FAMILY CAREGIVERS PERCEPTION, STRATEGIES AND CHALLENGES IN MEETING NUTRITIONAL NEEDS OF PATIENTS ATTENDING MAINTENANCE HEMODIALYSIS AT IRINGA REGIONAL REFERRAL HOSPITAL

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By

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"A Dissertation Submitted in Partial Fulfillment for Dissertation for the Degree of Masters of Science in Nephrology Nursing of the Muhimbili University of Health and Allied Sciences"

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CERTIFICATION

The undersigned certifies that they have read and hereby recommend for the acceptance by the Muhimbili University of Health and Allied Sciences a dissertation entitled **"Family Caregivers Perception, Strategies and Challenges in Meeting Nutritional Needs to Patients Attending Maintenance Hemodialysis at Iringa Regional Referral Hospital''** in partial fulfillment of the requirement for the degree of Master of Science (Nephrology Nursing) of the Muhimbili University of Health and Allied Sciences

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DECLARATION AND COPYRIGHT

I, **Steven P. Dudiyeck**, declare that this dissertation is my original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature …… Date: ……

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DEDICATION

I dedicate this dissertation to God Almighty my creator, strong pillar and source of my inspiration, wisdom, knowledge and understanding. I dedicate the work to my beautiful daughter Joan Steven Pascal for her daily caring and support during the entire period of my studies. I intentionally dedicate this work to my family, and my parents for good parenting and education foundation that has brought me to this level. The Lord continues to bless them abundantly and long living lives with good health, Amen.

ABSTRACT

Background

Malnutrition is common in patients with chronic kidney disease (CKD). A higher risk of infection, cardiovascular disease, and metabolic changes, all of which raise morbidity and mortality are linked to malnutrition. Family caregiver help patients prepare food and support their adherence to the prescribed diet. Thus, it is crucial to investigate family caregivers' experience in providing nutritional care to hemodialysis patients.

Aim

This study aims to explore family caregivers' perception, strategies and challenges in meeting nutritional needs of hemodialysis patients at Iringa Regional Referral Hospital.

Methods

An explorative qualitative study design was used to explore the caregivers experience in providing nutritional support to the patients undergoing maintenance hemodialysis. Family caregivers were selected using non-probability purposeful technique guided by saturation principle. In-depth interview was carried out, the interviews were audio recorded and transcribed. The data was analyzed using thematic approach that is familiarizing with data, generating initial codes, searching for themes, reviewing themes, naming themes and report writing.

Results

Family caregivers reported to provide nutritional support to patients undergoing maintenance hemodialysis based on their common experience and by using different printouts and posters given to the patients. On perception participants reported dietary recommended, diet restricted, fluid modification and benefits of adhering recommended food, participants reported to utilize four strategies in nutritional care including meal preparation techniques, eating of produced food, handling communal eating and drinking, assessing adherence to dietary

recommendation. Additionally, caregivers reported to face four barriers in providing nutritional care. These barriers are inadequate understanding, financial constraints, and overzealous restriction during supportive nutritional practices. They expressed the need for government support, nutritional education, and reduced cost of treatment.

Conclusion and recommendation

Family caregivers play great role in provision of nutritional support to patients attending maintenance hemodialysis. Caregivers are resourceful as a link to provide nutritional care as they spend much time with patients and they directly involve with provision of care. Additionally, caregivers are the bridges to link patient's problem directly without errors to the health care providers like doctors, nurses and dietitians to meet patient's needs. Health care providers need to provide the family caregivers with knowledge concerning kidney diseases in nutrition care to improve the quality of hemodialysis patients.

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LIST OF ABBREVIATIONS

CKD	Chronic kidney disease
ESKD	End Stage Kidney Disease
GI's	gastrointestinal infections
HD	Hemodialysis
IRRH	Iringa Regional Referral Hospital
LMICs	Low Middle Income Countries
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
STD VII	Standard seven

DEFINITION OF TERMS

Family caregivers are relatives who have a close personal relationship with a patient suffering from chronic illness and offer a wide spectrum of support. Or rely on non-professional health care providers, such as family and friends to manage the long-term condition throughout the trajectory of the disease(Tong et al., 2008).

Hemodialysis consist a complex procedure for patients that require frequent hospital or dialysis centers visits, mainly three times a week, thus implying substantial changes in the normal way of patients' living(Gerasimoula et al., 2015).

Nutritional care is the process that involves distinct, inter-related steps that should be provided in the systematic sequences; it implies basic duty to provide adequate and appropriate food and drinks to patients(Cardenas et al., 2019).

End stage kidney disease is a chronic disease that exerts a great negative impact on patients' health-related quality of life mainly due to the accompanied impairment or to the imposed limitations in almost all domains of their daily lives(Gerasimoula et al., 2015).

CHAPTER ONE

1.0 BACKGROUND AND INTRODUCTION

1.1 Background

Chronic kidney disease is a global public health problem. Patients suffering from chronic kidney disease (CKD) have various comorbidities such as hypertension and diabetes mellitus(Rashid et al., 2021a)**.** Over 752.1 million individuals worldwide are impacted by CKD, which also causes 2.1 million fatalities annually(Cockwell & Fisher, 2020)**.** The prevalence of CKD is rising and disproportionately affecting low and middle income countries(LMIs), where there is a deficiency in early identification of the disease(George et al., 2017)**.** According to estimates, the prevalence of CKD in European nations ranges from 3.3% to 10.4%. In Asia, CKD is estimated to affect about 33.3% mostly in China and India. In Africa 10.1% are estimated to suffer from CKD, according to the systematic review data of CKD patients, it shows the prevalence reported to be low in Northern African countries at about 4%, and the prevalence is reported to be higher at Western/central African countries about 16.5%(Id et al., 2018). In Tanzania, a community-based studies revealed variable prevalence of CKD ranging from 2.3% to 12.4%(P. K. Bramania & Furia, n.d.). A study conducted in Mwanza reported prevalence of CKD to be 2.3% in rural areas, and 7.4% in towns, and was associated with lower physical activity, hypertension, older ages, and affluent lifestyles (Peck et al., 2016)**.** Additionally, the study carried out in Kisarawe, a rural district of Tanzania, estimated that 12.4% of people had CKD stage III, IV, and V. Notably, CKD stage V prevalence was highest among young people(Ploth et al., 2018).

Malnutrition is the widespread and serious complication of end-stage kidney disease(ESKD) and chronic kidney disease(Zha & Qian, 2017). Malnutrition is reported to affect about 42.7% of patient with chronic kidney disease(Rashid et al., 2021a). Generally, in African countries, the epidemiological data of end stage kidney disease patients with malnutrition is scarce but the prevalence is estimated to be 13.6%(Id et al., 2018). Furthermore, the research conducted in Cairo, Egypt reported that malnutrition is high among CKD patients on hemodialysis which was categorized to moderate which was 50% and severe malnutrition was about 17%(Zaki et

al., 2019). In Tanzania CKD malnutrition was categorized to severe malnutritious patients which was about 1.9% and patients those are underweight accounted about 16.9%(P. Bramania et al., 2021). Malnutrition is very common among hemodialysis patients at Muhimbili National Hospital, especially those on longer duration of hemodialysis, and diabetic patients. It is recommended that hemodialysis patients should be regularly assessed for malnutrition and appropriately treated which if left unattended heralds worse outcomes(P. Bramania et al., 2021).

Malnutrition is multi-factorial disorders that affect both dialysis patients and non-dialysis patients. Low social and economic status, decreased appetite, low dietary food intake, delay in medical attention and satiety are associated with malnutrition(Ameh et al., 2016)**.**The impacts of malnutrition on people with end-stage kidney disease include decreased muscle function due to fat depletion, inflammations, uremia, hormonal imbalance, mineral bone diseases, metabolic derangement(Zha & Qian, 2017)**.**

Management of malnutrition in patients with CKD requires both combined and distinctive approach. The renal dietitian is required to assess and manage the nutritional issues in patients with CKD. Other members include the nephrologist, social workers, caregivers and clinicians. According to quality of service in patients undergoing hemodialysis, CKD patients need to be free from stress, decreased physical activity, social isolation, fear and stigma(Morais et al., n.d.). Health care providers should prioritize patient-centered care by paying attention to their preferences and requirements. This will facilitate and improve treatment planning to preserve patient's health and give them comfortable and satisfying hemodialysis experience.(Vafaei & Nobahar, 2017).The role of family caregivers to CKD malnutrition patients is to ensure their patients do not develop other comorbidity and adhere to dietary recommendations, providing holistic care, mental health, emotional support, personal hygiene, meals preparation, providing prescribed medicine(Ebadi et al., 2018). Finally, careful and continuous monitoring of nutritional care is essential for sustaining lives(Iorember, 2018).

Currently nurses and other health care providers provide nutritional education to care givers and patients with CKD who are on hemodialysis. However, it not yet explored on how such

nutritional educations has implications to care giver understanding of the importance of nutrition to the patients' outcome. Furthermore, exploring care givers' experiences is crucial in providing an insight of their roles, practices and barriers encountered during provision of nutritional support to their patients who are undergoing hemolysis(Salehitali et al., 2018).

