ADVANCE CARE PLANNING BETWEEN CLINICIANS AND PATIENTS ON MAINTENANCE HEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL, NAIROBI COUNTY KENYA

BY

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OCTOBER 2020.

DECLARATION

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CERTIFICATE OF APPROVAL

We the undersigned supervisors, confirm that this research thesis has been submitted with our full approval.

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DEDICATION

I dedicate this work to the Almighty God for according me life and good health throughout the course of this work. It is also dedicated to my mother Mwaka Mwaiwe and my entire family for the love, encouragement and support and to all those patients on maintenance hemodialysis for their positivity and resilience.

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TABLE OF CONTENTS

DECLARATION ii

CERTIFICATE OF APPROVAL iii

DEDICATION…………………..…………………………………………………………..iv

ACKNOWLEDGEMENT……………………………………………..……………………v

LIST OF FIGURES x

LIST OF TABLES xi

ABBREVIATIONS xii

OPERATIONAL DEFINITIONS xiv

ABSTRACT xv

CHAPTER ONE: INTRODUCTION 1

- 1.1. Background Information 1
- 1.2. Problem Statement 3
- 1.3. Justification of the Study 4
- 1.4. Significance of the Study 5
- 1.5. Research Questions 6
- 1.6. Study Objectives 6
  - 1.6.1. Broad Objective 6
  - 1.6.2. Specific Objectives 6

CHAPTER TWO: LITERATURE REVIEW 7

- 2.1. Introduction 7
- 2.2. Overview of Chronic Kidney Disease and End Stage Kidney Disease 7
  - 2.2.1. Definition of CKD and ESKD 7
  - 2.2.2. Epidemiological trends of CKD and ESKD 7
  - 2.2.3. Socio-demographic Characteristics of ESKD patients 8
- Management approaches for ESKD 10
  - 2.2.4. Conservative management (Non-dialytic care/Supportive) for ESKD 10
  - 2.2.5. Renal Replacement Therapies (RRT) 10
- 2.3. Knowledge level of Advance care planning among patients 11
- 2.4 Uptake of Advance care planning by patients 12
  - 2.4.1 Advance care planning discussions 13
  - 2.4.2 Advance directives (ADs) 14

2.5 Advance care planning preferences of Patients on Maintenance Hemodialysis 14
  2.5.1 Advance care planning discussions and Surrogate decision making 15
  2.5.2 Conservative management and Renal Replacement Therapies 16
  2.5.3 Aggressive life-sustaining therapies and Referral to a Palliative care center 17
  2.5.4 Place of Death 17
2.6 Clinicians' practice of Advance care planning 17
2.7 Study Variables 19
2.8 Hypothesis 19
2.9 Conceptual framework 20
2.10 Theoretical Framework 21
CHAPTER THREE: MATERIALS AND METHODS 23
3.1. Introduction 23
3.2. Study design 23
3.3. Study area 23
3.4. Study population 24
3.5. Inclusion criteria 24
3.6. Exclusion criteria 24
3.7. Sample size calculation 25
  3.7.1. Sample size for ESKD patients – Questionnaire-based study 25
  3.7.2. Sample size for key informant interviews-based study 26
3.8. Sampling Method 26
3.9. Screening and Recruitment of Participants 26
3.10 Data collection tools 27
3.11 Reliability and Validity 27
  3.11.1 Internal consistency reliability 27
  3.11.2 Validity 27
3.12 Pre-testing 27
3.13 Data collection assistants 28
3.14 Data collection procedure 28
  3.14.1Quantitative data collection procedure 28
  3.14.2Qualitative Data collection 28
3.15 Control of data quality 29

3.16 Data cleaning and entry ... 29
3.17 Data analysis and presentation ... 29
3.18 Ethical consideration ... 30
3.19 Limitations ... 30
3.20 Delimitations ... 30
3.21Plan for dissemination of data ... 31
CHAPTER FOUR: RESULTS ... 32
4.1 Introduction ... 32
4.2 Demographic characteristics of respondents ... 32
4.3Patient’s Knowledge on Advance care planning ... 33
4.3.1Knowledge of the disease as life limiting ... 33
4.3.2 Knowledge on whether the disease can be cured ... 33
4.3.3Heard of Advance care planning ... 34
4.3.4Educated/given information on advance care planning ... 35
4.3.5Knowledge on components of advance care planning among respondents ... 36
4.3.6Knowledge about advance care planning discussions ... 37
4.3.7Knowledge on living will/advance directives ... 38
4.38Knowledge on surrogate/alternative decision making among the respondents ... 39
4.4Uptake of advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital ... 39
4.4.1Mental alertness at the time of diagnosis among respondents ... 39
4.4.2Education about health condition prior to dialysis among respondents ... 40
4.4.3Choice of hemodialysis ... 41
4.4.4Advance care planning discussion ... 41
4.4.5Surrogate/alternative decision making ... 42
4.4.6Uptake of advance directives/living will. ... 42
4.5 Patients’ preferences on Advance care planning ... 42
4.5.1Willingness to have advance care discussion ... 42
4.5.2Willingness to have a documented living will ... 43
4.5.3Willingness to have surrogate decision maker ... 44
4.5.4. The surrogate decision maker choice among the respondents ... 45
4.5.5End of life care preferences of patients on maintenance hemodialysis at Kenyatta National Hospital ... 45

4.5.6Preferences regarding HD 47
4.2.1 Place of death preference 47
4.6Clinicians' practice of advance care planning with patients on maintenance hemodialysis at Kenyatta National Hospital 48
4.6.1Patients' Knowledge on advance care planning 48
4.6.2Advance care planning discussions 48
4.6.3Identification of patients' care preferences 49
4.6.4Surrogate decision making and Advance directives 50
4.6.5Opinions about up scaling advance care planning 50
4.7Association between patients' characteristics and uptake of advance care planning 52
CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECCOMMENDATION 53
5.1 Introduction 53
5.2 Discussion 53
5.2.1 The level of knowledge on advanced care planning among patients on maintenance hemodialysis at Kenyatta National Hospital renal unit 53
5.2.2 The uptake of advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital 54
5.2.3 Advance care planning preferences of patients on maintenance hemodialysis at Kenyatta National Hospital. 56
5.2.4 Clinicians' practice of Advance care planning with patients on maintenance hemodialysis. 57
5.2.5 Association between patients' characteristics and uptake of advance care planning ... 57
5.3 Conclusion 59
5.4 Recommendations 59
BIBLIOGRAPHY 60
APPENDICES 67
Appendix I: Participant information sheet and information sheet consent form 67
Appendix II: Maelezo kwa mshiriki kuhusu utafiti 71
Appendix III: Questionnaire 75
Appendix IV: Key Informant Information sheet and Consent form 83
Appendix V: Interview Schedule/guide on clinicians' practice of advance care planning with patients on maintenance hemodialysis. 87
Appendix VI: KNH-UON ERC Approval letter 88
Appendix VII: Similarity index report 90

LIST OF FIGURES

Figure 2. 1: Conceptual framework 20
Figure 2. 2: The Health Belief Model.. 22
Figure 4. 1: Respondents of the illness as life limiting.. 33
Figure 4. 2: Respondents assertion on whether the disease can be cured.................................... 33
Figure 4. 3: Heard of Advance care planning.. 34
Figure 4. 4. : Source of ACP information.. 34
Figure 4. 5: Whether respondents received information/education on ACP 35
Figure 4. 6: Respondent’s source of information/education on ACP 35
Figure 4. 7: Respondents mental alertness at the time of diagnosis 40
Figure 4. 8: Respondents educated about health condition... 40
Figure 4. 9: Respondents willing to ACP Discussions 43
Figure 4. 10: Respondents willingness to having a documented living will 44
Figure 4. 11: Willingness to have a surrogate decision maker among respondents 45
Figure 4. 12: Respondent’s choice of surrogate decision maker 45
Figure 4. 13: Respondent’s advance care option preference 46
Figure 4. 14: Respondent’s place of death reference.. 47

LIST OF TABLES

Table 2. 1: Study variables.. 19

Table 4. 1: Respondents demographic characteristics 32
Table 4. 2: Respondents' knowledge of what advance care planning entails............................... 36
Table 4. 3: Knowledge on advance care planning discussions among the respondents 37
Table 4. 4: Knowledge about living will 38
Table 4. 5: Knowledge about alternative/surrogate decision making among respondents........... 39
Table 4. 6: Respondents Choice of hemodialysis 41
Table 4. 7: Respondents uptake of advance care planning discussion 41
Table 4. 8: Respondents' selection and documentation of surrogate decision makers................ 42
Table 4. 9: Advance directives.. 42
Table 4. 10: Respondent preferences on HD at end of life 47
Table 4. 11: Chi-square test for association between patients' characteristics and ACP uptake.. 52

ABBREVIATIONS

ACP	Advance Care Planning
ADs	Advance Directives
CKD	Chronic Kidney Disease
CPR	Cardiopulmonary Resuscitation
EoL	End of Life
EoLC	End of Life Care
ERC	Ethics and Research Committee
ESKD	End Stage Kidney Disease
GFR	Glomerular Filtration Rate
HBM	Health Belief Model
HD	Hemodialysis
HIV	Human Immunodeficiency Virus
ICU	Intensive Care Unit
KDIGO	Kidney Disease Improving Global Outcomes
KDOQI	Kidney Disease Outcomes Quality Initiative
KEHPCA	Kenya Hospices and Palliative Care Association
KNH	Kenyatta National Hospital
LMIC	Low- and Middle-Income Countries
MES	Managed Equipment Services
NCDs	Non-Communicable Diseases
PD	Peritoneal Dialysis
QoL	Quality of Life
RRT	Renal Replacement Therapy
RT	Renal Transplantation
SDM	Shared Decision Making
SPSS	Statistical Package for Social Sciences

UON	University of Nairobi

OPERATIONAL DEFINITIONS

Advance care planning - an evidence-based process of trying to establishing care preferences and future plans of care, goals and selection of a surrogate decision maker in the inevitable event that a patient lacks the cognitive ability to make future care decisions with advancing illness

Advance directives - documented future care decisions or a living will that delegates to a surrogate decision-maker lasting power of attorney to remain in effect during the incompetency of the person making it

Shared decision making - is the process that integrates the best evidence from research and practice with the patient's values, beliefs and preferences

Clinician – For the purpose of this study, a clinician is a medical doctor who has successfully undergone the prescribed training to practice as a nephrologist

Patient on maintenance HD-This is a patient with confirmed end stage kidney disease who is being managed through hemodialysis in order to replace some of the diminished kidney functions such as removal of excess fluid, metabolic waste products and correction of electrolytes imbalances**.**

ABSTRACT

Background: End-stage kidney disease (ESKD) is a leading global threat to health with incidences and mortality rates higher than most cancers. Much of the symptom burden and the deterioration of functional independence post-initiation of hemodialysis are therapy-related. However, advance care planning (ACP), in most cases, is avoided until the last stages of life when patients' autonomy and free will are diminished. ACP is not done in nearly 50% of patients, and only about 5% of patients who need ACP receive it in Africa. Unlike in cancer patients, it's only sporadically done in hemodialysis patients or, in most cases, not done at all. Thus, it is essential to understand patients’ and clinicians’ perspectives regarding advanced care planning.

Aim of the study: To assess knowledge, uptake and preferences on advance care planning of patients on maintenance hemodialysis as well as advance care planning practice of renal clinicians at Kenyatta National hospital (KNH).

Methodology: A descriptive cross-sectional mixed methods research design using quantitative and qualitative approach was employed in this study. The study area was KNH renal unit. Ethical approval was sought from KNH-UoN ERC prior to collecting data. A structured interviewer administered questionnaire used to collect quantitative data from 99 patients on their knowledge, preferences and uptake of ACP. Using interview guide, qualitative data regarding practice of ACP was obtained from two key informant interviews, who were clinicians.

Quantitative data was analyzed using statistical package for social sciences (SPSS) version 26. Both descriptive and inferential approaches were used to examine distribution of variables. Continuous data was analyzed using mean (SD) and median (Interquartile Range). Categorical data was analyzed using frequencies (n) and percentages (%). Results were presented using of tables, charts, and graphs. A Chi-square test for the association was used to determine the association between patient characteristics and ACP uptake. The rejection level was determined at a 0.05 level of significance.

Content analysis was used to analyze qualitative data. Audio-recorded files were transcribed and manually analyzed to develop patterns and themes based on presence of key words across the two transcripts.

Results: Slightly more than half (58.6%) of patients were male, the average was 44 years. 36.4% of the respondents heard of ACP while 11.1% had been educated on ACP. 52% had not heard of a living will while 58.8% thought that their doctors could overrule their living will. 7% had ACP discussions while 86.9% had specific preferences regarding their care yet they had not had such discussions. 79% were willing to have ACP discussions. None of the respondents had documented a surrogate decision maker or a living will. 92% and 90.9% were willing to have living wills and surrogate decision makers respectively. Regarding end of life care, 46.5% and 26.3% preferred hospital care and home respectively as their place of death. There was significant association between uptake of ACP and knowledge on ACP (p=0.001), marital status (p=0.026) as well as preferences at end of life (p=0.049).

On clinicians' practice of ACP, clinicians confirmed that patients' knowledge of ACP was limited and that their practice of ACP was low. They attributed this to patients coming in very late, uncertainty of estimating life expectancy as well as fear that ACP could have negative psychological effects on their clients

Conclusion: The study indicated that there was limited patients' knowledge and uptake of ACP. Clinicians' practice of ACP was similarly low. However, majority of patients expressed willingness to engage in ACP.

Recommendations: The findings underscore the need for clinicians to put more effort to create awareness of ACP among patients on maintenance hemodialysis. The management of KHN also needs to organize constant trainings for, clinicians on initiation of ACP discussions and ACP implementation. Lastly there's need for KNH management to develop policies to guide ACP practice as well as to include ACP as one of the services in the KNH renal services charter.

CHAPTER ONE: INTRODUCTION

1.1.Background Information

Advance care planning (ACP) is an evidence-based process of establishing future plans of care, goals, care preferences and selection of a surrogate decision-maker in the inevitable event that a patient living with a life-limiting condition lacks the cognitive ability to make future care decisions with advancing illness (O’Halloran et al., 2018). ACP aims at assisting patients in having an in-depth understanding of the trajectory of their condition and is a dynamic process where care preferences might change as the condition progresses (Goff et al., 2019). The components of ACP are advance care planning discussions and advance directives (ADs). Patients undergoing maintenance hemodialysis are expected to have clear and sufficient knowledge of advance care planning, which is essential in influencing patient preferences.

Advanced Directives (Ads) are documented future care decisions or a living will that delegates to a surrogate decision-maker lasting power of attorney to remain in effect during the incompetency of the person making it (Goff et al., 2019). ACP discussions ultimately lead to a shared decision making (SDM) process that integrates the best evidence from research and practice with the patient's values, beliefs, and preferences (Stephenson & Bradshaw, 2018). In SDM, at least two participants are involved. They share information and take steps to build a consensus about the preferred treatment, and where an agreement is reached on the treatment with joint responsibility” (Stephenson & Bradshaw 2018).

Over the years ACP has been lauded for improving patients' quality of life (QoL), reducing stress, depression, and anxiety in patients and their caregivers, reducing inpatient admissions, increasing uptake of hospice and palliative care services, offering patients adequate time to prepare for their demise and help family members through bereavement and grief (Goff et al., 2019). In addition, a growing worldwide body of evidence has nowadays made the provision of quality ACP and affordable end of life care (EoLC) a policy priority in most developed countries. There's an equally increasing demand for the integration of ACP and EoLC into the mainstream healthcare (Reville & Foxwell, 2014)

According to the WHO (2019), the annual rate of people who need ACP and EoLC is about 20 million people, yet Ding et al., (2019) report that there's an increasing deviation between its need and supply especially in developing nations and rural areas. ACP and ADs uptake even in developed countries where the practice has been existent for considerably longer periods has been notably low. A study by Omondi et al. (2017) cited that the uptake of ACP and ADs was at 14%, 43.6%, and about 33% in Australia, Canada, and the United States of America, respectively. This uptake was majorly in oncology cases.

ACP is rarely done in Africa, and ADs are almost entirely not completed (Omondi et al., 2017). This presents the need to understand the level of knowledge among patients on ACP as well as the practice of ACP among clinicians who are tasked with educating patients about ACP. ACP and EoLC were reported to be effectively delivered in only four countries, namely Kenya, South Africa, Zimbabwe, and Uganda, by 2007. However, this service was largely donor-funded (Clark, Wright, Hunt, & Lynch, 2007). The situation has greatly improved, and by 2015 ACP was being delivered in 50% of African countries. However, only 5% of people who were in need received it, and the service was mainly linked to cancer patients despite HIV and other chronic conditions such as end stage kidney disease (ESKD) contributing to more deaths than cancers (Downing et al., 2015).

Abbasi et al. (2010) outline that ESKD, the last stage of chronic kidney disease (CKD) as an irreversible deterioration of kidney function characterized by a GFR of less than 15ml per minute per 173m^2 surface area of the body. Global incidences of ESKD are on the rise, and the annual mortality rate attributed to it was reported to be between 20-25%. This figure was way higher than that of neoplastic conditions such as prostate, breast and metastatic colorectal cancer (Dowen et al., 2017; Grubbs et al., 2014 & Lazenby et al., 2017). However, as opposed to intensive care unit and cancer patients, ESKD patients receive very little involvement if any in ACP and less emphasis is placed on providing quality end of life care (EoLC) to these patients (Lazenby et al., 2017). Reville & Foxwell (2014)&Downing et al., (2015) equally observed that ACP and EoLC are majorly offered to patients with cancer, human immunodeficiency virus (HIV) and those in intensive care unit (ICU), but rarely do patients with other chronic life-limiting conditions such as ESKD.

Landry (2019) reported that ACP discussions, identification of care preferences, shared decision making (SDM), and filling of advance directives (ADs) in hemodialysis patients are only sporadically done and, in most cases, not done at all. As high as 50% of these patients don't have such discussions while less than 30% of Americans had ADs as per the Centers for Disease Control and Prevention (Tripken, Elrod, & Bills, 2018). In addition, Mehter et al. (2018) point out that a significant number of patients, would prefer less aggressive care at the end of their lives, yet discussions are often put aside until the patient is too ill to make such decisions. This puts the family into a surrogate decision-making role at an emotionally intense time with little or no insight of the patient's wishes or the medical basis of such decisions (Tripken et al., 2018). The situation is not different among ESKD patients on Hemodialysis who prefer to have such information and discussions in earlier stages of their disease (Landry, 2019). This emphasizes the need to encourage advance care planning (ACP) in this population of patients.

Although there are 65 hospices and palliative care centers in Kenya, according to the Kenya Hospices and Palliative Care Association (KEHPCA), these centers are majorly concerned with meeting the palliative care needs of cancer patients ("KEHPCA," 2019). In addition, there's no law in Kenya regarding ADs, and the practice of ACP is mainly institutionally guided (Omondi et al., 2017). There's equally a paucity of studies and information on ACP and palliative care services offered to ESKD patients in Kenya. Thus, it is obvious that most patients with ESKD have unmet ACP and EoLC needs. This provides the need to understand the level of knowledge on advance care planning among patients, their uptake and care preferences as well as the practice of ACP among clinicians working with patients on maintenance hemodialysis.

1.2.Problem Statement

In Kenya, there has been an increase in the number of peripheral dialysis centers in the counties through the Managed Equipment Services (MES) since 2015. However, Murumba (2017) reported that at least 60 patients still had dialysis at the Kenyatta National Hospital (KNH) per day. Despite Kenya having 65 palliative care centers and hospices, the investigator never came across any documented information on ACP, ACP discussions, or advanced care preferences in chronic hemodialysis patients in Kenya. It was therefore, not possible to clearly establish if ACP, EoLC discussions, and completion of ADs are done, at what point it is done, if any, and the care preferences of these patients at KNH, which is the biggest referral hospital in the country.

