines on how the transitioning should occur ____

14. What do you feel made the transitioning process easy for your child?____

15. What, in your opinion, do you feel could be put in place in order to make transitioning easier?____

____

____

____

____

16. What differences are there, if any, in terms of care between the pediatric and adult clinics?

☐Providers ____

☐Decision making____

☐Others: ____

____

____

____

____

Dodoso

WAZAZI WA WATOTO KATIKA KLINIKI YA WATU WAZIMA

Tarehe: _____________

1. Mtoto wako ana umri wa miaka ngapi?
____

2. Ugonjwa wa kisukari ulipatikana mtoto akiwa miaka mingapi?
____
______

3. Mtoto wako alianza kufuatiliwa akiwa miaka mingapi katika kliniki ya watu wazima?
____
____

4. Mtoto wako amekuwa kwenye kliniki ya watu wazima kwa muda gani sasa?
____
____

5. Wakati wa kuvuka kwenda kwa upande wa watu wazima nini kilitendeka? Tafadhali fafanua.____
____
____
____
____
____
____
____

6. Madaktari kwenye kliniki ya watoto walijadiliana nawe kuhusu kuvuka kwenda upande wa watu wazima kabla haujaenda huko?

☐Ndio.

☐La

Kama ndio, mlijadiliana nini?

☐Kubadilika kwa siku ya kuonekana kwenye kliniki

☐Kubadilika kwa mhudumu wa afya

☐Kubadilika kwa fomu kutoka kwa ile ya watoto hadi ya watu wazima

☐ Kubadilika kwa chumba cha kuonekana

☐Mengine:

____
____
____
____
____
____
____
____
____

7. Mtoto wako alikuwa anajua kuhusu ugonjwa wa kisukari ulio nao kabla ya kupita kwenda upande wa watu wazima?

☐Ndio

☐La

8. Kulikuwa na mpangilio uliokuwa umeandikwa ili utumiwe wakati wa mpito?

☐Ndio

☐La

9. Mtoto wako alihusika katika kuandaa mpangilio uliokuwa umendikwa ili kutumiwa wakati wa mpito?
☐Ndio

☐La

10. Kuna mpangilio wowote uliotumika wakati wa mpito?

☐Ndio

☐La

11. Unaona kama mtoto wako alikuwa tayari kuvuka kwenda upande wa watu wazima?
☐Ndio
Tafadhali fafanua:

____
____
____
____
____
____

☐La

Tafadhali fafanua:

____

____

____

____

____

____

12. Mtoto wako alipata shida zozote wakati wa kuvuka kutoka upande wa watoto hadi wa watu wazima?

☐Ndio.

Zipi?

____

____

____

____

____

☐La

13. Kuna mambo yoyote yaliyofanya mpito uwe rahisi kuliko vile mlitarajia?

____

____

____

____

____

14. Ni mapendekezo yapi ungetoa ili kuboresha mpito kutoka upande wa watoto hadi wa watu wazima?____

____

____

____

____

5. QUESTIONNAIRE FOR HEALTH CARE PROVIDERS

Date:______________

1. Designation

☐Pediatrician

☐Internist

☐Medical Officer

☐Clinical Officer

☐Nurse

☐Other: ____________________________________

2. Clinic Currently Working at

☐Adult

☐Pediatric

3. Length of time worked at the clinic

___________________________months

4. At what age do adolescents transition from the pediatric to adult care?
____
___

5. What do you understand by the term " transitioning'?____
____
____
____
____
____
____

6. Have you ever moved an adolescent with diabetes from the pediatric to adult clinic?

☐Yes

☐No

7. If yes to the above question, how did you move the adolescents from the pediatric clinic to the adult clinic? ---

8. Which of the following have you ever done for the adolescent. Changed the adolescent's:

☐Clinic

☐Clinic day

☐Insulin dosage to adult

☐Encounter form from the pediatric to the adult form

☐Consultation form

☐Clinician attending to them at the clinic

☐Other

9. Was there a written plan for the child's transitioning?

☐Yes
☐No

10. If yes to number '9', is the plan individualized for each patient?

☐Yes

☐No

11. Is the adolescent informed of his/her diagnosis before transitioning to the adult side?

☐Yes
☐No

12. Is there a policy that guides on transitioning?

☐Yes

Please explain.

____
____
____

☐No

13. Are there any criteria for selection of those who should be considered for transitioning?

☐Yes
  ☐Age
  ☐Glycemic control
  ☐Ability to administer insulin by themselves

  ☐Other

Please explain:

____
____
____

☐No

14. Is there any discussion that is held with the adolescents and their care givers in order to prepare them for transitioning?

☐Yes. Please explain.

____
____
____

☐No

15. Do you set specific dates when transfer to the adult care will occur?

☐Yes____

How long before the intended day of transfer is the date set?

☐1-6 months

☐5-12 months

☐> 1 year

Is it in consultation with the adult care providers?

____

☐No

16. Do you prepare medical summaries that are given to the patients and the adult care givers before the transfer to the adult side?

☐Yes

☐No

17. Is there follow up done after transfer to find out how the adolescents fare on in the adult side?

☐Yes
Please explain.

____
____
____

☐No

18. How come there is no payment for equipment (glucometers and strips) on the pediatric side while they pay for the same on the adult side?-------------------------
---
---

19. Why do you think the adolescents feel that the pediatricians are friendlier than the physicians?---
---
---

20. How come patients in the adult clinic take a longer time before they see the doctor compared to the pediatric clinic?---
---

Appendix VIII: FGD Guide For Adolescents In The Pediatric Clinic

1. What is your understanding of "transitioning from the pediatric to the adult clinic"?
2. How ready are you for transition to the adult clinic? Please explain
3. What do you think is the best time for transitioning to the adult clinic?
4. What are some of the fears of transitioning to the adult clinics?
5. What can be put in place to make the transition process acceptable amongst the adolescents?
6. Have you discussed about transitioning to adult service with:
   - Health care workers
   - Care givers

   If yes what did you discuss about?

7. What are some of the barriers to successful transitioning?
8. Is there anything else about transitioning that you would like to tell us?

Appendix IX: FGD Guide for Adolescents in the Adult Clinics

1. What happened when the time came for you to be followed up at the adult clinic
2. What was the process like?
3. Did any health worker at the pediatric clinic discuss with you about follow up at the adult diabetic clinic?

   Probe on what was discussed.
4. a. Was there a written plan for your transitioning?

   b. Were you involved in preparing the transitioning plan? Please explain
5. Were you informed of your diagnosis before transitioning to the adult side? Please explain
6. Was there any existing guideline used for your transitioning?
7. Did you feel prepared to change to an adult health care provider?
8. Were there any difficulties that you faced during the transitioning period?
9. What do you feel made the transitioning process easy for you?
10. Were there any benefits that you would associate with transitioning?
11. What would you like improved in the process
12. What differences are there, if any, in terms of care between the pediatric and adult clinics?
13. Is there anything else about transitioning that you would like to tell us?