1.2 Problem statement

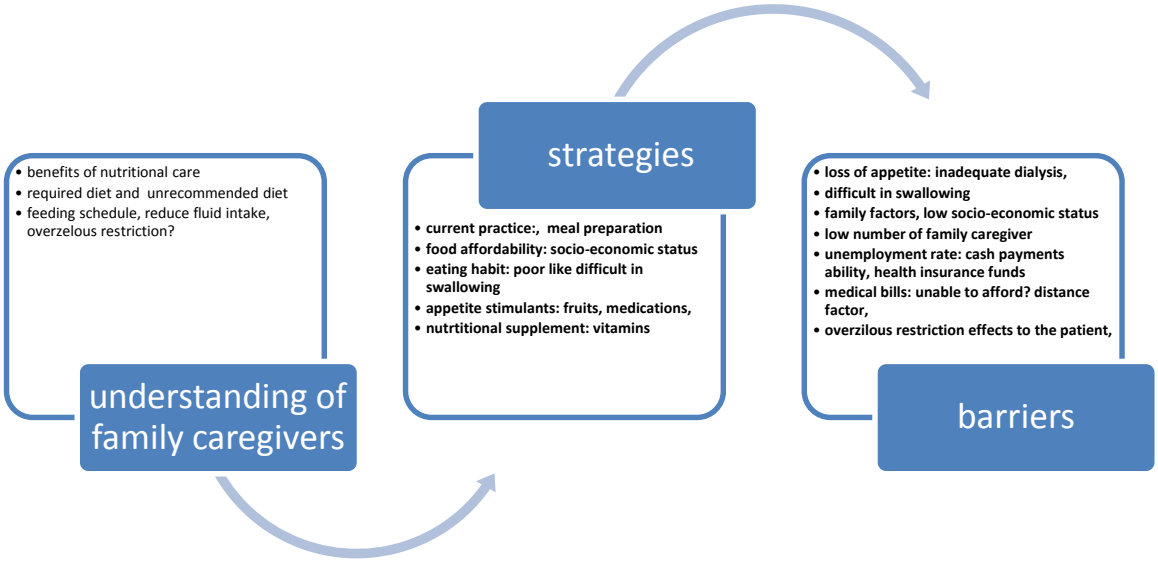
Malnutrition due to its devastating consequences in terms of quality of life, morbidity, hospitalization and mortality, it affects 42.7% of end stage kidney disease patients worldwide(Rashid et al., 2021a). In Asia, India 56% of end stage renal disease patients are malnourished(Rashid et al., 2021a). In Africa, the study carried out in Nigeria on comparing CKD patients on hemodialysis to CKD patients who not yet commenced in hemodialysis over 6 months, report showed that those CKD hemodialysis patient are highly malnourished compared to CKD patients who not yet commenced on hemodialysis(Liman et al., 2015). Low-middle income countries host large number of end stage renal disease patients with malnutrition(George et al., 2017). In Tanzania 61.2% of patients suffering from end stage kidney disease were found to be malnourished(P. K. Bramania & Furia, n.d.).

Several interventions are current in place within health facilities to optimize nutrition status among patients undergoing hemodialysis(Hajira et al., 2013). However, it is not yet clear on how such nutritional education is adopted and implemented at family level to ensure continuum of nutritional care and hence patients' optimal nutritional status(Mcdonald et al., 2014). Most of the previous studies highlighted the roles of health care providers in ensuring optimal nutritional status of the patients undergoing hemodialysis (Benjamin, 2021). Involvement of family caregivers in planning for provision of nutrition support is important to ensure continuum nutritional support at home(Gerasimoula et al., 2015). However, for maximum involvement their perceptions on patient's nutritional needs, feeding practices and means on how to support and meet those nutritional needs should be examined(P. Bramania et al., 2021). Because we don't have data showing caregivers in the country involving hemodialysis patient this study will explore family care givers experience in providing nutritional care to their patients undergoing hemodialysis.

The study is expected to provide existing gaps and barriers as well as opportunities to integrate family caregiving toward improving nutritional care support to CKD patients attending maintenance hemodialysis.

1.3 Conceptual framework

This study is adopting Loretta William's theory of dynamic caregiving. According to Loretta care giving is providing care for daily needs of some people that is unable for themselves. It involves addressing the physical and psychological need to promote continuous support and attention and mostly this occurs in the home. According to the theory, the concepts of this theory are commitment, expectation, management and negotiation. Through these concepts caregiver has the responsibility to make life changes according to patient's priority. Patients with chronic kidney disease on maintenance hemodialysis are recognized to get enough care and measures in their lives. Also, the theory reflects on what caregivers need to provide to their patients for example in meal preparation for example ways of cooking vegetables for removing high potassium content, dietary restriction like foods containing phosphorus, potassium, high protein food, blood pressure measurements, feeding schedule maintenance and reducing fluid intake. On adherence to this, they should base on current practice especially in food preparation, eating habit through dialysis as the source of improving appetite, food affordability cost especially for types required by CKD patients, fruits, overzealous, appetite stimulant like use of multivitamins and nutritional supplement provision. By addressing all these also theorist has linked them with the challenges or barriers to adhere like loss of appetite due to inadequate dialysis, diet restriction and medical bills for payment either cash or insurance funds, difficult in swallowing due to GI's problems, depression, social economic status of the family, unemployment rate for most of the families in affording services and low number of family caregivers worrying for decline in production activities and incomes. This theory was preferred because it can be applied in interviewing the caregivers on nutritional care to the patient of CKD attending maintenance hemodialysis. This theory predicts that it might be helpful if family caregivers are involved in care making decision of the hemodialysis patients.



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Figure 1: Lorreta William theory of dynamic caregiving

1.4 Rationale of the study

Family care givers plays big role in taking care of their patients attending hemodialysis hence it is important to be aware of the nutritional care, so that they can identify patient's needs and to adopt them for healthier diet for better health result. Nutritional health is important to hemodialysis patient to ensure a well-balanced diet tailored to the needs of dialysis patients is crucial for managing their health, supporting their treatment, and enhancing their quality of life**. To** fulfill this, it is crucial to explore their experiences in providing nutritional need to hemodialysis patients. The information gained will be useful in knowing the practice and strategies employed by family caregivers in providing nutritional needs to hemodialysis patients if it is useful to be copied or not, helpful in revealing barriers encountered by family caregivers in caring CKD hemodialysis patient also the information gained will be helpful in establishing good rapport for further studies to be conducted in other regions of the country to see comparison and more details on nutritional care to hemodialysis patient to make systematic review of the data.

1.5 Research questions

1.5.1 Broad research question

What is the family **caregiver's perception, strategies and challenges** in meeting nutritional needs to Hemodialysis Patients at Iringa Regional Referral Hospital?

1.5.2 Specific research questions

i. What is **the perception** of the family caregivers of the patients attending hemodialysis on nutritional needs of their patients at Iringa Regional Referral Hospital?
ii. What are the strategies employed by family care givers in supporting dietary adherence to patients attending hemodialysis at Iringa Regional Referral Hospital?
iii. What are the challenges encountered by family care givers in meeting nutritional needs to patients attending hemodialysis patients at Iringa Regional Referral Hospital?

1.6 Research objectives

1.6.1 Broad objective

To investigate family caregivers' perception, strategies and challenges in meeting nutritional needs to hemodialysis patients at Iringa Regional Referral Hospital.

1.6.2 Specific objectives

i. To explore family care givers perception of the nutritional needs of patients attending hemodialysis at IRRH.
ii. To describe strategies employed by family care givers in supporting dietary adherence to patients attending hemodialysis at Iringa Regional Referral Hospital.
iii. To explore challenges encountered by family care givers in meeting nutritional needs to patients attending hemodialysis patients at Iringa Regional Referral Hospital.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Family caregivers perception on requirements and feeding practice

Family caregivers understanding on nutritional needs toward hemodialysis patient is important and mandatory in improving lives of the patient among CKD patient(Matthews et al., 2022). Most of the studies conducted were based on knowledge and experience among health care providers and patients themselves while caregivers as the crucial part of care were excluded(Sumari et al., 2023)**.** The goal of providing hemodialysis patients with the necessary nutrition should be achieved through the use of various interventional strategies. In cases where patients are unable to manage their own care, family caregivers are accountable for providing nutritional support to those individuals. In order to extend the lives of hemodialysis patients, health care professionals such as dieticians, clinicians, and nurses should educate caregivers about nutrition(Belasco & Sesso, 2002)**.** To help their patients to achieve dietary regulation, they ought to continue offering ongoing counseling, because they interact directly with their hemodialysis patients, family caregivers should receive nutritional education on their patients(Lee et al., 2016)**.**

To emphasize on the part of understanding, India is the top-ranking nation with the highest frequency of malnutrition linked to CKD patients(Rashid et al., 2021a). This would imply that the individuals who provide hemodialysis care are not well versed in meeting nutritional needs of hemodialysis or CKD patients. The medical staffs must emphasize or give nutritional care instructions to the caregivers because they are actively involved in the patient's care. India has the highest incidence (14.75%), followed by Brazil (8.19%)(Rashid et al., 2021b). The results indicated that the prevalence of CKD associated malnutrition was higher in developing countries with growing economies, Mexico, at 73.7%, Jordan, at 61.7%, and India at 56.7% than in developed nations such as Australia (19.7), Europe (18.2%). In India, the prevalence of malnutrition was also higher as compared to its neighbor countries such as China 37.9%, and Iran 28.3%(Rashid et al., 2021b)**.** The reason for that malnutrition associated with CKD has been suggested in this study has been socio-economic reason, education status, and delay of

reporting problem to the available medical facilities, no direct involvement of relatives while family caregivers are responsible to give out the truth on that(Rashid et al., 2021).