Likewise, ACP was not among the services offered at KNH renal unit according to their service charter. Furthermore, there was no operational framework or guide/standard operating procedures to guide the conduction of these discussions. It was therefore left to the clinicians to decide if and when to have these discussions with the patients and their families. This strongly suggests that although considerable strides had been made in equipping renal care centers, there remains a gap in identifying patients' care needs and involving them in care decision-making in line with their values, beliefs, and preferences.

Patients on maintenance hemodialysis are vulnerable and require efficient care, especially when they are unable to make decisions on their own. ACP presents an approach that can help patients plan effectively for their EoLC. Clinicians are expected to educate patients on ACP and the need to develop ADs for easy EoLC. The study focused on establishing patient knowledge on ACP, ACP uptake and preferences as well as clinicians' practice of ACP with patients on maintenance hemodialysis in Kenyatta National Hospital.

1.3.Justification of the Study

According to KEHPCA (2020), ACP discussions offer patients with life-limiting conditions, their families and clinicians an opportunity to have honest conversations about care preferences, values, wishes to guide care decisions and the execution of certain kinds of care therapies in future and towards patients' final moments of life. As noted earlier, ACP is making tremendous progress in various parts of the word as earlier noted yet, not so many strides have been made in Kenya, largely due to cultural beliefs and practices (Mah, Powell, Mal, Gikaara, & Chalklin, 2019). Even with studies revealing that ESKD related mortality rate is much higher than of most cancers, it is more likely to have such discussions in cancer and ICU patients and their families as opposed to ESKD patients (Grubbs et al., 2014; Lazenby et al., 2017).

It is like a taboo to imagine about death, let alone have open conversations about it, yet studies have shown that a majority of patients would prefer comfort to more aggressive life-sustaining therapies in their dying moments (Mah et al., 2019). This often leaves terminal patients and their families penniless while chasing a mirage in futility, denying them enough time to prepare about their death.

In view of this, it was vital to delve more into this matter to look exactly at the implementation of ACP, care discussions, and advance care preferences among ESKD patients on maintenance hemodialysis at KNH.

1.4.Significance of the Study

The study focused on patients on maintenance hemodialysis before the onset of serious complications, which are likely to have a detrimental influence on patients' ability to make decisions pertaining to ACP. The results of this study will provide more insight into the level of ACP done at the KNH renal unit. It will, therefore, create an impetus for healthcare stakeholders to develop strategies to improve ACP, demystify death, and address challenges faced by clinicians and patients in having meaningful discussions on ACP. This study will also form a basis for studies to be conducted in Kenya on ACP and hopefully lead to effective integration of ACP into care frameworks for managing life-limiting conditions.

1.5.Research Questions

1. What is the level of knowledge on advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital?
2. What are the advance care planning preferences of patients on maintenance hemodialysis at Kenyatta National Hospital?
3. What is the uptake of advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital?
4. How do clinicians practice advance care planning with patients on maintenance hemodialysis at Kenyatta National Hospital?

1.6.Study Objectives

1.6.1. **Broad Objective**

To assess advance care planning between clinicians and patients on maintenance hemodialysis at Kenyatta National Hospital renal unit

1.6.2. Specific Objectives

1. To establish the level of knowledge on advanced care planning among patients on maintenance hemodialysis at Kenyatta National Hospital renal unit.
2. To determine the uptake of advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital.
3. To identify the advance care planning preferences of patients on maintenance hemodialysis at Kenyatta National Hospital.
4. To establish clinicians’ practice of advance care planning with patients on maintenance hemodialysis at Kenyatta National Hospital.

CHAPTER TWO: LITERATURE REVIEW

2.1.Introduction

This chapter offers an overview of previous studies that focused on advanced care planning and care preferences among end-stage kidney disease patients on Hemodialysis. The investigator used peer-reviewed articles published in various related databases and well as official websites of health-related organizations. Some of the databases used include Open Access for Africa, Cochrane library, PubMed, Google Scholar, EMBASE, and Elsevier. A literature search was also done in search engines such as HINARI. The organization and citation of the studies obtained were done through Mendeley. Some of the keywords used in the literature search included end-stage kidney disease care, advanced care planning, end of life care, advance directives, shared decision making, hospice care, among others. They discussed literature is organized into an overview and management of CKD and ESKD, patients' level of knowledge on ACP, clinicians' practice of ACP, patients' uptake of ACP and advance care planning preferences of ESKD patients.

2.2.Overview of Chronic Kidney Disease and End Stage Kidney Disease

2.2.1. Definition of CKD and ESKD

Chronic kidney disease (CKD) is defined by Kidney disease: Improving global outcome (KDIGO) as more than three months anomaly in kidney structure and function with significant health adversities. On the other hand, ESKD is a progressive and irreversible loss of glomerular function, which in the absence of RRT can lead to life-threatening complications including but not limited to hyperkalemia, pulmonary edema, and anemia. The clinical marker of ESKD is a residual renal function denoted by a GFR of less than 10 ml/min/1.73m^2(Rodger, 2012).

2.2.2. Epidemiological trends of CKD and ESKD

Nugent et al., (2011) documented that CKD was the 12th and 17th highest global causes of death and disability respectively and with the continued surge of hypertension and diabetes both of which potentiate and worsens CKD development and progression to ESKD, CKD was predicted to be a profound medical challenge in the 21st century and beyond.

Peng et al. (2017) approximate that 200 million people suffer from CKD globally, and Lancet reported that about 3 million people suffer from CKD worldwide annually (Murumba, 2017). In other studies on the same, Dienemann et al., (2016) & Kaze, Ilori, Jaar, & Echouffo-tcheugui, (2018) reported that between 10 and 16% of all adults suffer from CKD worldwide. Roberti et al., (2018) were more elaborate in noting that 500 million people suffer from CKD globally, among this 80 % from low- and middle-income countries (LMIC) while those with end-stage kidney disease (ESKD) requiring renal replacement therapy (RRT) were estimated to be 3 million.

In the African setup, a study on the burden of CKD in Africa done by Elhafeez et al., (2018) found out that the prevalence was 15.8% in the general population while that in high-risk population was 32.3%. Worth noting in this study is that the overall prevalence in the general population was higher in sub-Saharan Africa (17.7%) compared to North Africa (6.1%).

We must, with the existence of this compelling evidence, appreciate that CKD is a major determinant of poor health outcomes and continues to be a significant global concern. However, less emphasis has been given to CKD and, by extension, ESKD as opposed to other conditions such as cardiovascular disease, cancer, diabetes, and chronic respiratory disease (Couser et al., 2011; Dienemann et al., 2016; Roberti et al., 2018). This can be attributed to lack of awareness, lack of adequately trained and competent renal health care workforce, as well as the high cost of renal care services such as hemodialysis, peritoneal dialysis, and kidney transplantation. The progression of CKD to ESKD and its treatment is, therefore, heavily dependent on the specific country's economic security or affluence.

2.2.3. Socio-demographic Characteristics of ESKD patients

The development and progression of CKD to ESKD is closely related to age, gender, confounding co morbidities (diabetes, cancer, cardiovascular and autoimmune diseases), areas of residence, economic status, lifestyle habits among others (Abd Elhafeez et al., 2018; Couser et al., 2011; George et al., 2017; Kaze et al., 2018; Levin et al., 2017). In a study among the Canadian population, Chartier et al., (2018) found out that ESKD was more prevalent in women (31.8/1000) than in men (25.9/1000). This was probably due to the more women living sedentary lives than men. The rates were equally higher in older citizens > 65 years (97.9/1000) than in younger citizens (45 to 64 years – 20.6/1000, 18 to 44 years – 7.9/1000). This is most likely due to increasingly declining organ function with advancing age.

Similarly, the prevalence was expectedly higher in low income earning citizens. Prevalence rates were also high in urban than in rural areas probably because of unhealthier lifestyles (drinking alcohol, smoking, sedentary lifestyle, drug abuse, and unhealthy foods) in urban areas than in rural areas or incomplete coverage of data from rural areas. A higher prevalence of ESKD was as well found in people suffering from diabetes and hypertension than in other people (Chartier et al., 2018).

Conversely in another study conducted in a tertiary facility in Ghana, CKD and ESKD were more prevalent in males (64.5%) than in females (35.5%) an observation that was comparable to studies done in the United States, Spain, and Nigeria (Amoako et al., 2014). This was attributed to the fact that the risk factors for CKD, such as smoking, alcohol intake, and hypertension, are more common in males than in females. Variations in health-seeking behavior are also an important factor as more women are more likely to seek screening services than men. The peak age for ESKD was 40 - 49 years, with 82.9% of patients being less than 60 years of age. This finding was comparable to studies done in Nigeria and other developing nations. However, this scenario is in contrast to developed countries (Amoako et al., 2014). This could be due to a higher prevalence of infectious diseases leading to glomerulonephritis is the leading cause of CKD, lack of comprehensive treatment strategies for kidney diseases and their risk factors such as diabetes and hypertension and a higher prevalence of HIV infections in developing nations. In that cohort, a high unemployment rate (37.9%) was noted

A related study encompassing Asian and African data revealed that the majority of patients were between 41 and 60 years, and only 26.8% were above 60 years. Males were the majority accounting for 66% of the patients, 64.3% were residing in urban areas, about half of the patients were from low, 37.3% were from the middle, and 19.5% from the high socioeconomic background (Journal, 2008). In another study done in Ethiopia, 52% of the patients were male, 69.7% lived in rural areas, and more than half had diabetes and hypertension (Kumela Goro et al., 2019).

2.2.4 Management approaches for ESKD

2.2.4.1 Conservative management (Non-dialytic care/Supportive) for ESKD

This refers to the care of ESKD patients without RRT. KDIGO describes it as the patient-focused care of stage 5 CKD patients that is holistic in nature. Conservative care is provided to patients who either opt not to undergo RRT or are deemed not suitable for renal replacement such as those patients with advanced age, advanced co morbidities as well as those patients who refuse aggressive life-sustaining treatment. Alston & Burns (2015) reported that 30% of patients started on hemodialysis aged 70 and above died within the first year, while more than half of the patients died within two years. The 5-year survival was less than 20%. Worth noting is that Alston & Burns, (2015) noted that patients managed conservatively demonstrated a better QoL than patients put on dialysis. Conservative care, therefore, aims to provide patients with a better QoL and ACP by focusing on symptom management, minimizing the threat posed by co morbidities, improving functional independence, preserve RRF where possible (Murtagh et al., 2016).

Some of the key components of conservative management for CKD include managing metabolic disturbances such as diet control and restriction, anemia, mineral and bone metabolism disturbances, edema, metabolic acidosis, hyperkalemia, hyperphosphatemia, and hypocalcemia. Others components are symptom management such as pain, nausea and vomiting, pruritis, dyspnea, anxiety, depression as well as optimizing the general QoL (Castro, 2019)

2.2.4.2 Renal Replacement Therapies (RRT)

The backbone to the effective management of ESKD is early identification and referral of CKD patients at high risk of developing ESKD, early identification, and treatment of reversible factors leading to ESKD and trying to conserve residual renal function (Rodger, 2012). Currently, there are three renal replacement therapies for ESKD, namely renal transplantation (RT), hemodialysis (HD) and peritoneal dialysis (PD). Renal transplantation offers a better quality of life (QoL) dialysis. This includes less fluid and dietary restriction, better sexual function, more personal freedom, and physical wellbeing (Carpenter, Milford & Sayegh, 2010). However, there's no compelling evidence suggesting better survival with either type of dialysis (Liem, Bosch, & Myriam Hunink, 2008).

PD was the earliest RRT modality to be used by mankind in 1923 (Royal North Shore Hospital, 2016). In PD, the peritoneum acts as the dialyzer membrane, and the peritoneal cavity serves as the dialysate compartment. PD is less efficient in removing solutes from the body compared to HD. Therefore, it is less efficient in providing dialysis to large and obese patients as well as those patients residual renal function (RRF) is highly diminished (Rodger, 2012).

As noted earlier, pre-emptive transplantation is the ideal treatment for ESKD. Likewise, related live donor transplantation options should be fully exploited before opting for a deceased donor. For optimal transplantation and graft survival, patient's preferences, presence of cardiac or respiratory disease, peripheral vascular disease, obesity, malignancy, or chronic infection such as hepatitis and HIV and patient's ability to adhere to medication orders have to be considered (Rodger, 2012).

HD is a life-sustaining therapy that entails the intermittent or continuous artificial removal of waste products, toxins, and excess water from the body through the passage of blood through an extracorporeal blood circuit and a dialyzer. It also involves the removal or addition of electrolytes. Hemodialysis is done with a hemodialysis machine, and the therapy dates back to 1943 (Rocco et al., 2015).

2.3.Knowledge level of Advance care planning among patients

Advance care planning among patients is defined by the level of knowledge and the underlying interaction with healthcare providers. High level of knowledge on ACP allows patients to make decisions regarding what they want in relation to end of life planning. Goff et al. (2019) found that barriers to effective advanced care practice included limited knowledge among patients which is caused by high caseload among nephrologists and social workers and lack of continuous training of healthcare workers to offer quality services.

O'Halloran et al. (2018) conducted a systematic realist review investigating the implementation of advance care planning among hemodialysis patients. The findings revealed that a higher number of patients did not have knowledge or the advance care planning and ADs. The relationship between patients and healthcare workers influenced the implementation of ACPs practice. The challenges hindering ACPs identified included lack of training among healthcare workers, administrative complexities and patients’ knowledge and attitude.

Lack of adequate knowledge has been a major detrimental factor to success ACP practice. According to Kermel-Schiffman and Werner (2017), 45% of the respondents knew some aspects of ADs but did not have knowledge on other key aspects of ACP such as patient self-determination. Only 18.9% of the participants reported having moderate level of knowledge regarding ACPs in general. The lower level of knowledge presented a difficult context where it would be possible to implement ACPs successfully.

2.4 Uptake of Advance care planning by patients

Patients uptake of ACP has over the years been influenced by a myriad of factors including but not limited to race, economic status, level of education, knowledge and awareness of ACP, marital status, presence of support systems as well as the initiative of healthcare providers (Kermel-Schiffman and Werner (2017; Chen et al., 2018; Lazenby et al., 2017 & Axelsson et al. 2018).

While doing a meta analysis of factors influencing the uptake the engagement of patients on ACP Spelten et al.,(2019) observed that whites were more likely to engage in ACP compared to people of other races. On the other hand, Balboni et al., (2013) found out that religiosity was directly proportional to ACP uptake and preference of aggressive life sustaining therapies toward end of life. Similarly lower socioeconomic status and level of education were found to negatively impact the uptake of ACP (Weathers et al., 2016)

Marital status was equally pointed out as a strong factor determining patients' uptake of ACP. Patients who were married significantly had higher likelihood of ACP uptake compared to patients who were not married citing social and emotional support from their spouses (Detering, Hancock, Reade, & Silvester, 2010). A similar finding was reported by McGlade et al., (2017) where provision of social support positively impacted ACP uptake.

While assessing patient related factors influencing ACP uptake Spelten et al., (2019) found out that awareness and comprehension of ACP were the most significant determinants of ACP uptake. In addition, McGlade et al., (2017) reported that patients who had sufficient knowledge on ACP were more likely to engage in ACP. Lack of knowledge on ACP has also been implicated to negatively affect readiness, receptiveness and willingness to engage in ACP (Spelten et al., 2019 ; Weathers et al., 2016).

2.4.1 Advance care planning discussions

Adult ESKD patients on HD face numerous difficult decisions to make regarding their care. These include deciding whether to initiate dialysis, preference for aggressive life-sustaining therapies such as ICU admission and cardiopulmonary resuscitation (CPR), whether and at what point to be referred to palliative care centers near their areas of residence, when to terminate HD if it no longer offers meaningful benefits as well as where and how they prefer to die (Sara Ann Combs, 2016). ACP discussions and SDM should be initiated prior to commencing HD or when evidence does not suggest that further therapy will improve the functional status or prolong life (Stephenson & Bradshaw, 2018).

Death and dying issues are, in most cases, avoided until the last stages of life when the prognosis is evidently poor, and patients' autonomy and free will is markedly diminished. Patients therefore have little information about end of life issues and ACP(Chen et al., 2018; Lazenby et al., 2017). Axelsson et al. (2018) found out that most ESKD patients don’t have meaningful ACP discussions and have many unmet EoLC needs. This observation is similar to the findings of Jayanti et al. (2015), who reported that the majority of HD patients rarely participated in care decision making.

Despite this, renal replacement education and SDM on RRT modality selection among ESKD patients have been inadequately practiced over the years (Goovaerts et al., 2015). Landry (2019) similarly reported that ACP in hemodialysis patients is only sporadically done and, in most cases, not done at all. Therefore, patients' preferences regarding ESKD management choices are often misinformed as such discussions are scarcely done or avoided at all. Studies found out that less than 10% of ESKD patients had discussed ACP or end of life issues with their nephrologists (Amro et al., 2016; Davison, 2010).

Another study among HD patients by (Ladin, Buttafarro, Hahn, Koch-Weser, & Weiner, 2018), 25% of the participants had not considered advanced care preferences at all and only 13% had discussed their preferences with healthcare providers, yet 80% expressed interest in discussing the same. Half of the participants had discussed the end of life within their social networks. In addition, Mah et al. (2019) discovered that less than 50% of patients living with life-limiting conditions had neither had meaningful advance care discussions or filled ADs. The finding was worse on elder ESKD patients. Their knowledge concerning the same was expectedly insufficient. A similar explanation for such a finding was reported by Unseld et al., (2019).

2.4.2 Advance directives (ADs)

Advance directives are important components of the management framework of life-limiting conditions such as cancer and ESKD. However, multiple studies have shown that the use of ADs is still quite low(Sara A Combs & Davison, 2017; Erdley, Hetherington, Norfolk, & Kitchen, 2010; Ladin et al., 2018; Mah et al., 2019). A study among HD patients by Ladin et al., (2018), found out that only 30% had a living will. A similar finding was reported by Mah et al. (2019), where more than 50% of patients living with life-limiting conditions had didn't have ADs. Furthermore, less than 30% of Americans had ADs as per the Centers for Disease Control, and Prevention (Tripken et al., 2018). This finding was attributed to lack of sufficient information about ADs attributed to lack of proper institutional guidelines on use of ADs and reluctance of healthcare providers to provide such information. Davison, (2011) similarly point out that many most patients on maintenance HD don't have ADs yet more than 50% of family members and nephrologists could not accurately predict patients' preferences on initiating or terminating life-sustaining therapies such as dialysis and CPR. However, many of these decisions were made in very advanced stages of illness when clearly patients had lost the decision-making abilities. In another study by Omondi et al. (2017), the uptake of ADs in a tertiary private health facility in Kenya was found to be 41.2%. However, the majority of the assessed records were of oncology patients. In the same study, Omondi et al. (2017) cited that the uptake of ACP and ADs was at 14%, 43.6%, and about 33% in Australia, Canada, and the United States of America, respectively.

2.5 Advance care planning preferences of Patients on Maintenance Hemodialysis

A study to assess decision-making experience among ESKD patients in Ghana revealed that patients recognized and appreciated the life-threatening nature of ESKD if left untreated, yet many of them drew hope, especially from their religious beliefs of a complete cure. Patients did not view ESKD as terminal and had neither considered discussing with their healthcare providers about conservative management, RRT, nor end of life care. (Boateng, East, & Evans, 2018). On the other hand, Lazenby et al., (2017) reported that some patients on chronic Hemodialysis don't recognize that they are living with a life-limiting condition and that dialysis in itself doesn't necessarily improve their quality of life (QoL). Some even have false beliefs that they can be kept on dialysis indefinitely.

