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PALLIATIVE CARE NEEDS OF PATIENTS ON MAINTENANCE HEMODIALYSIS AT THIKA LEVEL 5 HOSPITAL, KIAMBU COUNTY, KENYA

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ABSTRACT

Globally, a huge gap exists between the required and the available renal palliative care services. The gap is particularly worse in low-and-medium income countries despite having the highest percentage of patients requiring palliative care. Maintenance hemodialysis patients contribute a sizable percentage of the global renal patient population in need of palliative care. Successful provision of adequate palliative care services requires a holistic understanding of the patients' needs. The purpose of this study was to explore the palliative care needs of patients on maintenance hemodialysis at Thika Level 5 Hospital. A qualitative descriptive design was used to explore the palliative care needs of the patients at the institution. Purposive sampling was used to recruit participants. Data collection was conducted for a period of one month at the hospital's renal unit. A total of twelve maintenance hemodialysis patients participated in the study. Audiotaped semi-structured interviews were used to conduct data collection. Thematic analysis was used to analyze the data. The study findings showed that maintenance hemodialysis patients have many palliative care needs. The needs regard to physical, psychological and social aspects. Distressing physical symptoms were identified as the primary physical needs where fatigue, skin changes and fluctuations in appetite were reported as the most prominent symptoms. Difficult thoughts related to uncertainty about the future, caregiver burden, inability to get more children, stress and worry as well negative self-image were reported as the psychological needs experienced by the patients. Interruption of social roles, abandonment by friends and financial burden on the family were revealed as the social needs of the patients. To deal with their illness and treatment related challenges, the patients primarily utilized spiritual coping where prayers were reported to be the most utilized coping method. Lack of knowledge on palliative care and fear of being judged were identified as patient related barriers to meeting palliative care needs of the patients. Understanding the palliative care needs of maintenance hemodialysis patients has important implications on practice and policy making. Findings could be used in developing renal palliative care services provision policies and protocols to use as a guide in the identification and provision of palliative care to maintenance hemodialysis patients. Also, nephrology nurses and other renal care team healthcare professionals could use the findings to develop strategies of addressing patient related barriers to meeting palliative care needs. For research, studies could be done to evaluate the influence and perspective of healthcare providers in the provision of palliative care to maintenance hemodialysis.

Key Words: *Palliative Care, Hemodialysis*

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INTRODUCTION

Globally, the percentage of patients with unmet palliative care needs has been on the rise (Axelsson et al., 2018; Hum et al., 2021). The World Health Organization (WHO) estimates that only 14% of 56.8 million people across the globe in need of palliative care receive it every year (Clark et al., 2020). The highest percentage of people requiring palliative care (78%) are reported to be residing in low- and medium-income countries (LMIC). Patients with end stage renal disease (ESRD) particularly those on maintenance hemodialysis contribute a sizable percentage of the global patient population requiring palliative care. According to Sturgill & Bear (2019), approximately 2.2 million people across the globe receive dialysis where 89% of the patients utilize hemodialysis. In Kenya, anecdotal data shows that the number of patients on maintenance hemodialysis rose from 300 in 2006 to 2400 patients by March 2018 (Kabinga et al., 2019). However, the number could be much higher as many cases of end stage renal disease remains unreported and undiagnosed in the country (Otieno et al., 2020; Mwenda et al., 2019).

Chronic hemodialysis is associated with increased symptoms burden, functional limitations, cognitive impairment, uncertainly about life and death as well as high caregiver burden (Axelsson et al., 2018; Eneanya et al., 2017). Despite having a complex illness trajectory, provision of palliative care in patients on maintenance hemodialysis has been sub-optimal as compared to other life-limiting diseases such as cancer. Globally, it is estimated that less than 20% of patients with ESRD access palliative care as compared to 55% and 39% of patients with cancer and heart failure consecutively. In 2019, a study conducted in 5.23 million patients with ESRD on dialysis from 2006 to 2014 in the US reported that only 1.5 percent of these patients were reported to have accessed palliative care (Wen et al., 2019). Similar to other LMICs, the provision of palliative care to hemodialysis patients residing in Sub-Saharan Africa is estimated to be marginal due to the absence of integrated palliative care delivery models in their healthcare systems (Bagasha et al., 2020; Bates et al., 2017). In Kenya, only 14,552 persons out of the 800,000 patients requiring palliative care services every year have access (Ministry of Health, 2021).

Palliative care provides a supportive framework critical to the management of distressing experiences encountered by patients on maintenance hemodialysis. The care has been associated with decreased burden of debilitating symptoms, enhanced advanced care planning, reduced utilization of healthcare and enhanced coping of the patient’s caregiver (Wen et al., 2019; Eneanya et al., 2017; Liem et al., 2022). Globally, the significance of this care in supporting persons with chronic kidney disease is increasingly being recognized. In 2021, the Kenyan government released the Kenya Palliative Care Policy 2021-2030 to provide guidance to policy makers, healthcare providers and other stakeholders on how palliative care should be organized and delivered in the country (Ministry of Health, 2021). With increasing number of chronic hemodialysis patients and centers, more integration of palliative care delivery models will be required. Between 2006 and March 2018, the number of hemodialysis units increased by 920% from 10 to 102 units while hemodialysis patients increased by 700% during the same period (Kabinga et al., 2019).

Palliative care needs of patients on maintenance hemodialysis are diverse and vary from one patient to another. Studies have shown that many hemodialysis patients experience a high symptom prevalence including pain, shortness of breath, fatigue, pruritus, concentration difficulties and constipation (Axelsson et al., 2018; Hum et al., 2021; Grubbs, 2018). On average, dialysis patients have been reported to experience 8 symptoms where 5 of them are graded as severe (Sturgill & Bear, 2019). Other studies have also highlighted that chronic hemodialysis patients experience challenges with advanced care planning and engagement in end-of-life communication (Imamah & Lin, 2021; Boje et al., 2021; Eneanya et al., 2017). Increased family burden and functional limitation are challenges that has also been well documented in literature globally (Liem et al., 2022, Bates et al., 2017).