Family caregivers can be valuable information sources for formal caregivers to plan treatment for chronically ill patients who are mainly cared for at home. The present results can help us increase the existing knowledge on the impact of end-stage kidney disease and hemodialysis on the patients' quality of life. It seems that addressing the issues related to quality of life, mentioned by the caregivers, can positively affect the patients' quality of life and even reduce the caregivers' burden according to study conducted in Tehran-Iran(Hejazi et al., 2021).

Iranian researchers undertook a study to learn more about the private lives of persons who provide care to hemodialysis patients. The result of this study demonstrated an increase in the burden of life related to providing care of hemodialysis patients, and they emphasized the necessity for the government and health policy makers to support these people in lessening this burden. It should be remembered that that patients attending hemodialysis are psychologically not proper and mostly who take care of that are family care givers and this implies that both patients and care givers are supposed to attend to hospital for hemodialysis and this is increased work load while production of other social needs decrease, as the most of the time they spent taking care of their patients. The study reveals that hemodialysis is expensive and requires frequent attendance, leading to life instability for the patient(Ebadi et al., 2018). Also, according to subjective global assessment, the protein energy wasting is high among ESRD patients and the result was 23% moderate, 5% severe malnutrition hence this was associated with increase in mortality rate(Mutsert et al., 2009). Locally there is no systematic review data of all region in Tanzania but according to two studies conducted at Dar es salaam at MNH to the patients on maintenance hemodialysis with malnutrition inflammatory complex shows that 46.3% moderate, 24.1% mild in moderate and 21.9% severe(P. K. Bramania & Furia, n.d.).

Another study carried out at Dar es Salaam's Muhimbili National Hospital, the patients with chronic kidney disease (CKD), those undergoing long-term dialysis, and those with co-existing conditions like diabetes mellitus are all susceptible to malnutrition. In order to avoid

complications from CKD, extra effort needs to be made to raise awareness among those who provide care for patients who attend hemodialysis. Even though there are many reasons why hemodialysis patients become malnourished, maintaining optimal nutrition seems to be difficult. These patients need a thorough evaluation and customized treatment plans that may include oral supplements, appetite stimulants, sufficient hemodialysis, dietician advice, and other medical treatments. All family caregivers need to be instructed in this matter(P. Bramania et al., 2021).

2.2 Strategies employed by family caregivers on adhering nutritional needs to CKD hemodialysis patients

An individual providing care may experience instability and ambiguity in their personal life. Therefore, more attention should be paid by government, legislators, non-governmental organizations, and health care providers to assist these individuals. When it comes to hemodialysis patients, the majority of family caregivers are typically housewives, husbands, and sons or daughters. It appears that there is imbalance in the lives of these family caregivers when it comes to the affordability of hemodialysis because of these differences in life status, which has caused psychological and financial distress among family members. Nephrologists, nurses, clinicians and dietitians should be responsible to encourage family caregivers in taking care of their patients so as to prevent them from anxiety, depression and discomfort(Ebadi et al., 2018).

The study, which was implemented in Singapore, intends to educate hemodialysis patients and caregivers about the mechanism and viewpoints that are explored. Reports state that the caregivers were informed about every aspect of their patient’s health, including appetite and eating patterns. Even though it was making the patients depressed, they have tried to calm their patients when they are in that situation. Additionally, they mentioned that a few of their patients felt emotionally uncomfortable, which may indicate that they did not accept their situation. Consequently, when these patients expressed dissatisfaction, they tried to make them happy. Due to the priority placed on their health, patients did not become agitated (Lee et al., 2016).

Additionally, in a different Singaporean study that looked at cultural perspectives on the factors that encourage and hinder treatment compliance. They also mentioned that patients were required to attend hemodialysis three times per week so they could receive instruction on dietary management and exercise, and this was very important in patients' decision-making on disease management. Family caregivers of that country were involved in patients' self-decision on disease management because it was part of their cultural heritage (Griva et al., 2013) .

When hemodialysis patients with end stage renal disease were examined for compliance with dietary advice, it was suggested that the methods used to support the patients included giving them nutritional information, having them attend nutritional counseling, making the counseling services affordable and convenient, and having a conversation with a health care provider about dietary adherence in Dar es Salaam, but for patients who were extremely sick, caregivers were not taken into consideration(Benjamin, 2021).

2.3 Challenges encountered by family caregivers

Hemodialysis is a crucial treatment for patients with end stage-stage kidney disease, but not all family caregivers are able to take advantage of this opportunity because of the high expenses of care, time commitment, and decline in economic and production activity, medical necessity, and payments. The reason it is tiresome is that most family caregivers are female, and most families have kids. Family caregivers bear a burden when their loved one needs hemodialysis because most patients need special diet and treatments, which require continues care and coping mechanisms. Nurses should provide an appropriate knowledge regarding hemodialysis and complications, how to help patients on hemodialysis to cope with the situation to decrease burden on family caregiver and improve outcome of the patients' care.

In support of this, the study conducted in Brazil at St. Sao Paulo, husbands/wives encountered the majority of the difficulties faced by family members who provided care for patients receiving hemodialysis. Unemployed caregivers when compared to non-caregivers, some of them experienced mental health issues like depression and psychiatric disorders. They also dealt with chronic illnesses and the need for treatment. The main factor affecting the majority of caregivers was their socioeconomic situation (Belasco & Sesso, 2002).

In a study conducted in southern Ethiopia, caregivers for the families of hemodialysis patients were the focus. This study set out to explore experiences of southern Ethiopian primary family caregivers for hemodialysis patients. Family caregivers had to deal with issues like emotional instability and outbursts, caregiver's exhaustion, health-related distortions, financial constraints, and societal harm.

Locally, the study's finding revealed that about half of the participants did not adhere to the suggested diet. Additionally, studies indicated that permanent residency significantly impacted dietary adherence, leading researchers to surmise that person's place of residence would have an impact on the variety of foods available, and the family caregivers seems to be responsible on that, the rate of unemployment makes people even poorer, which would make CKD patients disregard dietary recommendations (Benjamin, 2021). At MNH the challenge is, there is no study conducted to the caregivers but it was only for patients and the result shows that long term hemodialysis patient mostly suffered from malnutrition and they should be treated to avoid herald outcomes if left untreated (P. Bramania et al., 2021).

CHAPTER THREE

3.0 STUDY METHODOLOGY

This chapter presents the study design, study area, study population, sample size determination, sampling procedures and methods that were used to generate and analyses data.

3.1 Study design

This study used a qualitative approach with exploratory study design. The research approach and design was chosen due to the nature of study that focuses more on exploring the lived experiences of participants rather than quantifying the problem under study. The researcher wanted to gather and analyses information regarding the experience of the family caregivers of the patient undergoing hemodialysis on meeting nutritional needs. Information regarding caregivers' perceptions of nutrition needs, strategies employed in supporting dietary adherence as well as challenges encountered in meeting nutrition needs of their patients on hemodialysis is scarce. Therefore, the choice of this study design was appropriate as it provides the researcher an ability to generate thick description of the lived experience of family caretakers who are directly involved in taking care of patients undergoing maintenance hemodialysis at IRRH. Furthermore, the qualitative exploratory method give the researcher an opportunity to probe more on participants and allow participants to be free in providing responses as they reflect from their experiences on caring patients undergoing maintenance hemodialysis. Through this approach, the researcher was able to elicit emerging issues that could not be captured with other research study approaches like quantitative approach.

3.2 Study setting

The study was conducted at at Iringa Regional Referral Hospital (IRRH). The selection of the site was based on the following reasons; IRRH- is a regional referral hospital that receives patients from Kilolo, Mufindi, and Municipal, Iringa districts hospitals as well as other nearby regional hospitals. IRRH offers a specialized inpatient and outpatient services to patients with various medical and surgical conditions including renal services. The hospital has a total capacity of 400 beds for inpatients. The IRRH has been providing hemodialysis for more than a year. The hemodialysis is equipped with ten working hemodialysis machine, ten beds with tables and chairs. The unit offers dialysis treatment to about 20 patients with an approximate of seven patients per day. The dialysis unit has 6 nurses and 3 medical doctors. The dialysis services are conducted once per day daily that is only one shift per day unless there is emergency dialysis. Caregivers cooperate well with health care providers in every matter concerning dialysis; most of the caregivers are peasant and civil servants.

3.3 Study population

The study population in this study was family caretakers of patients receiving hemodialysis therapy at Iringa Regional Referral Hospital.

The total number of patient receiving dialysis is 20 patients and almost all patients are accompanied by family caretakers during hospital visit for dialysis. Family caretakers usually are present during the whole course of hemodialysis process and are involved in care taking process both at hospital and at home. Therefore, such family caretakers are the key players in providing care for these patients; hence their experiences on meeting nutrition needs can be explored to gain insight into areas that need improvement.

3.3.1 Inclusion criteria

The study included closely related family caregivers of the patient’s attending hemodialysis for more than three months and aged above 18 years. The closely related family caregivers including blood related caregivers.