In another study, Ladin et al. (2018) equally reported that cultural and religious beliefs and practices, especially in the African setting are majorly hinder ACP and completion of ADs. African cultures largely do not encourage discussions about death, let alone contemplating the death of a loved one. The African traditional religion believes in life after death. Those who die ultimately become ancestors, something which can't be achieved in the event that death is achieved through unnatural ways such as the use of ADs (Ekore & Lanre-Abass, 2016; Mah et al., 2019). All these perceptions which are religiously and culturally rooted make the uptake ACP and ADs very low.

As highlighted earlier in this study, ESKD patients have higher mortality rates than most other conditions, including cancers and cardiovascular diseases. Worryingly not much research has been done to explore ESKD patients' preferences for end-of-life care (Axelsson et al., 2018).

Care preferences in ESKD patients include immediate as well as EoL preferences. Immediate care preferences include the decision to be put on RRT or conservative non-dialytic care. EoL care preferences include admission to ICU, consenting to aggressive life-sustaining therapies such as mechanical ventilation and CPR, referral to a hospice, or a palliative care center as well as where and how a patient prefers to die.

2.5.1 Advance care planning discussions and Surrogate decision making

Although the practice of ACP in HD patients, as reported by Mehter et al. (2018), is still very low and, in most instances done very late, majority of these patients prefer to have such information and discussions in earlier stages of their disease (Landry, 2019). In addition, while assessing adult ESKD patients' care preferences, Jayanti et al. (2015) reported that patients largely preferred to have advance care discussions and participate in SDM. Similarly, Erdley et al., (2010) noted that ESKD patients and their families prefer to be informed and talk about their illness, the expected duration of HD therapy, the effects of the therapy on their lives and well-being and about the end of life issues more than according to the general expectation of healthcare providers. As high as 97% of patients prefer their nephrologists discuss with them about prognostic information and end of life care without being prompted to (Chen et al., 2018; Lazenby et al., 2017; Davison 2011). This is because HD patients, owing to constant interaction with their healthcare providers, have a lot of confidence in care providers to manage their symptoms, address ACP, as well as provide psychological support in a timely and effective manner offers the perfect environment to have such discussions (Erdley et al., 2010).

While assessing the choice of a delegated attorney among ESKD patients on maintenance dialysis, Jahdali, Baharoon, & Al-ghamdi, (2009), reported that 77% of the respondents felt that if they were not in a position to decide about CPR, their physician should make that decision on behalf of them. 23% wanted the decision to be made by family members. However, only 26% agreed to their physicians, making the decision against CPR on their behalf.

2.5.2 Conservative management and Renal Replacement Therapies

While doing a value-based evaluation of dialysis versus conservative care in older patients with advanced chronic kidney disease, Verberne et al., (2018) reported that out of 366 participants, 240 (65.6%) opted for dialysis and 126 (34.4%) participants opted for conservative management. No participant opted for transplant. 6 participants underwent transplant only after dialysis had failed. The patients who opted for conservative management were much older in comparison to those who opted for dialysis. In another similar study, 90% of the participants chose dialysis compared to 10% who opted for conservative management. Conversely, age did not significantly affect treatment preferences in this study compared to expected life expectancy. Most patients with higher expected life expectancy preferred dialysis to conservative, while those with lower expected life expectancy opted for conservative management (Morton et al., 2012). Interestingly, after being educated on the therapy options available to them and having considered the opinion of their physicians, more participants (39%) chose conservative management compared to Hemodialysis (35%), peritoneal dialysis (24%) and preemptive live donor transplantation (2%) (Teruel et al., 2015).

2.5.3 Aggressive life-sustaining therapies and Referral to a Palliative care center

Only about 17% of CKD patients understood the role of hospice and palliative care services, of which most of them were negative about the service (Sara A Combs & Davison, 2017). On the other hand, Mehter, McCannon, Clark, & Wiener (2018) pointed out that a significant number of patients would prefer less aggressive care at the end of their lives. However, in a contrasting finding of which 96.2% of the participants were HD patients, 82.5% and 81.3% of the participants preferred CPR and invasive mechanical ventilation. These preferences were based on perceived treatment burden and outcome. Similarly, Jahdali, Baharoon, & Al-ghamdi (2009) reported that 79% of HD patients only consented to CPR or mechanical ventilation if it would guarantee full recovery and independence afterward, while only 35% consented if the procedure would result in organ dysfunction such as brain damage. In the same study, 20% still opted to be admitted to ICU even if the admission would least likely alter the outcome.

2.5.4 Place of Death

About preferences in place of death, 48.7% preferred to die in their homes, 32.5% in a hospital, 15% in a hospice while 38% didn't have a preference of where they die (Janssen, Spruit, & Schols, 2013). On the other hand, Jahdali et al. (2009) reported that 73% of participants preferred their home as the place of terminal care, and the number rose to 87% if the home care was provided by a healthcare provider.

2.6 Clinicians' practice of Advance care planning

Despite Landry (2019) arguing that dialysis increases patients' life expectancy as well as boost agility, ESKD in older patients is often compounded with multiple co morbidities and complications that reduce their quality of life (QoL) and estimated life expectancy. Therefore older patients may not prolong their lives or improve their functional status through hemodialysis (O'Halloran et al., 2018). Furthermore, in a study to investigate the functional status of adult patients before and after initiation of dialysis Tamura et al. (2009) discovered that there was a strong positive correlation between initiation of dialysis and declining functional status of the subjects. A similar observation was reported by Grubbs et al. (2014), who noted that among ESKD patients undergoing maintenance dialysis, the symptom burden was largely precipitated by the therapy, especially in those patients in their final moments of life. It is, however, bewildering to note that the practice of ACP and ADs uptake is still very low in this category of patients (Boateng et al., 2018; Omondi et al., 2017; Stephenson & Bradshaw, 2018).

Visser, Deliens, & Houttekier (2014) noted that ACP practice had been largely clinician initiated and directed. As such, the study largely attributes the low uptake of ACP in hemodialysis patients to the failure of clinicians to initiate such conversations with their clients. Goff et al., (2019) partly attributed this to the perceptions among clinicians that patients don’t actually need this kind of discussions during their illness because that such kind of discussions might lead to hopelessness and psychological and emotional disturbances. Another reason could be clinicians’ lack of confidence and competency in handling such discussions, successfully guiding patients’ through the emotional turmoil brought about by poor prognostic information among others (Visser et al., 2014)

Clinicians’' opinions and beliefs also play a big role in ACP. Some health care providers have conflicting personal beliefs, ethical values, and negative opinions about ACP and ADs. The discussion of ACP and EoL issues is also sometimes viewed as an indirect admission of failure and inability of clinicians to treat and manage patients' conditions. Therefore most health care providers usually avoid ACP and EoL issues until very late when the prognosis is undoubtedly very poor (Visser et al., 2014).

2.7 Study Variables

Variable	Type of data	Measurement
Independent Variables		
Patient characteristics		
Age	Continuous	Ratio
Gender	Categorical	Nominal
Marital status	Categorical	Nominal
Religion	Categorical	Nominal
Source of Income	Categorical	Nominal
Intervening Variable		
Institutional factors		
Policies	Categorical	Nominal
Guidelines	Categorical	Nominal
Standards	Categorical	Nominal
Dependent Variable		
Uptake of Advance care planning	Categorical	Nominal

Table 2. 1: Study variables

2.8 Hypothesis

1. There is no significant association between patients' characteristics and uptake of advance care planning.

2.9 Conceptual framework

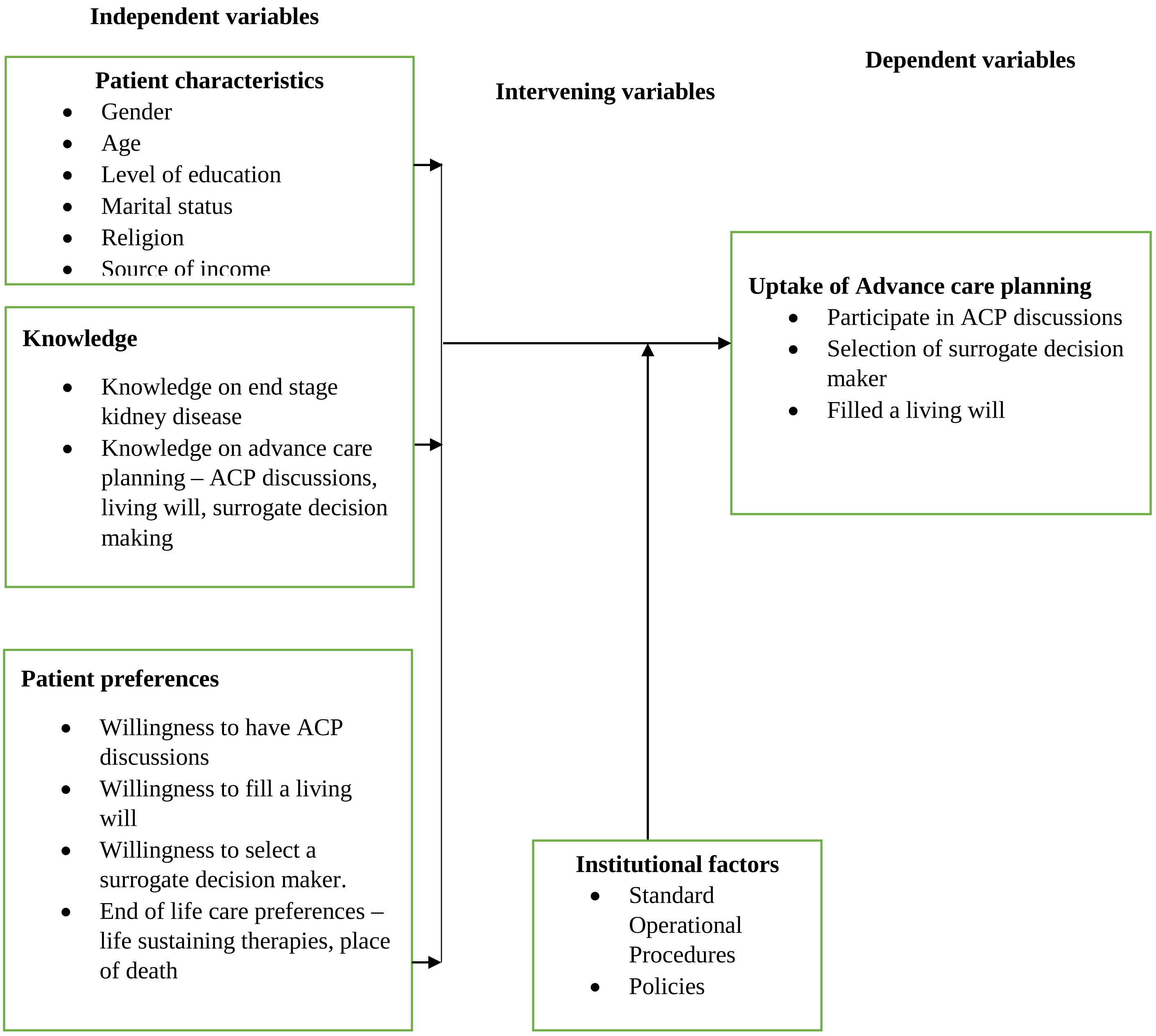


Figure 2. 1: Conceptual framework

2.10 Theoretical Framework

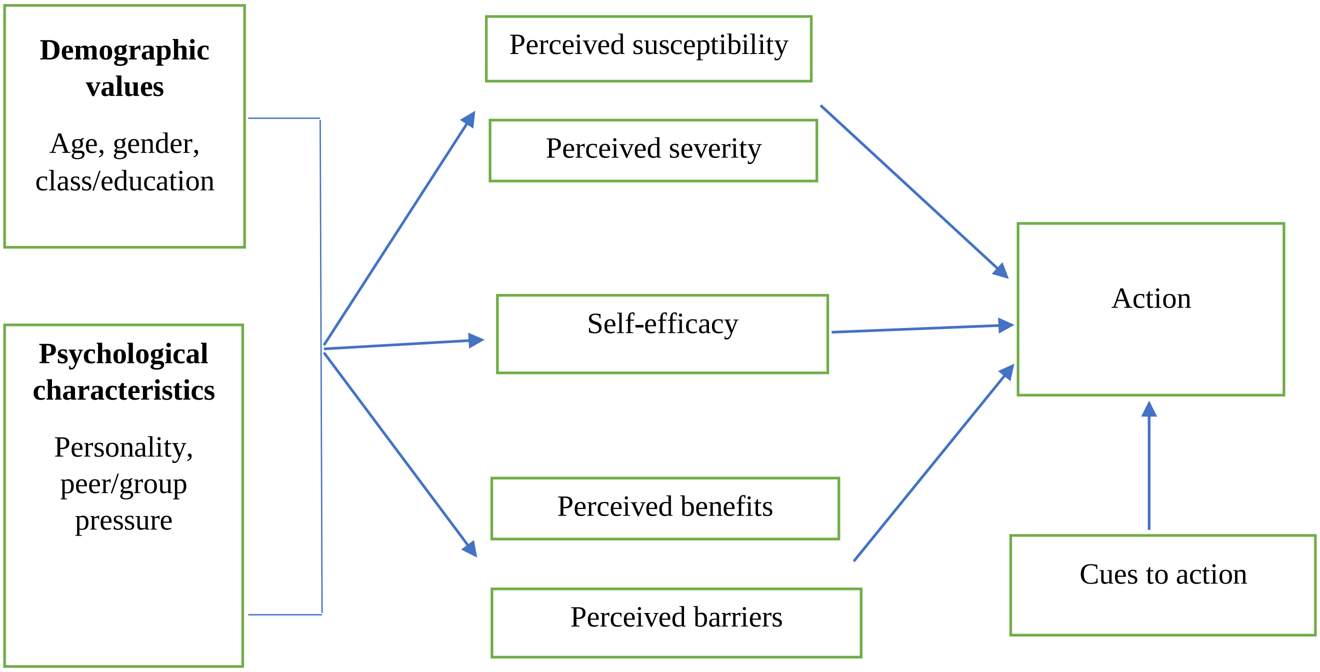
This study adopts the Health Belief Model (HBM) as developed by Irwin M. Rosenstock, Godfrey M. Hochbaum, S. Stephen Kegeles, and Howard Leventhal in the 1950s. This model was developed by Psychologists at the United States public health service as a means to explain the reluctance to adopt disease screening and prevention strategies (Abraham & Sheeran, 2016). The uses of HBM later extended to study patients' responses to symptoms and compliance with medical treatments. This is the basis of this study.

An Individual's representation of health and health-related behavior as outlined in the HBM is broadly categorized into two aspects, namely threat perception and behavior evaluation. These are the two broad constructs. The fundamental philosophy behind this theoretical model is that health-related behavior is to a large extent driven by the desire to avoid illness or get well by limiting complications if one is already ill and the belief that a certain behavior (Treatment therapy) will prevent, cure or provide significant symptom relief (Chin, Mansori, & Costa, 2019). The HBM, as is currently understood, has six constructs of which the latter two have been developed over time through research.

The constructs

- Perceived susceptibility - This is the individual’s subjective feeling of being at risk of acquiring an illness or suffering further from complications if already ill. For ESKD patients and their doctors, the perceived risk of the patient suffering from complications resulting from altered kidney structure and function is paramount to ACP and compliance to a certain kind of therapy.
- Perceived severity – If the complications that can occur due to failure to adopt ACP or comply with a certain therapy are deemed severe enough or possibly fatal, then the patient is more likely to comply.
- Perceived benefits – For HD patients to choose a particular advanced care option, they must have the belief and confidence that that option will yield meaningful benefits in alleviating symptoms, improve functional status, and promote independence and self-reliance.
- Perceived barriers – patients will adopt a particular therapy if it offers not only significant benefits but also is feasible, accessible, and at a cost that the patient can afford.

- Self-efficacy – A person's confidence in his/her ability to successfully undertake a care option as well as the confidence he has in his/her significant others to make decisions in the best interest of the patient is an important factor for the patient to pursue a certain therapy.
- Cues to action – The impetus needed to trigger the decision-making process of choosing a particular path of care can be internal such as the severity of symptoms or external such as advice from family members or health messages from healthcare professionals.



Adapted from Abraham & Sheeran (2016)

Figure 2. 2: The Health Belief Model

CHAPTER THREE: MATERIALS AND METHODS

3.1.Introduction

This chapter gives an overview of the study design, the study site and population, the data collection instrument and data collection procedure, data management, data analysis and presentation, limitations and delimitations, ethical considerations, and dissemination of findings.

3.2.Study design

This was a cross-sectional mixed-methods study. The use of both quantitative and qualitative data presented an effective understanding of the underlying research objective (Rodrigues, 2016). Quantitative data was collected from patients undergoing maintenance hemodialysis at the renal unit to identify the level of knowledge, advance care planning preferences and their uptake of advance care planning. Qualitative data was obtained from clinicians to understand their practice of advance care planning with patients on maintenance hemodialysis. The information was obtained at one point in time, which enhanced the quality of the findings in response to the underlying research objective. A mixed methods approach helped the researcher to have an in-depth exploration of the variables in their entirety and without manipulation. A cross-sectional design was adopted because it saves time, relatively inexpensive, and minimized chances of unforeseen confounders occurring during the study period.

3.3.Study area

Kenyatta National Hospital (KNH) was the study site because it is the largest teaching, research and referral hospital in Kenya as well as the East African region. It has many specialized units including but not limited to renal, cardiology, accident and emergency, obstetrics and gynecology and ICU with their specialized theatres. The renal unit receives the highest number of clients with ESKD in the country who require different renal care services ranging from counseling, peritoneal dialysis, hemodialysis as well as renal transplantation. KNH has some of the best renal physicians in the country. KNH renal unit serves both inpatient and outpatient clients for hemodialysis for patients with both AKI and ESRD. Averagely, more than four hundred hemodialysis sessions are done every week at KNH. The unit has at least five renal physicians and continues to train more (Murumba, 2017).

In the renal unit, there's a counseling department that spearheads patient preparation on the psychosocial adjustments expected of the clients as they undergo Hemodialysis as well as counseling them on other care options in ESKD such as renal transplantation. The renal health care team (the nurses and doctors) explains to the clients all that they are expected to know about Hemodialysis and other RRT modalities while the nutrition team spearheads counseling clients with renal failure on dietary modifications.

3.4.Study population

The study population included clinicians working in the renal unit and also patients with confirmed end stage renal disease who were at least 18 years of age and had been undergoing maintenance hemodialysis for the last twelve months at KNH renal unit. This age group of patients was used because of the sensitivity of the area of focus in this study. It comprises the legal adult age in Kenya; hence the data obtained can be trusted to be of independent thinking. Approximately 150 clients with ESKD seek hemodialysis at the renal unit. This is according to the data obtained from the statistics department at Kenyatta national hospital.

3.5.Inclusion criteria

- Clients with confirmed end-stage kidney disease
- Adult clients who had been undergoing hemodialysis at the renal unit consistently for at least 12 months (120 according to KNH statistics)
- Clients who agreed to participate by giving the informed consent
- Clinicians (renal physicians) who had worked in KNH renal unit for at 5 years and consented to participate in the study.

