Assessing Readiness and Support for Advance Care Planning among Chronic Kidney Disease Patients at Komfo Anokye Teaching Hospital, Ghana

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A list of the number of manuscript pages - 30

Number of tables – 3

Word count - 5500

Abstract

This study examines the impact of advance care planning on the quality of life for patients with chronic kidney disease (CKD). It specifically investigates the readiness and support provided by healthcare professionals at Komfo Anokye Teaching Hospital. Utilizing a qualitative descriptive design, one-on-one interviews were conducted with CKD patients at the renal clinic, employing a semi-structured interview guide for thematic analysis of audio data. The findings reveal a significant gap in understanding among CKD patients, with participants acknowledging their vulnerability to renal failure, often associated with a medical history of diabetes and hypertension. Despite recognizing potential outcomes such as dialysis dependency or death, some retained hope for a cure, relying on faith. The initial kidney failure diagnosis induced shock and distress, influencing preferences for home-based care, including dialysis, for the majority, while a minority favored hospital care to protect their children from psychological trauma. Most participants deemed legal preparations unnecessary, citing limited assets or a lack of concern for posthumous estate execution. These insights underscore the necessity for targeted education and support in advance care planning, providing valuable information for interventions and policies aimed at enhancing patient outcomes in CKD care and end-of-life planning.

Keywords: Palliative care, Advance care planning, Chronic kidney disease, Patient-centered care

1. Introduction

Chronic kidney disease (CKD) poses a formidable global public health challenge, affecting 10% to 15% of the world's population. Sub-Saharan Africa, notably Ghana, grapples with a pronounced CKD prevalence, reaching 13.9% and 13.3%, respectively (Hill et al., 2016; Abd ElHafeez et al., 2018). This condition stands as a significant contributor to medical admissions, elevating morbidity and mortality rates in Ghanaian healthcare settings (Amoako et al., 2014; Abd ElHafeez et al., 2018; Okyere et al., 2019).

Patients diagnosed with CKD undergo a progressive decline in health, despite interventions like medications and dialysis. This persistent deterioration emphasizes the need for comprehensive palliative care, addressing not only the physical symptoms but also the psychosocial and spiritual aspects of patients and their families (WHO, 2018). Central to palliative care for CKD is advance care planning, a process facilitating patients in articulating their preferences for future medical treatments in incapacitating scenarios (Rietjens et al., 2017). This involves discussions on the disease, prognosis, decision-making plans, end-of-life preferences, healthcare proxies, and living wills, aiming for a compassionate end-of-life experience aligned with patient and family preferences (Carr & Luth, 2016).

Advance care planning stands as a crucial component in improving the quality of life for CKD patients. This proactive approach not only empowers patients but also actively involves them in critical care decision-making processes, thereby fostering a sense of autonomy and control over their medical journey (Rietjens et al., 2017). For CKD patients, navigating the complexities of their condition can be particularly challenging, making the role of advance care planning even more pivotal. By providing a platform for open communication, discussing treatment preferences, and addressing end-of-life concerns, advance care planning becomes an integral part of the comprehensive care paradigm for CKD patients (Carr & Luth, 2016).

Healthcare professionals play a pivotal role in initiating these discussions and guiding patients and families in comprehending CKD, its prognosis, and making informed decisions about future care (Ofosu-Poku, 2021). Early initiation of these conversations is vital, especially given the challenging decision-making scenarios CKD patients might confront, such as the administration of treatments like dialysis, potentially misaligned with their wishes (Davison, 2010; Wong et al., 2012). On the contrary, early discussions about advance care planning increase the likelihood of honoring patients' and families' wishes, thus enhancing end-of-life care (Detering et al., 2010; Lorenz et al., 2008).

In low-income countries like Ghana, diagnosed CKD patients often grapple with advanced stages of the disease, amplifying the significance of discussions about advance care planning. This necessitates a profound understanding of the financial burdens, psychosocial challenges, and care plans associated with the disease's progression. Thus, advance care planning becomes an integral component for providing holistic care to CKD patients (Holley, 2012).

Palliative care, deeply embedded in the basic training of healthcare professionals, is well-suited to assist CKD patients and their families through advance care planning (Rak et al., 2017). Numerous studies consistently demonstrate that comprehensive advance care planning can alleviate anxiety and depression, facilitate decision-making, address psychosocial issues early in the disease course, and significantly enhance the quality of life for patients and their families, irrespective of the disease's progression (Diop et al., 2017; Hasson et al., 2020).

