AN EVALUATION OF PERCEPTIONS ON MAINTENANCE HAEMODIALYSIS SERVICES IN A RESOURCE LIMITED SETTING: A QUALITY OF CARE SURVEY

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DECLARATION OF ORIGINALITY

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TABLE OF ABBREVIATIONS

AKI	Acute Kidney Injury
AUSDIAB	Australian Diabetes, Obesity and lifestyle Study
CKD	Chronic kidney disease
eGFR	Estimated Glomerular filtration rate
ESRD	End-stage renal disease
KHSSP	Kenya Health Sector Strategic and Investment Plan
KNH	Kenyatta National Hospital
LMICs	Low & Middle income countries
MTRH	Moi Teaching & Referral Hospital
NHANES	National Health and Nutrition Examination Survey
NHSSP II	2nd National Health Sector Strategic Plan
NKF	National Kidney Foundation
RRT	Renal Replacement Therapy
SPSS	Statistical Package for the social Sciences
UON	University of Nairobi
USRDS	US Renal Data System

ABSTRACT

Background

The provision of maintenance dialysis is challenging the world over, but more so in the developing world. The main contributor to this situation is the lack of standardization of practices and inequitable resource allocation, which affect quality of service provision in resource limited settings. There are several challenging aspects in the management of end stage renal disease patients on chronic dialysis that impact on individual patient outcomes. This study evaluates the perception of end stage renal disease patients and providers on the quality of maintenance hemodialysis services.

Objective of the study

This study aimed to evaluate the perceptions on the quality of haemodialysis service provision among end-stage renal disease patients and providers at the Kenyatta National Hospital, Nakuru General ospital and Machakos Level 5 Hospital.

Study design & Methodology

A descriptive cross-sectional hospital based study. The study employs a mixed method approach, incorporating both quantitative and qualitative methods. The tools for the study comprise a semi-structured questionnaire administered to ESRD patients, a guide for key informant interviews administered to providers, a simple checklist for resource

availability and participatory observation. A triangulated approach for analysis will be achieved by including the perspectives of ESRD patients and health care providers at three different study sites.

Results

144 patients with end-stage renal disease receiving regular maintenance hemodialysis, aged between 18 and 95 years, participated in the study. There were eighty nine males (61.8%) and fifty five females (38.2%), with a female-to-male ratio of 1:1.62. The mean age of the participants was 48.3 ± 16.5 years. The mean duration of hemodialysis was 20.8 ± 25.9 months. Approximately three quarters (76.6%) of the study participants had medical cover provided by the National Health Insurance Fund.

In the 5-item Doctors' Communication and Caring Domain (DCC), the positive response, i.e. always & usually, was selected most frequently to each question in the domain, ranging from 77.2 to 86.9%. In the 12-item Quality of Dialysis Center Care and Operations (QDC), the highest proportion of negative responses were to delays in being connected to machine, explanation of blood test results and handling problems that arose during dialysis. The top 3 recommendations given by patients were: Increase in dialysis machines, comprehensive NHIF funding and improvement in service delivery. Financial constraints, high patient burden and shortage of staff and machines were the main challenges to the provision of hemodialysis services according to the health service providers. The main interventions recommended were financial interventions, capacity building, on job training of nurses, referral and transplantation services.

Conclusion

In this study patient and provider perceptions, as well as an assessment of resource availability were focal to the evaluation of the quality of maintenance haemodialysis services. Patient perception to the provision of services was positive overall. The aspects of care perceived negatively include: waiting time, explaining aspects of care and blood results in a way that is easy to comprehend and concerning doctors the amount of time spent with the patient. The recommendations proposed by patients and providers are all currently being implemented through the intervention of relevant stakeholders.

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CHAPTER ONE: INTRODUCTION

The modern era has seen a significant shift in the patterns of disease burden with an increase in chronic diseases; prominent among them is Chronic Kidney Disease (CKD). This shift has contributed to an increased strain on renal health care provision the world over, but more so in developing countries. From its debut in the 1940s, hemodialysis has been firmly established as a cornerstone in the conservative management of CKD.(1) Despite the gains made in the field of Renal Replacement Therapy (RRT), several challenges exist in its execution in the developing world; with special reference to Sub-Saharan Africa. Limitations in the provision of regular maintenance hemodialysis include paucity of well-equipped dialysis centers, lack of decentralization of renal health care services, poor staffing of existing facilities, lack of a critical mass of highly trained specialists and inadequate funding.(2) Globally, more than 100 countries with a combined population of more than a billion people, lack the capacity for chronic maintenance dialysis and renal transplant. Resultantly, more than 1 million deaths have been recorded annually from end stage renal disease.(3,4)

A priori assertions of the state of renal health care are now entirely backed by ample literature that explicitly highlights the challenges unique to these settings. These challenges cover a wide scope from hindrances to the access of quality hemodialysis to obstacles in the day-to-day provision of dialysis as a treatment modality in end- stage renal disease (ESRD).

Kenya is no exception to these challenges, with a notable increase in the burden of CKD and a resultant increase in the demand for renal health care and RRT. In-center hemodialysis is the main mode of RRT in the country. Like several other developing nations, Kenya lacks a national registry for patients undergoing maintenance dialysis in public facilities.(5) According to Ministry of Health estimates, approximately 1 million Kenyans suffer from kidney related diseases, and the figure has risen rapidly over the past decade. According to Bambgoye et al(6) the prevalence stands at 15.6 ESRD patients per million population in Kenya.

Following devolution of specialized health services to the counties, there were 49 dialysis units in public facilities across the country, 32 of which were fully operational by July 2017.(7) These include dialysis centers in Baringo, Bomet, Bungoma, Embu, Garissa, Homabay, Kakamega, Kericho, Kiambu, Kisii, Kisumu, Kitui, Kwale, Laikipia, Machakos, Meru, Mombasa, Muranga, Nakuru, Nandi, Narok, Nyamira, Nyandarua, Nyeri, Siaya, Taita – Taveta, Tharaka Nithi, Thika, Trans-Nzoia, Uasin Gishu and Vihiga; in addition to the national referral hospitals, Kenyatta National Hospital and Moi Teaching and Referral Hospital.

CHAPTER 2: LITERATURE REVIEW

2.1 BURDEN & IMPLICATIONS OF CKD WORLDWIDE

The prevalence of CKD in the United States (US) has been on the rise. The National Health and Nutrition Examination Surveys (NHANES) demonstrated an increase in prevalence of CKD with a rise in the estimates in the 1999-2004 survey compared to the 1988- 1994, 13.1 per cent (95 % CI, 9.1 – 10.9) and 10.0 per cent (95% CI, 12.0-14.1), respectively. The surveys took into consideration a modest increase in micro albuminuria, as well as a rise in moderate to severely reduced estimated glomerular filtration rate (eGFR).(8) The NHANES III estimated the prevalence of CKD in adult US population at 11 per cent.(9) The Australian Diabetes, Obesity and Lifestyle (AusDiab) study showed the prevalence renal impairment among Australian adults was 12.1 per cent.(10)

Currently, CKD ranks the twelfth highest cause of mortality and the seventeenth highest cause of disability worldwide.(11) Along with the burden of disease an additional burden of the economic implications of RRT is imposed on individuals with ESRD, their families and communities. Nowhere is this brunt to this burden heavier than in resource limited settings within developing countries. The burden of CKD is on the rise among developing nations.(11)

The ultimate outcome of CKD is ESRD, the rate of progression is determined by individual risk factors and co-morbities.(12) The worldwide increase in diabetes and hypertension has contributed significantly to the rising levels of CKD.(13) According to Sumaili et al., in the Democratic Republic of Congo (DRC) estimates showed the prevalence of CKD was 44 per cent among individuals with hypertension and 39 per cent among individuals with diabetes.(14) India is currently on record for among the highest prevalence of

diabetes and hypertension worldwide(15), with diabetic nephropathy documented as the leading cause of CKD in this population.(16)

Nugent posits that the affluence of a nation has major bearings on the progression from CKD to ESRD, and the treatment modalities available. This has an impact on the significantly higher CKD stage mortality in low and middle income countries (LMICs).(11) Determination of the burden of disease in developing countries is challenging owing to the lack of renal registries, coupled with the lack of capacity for screening in all but the high risk groups for CKD.

The rising prevalence of chronic diseases (CDs) and CKD poses an immense burden on LMICs. Much of this burden is attributable to costly and long-term medical expenditures. With regards to RRT, less than 10 per cent of patients in developing countries gain access to treatment.(11) It is difficult to highlight the economic impact of disease owing to the lack of sufficient epidemiological evidence demonstrating CD burden, as well as a lack of cost of intervention studies in LMICs.(17) Lawrencia et al., reiterates that among the few studies on cost of dialysis, none exist in developing countries.(18)

There too exists a psychosocial burden on patients undergoing maintenance dialysis, as Kamau et al, points out that the Health-Related Quality of Life measures were reduced among the Kenyan population undergoing dialysis at a tertiary institution.(19)

2.2 CHALLENGES IN THE PROVISION OF MAINTENANCE HEMODIALYSIS

Despite the burden of CKD and ESRD being 3 to 4 times higher in Africa, as compared to the developed world, the uptake of RRT remains poor.(20) These inherent difficulties in the provision of adequate and sustainable haemodialysis services stems from a lack of availability and accessibility of resources vital to service provision.

Bello points out that infrastructure is insufficient in most parts of Sub-Saharan Africa; and even where services are available, they remain inaccessible to the majority because of inequitable allocation of health resources.(20)

Several studies document the deficit of trained health care professionals (21,22) This has been in part attributed to few medical training institutions, with 12 among 53 African countries having one medical school and 11 having none.(20) It has also been credited to the constant rate of attrition of health and health- allied workers, who seek employment opportunities in developed countries. The practise of nephrology also has borne the brunt of this attrition.(22,23) According to The World Bank development indicators, low and middle income countries (LMICs) fall below the 2015 world average of physicians and nurses per 1000 people of 1.5 and 3.3, respectively.(24)

Kwalima et al. identifies adequacy of resources, i.e., health care providers as well as high cost as the main barriers to access to maintenance haemodialysis in resource limited settings.(25)

Ndambuki recommends that in order to ensure continued patient satisfaction, an increase in the numbers of dialysis centre staff as well as an increase in the availability of dialysis machines should be considered.(26)

2.3 THE IMPORTANCE OF EVALUATING HEALTH SERVICE DELIVERY

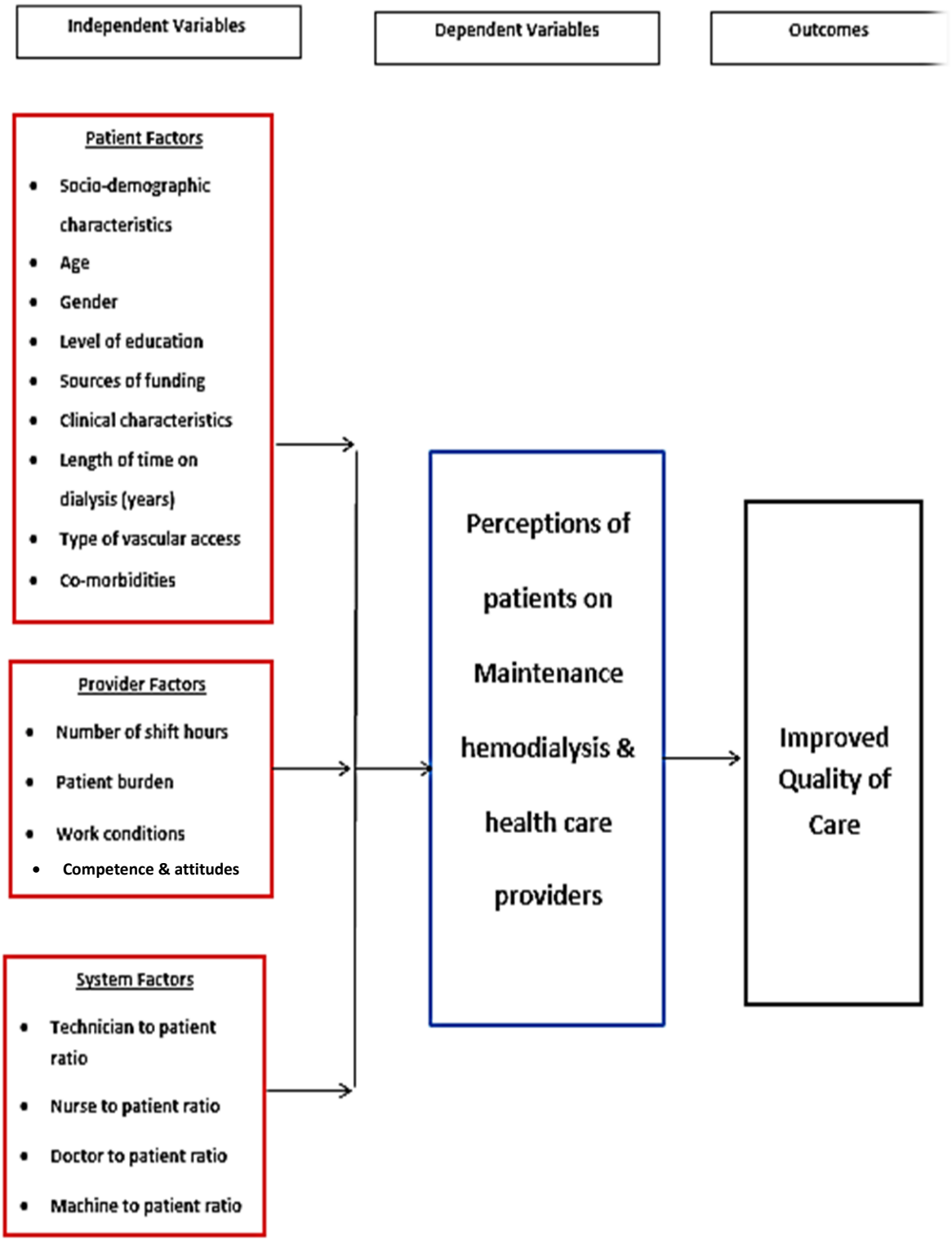
In spite of the vast challenges that hinder the provision of haemodialysis in resource-limited settings, an effort must be made to establish and consolidate quality of care practises. In order to achieve this objective a tradition of routine evaluation and monitoring must be inculcated in all aspects of health service delivery.