3.6.Exclusion criteria

- ESKD patients who were mentally unstable
- Critically ill patients who were unable to communicate
- Post-transplant patients on maintenance hemodialysis

3.7.Sample size calculation

3.7.1. Sample size for ESKD patients – Questionnaire-based study

Fisher’s formula was used to calculate the sample size of clients for this study

$n=Z^2pq/d^2$

Where,

n is the desired sample size when the population is >10000

Z is the normal deviation at the desired confidence interval (95%) = 1.96

p is the proportion of the population with the desired characteristics (50% will be used)

q is the proportion of the population without the desired characteristics

d is the degree of precision (5%)

Therefore;

$n=1.96^2\ [(0.5)\ (0.5)] / [(0.5)\ (0.5)]$

n=384

The population of ESKD patients undergoing maintenance hemodialysis was small (<10,000); hence there was a need to use finite population correction factor as follows:

$nf=n/[1+n/N]$

Where;

nf is the desired sample size for population <10,000

N is the total population. (The estimated number of patients above 18 years of age with end-stage renal disease on hemodialysis at the renal unit for at least twelve months) (N= 120).

n is the calculated sample size

Therefore;

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

$nf = 384 / [1+3.2]$

nf = 384 / 4.2

nf = 91

In taking care of the non-respondents, 10% of the sample size was determined hence the Final Sample size was 100

The sample size was 100 participants.

3.7.2. Sample size for key informant interviews-based study

Key informant interviews were conducted to provide information on clinicians' practice of advance care planning with patients undergoing maintenance hemodialysis at KNH renal unit. There were 5 clinicians working with patients on maintenance hemodialysis. 2 clinicians were selected for key informant interviews based on their vast experience of renal care practice and involvement in training and mentorship of aspiring clinicians.

3.8.Sampling Method

A simple random sampling method was used for patients who met the inclusion criteria. This gave every client an equal chance to participate in the study and minimized bias. 120 pieces of paper were assigned 100 yes and 20 no. The papers were folded. Any client who met the inclusion criteria and picked a yes was included in the study.

Purposive sampling was used to recruit participants for the key informant interviews. The researcher targeted clinicians in the renal unit who were directly involved in the management of patients undergoing maintenance hemodialysis. This presented the need to focus on purposive sampling, considering that the characteristics of those clinicians were known. Apart from them being clinicians, other characteristics of interest were experience of at least 5 years in renal care practice and involvement in training and mentoring of aspiring clinicians.

3.9.Screening and Recruitment of Participants

The daily booking register was reviewed by the principal researcher and the trained research assistants on a daily basis from Monday to Wednesday to identify patients scheduled for maintenance HD sessions. This ensured that all patients on maintenance HD had a chance to participate in the study. Eligible patients were selected on a daily basis and then appropriately informed of all the relevant information about the study. They were duly taken through the consenting procedure, and the researcher asked questions to ascertain their understanding before those willing to participate were allowed to sign the consent forms voluntarily. Upon obtaining signed informed consent, patients were enrolled for the study. Key informants for the in-depth interviews were identified by the researcher, and interview sessions were conducted in privacy. This was after obtaining signed and informed consent too.

3.10Data collection tools

Data from the patients was collected using a researcher administered structured questionnaire, which had closed-ended questions. The questionnaire was divided into four sections namely socio-demographic characteristics, knowledge of ACP, uptake of ACP, and ACP preferences.

Interviews were used to collect qualitative data. Key informant interviews were conducted using an interview guide containing open-ended questions that was used to probe the clinicians. The researcher developed the interview guide based on available literature on the study objective as well as expert opinion from nephrologists and study supervisors.

3.11Reliability and Validity

3.11.1 Internal consistency reliability

Internal consistency for the questionnaire was determined by measuring Cronbach's alpha coefficient, whereby a coefficient of 0.7 or more was regarded as an acceptable level of internal consistency (Landis & Koch, 1977).

3.11.2 Validity

The validity of the questionnaire was observed by structuring the tool in line with the specific objectives and also by engaging the researcher's supervisors and experts in renal care to review the tool before it was used. The tool was also pretested in a population of patients with similar characteristics as the target population.

3.12Pre-testing

The data collection tool for the patients was pre-tested at the renal unit of Thika level 5 hospital. Written consent was administered to the clients participating in the pretest. This helped to refine the tool, address inconsistencies, repetitions, and clarify ambiguous questions in order to effectively answer the research questions. 10% (10) of the sample size was used. The interview guide was presented to the research supervisors and experts in renal care for cross-checking and correction.

3.13Data collection assistants

Two nephrology nursing students from East Africa Kidney Institute (EAKI) were selected. They were trained and inducted on the questionnaire, data collection procedure, and consenting process, and how to evaluate the questionnaire for completeness before data collection commenced.

3.14Data collection procedure

3.14.1Quantitative data collection procedure

After obtaining a letter of approval from Kenyatta National Hospital/University of Nairobi Research Ethics Committee (KNH-UoN ERC) and a study registration certificate from KNH, the researcher, together with his assistants, introduced themselves to the management of KNH renal unit and sought authorization to collect data from the respondents. The research team, upon authorization, then familiarized themselves with the staff and patients in the unit. With the help of the renal nurses, the researcher identified the respondents, explained the purpose of the study, and obtained their consent of participation in the study. The potential participants who met the inclusion criteria were then offered a written consent in a language they understood to sign.

Patients who met the inclusion criteria and agreed to consent were randomly selected to participate in the study. Data collection was done on a daily basis based on the number of patients available to participate with a review of the inclusion criteria. The research team collected the data over a period of 3 days.

3.14.2Qualitative Data collection

Before conducting the interviews, the key informants were required to consent to the study. The availability of the key informants was determined to ensure efficient data collection process. The researcher then scheduled appointments with the key informants for the interviews. Key informants independently set their own free time, where they would be less distracted and able to provide honest and accurate responses. The researcher used the interview guide to conduct the interviews. Two interviews were conducted where each interview took approximately 15 minutes. The Interviews were recorded using an audio recorder, ensuring that each of the interviews was labeled accurately. The researcher who was the interviewer also took notes to help identify key aspects of the responses provided. This was useful during transcription in cases where some of the recorded responses were not clearly audible. These interviews were conducted in private. The interviews were conducted on two different days.

3.15Control of data quality

Study questionnaires were assigned unique serial numbers before data collection to avoid a mix-up or duplication of recordings. After data collection, the researcher reviewed each questionnaire to ensure clarity, relevance of the responses, and completeness. A database was then developed using a password-protected Microsoft Access to cover all the value ranges as stipulated in the data collection tool. Data was verified by carrying out double entry checks and comparisons.

3.16Data cleaning and entry

Accepted questionnaires were stored in a lockable cabinet to avoid unauthorized access and manipulation. Incomplete questionnaires and those with irrelevant responses were not included for data analysis. Data was then entered in the database previously created. Once the entry was complete, data was compared with the data in the hard copy questionnaires to ensure that the correct data was captured.

3.17Data analysis and presentation

Quantitative data was first entered into an excel before being transferred to Statistical Package for Social Sciences (SPSS) version 26.0 computer software for analysis. This data was analyzed using both descriptive and inferential analysis approaches. Categorical data was summarized in the form of counts and percentages, while continuous data was summarized using mean (SD) and median (IQR). A chi-square test for association was conducted to determine patients' characteristics that were associated with advance care planning uptake among patients on maintenance hemodialysis. Statistical significance of the obtained results was determined using P-values. The level of confidence was set at $p<0.05$. Presentation of the results involved the use of frequency distribution tables, pie-charts, and bar graphs

For analysis of qualitative data, the researcher transferred the audio-recorded data from key informant interviews to a laptop. Data was transcribed verbatim into Microsoft office word documents. Data analysis was manually done through content analysis. Data was coded and deductively analyzed to identify keywords and develop themes and patterns. This involved re-reading and developing themes based on the presence of key words across the 2 transcripts. Emerging observations in the study population were also described through content analysis. This data was presented in a narrative format using illustrative quotes.

3.18Ethical consideration

The study was conducted upon approval from the researcher's supervisors and the department of Medical-Surgical Nursing in the school of Nursing Sciences of the University of Nairobi. Thereafter, ethical clearance was obtained from KNH-UoN ERC to carry out the study. Study participation was voluntary, and study participants had the right to withdraw their participation in the study at any point. The clients who gave a verbal consent of participation after being carefully explained regarding the purpose of the study were offered written consent forms to sign before data was collected. In order to uphold non malficience in light of the global Covid-19 pandemic, appropriate approval was obtained from KNH/UON ERC and the management of KNH to carry out this study. This included a personal commitment of the researcher to observe and uphold the laid down measures to prevent the spread including but not limited to hand washing, sanitizing, wearing of face masks and keeping the required physical and social distance. All participants were treated equally and fairly and were not exposed to any form of harm. Participants were kept anonymous as no names or any other identification particulars were written on the questionnaires. Questionnaires were only assigned numeral codes in order to track and account for all tools completed. All information obtained during the study was treated as private, and a high level of confidentiality was observed.

3.19Limitations

- There was an anticipated response bias because the questionnaire was interviewer-administered.
- The study touched on sensitive aspects of human life, which elicited emotional upheaval in some respondents.
- Conducting this research posed the risk of contracting or spreading Covid-19 disease in case of a breach of the laid down guidelines.

3.20Delimitations

- The researcher and his assistants tried to minimize response bias by not attempting to clarify or expound on any of the questions. Also, similar questions were asked in a similar way to all the participants.
- The research team minimized emotional breakdowns by making sure that the study was well explained to the respondents before data collection was done. The principal

investigator also worked with the counselor in the unit to take care of respondents who got emotional breakdowns in the process.

- The research team demonstrated commitment to uphold the laid down Covid-19 disease prevention regulations before being approved to collect data. The team ensured strict adherence to those regulations while conducting the study and offered patient education to foster the same where necessary.

3.21Plan for dissemination of data

Report copies of this study were presented to KNH-UoN ERC, the renal unit at KNH, UoN School of Nursing Sciences faculty, and UoN library for depository and future references. The results of this study will be presented in scientific conferences. A manuscript for the study was written for publication in peer-reviewed journals.

CHAPTER FOUR: RESULTS

4.1 Introduction

The study was conducted to assess advance care planning between clinicians and patients on maintenance hemodialysis at Kenyatta National Hospital. The study employed a mixed methods approach where both qualitative and quantitative data was collected. Quantitative data was collected from patients while two key informant interviews were conducted which targeted two renal physicians working at KNH. A total of 100 questionnaires were issued with 99 fully filled and returned for data analysis representing a 99% response rate while one respondent declined to participate in the study midway through the data collection process.

4.2 Demographic characteristics of respondents

The respondent's demographic characteristics were assessed as presented in table 4.1.

Table 4. 1: Respondents demographic characteristics

Variable		**Frequency**	**Percentage**
Gender	Male	58	58.6
	Female	41	41.4
Age	Mean ±SD	44.19±11.8	
	Median (IQR)	43 (36.5 - 53)	
	<30 years	11	11.1
	31 – 50 years	58	58.6
	>50 years	30	30.3
Education level	None	1	1.0
	Primary	17	17.2
	Secondary	46	46.5
	Tertiary	35	35.4
Marital status	Single	21	21.2
	Married	68	68.7
	Divorced	1	1.0
	Widowed	8	8.1
	Separated	1	1.0
Religion	Christian	94	94.9
	Muslim	4	4.0
	Hindu	1	1.0
Type of residence	Rented	57	57.6
	Own house	29	29.3
	Hosted by family members	13	13.1
Employment	Employed	64	64.6
	Not employed	35	35.4

Slightly more than half of the respondents, 58(58.6%) were male. The average age was 44 years with more than half, 58(58.6%) aged between 31 and 50 years. Almost half of the respondents, 46(46.5%) had secondary level education, 35(35.4%) had tertiary education while only 1(1.0%) had no formal education. About two thirds of the respondents, 68(68.7%) were married, 94(94.9%) were Christians, slightly more than half, 57(57.6%) lived in rented residence while more than half of the respondents, 64(64.6%) were employed as shown in Table 4.1.

4.3Patient's Knowledge on Advance care planning

4.3.1Knowledge of the disease as life limiting

Respondents were asked if they knew their illness was life limiting as illustrated in figure 4.1

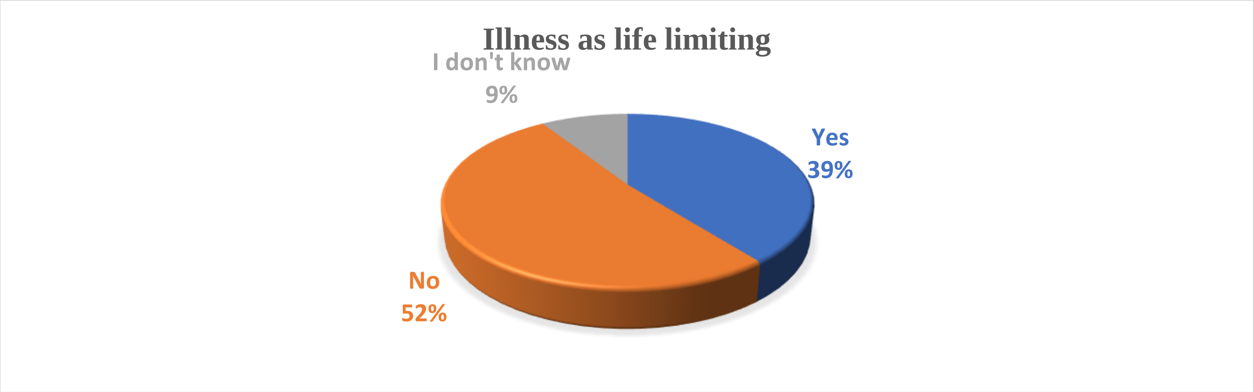


Figure 4. 1: Respondents of the illness as life limiting

About half, 51(52%) identified that their illness is not life limiting while 9% did not know if their illness is life limiting or not.

4.3.2 Knowledge on whether the disease can be cured

Respondents were asked whether their illness was curable or not as illustrated in figure 4.2.

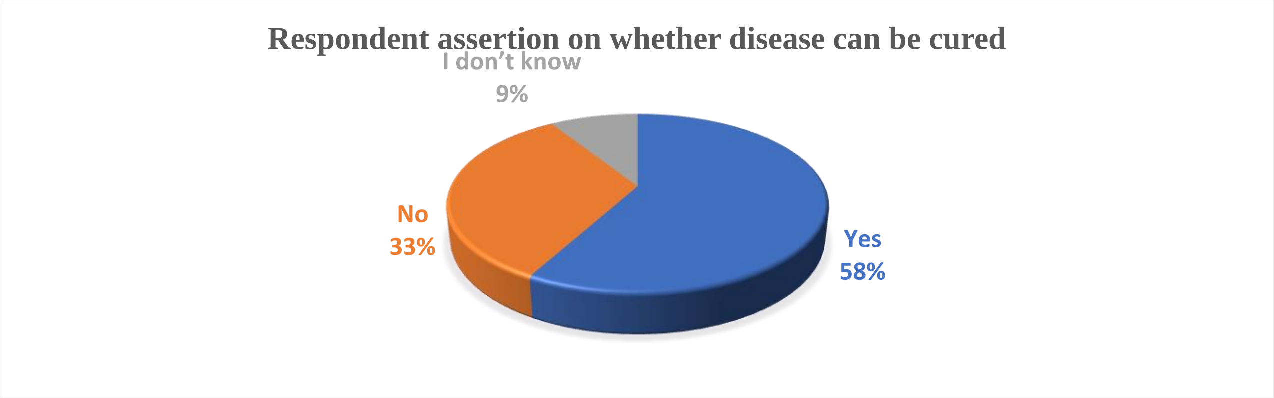


Figure 4. 2: Respondents assertion on whether the disease can be cured

57(58%) of the respondents asserted that the disease can be cured while only about a third, 33 (33%) stated that the disease cannot be cured.

4.3.3Heard of Advance care planning

Respondents were asked whether they had ever heard of advance care planning as shown in figure 4.3.

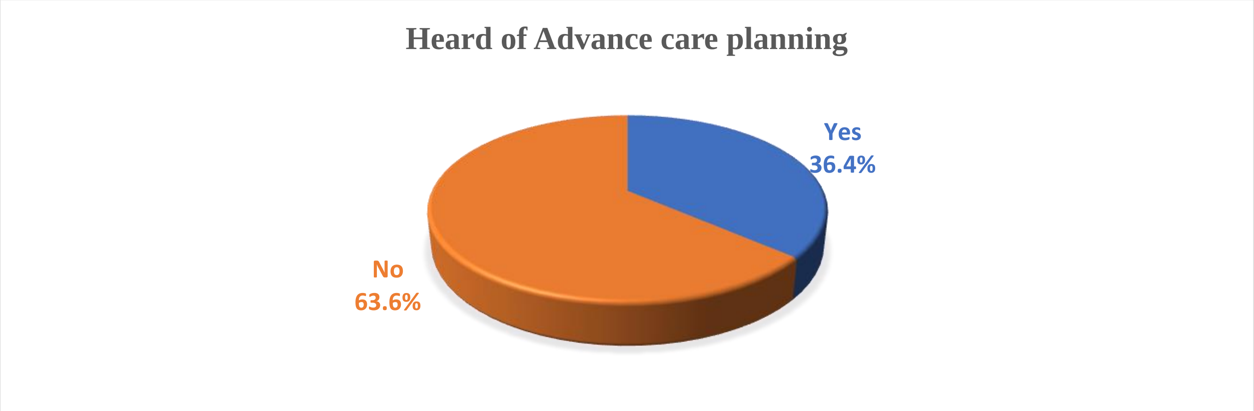


Figure 4. 3: Heard of Advance care planning

More than half of the respondents, 63(63.6%) stated that they had not heard of advance care planning hence no knowledge. Only 36(36.4%) of the respondents had ever heard of it.

4.3.3.1Source of information on Advance care planning

The 36 respondents who had heard of advance care planning were asked about their source of information as illustrated in figure 4.4

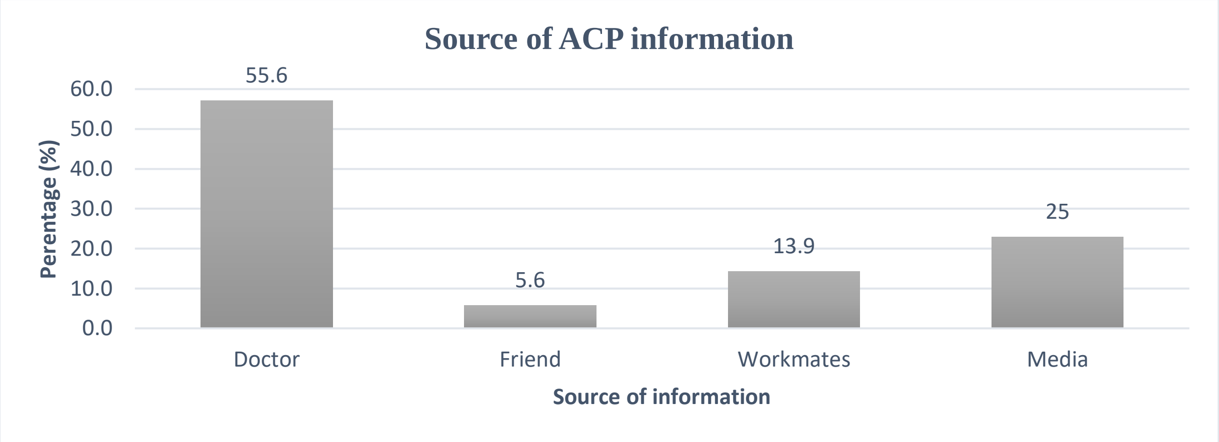


Figure 4. 4. : Source of ACP information

About half of them heard of it from doctors 20(55.6%), Media 9(25%), workmates 5(13.9%) and 2(5.6%) from friends.