Despite the urgency of these issues, studies among CKD patients at Komfo Anokye Teaching Hospital (KATH) have indicated a lack of insight into their condition and poor preparedness for dealing with the challenges it presents (Eghan et al., 2009; Amoako et al., 2014; Tannor et al., 2019). In this context, this research seeks to address fundamental questions concerning CKD patients' preparedness, the role of healthcare professionals, and patient attitudes toward advance care planning. The study, conducted from the perspective of CKD patients receiving care at the renal clinic of KATH, aims to assess the attitude and preparedness of CKD patients for advance care planning. Specific objectives include evaluating the knowledge of CKD patients about their diagnosis and prognosis, exploring the preparedness of CKD patients for advance care planning, and describing the attitudes of CKD patients toward advance care planning. This research is vital for tailoring and enhancing advance care planning initiatives for CKD patients in Ghana, ultimately contributing to a more compassionate and patient-centered approach to end-of-life care.

2. Methods

Design

This study utilized a qualitative descriptive design to investigate the attitudes and preparedness of patients with CKD regarding advanced care planning. The qualitative approach is well-suited for exploring the experiences and attitudes of a specific group of respondents, addressing questions related to 'what,' 'why,' and 'how' concerning a particular phenomenon (Palinkas et al., 2015). The choice of this research method was guided by the nature of the research objectives. Consequently, it allowed for a comprehensive and in-depth exploration of patients' attitudes toward advance care planning among those with CKD. This approach was selected to minimize bias and ensure that the study provides a holistic understanding of the subject matter.

Sampling

The target population of this study comprised patients with Chronic Kidney Disease (CKD) who were receiving care at the KATH's renal clinic. The renal clinic provided outpatient services on Wednesdays and Thursdays, with the clinic records from 2020 estimating that around 480 patients were seen each year. Typically, there were 10 to 30 patients attending the clinic on any given day.

To be eligible for inclusion in the study, patients had to meet the following criteria: (1) Have a diagnosis of CKD and be receiving care at the renal clinic for a minimum of one month; (2) May or may not be on hemodialysis; (3) Be 18 years of age or older. Exclusion criteria involved patients with: (1) Altered mental status; and inability to communicate in English or local language (Twi).

The study utilized the purposive sampling technique to select participants, a non-probability method commonly employed in qualitative research. This approach involves the deliberate selection of individuals by the researcher, targeting those who can provide pertinent information related to the research topic. In the current investigation, participants were specifically chosen based on predefined criteria, ensuring their ability to offer valuable insights into the subject of interest. The interview pool consisted of 12 participants, contributing to a comprehensive exploration of the research objectives.

Data collection

Data for the study was collected using structured interviews with participants. A semi-structured interview guide was meticulously designed in line with the study's objectives and informed by an extensive review of relevant literature. The guide included open-ended questions with probing queries to elicit comprehensive responses. Before data collection, the interview guide underwent rigorous review by the research team to ensure its appropriateness and comprehensiveness. To validate and refine the instrument, a pre-test was conducted with two participants. This exercise aimed to assess question clarity and enhance the researcher's interviewing skills. Adjustments were made based on pre-test results, finalizing the interview guide.

Participants were informed that their involvement was voluntary, and they could withdraw from the study at any point without repercussions. Emphasis was placed on the confidentiality of their information, and informed consent was documented through signed or thumb printed consent forms. Participants received a copy of these forms for their reference. A suitable interview environment was arranged, with essential amenities like water and tissue paper readily available to address potential emotional challenges. Participants were also educated about COVID-19 prevention measures following protocols from health authorities.

Interviews were conducted face-to-face, lasting an average of 15 to 30 minutes, with some extending up to one hour. These discussions took place in both English and Twi languages to ensure effective communication. Participants consented to audio recording of the interviews, and detailed field notes were taken to capture non-verbal cues and personal reflections. The data collection process strictly adhered to ethical standards to ensure participants' comfort and cooperation throughout the interviews.