Groenewegen recognizes that the evaluation of health systems reaches beyond mere patient satisfaction. He posits that quality of care from the user's perspective is multifaceted, the significance is attached to aspects of care and patient experiences.(27) According to Shaller, systematic review and feedback is one of the main factors that promotes patient centered care.(28)

The report of the Auditor General published 2012 (29) propounded value insights at a time there was a lack of service delivery standards. The audit evaluated waiting time standards for the delivery of specialized services at the Kenyatta National Hospital. Renal services also came under scrutiny. The findings of the audit revealed that the low frequency of haemodialysis among ESRD patients was majorly attributable to inadequate equipment capacity. Following the recommendation made to increase the capacity of the dialysis unit, KNH procured three additional dialysis machines in 2011/2012 and budgeted for 5 more. Additionally, a new water treatment plant was installed in August 2009 and the maintenance of the old unit was undertaken in July 2010.

This illustration lends credence to a common axiom in health care quality improvement *'You cannot manage what you cannot measure.'- Peter Drucker*.

Figure 1: Conceptual Framework



2.4 PATIENT CENTERED CARE

The field of medicine over years past has evolved to incorporate patients and their care givers in health care models. The International Alliance of Patients' Organizations (IAPO)(30), in its Declaration on Patient-Centered Healthcare, explicitly states that patient-centered health care systems should address patients' needs and preferences; thereby increasing the acceptability and cost effectiveness of the services. The IAPO(30) is currently the only global convention advocating for patient-centered health care globally. The declaration set out five core principles of patient-centred care: respect, choice and empowerment, access and support, patient involvement in health policy and information.

As defined by the Institute of Medicine, patient-centred care are practises that foster partnerships among health care practitioners, patients and caregivers, to ensure that patients' preferences and expectations are met; and that the patients' are furnished with the information they need to make informed decisions about their own health care. In the same publication, the Institute of Medicine regards patient-centred health care as one of six chasms in health care provision.(31) Epstein points out that patient-centred care is a quality of interpersonal, professional and organizational relationships.(32)

This approach has been found to improve outcome, as Stewart reiterates, patient-centred communication which creates common ground, where both the clinician and patient are involved. He also found that it had a positive impact on health status and amplified the efficiency of care.(33) Engelhardt et al. asserts that patient-centred care is fundamental to improved patient-physician relations and therefore portend better patient outcomes.(34)

2.5 PATIENT EXPERIENCES

As defined by the Beryl Institute is 'the sum total of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care.(35) The measurement of patient experience is important because it informs several aspects of patient care, ameliorates decision making, meets patients' expectations, as well as allowing for monitoring and evaluation of health care service provision.(36) Boulding et al., asserts that the measurement of patients' expectations can yield valuable information an organization to aid in improvement of service delivery and ultimately patient outcomes.(37)

As it stands, there lacks a consensus on how to adequately measure patient experience. According to Wiig et al., the appropriate tools for measuring and utilizing patient experiences, as a quality improvement initiative, are lacking. He argues that despite their existence, no meaningful utility can be derived from these measures.(38) Manary et al., corroborates this view. He aptly points out three areas of concern about patient reported measures. Firstly, he discounts patients' feedback on the grounds of credibility. In his view, the lack of objectivity arises from the patients' individual disposition and lack of medical expertise. Secondly, the measure is fraught with confounders that are often time remote from health service delivery; for instance the interpersonal relationship between patients and their caregivers. Thirdly, patient gratification by the fulfilment of a priori desires has the potential to bias the measure.(39)

In light of these arguments, a question is posed as to whether a measure of patients' experiences is achievable. In answer to this question, LaVela et al., proposes that the starting point of such an exercise would encompass the formulation of a standardized definition of patient experience, as well as the establishment of a set of measurable indicators.(40)

LaVela astutely observes that measure of patient experience has been further complicated by the several terms have been compared to, and described as synonymous with it. In some instances, quality of care has been equated to measurement of patient experiences; while in others, access to services has been associated with it. Some of the corresponding and potentially over-lapping patient-reported measures include: patient satisfaction, perceptions and preferences.(40)

2.6 PATIENT SATISFACTION & PERSPECTIVES

LaVela et al., defines patient satisfaction as a *predominantly affective judgment formed by the patient alone, influenced by internal and external factors.* LaVela distinguishes this from perceived quality, which is by and large a cognitive assessment. Cronin et al. recapitulates this view by stating that patient satisfaction is not synonymous with patient perception. He opines that perceptions are drivers of satisfaction.(40)

Bleich et al., suggests that patient satisfaction with a health care system is influenced more by factors external to the health care system than by their experience of care as a patient. In her opinion measurements of satisfaction are limited in value as a basis for improvement of quality and cannot be considered an indicator in key health sector reform. In Bleich's view,(41) measures of experience assess the *responsiveness of a health care system,* a concept coined by the World Health Organization (WHO). (42)

LaVela et al, views patient perspectives as the orientation that determines the evaluation of experience. She proposes that a health care organization can seek to alter patient perceptions by scaling-up the quality of the actual services provided.(40) Cronin et al., points out that measures that seek to capture patients' perspectives on health service provision can be determinants of satisfaction, but cannot be equated with satisfaction.(43)

2.7 APPROACHES TO MEASUREMENT OF PATIENT EXPERIENCES

According to LaVela et al., there are three approaches to measure patient experience: qualitative, quantitative and mixed-methods. LaVela cautions that in selecting an approach, due consideration should be given to the complexity and evolving nature of health care delivery systems. (40) The mixed method approach, which combines both qualitative and quantitative aspects, is recommended as it allows for a broader scope than would the application of a single method alone. Wisdom et al, defines mixed methods as the systematic integration of both qualitative and quantitative data within a process or system of enquiry. Such an approach results in better and more synergistic use of data.(44) The strength of mixed method approach lies in the principle of triangulation or cross-validation, which enables researcher to point out areas of convergence of data lending validity to findings.(40) According to Wisdom et al, an exploratory sequential design involving two phases, a preliminary quantitative and an ensuing qualitative, allows for further exploration of the quantitative data set. Additionally, mixed method approach can be utilized to construct survey designs with application of the exploratory sequential design. The main premise of the development of these surveys, as Wisdom points out, lies in the collection of qualitative exploratory data, which upon analysis form the basis of the formulation of psychometric tools that are adapted to the intended study population. Mixed methods are advantageous as they reflect the participant's standpoint, provide methodological flexibility, and further more allow for the collection of comprehensive data.

The limitations of mixed methods, as observed by Wisdom et al, comprise of an increase in the complexity of the evaluation, necessity for a multidisciplinary approach and the laborious and resource intensive nature of the study design.(44)

2.8 THE IN-CENTRE HEMODIALYSIS CAHPS (ICH-CAHPS) SURVEY

The In-Centre Haemodialysis Consumer Assessment of Health Providers and Systems (ICH-CAHPS) survey (45) is a tool designed to measure the experiences of end stage renal disease patients receiving in-centre haemodialysis. The CAHPS (46) is registered under the Agency for Healthcare Research and Quality (AHRQ).(47) The measures in the ICH-CAHPS were formally endorsed by the National Quality Forum (NQF)(48), an agency established to standardize health quality measures, in 2007.

The goal of the questionnaire is to garner information on patient care through core topic questions that are grouped into composites and global rating sections as follows: [1] Nephrologist communication and caring, [2] Quality of dialysis centre and operations, [3] Providing information to patients and [4] Global rating scores.

The quality of dialysis centre care and operations can further be divided into: dialysis centre staff communication, caring, professionalism and competence; as well as dialysis centre operations. The provision of information to patients encompasses questions related to types of information nephrologists and/or dialysis staff share with patients. It examines the extent of the patient's knowledge on their condition, care, rights and shared decision making between patients and providers.

The survey also includes information on demographics, health status and co-morbid conditions. An inquiry is made as to whether a proxy respondent was sought to answer the questionnaire.

2.9 PROVIDER PERSPECTIVE

The incorporation of the perception of providers is an under explored, and yet invaluable facet in the assessment of the patient experience of health service delivery. There is a paucity of data on the perceptions among health care providers to health services in resource limited settings. It is anticipated that such an effort would lend credibility to the patient experience, owing to the vast experience that providers offer.

In the assessment of the perception of health care providers, in-depth interviews are appropriate and objectively capture the experiences of providers.(40)

In-depth interviews are a modality of qualitative data collection that seek to explore, through an interview process, the insights perspectives and perceptions of a select group of key informants. The characteristics of in-depth interviews entail open-ended questions in a semi-structured format that allows for exploration of emerging themes in a conversational manner, while actively recording the responses. The advantage of this modality is that it is discovery-oriented and allows for exploration of emerging themes.(49)

The analysis of in-depth interviews is based upon the principle of qualitative content analysis, which has three facets, namely: Conventional, directed or summative. Content analysis allows for a flexible and interpretive approach to textual data.(50)

2.10 STUDY RATIONALE

2.10.1 PROBLEM STATEMENT

As enshrined in the Constitution of Kenya, chapter 4 section 43(1) (a), every person has the right to the highest attainable standard of health, which includes the right to health care services, including reproductive health.(51) In the determination of the quality of health-care has five considerations are made: Availability, Accessibility, Acceptability, Accountability and Appropriateness.(52)

In a bid to improve hemodialysis service delivery effort has been made to decentralize this specialized service to county based referral units.(7) Despite these commendable gains, it is noteworthy that these facilities are only available in urban areas, limiting access to the rural and more marginalized localities which form large percentage of the population.(53,54) In addition, in view of the complexities of maintaining renal dialysis equipment in good working condition, service delivery may inevitably be hampered due to high operational costs involved.(2,55,56)

The cost of hemodialysis in public hospitals, although subsidized by cost-sharing efforts and resource allocation by National Government, remains far above the reach of several Kenyans who live below the poverty line. Since this vital service comes at a cost, it is encouraged of patients to enroll on to a national health insurance plan to cater for a percentage of the costs, the monthly installments of which are a further financial strain to the average Kenyan.

There are 29 nephrologists in Kenya to serve an estimated 4.2 per million population.(57)

Coupled with the perennial shortage of qualified hospital staff hampers the effort to provide quality dialysis services in the counties. Most health professionals inequitably are located in urban areas, and more so in the main cities.

For these reasons it is increasingly a challenge to stem the tide of the rapidly rising prevalence of end stage renal disease that is sweeping our nation.

2.10.2 STUDY JUSTIFICATION

The Kenya Health Sector Strategic and Investment Plan (KHSSP) 2013-2017 (58) in accordance with the overall Vision 2030(59) seeks promote the quality of life of all Kenyans to a standard comparable to that enjoyed in the developed world. In order to realize this goal, the policy aims to support the *provision of support the provision of equitable, affordable and quality health and related services at the highest attainable standards to all Kenyans.* This is in-keeping with the 2nd National Health Sector Strategic Plan (NHSSP II) 2005-2010(60), which targeted the obliteration of health-related inequalities among Kenyans, as well as the reversal of the downward trend that was pervasive in key health sector outcome indicators.