The provision of renal palliative care is done by a multidisciplinary team composed of nephrologists trained in palliative care, nurses, social workers and other healthcare professionals (Lam et al., 2019). However, nurses play a key role in the provision of palliative care to patients on maintenance hemodialysis because they have more contact with them and can monitor their needs closely. The support provided by nurses is largely dependent on their understanding of the patient's palliative care needs. Despite the importance of having an understanding of these needs in the provision of palliative care, no study has been conducted to investigate the palliative care needs of patients on maintenance hemodialysis to date in Kenya. The aim of the study was to explore the palliative care needs of patients on maintenance hemodialysis at Thika Level 5 Hospital (TL5H).

Problem Statement

Provision of palliative care to patients on maintenance hemodialysis is sub-optimal (Liem et al., 2022; Axelsson et al., 2018; Imamah & Lin, 2021). It is estimated that only 25% of dialysis patients receive palliative care (Schell & Johnson, 2021; Tavares et al.,2020). The percentage is however reported to be much lower in low-and-medium-income countries. In Kenya, provision of palliative care is largely focused on patients suffering from cancer and accessibility of the care for patients with other diseases is low (Kenya Hospice and Palliative Care Association, 2020). Despite having an increased number of dialysis centers in the country especially through the Managed Equipment Services (MES) program, documented information on palliative care provision in maintenance hemodialysis patients is scarce. In Kiambu County, availability of palliative care specifically for maintenance hemodialysis patients is very low. This strongly suggest that despite considerable achievements having been made in equipping dialysis centers in the county, a gap exists in the identification and provision of palliative care to patients undergoing maintenance hemodialysis.

Hemodialysis patients are vulnerable and experience numerous challenges related to their care (Raina et al., 2018; Sarfo-Walters & Boateng, 2020). Palliative care enhances coping of these patients and their families by promoting effective management of symptoms, improved functioning, enhanced advanced care planning and reduced caregiver burden (Wen et al., 2019; Eneanya et al., 2017; Liem et al., 2022). Additionally, it reduces the burden of care on healthcare systems hence resources can be diverted to other urgent needs. Successful delivery of adequate and optimal palliative care to hemodialysis patients is dependent on accurate identification of palliative care needs of the patients. The study sought to explore the palliative care needs of patients on maintenance hemodialysis at the Thika Level 5 Hospital (TL5H).

Research Objectives

The main objective of the study was to explore the palliative care needs of patients on maintenance hemodialysis at the Thika Level 5 Hospital. The specific objectives were;

- To describe the physical needs of patients on maintenance hemodialysis at Thika Level 5 Hospital.
- To examine the psychological/mental needs of patients on maintenance hemodialysis at Thika Level 5 Hospital.
- To explore the social needs of patients on maintenance hemodialysis at Thika Level 5 Hospital.
- To explore patient related barriers to meeting these needs in patients on maintenance hemodialysis at Thika Level 5 Hospital.

The study was guided by the following research questions;

- What are the physical needs of patients on maintenance hemodialysis at Thika Level 5 Hospital?
- What are the psychological/ mental needs of patients on maintenance hemodialysis at Thika Level 5 Hospital?
- What are the social needs of patients on maintenance hemodialysis at Thika Level 5 Hospital?
- What are the patient-related barriers to meeting these needs in patients on maintenance hemodialysis at Thika Level 5 Hospital?