3.3.2 Exclusion criteria

This study excluded family caregivers who are not closely involved in care giving below three months of dialysis and those of aged below 18 years. Additionally, those who cannot speak and mentally unfit were excluded.

3.4 Sample size

The sample size for this study was not predetermined. This is because in qualitative study is difficult to determine the sample size prior to the actual study. Instead, the final sample size of the study is determined by the principle of **saturation (Polit, D.F. and Beck, 2004).**The saturation point determined the sample size of the study after the participants started to provide almost the same information. Hence, in this study I stopped to recruit participants at 20^{th} interviews after noting no new information on the phenomenon being explored is generated from subsequent interview.

3.5 Sampling technique

Participants for study were selected purposively. This means, the participants were selected according to their experience of taking care for hemodialysis patients for at least three-months of attending dialysis. To ensure the patients were well represented, the researcher selected participants who were believed to be best positioned to provide data required for the study. To ensure maximum variations, study included family caregivers who are both male and females, with different levels of education from those who have never been to school (informal education), the one with primary, secondary, diploma, and degree level of education. To avoid selection bias participants were targeted and given equal chance of participation to the study.

3.6 Data collection tool

Interviews were conducted using interview guide that had set of pre-determined questions and followed by probing questions. The guide comprised two sections; that is demographic description of the participants and another section involved open ended questions with a probing question to obtain detailed information. The interview question was prepared by a researcher following a thorough literature review and in consultation with supervisors. The

developed English tool was being translated to Swahili to make the questions and probes more understandable, clear and addressed intended study objectives.

3.7 Data collection method

Data was collected for a period of one month from April to May, 2024 .The family caregivers who agreed to take part in the study were contacted to schedule an interview. Before conduction of the interview the participants were asked sign the consent. The interview was conducted by the principal investigator using face-to-face in-depth interview guide. The interview was conducted at private quite room. An interview was carried out and digital audio record was used. The investigator has been interviewing the participant while the assistant investigator has been recording and taking field notes and additional observation in the notebook. In order to maintain confidentiality and privacy, the interview took place in the quite-private room to ensure privacy. An interview lasted for about thirty to sixty minutes. A researcher listened to the initial data and tries to identify important aspects and concepts that need clarification and deep understanding in the next interview.

3.8 Data management

All information and collected data and observation were confidential. To achieve this, participants were provided participation numbers with S and number from S1 to S20 instead of providing real names of the participants. Audio records stored in the password secured computer which was accessed by the researcher only. Notebook with noted observation was safely stored by a researcher to avoid other people who are not involved in the study to access any data or information about the study.

3.9 Data analysis

Data analysis begun during data collection; the first interview was transcribed and discussed with supervisors to identify whether there was a gap in interview conducted. After each data collection, the interview was transcribed and initial codes were generated. The process continued, and all codes generated again were then discussed with supervisors and allowed to proceed with the next step. The initial codes generated from all interviews were then organized by excel and grouped into similar codes to form subthemes, then themes. This is

thematic analysis that involved both deductive and inductive approach in which deductive approach was applied first and followed by inductive. In collaboration with supervisors, refining and remaining of the themes were done, and report writing began after following the six steps of thematic analysis. Generally the data was analyzed using thematic approach that is familiarizing with data, generating initial codes, searching for themes, reviewing themes, naming themes and report writing.

3.10 Ethical consideration

The Muhimbili University of Health and Allied Sciences Senate of Research and Publication provided ethical permission for the research to be conducted. Iringa Regional Referral Hospital's Executive Director granted permission to conduct research. The researcher consulted the family caretakers of patients who were undergoing hemodialysis and informed verbally about the purpose of the study. Family caretakers who agreed to participate in the study were given an opportunity to ask questions and clarification and requested to give their consent in writing. Participants were informed of their right to any time from the study without providing any explanation. To ensure confidentiality all participants were numbered S1 to S20 in order to protect their privacy and ensure anonymity of the data.

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter presents findings from an in-depth interview with twenty (20) family caregivers of the patients undergoing hemodialysis. The characteristics of these caregivers are summarized in table 1.

4.2 Characteristics of study participants

The study recruited twenty family caregivers of the patients undergoing hemodialysis who have been taking care of the patients for at least more than three months. Twelve (12) were female and eight (8) were male participants. The age range of the participants was between 18 years old to 65 years old. Among the study participants, the youngest aged 23 years old and oldest aged 65 years old. Majority of the participants are self-employed that is peasant, drivers, small businessman. Only 4 participants had less than one year of experience in caring patients undergoing hemodialysis. No participants with informal education, among 20 participants, five (5) had the lowest level of education which is primary education. The rest had level of education from form four up to university education (Table 1).

Table 1: Social demographic characteristic of participants (N=20)

VARIABLES	VALUES	FREQUENCY (N=20)	PERCENT (%)
Age	>18-35 years	10	50
	36-65 years	10	50
Sex	Male	8	40
	Female	12	60
Marital status	Married	12	60
	Unmarried	8	40
Education level	Informal education	0	0
	Primary (std vii)	5	25
	Secondary (form iv)	5	25
	Advance level(form vi)	2	10
	College education	2	10
	University education	6	30
Employment status	Employed	5	25
	Unemployed(self-employed)	15	75
Relationship to the patient	Blood closely related	20	100
	Blood unrelated	0	0
HD patient duration of taking care	>3months to 11 months	4	20
	1 year and above	16	80

Caregivers' perception of meeting nutritional needs of patients undergoing dialysis

Three themes emerged from analysis of interviews; the themes are; Caregivers perceptions on nutritional requirements, restriction and benefit of adherence to patient undergoing hemodialysis. Strategies for achieving patients' dietary recommendation and challenges in achieving dietary adherence to patients undergoing hemodialysis. The themes and corresponding subthemes are summarized in Table 2 below.

Table 2: Themes and subthemes describing family caregivers' experience of meeting nutrition needs of patients undergoing hemodialysis

	Thematic question	Subthemes	Themes
1	What is caregiver's understanding of nutritional needs for patient undergoing maintenance hemodialysis?	• Recommended dietary requirements for patients undergoing hemodialysis • Restricted foods for patients undergoing hemodialysis • Fluid restrictions for patients undergoing hemodialysis • Benefits of adhering to dietary recommendations for patients undergoing hemodialysis	Caregiver's perception of nutritional requirements
2	What are the caregivers' strategies used to ensure patients' adherence to dietary recommendations?	•Proper and specialized meal preparation techniques •Utilizing home and community produced foods •Use of natural and medicinal additives to promote appetite •Close follow up of patient adherence to recommended diets	Employed strategies for dietary in supporting dietary adherence
3	What are challenges encountered by family caregivers in meeting nutritional needs of patients undergoing maintenance hemodialysis	• Inadequate understanding on dietary requirements • Financial constraints in meeting cost for recommended diets • Handling patient's overzealous dietary restriction • handling complex dialysis schedule to the patients undergoing hemodialysis	Challenges encountered in ensuring dietary adherence

4.3 Caregiver's perception on nutritional requirements

This theme explains the understanding of caregiver's on nutritional modification required for patients who undergoing hemodialysis. The Theme is organized into four subthemes that include Dietary recommended to the patients undergoing hemodialysis, Dietary foods restricted to the patient's undergoing hemodialysis, fluid restricted to the patient undergoing hemodialysis, and the benefits of nutritional adherence to patients undergoing hemodialysis.

- **Recommended dietary requirements for patients undergoing hemodialysis**

Participants of this study reported the necessity of nutritional adjustment for patients undergoing hemodialysis treatment and they reported that it depend on patient's disease condition. The adjustment was thought to be driven by the disease process and its treatment options. For example participants reported that, patients with ESKD are unable to remove nitrogenous waste products from the body, therefore they need food adjustments like eating food which does not affect their health more by not increasing toxicity in the body. They also reported that during hemodialysis treatment, patients lose nutrients through the dialyzer, so they need to consume food which retains some nutrients in the body. Therefore, nutritional adjustment was necessary for the maintenance of optimal nutritional health of the patients.

"…Most of patients undergoing hemodialysis, they are considered as the patients reached end stage in functions of their kidneys so they cannot consume everything because some other foods can result to more toxicity in their blood system…" S06

- **Restricted foods for patients undergoing hemodialysis**

Participants believed that patients with end stage renal diseases, their kidneys are not functioning so they are restricted to eat some of the foods in order to avoid accumulation of nitrogenous waste product in the body. The function of kidney is to remove those waste products and if they are not removed they make condition of the patient more worsen. Therefore they believed that some foods are more harmful to patients than other food.

"..Patients undergoing hemodialysis are also restricted from some types of food for example red meat/beef, due to high protein content and some fruits like watermelon due to the reason that they can add more water while kidney tends to fail in removing that fluid in the body…" S01.