This study sought to conduct a situational analysis at the Kenyatta National Hospital, Nakuru General & Machakos level 5 hospitals, in order to gain a clearer understanding of the challenges faced in the provision of maintenance hemodialysis in resource limited settings. This effort resonates closely with the overall theme of the KHSSP 2013-2017(58) and the NHSSP II 2005-2010(60). The study aspires to aid hospital administrators, and relevant stakeholders to define and prioritize health quality improvement strategies, health action plans and interventions by providing a balanced perspective into the potential gaps in the provision of hemodialysis services.

2.11 RESEARCH QUESTION & OBJECTIVES

2.11.1 RESEARCH QUESTION

What is the perception on the quality of hemodialysis services in Kenya? A case study of three centers, namely: Kenyatta National Hospital, Nakuru Provincial General Hospital & Machakos Level 5 Hospital?

2.11.2 BROAD OBJECTIVE

To evaluate the perceptions of patients and providers on the quality of maintenance hemodialysis in Kenya, a case study of the Kenyatta National Hospital, Nakuru Provincial General Hospital & Machakos Level 5 Hospital.

2.11.3 SPECIFIC OBJECTIVES

i. To determine patient perceptions on the quality of maintenance hemodialysis at Kenyatta National Hospital, Nakuru Provincial General & Machakos Level V Hospitals.

ii. To determine provider perceptions on the quality of maintenance hemodialysis at Kenyatta National Hospital, Nakuru Provincial General & Machakos Level V Hospitals.

2.11.4 SECONDARY OBJECTIVE

i. To determine the available resources necessary for the provision of maintenance hemodialysis at the three centers.

ii. To compare the overall perception on the quality of maintenance hemodialysis of the three centers.

CHAPTER THREE: STUDY METHODS

3.1 STUDY DESIGN

A descriptive cross-sectional hospital based multicenter study.

3.2 STUDY AREA DESCRIPTION

This study was conducted at the Renal Unit in Kenyatta National Hospital, Nakuru Provincial General Hospital & Machakos level 5 Hospital.

Kenyatta National Hospital is the largest national referral hospital in Kenya. The Renal Unit serves between 250 and 300 renal patients per month. The unit was operational from 1972. Nakuru Provincial General Hospital, located in Nakuru County, is the regional teaching and referral unit with specialized services. The hospital serves a population of approximately 3.6 million in South Rift as well as patients from neighbouring counties. The unit was operational from 2010. Machakos Level 5 Hospital is a modern facility and the main referral unit in Machakos County. The catchment population is drawn from Machakos and parts of neighbouring Makueni County. The unit was operational from 2015.

3.3 SELECTION OF STUDY CENTRES

The choice of three centres, namely Kenyatta National Hospital, Nakuru provincial General Hospital and Machakos Level 5 Hospital was based on convenience sampling. These centres represent established and emerging facilities, respectively**.**

3.4 STUDY POPULATION

The target population comprised:

i. Patients with ESRD on maintenance hemodialysis for a duration exceeding 3 months

ii. Registered nurses stationed in the dialysis unit with a minimum requirement of 6 months' experience in Renal unit

iii. Consultant Physician/ Nephrologist & Residents stationed at the dialysis unit.

3.4.1 Inclusion Criteria

- Age above 18 years
- Informed consent

3.4.2 Exclusion Criteria

- Cognitive impairment

3.5 SAMPLE SIZE ESTIMATION

3.5.1 Sample size for Patients – Questionnaire based study

A single proportion formula was used to determine the sample size for patients

$$n = \frac{Z^2 P (1-P)}{d^2}$$

Where; n = the desired sample

z = 95% confidence interval or 1.96

d = degree of precision usually set at 0.05

P = 0.5

P = 50% representing the proportion of patients with positive perception of quality of haemodialysis services in each of the items in the three subdomains (DCC, QDC and PIP).(61)

$$n = \frac{1.962 \times 0.5 (0.5)}{0.052} = 384$$

But for the population less than 10 000, the following formula was used.

Nf = n/1+ (n/N) (Dohoo et al.) (61)

Where; nf = desired sample for population less than 10 000

n = desired sample size for population greater than 10 000.

N = estimate of the population size = 200

nf = 384/ (1+1.92)

nf = 130

3.5.2 Stratification of sample to each study site

Sample size was further stratified according to the proportion of ESRD patients undergoing hemodialysis at each center. Resultantly, the number of patients for each center was 90 patients at Kenyatta National Hospital, 30 patients at Nakuru General Hospital and 15 patients at Machakos Level 5.

3.5.3 Sample size for providers for in-depth Interviews

Thirteen health care providers were included based on the principle of saturation (62) For purposes of this study, 2 nurses and one doctor were interviewed at both the Nakuru Provincial

General Hospital & Machakos Level 5 Hospital. At the Kenyatta National Hospital, 4 Registered Nurses, 2 residents, and 1 counsellor were selected for participation in the study.

3.6 SAMPLING METHOD

Convenience sampling was employed to recruit patients to complete the questionnaires. Purposive sampling was used in recruitment of participant in the key informant interviews.

3.7 CASE DEFINITION

Chronic Renal failure was defined as a glomerular filtration rate <15mL/min/1.73m^2. The term end-stage renal disease implies CKD that necessitates RRTs like hemodialysis or renal transplantation.

3.8 PARTICIPANT SCREENING & RECRUITMENT

The principal investigator (PI) and trained research assistants reviewed the daily booking list to ascertain the patient scheduled to be dialyzed for the day. Patients who were eligible were selected to participate in the study. The patients were then be furnished with all the relevant information about the study. They were then taken through the consenting procedure. *(See appendix I)* Upon receipt of informed consent, patients were enrolled into the study. A simple study proforma was then administered directly to the patient to capture the relevant socio-demographic and clinical characteristics required. *(See appendix II)*

For the in-depth interviews, key informants were identified by the principal investigator. Sessions were held in private. Consent was obtained from the interviewees before commencing the session. *(See appendix IV)*

3.9 DATA COLLECTION

3.9.1 Data collection procedure for Patients

A semi-structured questionnaire, comprising of both open and closed ended questions, to determine patient perceptions on the quality of maintenance hemodialysis service provision was used to collect data.

The questionnaire was interviewer administered, either by the Principal Investigator or a trained research assistant. The research assistant, who is a registered nurse with experience in the dialysis unit, was trained by the Principal Investigator on how to administer the questionnaire.

Each of the questions in the questionnaire was read out in a comprehensible manner to each recruited patient. The answers furnished by the patients were recorded in the questionnaire in the spaces provided.

For patients who lack comprehension of the English language, a Swahili version of the questionnaire was administered, the responses obtained were translated back to English. *{See appendix III}*

3.9.2 Data collection procedure for Providers

An in-depth interview guide, comprising eight open-ended questions, was used to guide the sessions *{See appendix IV}*. Interview conversations were audio recorded for transcription later. Questions were read out by the interviewer and the respondent allowed sufficient time to answer each question. Interviewer made notes on the responses given by the interviewee. In instances in which audio recordings are not possible, interviewer's notes provided means of capturing interviewee's responses. All interviews were carried out in private

3.10 STUDY TOOLS

A semi-structured questionnaire was used to evaluate the perception of patients. It comprised of both open and closed ended questions (See appendix III). The study tool, in order to suit the purposes of this study, has been operationalized by the investigator with the multiple choice questions being modified from the In-Center Hemodialysis Consumer Assessment of Health Providers and Systems (ICH–CAHPS) questionnaire *(See appendix III).* The questionnaire comprises core topic questions that are grouped into composites as follows:

i. Doctors' communication and caring (DCC) scale – 5 questions
ii. Quality of dialysis centre and operations (QOC) scale – 15 questions
iii. Providing information to patients (PI) scale – 8 questions

The tool has been found to have internal consistency, reliability and validity, by way of psychometric analyses. It has been shown to be valuable in discriminating variation in quality of care among dialysis facilities.(63) According to Wood et al, the ICH CAHPS is a useful and informative tool for the evaluation of patient experiences with dialysis care. (64)

An additional four open ended questions were added at the end of the multi-choice questions, in order to obtain further information from patients concerning their perception of haemodialysis service provision.

A Key informant interview guide comprising eight open-ended questions was used to capture providers' experiences and perceptions on the quality of haemodialysis services. The tool was developed based on relevant literature(49) and with the input of my supervisors *(See appendix IV).* The principle underlying the in-depth interviews is the conventional content analysis, which has been shown to yield valid and reliable results. (50)

3.11 INTERNAL CONSISTENCY RELIABILITY

The internal consistency was determined by measuring Cronbach's alpha coefficient. A coefficient of ≥ 0.7 is interpreted as an acceptable level of internal consistency.(65)

Table 1: Internal Consistency Reliability

	SUBSCALES	
	DCC	**QDC**
Average inter-item covariance:	0.31	0.42
Number of items in the scale:	5	12
Scale reliability coefficient (Cronbach's Alpha):	0.76	0.90

The Coefficient α or Cronbach's alpha was calculated as the measure of internal consistency reliability. The two sub-scales, Doctors' Communication and Caring (DCC) and Quality of Dialysis Centre Care and Operations (QDC) were evaluated for internal consistency reliability.

The Coefficient α of the 5-item Doctors' Communication and Caring (DCC) domain was found to be 0.76. Whereas that of the 12-item Quality of Dialysis Centre Care and Operations (QDC) was found to be 0.90.

3.12 DATA QUALITY CONTROL

Study proforma and questionnaires were provided a unique serial number to avoid duplication of recordings. The data was verified on a weekly basis to ensure completeness following collection. Data entry was on a continuous basis into a password protected Microsoft Access database.

3.13 DATA PROCESSING, STATISTICAL ANALYSIS AND INTERPRETATION

Data derived from the sociodemographic and clinical characteristics was disaggregated by center. Upon demonstration of similarity between the baselines, the data was analyzed together.

The data was coded, cleaned and analyzed using SPSS version 21.0. Descriptive data was presented as percentages for discrete variables, while continuous variables were presented as means and medians.

Each item was scored and subsequently presented as a percentage; there upon comparisons were generated among the three centers.

Inferential statistics were used to test the association between the proportions of positive responses to the various items in each subscale in the different units, using Pearson Chi-square test.

All statistical tests were interpreted at 5% level of significance.

Presentation of this data was done using frequency tables, bar charts and *graphs (See appendix VI).*

Data retrieved from the resource availability checklist was summarized in a table to allow for comparisons between the three different centers.

Data retrieved from the audio recordings was transcribed. Qualitative data was coded through content analysis according to the emerging themes. Unique responses were recorded verbatim

3.14: ETHICAL CONSIDERATONS

This study was carried out upon approval from the Department of Clinical Medicine and Therapeutics (UON) and the Kenyatta National Hospital /University Of Nairobi – Ethics & Research committee (KNH/UON-ERC).

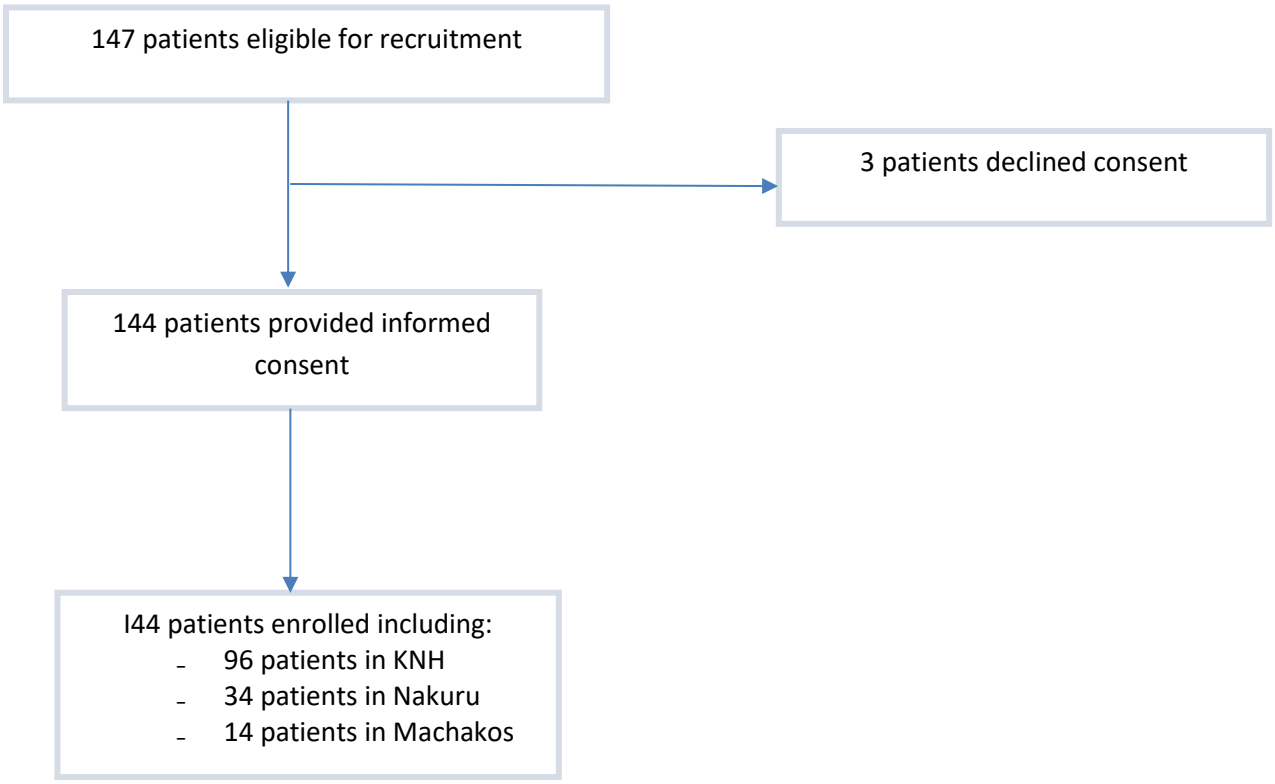
The purpose of the study was then clearly explained to the eligible participants after which informed consent was obtained. *(See appendix I)*

Confidentiality was maintained at all times. An anonymous study-number was assigned to each study subject. This was the sole identification appearing on the study proforma and questionnaire. The subjects reserved the right to withdraw from the study at any point.