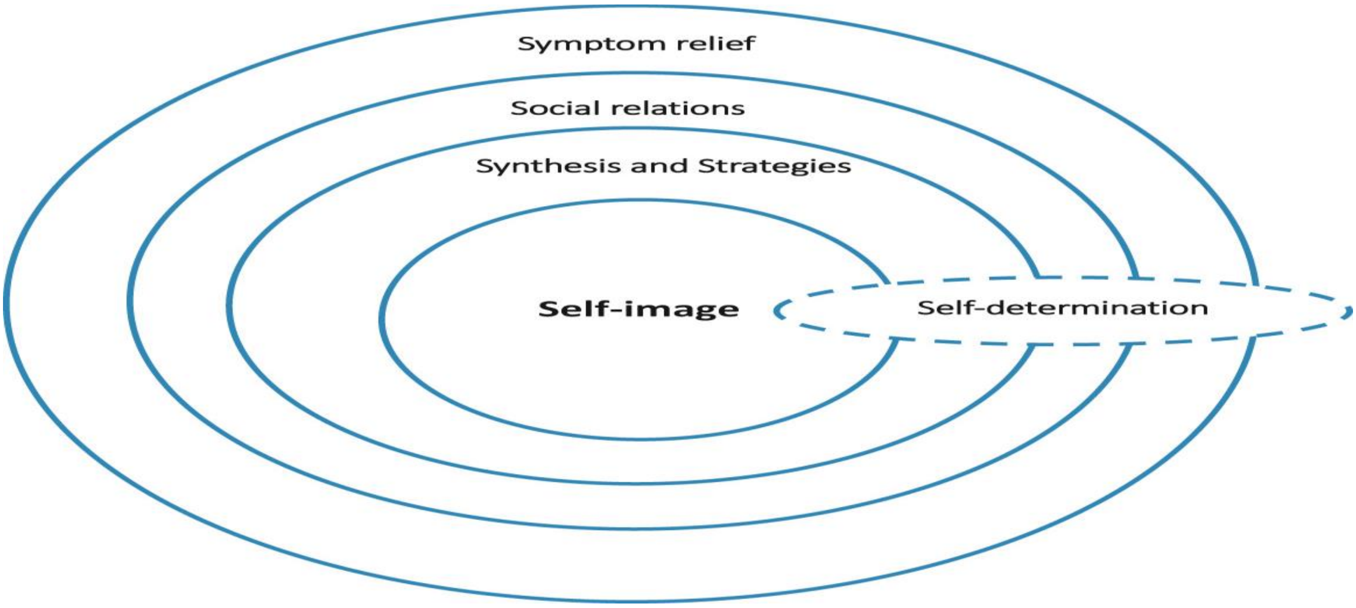
LITERATURE REVIEW

Theoretical Framework

This study adopts the 6S-model for person-centered palliative care. The model was developed by a multidisciplinary team known as the 6S-research group in the early 1990's (Österlind & Henoch, 2021). The model promotes opportunities for individuals with life limiting illnesses to live a high-quality life as possible during the last stage of life whether short or long. The 6S-model is composed of six concepts. The concepts represent a holistic view of a person's needs influenced by illness transition concerns. They are influenced by the different changes that occur in the body and mind of patients, existential difficulties they face as well as increased dependency which threatens a person's identity (Österlind & Henoch, 2021). This forms the basis of this study.

At the core of the model is self-image. It represents a person's identity and emphasizes that every patient should be empowered with opportunities of preserving a good view of themselves regardless of the illness they are suffering from. Central to the preservation of self and self-image is optimal relief of symptoms. In the model, symptom relief exemplify a patient's physical suffering and physical care (Henoch & Österlind, 2019). Emphasis is placed on symptom relief as they are the main reason why ill persons seek healthcare. On the other hand, social relations reflect an individual's social needs including fellowship with others and available social support systems. Synthesis entails providing a person with an opportunity to tell about their life story, their view about illness and interpretation of life.

Strategies reflect a patient's choice of approaches for meeting their needs during their last period of life to the extent that is possible. The model emphasizes that a patient should be an active co-creator of these strategies. Lastly, the concept of self-determination reflects the psychological needs of an individual. It also emphasizes that a patient's beliefs and values should be considered in planning their care. Healthcare professionals should respect and acknowledge the choices and preferences of patients in their final phase of life.



Adapted from Osterlind & Henoch, 2021

Figure 1*: *Theoretical Model

EMPIRICAL REVIEW

Overview of Palliative Care

Renal Palliative Care

The international organization KDIGO emphasizes that it is critical for all renal patients to access palliative care (Davison et al., 2015; Sturgill & Bear, 2019). The care seeks to prevent and relieve patients and their families from suffering by addressing their needs holistically. Palliative care is composed of several key components which include effective symptom identification and management, effective communication, continuity of care, advanced decision making, coordination of services, terminal care and bereavement support (Gelfand et al., 2020; Ministry of Health, 2021).

Palliative Care Statistics

Statistics from WHO indicates that approximately 56.8 million people require palliative care globally (Clark et al., 2020, Ministry of Health, 2021). Statistics indicate that 78% of these people reside in low-and-medium income countries. However, only a small percentage (14%) of the population is able to access palliative care. In Africa, an estimated 9.67million people require palliative care but the unmet demand is overwhelming (African Palliative Care Association, 2022). It is estimated that only 55% of countries in Africa have some form of identified palliative care activities but integration of the care in their healthcare systems is only available in 9% of the countries. Similar to other countries, Kenya faces a huge unmet demand of palliative care.

A report by the Kenya Health Facility Assessment that was conducted in 2018, reported that approximately 77% of healthcare facilities in the country had no palliative care services (Ministry of Health, 2021). Currently only 78 health facilities out of the 9695 officially registered health facilities have integrated palliative care in their programs. Additionally, only 7% of the hospitals providing palliative care have all tracer items such as morphine (Ministry of Health, 2021). Majority of these services focus on cancer patients while patients with ESRD and other life limiting illnesses have less access.

Overview of End-Stage Renal Disease (ESRD)

Patients with ESRD have significant renal function impairment and require renal replacement therapies (RRT) to support their survival. According to Suriyong et al. (2022), the prevalence of CKD patients in stage 3-5 across the globe is 10.6% with a 7% increase in patients with ESRD. In 2020, it was estimated that 786000 patients lived with ESRD in the US where 71% of the patients were on dialysis while 29% had a kidney transplant (United States Renal Data System, 2020). In Asia, Taiwan has the highest prevalence of treated ESRD of 3587 per million populations with Bangladesh having the highest increase of ESRD cases of 197% between 2009 and 2018 (Thurlow et al., 2021). In Africa, aggregate data on ESRD is limited and the vast majority of the cases remain undiagnosed and untreated.

According to Thurlow et al. (2021), sub-Saharan Africa has a lower prevalence of treated ESRD as compared to other developing countries of less than 100 cases per million populations. This is attributed to limited access to kidney replacement therapies (KRT) which is estimated to be less than 10% for adults with ESRD. Dialysis is the predominant KRT therapy globally. Health statistics indicate that approximately 2.2 million people across the globe receive dialysis where 89% of the patients utilize hemodialysis (Sturgill & Bear, 2019). In Kenya, anecdotal data shows that 2400 patients were on maintenance hemodialysis by March 2018 (Kabinga et al., 2019). ESRD patients on maintenance hemodialysis experience a complex illness trajectory characterized by numerous health and lifestyle related challenges. Availability of supportive care enhances effective coping of the patients and their families with these challenges (Axelsson et al., 2018; Eneanya et al., 2017; Liem et al., 2022).

Physical Needs of Patients on Maintenance Hemodialysis

Maintenance hemodialysis patients experience a wide variety of physical problems (Lou et al., 2019). The challenges result from a high physical symptoms burden, reduced functional status, and impaired physical ability (Axelsson et al., 2018; Imamah & Lin, 2021; Bates et al., 2017; Boje et al., 2021; Nia et al., 2022). Physical symptoms specifically are a huge problem for patients on maintenance hemodialysis therapy. Examples of predominant distressing symptoms experienced by the patients include fatigue, pain, breathlessness, insomnia, pruritus, nausea and vomiting (Imamah & Lin, 2021; Boje et al., 2021; Liem et al., 2022; Lou et al., 2019; Lanini et al., 2022). On average, 4.5 of these symptoms are rated as severe and significantly impact the functional status and physical ability of the patients (Sturgill & Bear, 2019).