Ethical consideration

Ethical approval for the study was granted by the Institutional Review Board of KATH, and the research proposal received approval from the Academic Board and Research & Ethics Committee of Ghana College of Nurses and Midwives. The study was officially registered at the Research and Development Unit of Komfo Anokye Teaching Hospital. The head of the Renal Clinic was informed about the study to seek their support and cooperation in recruiting participants. Patients at the renal clinic were approached and provided with a comprehensive explanation of the study. Those willing to participate were interviewed in a private counseling room to ensure confidentiality.

An introductory letter was obtained from the Ghana College of Nurses and Midwives Ethics Committee. Ethical clearance, referencing KATHIRB/AO/062/21, was also obtained from the Institutional Review Board of Komfo Anokye Teaching Hospital in Kumasi, Ghana. Written informed consent was provided to all participants. The study informed them that they had the freedom to withdraw at any time if they wished to do so. Participants consented to the recording of interviews, which were subsequently anonymized and transcribed. The interview data were securely stored on a password-protected (encrypted) computer.

Privacy and confidentiality of participants were carefully maintained during the interview process to protect them from any harm.

The researcher took measures to minimize emotional distress and psychological trauma, as some of the interview questions were distressing. However, a distress protocol was in place to manage any occurrences of distress.

Data analysis

Semi-structured face-to-face interviews were audio-recorded, and the data was manually coded and analyzed. The recorded interviews were played back multiple times to ensure data accuracy and transcribed verbatim. Interviews were conducted in Twi and transcribed into English by the researcher.

Signed consent forms, hard copies, transcripts, and audio recordings of the interviews were securely stored on an external drive for a minimum of five years. Access to this storage is restricted to the researcher and the research team. Additionally, all electronic data was saved in a folder on the researcher's personal computer, protected by a password known only to the researcher.

To maintain confidentiality, participants' names were pseudonymized, and each interview was transcribed verbatim. Field notes were included as needed. Transcripts were coded, and themes and sub-themes were generated, then analyzed using thematic analysis.

3. Results

3.1 Demographic characteristics of study participants

The demographic profile of the patients with CKD who participated in the study is presented in Table 1. It includes information regarding their gender, age, marital status, number of children, educational background, religion, duration of care received from the renal unit, and any co-morbid conditions.

3.2 Themes and Sub-themes

Themes and sub-themes developed following a thematic analysis of transcribed data has also been presented in Table 2 below. Three (3) themes and eight (8) sub-themes were developed.

3.3 Knowledge About CKD

The first major theme emerging from the interviews pertains to the participants' knowledge and understanding of their condition. This theme encompasses their comprehension of Chronic Kidney Disease (CKD), its risk factors, clinical features, and the progression of the disease. It has been further classified into three sub-themes: diagnosis and risk factors of CKD, clinical features, and disease progression.

3.4 Knowledge About the Diagnosis and Risk Factors

The majority of participants were under treatment for hypertension and were aware of their kidney disease. However, they demonstrated limited in-depth knowledge about the disease. One participant shared:

"My blood pressure was extremely high at about 260/100mmHg, prompting me to seek medical attention. After undergoing laboratory tests, the doctor informed me that I had a kidney problem." (Participant 2)

The study also explored the causes or risk factors of CKD among the participants. While the overall knowledge about kidney disease's causes and risk factors was relatively low, some participants displayed familiarity with the kidney's function. For instance:

"I had limited knowledge about the kidney, so I inquired with the doctor, who explained that the kidney is responsible for eliminating waste substances like urine from the body. It also produces a specific chemical aiding in red blood cell formation. Sometimes, I appear pale because of kidney damage. I require dialysis to support kidney function." (Participant 6)

A few participants who were known to have hypertension and diabetes recognized these conditions as potential precursors to CKD:

"I sought care at the renal clinic due to kidney problems. I have hypertension and prostate enlargement. This morning, my creatinine level was at 200mcmol/l, which concerns me. I've read about CKD, and if creatinine remains elevated, it's a warning sign of kidney failure. Given my hypertension, which is a CKD risk factor, I'm deeply concerned about the disease's progression." (Participant 5)

3.5 Knowledge About Clinical Features of the Disease

Clinical manifestations provide critical insights into the condition. Some participants, however, claimed they did not exhibit any signs of kidney disease. One participant expressed:

"The hospital conducted various tests, including ECG and renal function tests. After the investigations, they informed me of acute renal disease. I was taken aback by the kidney failure diagnosis, as I hadn't experienced any symptoms and was unaware of the clinical signs associated with kidney disease. I was leading a normal life and working hard, and now I'm dealing with this condition." (Participant 8)