Completed proformas and questionnaires were stored securely at all times. These documents will be stored for the prescribed duration following conclusion of the study, and will be destroyed thereafter.

CHAPTER 4: RESULTS

Figure 2: Flowchart of regular maintenance hemodialysis patient recruitment



One hundred and fifty patients with end-stage renal disease on regular maintenance hemodialysis at three centers were screened. One hundred and forty four patients (98%) consented and were enrolled into the study.

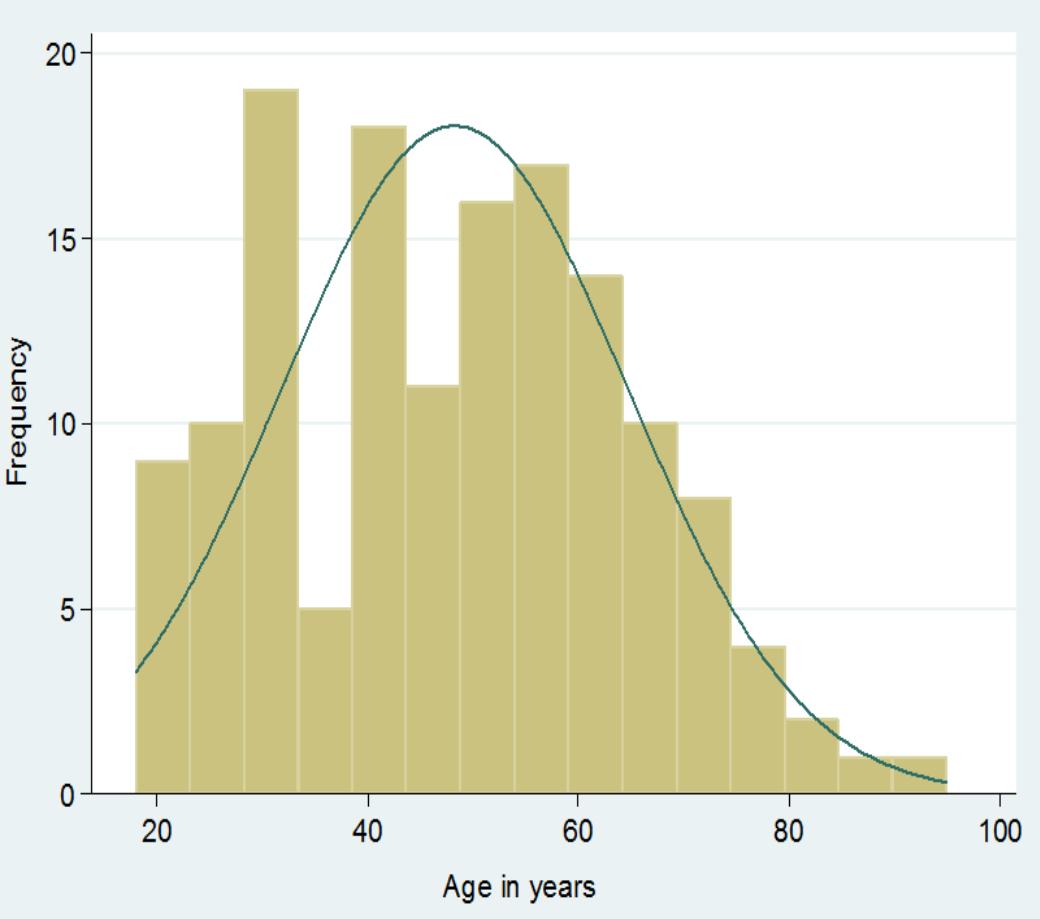
4.1 SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF STUDY POPULATION

Table 2: Baseline characteristics of ESRD patients on maintenance hemodialysis

Characteristics	**KNH (n = 96) n(%)**	**Nakuru (n = 34) n(%)**	**Machakos (n = 14) n(%)**
Age			
< 20	2(2)	1(3)	0(0)
20-44	44(46)	11(32)	3(21)
45-64	37(39)	14(41)	7(50)
65 and above	13(14)	8(24)	4(29)
Sex			
Male	55(57)	20(58)	12(86)
Female	41(43)	14(42)	2(14)
Education			
Illiterate	0(0)	2(7)	2(14)
Primary	25(26)	9(26)	4(29)
Secondary	47(49)	13(38)	5(36)
Tertiary	24(25)	10(29)	3(21)
Sources of funds for haemodialysis			
Salary	5(4)	2(5)	2(10)
Personal business/farming	3(3)	3(8)	3(15)
Family contribution	15(13)	2(5)	1(5)
Donations	4(4)	0(0)	0(0)
Private Insurance	3(3)	1(3)	1(5)
NHIF	82(73)	30(79)	13(65)
Duration on dialysis			
<12 months	55(57)	14(41)	4(29)
12-23 months	19(20)	4(12)	2(14)
24-35 months	10(10)	6(18)	2(14)
>36 months	12(12)	10(29)	6(43)

Baseline characteristics of ESRD patients on maintenance hemodialysis were disaggregated by center and were found to be similar. Note that a proportion of study participants had more than one source of funding.

Figure 3: Age distribution of ESRD patients on maintenance hemodialysis



Mean age = 48.3 years

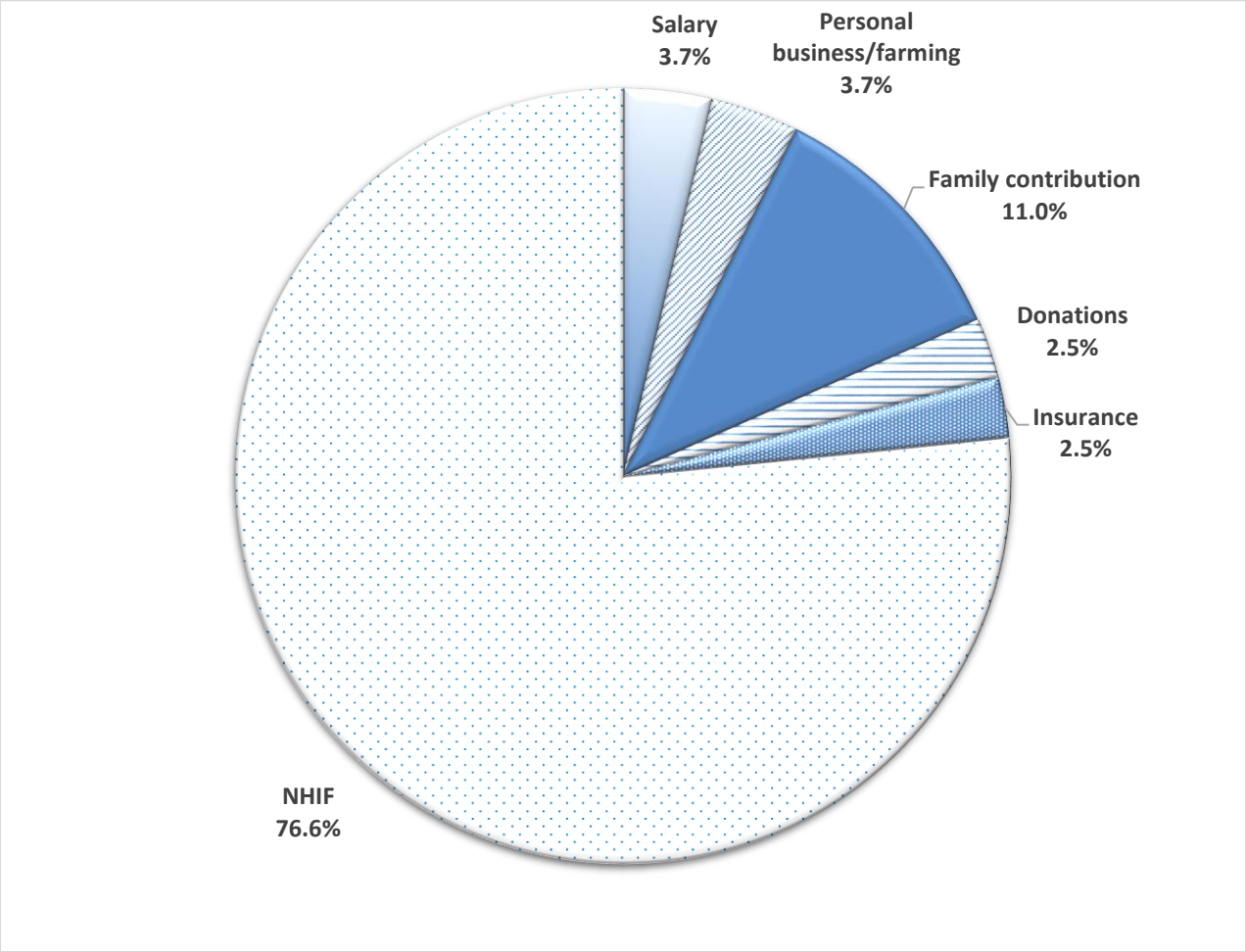
Std. Dev. = 16.5 years

N = 144

One hundred and forty four patients with end-stage renal disease receiving regular maintenance hemodialysis, aged between 18 and 95 years, participated in the study. There were eighty nine males (61.8%) and fifty five females (38.2%), with a female-to-male ratio of 1:1.62. The mean age of the participants was 48.3 ± 16.5 years.

Majority of the study participants were literate (97.2%). 45.8% had attained secondary level education, while 25.7% had attained tertiary level education.