In a study involving Danish patients, Boje et al. (2022) found out that the most predominant physical symptom experienced by the patients was fatigue which was reported by 89% of the study participants. Other symptoms reported by the patients included dizziness, impaired memory, pain, shortness of breath, sleep problems, constipation among others. The presence of these symptoms was also reported to have an impact on the functional status and physical ability of the patients. In another study, Liem et al. (2022) also found out that fatigue was a major physical symptom among patients undergoing maintenance hemodialysis. Fatigue was reported to be present in up to 89% of the participants where all five dimensions of fatigue were found to be higher than in the general population. Axelsson et al. (2018) found out that during the last weeks of life, ESRD patients reported that they often experienced pain (69%), shortness of breath (22%), nausea and vomiting (17%) and respiratory secretion (46%).

Psychological/Mental Needs of Patients on Maintenance Hemodialysis

Disease progression, dialysis therapy and treatment outcomes are always on the minds of patients on maintenance hemodialysis (Davison et al., 2015). Patients experience different challenges related to psychological symptoms, body image changes and different losses that impact their coping with disease and treatment (Boje et al., 2021; Liem et al.,2022; Grubbs, 2018). As part of the high symptom burden experienced by patients on maintenance hemodialysis, psychological manifestations such as depression and anxiety are ranked as some of the most prevalent symptoms. This was also observed by Liem et al. (2022) who conducted a study involving Danish patients and found out that anxiety and depression were high among the participants at 32.6% and 29.5% respectively. The high prevalence of the symptoms affected patient coping and the researchers observed that palliative care could be beneficial to the population.

In a meta-synthesis involving 22 studies on renal palliative care, Imamah & Lin (2021) found out that ESRD patients experienced changes in emotional status caused by depression, psychological suffering, emotional changes, coping techniques as well as emotional burden of distress. Also, psychological symptoms such as anger, frustration, guilt, and unhappiness were noted to have been prevalent in the reviewed studies. On the other hand, Sadeghian et al. (2016) in their study involving 42 maintenance hemodialysis patients reported that the patients had different levels of body image disturbance. The results of disturbance were low (64.3%), moderate (19%) and high (16.7%) among participants. Body image disturbance is a common distressing psychological factor in hemodialysis patients (Nia et al., 2022; Sadeghian et al., 2016).

Social Needs of Patients on Maintenance Hemodialysis

Different changes occur in the lives of maintenance hemodialysis patients that significantly impact their social life. The changes include increased dependence on family members, altered social roles, reduced time with friends and dealing with advanced treatment decisions (Nikkhah et al., 2020; Imamah & Lin, 2021; Boje et al., 2021; Bates et al., 2017; Axelsson et al., 2018). Increased dependence on family members is a key change that maintenance hemodialysis patients experience as a result of reduced body function and emotional changes (Imamah & Lin, 2021). In a study conducted by Zhang et al. (2016), 51% of caregivers participating in the study reported that their burden ranged between mild to moderate levels while 25.2% of the caregivers reported they had a moderate to severe burden of caring for their relatives. The results also showed that 76.2% of the caregivers were experiencing physical and emotional distress.

In a systematic review of 61 studies on the burden of caregivers, Gilbertson et al. (2019) found out that caregivers had a poor quality of life due to high patient care burden as compared to the general population. Also results from four studies reviewed showed that dialysis caregivers had poorer outcomes as compared to renal transplant recipients' caregivers. In another study, Boje et al. (2021) found out that maintenance hemodialysis patients had feelings of loss of self-control, shame and helplessness due to high dependence on relatives or other people involved in assisting them to deal with treatment and day to day activities. Imamah & Lin (2021) also reported that maintenance hemodialysis patients in their reviewed studies had experienced dramatic changes in their social relationships with family, friends and at work. Some patients reported that they had lost their jobs, lost relationship with their sexual partners and close friends while others became overly dependent on their family members.

Patient Related Barriers to Meeting Needs

Globally, a consensus has been reached that maintenance hemodialysis patients should have adequate access to palliative care. However, only a small percentage of these patients have access to these services globally (Eneanya et al., 2017; Metzger et al., 2021). Various barriers related to patients, healthcare systems and patients impede adequate provision of palliative care (Nikkhah et al., 2020; Wearne et al., 2021; de Barbieri et al., 2022; Boje et al., 2021). Specifically, for patients, factors such as lack of knowledge about palliative care, negative attitude and unfavorable cultural practices have been reported to act as barriers to meeting their palliative care needs (Nikkhah et al., 2020; Boje et al., 2021).

In a study that sought to explore the palliative care needs of Danish patients, Boje et al. (2021) reported that some patients chose not to report the symptoms and needs they experienced to their healthcare professionals. The study participants felt that the symptoms they had experienced previously had not been treated effectively and therefore did not see the need to report additional distressing symptoms experienced. In another study by de Jong et al. (2021) to evaluate the non-medical barriers in provision of care to ESRD patients, it was reported that patients lack of knowledge, social-cultural background and negative attitudes impended the provision of comprehensive care to the patients. These factors compounded misconceptions which affect the patient's uptake of different ESRD treatment approaches available.