4.3.4Educated/given information on advance care planning

The 36 respondents who had heard of ACP were asked if they had been educated on the same as shown in figure 4.5

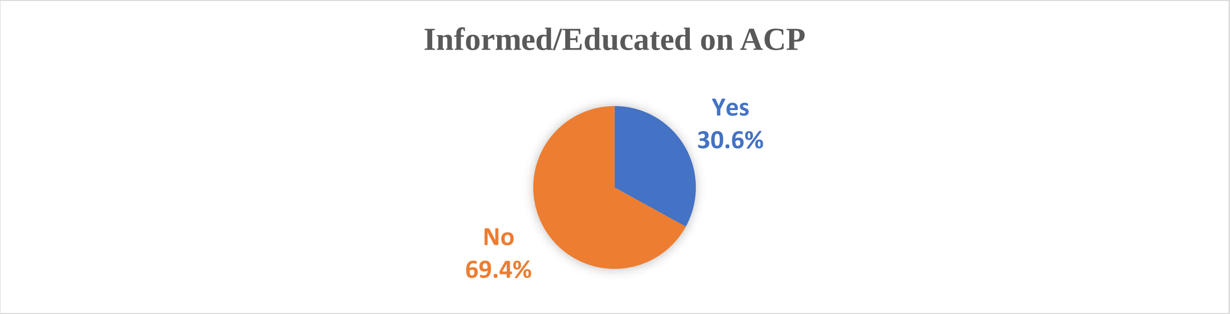


Figure 4. 5: Whether respondents received information/education on ACP

Only 11(30.6%) of them had been informed/educated on advance care planning as shown in Figure 4.5. This translates to only 11.1% of all respondents who had been informed/educated on advance care planning while the majority, 88(88.9%) hadn't been informed/educated.

4.3.4.1Source of information/education among respondents

The 11 respondents who had received information/educated on ACP were asked about the source of their information as illustrated in figure 4.6.

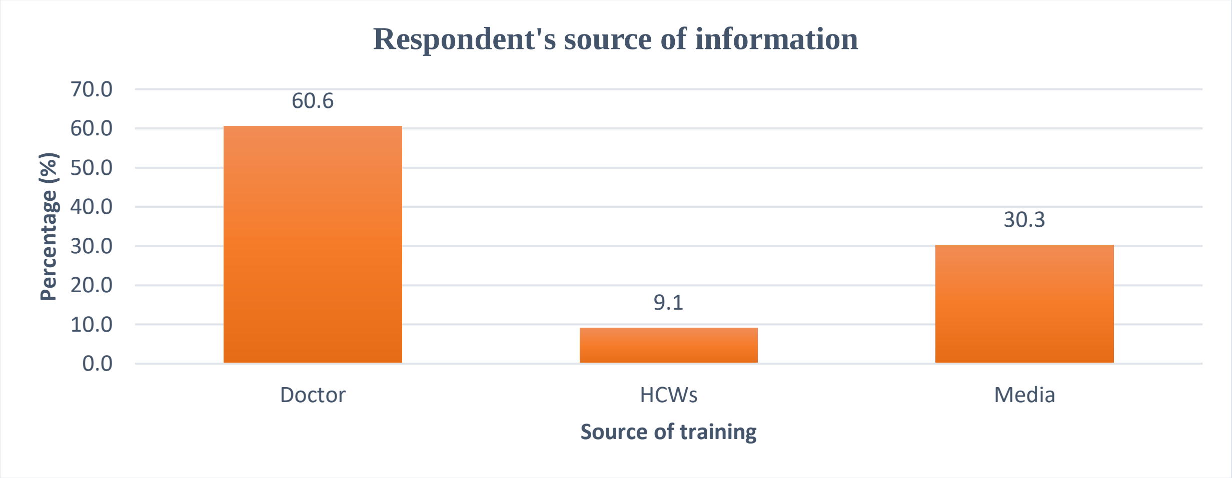


Figure 4. 6: Respondent's source of information/education on ACP

Close to two thirds 7(63.6%) got the information from doctors, 3(27.3%) from the media and 1(9.1%) from other healthcare workers.

4.3.5Knowledge on components of advance care planning among respondents

Details regarding advance care planning were assessed among the 36 respondents who had heard of advance care planning as illustrated in Table 4.2.

Table 4. 2: Respondents' knowledge of what advance care planning entails

	Yes (%) n (%)	No n (%)
It includes having a discussion to understand my condition well	33(91.7)	3(8.3)
It includes identifying my beliefs and values	16(44.4)	20(55.6)
It includes identifying my preferences and goals of care	31(86.1)	5(13.9)
It includes writing down my wishes and care preferences to be used in future when I cannot independently make decisions for myself.	15(42)	21(58)
It includes writing down my wishes about what I want to be done regarding my body and property when I die.	7(19.4)	29(80.6)
It includes selecting someone who will make care decisions on my behalf when I am not able to.	27(75)	9(25)

Most of the respondents, 33(91.7%), 31(86.1%) and 27(75%) knew that discussions, identification of care goals and preferences and surrogacy decision making respectively, are integral parts of advance care planning. However, there was insufficient knowledge on advance directives among the respondents. More than half 21(58%) identified that ACP does not include writing down wishes and preferences for future use. Likewise, more than half of the respondents 20(55.6%) didn't know that identification of their values and beliefs is a component of advance care planning.

4.3.6Knowledge about advance care planning discussions

Respondents' knowledge on advance care planning discussions was assessed as shown in table 4.3.

Table 4. 3: Knowledge on advance care planning discussions among the respondents

	Yes n (%)	No n (%)
It is only my doctor who can initiate a discussion on advance care planning	12 (33.3)	24 (66.7)
I am allowed to ask my doctor to have a discussion on advance care planning	24 (66.7)	13(33.3)
Discussions on advance care planning should be done when medical interventions are less likely to yield beneficial outcomes	7 (19.4)	29 (80.6)
Care decisions should be based on my values and beliefs and evidence from research and practice.	20(55.6)	16 (44.4)

The findings showed that among the 36 respondents who had heard of advance care planning, more than half 24(66.7%) knew that they are allowed to ask their doctors to initiate advance care planning discussions. Regarding key principles of advance care planning, slightly more than half, 20(55.6%) of the respondents knew that care decisions should be based on their values and beliefs and evidence from research and practice. However, most of the respondents didn't have the right information on when these discussions should be initiated. Most of the respondents, 29(80.6%) responded that discussions should be done when medical interventions are less likely to yield beneficial outcomes as shown in Table 4.3.

4.3.7Knowledge on living will/advance directives

Respondents were asked questions concerning their knowledge on ADs as illustrated in table 4.4.

Table 4. 4: Knowledge about living will

	Yes n (%)	No n (%)
It should be developed when medical interventions are less likely to yield beneficial outcomes	12(70.6)	5 (29.4)
The person who I select to make decisions on my behalf can develop a living will for me when I am not able to	4 (23.5)	13(76.5)
My doctor can overrule my living will if he thinks a certain therapy can yield beneficial results.	10 (58.8)	7 (41.2)
It can only be written with my input/participation.	13 (76.5)	4 (23.5)
It can include instructions to remain in effect after my death.	5 (29.4)	12 (70.6)
I have never heard of it	19 (52.8)	17 (47.2)

From the analysis of the 36 respondents who had heard of advance care planning, about half of them, 19(52.8%) affirmed not having heard of a living will/advance directive. Among the 17 respondents who had heard of a living will, more than half, 10(58.8%) did not know that doctors cannot overrule their living will even if they thought a certain therapy could yield beneficial results as shown in Table 4.4.

4.38Knowledge on surrogate/alternative decision making among the respondents

Respondents were asked about their knowledge on surrogate/alternative decision making as illustrated in table 4.5.

Table 4. 5: Knowledge about alternative/surrogate decision making among respondents

Respondents were asked about their knowledge on surrogate/alternative decision making as illustrated in Table 4.5	Yes n (%)	No n (%)
It only comes into effect when I don't wish to or not able to participate in making decisions on my care	29 (80.6)	7 (19.4)
It mostly comes into effect during my end of life care	27 (75)	9 (25)
Decisions should be made in my best interests while respecting my values and wishes.	29 (80.6)	7 (19.4)
The person who I select to make decisions on my behalf must be my close family member.	13 (36)	23 (64)
My family can in some instances overrule my choice of an alternative/surrogate decision maker.	4 (11)	32 (89)
My doctor can in certain instances overrule the care decisions of my alternative/surrogate decision maker	21(58)	15 (42)

The findings show that among 36 respondents who heard about ACP, most 32(89%) knew that their family cannot overrule their choices of an alternative surrogate decision maker. The analysis also found that, majority 29(80.6%) had knowledge that the surrogate decision only comes into effect when they are unable to participate in making of these decisions. The results also found that more than half 21(58%) did not know that doctors cannot overrule the care decisions made by their surrogate decision makers.

4.4Uptake of advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital

4.4.1Mental alertness at the time of diagnosis among respondents

All the 99 respondents were asked whether they were mentally alert to make independent decisions at the time of their diagnosis as shown in figure 4.7

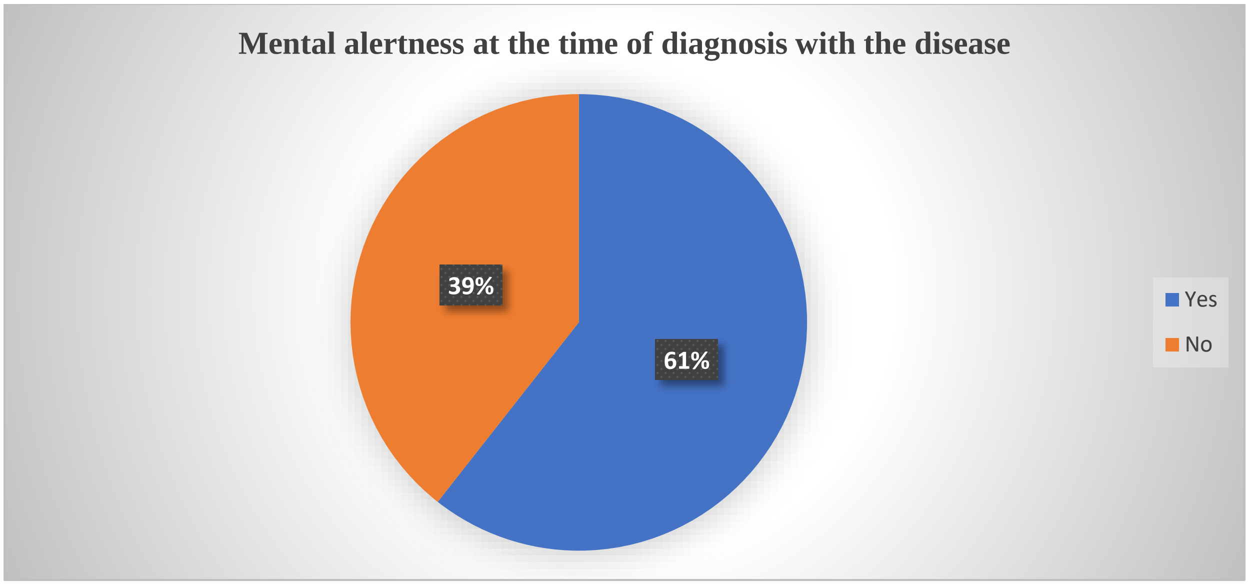


Figure 4. 7: Respondents mental alertness at the time of diagnosis

Close to two thirds of the respondents, 61(61%) of the respondents identified that they were mentally alert while 38 (39%) were not mentally alert to make independent decisions when they were first diagnosed with their condition.

4.4.2Education about health condition prior to dialysis among respondents

61 respondents who were alert during diagnosis were asked whether they were educated about the health condition as shown in figure 4.8.

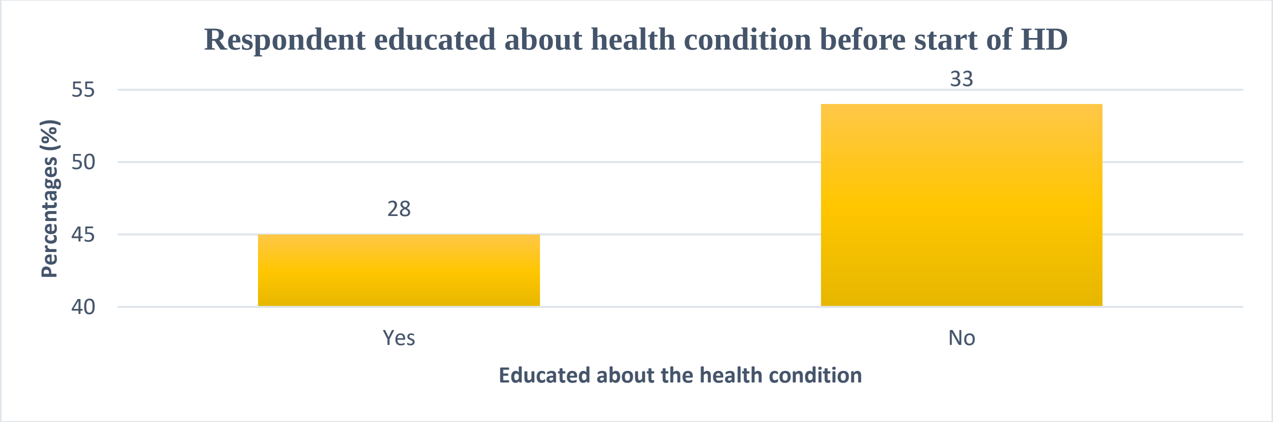


Figure 4. 8: Respondents educated about health condition

Close to half of them 28(45.9%) agreed that they were informed while 33(54.1%) were not educated about their condition.

4.4.3Choice of hemodialysis

The 61 respondents who were mentally alert at the time of diagnosis were asked about their preference for HD and whether they participated in choosing it. The findings are shown in table 4.6.

Table 4. 6: Respondents Choice of hemodialysis

Hemodialysis uptake	I participated in Choosing HD n (%)	I did not participate in choosing HD n (%)
HD was my preferred care option	20 (32.8%)	6(9.8%)
HD was not my preferred care option	5 (8.2%)	30 (49.2%)

Slightly more than half of respondents, 35(57.4%) asserted that HD was not their preferred care option while 26(42.6%) asserted that it was their preferred care option. About half of the respondents, 30(49.2%) responded that HD was not their care option and did not participate in choosing it. Only about a third, 20(32.8%) responded that it was their preferred option of care and they participated in choosing it. On the other hand, 6 (9.8%) of the respondents asserted that HD was their preferred care option yet they did not participate in choosing it while it was not the preferred care option for 5(8.2%) respondents yet they participated in choosing it.

4.4.4Advance care planning discussion

Respondents were asked questions regarding advance care planning discussion as shown in table 4.7.

Table 4. 7: Respondents uptake of advance care planning discussion

Uptake of advance care planning discussion	I have heard such a discussion with my doctor	I have not heard such a discussion with my doctor
	n (%)	n (%)
I have specific wishes about my care	7 (7.1)	86(86.9)
I don’t have specific wishes about my care	0 (0)	6 (6.1)

From the analysis, majority, 93(94%) of the respondents had specific wishes about their care yet only 7(7.1%) had had advance care planning discussions with their doctors.

4.4.5Surrogate/alternative decision making

Respondents were asked about surrogate or alternative decision making with focus on uptake and documentation of surrogate decision makers as shown in table 4.8.

Table 4. 8: Respondents' selection and documentation of surrogate decision makers

Uptake of surrogacy decision making	I have selected someone who will make decisions on my behalf if I'm not able to	I haven't selected someone who will make decisions on my behalf if I'm not able to
	n (%)	n (%)
I have documented someone who will make decisions on my behalf if I'm not able to	0 (0)	0(0)
I haven't documented someone who will make decisions on my behalf if I'm not able to	81 (81.8)	18 (18.2)

Majority, 81(81.8%) of the respondents had a surrogate decision maker in mind yet none had documented that person. 18(18.2%) of the respondents had neither selected nor documented a surrogate decision maker.

4.4.6Uptake of advance directives/living will.

Respondents were asked about having developed an advanced will as shown in table 4.9.

Table 4. 9: Advance directives

Advance directive	**Yes**	**No**
Do you have a living will/advance directive?	0 (0%)	99 (100%)

None of the respondents, 0 (0%) had a living will/advance directive.

4.5 Patients' preferences on Advance care planning

4.5.1Willingness to have advance care discussion

The respondents who did not have advance care discussions were asked their willingness to have a discussion as shown in figure 4.9.

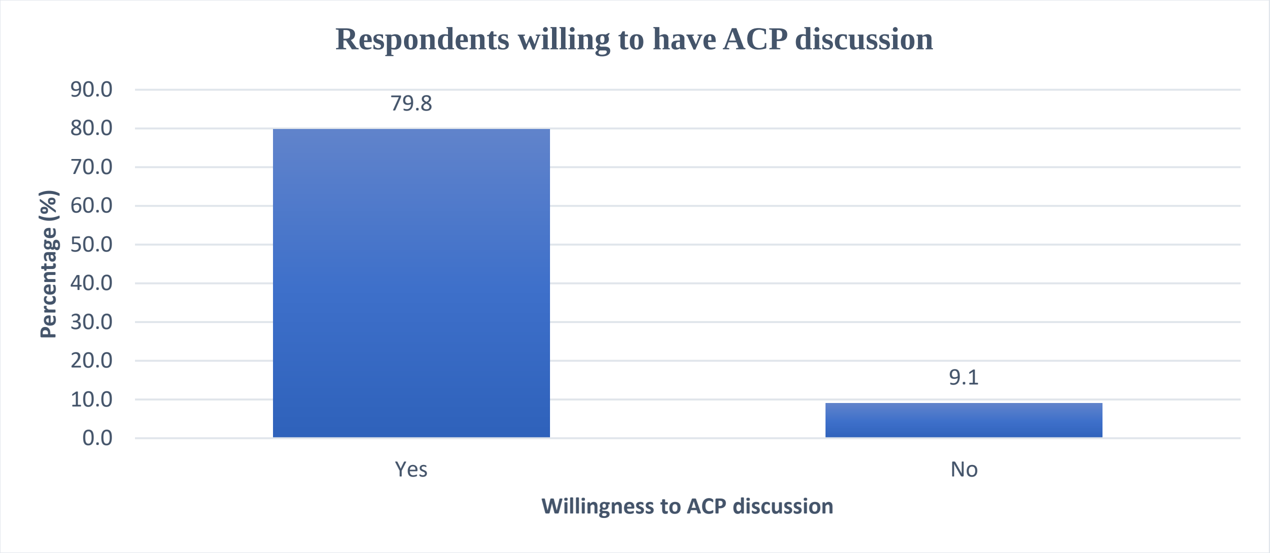


Figure 4. 9: Respondents willing to ACP Discussions

Majority of the respondents, 79(79.8%) were willing to have a formal advance care discussion with their physicians. The main reasons identified as contributing to the willingness to have an advance care discussion include that it helps to plan well for the remaining family members; it allows the patient and family members to make economically viable decisions about their care through choosing of therapies. Other factors that were identified include making peace with the maker and have control over the remainder of life. The respondents who were not willing to have an advanced care discussion cited negative psychological impact on their mind affecting their compliance to care, as well as religion and culture.