- **Fluid restrictions for patients undergoing hemodialysis**

Participants described that, the kidney is involved in ensuring balance of the fluid in the body. According to participants the kidney disease leads to kidney failure that causes a patient fail to balance fluid. Participants reported that due to kidney failure, their patients have to drink little amount of water. They further mentioned that their patients are required to drink one liter of fluid per day. According to participants, this one liter per day comprises of all fluids including tea, juice and water. To ensure this is adhered, participants used to remind their patients on the need to restrict excessive use of fluid

"..I know that patient does not urinate at all, so I should tell him to drink water during medication and after eating only in order to avoid fluid accumulation in the body which result in swelling due to failed kidney for removing that fluid in the body…"S04

Benefits of adhering to dietary recommendations for patients undergoing hemodialysis
Participants mentioned that, there is need for patients to follow instruction for dietary intake instruction, because it help their patients to become better . Others were opinioned that, adhering to dietary recommendation contributes to relief of symptoms and overall improvement of patients symptoms. Though participants pointed out benefit of following instruction regarding dietary recommendation, some were concerned of failure to meet goals for dietary restriction given due to their social economic status. However, participants generally opinioned that adherence to dietary recommendation is advantageous to the patients undergoing maintenance hemodialysis. Participants mentioned some benefits for dietary restrictions as it can be seen in the narration below.

"…. Benefits of adhering nutritional requirements to the patient undergoing hemodialysis are many. What we are seeing once we start to adhere to dietary restrictions our patient's appetite

increases after dialysis, making patient stable and free from infection like skin infection and continuing with smaller daily activities…" S10

4.4 Strategies employed to incorporate dietary recommended food to the patients undergoing hemodialysis

This theme describes strategies that can be applied by caregivers to attain the dietary recommendation to their patients. It is divided into four subthemes; first proper and specialized meals preparation techniques to the patients undergoing hemodialysis, utilizing home and community produced foods, like maize, vegetables, use of natural and medicinal additives in promoting appetite of the patient undergoing hemodialysis, handling communal eating and drinking, and close follow up of patient's adherence to dietary recommendation to patient undergoing hemodialysis.

Proper and specialized meals preparation techniques

Caregivers explained that preparation of the meals is not different from other normal foods but the issue is preparing different food at different time, it seems like the wastage of time and disturbance to the caregivers. Participants of this study reported that meal preparation is individualized because some patients are diagnosed with more than one disease, so it depends on disease that a patient is suffering from. Most of the participants reported that, they boiled vegetables first to reduce amount of potassium, the same applied to rice and dry beans.

"…We always boil vegetable and discard first water, after that we cook it without adding tomatoes and salt but we include onions and carrots in meal preparation because some vegetables contain much potassium which is not good for kidney health, so we cook like this way…" S02

"..Brown rice cooking we wash it four times then we wait for one hour then we wash again to reduce potassium that is not good for health…"S10

Utilizing home and community produced foods

Participants in this study reported that, most of the food they produce on their farms and those foods include maize grain, vegetables and wheat. They reported that foods required to the patients are almost available but only some of the items they buy from the markets. Most of the participants reported that foods are available and affordable cost. Also, they reported to grow chicken and livestock keeping.

"...Most of the green leafy vegetables we grow them at home and maize also we grow at our farm, so there is plenty of recommended vegetables and other food that having small amount of poisonous potassium in the human body..."S07

"....White meet of chickens is recommended, so we livestock some chicken at home, in case of providing meet we use our chicken as we were told other red meats may cause negative impact to kidney of patient and lead to worse condition..." S012

Use of natural and medicinal additives in promoting patient's appetite

Participants in this study reported that it is difficult to manage patient's appetite and sometimes the appetite change can be fluctuated by other disease conditions accompanied by renal disease. In communal events sometimes there are foods and drinks that may bestow patient to enter eating or drinking unexpectedly. Hence, they reported that they always ask patient on option of foods those might be suitable for him/her to eat to improve health. For increasing patient's appetite, participants reported that, they add lemons to the food, and fruits such as water melon and oranges in small quantity, but if condition of the patient is worse they consult health care providers.

"...In improving appetite of my patient sometimes I add some lemons in vegetable and some salt to get appetite rather than letting patient with empty stomach.." S01

"...According to my understanding, patient's appetite loss sometime can be facilitated by disease condition or other disease and not only the kidney, but if he lacks appetite we provide him with tablets to increase appetite like vitamin B complex...." S03

Close follow up of the patient's adherence to recommended diets

Participants reported that, to know the patient if he/she consumed unrequired food is not easy but according to experience acquired from hospital they notice some physical changes from the body like swelling of the body, difficulty in breathing. If they notice these assume that, patient has eaten food that is not recommended or in excess amount especially fluids.

"..How can I know if my patient has taken some restricted food and drinks in the community event by assessing difficulty in breathing I can guess that patient he might have eaten something that is not required like he may have taken a lot of water." S09

"..When we attend the dialysis session nurses always can reveal that the patient has taken something in excess by measuring weight and tell us what they noticed in changes of health of my patient..."S05

4.5 Challenges in supporting dietary adherence to patient undergoing hemodialysis

This theme describes barriers experienced by caregivers in providing nutritional support to patients undergoing maintenance hemodialysis. The barriers are organized into four subthemes. First barrier is inadequate understanding among caregivers of hemodialysis patients, financial constraints among caregivers of hemodialysis patients, overzealous restrictions in handling recommended diet to hemodialysis patients, complex dialysis schedule handling measures to hemodialysis patients.

Inadequate understanding on dietary requirements

Caregivers felt that they don't have adequate knowledge about kidney disease and the failure of the kidney. They explained that they heard it from patients themselves partially and reading some posters which are inadequate in supporting nutrition to the patients they are taking care.

"...I think we need more education on what are the causes of kidney disease, symptoms of this disease and how to prevent it because most of us we don't know until somebody in the family is diagnosed as a kidney patient…" S07

"…I am sure that people afraid of checking their health, for example in the society people believes that if patient commence on dialysis he/ she might die early, I think it is due to lack of education…" S10

Financial constraints among caregivers of the patients undergoing hemodialysis

Participants commented that, dialysis service is very expensive and in the community there are so many patients dying without knowing what killed them. If the cost of service could be affordable we can get many suspects in the community. Participants explained that lack of economic support is the disaster to the health of their patient and some of the patients lack insurance, so they struggle with high cost services and others tends to disappear and die.

"…Sometimes someone can sell his all properties to attend dialysis without success, you come to hospital daily for dialysis and finally you lose all and you die, I have an experience we realized three people who we started dialysis together they died due to lack of money…"S04

"…I think most of the people we started together the dialysis service they are now no longer available and I witnessed death of three of them due to failure of daily service payment and some lacks fare to come to hospital.." S06

Handling patient's overzealous restrictions on recommended diets

Overzealous restrictions in handling recommended diet to hemodialysis patients as it involve many restriction to the diet to patients, some caregivers complained that they wonders why their patient are restricted to most of the food that contains nutrients and still they are doing dialysis and during dialysis patient can lost the remained nutrients.

"We cannot find all the recommended food at once, sometimes we buy piece of chicken to the patient because he is restricted from read meet that believed to increase potassium in the body". S01

"Due to dietary restriction my patient, some of the relatives are not cooperative so I am fighting for my patient alone to get what is needed, I think this is tedious and disturbance to patients condition because he does not fulfill required diets". S08

Handling of complex dialysis schedule

Management of complex dialysis schedule to the patient undergoing hemodialysis schedule, caregivers explained that to attend three sessions per week is not easy due to different reasons from different patients. Some of the mentioned reasons by most of the caregivers are about insurance and user fee payment.

".....Coming to dialysis needs fare to transport and we come from afar this hospital, so sometimes we miss dialysis schedule due to lack of fare and money to pay for dialysis service sometime, I think this not healthy to the patient". S13

"....For the patient staying for many hours in the machine make patient more worse without eating anything what we do is to buy him bites, this turn us out of budget as we do not have enough capital to handle other emergencies…"S10

CHAPTER FIVE

5.0 DISCUSSION

5.1 Discussion

This chapter discusses the experience of family caregivers experience in providing nutritional support the patients undergoing maintenance hemodialysis at Iringa Regional Referral Hospital. The discussion provides unique perspectives on how caregivers provide nutritional support to their patients to improve their health. It also highlights strategies and barriers in supporting nutritional needs to the patients undergoing hemodialysis.

5.1.1 Caregivers' perception in dietary modification to patients undergoing hemodialysis

Caregivers play role of advisor, supporter, and providers of nutritional care to promote patient's adherence in nutritional recommendation in order to improve health outcome. Caregivers as participants of this study reported that, patients undergoing maintenance hemodialysis experience nutritional related complications like reduced excretion of waste product of metabolism and loss of nutrients during hemodialysis treatment. To minimize this, caregivers took role of advising, supporting and providing nutritional support to improve their nutritional adherence. Health nutritional education to caregivers of these patients focuses on reducing types of food that causes much accumulation of fluid and toxic substance, electrolyte and metabolic waste product oppositely enhances intake of food that meet patient's needs. These findings relate to that of the study conducted in Singapore on perspectives and experience of caregivers of the patients undergoing hemodialysis where caregivers reported nutritional counseling and education in dietary recommendation to hemodialysis patients(Belasco & Sesso, 2002).

In provision of nutritional support, caregivers cared patients in according to their unique conditions. They provided nutritional care based on patient presenting illness. Presence of comorbid conditions such as hypertension, diabetes and gastrointestinal infection and disabilities. According to the participants in this study they reported that patients experienced

weight gaining, fluid overload after consuming foods and fluids in plenty. Also some participants in this study guess that, their patients are malnourished due to lack of appetite, loss of nutrients in dialysis machine and this is similar to the study conducted in MNH by Bramania et al, showed the same that, most of the patients commenced on dialysis for more than one year became malnourished compared to those on dialysis below one year because they lose appetite and maintaining optimal nutrition is difficult(P. Bramania et al., 2021). Clinically this implies that, nutritional health education is highly needed among family caregivers of the patients undergoing maintenance hemodialysis. Though the participants shared everything regarding nutritional needs of hemodialysis patients but still there are missing things in nutrition of these patients.