METHODOLOGY

The research design utilized in this study was qualitative descriptive design. The study population was composed of ESRD 50 patients who had been on maintenance hemodialysis at TL5H renal unit. The study's sample size was informed by data saturation. A minimum of at least 12 participants have previously been recommended for qualitative studies in order to reach data saturation (Vasileiou et al., 2018). Purposive sampling was utilized to recruit participants. Data collection was done through individual face to face audiotaped semi-structured interviews. An interview guide developed from a review of literature on renal palliative care management guidelines and assessment tools was used during the interviews. A digital voice recorder was utilized to record the interviews which were then transcribed verbatim. The interviews were conducted in the hospital's renal unit on days that the patients came for their hemodialysis therapy. A register of all maintenance hemodialysis patients attending the study setting's renal unit was used to obtain potential study participants. All the audiotaped semi-structured interviews were audiotaped and transcribed verbatim into Microsoft word by the researcher. Organization of the interview transcripts was conducted using the NVIVO 14 qualitative analysis software program. In this study, the data analysis technique that was utilized is thematic analysis where the NVIVO 14 software was used for the process. The six general principles of thematic analysis by Braun & Clarke (2006) were used to guide this analysis. They include (1) familiarizing with the data set, (2) initial codes generation, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and lastly (6) producing the report. This process was iterative and therefore changes were made accordingly throughout the entire process.

FINDINGS

Physical needs of patients on maintenance hemodialysis at Thika Level 5 Hospital

Distressing physical symptoms

Participants in the study reported that they experienced different physical symptoms. However, the symptoms varied in severity and persistence. The severe symptoms cause distress to the patients and impact their day-to-day activities. The most distressing physical symptoms that were reported by majority of the participants were fatigue, changes in appetite and skin changes.

Fatigue

Fatigue was the most reported distressing physical symptom. Participants described fatigue as reduced physical endurance accompanied by body weakness. The presence of this symptom was reported to have an impact on the ability of participants to comfortably engage in different activities both at work and home.

KF001*: "I would say feeling* ***weak and fatigued*** *is the most challenging."*

KF002*: "I have two primary problems which are* ***fatigue and muscle aches****."*

Some participants recounted that the presence of fatigue also affected how other people viewed them especially at work. This is because they could not perform at the same level as compared to when they became ill and started hemodialysis.

KF012*: "Sometimes my colleagues think I am* ***pretending and I am just lazy*** *especially those who don't know about my illness…. this makes me feel sad."*

KF010*: "I think* ***people see me as useless nowadays. I get fatigued easily*** *and have to keep resting. It also frustrates me."*

Fluctuations in appetite

Maintenance hemodialysis patients are required to follow a strict dietary intake. Adequate consumption is needed to meet the unique dietary needs of these patients. However, some participants reported that it is hard to meet these requirements due to fluctuations in appetite. This affects their nutritional status.

KF005*: "Since I started my hemodialysis,* ***my appetite keeps fluctuating****. Today I might have a good appetite, tomorrow I don't want to see food. This happens often."*

KF010*: "My* ***appetite right now is not good****. It is not always bad though."*

Also, some participants attributed the changes in their appetite to the special renal diet. They outlined that the renal diet lacks varieties and the measures taken in its preparation makes it unattractive which impacts their appetite.

KF006*: "There are days I don't feel like eating since the* ***food is the same and not that attractive****."*

KF009*: "Before I got sick, I could eat everything. Now the dietary restrictions because of my renal failure cannot allow me to eat just anything. It is hard since the* ***renal diet is not that attractive****…. this affects my appetite."*

Skin Changes

Two forms of skin changes were reported by the participants during this study. The first change was on skin complexion. Some participants reported that their skin had become darker as compared to how they looked previously. This change affected how people viewed them as they looked different.

KF001*: "I have realized* ***I have become darker.*** *I look totally different compared to when I was not ill. Sometimes people fail to recognize me when we meet."*

KF005*: "My skin color has also changed.* ***I have become darker*** *and my skin used to be lighter than even yours."*

On the other hand, some participants reported that they had been experiencing skin irritation. The irritation brought embarrassment to some of the participants due to the persistent desire to scratch their skin. The scratching also caused discomfort and interfered with their texture.

KF011*: "****Skin irritation*** *is a problem for me since I have to keep scratching my skin even in public which is embarrassing."*

KF012*: "I have also noted changes on my skin……… my skin is* ***no longer smooth*** *as it used to be. This affects my self-esteem as I have to keep trying different skin products to return it the way it was previously."*

Psychological/mental needs of patients on maintenance hemodialysis at Thika Level 5 Hospital.

Difficult Thoughts

Majority of participants reported that they experienced difficult thoughts related to their treatment and everyday life. Many changes are expected to occur in the life of a maintenance hemodialysis patient and different thoughts arise from the changes. Participants in the study reported that their difficult thoughts were attributed to uncertainty about the future, stress/worry, caregiver burden and inability to get more children.

Uncertainty about the future

The lives of maintenance hemodialysis patients are surrounded by many uncertainties due to the nature of their illness. Participants expressed how difficult it is to know even how their health will be in the next days. They expressed how their health status changes from time to time and they kept thinking what will happen in the future. Also, some of them expressed difficulty in having concrete plans for the future. The unpredictability of their health status and other aspects in their life made it difficult to make any prior plans.

KF005*: "As I told you earlier, I feel this illness have made* ***my body unpredictable****. I can sleep well in the evening, but when I wake up I am sick and can't do anything. This unpredictability is very hard."*

KF008*: "There are a lot of things that are* ***unpredictable*** *with my illness and treatment. Today I might wake up well but tomorrow I am a different person."*

KF012*: "There are many things in my life that worry me. Those* ***uncertainties*** *will always give you difficult thoughts. There is now way you can completely avoid them."*

Stress and worry

Being ill causes patients and their families to experience different levels of stress. Participants in this study recounted how they experience stress and worries related to their illness and alterations of different aspects of their lives. Stress was reported to a major cause of difficult thoughts and persistent worry by the participants.