4.5.2Willingness to have a documented living will

Respondents who did not have a living will were asked about their willingness to have a living will

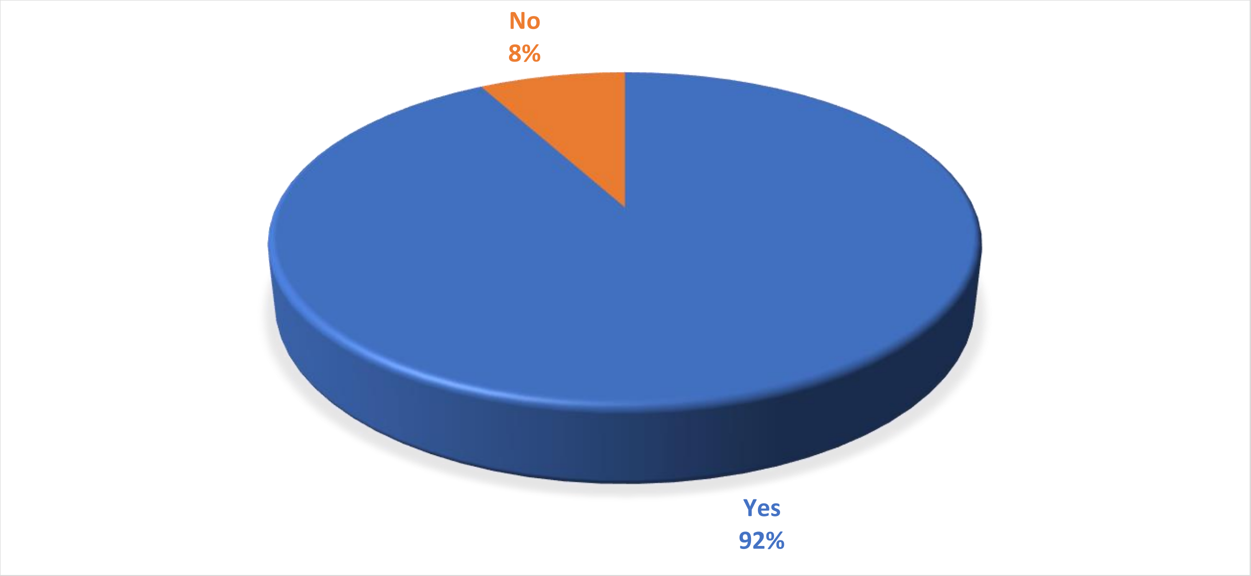


Figure 4. 10: Respondents willingness to having a documented living will

. Most of the respondents, 91(92%) were willing to have a living will while 8(8%) as shown in Figure 4.10. However, those who were not willing to have a living will, they cited that it was against their religion, culturally unacceptable, loss of medical benefits and would have psychological negative impact on the respondent.

4.5.3Willingness to have surrogate decision maker

The 99 respondents who had not documented their surrogate decision makers were asked about their willingness to document surrogate decision makers as shown in figure 4.11

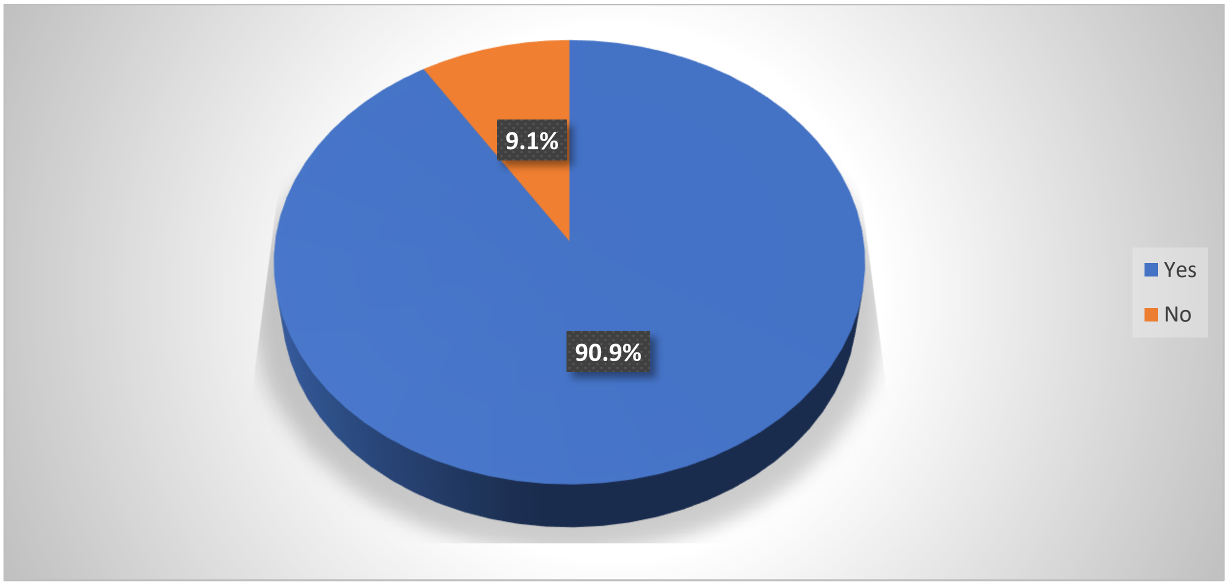


Figure 4. 11: Willingness to have a surrogate decision maker among respondents

Among the 99 respondents who had not documented their surrogate decision makers, 90(90.9%) were willing to document a surrogate decision maker as shown in Figure 4.10.

4.5.4. The surrogate decision maker choice among the respondents

90 respondents who were willing to document a surrogate decision maker were asked about their preferred choice as shown in Figure 4.12.

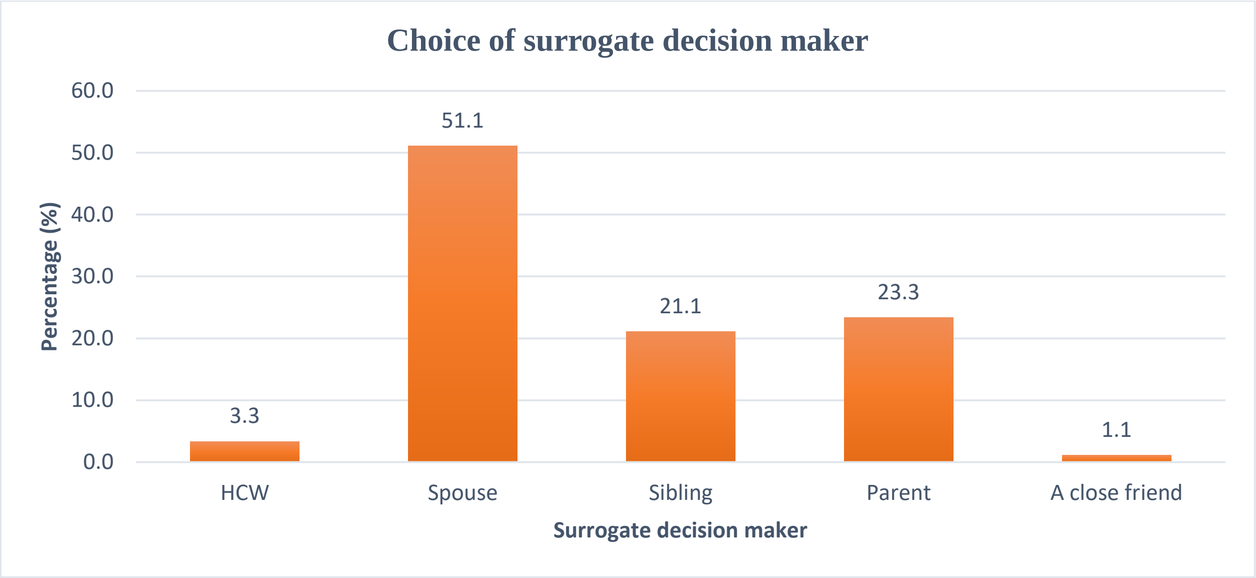


Figure 4. 12: Respondent's choice of surrogate decision maker

About half of them, 46(51.1%) preferred their spouses, 21(23.3%) parents and 19(21.1%) siblings.

4.5.5End of life care preferences of patients on maintenance hemodialysis at Kenyatta National Hospital

The respondents were asked about their preference of care when getting closer to final moments of their lives, and their responses were as indicated in figure 4.13.

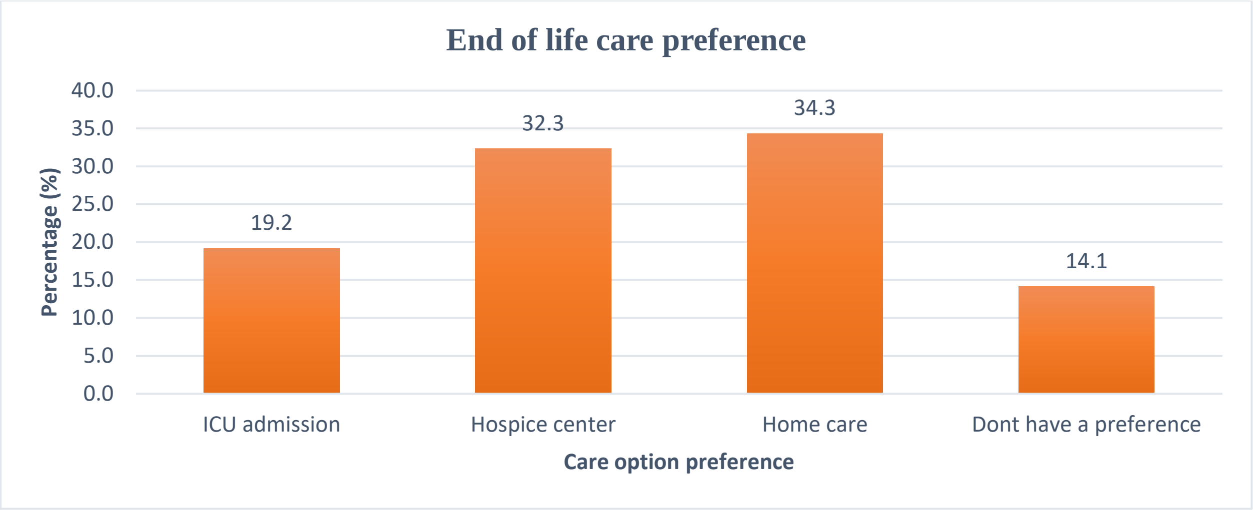


Figure 4. 13: Respondent's advance care option preference

About a third, 34(34.3%) preferred home based care, another third 32(32.3%) preferred hospice care, 19(19.2%) preferred ICU admission while 14(14.1%) did not have any preference.

4.5.6Preferences regarding HD

Respondents were also asked about their preferences regarding continuity of HD as shown in table 4.10.

Table 4. 10: Respondent preferences on HD at end of life

		Frequency	Percentage
Valid	Terminate dialysis	33	33.3
	Continue with dialysis until life ends	66	66.7

Two thirds of the respondents, 66(67.3%) asserted that they prefer to continue with dialysis until their life ends.

4.2.1 Place of death preference

Respondents were also asked about their place of death preference, slightly less than half of the respondents as shown in figure 4.14.

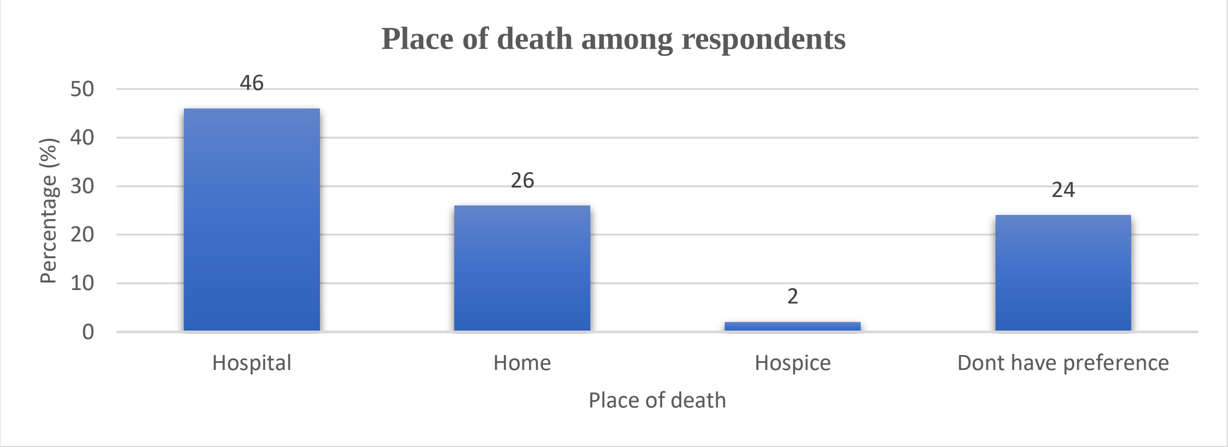


Figure 4. 14: Respondent's place of death reference

About half of the respondents, 46(46.5%) highlighted that they would prefer hospital as their place of death, about a quarter 26(26.3%) preferred home while another quarter 24(24.2%) did not have preference.

4.6Clinicians’ practice of advance care planning with patients on maintenance hemodialysis at Kenyatta National Hospital

4.6.1Patients’ Knowledge on advance care planning

The study included two clinicians who were engaged in in-depth interviews. The interviews discussed a wide array of elements regarding advance care planning. Knowledge, advance care discussions, ACP uptake and care preferences. Both participants asserted that patient knowledge on advanced care planning was inadequate. **Clinician 1** indicated that:

> “*So from my experience the first thing is that they [patients on maintenance hemodialysis] don’t seem to understand anything. Then they will tell you to do anything you can. So despite the fact that their kin is terminally ill, they still want you to do everything to save their kin’s life. So I doubt whether that is being receptive. It is denial and avoidance to make decisions*.”

> **Clinician 2** also affirmed that, “*Most of these patients fear discussing anything to do with end of life and they are not entertaining the idea. At least among those I have tried to engage...*”

4.6.2Advance care planning discussions

In assessing clinicians’ practice of advance care planning discussions with patients on maintenance hemodialysis, the participants stated that ACP discussions were very minimal. They highlighted challenges such as late presentation of patients to hospitals, uncertainty in estimating patients’ life expectancy, patients and relatives being disinterested in discussing end of life issues and the potential negative psychological impacts of ACP discussions. These challenges limit effective institution of advance care planning discussions necessary for achieving the needed goals. Even in the few instances where ACP discussions are done, they normally do them late when it is difficult for patients to make informed decisions as explained by one clinician.

, “*the patients present so late to the extent that the patient is not the primary person you are talking to because they can’t comprehend what you are saying. So, what you normally do is that in the initial stages the people you are talking to are the close relatives*.” **(Clinician 2)**

The participant (clinician 2) further asserted that,

> “*I must appreciate that we have encountered tremendous challenges and up to now the practice here is quite low. Top of the list being inadequate awareness or information among end stage kidney disease patients of their conditions leave alone advance care planning. I acknowledge that as healthcare workers and that should be a team effort we must do much more on that front*.”(**Clinician 2)**

On the other hand, clinician 1 attributed the low implementation of advance care planning to the complexity of estimating life expectancy of those patients

> “*The challenge with these late discussions is that it is not us to decide who lives and who dies because you cannot be absolutely sure of the life expectancy of these patients and sometimes they even outlive you people.”(***Clinician 1)**

The Clinician shifted the responsibility of initiating advance care planning discussions to other healthcare workers;

> “*So we normally talk to the relatives and it is usually never a primary duty of a doctor like me although I can discuss it with the patient. That’s the reason why in a renal unit we have to have counselors who will talk to them, tell them the probable outcome, the advantages of the various treatments and ideally we should have social workers.”***(Clinician1).**

The other clinician was also weary of the impact end of life discussions on patients’ compliance to subsequent care:

> “*So bearing in mind sometimes talking about advance care planning with these patients does more harm than good especially when you now have to talk about end of life issues. No one contemplates about death in our setting and telling someone that their condition is terminal would really affect them psychologically and that means a red flag on adherence.”**Clinician 2***

4.6.3Identification of patients’ care preferences

In assessing the identification of patients’ advance care preferences, the clinicians highlighted that it is not the duty of a physician to choose for the patient. One clinician asserted that:

> "*For us our duty is to give these terminal patients the maximum. It is not our duty to decide when they are going to die and most of us doctors, our duty is just to make the life comfortable but they have to know the state of their health and the possible outcomes*" (**Clinician 1)**

4.6.4Surrogate decision making and Advance directives

While assessing the practice of surrogate decision making and advance directives, most of the patients did not have a clear decision maker where in most cases they relied on physicians to outline what needs to be done. One clinician asserted that:

> "*In most instances they rely on you as the doctor to just do whatever possible to salvage the life of their loved one." (***Clinician 2)**

The other clinician also affirmed that, in most cases the patients don't document surrogate decision makers or advance directives;

> "*But still advance care planning is sparingly done and most of this planning doesn't go beyond the discussions, that is, patients don't document their surrogate decision makers or fill advance directives*." (**Clinician 1)**

4.6.5Opinions about up scaling advance care planning

The clinicians were also asked whether advanced care planning is something that should be up scaled. Both participants agreed that ACP is essential in management of patients although there are challenges which need to be controlled, e.g.

> "*It is a necessary part of their management but in our environment it is still very difficult because of illiteracy, ignorance and poverty. It's very obvious that we need to upscale this service so that we can pick up these patients earlier, when they are energetic and can engage in these discussions constructively and with an independent mind. And the point at which we need to start with is at the primary level*." (**Clinician 1)**

Clinicians presented recommendations regarding the approaches that need to be considered in improving ACP uptake e.g.

> "*In my view the time is absolutely prime to put more emphasis on this service. However, we must have concerted efforts all the way from policy makers, administrators to the healthcare workers on the ground. We must climb the tree from the bottom. The focus should start with concerted efforts to increase community awareness of renal diseases and the aspect of advance care planning in this population*." (**Clinician 2)**

4.7Association between patients' characteristics and uptake of advance care planning

A Chi-square test for association was conducted to investigate association between patient characteristics and advance care planning uptake as shown in table 4.11.

Table 4. 11: Chi-square test for association between patients' characteristics and ACP uptake

		Uptake of ACP				
		Yes	No	Chi-Square	Df	P-value
Education level	None	0	1(100%)	2.265	3	0.519
	Primary	3(18%)	14(82%)			
	Secondary	9(20%)	37(80%)			
	Tertiary	11(31%)	24 (69%)			
Marital status	Single	3(14%)	18(86%)	11.032	4	**0.026**
	Married	14(21%)	54(79%)			
	Divorced	1(100%)	0			
	Widowed	4 (50%)	5 (50%)			
	Separated	1(100%)	0			
Age group of the respondents	<30 years	2(18%)	9(82%)	0.184	2	0.912
	31 - 50 years	14(24%)	44(76%)			
	>50 years	7(23%)	23(77%)			
Religion	Christian	22(23%)	72(77%)	0.311	2	0.856
	Muslim	1(25%)	3(75%)			
	Hindu	0	1(100%)			
Employment status	Employed	18(28%)	46(72%)	2.43	1	0.119
	Not employed	5(14%)	30(86%)			
Knowledge of ACP	Yes	18(50%)	18(50%)	22.73	1	**p<0.001**
	No	5(8%)	58(92%)			
HD preference at end of life	Terminate dialysis	11(34%)	21(66%)	3.882	1	**0.049**
	Continue with life till ends	11(17%)	55(83%)			

The results showed that there was a significant association between advance care planning uptake and marital status, $x^2(4) = 11.032$, p= 0.026, knowledge of advance care planning and uptake $x^2(4) = 22.73$, p<0.001 as well hemodialysis preferences at end of life $x^2(4) = 3.88$, p= 0.049. There was no significant association between uptake of advance care planning and education level, $x^2(4) = 2.265$, p= 0.519, religion $x^2(4) = 0.311$, p= 0.856 and employment status $x^2(4) = 2.43$, p= 0.119 as shown in Table 4.11.

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECCOMMENDATION

5.1 Introduction

The study sought to assess advance care planning between clinicians and patients on maintenance hemodialysis at Kenyatta National Hospital renal unit. This chapter includes discussion on level of knowledge, uptake, preferences, clinicians' practice of advance care planning as well as conclusion and some recommendations made based on the results of this study.