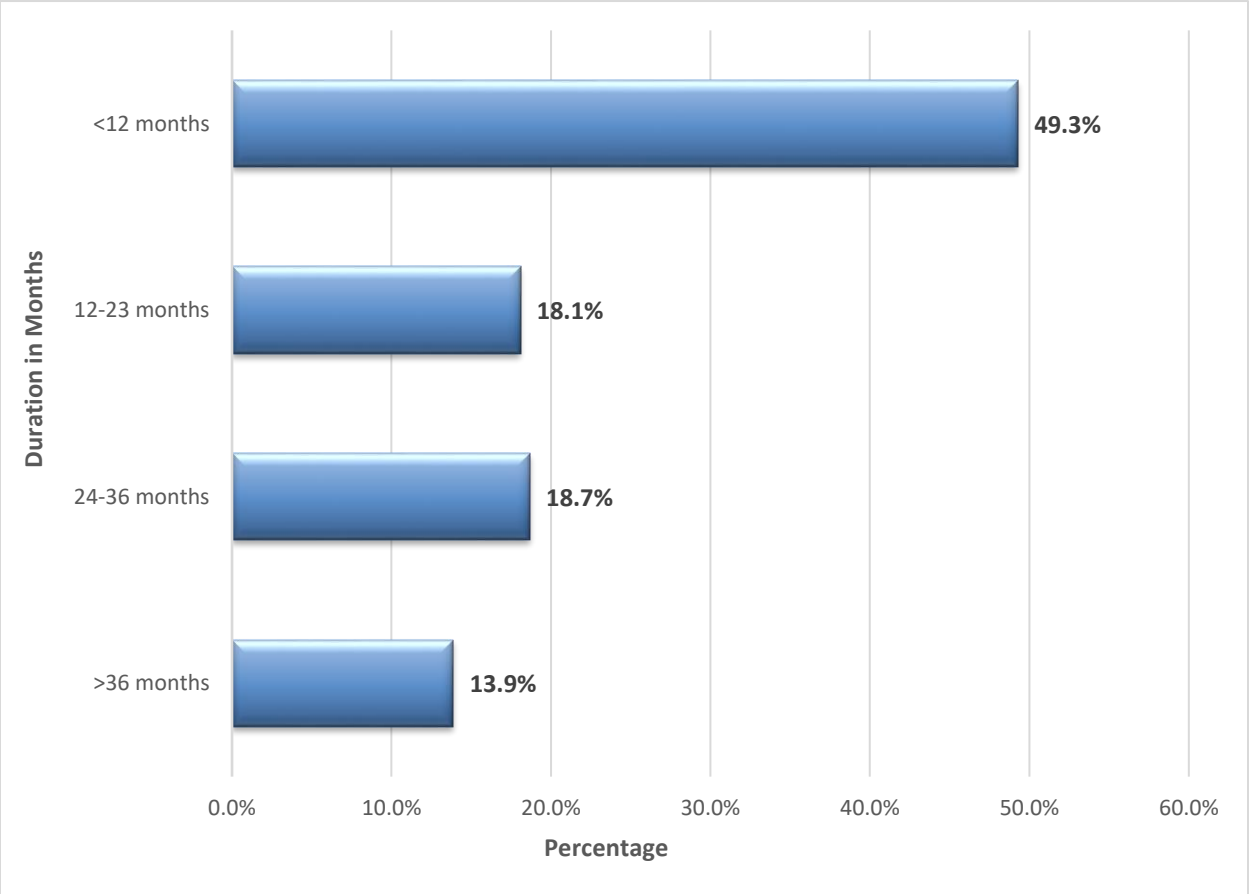
Figure 4: Sources of funds for regular maintenance hemodialysis



NHIF – National Health Insurance Fund

The pie chart above *(fig.4)* shows the proportion of the various sources of funding for hemodialysis among the study participants. Approximately three quarters (76.6%) of the study participants had medical cover provided by the National Health Insurance Fund.

Figure 5: Duration on maintenance hemodialysis

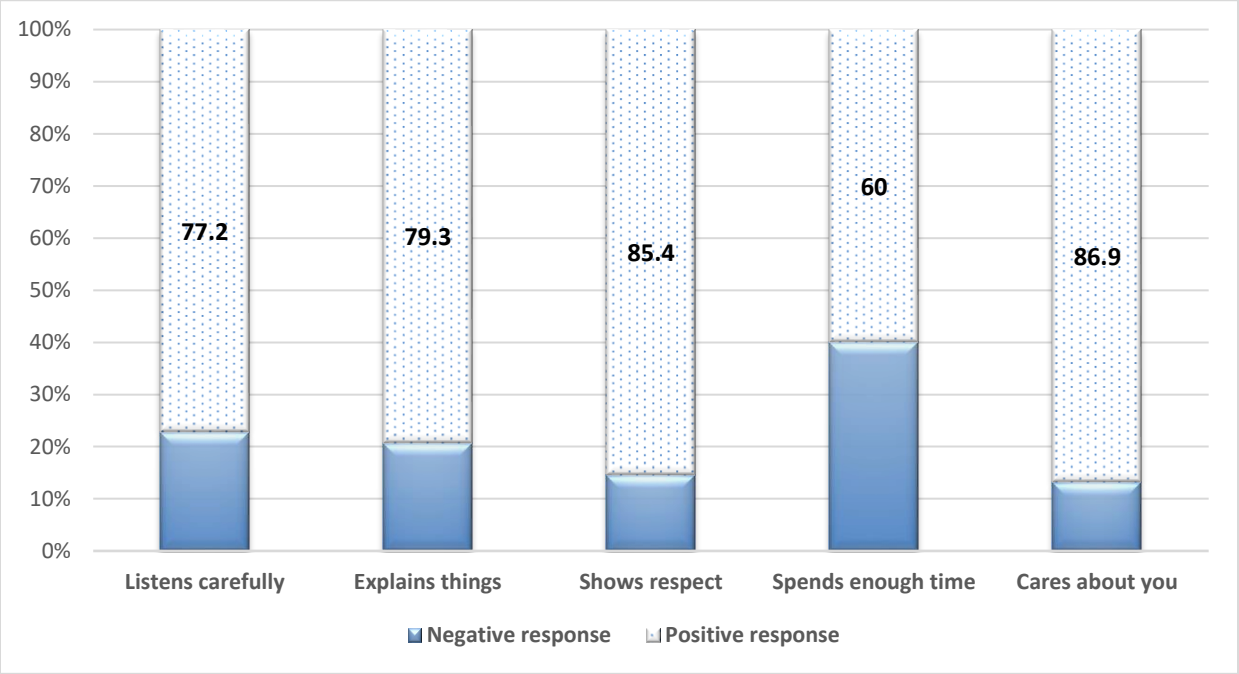


The mean duration of dialysis among study participants was 20.8 ± 25.9 months. Approximately half of the study participants (49.3%) having been on regular dialysis for a period of less than 12 months. The least amount of study participants (13.9%) had been on regular maintenance hemodialysis for a duration of >36 months.

Majority of the participants (70.8%) attended regular hemodialysis at the participating dialysis unit.

4.2 PATIENTS' RESPONSES TO THE THREE SUBSCALES

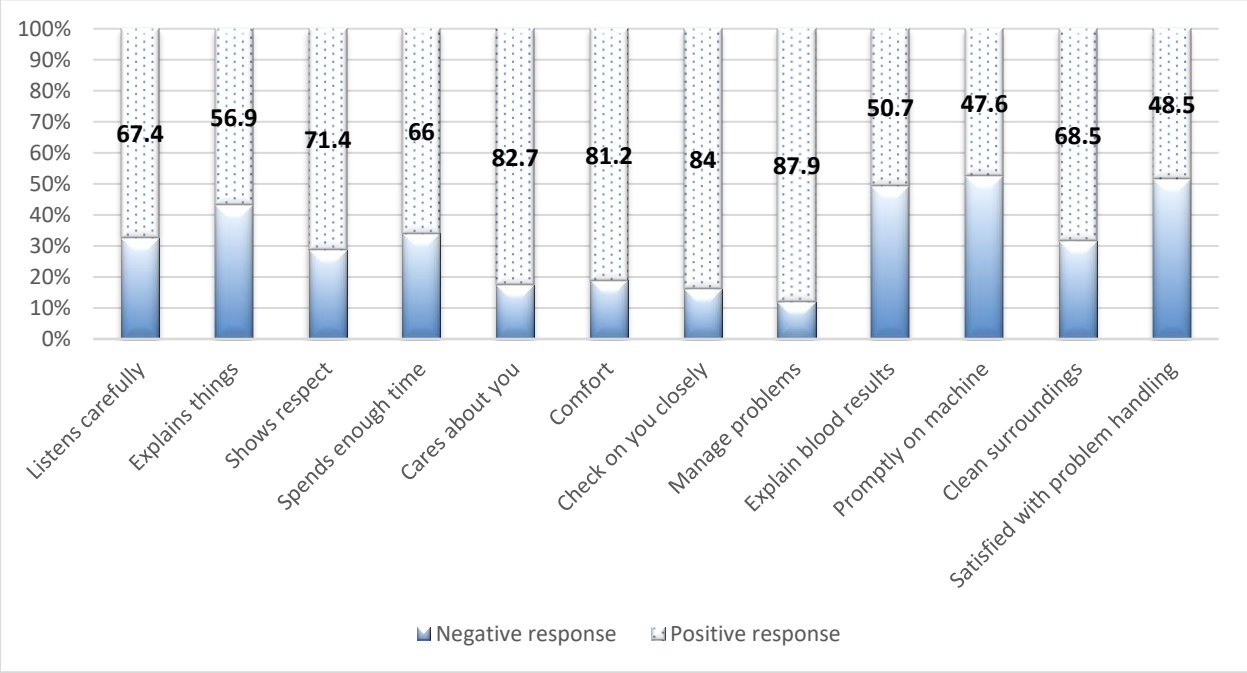
Figure 6: Responses to items in the Doctors' Communication and Caring (DCC) subscale



In the 5-item Doctors' Communication and Caring Domain (DCC), the positive response, i.e. always & usually, was selected most frequently to each question in the domain. Notably, 86.9% responding doctor cares about me, 85.4% responded doctor shows respect, 79.3% responding doctor explains things and 77.2% responding doctor listens carefully.

A comparatively lower proportion of study participants responded negatively i.e. sometimes or never, notably 40% in response to doctor spends enough time, 22.8% in response to doctor listens carefully, and 20.7% in response to doctor explains things.

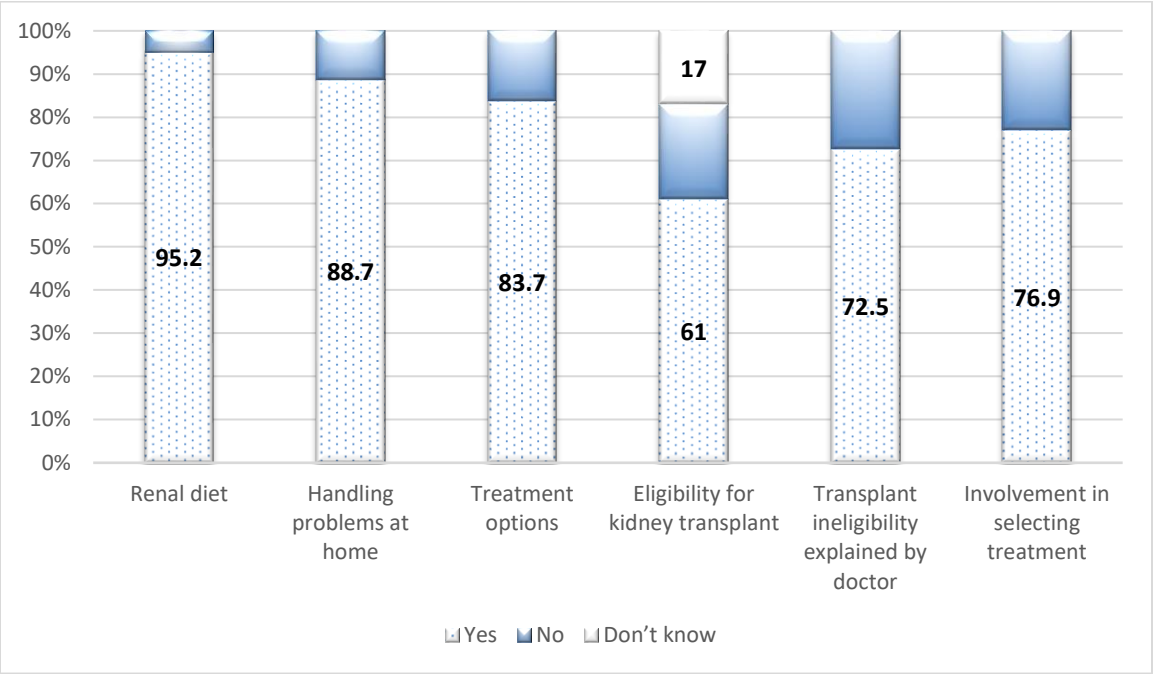
Figure 7: Response to items in the Quality of Dialysis Center Care and Operations (QDC) Subscale



In the 12-item Quality of Dialysis Center Care and Operations (QDC) the most frequent responses to the items in the composite are as follows:

According to 87.9% of the study participants, the dialysis center staff managed problems that arose during dialysis. When asked on whether the dialysis center staff checked on them as closely as they would have wanted during dialysis, 84% responded positively. Among the respondents, 82.7% and 81.2% claim that the dialysis center staff cared about them and made them feel as comfortable as possible during dialysis sessions, respectively. In response to the item, within the last 3 months how often did you get put on the dialysis machine within 15 minutes of your appointment time, 52.5% of the study participants responded negatively. 51.5% of study participants were not satisfied with problem handling, while 49.3% claimed that blood test results were not explained.

Figure 8: Responses in the Providing Information to Patients (PIP) Subscale



Among study participants, 95.2% responded positively when asked whether dialysis center staff informed them on the appropriate diet within the past 3 months. When asked whether the dialysis center staff ever told them what to do if they experienced a health problem at home, 88.7% of respondents were positive. When asked if the kidney doctors and dialysis center staff informed them as much as they would have wanted about the treatment options that are right for them, 83.7% responded positively.