KF002: "***I am worried. I must be worried****. You see, like right now I am sick and if my blood pressure goes high, I might even die. If my blood glucose levels go below the recommended level, the same can happen.* ***I must be worried****."*

KF001*: "You must be* ***worried*** *because all of my life changed when I received this diagnosis and was placed on dialysis."*

KF003*: "This disease and treatment brought me only problems. Take for example my catheter, I was told recently that it has to be changed since it is not effective and sometimes, I don't finish my dialysis sessions.* ***I am stressed*** *since I don't know where I will get money for a new catheter."*

Inability to get more children

Children are viewed as a blessing to the family and community at large. Parents desire to get a certain number of children and at different stages in their life. Child bearing for female patients on maintenance hemodialysis requires more unique care as compared to a normal patient due to the nature of their illness. Unfortunately, not many patients are able to afford the required intensive care and therefore having more children becomes difficult. In this study, some participants reported that they would have desired to get more children but they can no longer achieve this goal. Thinking about this issue weighed heavily on them.

KF001: *"Another concern is that* ***I had not finished getting children****. Now I cannot get more because of issues to do with hypertension and dialysis treatment. Now I cannot get more. It is hard on me."*

KF012*: "I would also* ***have liked to get more children but that is not possible****. How will I be able to afford more dialysis sessions and they cannot be covered by NHIF? I have slowly been convincing myself it is alright, but the truth is that I think about it sometimes. It hurts."*

Worry About Caregiver Burden

Caregivers form an important support system for patients on maintenance hemodialysis. They provide invaluable support to the patients which enhances their coping. In some cases, the caregivers do almost everything for their patients. Some participants in the study reported that they have difficult thoughts regarding the burden their caregivers are forced to deal with. They reported to be concerned about this burden and kept thinking about it.

KF006*: "It is already hard enough for her to meet her needs in these hard economic times and then now you* ***add my burden and that of my child****."*

KF008*: "My children have to sacrifice their money and time to support my treatments. I don't ask for anything but they keep coming. It's a sacrifice on their part and especially for my daughter* ***who stopped working in order to be caring for me at home****. I feel sometimes like it's too much for them."*

KF011*: "For my wife, she is not able to go to some places as she used to do before I became ill as she has to take care of me. You see that interrupts her activities as* ***I am dependent on her support.*** *This is also the same for my mum who also* ***accompanies me here and leaves her activities****."*

Negative Self Image

Occurrence of body changes impacts how an individual view themselves. The perception can either be positive or negative. In this study, some participants reported that they had experienced body changes which made them to view themselves negatively. The changes that were reported in the study that affected the self-image of participants included skin changes and weight alterations.

KF007*: "When you add weight and initially you were smaller, you first* ***lose self-esteem*** *and develop stretch marks all over your body. But as I said earlier, I have learnt to accept myself the way I am."*

KF006*: "My body has deteriorated. I used to be bigger and looked good. Look at me now, I have become* ***thin and darker****. Also, I can't even walk well."*

KF012: "I have become darker and my skin is no longer smooth as it used to be. This affects my ***self-esteem*** *as I have to keep trying different skin products to return it the way it was previously."*

Social needs of patients on maintenance hemodialysis at Thika Level 5 Hospital.

Spiritual Coping

Spirituality plays a huge role in the coping of many patients. When dealing with illness, many people turn to their spiritual beliefs for encouragement, healing and resolution of other challenges that they may be facing. Majority of participants in this study were Christians and expressed how important religion was to them when dealing with their illness, treatment needs and other day to day challenges. Spiritual coping occurred primarily through prayers and material support from church members.

Prayers

Prayers connect people with their God. Through prayers, an individual is able to communicate their wishes or request to their supreme being. Participants in this study reported that they used prayers as a way of coping. Specifically, prayers were reported to be important especially when one is dealing with difficult thoughts. Some participants also reverted to religious lessons to give themselves hope and encouragement when dealing with difficult moments.

KF001*: "**Mostly by praying** and relaxing. I tell God He knows everything including my worries.*

KF002*: When I experience such difficult thought, **I read the bible and pray** or look for a close friend and talk with them about the problem."*

KF005*: "The only way I deal with the difficult thoughts is through* **prayers***. Only God can help to remove such thoughts."*

KF006*: "My way of coping is **praying to God** and I ask Him to take away these bad thoughts and the pain of the illness. He knows the reason I have the disease and only Him can help me."*

Material Support

Maintenance hemodialysis patients have numerous needs and require a lot of support. In addition to providing prayers, some participants in the study reported that the church and its congregants occasionally provided them material support. This was important to the participants and enabled them to meet some of their needs.

KF002*: "The church has really supported me through prayers and **sometimes they give me something to meet my needs**. Finances are really hard for some like me who don't work.*

KF011*: "The church members also **help me to buy drugs** and give me some money to meet my needs such as **transport money** during my dialysis sessions."*

Financial burden on the family

The most important support system for any patient is their family. The support of the family is critical in the coping of every patient. During this process, the family is affected in different ways by the patients' illness and its treatment. In this study, participants reported that one of the most significant implications their illness had on their families is finances. Some attributed this burden to inability to work due to their illness, acquiring special diet and frequency of their dialysis sessions.

KF001*: "For my family for example, it has been forced to bear with the **high cost** of travelling for dialysis sessions, purchase of medications and provision of my special diet."*

KF002*: "The disease process has **affected my family financially** and they are not able to support me. This sometimes pushes me to work extra hard to meet my needs."*

KF003*: "Sometimes I am not able to get my diet since I don't have any work. I have to depend on my children. Sometimes I ask them **to send me money to purchase the food** and they say they don't have."*

Abandonment by friends

Friends are an important component in a patient's support system. They support patients through encouragement, financial and material support, visitations and listen to them when they have difficult thoughts. Majority of participants in the study reported that their friends abandoned when they became ill. The participants attributed this change to the friends viewing them as a burden while others thought their inability to frequently interact with them affected their friendship. Other participants reported that the remaining friends always lie by giving them fake promises. Only a few participants reported that their friends are still supportive.