Conversely, some participants could identify clinical features of the disease. One individual noted:

"Initially, I was informed about high blood pressure, but I didn't take the results seriously. After a few months, I began experiencing symptoms such as nausea, fatigue, loss of appetite, and a decrease in urination frequency, despite consuming ample water daily. I later noticed swelling in my ankles and feet. I returned to the hospital, and laboratory tests indicated kidney disease." (Participant 1)

This sub-theme also delves into participants' views on the potential progression of their ailment. Some acknowledged the likelihood of becoming dependent on dialysis due to their kidneys failing to regain normal function and even contemplated the possibility of death. For instance:

"The kidneys may no longer remove waste and urine from the body, resulting in complete damage, necessitating long-term dialysis. This disease can potentially lead to my demise." (Participant 9)

Another participant shared his perspective on disease progression while undergoing dialysis:

"From what I understand, I'm unable to urinate, which is why I'm on dialysis treatment. Initially, I had trouble sleeping, and my legs were swollen. However, over the past month, the swelling has decreased." (Participant 3)

In contrast, one participant expressed optimism grounded in faith, suggesting that the disease's progression ultimately rests with a higher power:

"I don't know, [pauses] I don't know [facial expression looking sad]. It all hinges on God because He knows everything. Even when a car breaks down, God provides the knowledge for

mechanics to repair it. So, I trust that God will equip doctors with the necessary knowledge to treat me. My hope lies in God, and I believe He will aid in my recovery." (Participant 6)

3.6 Attitudes of CKD Patients Toward Advance Care Planning

This theme explores the attitudes of patients with Chronic Kidney Disease (CKD) toward advance care planning, as revealed during the interviews with study participants. Four distinct sub-themes emerged: reactions to the diagnosis and prognosis, preferences regarding treatment wishes, choices for the location of care and end-of-life, and considerations about legal preparations. These sub-themes are discussed below, supported by participant quotes.

3.6.1 Attitude to Diagnosis and Prognosis

Participants commonly expressed feelings of shock and concern when they received their CKD diagnosis and prognosis from healthcare professionals. For instance, one participant, who was both shocked and distressed by the unexpected kidney disease diagnosis, recounted:

"I was surprised and worried at the same time because I woke up one day and I couldn't eat well... I went to the hospital myself, and the doctor said they should check my hemoglobin level, and he said the level was low, hence he would be giving me a transfusion. Finally, the doctor said I should see a specialist at the renal clinic, and here I am on this dialysis machine." (Participant 7)

Another participant, who had been diagnosed with stage 4 CKD, expressed his fear regarding the disease:

"I became afraid when told that I have a kidney problem." (Participant 9)

3.6.2 Preferences Regarding Treatment Wishes and Choices

Some participants expressed their wishes regarding treatment preferences, particularly when their condition deteriorates or nears the end of life. These wishes included the desire to discontinue life-sustaining treatments, investigations such as scans, liver function tests, and renal function tests. One participant shared:

"I wish to stop unnecessary investigations and treatments that will not bring me back to life and, at the same time, would cause financial loss to my family because my children are young, and the money wasted on trial and error procedures that doctors do could be saved for them. Leave me to die because everyone will die. I want to have a peaceful death, and so when I have pain, provide me with medicine to bring it under control." (Participant 10)

Conversely, other participants did not wish to withhold life-sustaining treatments, including dialysis, even when their condition declined. One participant emphasized his treatment preference:

"My wish is to find a cure. As I am communicating with you now, if I am told there is a cure somewhere or that doctors have found a breakthrough in treatment, I will quickly pursue that treatment. When the cost of dialysis treatment is reduced, everyone will be happy, allowing those on it for 30 years to manage the costs." (Participant 8)

Additionally, some participants felt that decisions about treatment preferences should be entrusted to medical professionals who possess the necessary expertise. One participant expressed this viewpoint:

"I'm not a doctor, and I don't have the knowledge to decide because the doctor has the expertise. I lack knowledge about managing my condition, so I can't tell him what to do or not." (Participant 3).