Among the study participants, 22% responded negatively when asked whether they were suitable candidates for renal transplant, with 17% lacking knowledge. Among the study participants who were not suitable candidates for kidney transplant, 27.5% report that the kidney doctor and the dialysis center staff failed to informed them why they were not eligible for kidney transplant. When asked whether they were involved as much as they wanted in choosing the treatment for kidney disease that was right for them at initiation 23.1% responded negatively.

4.3 COMPARISON OF THE PROPORTION OF POSITIVE RESPONSES IN EACH SUBSCALES IN THE PARTICIPATING FACILITIES

Pearson's chi-squared test was performed to assess the relationship between the positive responses generated from individual items in each of the three subscales in the three dialysis centers, i.e. Nakuru, Machakos and KNH. The results are as shown in tables *3, 4 & 5* below:

Table 3: Proportion of positive responses to items in the Doctors' Communication and Caring (DCC) subscale

Item	KNH (%)	Nakuru (%)	Machakos (%)	Total (n = 144)	P value
Listens carefully	70.8	93.2	82.4	77.2	0.026
Explains things	75.0	86.1	85.3	79.3	0.178
Shows respect	80.2	95.4	88.2	85.4	0.09
Spends enough time	46.9	90.9	76.5	59.3	<0.001
Cares about you	84.4	94.3	85.3	86.9	0.191

In response to the items pertaining to doctors listen carefully and spending enough time with patients in the last 3 months, there was a higher proportion of positive responses in Nakuru & Machakos compared to KNH, overall.

There was no significant difference between the centers with regards to doctors explaining things in a way that was easy to understand, showing respect to patients, and doctors caring about patients.

Table 4: Proportion of positive responses to items in the Quality of Dialysis Center Care and Operations (QDC) subscale

Item	KNH (%)	Nakuru (%)	Machakos (%)	Total (n = 144)	P value
Listens carefully to you	51	96	100	67.4	<0.001
Explains things	38.5	92.4	91.2	56.9	<0.001
Shows respect	58.3	90.8	97.0	71.4	<0.001
Spends enough time	51	93.7	94.1	66.0	<0.001
Cares about you	76	93.9	94.0	82.7	0.011
Comfort while undergoing dialysis	72.9	94.7	97.1	81.2	<0.001
Check on you closely during session	78.1	93.7	94.1	84.0	0.021
Manage problems	83.3	82	93.1	87.9	0.08
Explain blood results	33.3	92.3	84.8	50.7	<0.001
Promptly on machine	25.3	85.7	94.1	47.6	<0.001
Cleanliness of surroundings	52.1	100	100	68.5	<0.001
Satisfaction with care	44.4	60	66.7	48.5	0.657

Overall proportion of positive responses to the items in the subscale were higher in Nakuru & Machakos compared to KNH.

No significant difference was noted between the centers with regards to satisfaction with care and in the management of problems arising during dialysis.

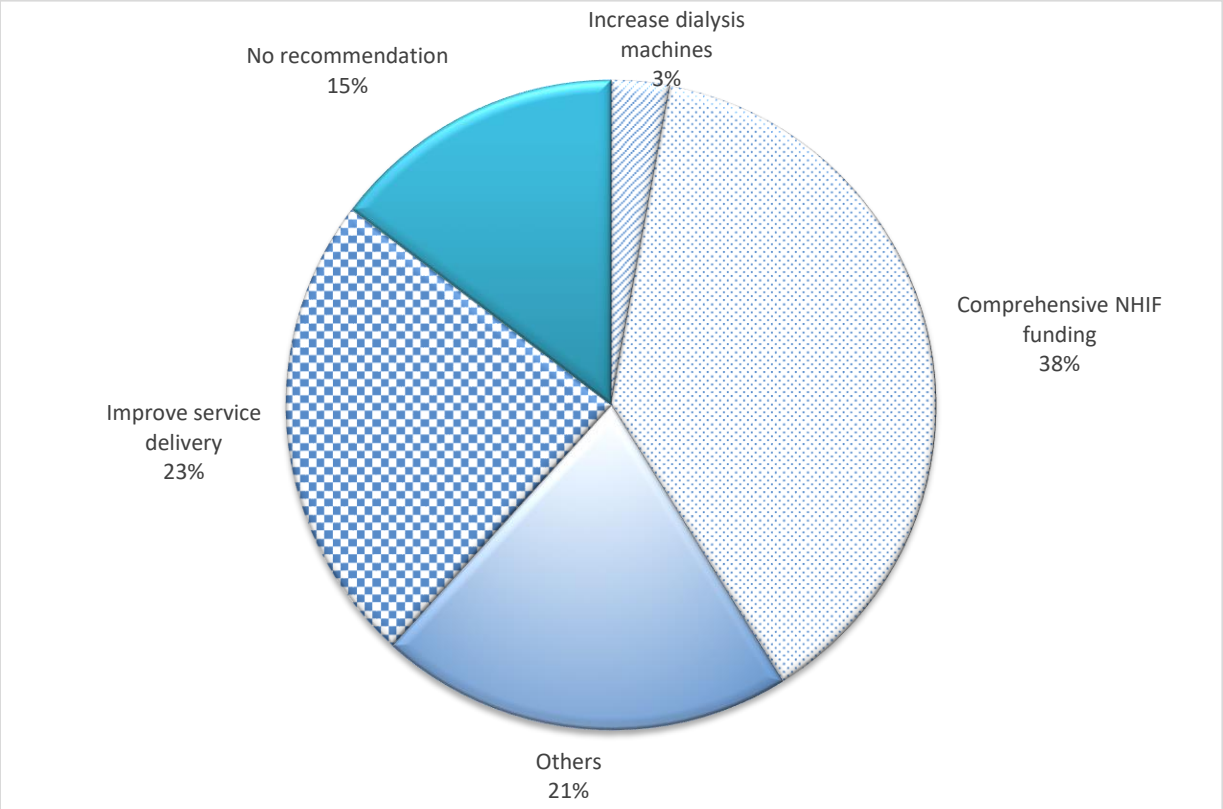
Table 5: Proportion of positive responses to items in the Providing Information to Patients (PIP) subscale

Item	KNH (%)	Nakuru (%)	Machakos (%)	Total (n = 144)	P value
Renal diet	96.9	92.3	94.1	95.8	0.684
Handling problems at home	88.5	100	84.8	88.7	0.341
Treatment options	78.1	92.9	88.2	83.7	0.366
Eligibility for renal transplantation	60.4	42.9	66.7	61.0	0.301
Transplant ineligibility explained by doctor	28.1	96.2	88.9	72.5	0.290
Involvement in selection treatment option	70.8	85.7	82.4	76.9	0.043

There was no significant difference between the units with regards to the items in the providing information to patients subscale. The exception was in response to the item, in the past 12 months, were you as involved as much as you wanted in choosing the treatment for kidney disease that is right for you, a significant difference exists between the centers.

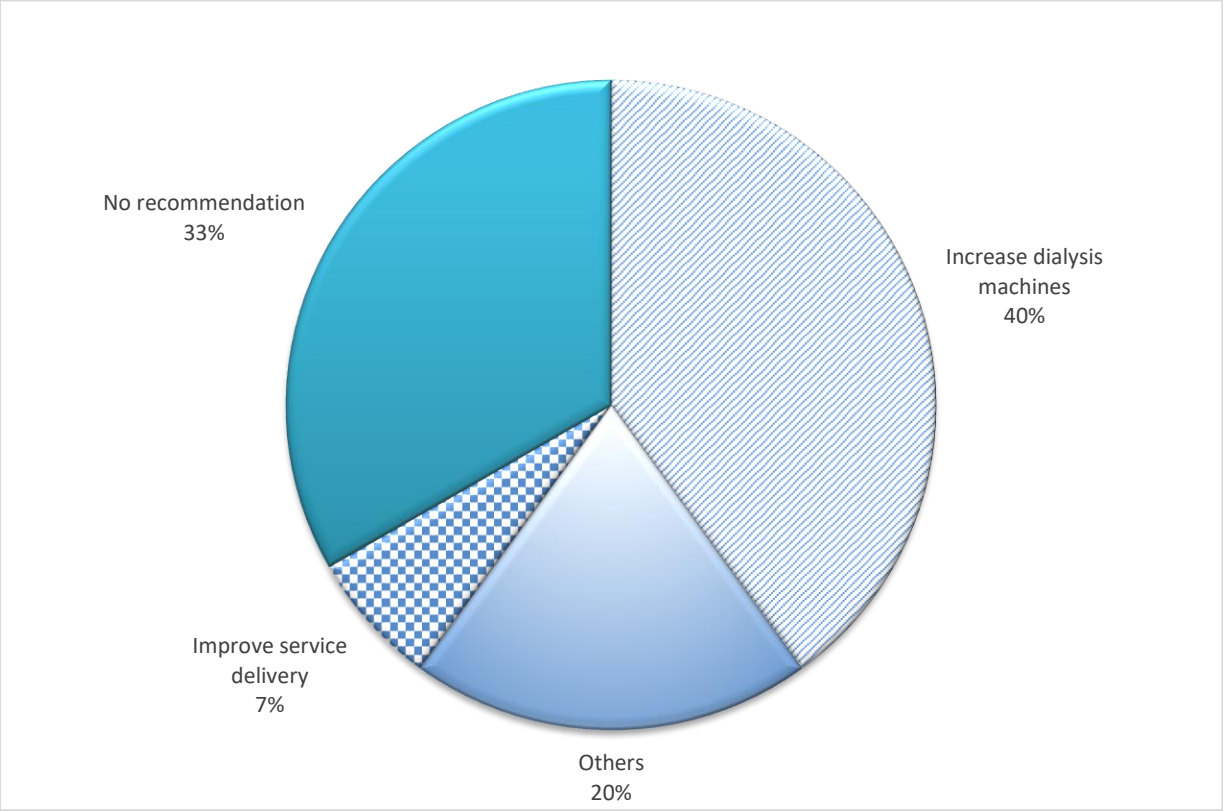
4.4 REPRESENTATION OF PATIENTS' RECOMMENDATIONS FOR IMPROVEMENT IN HAEMODIALYSIS SERVICES

Figure 9: Patients' recommendations for improvement in haemodialysis services in Machakos



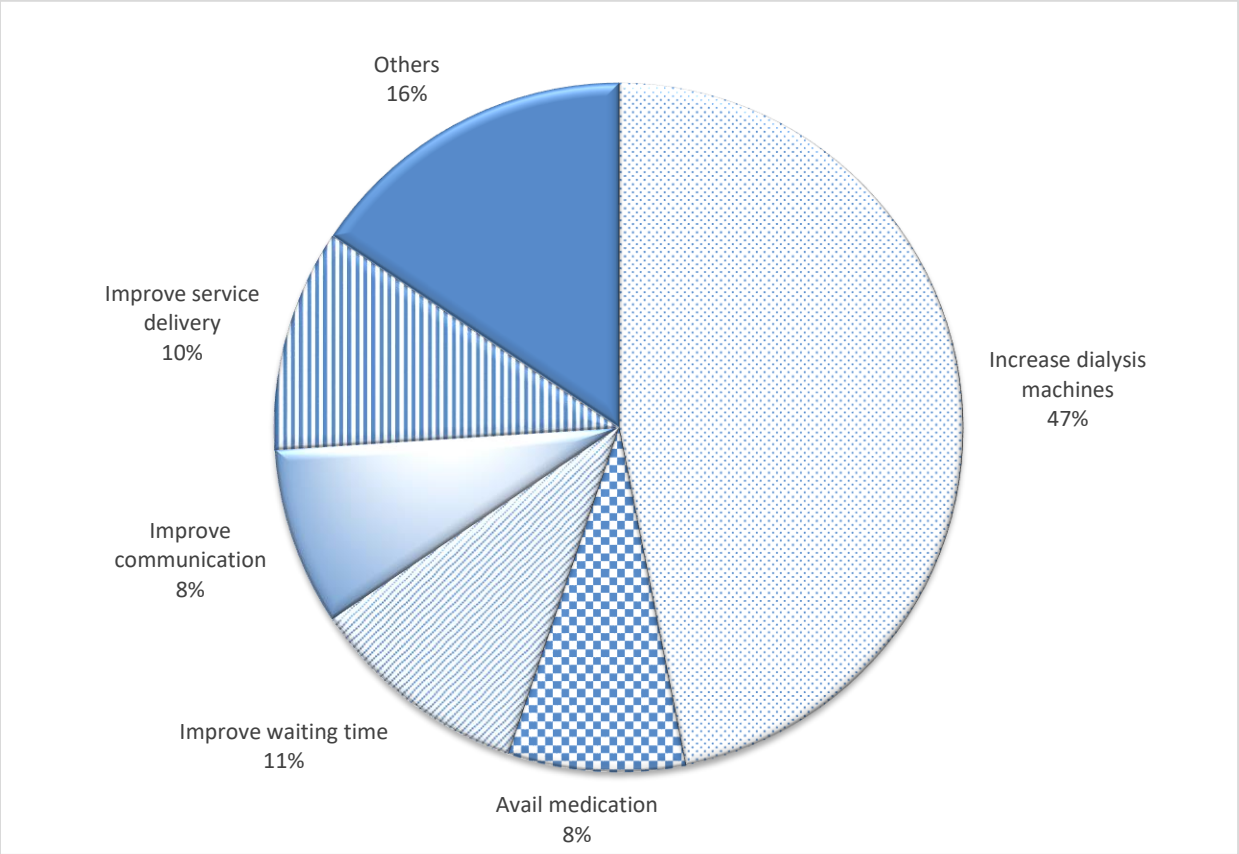
The pie chart above *(fig.9)* shows the proportion of the various recommendations among study participants on maintenance haemodialysis in Machakos. 38% recommended comprehensive NHIF funding, whereas 23% recommended improvement in service delivery. The category classified as 'Others' includes: Increase in staff, improve in communication, improve in waiting time and avail medication (21%).