KF001*: "My* ***interaction with my friends has been affected*** *as sometimes when they need me, I am not available."*

KF002*: "It has also changed how my friends used to interact with me. When I got sick,* ***most friends abandoned me****. If you call them, they think you are calling to ask for help."*

KF009*: "Before my illness and initiation of dialysis, I had many close friends and church members. After I became sick,* ***the friends started leaving one by one*** *and I cannot honestly even tell you whether there are any left. I think they say I became a burden and each time I called for help, all of them had excuses and lies. I also realized that even those pretended to care had fake sympathy."*

KF010*: "So,* ***my friends have reduced significantly*** *as compared to when I was not ill. You call someone today and they will either ignore your call or lie to you. They feel you are a burden now."*

Interruption of social roles

Many changes occur when a patient is diagnosed with end stage renal disease and is placed on maintenance hemodialysis. One of the aspects that is impacted is their normal functioning which interrupts their day-to-day activities. One of the changes related to functioning that participants in this study reported is interruption of social roles. They expressed how some of them lost their previous social positions while others decided to give them up voluntarily. For some participants, the roles were taken away since they were viewed as too sick to perform to the required level.

KF001*: "In the community for example,* ***if they want to appoint me for a certain position, I have to say no*** *because I am not as healthy as I was previously and they also sympathize with my health status. They say I have to relax because I am ill."*

KF002*: "The illness has* ***impacted my role significantly****. I feel I don't have anything to offer and therefore I can't even engage in the roles initially I had."*

KF005*: "****My social roles have changed****. Personally, I decided to step down from my previous roles as I was in no shape to take responsibilities………My mobility has been impacted a lot and therefore even carrying out such community responsibilities is a challenge for me."*

Patient related barriers to meeting these needs in patients on maintenance hemodialysis at Thika Level 5 Hospital.

Barriers to Accessing Palliative Care

Lack of knowledge

Majority of participants in the study reported that they have never heard about palliative care before. Only two participants reported that they knew about it and their understanding of the care was related to only certain components. The participants outlined that a person can only seek a service that they know exist. Without such knowledge, one can continue to suffer with a need that could have been addressed if they knew palliative care existed.

KF002*: "I have* ***never heard about palliative care****. I have learnt from your description."*

KF003*: "****I don't know about palliative care****. You know I am old and not very learned. There are many things I don't know about."*

KF004*: "****For me I would say its lack of knowledge****. Take me for example, I have never heard about palliative care. Here we only receive dialysis and get reviewed maybe only once a month or twice. So, the comprehensive care you talked about I have never heard about it."*

For the participants who said they have never heard about palliative care, an explanation was provided. They were asked to explain whether they think palliative care is important to them. Some of them outlined the components which are most important to them.

KF005: "***The care is important to us****. Being able to access all those services together would solve most of the problems we experience."*

KF008*: "Based on what you have explained;* ***I believe palliative care is very important to us*** *renal patients. Personally, the components of palliative care that I would be the most important to me are effective symptom identification and management, advanced decision making and effective communication."*

KF010*: "****Effective symptoms identification and management and effective communication*** *are important. For the management of symptoms, this is important because if they are severe, you cannot perform any activity including caring for yourself."*

Fear of Being Judged

Different factors influence what type of information we share with others. One of the factors that influence this decision is how we think the other person will perceive the information. In this study, some participants reported that fear of being judged might prevent them from seeking palliative care. Some believed that some of the needs they have are too personal and they would rather deal with them on their own instead of sharing with their healthcare providers.

KF001*: "****For me its fear****. For example, if I am feeling pain, I might fail to tell my doctor about it since I don't want to be injected."*

KF007*: "I would say* ***fear of being judged****. If I had difficult thoughts, I could hold back since I don't want anybody to know about them. Some things are meant to be personal. So, my attitude towards a particular issue will influence whether or not to open up."*

KF010*: "If you don't like to share your things for example because you feel you might be viewed negatively, obviously you will hide it****. It's fear****."*

DISCUSSION

Physical needs of patients on maintenance hemodialysis at Thika Level 5 Hospital. Studies have shown that maintenance hemodialysis patients experience a high burden of physical symptoms (Lou et al., 2019; Axelsson et al., 2018; Boje et al., 2022). The symptoms have different implications in the lives of the patients. Findings in this study show that patients in Thika Level 5 hospital experience a similar burden of physical symptoms. Participants reported that they experienced different physical symptoms that vary in severity and persistence. The most severe symptoms caused distress in the patients and affected their day-to-day activities. Three physical symptoms were identified by participants as the most distressing. They include fatigue, appetite fluctuations and skin changes.

In this study, maintenance hemodialysis patients identified fatigue as the most distressing physical symptom. These findings are similar to a study conducted by Boje et al. (2022) in Danish patients where 89% of the participants identified fatigue as the most predominant physical symptom. Liem et al. (2022) also found out that fatigue was a major physical symptom experienced by patients on maintenance hemodialysis. Participants in this study reported that fatigue affected their level of performance and functional status. The implication of reduced functional status at home was increased reliance on family members and other caregivers. On the other hand, some participants reported that reduced performance at work affected how their colleagues viewed them. This could be attributed to needing more time to perform similar tasks they performed with ease prior to dialysis and having to miss some work days during hemodialysis treatment and follow up clinics.

Psychological/mental needs of patients on maintenance hemodialysis at Thika Level 5 Hospital. Disease progression, hemodialysis therapy and life changes are often in the minds of maintenance hemodialysis patients (Boje et al., 2021; Imamah & Lin, 2021; Davison et al., 2015). Participants in this study reported that they experienced difficult thoughts related to different aspects of their lives and treatment. Uncertainty about the future was identified as one of the causes of difficult thoughts. The patients recounted how their illness and treatment made their lives unpredictable which impacted their future plans. Knowledge of what to expect in the future enables one to prepare adequately and lay down appropriate plans. Lack of this knowledge not only makes the lives of maintenance hemodialysis patients uncertain but also unsettled. For them, anything can happen in their lives at any point and this keeps them worried and have stress regarding how the future will be.