3.6.3 Attitudes of Patients with CKD Toward Place of Care and End-of-Life Decisions

Participants expressed their preference for receiving care at home when their condition deteriorated. However, they expressed concerns about the potentially high cost of in-home care. Consequently, they mentioned their willingness to consider hospital-based care when their condition worsened. For example, one participant stated:

"I would prefer to be cared for at home. However, the cost of in-home care is a concern for me. If the financial aspect were more manageable, I would choose to stay at home. Otherwise, I might consider coming to the hospital." (Participant 7)

Another participant echoed this sentiment:

"I would like to receive care at home because of the long distance between my house and the renal clinic. It would be more convenient if healthcare professionals could visit me at home, especially when I'm feeling too weak to make the trip to the hospital."

However, another participant expressed a different perspective, preferring to receive care in the hospital and eventually pass away there in order to protect his children from potential psychological trauma. He explained:

"I would prefer to be taken care of in the hospital and, when the time comes, to pass away here. I don't want my children to witness my death at home, as I believe it could have a lasting psychological impact on them." (Participant 2)

Regarding the preferred place of death, most participants expressed a desire to pass away at home. One participant emphasized:

"I would like to receive care at home. But when the end is near and my capacity diminishes, signaling that death is approaching, I want to be in the hospital, and I have informed my family to bring me here." (Participant 1)

Conversely, another participant wished not to die at home due to concerns about the potential psychological impact on his children. He stated:

"I prefer to receive care in the hospital and, if my time comes, to pass away here. I don't want my children to witness my death at home, as I believe it could have a lasting psychological impact on them." (Participant 2)

3.6.4 Attitude of Patients with CKD on Legal Preparation

Most participants had not prepared written documents concerning their healthcare proxy and living will. However, they had considered individuals who might take on these roles if the need arose. For instance:

One participant shared, *"I haven't thought about someone standing in to take care of my affairs when the disease progresses and I can't do anything for myself. However, my wife, who knows much about the disease and what I am going through, will stand in for me." (Participant 9).*

Another participant expressed, *"My eldest son knows much about how my disease is progressing, and if the condition worsens and I am not in a capacity to speak concerning my medical treatment advice and other affairs, he will stand in for me" (Participant 4).*

One participant had contemplated who would manage their affairs in the event of incapacity but had not yet officially appointed or documented the person:

"For my work and other affairs, I don't have anyone who is taking care of it, and I have contemplated it in my mind. However, in case I'm not able to do things myself when my condition doesn't favor me, my husband will stand in for me" (Participant 7).

Regarding wills, some participants had not prepared one because they believed they had no significant assets to leave behind. For example:

"I don't have any property to share. I live in one house with my wife and children. If I'm deceased, it belongs to them. I don't need a written or verbal document attached to it" (Participant 6).

Another participant explained, *"I have no intention of creating a will, but I believe in equal sharing. If I'm deceased and gone, the way my property is shared is not my concern. My dad didn't create a will, and that's the path I am also following" (Participant 8).*

However, one participant, influenced by past family experiences, had prepared a written will:

"I have a lawyer. I've discussed with him how my properties should be distributed. My father didn't create a will, and when he passed away, the family claimed all his property from us. I've learned not to follow in my father's footsteps" (Participant 5).

3.7 Preparation of Patients with CKD Toward Advance Care Planning

During the interview process, some participants displayed readiness or preparedness for advance care planning, while others did not. Quotes from participants illustrated their level of preparedness and readiness for advance care planning. The responses of patients with CKD indicating their preparedness for advance care planning are presented in Table 3 below.

4. DISCUSSION

4.1 Summary

This qualitative study, conducted at the Renal Clinic of Komfo Anokye Teaching Hospital in Ghana, extensively investigated the attitudes and preparedness of patients with chronic kidney failure concerning advance care planning. The findings indicated that all participants were cognizant of their kidney disease, recognizing its potential progression, with many acknowledging that their medical history of diabetes and hypertension heightened their vulnerability to renal failure. While participants generally comprehended the potential progression of their condition, leading to dependency on dialysis and, in some cases, death, a few remained hopeful for a cure, relying on their faith in the Supreme Being. The study also revealed that participants experienced shock and distress upon their initial kidney failure diagnosis. A majority expressed a preference for home-based care, including dialysis, while a minority favored hospital care to shield their children from potential psychological trauma. Regarding legal preparations, excluding one participant who had prepared a written will, most saw no need for a written or verbal will, attributing this lack of motivation to either having few assets to distribute or not being concerned about posthumous estate execution. These insights significantly contribute to our understanding of CKD care and end-of-life planning, providing valuable input for future interventions and policies to enhance patient outcomes and experiences.