Figure 10: Patients' recommendations for improvement in haemodialysis services in Nakuru



The pie chart above *(fig.10)* shows the proportion of the various recommendations among study participants on maintenance haemodialysis in Nakuru. 40% recommended an increase in dialysis machines, whereas 33% of those on regular maintenance haemodialysis had no recommendations. The category classified as 'Others' includes: Increase in staff, improve in communication, improve in waiting time and avail medication (20%).

Figure 11: Patients' recommendations for improvement in haemodialysis services in KNH



The pie chart above *(fig.11)* demonstrates the proportion of the various recommendations among the study participants on maintenance dialysis at the KNH. 47% recommended an increase in the number of dialysis machines, while 11% recommended an improvement in waiting time. Others (16%) includes: Comprehensive NHIF funding, increase in staff and no recommendations.

4.5 CHECKLIST FOR RESOURCE AVAILABILITY

Table 6: Checklist for comparison of resource availability in the three settings

	KNH	NAKURU	MACHAKOS
STAFFING:			
No. of Doctors			
- Nephrologist(s):	6	1	0
- Urologist(s):	20	0	0
- Vascular surgeon(s):	3	0	0
- Physician(s) and Medical Officer(s):	3	1	5
No. of Registered Nurses:	59	9	7
PATIENTS:			
No. of chronic patients on regular maintenance hemodialysis:	96	71	26
STAFF-TO-PATIENT RATIO:			
Overall staff-to-patient ratio:	1:2	1:4	1:3
Doctor-to-patient ratio:	1:10	1:35	1:9
Nurse-to-patient ratio:	2:3	1:8	1:3
DIALYSIS CENTER FACILITIES:			
No. of Dialysis Stations:	28	27	6
No. of Operational Machines:	11	14	6
Facility for Chronic HBV patients:	2	1	1

	KNH	NAKURU	MACHAKOS
FREQUENY OF HAEMODIALYSIS:			
No. of 3 sessions/ week:	3	0	0
No. of 2 sessions/ week:	40	65	26
TRANSPLANTATION:			
No. of patients on waiting list:	12	16	1
No. of Kidney Transplant Recipients:	151	13	0

The water assessment report of the three facilities was as follows:

At the Kenyatta National Hospital there were two water plants in working order. Water samples done bimonthly. In the Nakuru Renal Unit the water plant was in working order. At the Machakos Renal Unit, the water plant was in working order. The filters are changed on a monthly basis.

4.6 RESULTS OF KEY INFORMANT INTERVIEWS

Thirteen health care providers were recruited into this section of the study. They included 4 doctors, 8 nurses and 1 counsellor. The section is divided into two subsections:

- Challenges experienced in delivery of care to patients on hemodialysis
- Proposed strategies to overcome the challenges

Themes that arose from the interviews were coded and thematic analyses was conducted under each subsection.

4.6.1 CHALLENGES EXPERIENCED IN DELIVERY OF CARE TO PATIENTS ON HEMODIALYSIS

Under this subsection 15 themes arose as indicated in *table 6* below:

Table 7: Challenges encountered in health service provision to patients on maintenance hemodialysis

Main Themes	Frequency (n=13)	Percentage
Financial constraints	7	53.8
Patient burden	6	46.2
Shortage of staff	5	38.5
Organizational constraints i.e. fixed operating hours	4	30.7
Equipment malfunction/ breakdown	3	23.1
Shortage of equipment	3	23.1
Infrequent hemodialysis	3	23.1
Auxiliary Services such as blood transfusion services	2	15.4

- **Financial constraints**

It is implicit that hemodialysis places an enormous financial burden on patients, and is not sustainable unless a NHIF scheme is in place.

Excerpt 1 – The Nursing Officer In-charge in Machakos Renal Unit, a specialised nephrology nurse worked in the unit for a duration of one year and three months.

"…..First off, is the issue of cash payment poses to our patients. Indeed the NHIF scheme exists, but some of our patients are not benefactors as they don't have the slightest idea what NHIF is, as they come from remote areas. In some cases, they end up missing out on dialysis because they cannot afford the costs and they are not on the NHIF scheme….."

- **Patient burden**

The issue of a high patient burden has consistently come up in majority of the interviews. It poses a significant challenge to the work force.

Excerpt 2 – The Nursing Officer In-charge in KNH Renal Unit, a specialized nephrology nurse who has worked in the unit for a duration of fourteen years

"…..working hours and the patient burden have been factors all the while I have been here, we have a large clientele. You would find that one nurse is taking care of several patients, to the extent that the nurses were unable to take any breaks. Currently due to opening of centres in many counties, we are getting a relief because the number of patients have now reduced, and therefore we hope in future to serve our patients optimally….."

- **Shortage of staff**

  A sufficient number of nurses is mandatory in order to adequately meet the demand for timely services.

  Excerpt 3 – The Nursing Officer in Machakos stationed in the unit for one year.

  "…..There are times you find that you are only one or two nurses on the floor. That causes unnecessary delays. By way of example, we have 5 functioning machines. If I'm alone on the floor, it may take up to an hour for me to disconnect and reconnect patients on all the machines as compared if there were 2 or 3 nurses available to handle the same work load….."

- **Organizational constraints i.e. fixed operating hours**

  The long hours required to meet the demands of renal units take a toll on dialysis centre staff, especially in units that lack provision to cater for emergency cases.

  Excerpt 4 – The Deputy Nursing Officer In-charge in Nakuru Renal Unit, a specialised nephrology nurse who has worked in the unit for a duration of five years.

  "…..The other challenge is emergencies that can occur at all odd hours. We do not have the provision for night duty in this renal unit. So you can find a situation where you, as a member of staff may be called upon to remain behind up to 10 pm. In these instances you are still expected to attend to clients the following day….."

- **Equipment malfunction/ breakdown**

  The frequent break down of dialysis machines causes unnecessary delays in hemodialysis and inconveniences both staff and patients alike.

  Excerpt 5 – The Nursing Officer In-charge in Nakuru Renal Unit, a specialised nephrology nurse who has worked in the unit for a duration of six years.

  "…..We also experience frequent breakdown of dialysis machines, on occasion patients are scheduled for dialysis when machines are not functioning, and this causes a problem due to rescheduling of these patients….."

- **Shortage of equipment**

  Shortage of machines hampers service delivery and requires to be addressed.

  Excerpt 6 – The Nursing Officer in Machakos stationed in the unit for one year.

  "…..Shortage of machines for hemodialysis was an issue in the past, perhaps not as big an issue now….."

- **Infrequent hemodialysis**

  Inappropriate frequency of hemodialysis is experienced due to high patient burden and shortage of dialysis machines.

  Excerpt 7 – Nephrology nurse stationed at the KNH Renal Unit for past ten years.

  "…..mostly patients are to be dialyzed twice a week in KNH, because of the shortage of the machines and the patient burden it becomes difficult to meet this obligation in some cases, so that they may end dialyzing once….."

4.6.2 PROPOSED STRATEGIES TO OVERCOME CHALLENGES IN THE PROVISION OF HEMODIALYSIS SERVICES

Under this subsection 11 themes arose as indicated in *table 7* below:

Table 8: Proposed strategies to overcome challenges encountered in the provision of maintenance haemodialysis

Proposed strategies	Frequency (n=13)	Percentage
Training of staff	8	61.5
Creation of schedules and rotas	7	53.8
Administrative interventions	6	46.2
Increase in dialysis machines	6	46.2
Creating awareness on the importance of health insurance	5	38.5
Counselling services	5	38.5
Referral Services	3	23.1
Transplantation services	2	15.4
Fostering teamwork	2	15.4
Improve waiting time	2	15.4
Peritoneal dialysis as an alternative	1	7.7

- **Training of staff**

  On the job training of nurses will alleviate the existing shortages.

  Excerpt 1– The Nursing Officer In-charge in Nakuru Renal Unit, a specialized nephrology nurse who has worked in the unit for a duration of six years.

  "…..As for the human resource, there is not much that can be done currently, we are aware that a shortage exists all over the country, so even as we request for additional untrained nurses to join us with the intention of training them on the job, we do understand that it is difficult….."

- **Creation of schedules and rotas**

  Formulation of rotas and schedules allows for proper organization of services.

  Excerpt 2 – The Deputy Nursing Officer In-charge in Nakuru Renal Unit, a specialized nephrology nurse who has worked in the unit for a duration of five years.

  "….. We plan the patient's dialysis sessions so that only booked patients can be allowed to receive dialysis on any given day. Those who experience problems are allowed to call. We plan our duty rota and formulate call lists….."

- **Administrative interventions**

  Subsidies and waivers offer a relief especially regarding aspects of care not covered by NHIF.

  Excerpt 3 – The Nursing Officer In-charge in Nakuru Renal Unit, a specialized nephrology nurse who has worked in the unit for a duration of six years.

  "….With regards to the issue of payments, the management initially subsidized the costs when the patients raised issues, we can now say that it is almost entirely sorted out due to the NHIF….."

- **Creating awareness on the importance of health insurance**

  The acquisition of a NHIF cover is key in alleviating the enormous financial burden from patients on regular hemodialysis.

  Excerpt 4 – Renal nurse specialized in counselling stationed at KNH for the past nine years

  "…..I now actively enquire and encourage patients to have an NHIF cover to enable the patient to go through dialysis without the challenge of payment. I go to the extent of allaying any fear the family may have by encouraging them to take up an NHIF cover….."

- **Increase in dialysis machines**

  Excerpt 5 – Renal nurse stationed at KNH for the past five years

  "….Increase the number of machines. An increase in the number of staff so that patient can receive haemodialysis without delays. Third is the availability of the items for haemodialysis in constant supply so that patients are not sent to procure for elsewhere…."

- **Counselling services**

  Counselling is essential in order to increase understanding of the chronic nature of the disease and to increase compliance to treatment plan.

  Excerpt 6 – The Nursing Officer In-charge in KNH Renal Unit, a specialized nephrology nurse who has worked in the unit for a duration of fourteen years

  "…..What we have put place as a unit is to increase the number of counsellors in the unit such that we can start talking to these patients right from the renal and diabetic clinic before they present to the renal unit. We also involve the family members in the counselling which has proven beneficial in the understanding of the kidney disease and compliance to the treatment plan…"

CHAPTER 5: DISCUSSION

We report on the findings of the first local study evaluating perceptions on maintenance hemodialysis services among 144 patients and 13 healthcare providers within three settings: The Kenyatta National Hospital, Nakuru Provincial General Hospital and Machakos Level 5 Hospital. The three centers, consisting of an established and two emerging centers, were representative of the entire population of patients on maintenance hemodialysis in Kenya. The baseline socio-demographic and clinical characteristics of the study participants were found to be similar, therefore the study findings from the three centers were analyzed collectively.

In this study, the mean age of the patients on maintenance hemodialysis was 48.3 ± 16.5 years. This finding compares favourably with that of studies in the same population and setting. Kamau et al in a study on the determinants of Health-Related Quality of Life of end-stage renal disease patients on maintenance hemodialysis, reported a mean age of 44 ± 13.98 years.(19) The finding of male predominance of 61.8 % was in keeping with other studies carried out in a similar population and setting.(19,66)

An assessment of the level of education among patients with end-stage renal disease undergoing regular maintenance hemodialysis revealed that the majority were literate (97.2%). This finding was in line with to other studies carried out in KNH (19,66).

Three-quarters (76.6%) of the study participants had a medical cover provided by NHIF and is explained by the fact that NHIF settles a significant proportion of the cost of hemodialysis.