5.1.2 Strategies employed by caregivers to incorporate dietary recommendation to patients undergoing hemodialysis

In this study participants explained that, they are following nutritional recommendation given indirectly to the patient, for example in meal preparation they prepare the meal as normal food eaten as usual by family, also they cook vegetables through boiling it and discarding first water then they cook, in case of beans cooking they poured into water for four hours and then cooking follows and the most of the caregivers that prepare for food to the patients are women, or female gender compared to male. This is congruent to the study conducted in Iran by Ebadi et al, stated the same way that many caregivers for the patient who prepare food are housewives, daughters(Ebadi et al., 2018).

Caregivers utilized their normal experience by reading the printouts given to the patients despite their inadequate knowledge. The same as the study conducted in Singapore by Lee et al, reported that caregivers were involved in decision making for patients undergoing hemodialysis in terms of nutritional care, exercise during dialysis service they were provided some education on nutritional support to hemodialysis patients(Lee et al., 2016).

In handling communal eating, participants in this study suggested that they used to emphasize their patients to follow nutritional instructions in any attendance regarding community event against food available in that setting. This is consistent to the study held in Dar es salaam by

Benjamin et al, that caregivers were not informed but patients undergoing maintenance hemodialysis were given dietary advice as a method to support nutritional information and making it convenient and available for the service of hemodialysis patients(Benjamin, 2021).

In most of the African societies, care and decision making related health issue like treatment of the patients, land on the hand of family or relatives(Ebadi et al., 2018). Family caregivers are important in improving dietary adherence among hemodialysis patients. Caregivers in this study they reported that they need to be involved in decision making against nutritional support to their patients and they need health education and counseling during waiting for the dialysis patient when on machine. Family caregivers were seem as important in helping patient to compliance with nutritional care as they spend more time with the patient and they directly involve in meal preparation, finding food, eating habit, also assessing them against improper eating and changes.

5.1.3 Challenges in supporting dietary adherence to patient undergoing hemodialysis

In this study, caregivers experienced barriers like inadequate knowledge on nutritional support, financial constraint, and overzealous restriction on dietary recommendation barriers in provision of nutritional support to patients undergoing maintenance hemodialysis. Participants reported to lack adequate knowledge on nutritional support that limited them to achieve better the proper diets to provide their patients most of the participants complained that they only know few types of food e.g. brown rice and sorghum and green leafy vegetables and not more than that in depth. Participants reported that nothing more they know concerning kidney disease until one of the family member is diagnosed, they reported that they are not aware of causes, prevention of kidney disease and dietary recommended to kidney patients. This is congruent to the report from study.

In any care provision to patient, there is always cost paid or shared and in this study participants reported difficulty faced in attaining diets recommended to their patients due to financial instability among the families. Caregivers reported to fail to afford some of the foods prescribed to their patients especially those diets from markets and super markets. Most of the caregivers reported that they are peasants, non- government employees, and most of the

dietary recommended to be of high expenses from the market due fluctuations. This is consistent to the study done at Brazil stated the same, also study in Ethiopia explained the similar reason on financial instability and high expenses in services to hemodialysis patients(Belasco & Sesso, 2002). Therefore lack enough capital, unemployment and high expenses involving hemodialysis patient services hinders the provision of proper nutritional support to the patients undergoing maintenance hemodialysis.

Hemodialysis patients are mostly restricted patient with many types of food and fluid to consume. The participants in this study reported that, most of the available and easy foods are restricted, they believe that during dialysis patients lose a lot of nutrients and still they are restricted, so they don't know what does this implies concerning human health. The point of overzealous doesn't enter the caregiver's minds. Dietary restriction should involve renal dietitians who can educate relatives and advantages and disadvantage should also be taught to them as they reported. In the studies(P. Bramania et al., 2021),(Benjamin, 2021) report in dietary restriction or overzealous relate the same. Additionally, it seems that most of caregivers only known quantity of food given to the patients is fist size but it is advised that patient can eat food frequently but in small amount.

Generally, caregivers felt their provision of nutritional support to hemodialysis patients were inadequate and expressed the need to initiate deliberate effort to improve this care. They expressed the need of nutritionist, health care providers out rich to the community, media support and population areas to be given mass education on nutrition education, churches and schools to be kept with posters expressing health education on kidney disease and prevention. Additionally, formal nutritional health education nationally is required which states general requirement on nutritional need among HD patients to avoid confusion to the family caregivers of HD patients. This indicates that there should be a national standard guideline of nutrition to all hemodialysis patients.

5.1.4 Methodological considerations

Effort was done to ensure the accuracy and veracity of the scientific results is generated to make findings of this study trustworthy. The researcher used four criteria suggested by

Graneheim and Lundman (2004) to achieve this trustworthiness of findings. The four criteria applied in these results were: credibility, transferability, dependability and conformability. To ensure the findings are credible, the interviews were conducted by the researcher himself who is a nurse and has been working with patients undergoing dialysis for more than two years. The prolonged engagement in caring patients undergoing dialysis provided me with a framework to guide probing questions that were relevant as per research objectives. Furthermore, data were analyzed and interpreted by the researcher himself. However, to avoid this influence on the study, the researcher remained open minded to participant's perspectives while putting his pre understanding of the issues under research into bracket. Additionally, the researcher engaged supervisors who have extensive knowledge in dialysis and qualitative studies throughout the research process, discussed and reflected on any emerging issues collaboratively. To enhance credibility and dependability, the researcher also triangulated data collected from interviews with those from field notes at analysis stage, and categories and themes were shared with a supervisor who gave critical comments and suggestions. To confirm that the findings reflected informants' perspectives rather than researchers' understanding of the problem, the presented findings were supported by codes and quotes. Transferability was enhanced by providing the detailed description of the study context, process for data collection and analysis.

5.2 Study limitation

1. The emotional and psychological state of the caregivers at the time of data collection might influence their responses, particularly if they are experiencing stress or fatigue that can be assessed by the participant's facial expression.
2. Data on caregiver's experience are often collected through self-reported interview which can be subjective and prone to bias. Caregivers might not accurately remember or may exaggerate their experience and perceptions.

5.3 Strength of Study

1. This is the first study to be conducted at Iringa Regional Referral hospital on nutritional needs of the patients attending maintenance hemodialysis among caregivers; therefore, this study will pave way to other research to be conducted futherly in the other regions.
2. This study enables researcher to be flexible and easy adaptation to the research progress in gathering of information.
3. The study provides a deep and comprehensive understanding of the challenges experience and strategies employed by family caregivers in managing nutritional needs of hemodialysis patients.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATION

6.1 Conclusion

This study highlights the roles of caregivers in provision of nutritional support to the patients undergoing maintenance hemodialysis. Family caregivers play great role and they are the key team player in providing nutritional support to the patients undergoing maintenance hemodialysis. The perception of caregivers regarding the nutrition of hemodialysis patients is multifaceted and significantly impacts patient outcomes. Caregivers often recognize the critical role nutrition plays in managing the health and quality of life of patients undergoing hemodialysis. They generally understand the importance of dietary restrictions, recommended, fluid modification, benefit of adhering dietary recommended and the need for balanced nutrient intake to manage symptoms and complications associated with kidney failure. To enhance caregiver perceptions and capabilities in nutrition management, targeted education and support systems are essential. Implementing effective nutritional care strategies for hemodialysis patients among caregivers is essential for optimizing patient health and quality of life. Caregivers play a crucial role in managing the dietary needs of these patients, and their understanding and adherence to nutritional guidelines can significantly impact outcomes and key elements include meal preparation plan, use of available community food, use of natural and medicinal additives to stimulate appetite. Caregivers face several significant challenges in providing nutritional care to hemodialysis patients, which can impact both the effectiveness of care and patient outcomes. Key challenges include financial constraints, inadequate understanding, overzealous restriction, and complex dialysis schedule.

6.2 Recommendation to the hospital management team

Based on the findings from this study, the following are recommended

1. Family caregivers of the patients undergoing hemodialysis should be educated on all issues associated with renal failure and how to modify dietary aspect.

2. Routine community out riches should be conducted in the community, this will foster the collaborative and supportive effort from the society to reveal and diagnose new patients, modify prevention method and improvement of treatment of malnutrition to the patients undergoing maintenance hemodialysis.
3. Hospital should develop the special committee that will provide general health education concerning dietary issues on patients undergoing maintain hemodialysis together with their caretakers.
4. Ministry of health should develop national standard guideline for patients undergoing maintenance hemodialysis to avoid misunderstanding and confusion to the caregivers because they provide continuum care to the patients.
5. A further study exploring the perspectives of health care providers and caregivers should be conducted to facilitate the comprehension of challenges in providing nutritional support to the patient so that the deliberate effort should be developed to meet the nutritional needs for health care providers, patients and their caregivers.