4.2 Knowledge of Patients with CKD About Advance Care Planning

Patient awareness of chronic kidney disease (CKD) is crucial, as appropriate treatment depends on both physician awareness and patient understanding. In this study, participants demonstrated limited in-depth knowledge about CKD, aligning with findings from a Nigerian study by Odubanjo et al. (2011), which reported low CKD awareness and its correlation with a high mortality rate (between 40% and 50%).

While most participants understood the predisposing factors and clinical manifestations of CKD, some remained unaware of the disease's cause. This finding is consistent with Gray et al.'s (2016) study, which revealed that a significant portion of patients attributed CKD to alcohol (23%), did not have knowledge about CKD (44%), and were unsure about its cause (38%).

Clinical manifestations provided insight into the disease's occurrence and symptom presentation. Some participants in this study did not notice any CKD signs and symptoms, which is supported by Brown et al.'s (2015) report that CKD often lacks specific symptoms in the early stages.

However, most participants could identify CKD symptoms such as fatigue, urination difficulties, edema, and shortness of breath, all of which significantly affected their quality of life. An emphasis was placed on anemia as a significant symptom leading to frequent blood transfusions, aligning with James et al.'s (2020) findings, which highlighted fatigue and anemia as common symptoms impacting patients' health-related quality of life.

4.3 Knowledge of Patients with CKD About Disease Progression

Patients with chronic kidney disease tend to deteriorate over time and progress to end-stage kidney disease. In this study, most participants were unaware of the severity and progression of CKD, consistent with the findings of qualitative studies in which patients displayed little knowledge of the disease's severity.

4.4 Attitude of Patients with CKD Toward Advance Care Planning

In this study, participants expressed their attitudes towards discussing various aspects of advance care planning (ACP) during the later stages of their disease or end of life. These ACP topics included diagnosis and prognosis, treatment preferences, preferred place of care, health care proxies, and the creation of verbal or written wills.

Participants typically reacted with shock upon learning of their CKD diagnosis and prognosis. This emotional response corresponds with the findings of studies that have explored patient perceptions of medical treatment, such as Morton et al. (2010) and Zalai et al. (2012), which reported that patients were unprepared and shocked by their diagnosis and the disease's progression.

When it came to treatment preferences, some participants expressed a desire for life-sustaining treatments like dialysis during the end of life. These preferences align with findings from a survey of patients across various renal clinics in Australia, which revealed that many patients would opt for dialysis over other comfort measures (Morton et al., 2012).

Furthermore, some participants preferred that physicians make decisions about treatment options when their disease deteriorated and they approached the end of life. This preference echoes the sentiments of family caregivers in Ghana, as outlined by Ofosu-Poku et al. (2020). Patients and family caregivers in these contexts tend to place their trust in primary doctors and may not feel involved in the decision-making process due to their limited understanding of the disease.

ACP encompasses the patient's ability to choose the place of care. In this study, participants expressed a preference for home care, while others preferred care at a healthcare facility. Those favoring home care cited the convenience of receiving care in a familiar environment due to difficulties accessing healthcare facilities in their weakened state. This preference for home care corresponds to studies by the Canadian Health Association (2009), where patients voiced their desire to receive care at home to maintain independence.

Some patients wished to receive care at home but expressed concern about the cost, which often led them to opt for healthcare facility-based care when their condition worsened. Others preferred hospital care to protect their children from potential psychological trauma. This finding aligns with a qualitative study by Sandsdalen (2016), which highlighted varying patient preferences for either home-based or facility-based palliative care.

Regarding the choice of a healthcare proxy, most participants implicitly knew who would take on this role, even though they had not explicitly appointed one. This reflects a common trend observed in patients who trust their family members to make decisions on their behalf when needed (Boateng & East, 2018).

When it came to preparing wills, most participants lacked the motivation to create one, as they either had minimal assets to distribute or felt untroubled by the posthumous execution of their estate. This finding is consistent with thematic analysis by Irfana et al. (2015) in the East Midlands, which suggests that patients' readiness to participate in different aspects of ACP depends on their personal values and preferences.