5.2 Discussion

5.2.1 The level of knowledge on advanced care planning among patients on maintenance hemodialysis at Kenyatta National Hospital renal unit

The study sought to investigate the level of knowledge on advance care planning and its components among patients on maintenance hemodialysis. The study established that patients had low level of knowledge on the concept of advance care planning since only 36% of the respondents affirmed to having heard of advance care planning before. This was confirmed by the two clinicians who indicated that patients were not aware of such planning which made it difficult for them to understand the details of ACP and its importance in healthcare delivery. These findings are echoed by O'Halloran et al. (2018) who conducted a systematic review which revealed that a high number of patients did not have knowledge on advance care planning. Likewise, Kermel-Schiffman and Werner (2017) established that only 18.9% of their participants had moderate level of knowledge regarding ACP in general. This might be attributed to lack of patient education on ACP across different settings including hospitals and media outlets. The clinicians further affirmed they hold very few discussions with patients on maintenance hemodialysis and that many patients lack interest in information relating to end of life which also limited patient knowledge on ACP.

Analysis of respondents who had heard of advance care planning in this study revealed moderate knowledge on some aspects of advance care planning despite being aware of the existence of advance care planning. More than half knew that discussions, identification of care goals and preferences and surrogacy decision making respectively, are integral parts of advance care planning. However less than half identified that ACP does include writing down wishes and preferences for future use while more than half affirmed not having heard of a living will/advance directive. Kermel-Schiffman and Werner (2017), in a systematic review revealed that participants knew some aspects of ACP, but did not know others. Inconsistencies were found in the types of instruments and the number of items used to assess knowledge. The participants who participated in the study identified that there is a combination of factors which have led to reduced understanding on ACP with healthcare workers being identified as key part in failure to introduce patients to ACP. These findings are comparable to a quantitative study conducted by Chehuen Neto et al. (2015) who revealed that only 8% of healthcare professionals knew how to write a living will, most of them (74%) felt safer with its regulation and 62% would do it themselves. This shows that there exists knowledge gap on both the part of the patient and healthcare workers.

Lack of adequate knowledge has been a major detrimental factor to successful ACP practice. According to Kermel-Schiffman and Werner (2017), 45% of the respondents knew some aspects of ADs but did not have knowledge on other key aspects of ACP such as patient self-determination. The lower level of knowledge presented a difficult context where it would be possible to implement ACPs successfully. Additionally, Sellars et al. (2015) in a study conducted in Australia showed that Less than 50% of case managers felt confident regarding their knowledge and skills in ACP domains, 85% did not believe ACP was done well within their service. Few healthcare professionals are confident in successfully engaging their patients in advance care planning.

5.2.2 The uptake of advance care planning among patients on maintenance hemodialysis at Kenyatta National Hospital

The study also set out to determine the uptake of advance care planning among respondents. The results from this study revealed that almost all (93%) of respondents had never held advance care planning discussions. However, almost all of them were willing to have the discussions because they believed that having advance care discussions would help them plan well for the remaining family members, allow them and family members to make economically viable decisions about their care through choice of therapies. Other respondents also highlighted that it would help in making peace with their maker and have control over the remainder of life.

These findings are in line with the findings from other studies (Chen et al., 2018; Lazenby et al., 2017). Axelsson et al. (2018) stressed that death and dying are issues not discussed often until the very last days of life, leading to patients having little information about end of life issues and advance care planning. This echoes the findings of this study in which all the clinicians' interviewed argued that among the few instances where ACP discussions are held, most are done very late. Likewise, while assessing knowledge on ACP discussions among patients, this study revealed that majority of patients believed that discussions should be done when medical interventions are less likely to yield beneficial outcomes.

In addition, this study found out that most patients had specific wishes regarding their care yet very few had discussed those wishes with their doctors. This mirrors the findings Jayanti et al. (2015) observed; that majority of the patients on maintenance hemodialysis rarely participate in care decision making. Similarly, Davision (2010) and Amro et al. (2016) identified that less than 10% of patients with ESKD had discussed ACP or any end of life issues with their nephrologists. These results are also affirmed by Mah et al. (2019) who stated that less than 50% of patients living with life-limiting conditions had neither had meaningful advance care discussions nor filled ADs. These findings are explained by the responses of the key informants in this study who attributed the low level of advance care planning to patients presenting late, complexity of estimating patients' life expectancy and fear among clinicians that such discussions might cause psychological effects that might affect the patients' compliance with care going forward. Similar reasons were outlined by Visser, Deliens, & Houttekier (2014) who attributed the low uptake of ACP in hemodialysis patients to the failure of clinicians to initiate such conversations with their clients. In addition Goff et al., (2019) partly attributed it to the perceptions among clinicians that patients don't actually need this kind of discussions during their illness because that such kind of discussions might lead to hopelessness and psychological and emotional disturbances.

Thus findings from this study showed that none of respondents had documented a living will ADs. This was attributed mainly to patients' lack of knowledge and preparedness and reluctance of healthcare providers to engage these patients in meaningful ACP. Multiple studies have echoed these sentiments, highlighting that the use of ADs is still very low in different parts of the world (Sara A Combs & Davison, 2017; Erdley et al., 2010; Ladin et al., 2018; Mah et al., 2019). Nonetheless, there has been a higher uptake of ADs in developed countries. In a study conducted in United States, around 30% of HD patients had ADs (Trip ken et al., 2018). It was revealed that higher level of knowledge on ADs and improved care guidelines in dialysis centers explained the increase in uptake.

5.2.3 Advance care planning preferences of patients on maintenance hemodialysis at Kenyatta National Hospital.

Findings from this study revealed that majority of patients had specific preferences about their care including having ACP discussions, documentation of ADs and surrogate decision makers. However, none of the respondents had documented surrogate decision makers or Ads while only 7.1% had had some form of ACP discussions. These findings are comparable to the findings of multiple previous studies. Axelsson et al. (2018) found out that most ESKD patients had not had meaningful ACP discussions and had many unmet EoLC needs. Similarly Erdley et al., (2010) noted that ESKD patients and their families preferred to be informed and talked to about their illness, the expected duration of HD therapy, the effects of the therapy on their lives and well-being and about the end of life issues in comparison to the general expectation of healthcare providers. As high as 97% of patients desired that their nephrologists discussed with them prognostic information and end of life care without being prompted to (Chen et al., 2018; Lazenby et al., 2017; Davison 2011). The findings of these studies are attributable to the understanding among a number of patients that their healthcare providers are the ones who are supposed to initiate ACP discussions while few clinicians' practice ACP with their clients. This reasoning is supported by the findings of Visser, Deliens, & Houttekier (2014) who noted that ACP practice had been largely clinician driven.

Preferences regarding HD were also assessed in this study. Most of the respondents affirmed that they would like to continue with HD till the last day, with hospital being the preferred place of death. In addition, patients in this study either had limited knowledge or did not appreciate that the major symptom burden and deterioration of functional independence towards end of life is actually attributed to HD therapy as reported in previous studies (O'Halloran et al., 2018 ; Tamura et al., 2009).

The respondents were asked about their preference of care when getting closer to final moments of their lives, about a third(34.3%) preferred home care, another third (32.3%) preferred hospital care, 19 (19.2%) preferred ICU admission while 14(14.1%) did not have any preference of any care option preference. With regards to place of death, home and hospital care were the most significant among the respondents. These findings are comparable to Jahdali et al. (2009) reported that 73% of participants preferred their home as the place of terminal care, and the number rose to 87% if the home care was provided by a healthcare provider. Similarly, Janssen et al. (2013) highlighted that 48.7% of patients preferred to die in their homes, 32.5% preferred a hospital, while only 15% preferred a hospice. 38% didn't have a preference on place of death. This can probably be explained by the presence of a greater support system in the hospitals and homes as perceived by patients.

5.2.4 Clinicians' practice of Advance care planning with patients on maintenance hemodialysis.

Clinicians were asked to rate their level of ACP practice with patients on maintenance hemodialysis. Both of them agreed that there are tremendous challenges to the practice of ACP and that still the practice is low. These findings are congruent with the findings of Visser, Deliens, & Houttekier (2014) who noted that ACP practice had been largely clinician initiated and directed and their engagement with hemodialysis patients was low. The two clinicians attributed this low level of practice to patients presenting very late for care, uncertainty to estimate patients' life expectancy, high workload as well as the fear that initiating ACP discussions in their set up might lead to negative psychological effects on their patients. This would in turn negatively affect patients' compliance to care. In addition, the low practice of ACP can probably be attributed to the fact that there is currently no policies/operational framework clearly guiding ACP practice at KNH. ACP is also not among the services outlined in the KNH renal unit service charter. This reasoning is comparable to the findings of Goff et al., (2019) who cited perceptions among clinicians that patients don't actually need this kind of discussions during their illness because such discussions might lead to feelings of hopelessness and psychological and emotional distress.

5.2.5 Association between patients' characteristics and uptake of advance care planning

A Chi-square test for association was conducted to investigate association between patient characteristics and advance care planning uptake. The findings revealed a significant association between uptake of ACP and knowledge of ACP, marital status as well as preferences at end of life. These findings are comparable to the findings of Detering, Hancock, Reade, & Silvester, (2010) who reported that patients who were married significantly had higher likelihood of ACP uptake compared to patients who were not married. This can probably be attributed to availability of support within the family structure (McGlade et al., 2017). Similarly Spelten et al., (2019) found out that awareness and comprehension of ACP were the most significant determinants of ACP uptake. McGlade et al., (2017) similarly reported that patients who had sufficient knowledge on ACP were more likely to engage in ACP. Lack of knowledge on ACP was implicated to negatively affect readiness, receptiveness and willingness to engage in ACP (Spelten et al., 2019 ; Weathers et al., 2016).

However, the findings of this study did not reveal significant association between ACP uptake and age, level of education, religion as well as employment status of the respondents. These findings are incongruent with the findings in various previous studies. Balboni et al., (2013) a study done in Melbourne, Australia, found out that religiosity was directly proportional to ACP uptake and preference of aggressive life sustaining therapies toward end of life. Lower socioeconomic status and level of education were also found to negatively impact the uptake of ACP (Weathers et al., 2016). The findings of this study can are explained by the fact that only 36.4% of patients had heard of ACP and only 11.1% had been educated/given information on ACP. Majority of patients therefore had low knowledge of ACP which is the factor that was most significant in this study.

5.3 Conclusion

There is limited knowledge of ACP among patients on maintenance hemodialysis due to lack of awareness and appropriate education. As a consequence, the uptake of ACP remains very low. Similarly, few patients on maintenance HD in KNH have been engaged in advance discussions with none neither having a living will nor documented surrogate decision maker. This has been attributed to limited knowledge among patients regarding implementation, reluctance by clinicians to engage patients in ACP discussions and lack of hospital policies on structure/operational framework to facilitate successful implementation of ACP. The study also identified that the minority of patients' decision not to partake in ACP is influenced by a number of factors such as negative psychological impact, religion and culture. These elements need to be effectively addressed to help patients on maintenance HD to meaningfully participate in ACP.

5.4 Recommendations

- There is need for the KNH management to develop policies/operational framework to guide successful implementation of ACP with patients on maintenance hemodialysis. This will upscale clinicians' practice of ACP.
- Clinicians and other healthcare professionals should develop strategies for creating awareness of ACP among patients on maintenance hemodialysis.
- There is need for KNH management to train and retrain clinicians and other healthcare professionals working with patients on maintenance hemodialysis on initiation of ACP discussions and ACP implementation as part of capacity building.
- More studies need to be done focusing on ACP, knowledge and perspectives of healthcare workers and patients on maintenance hemodialysis towards ACP.

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APPENDICES

Appendix I: Participant information sheet and information sheet consent form

Title: Assessment of Advance Care Planning Practice between clinicians and patients on maintenance hemodialysis at Kenyatta national Hospital, Nairobi County Kenya.

Investigator: Samson John Betunda Mgala

Introduction: I am a student studying a Master of Science degree in Nursing at the School of Nursing Sciences of the University of Nairobi. I'm conducting a study at Kenyatta National Hospital renal unit entitled Advance care planning and preferences in a group of end stage kidney disease patients on hemodialysis at Kenyatta National Hospital, Nairobi Kenya. This study is part of my academic requirements towards being awarded the degree.

This communication is purposed to provide necessary information that will enable you to make an informed decision regarding your participation in this study or not. You are free to ask any questions pertaining this study and I'll ask you some questions to assess your understanding before you can decide to sign the consent form or not.

Purpose of the study: The aim of this study is to establish patients' level of knowledge, advance care planning preferences, uptake of advance care planning and clinicians' perception on advance care planning with patients on maintenance hemodialysis at Kenyatta National Hospital renal unit (KNH. The findings of this study will be important to promote patients' and health care providers' participation in shared decision making regarding their care as well as identify care practice gaps and inform policy on the same.

Participation: This will entail responding to questions from the questionnaire as posed by the principal investigator or his assistants. The investigator or his assistants will then fill the responses as given by the participants into the questionnaires. Participation in this study will be solely voluntary. You have the right to agree or refuse to participate in the study. You can also withdraw your participation or opt not to answer any question at any time without incurring any negative consequences.

Benefits: Participants will not get any monetary benefits for participating in this study. However, this study will generate important findings which will be shared with the hospital management, with other decision and policy makers as well as be presented in scientific conferences to inform practice and guidelines to improve patient's and health care providers' participation in advance care planning and care decision making.

Risks: Data collection for this study is noninvasive. There are no expected physical or any other forms of risks for participating in the study. However, some questions might trigger negative or emotional feelings as the study touches on sensitive issues of life. If that happens, the unit's counselor will help you through. Data collection will be halted until such a time you will be ready to continue or be stopped ultimately if you feel not to continue thereafter.

Confidentiality: The information that you will provide will only be used for the intended purpose of this study. Your privacy will be upheld with the utmost confidentiality and your name will not be written in the questionnaire to ensure you remain anonymous. All questionnaires will be kept in a locked box and be only accessible to people directly involved in the study. All electronic files generated from the study will be password protected.

Conflict of interest: The investigator, assistants or the supervisors declare no conflict of interest amongst them.

CONSENT FORM

Having been satisfactorily informed of the nature of the study and my role herein, I hereby consent voluntarily and without coercion to be a participant. I understand that there are no direct monetary benefits or anticipated risks attached to this study and that my refusal to answer any question or withdrawal at any point in this study will not attract any kind of negative consequences or affect my treatment rights in any way. I have also been duly informed that any information I give as part of this study will be handled with utmost confidentiality. I understand that my personal identification details will not be captured as I participate in this study. I hereby without coercion confirm that all my fears and concerns regarding my participation in this study have been satisfactorily addressed. The researcher has also asked me questions to ascertain my comprehension of the provided information.

Signature of the participant/Thumbprint ………………………. Date ………………………

I can confirm that I have clearly and in detail explained the nature of this study and the contents contain here in the consent form. The participant has voluntarily and without any undue pressure opted to participate in this study.

Investigator ….………………………… Signature …………… Date …………………………

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Appendix II: Maelezo kwa mshiriki kuhusu utafiti

Jina la utafiti: Ufahamu wa mpango wa utunzaji wa mapema baina ya wahudumuwa afya na wagonjwa wanaopata huduma za usafisaji wa figo (Hemodialysis) katika Hospitali ya Kitaifa ya Kenyatta, Nairobi Kenya.

Jina la mtafiti: Samson John BetundaMgala

Utangulizi: Mimi ni mwanafunzi anayesoma Shahada ya uzamili ya Sayansi ya Uuguzi katika Chuo cha Sayansi ya Uuguzi cha Chuo Kikuu cha Nairobi. Nafanya utafiti katika kitengo cha figo cha Hospitali ya Kitaifa ya Kenyatta kinachoitwa Upangaji wa utunzaji wa mapema na upendeleo katika kikundi cha wagonjwa wa magonjwa ya figo ya hatua ya mwisho juu ya wanaopata huduma za usafisaji wa figo (Hemodialysis) katika Hospitali ya Kitaifa ya Kenyatta, Nairobi Kenya. Utafiti huu ni sehemu ya mahitaji yangu ya kielimu kuelekea kukabidhiwa digrii hiyo

Mawasiliano haya yamekusudiwa kukupa habari muhimu ambayo itakuwezesha kufanya uamuzi unaofaa kuhusu ushiriki wako katika utafiti huu au la. Uko huru kuuliza maswali yoyote yanayohusu utafiti huu na nitakuuliza maswali kadhaa ili kutathmini uelewa wako kabla ya kuamua kusaini fomu ya idhini au la.

Azimio la utafiti: Madhumuni ya utafiti huu ni kuanzisha mapema njia za upangaji wa utunzaji na upendeleo wa utunzaji katika kikundi cha wagonjwa wa magonjwa ya figo ya hatua ya mwisho juu ya wanaopata huduma za usafisaji wa figo (Hemodialysis) katika Hospitali ya Kitaifa ya Kenyatta. Matokeo ya utafiti huu yatakuwa muhimu kukuza ushiriki wa wagonjwa katika kufanya maamuzi ya pamoja kuhusu utunzaji wao na kutambua mapengo ya mazoezi ya utunzaji na sera ya habari hiyo hiyo.

Ushiriki: Hii itajumuisha kujibu maswali kutoka kwa dodoso kama inavyosemwa na mpelelezi mkuu au wasaidizi wake. Mpelelezi au wasaidizi wake watajaza majibu kama waliyopewa na washiriki kwenye dodoso. Ushiriki katika utafiti huu utakuwa wa hiari tu. Una haki ya kukubali au kukataa kushiriki katika utafiti. Pia unaweza kuondoa ushiriki wako au uchague kutojibu swali lolote wakati wowote bila kuleta athari mbaya.

Faida: Washiriki hawatapata faida yoyote ya kifedha kwa kushiriki katika utafiti huu. Walakini, utafiti huu utatoa matokeo muhimu ambayo yatashirikishwa usimamizi wa hospitali, pamoja na watunga maamuzi na watunga sera na pia kuwasilishwa katika mikutano ya kisayansi ili kuarifu mazoezi na miongozo ya kuboresha ushiriki wa mgonjwa katika upangaji wa utunzaji na uamuzi wa utunzaji.

Athari: Ukusanyaji wa data ya utafiti hautahusisha kudunga au kukata ngozi yako. Hakuna aina inayotarajiwa ya hatari ya mwili au aina nyingine yoyote kwa kushiriki katika utafiti. Walakini, maswali kadhaa yanaweza kusababisha hisia hasi au za kihemko wakati uchunguzi unagusa maswala nyeti ya maisha. Ikiwa hiyo itatokea, mshauri wa kitengo atakusaidia. Ukusanyaji wa data utasimamishwa hadi wakati kama huo utakuwa tayari kuendelea au kusimamishwa mwishowe ikiwa unahisi kutokuendelea baadaye.

Usiri: Habari ambayo utatoa itatumika tu kwa madhumuni yaliyokusudiwa ya utafiti huu. Habayi hizi zitasimamiwa na usiri mkubwa na jina lako halitaandikwa kwenye dodoso ili kuhakikisha unabaki bila kujulikana. Dodoso zote zitahifadhiwa kwenye sanduku lililofungwa na kupatikana tu kwa watu wanaohusika katika utafiti. Faili zote za elektroniki zinazotokana na habari za utafiti huu zitalindwa kwa nywila

Masilahi fiche: Mpelelezi, wasaidizi au wasimamizi wanatibithisha kwamba hakuna masilahi fiche kati yao.