6.3 Recommendation to the caregivers of the patients

1. Caregivers should agree to collaborate with health care providers on nutritional education and apply it to improve patient's living.
2. Caregivers should accept to organize community meeting which will be used as the chance to confer nutritional education easily to the society
3. Caregivers should consult dietitian on matters concerning diets of hemodialysis patients.
4. Posters supplies given to the patients should also be provided to the caregivers and kept in other populated places like bus stands, schools, churches, and mosques.

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8.0 APPENDICES

8.1 Appendix I: English version questionnaire

PART 1: SOCIO-DEMOGRAPHIC DATA

ID NO …….

Age …… Gender…… Marital status……HD duration…….

Educational level…… Employment status……Relationship……

PART 2: **Family caregiver's understanding of the nutritional needs of CKD patients attending hemodialysis at IRRH**

QN1. What is your understanding toward the patient undergoing maintenance hemodialysis?

Probes: a. what types of food required by the patient undergoing hemodialysis?

b. What are the types of food are not allowed to the patient undergoing hemodialysis?

c. What is your perception about nutrition of the patient undergoing hemodialysis?

d. How hemodialysis affects nutrition pattern of hemodialysis patient?

e. What is the amount or quantity patient need to consume per day?

f. What quantity of fluid HD patient allowed drinking per day?

PART 3: **To explore strategies employed by family care givers in supporting dietary adherence to patients attending hemodialysis at Iringa Regional Referral Hospital**

QN2. How do you help the hemodialysis patient to meet nutritional need?

Probes: a. How do you prepare in terms of cooking the food for HD patient?

b. What is the reliability for the food for the patient undergoing HD?

c. In any ceremonial attendance how do you do to help HD patient?

d. How do limit the drinking beverage for the patient undergoing HD?

e. How do you know that, patient has attained the limitation of food and drinks in a ceremony?

f. what are the nutritional benefits HD patient get from hemodialysis?

g. As the patient's caregiver, what are your primary duties on HD patient?

PART 4: **To explore the barriers encountered by family care givers in meeting nutritional needs to patients attending hemodialysis patients at Iringa Regional Referral Hospital**

QN3. What are the obstacles do you face when giving the patient nutrition care?

. Probes: a. how are you dealing with food restrictions/overzealous?

b. How does the cost of foods affect HD patient negatively?

c. How food aversion affects HD patient's life?

d. How coordination with the patient's healthcare team affects?

e. How do you manage the patient's appetite?

f. How does the distance of health facility affect patient's nutritional status?

QN4. What do you need so that you can provide nutritional support to HD patient?

Probes: a. what do you think are the importance of nutritional education to HD patient?

b. What is the importance of community out rich of health care providers to HD patients?

c. What is the importance of posters in educating HD patients?

d. What is the importance of emotional support to HD patient?

e. What is the importance of financial support to HD patient?

8.2 Dodoso II: Dodoso la kiswahili

SEHEMU 1: Taarifa binafsi ya mshiriki

Nambari ya mshiriki……

Umri……..Jinsia……Hali ya ndoa……Muda aliohudumia.....

Elimu ……Hali ya ajira……Uhusiano……..

SEHEMU 2**. Uelewa wa ndugu wa mgonjwa wa kusafishwa figo juu ya hali ya lishe kwa mgonjwa wa figo**

Swali 1. Unaelewa nini kuhusu wagonjwa wanaosafishwa figo?

Kudadisi: a.Aina zipi za vyakuala zinahistajika kwa mgonjwa anaesafishwa figo?

b. Aina zipi za vyakula hazipaswi kwa mgonjwa anaesafishwa figo?

c. Nini mtazamo wako juu ya lishe kwa wagonjwa wanaosafishwa figo?

d. Usafishwaji wa figo unachangia nini katika afya ya lishe kwa mgonjwa wa figo?

e. Ni kiasi gani cha achakula mgonjwa wa figo anaweza kula kwa siku?

f. Ni kiasi gani cha vimiminika mgonjwa wa figo anaruhusiwa kunywa kwa siku?

SEHEMU 3: **Kudadisi ni aina gani ya uzoefu wanaoutumia ndugu watoa huduma kwa wagonjwa wanaohudhuria huduma ya usafishaji wa figo katika Hospitali Rufaa ya Mkoa wa Iringa.**

Swali 2. Unawezaje kumsaidia mgonjwa anaesafishwa figo kufikia maleongo ya lishe?

Kudadisi: a. Jinsi gani unaandaa vyakula mfano upande wa kupika?

b. Vipi kuhusu upatikanaji wa aina za vyakula kwa mgonjwa anaesafishwa figo?

c. Katika matukio kama sherehe unawezaje kumsaidia mgonjwa anaesafishwa figo?

d. Unawezaje kumzuia mgonjwa anaesafishwa figo na vinywaji kwenye sherehe?

e. Unawezaje kujua mgonjwa kafuata maelekezo ya lishe akiwa kwenye sherehe?

f. Unaweza kuniambia faida za lishe mgonjwa anapata kupitia kusafishwa figo?

g. Wewe kama ndugu wa mgonjwa, ni yapi majukumu yako ya msingi kumsaidia?

SEHEMU 4: **Kudadisi ni changamoto zipi wanazokutana nazo ndugu watoa huduma wa wagonjwa wanaosafishwa figo katika upande wa lishe Hospital ya Rufaa ya Mkoa wa Iringa**

Swali 3. Zipi ni changamoto upatazo katika kutoa huduma ya lishe kwa mgonjwa?

Kudadisi: a. Unawezaje kupambana na vizuizi vingi kwa aina za vyakula kwa mgonjwa?

b. kwa vipi gharama ya maisha inaweza athiri lishe ya mgonjwa anaesafishwa figo?

c. Mgonjwa anaesafisha figo kuchukia aina ya chakula inawezaje kudhorotisha afya?

d. Mfumo wa utoaji huduma unachangiaje katika kudhoofisha afya mgonjwa wa figo?

e. Kwa namna gani unaweza boresha hamu ya kula kwa mgonjwa anaesafishwa figo?

f. Je umbali wa huduma ya afya unachangiaje kudhoofu afya ya lishe ya mgonjwa?

Swali 4. Unahitaji nini ili kuweza kutoa huduma ya afya ya lishe kwa mhonjwa anaesafisha figo?

Kudadisi: a. Kuna umuhimu wa elimu ya afya juu ya lishe kwa mgonjwa anaesafishwa figo?

b. Kuna umuhimu wa watumishi wa afya kutoa huduma ya mkoba kwa ajili ya afya ya lishe kwa jamii?

c. Upi umuhimu wa kuweka mabango na vipeperushi vya lishe kwa wagonjwa wanaosafishwa figo?

d. Kuna umuhimu gani wa mchango wa kihisia kwa wagonjwa wanaosafishwa figo?

e. Kuna umhimu gani wa mchango wa kifedha katika huduma ya lishe ya mgonjwa anaesafishwa figo?

8.3 Appendix III: Informed consent form for study participant: English version

Title of the study: Family care givers experience in meeting nutritional needs to hemodialysis patients at Iringa Regional Referral Hospital

Introduction:

I am Steven P Dudiyeck, a postgraduate at Muhimbili University of Health and Allied Sciences pursuing a Master of Science in Nephrology Nursing. This consent form's primary objective is to give you comprehensive information about the study's objectives and assist you in making an informed decision to in the research. Next, I will want you to sign this form to indicate that you understand the goal of the study and you agree to participate.

The purpose of the study:

The purpose of the study is to investigate how family caregivers at Iringa Regional Referral Hospital in Tanzania handle their hemodialysis patients' nutritional needs.

The methods used in the study were as follows:

Enrollment in this study is entirely voluntary. You will be given self-administered questionnaire to answer after you consent to participate in the study. It should take you only thirty to sixty minutes to complete. Should clarification or assistance be required, the lead investigator will be on hand to provide it.

Advantages of participating:

The benefit, if you are found to be ill throughout the course of the study, you will receive early treatment and counseling from professional social workers, which is a benefit. I will recommend to hospital administration that an early diagnostic department be established to

address any problem in the future like depression, catering to both patients and their caregivers.

Participation risks:

Nothing negative will come from participating in this study. Though there is always a chance that volunteers in the study could encounter physical, psychological, social or emotional dangers.

Restitution/compensation:

Participation in this study is completely voluntary and comes with no financial or non-financial compensation.

Confidentiality of the study:

All participants in this study will remain anonymous, as will their answers. To preserve security and guarantee that information is accessible to authorized users only, participants will be represented by unique codes, and computers storing data will employ passcodes. A secured cabinet will also house the filed notebook and other supplies needed to gather data from the field.

Right to withdraw from the study:

You are free to withdraw from the study at any moment after choosing to willingly engage in it. You won't be denied access to Iringa Regional Referral Hospital services just because you declined to take part in the trial.

Questions/concerns regarding the study:

Please feel free to contact me at email address:sefududieck@gmail.com or by phone at 0766823604 if you have any queries about taking part in this study.

Consent form for participant:

I have read the consent form and have understood the precise information that is necessary. I was given the chance to ask questions, and I was satisfied with the way that any requested explanation was handled. The advantages and disadvantages of taking part in this study were clearly stated. I am aware that taking part in this study is entirely voluntary and quitting at any moment won't have any negative effect. The investigator guarantees the preservation of the information's confidentiality.

I agree to take voluntary role in this research study.