4.5 Patient Preparation for Advance Care Planning

In this study, participants exhibited varying levels of preparedness and readiness for advance care planning. Their engagement in ACP topics was determined by their values and interests, and they often shifted discussions or avoided certain topics if they lacked interest. This observation is consistent with research by Zwakman et al. (2018; 2021), which highlight that patients' readiness to participate in different aspects of ACP is influenced by their values and preferences.

5. Conclusion

This study conducted at the Renal Clinic of Komfo Anokye Teaching Hospital, Ghana, reveals a significant knowledge gap among chronic kidney failure (CKD) patients regarding advance care planning. Despite their awareness of the condition and its potential progression, particularly among those with diabetes and hypertension, participants acknowledge an increased vulnerability to renal failure. Some maintain hope for a cure, relying on faith even while recognizing the potential trajectory towards dialysis or death. The initial diagnosis of kidney failure induces shock and distress, underscoring its emotional impact. Preferences for care reveal a majority favoring home-based options, including dialysis, while a minority opts for hospital care to shield their children from trauma. Regarding legal preparations, a majority perceive no need, often attributing it to a lack of assets or a perceived lack of concern for posthumous estate execution. These insights underscore the imperative for targeted education and support in advance care planning. The study provides valuable insights for interventions and policies to enhance patient outcomes, highlighting a critical opportunity to improve patient understanding and willingness to engage in advance care planning. Active involvement of healthcare professionals has the potential to positively impact the overall quality of life for CKD patients, emphasizing their pivotal role in fostering a comprehensive and patient-centered approach in chronic kidney disease care.

Acknowledgment: We extend our sincere gratitude to Komfo Anokye Teaching Hospital, Kumasi, Ghana for their invaluable support to the corresponding author during her professional program in palliative care.

Competing Interests: The authors declare no conflict of interest.

Funding Statement: This work was supported by the Komfo Anokye Teaching Hospital, Kumasi, Ghana

7. References

Abd ElHafeez S, Bolignano D, D'Arrigo G, Dounousi E, Tripepi G and Zoccali C (2018) Prevalence and burden of chronic kidney disease among the general population and high-risk groups in Africa: a systematic review. *BMJ Open 8*(1), e015069.

Amoako YA, Laryea DO, Bedu-Addo G, Andoh H and Awuku YA (2014) Clinical and demographic characteristics of chronic kidney disease patients in a tertiary facility in Ghana. *The Pan African Medical Journal* 18.

Boateng EA and East C (2018) Decision-making experiences of patients with end-stage kidney disease (ESKD) regarding treatment in Ghana: qualitative study. *BMC Nephrology* 19, 371

Brown MA, Collett GK, Josland EA, Foote C, Li Q, and Brennan FP (2015) CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *Clinical Journal of the American Society of Nephrology* 10(2), 260-268.

Canadian Healthcare Association (2009) Home Care in Canada: From the Margin to Mainstream. Ottawa, Ontario.

Carr D and Luth E (2016) End of life planning and health care. Handbook of ageing and social sciences, 8th edition , New York, Academic press pp. 375-394.

Davison SN (2010) End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clinical Journal of Americal Society of Nephrology* (5), 195-204.

Deterring KM, Hancock AD, Reade MC and Silvester W (2010) The impact of advance planning on end of life care in elderly patients: A randomized controlled trial, *BMJ* 340: c1345.

Diop MS, Rudolph JL, Zimmerman KM, Richter MA and Skarf LM (2017) Palliative care interventions for patients with heart failure: a systematic review and meta-analysis. *Journal of palliative medicine 20*(1), 84-92.

Eghan BA, Amoako-Atta K, Kankam CA and Nsiah-Asar A (2009) Survival pattern of hemodialysis patients in Kumasi, Ghana: a summary of forty patients initiated on hemodialysis at a new hemodialysis unit. *Hemodialysis International 13*(4), 467-471.

Gray NA, Kapojos JJ, Burke MT, Sammartino C and Clark CJ (2016) Patient kidney disease knowledge remains inadequate with standard nephrology outpatient care. *Clinical kidney journal* 9(1), 113-118.

Hasson F, Nicholson E, Muldrew D, Bamidele O, Payne S, and McIlfatrick S (2020) International palliative care research priorities: A systematic review. *BMC Palliative Care 19*(1), 16.