The findings in this study also showed that some participants were disturbed by inability to get more children. Female participants reported that they had planned to bear more children prior to being placed on maintenance hemodialysis. However, the high cost of maintaining a pregnancy with their illness and unpredictability of their well-being made it very hard to achieve their goal. These findings are different to other studies conducted in a similar population. Studies by Imamah & Lin (2021) and Bates et al. (2017) found that participants reported that their sexual life had been affected by the disease. They had no desire or energy to engage in sexual activities. This could have an impact the participants' reproduction. The variation in findings in this study could be attributed to low economic status of the participants where majority of them only depend on the national insurance fund to finance their hemodialysis treatment. Any additional cost such as more frequent dialysis which is needed in pregnancy and extra obstetric care is impossible for the patients to meet.

Social needs of patients on maintenance hemodialysis at Thika Level 5 Hospital. Participants also reported that they had experienced changes in their friendship. Majority of the friends abandoned them when they became ill and were placed on hemodialysis. The friends started viewing the patients as a burden who only contacted them for support. Some participants felt that their friends disappeared as they had no time to interact with them due to their treatment schedules. Only a few friends had been left to support the participants and this had an impact on their coping. Axelsson et al. (2018) found out that maintenance hemodialysis patients experienced changes in relations particularly with close friends and family members. Friends form an important component of the patients' support system and their support is crucial in coping of the patients.

The findings in this study also showed that participants experienced changes in their social roles. Majority of the participants lost the roles they previously held due to impaired performance and lack of time to accomplish the required tasks. These findings are consistent with the findings of studies conducted by Nikkhah et al. (2020) and Imamah & Lin (2021) where they found participants reported role changes due to impaired functioning and reduced performance. Some of the participants excluded themselves from the positions since they felt that they offered less contribution and felt like a burden. Instead of adding value, the patients felt that they were dragging the other members behind and therefore gave up their positions so that someone else who is capable can fill up their positions.

Patient related barriers to meeting these needs in patients on maintenance hemodialysis at Thika Level 5 Hospital.

Different patient related barriers to meeting palliative care needs have been reported in previous studies. They include lack of knowledge about palliative care, negative attitude and unfavorable cultural practices (Nikkhah et al., 2020; Boje et al., 2021). Findings in this study also showed that different patient related barriers affected the ability of maintenance hemodialysis patients to meet their palliative care needs. Participants reported that lack of knowledge was the greatest barrier to meeting these needs. Most of them heard about palliative care during the interview and were even surprised that it existed. The findings are consistent with the results of de Jong et al. (2021) who found out that participants reported that lack of knowledge and information impacted the ability of patients to meet their treatment related needs. This indicates that more education regarding palliative care in maintenance hemodialysis patients could play a significant role in meeting their needs.

Participants also expressed that fear of being judged also affected their ability to meet their palliative care needs. They deemed some information to be too private and embarrassing and would rather suffer with it instead of sharing with their healthcare providers. This finding does not compare with previous studies which reported fear to be one of the barriers of accessing palliative care. This could be attributed to personal and cultural practices of the participants where some things are deemed as embarrassing in the society or are not supposed to be talked about. However, this barrier can be addressed by building more trust with the patients so that they can be comfortable to discuss any aspect of their illness. Participants also expressed their belief that palliative care was important after a description was provided on what palliative care is composed of. This was an important finding as it demonstrated the readiness of participants to learn more about palliative care and have it integrated in their care.

CONCLUSION

Overall, findings in this study revealed that maintenance hemodialysis patients have many palliative care needs. The needs regard physical, psychological and social aspects. Also, there are several patient related barriers to meeting these needs. The results of this study can help to inform policy makers, hospital administrators and renal nurses on what palliative care services should be provided to maintenance hemodialysis patients. Furthermore, the results can inform the development of policies and operational frameworks to guide the identification and provision of palliative care in this patient population. Despite having several limitations, the findings will add to the body of literature on the provision of palliative care in maintenance hemodialysis patients.

Objective 1: Distressing physical symptoms are the primary physical palliative care needs experienced by patients on maintenance hemodialysis. Fatigue, skin changes and fluctuations in appetite are the most distressing symptoms experienced by the patients.

Objective 2: Difficult thoughts related to uncertainty about the future, caregiver burden, inability to get more children, stress and worry as well negative self-image form the psychological/mental palliative care needs experienced by maintenance hemodialysis patients.

Objective 3: Interruption of social roles, abandonment by friends and financial burden on the family form the social palliative care needs of maintenance hemodialysis patients. To deal with their illness and treatment related challenges, the patients primarily utilized spiritual coping where majority of the patients utilize prayers to cope with their challenges.

Objective 4: Lack of knowledge on palliative care and fear of being judged are the main patient related barriers to meeting palliative care needs in patients on maintenance hemodialysis.

RECOMMENDATIONS

Based on the conclusions of the study, the following recommendations are suggested for action.

Objective 1: The county government and hospital administration are recommended to develop policies and protocols on the identification and management of palliative care needs including distressing physical symptoms in maintenance hemodialysis patients. This will ensure that the patients and their families receive evidence-based comprehensive palliative care.

Objective 2: The county government is recommended to hire more renal psychologists to enhance the coping of maintenance hemodialysis patients and their families with psychological and emotional stresses they experience.

Objective 3: The hospital administration is recommended to enhance the provision of social support to maintenance hemodialysis patients to promote positive coping such as incorporating them in social support groups for patients with terminal illnesses and encouraging families and friends to continue proving the patients with needed support.

Objective 4: Nephrology nurses and other members of the renal care team should develop strategies of providing comprehensive patient education regarding palliative care and its components. This will ensure that maintenance hemodialysis patients have adequate knowledge regarding the available palliative care services and get reassurance that healthcare professionals will support all their needs without judgement.

Further research is needed to determine healthcare providers influence and perspectives in the identification and management of palliative care needs in maintenance hemodialysis patients.

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