Participant's name……
Participant's signature…….
Date…….
Investigator's statement

The participant listed above has received a thorough explanation from me, the undersigned, on the goals of the study, its advantages, the dangers involved, and how to withdraw from it or to continue with it.

Investigator's name……..
Investigator's signature…….
Date……...

8.4 Kiambatanisho IV:Fomu ya kuomba ridhaa kwa mshiriki

Kichwa cha utafiti: Uzoefu wa ndugu watoa huduma wa wagonjwa wanaosafishwa figo upande wa lishe katika Hospitali ya Rufaaa ya Mkoa wa Iringa.

Utangulizi:

Mimi Steven P Dudiyeck ni mwanafunzi wa shahada ya uzamili katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili ninaye bobea magonjwa ya figo katika fani ya uuguzi. Dhumuni la msingi la kukupatia hii fomu ya ridhaa ni kukupa wewe taarifa muhimu juu ya malengo ya utafiti huu na kukusaidia wewe kufanya maamuzi sahihi kushiriki katika utafiti huu. Baadaye ntakuomba usaini fomu hii kuonesha unakubaliana na umeelewa dhumuni la tafiti hii na kushriki kwa hiari.

Dhumuni la utafiti huu:

Ni kuchunguza juu ya Uzoefu wa ndugu watoa huduma wa wagonjwa wanaosafishwa figo upande wa lishe katika Hospitali ya Rufaaa ya Mkoa wa Iringa.

Njia zitakazotumika katika utafiti ni kama ifuatavyo:

Kushirki katika tafiti hii ni hiari kwa mshiriki. Utapewa dodoso lenye maswali ya kujibu na baadae utajibu maswali yaliyopo kama umekubali kushiriki. Dodoso litachukua muda wa dakika thelathini mpaka sistini tu kukamilisha.

Faida za kushiriki utafiti huu:

Mshiriki atapata faida za moja kwa moja ya kuonana na mtaalamu wa huduma ya jamii endapo atagundulika kuwa na ugonjwa kwaajili ya ushauri. Pia Kwa baadae utafiti huu utasaidia kushauri uongozi wa Hospitali kuangalia namna ya kuanzisha kitengo cha utambuzi wa mapema ili waweza kutoa huduma hospitalini hapa kwa wagonjwa na ndugu za wagonjwa wanaofika kupatiwa huduma za matibabu.

Hatari yoyote kwa mshiriki

Hakuna hatari yoyote wala madhara ya kushiriki katika utafitin huu. Ingawa siku zote huwa kuna nyakati mshiriki anaweza kukumbana na changamoto za kimwili, kisaikolojia, na kihisia.

Fidia kwa mshiriki:

Kushiriki utafiti huu ni kwa hiari na hakutakuwa na fidia yoyote inayohusiana na kifedha wala kisicho cha kifedha.

Usiri wa utafiti:

Washiriki wote katika utafiti huu watabakia kuwa wasiri pamoja na majibu watakayotoa. Ili kulinda usiri wa taarifa hizi, zitabaki kuwa siri kwa mamlaka inayohusika tu, pia washirika wa tafiti hii, watapewa herufi maalumu, na kompyuta zitatumika kuhifadhi taarifa ambazo zitahifadhiwa kwa nywila maalumu. Pia daftari zote na vifaa vyote vitakavyotumika katika ukusanyaji wa taarifa zitahifadhiwa kwenye kabati maalumu.

Haki ya kujiondoa katika utafiti huu:

Kama mshiriki unaweza kujiondoa kwenye utafiti muda wowote kwa kuwa umechagua kushiriki kwa hiari. Hii haitaathiri upatikanaji wa huduma za kiafya katika Hospitali ya Rufaa ya Mkoa wa Iringa kwa kuwa tu umejiondoa.

Maswali/Mawasiliano kuhusu utafiti:

Ukiwa kama mshiriki tafadhali kuwa huru huru kuwasiliana na mimi kama una swali lolote kuhusu utafiti huu. Barua pepe: sefududieck@gmail.com na simu 0766823604.

Fomu ya ridhaa kwa mshirikiFomu ya kuomba ridhaa ya ushiriki:

Nimesoma fomu ya ridhaa na nimeelewa taarifa muhimu inayohitajika. Nimepewa nafasi ya kuuliza maswali, na nimerihika na jisni kila taarifa inayohitajika itakavyobebwa. Faida na hasara za kushiriki utafiti huu zimeainishwa bayana. Naelewa kushiriki utafiti huu ni kwa hiari

na kujiondoa kwenye tafiti hii muda wowote haitaleta madhara kwangu. Mtafiti amenihakikishia usiri na uhifadhi wa taarifa nitakazotoa.

Jina la mshiriki …….....

Sahihi ya mshiriki …….....

Tarehe ya utafiti…….....

Kauli ya mtafiti

Mshiriki yeyote aliatajwa hapo juu, amepokea maelekezo kutoka kwangu kuhusu dhumuni la utafiti, faida zake, hatari zitakazojitokeza na namna anaweza kujiondoa muda wowote bila madhara kumpata au kuendelea na utafiti.

Jina la mtafiti……

Sahihi ya mtafiti ……..

Tarehe ya utafiti……

8.5 Appendix V: Ethical clearence

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/2115 Date: 25/03/2024

MUHAS-REC-03-2024-2115
STEVEN P DUDIYECK
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: FAMILY CAREGIVERS EXPERIENCE IN MEETING NUTRITIONAL NEEDS TO PATIENTS ATTENDING MAINTENANCE HEMODIALYSIS AT IRINGA REGIONAL REFERRAL HOSPITAL

Reference is made to the above heading.

I am pleased to inform you that the Chairman has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 25/03/2024
EXPIRATION DATE OF APPROVAL: 25/03/2025

STUDY DESCRIPTION:
Purpose:

The purpose of this explorative qualitative study is to explore family caregivers experience in meeting nutritional needs to hemodialysis patients at Iringa Regional Referral Hospital.

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided: https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2014554.pdf and in the MUHAS archives.

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The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain Data Transfer Agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain Material Transfer Agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country.
8. Apply for and obtain permission to publish the results from National Institute for Medical Research. The application should be before submitting to a publisher and not concurrently through the email publications@nimr.or.tz.
9. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10-(2)
10. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
11. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz/.

Dr. Nahya Salim Mabsoud,

Chairperson, MUHAS Research and Ethics Committee

University of Health and Allied Sciences
DIRECTOR
Research, Publications & Innovations
Box 65001
Mubimbili

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8.6 Appendix VI: Introduction letter

UNITED REPUBLIC OF TANZANIA
MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY
MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR – POSTGRADUATE STUDIES

In reply quote:
Ref. No. HD/MUH/T.454/2022 26th March, 2024

The Executive Director,
Iringa Regional Referral Hospital,
P.O. Box 260,
IRINGA

Re: INTRODUCTION LETTER OF STEVEN P. DUDIYECK

The bearer of this letter is Steven P. Dudiyeck (HD/MUH/T.454/2022), a student at Muhimbili University of Health and Allied Sciences (MUHAS) pursuing MSc. Nephrology Nursing.

As part of his studies he intends to do a study titled: **"Family Caregivers Experience in Meeting Nutritional Needs to Patients Attending Maintenance hemodialysis at Iringa Regional Refferral Hospital."**

The research has been approved by the Chairman of University Senate.

Kindly provide him the necessary assistance to facilitate the conduct of his research.

We thank you for your cooperation.

Ms. Victoria Mwanilwa
For: DIRECTOR, POSTGRADUATE STUDIES

c.c. Steven P. Dudiyeck

9 United Nations Road; Upanga West; P.O. Box 65001, Dar Es Salaam: Tel. G/Line: +255-22-2150302/6; Ext. 1015; Direct Line:+255-22-2151378;Telefax:+255-22-2150465;E-mail:dpgs@muhas.ac.tz;Web:https://www.muhas.ac.tz

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8.7 Appendix VII: Permission letter

THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

IRINGA REGIONAL
Phone No : 026 - 2702264
Fax: 026 – 2702264
Email barua@iringarrh.go.tz
moi@iringarrh.go.tz
Reply please quote:

Medical Officer In Charge,
Iringa Regional Referral Hospital
Kinondoni Street
P.O. Box 260,
IRINGA

Ref.No. IRRH/E.10/16/Vol. XXXIII/160 04th July, 2024

Mr. Steven P. Dudiyeck,
Muhimbili University of Health and Allied Sciences,
P. O. Box 65001,
DAR ES SALAAM

REF: **PERMISSION TO CONDUCT RESEARCH IS "FAMILY CAREGIVERS EXPERIENCE IN MEETING NUTRITIONAL NEEDS TO PATIENTS ATTENDING MAINTENANCE HEMODIALYSIS AT IRINGA REGIONAL REFERRAL HOSPITAL"**

Refer to the heading captioned above.

2. I am glad to inform you that permission has been granted to conduct your research "Family Caregivers Experience in Meeting Nutritional Needs to Patients Attending Maintenance Hemodialysis at Iringa Regional Referral Hospital.

It is my sincere hope that ethical issues and Hospital protocols shall be observed.

Dr. Alfred M. Laison
Medical Officer Incharge
Iringa Regional Referral Hospital
IRINGA

MEDICAL OFFICER INCHARGE
IRINGA REGIONAL REFERRAL HOSPITAL
P.O. BOX 260
IRINGA

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