Hill NR, Fatoba ST, Oke JL, Hirst JA, O'Callaghan CA, Lasserson DS and Hobbs FR (2016) Global prevalence of chronic kidney disease–a systematic review and meta-analysis. *PloS one 11*(7), e0158765.

Holley JL (2012) Advance care planning in CKD/ESRD: an evolving process. *Society of Nephrology: CJASN*. 7 (6) 1033-1038.

Irfana M (2015) A survey of older people attitude toward advance care planning. *Age and ageing* 44(3) 371-376.

James G, Nyman E, Fitz-Randolph M, Niklasson A, Hedman K, Hedberg J, Wittbrodt ET, Medin J, Moreno QC, Allum AM and Emmas C (2020) Characteristics, Symptom Severity, and Experiences of Patients Reporting Chronic Kidney Disease in the PatientsLikeMe

Online Health Community: Retrospective and Qualitative Study. *Journal of Medical Internet Research* 22(7):e18548

KATH. (2016) About Us/Our History. Retrieved from https://kath.gov.gh/our-history/

Lorenz KA, Lynn J, Dy SM and Shugarman LR (2008) Evidence for improving Palliative care at the end of life: A systematic review. *Annals of Internal Medicine* 148: 147-159.

Morton RL, Tong A and Howard K (2010) The view of patients and carers in treatment decision making for chronic kidney diseases: systematic review and thematic synthesis of qualitative studies. *BMJ* 340:c112

Morton RL,Snewlling P and Webster AC (2012) Factors influencing patient choice of dialysis versus conservative care to treat end-stage-kidney. CMAJ 184,E277-E2283

Odubanjo MO, Oluwasola AO, Kadris S (2011) The epidermmmiology of end-stage renal disease in Nigeria: the way forward. *International Urology and Nephrology* 43(3), 785-92.

Ofosu-Poku R, Owusu-Ansah M, Antwi J (2020) Referral of Patients with Nonmalignant Chronic Diseases to Specialist Palliative Care: A Study in a Teaching Hospital in Ghana. *International Journal of Chronic Diseases* 8432956:11.

Ofosu-Poku R (2021) Who is making decisions: An open letter to healthcare professionals in the developing world. In: Suggestions for Addressing Clinical and Non-Clinical Issues in Palliative Care. Editor: Marco Cascella. 95410.

Okyere P, Okyere I, Yaw FM and Osafo C (2019) MON-266 pattern of renal diseases at Komfo Anokye Teaching Hospital, Kumasi-Ghana: a 13-year review. *Kidney International Reports 4*(7), S408.

Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N and Hoagwood K (2015) Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health 42*(5), 533–544.

Rak A, Raina R and Theodore T (2017) Palliative care for patients with end-stage-renal disease: approach to treatment that aims to improve quality of life and relieves suffering for patients and families with chronic illness. *Clinical kidney journal* 10, 68-73.

Rietjens J, Sudore RL, and Connolly M (2017) Definition and recommendation for advance care planning: an international consensus supported by the European Association for Palliative Care, *Lancet Oncol* 18(9)543-551.

Sandsdalen T, Hov R, Høye S, Rystedt I and Wilde-larsson B (2015) Patients' preferences in palliative care : A systematic mixed studies review. *Palliative Medicine* 1–21.

Tannor EK, Norman BR, Adusei KK, Sarfo FS, Davids MR and Bedu-Addo G (2019) Quality of life among patients with moderate to advanced chronic kidney disease in Ghana-a single centre study. *BMC nephrology 20*(1), 122.

World Health Organization. (2018). WHO definition of palliative care. Retrieved from http://www.who.int/cancer/palliative/definition/en/Accessed 3 Aug. 2018

Zalai D, Szeifert L and Novak M (2012) Psychological distress and depression in patients with chronic kidney disease. In Seminars in dialysis. Oxford, UK: Blackwell Publishing Ltd, pp. 428-438.

Zwakman M, Jabbarin LJ and Van Delden J (2018) Advance care planning: a systematic review about the experiences of patients with life-threatening or life-limiting illness. *Palliative Medicine* 32(8): 1305-1321.

Zwakman M, Milota MM and van der Heide A (2021) Unraveling patients' readiness in advance care planning converstion: a qualitative study as part of the ACTION Study.

Support Care Cancer 29,2917-2929.