FOMU YA IDHINI

Kwa kuwa nimearifiwa kikamilifu na kuelewa asili ya utafiti na jukumu langu hapa, nikiri kwa hiari na bila kulazimishwa kuwa mshiriki. Ninaelewa kuwa hakuna faida za moja kwa moja za kifedha au hatari inayotarajiwa kwenye utafiti huu na kwamba kukataa kwangu kujibu swali au kujitoa kwa wakati wowote katika utafiti huu hakutavutia aina yoyote ya matokeo hasi au kuathiri haki yangu ya matibabu kwa njia yoyote. Pia nimejulishwa kwa usahihi kuwa habari yoyote ambayo ninatoa kama sehemu ya utafiti huu itashughulikiwa kwa usiri mkubwa. Ninaelewa kuwa maelezo yangu ya kutambulisha ubinafsi wangu hayatanakiliwa kadri ninashiriki katika utafiti huu. Kwa hivyo bila kulazimisha nithibitisha kwamba hofu na wasiwasi wangu wote kuhusu ushiriki wangu katika utafiti huu umeshughulikiwa na nimeridhika. Mtafiti pia ameniuliza maswali ili kuhakikisha ufahamu wangu wa habari iliyotolewa.

Saini ya mshiriki / Alama ya kidole gumba ………………………. Tarehe ………………………

Ninaweza kudhibitisha kwamba nimeelezea wazi na kwa undani asili ya utafiti huu na yaliyomo hapa katika fomu ya idhini. Mshiriki amejitolea kwa hiari yake na bila shinikizo yoyote isiyo na maana na aliamua kushiriki katika utafiti huu

Mtafiti…........……… Saini …………………...... Tarehe ....……………………………

Kwa ufafanuzi wowote, tafadhali wasiliana

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Appendix III: Questionnaire

TITLE: ASSESSMENT OF ADVANCE CARE PLANNING BETWEEN CLINICIANS AND PATIENTS ON MAINTENANCE HEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL, NAIROBI COUNTY KENYA

GENERAL INFORMATION

1. Study serial Number: ....

2. Facility: ....

3. Ward/Unit: ....

INSTRUCTIONS

Please do not write participant's name anywhere in this tool

Put a tick (√) in the space provided next to the selected response

Where there are no choices given, please write the responses in the spaces provided.

SECTION 1: PATIENTS' DEMOGRAPHIC CHARACTERISTICS

1. Gender: Male …… Female …….
2. Age (In years): ……………………….
3. Education level: None…… Primary…… Secondary…. Tertiary …….
4. Marital status: Single …… Married ……. Divorced …… Widowed ……. Separated …….
5. Religion: Christian …… Muslim ……. Hindu …... Other (Specify) ………………
6. Source of income: Formal employment ……. Self employment..…… Not employed…………...

SECTION 11: PATIENTS' KNOWLEDGE ON ADVANCE CARE PLANNING

7. Do you think that your illness is life limiting/ life threatening? Yes………. No ………. I don't know ………………...

8. Do you think you it is possible for your illness to be cured? Yes ……… No ……… I don't know ………

9. Have you ever heard of advanced care planning/ planning in advance for future care goals and interventions? Yes ………… No………….

10. If your response to Q9 above is yes, where did you hear of it from? (Tick all that apply)

My doctor	
My family members	
My friend	
My workmates	
From the media	
Any other (Specify)	

11. Have you ever been given information/educated on advance care planning? Yes…….. No………….

12. If your response to Q11 above is yes, who gave you that information?

My doctor	
Other healthcare workers	
From the media	
Any other (Specify)	

If the response to Q10 above is no, please proceed to section III

13. In your understanding, what does advance care planning entail? (Tick all that apply)

It includes having a discussion to understand my condition well	
It includes identifying my beliefs and values	
It includes identifying my preferences and goals of care	
It includes writing down my wishes and care preferences to be used in future when I cannot independently make decisions for myself.	
It includes writing down my wishes about what I want to be done regarding my body and property when I die.	
It includes selecting someone who will make care decisions on my behalf when I am not able to.	

14. About advance care planning discussions, select all that are true in the table below.

It is only my doctor who can initiate a discussion on advance care planning	
I am allowed to ask my doctor to have a discussion on advance care planning	
Discussions on advance care planning should be done when medical interventions are less likely to yield beneficial outcomes	
Care decisions should be based on my values and beliefs and evidence from research and practice	

15. About a living will, select all that are true in the table below.

It should be developed when medical interventions are less likely to yield beneficial outcomes	
The person who I select to make decisions on my behalf can develop a living will for me when I am not able to	
My doctor can overrule my living will if he thinks a certain therapy can yield beneficial results.	
It can only be written with my input/participation.	
It can include instructions to remain in effect after my death.	
I have never heard of it	

16. About alternative/surrogate decision making, select all that is true in the table below.

It only comes into effect when I don't wish to or not able to participate in making decisions on my care	
It mostly comes into effect during my end of life care	
Decisions should be made in my best interests while respecting my values and wishes.	
The person who I select to make decisions on my behalf must be my close family member.	
The person who I select to make decisions on my behalf can in certain instances overrule the care decisions I made.	
My doctor can in certain instances overrule the care decisions of my alternative/surrogate decision maker	

SECTION III: PATIENTS' UPTAKE OF ADVANCE CARE PLANNING

17. When you were first diagnosed with this condition, were you mentally alert to make an independent decision? Yes ……... No ……

18. If your response to Q17 above is yes, were you informed / educated about your condition before you started dialyzing? Yes…………………. No …………

19. About being put on hemodialysis:

Hemodialysis	I participated in choosing it	I did not participate in choosing it
It was my preferred care option		
It was not my preferred care option		

20. About having a discussion on advance care planning with my doctor:

Advance care planning discussion	I have had such a discussion with my doctor	I haven’t had such a discussion with my doctor.
I have specific wishes about my care		
I don’t have specific wishes about my care		

21. About alternative/surrogate decision making:

Alternative/surrogate decision making	I have selected someone who will make decisions on my behalf if I’m not able to	I haven’t selected someone who will make decisions on my behalf if I’m not able to
I have documented someone who will make decisions on my behalf if I’m not able to		
I haven’t documented someone who will make decisions on my behalf if I’m not able to		

22. Do you have a living will/advance directive? Yes ……. No ……

SECTION IV: PATIENTS' PREFERENCES ON ADVANCE CARE PLANNING

23. If you haven't had a discussion about care goals, care preferences including end of life care with your doctor, are you willing to do so? Yes ………. No ………………

24. If your response to Q23 above is yes, what are your reasons?

Reason	**Tick all that apply**
It helps me to have control over the remainder of my life	
It gives me an opportunity to make peace with my maker	
It allows me and my family to make economically viable decisions about my care by choosing therapies which have significant possible outcomes and at an affordable price	
It helps me to plan well for my remaining family members/off springs and have a written will	
Other reasons (Specify)	

25. If your response to Q23 above is no, what are your reasons? (Tick all that apply)

It's against my religion	
It's culturally unacceptable	
It will psychologically disturb me and negatively affect my compliance to treatment	
It will be emotionally intense and will destabilize my family	
I might lose some of my trusted friends	
I don't have confidence in the doctors here	
Any Other ……..	

26. If you don't have a living will, are you willing to have one? Yes …………. No …….

27. If you haven't documented an alternative/surrogate decision maker, are you willing to do so? Yes …………… No ……………….

28. If your response to Q26 above is no, what are your reasons?

Reason	Tick all that apply
It’s against my religion	
It’s culturally unacceptable	
Other people might take advantage of my illness and plot to eliminate me and dispose me of my possessions.	
It might make me lose some of my medical cover benefits	
It will psychologically disturb me and negatively affect my compliance to treatment	
I might lose some of my trusted friends	

29. If your response to Q27 above is yes, who would you prefer to make decisions on your behalf about your health if a time comes when you are not able to?

Decision makers	Tick only one
My health care provider	
My spouse	
My sibling	
My parent	
A close friend	
Any other (Specify)	

30. When you get closer to your final moments of life which of these advance care options would you prefer? (Chose only one)

Advance care option	
ICU admission for life sustaining interventions	
Referral to a hospice care center	
To be discharged home under the care of a qualified heath care provider	
I don’t have any preference	

31. When you get closer to your final moments of life which among these options regarding hemodialysis would you prefer? (Chose only one)

Terminate dialysis and be managed conservatively/through palliation	
Continue with dialysis till life ends	

32. Where would you prefer to be your place of death? (Chose only one)

At the hospital	
At my home	
At a hospice/palliative care center	
I don’t have a preference	

Appendix IV: Key Informant Information sheet and Consent form

Title: Assessment of Advance Care Planning Practice between clinicians and patients on maintenance hemodialysis at Kenyatta national Hospital, Nairobi County Kenya.

Investigator: Samson John Betunda Mgala

Introduction: I am a student studying a Master of Science degree in Nursing at the School of Nursing Sciences of the University of Nairobi. I'm conducting a study at Kenyatta National Hospital renal unit entitled Advance care planning and preferences in a group of end stage kidney disease patients on hemodialysis at Kenyatta National Hospital, Nairobi Kenya. This study is part of my academic requirements towards being awarded the degree.

This communication is purposed to provide necessary information that will enable you to make an informed decision regarding your participation in this study or not. You are free to ask any questions pertaining this study and I'll ask you some questions to assess your understanding before you can decide to sign the consent form or not.

Purpose of the study: The aim of this study is to establish patients' level of knowledge, advance care planning preferences, uptake of advance care planning and perception of clinicians on advance care planning with patients on maintenance hemodialysis at Kenyatta National Hospital renal unit (KNH. The findings of this study will be important to promote patients' and health care providers' participation in shared decision making regarding their care as well as identify care practice gaps and inform policy on the same.

Participation: This will entail responding to questions from the questionnaire as posed by the principal investigator. The investigator will be audio recording your responses as well as take short notes during the interview. Participation in this study will be solely voluntary. You have the right to agree or refuse to participate in the study. You can also withdraw your participation or opt not to answer any question at any time without incurring any negative consequences.

Benefits: Participants will not get any monetary benefits for participating in this study. However, this study will generate important findings which will be shared with the hospital management, with other decision and policy makers as well as be presented in scientific conferences to inform practice and guidelines to improve patient's and health care providers' participation in advance care planning and care decision making.

Risks: Data collection for this study is noninvasive. There are no expected physical or any other forms of risks for participating in the study.

Confidentiality: The information that you will provide will only be used for the intended purpose of this study. Your privacy will be upheld with the utmost confidentiality and your name will not be captured anywhere to ensure you remain anonymous. Collected data will only accessible to people directly involved in the study. All electronic files generated from the study will be password protected.

Conflict of interest: The investigator or the supervisors declare no conflict of interest amongst them.

CONSENT FORM

Having been satisfactorily informed of the nature of the study and my role herein, I hereby consent voluntarily and without coercion to be a participant. I understand that there are no direct monetary benefits or anticipated risks attached to this study and that my refusal to answer any question or withdrawal at any point in this study will not attract any kind of negative consequences or affect my treatment rights in any way. I have also been duly informed that any information I give as part of this study will be handled with utmost confidentiality. I understand that my personal identification details will not be captured as I participate in this study. I hereby without coercion confirm that all my fears and concerns regarding my participation in this study have been satisfactorily addressed. The researcher has also asked me questions to ascertain my comprehension of the provided information.

Signature of the participant/Thumbprint ………………………. Date ………………………

I can confirm that I have clearly and in detail explained the nature of this study and the contents contain here in the consent form. The participant has voluntarily and without any undue pressure opted to participate in this study.

Investigator …..………………………… Signature …………… Date …………………………

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Appendix V: Interview Schedule/guide on clinicians' practice of advance care planning with patients on maintenance hemodialysis.

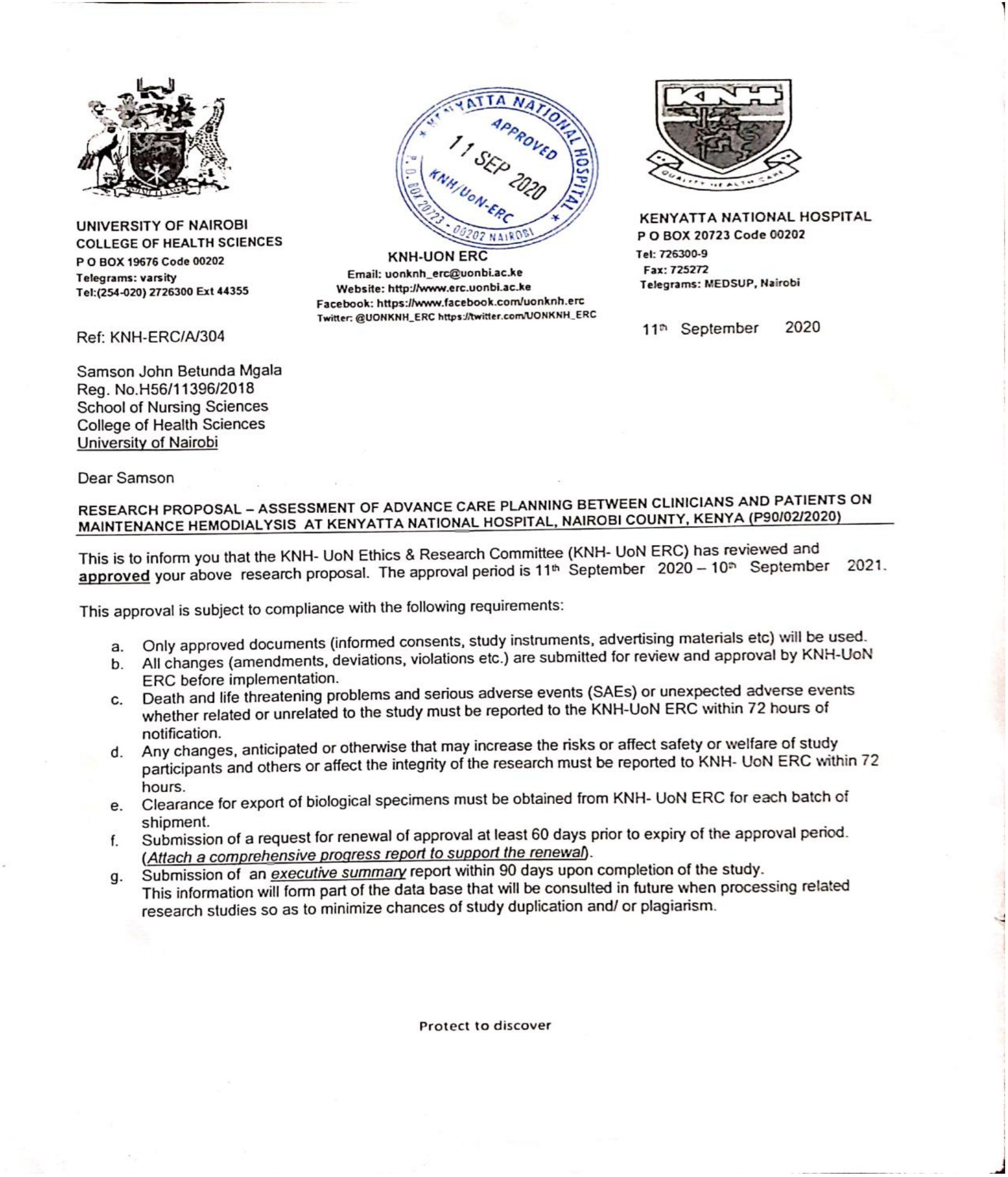
TITLE: ASSESSMENT OF ADVANCE CARE PLANNING BETWEEN CLINICIANS AND PATIENTS ON MAINTENANCE HEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL, NAIROBI COUNTY KENYA

General Question	1. How many years of experience do you have in renal care?
Clinicians' practice of Advance care planning.	2. Advance care planning has been lauded worldwide as a critical component for managing life limiting conditions. With emphasis on the number of cases done against those who need the service and the challenges encountered, Please share your experience while implementing it with patients on maintenance hemodialysis. i. Advance care planning discussions ii. Identification of patients' care preferences and filling of advance directives. iii. Selection and documentation of surrogate decision makers. 3. Do you feel it's time to upscale the implementation of advance care planning at Kenyatta National Hospital? - Why?
General Question	Is there anything you would like to add?

I'll be analyzing this information I have collected from you and your colleagues and submit a report to the unit. I'll be happy to send you a draft copy of the same for review if you are interested.

Thank you for your time and participation

Appendix VI: KNH-UON ERC Approval letter



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KENYATTA NATIONAL HOSPITAL
APPROVED
11 SEP 2020
KNH/UoN-ERC
P. O. BOX 20723 - 00202 NAIROBI

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
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KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
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Telegrams: MEDSUP, Nairobi

11th September 2020

Ref: KNH-ERC/A/304

Samson John Betunda Mgala
Reg. No.H56/11396/2018
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Samson

RESEARCH PROPOSAL – ASSESSMENT OF ADVANCE CARE PLANNING BETWEEN CLINICIANS AND PATIENTS ON MAINTENANCE HEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL, NAIROBI COUNTY, KENYA (P90/02/2020)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 11th September 2020 – 10th September 2021.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
g. Submission of an *executive summary* report within 90 days upon completion of the study.
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover

For more details consult the KNH- UoN ERC website**http://www.erc.uonbi.ac.ke**

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Director, School of Nursing Sciences, UoN
Supervisors: Dr. Eunice Omondi, School of Nursing Sciences, UoN
Dr. Sabina Wakasiaka, School of Nursing Sciences, UoN

KNH/R&P/FORM/01

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Study Registration Certificate

1. Name of the Principal Investigator/Researcher
   SAMSON JOHN BETUNDA MGALA
2. Email address: coolsam096@gmail.com Tel No. 0713453471
3. Contact person (if different from PI)
4. Email address: Tel No.
5. Study Title
   ASSESSMENT OF ADVANCE CARE PLANNING BETWEEN CLINICIANS AND PATIENTS ON MAINTENANCE HEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL, NAIROBI COUNTY, KENYA.
6. Department where the study will be conducted RENAL UNIT
   (Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the KNH Department where the study will be conducted.

   Name: Signature Date
8. Endorsed by KNH Head of Department where study will be conducted.

   Name: DR. JOHN NGIGI Signature Date 29.9.2020
9. KNH UoN Ethics Research Committee approved study number P90/02/2020
   (Please attach copy of ERC approval)
10. I SAMSON JOHN BETUNDA MGALA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.

    Signature Date 24/09/2020
11. Study Registration number (Dept/Number/Year) Renal Unit /139/2020
    (To be completed by Medical Research Department)
    29 SEP 2020
12. Research and Program Stamp

All studies conducted at Kenyatta National Hospital <u>must</u> be registered with the Department of Medical Research and investigators <u>must commit</u> to share results with the hospital.

Appendix VII: Similarity index report

ASSESSMENT OF ADVANCE CARE PLANNING BETWEEN CLINICIANS AND PATIENTS ON MAINTENANCE HEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL.

ORIGINALITY REPORT

SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS
11%	7%	6%	2%

PRIMARY SOURCES

1	"EAPC Abstracts", Palliative Medicine, 2019 Publication	<1%
2	Puneet Kishore Bramania, Paschal Ruggajo, Rimal Bramania, Muhiddin Mahmoud, Francis Fredrick Furia. "Prevalence of Malnutrition Inflammation Complex Syndrome among Patients on Maintenance Haemodialysis at Muhimbili National Hospital in Tanzania: A Cross-Sectional Study", Research Square, 2020 Publication	<1%
3	pdfs.semanticscholar.org Internet Source	<1%
4	Ile Kermel-Schiffman, Perla Werner. "Knowledge regarding advance care planning: A systematic review", Archives of Gerontology and Geriatrics, 2017 Publication	<1%
5	erepository.uonbi.ac.ke	