According to this study, the mean duration on hemodialysis was found to be 20.8 ± 25.9 months among study participants. Approximately half (49.3%) of the population had been on dialysis for a period less than 12 months. This is similar to studies carried out in the same patient population.(19) Dantoye et al, in a single-center 7 year experience with ESRD care in Nigeria, attributed this finding to a high drop-out rate from hemodialysis care through non-compliance or death.(67)

The findings of this study demonstrate that a significant proportion of study participants had a positive perception, as depicted by the response always or usually, to the items in the Doctors' Communication and caring (DCC) subscale, ranging between 60% and 86.9%. The negative perception, as depicted by responses sometimes and never, to the DCC subunit ranged between 13.1% and 40%. Accordingly, Farley et al in a case study of a successful quality improvement intervention using the ICH-CAHPS in the US (68), demonstrated the proportion of negative perception to the DCC subunit ranging between 18% and 33%. The overall positive perception is an indicator that doctors' communication, as well as care rendered to patients on maintenance hemodialysis has a bearing on patient perception on the quality of care received.

The positive perception, as depicted by responses usually and always, to the items in the Quality of Dialysis Center care and Operations (QDC) subscale ranged widely between 47.6% and 87.9%. Conversely, the negative responses, depicted by the response sometimes and never, ranged between 12% and 52.5%. This indicates mixed perception among study participants to certain aspects of dialysis center staff communication and

operations. Delays in connecting to machine stood out with 52.5% of study participants responded negatively. In an audit of waiting time in the KNH Renal Unit, delays to the timely provision of hemodialysis was attributed to the shortage of the number of dialysis machines available, as well as the rising patient burden. Both these factors resulted in an increase in waiting time.(29)

Similarly, a mixed response was drawn when study participants were asked if they were satisfied with the manner in which dialysis center staff handled problems that arose during dialysis. This was similar to Ndambuki et al (26) who, in a study on the level of patient perception and satisfaction with renal nursing services in KNH, found a mixed response, from neutral to satisfied, when patients were asked whether they were satisfied with renal nurse handling of problems that arose in dialysis, as well as explanations offered for delays and attitude whilst handling complaints. This was attributed to the demand on the nursing staff due to the high patient burden, but also due to a lack of motivation among dialysis center staff, according to the findings of that study.(26)

Majority of study participants were positive when asked about the provision of information on various aspects of care. In reference to eligibility for kidney transplantation, in our study 61% of respondents were eligible for kidney transplantation. Kwalima et al (25) in a study on the barriers to access of hemodialysis services in KNH, found that 64% of respondents were willing to procure kidney transplant in KNH. The reasons cited were affordability, ease of follow up and confidence in the skill level of the specialists involved.

Despite the overall positive response to the items in the Doctors' Communication and Caring subscale, Nakuru and Machakos performed better than KNH with regards to doctors spending enough time with the patients in the last 3 months. The reasons for this finding are beyond the scope of this study.

In the Quality of Dialysis Center care and Operations (QDC) subscale, Nakuru and Machakos performed better when compared to KNH in areas of staff explaining things in a manner that was easy to understand, explanation of blood test results and connecting to dialysis machine within 15 minutes of patient's arrival in the renal unit. This was similar to the findings of another study conducted within the KNH Renal unit. (26)

Recommendations for the improvement of hemodialysis services varied in the different facilities. The call for comprehensive NHIF cover to extend beyond dialysis-related costs, to include purchase of dialysis catheter and medication is in a bid to further alleviate financial burden from patients undergoing regular maintenance hemodialysis. Additional costs associated with hemodialysis act as a barrier to access of this vital service. In line with this, a study carried out in KNH demonstrated that occasionally items required for dialysis would ran out, forcing patients to source the items outside the hospital.(25) This poses an additional burden on these patients. Naicker et al (57) points out that costs associated with hemodialysis are prohibitive and as a result self-funded end-stage renal disease patients in Sub-Saharan Africa are unable to sustain hemodialysis for more than 6 months. Half of the study participants in KNH, and two fifths of those in Nakuru, recommended an increase in dialysis machines. Correspondingly a study carried out in

KNH concluded that an increase in the number of dialysis machines would improve the overall perception of the quality of hemodialysis services. (26)

The number of staff in the different cadres was an important consideration in our study.

The total number of nephrologists in Kenya currently stands at twenty nine. According to Bello et al (69), in a study on the challenges and opportunities in care on CKD patients in Europe, Kenya ranks among the lowest countries in the world having <1 nephrologist per million population. Comparisons drawn from other countries of nephrologists per million population include: Italy 53, the United states 28, the United Kingdom 8, both Tunisia and Egypt 7, Rwanda 0.20 and Uganda 0.15. This finding highlights the challenges attendant to growing a substantial nephrology work force including the high cost of specialist training and the inequitable distribution of the work force within resource limited settings.

According to the 2014 World Development Indicators published by the World Bank (17), the number of Kenyan nurses per 1000 population was 0.9. This fell below the world standard that stood at 3.3 per 1000 population. In our study two aspects stand out, firstly the shortage of skilled renal nurses and secondly the inequitable distribution between the facilities. It should however be noted that at the time of the audit the KNH Renal unit was under renovation with a significant proportion of the patient population referred to external facilities for continuation of hemodialysis.

Financial constraints were deemed to be one of the main challenges to the provision of hemodialysis services. Although a popular option, NHIF coverage is not 100%, meaning

that there is still a proportion of the dialysis population who are self-sponsored. According to Naicker et al (53) majority of self-sponsored patients in Sub-Saharan Africa are unable to sustain dialysis for a duration exceeding 6 months. In this regard, the proposed strategy is to create awareness of the benefits of a NHIF scheme and to seek administrative interventions such as subsidies and waivers for additional treatment related costs that are not covered by the NHIF.

The rising patient burden coupled with the shortage of both staff and equipment places undue strain on hemodialysis service delivery. According to Ndambuki et al (26) the number of dialysis machines in operation at that time barely met the patient demand, except in instances that patients opted to dialyze in external facilities or defaulted. The proposed strategies to mitigate the issue of resource availability include improving organization within the units by use of schedules and rotas, fostering strong teamwork, technical support to ensure that the available machines remain in good working condition and on job training of staff.

It is noteworthy that some of the interventions recommended in this study are ongoing with an additional seventeen dialysis units having been constructed and set to commence providing services.(7)

5.1 CONCLUSION

In this study patient and provider perceptions, as well as an assessment of resource availability were focal to the evaluation of the quality of maintenance hemodialysis services. Patient perception to the quality of services was positive overall. The aspects of care perceived negatively included: waiting time, explaining aspects of care and blood results in a way that is easy to comprehend and concerning the amount of time doctors spent with the patient. The recommendations proposed by patients included: increase in dialysis machines, comprehensive NHIF funding, improvement in service delivery and improvement in waiting time.

The perception of providers was that financial constraints, patient burden and shortage of staff hampered service delivery. The recommendations made in this regard included: financial interventions such as NHIF, capacity building to cater for rising patent burden, referral and transplantation services.

The implications of this study are that the participation of patients and providers in the evaluation of the quality of maintenance haemodialysis services offers valuable insight into the unique challenges faced and potential improvement strategies, it should therefore be encouraged.

5.2 RECOMMENDATIONS

i. Sensitize the staff on the report and set strategies for improvement in maintenance hemodialysis service delivery.

ii. Creation of awareness of NHIF scheme, especially in the rural areas and implementing appropriate administrative interventions to increase access to hemodialysis services.

iii. Address patient concerns by increasing machines, training more staff to cater for the high patient burden & allocating more specialists.

5.3 LIMITATIONS

i. Due to time constraints the study design selected permits for an assessment at one point in time. A longitudinal design would be suitable to allow for a follow up assessment as an exact measure of improvement.

ii. Response bias was anticipated because the questionnaire was interviewer administered. The principal investigator and research assistants sought to minimize this by making no attempt to expound on or clarify any of the questions.

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APPENDIX I: CONSENT FORM

AN EVALUATION OF MAINTENANCE HEMODIALYSIS SERVICE PROVISION IN RESOURCE LIMITED SETTINGS: A QUALITY OF CARE SURVEY

Part I: Information Sheet

Introduction

My name is Dr. Kariuki. I am doing to study to evaluate the services you receive in the Renal Unit at [The Facility] I seek your participation in this study because you undergo hemodialysis in this unit. Make sure you thoroughly read this form and feel free to ask any questions/ clarifications at any point, before going ahead and taking part in the study.

What is study about?

In carrying out this study, I want to understand your experience and perception of the hemodialysis service provided at the [The Facility]. This information is important as it informs the staff and administrators of the Renal Unit whether or not you are content with the service delivery. Your contribution to this study will assist in the effort of improving of service delivery in the Renal Unit.

What we will ask you to do

If you accept to participate in the study we will give you a structured questionnaire containing 32 questions to help us know more about you and your experience while undergoing dialysis at the renal unit.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this center will continue and nothing will change.

Risks

There is a risk that you may share some personal information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the survey if you feel the question(s) are too personal or if talking about them makes you uncomfortable

Benefits

The benefit you will derive is that your opinion on the provision of hemodialysis as a service will be taken into account. Your participation is likely to help us find out more about ways to improve hemodialysis services and patient care.

Reimbursements

You will not be provided any incentive to take part in the study.

Confidentiality

The information obtained from of this study will be kept private. In the event that we publish the results obtained we will not include any information that will make it possible to identify you. The records will be kept in a secure lock cabinet/ password protected computer only the researchers will have access to the records.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following: Dr. Kariuki, Resident, Department of Clinical Medicine and Therapeutics, University of Nairobi, Mobile No. 0732767121. Alternatively, contact the Chairperson KNH/UoN/ERC Tel. No. +2542726300 Ext 44102.

Part II: Certificate of Consent (**This section is mandatory)**

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant_____
Signature of Participant _____
Date _____
Day/month/year

If illiterate [1]

Print name of witness_____ **Thumb print of participant**
Signature of witness _____
Date _____
Day/month/year

Statement by the researcher/person taking consent

I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy has been provided to the participant.

Print Name & Signature of Researcher/person taking the consent_____

Date _____
Day/month/year

[1] A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb print as well.

APPENDIX II: STUDY PROFORMA

GENERAL INFORMATION

1. Study serial Number: …….
2. I.P. NO: …….
3. Telephone contact: …….
4. Home address: ……..
5. Age: ……..
6. Sex: Male □ Female □
7. Education level: None □ Primary □ Secondary □ Tertiary □
8. Sources of funds for hemodialysis: Salary □ Personal business/farming □ Family contributions □ Donations □ Insurance □ Other (Specify): _____

CLINICAL CHARACTERISTICS

10. Aetiology of CKD
    - □ Diabetes
    - □ Hypertension
    - □ Diabetes and Hypertension
    - □ Glomerulonephritis
    - □ HIV
    - □ Obstructive Uropathy
    - □ Polycystic Kidney Disease
    - □ Unspecified cause
    - □ Other (Specify): _____

9. How long have you been on hemodialysis at KNH? …… (Months/Years)
10. Is this your regular dialysis center? Yes □ No □
11. Type of vascular access? Fistula /Graft □ Tunneled catheter □ Non-tunneled catheter □

APPENDIX III: STUDY TOOL

AN EVALUATION OF MAINTENANCE HEMODIALYSIS SERVICE PROVISION IN RESOURCE LIMITED SETTINGS: A QUALITY OF CARE SURVEY

Your Doctors

These are doctors most involved in your dialysis care now. This includes doctors that you see in the dialysis unit and at the renal clinic.

1. In the last 3 months, how often did your doctors listen carefully to you?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

2. In the last 3 months, how often did your doctors explain things in a way that was easy for you to understand?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

3. In the last 3 months, how often did your doctors show respect for what you had to say?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

4. In the last 3 months, how often did your doctors spend enough time with you?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

5. In the last 3 months, how often did you feel your doctors really cared about you as a person?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

The Dialysis Center Staff

For the next questions, dialysis center staff does <u>not</u> include doctors. Dialysis center staff means nurses, technicians, dietitians, and social workers at this dialysis center.

6. In the last 3 months, how often did the dialysis center staff listen carefully to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

7. In the last 3 months, how often did the dialysis center staff explain things in a way that was easy for you to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

8. In the last 3 months, how often did the dialysis center staff show respect for what you had to say?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

9. In the last 3 months, how often did the dialysis center staff spend enough time with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

10. In the last 3 months, how often did you feel the dialysis center staff really cared about you as a person?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

11. In the last 3 months, how often did dialysis center staff make you as comfortable as possible during dialysis?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

12. In the last 3 months, did dialysis center staff keep information about you and your health as private as possible from other patients?

1☐ Yes
2☐ No

13. In the last 3 months, did you feel comfortable asking the dialysis center staff everything you wanted about dialysis care?

1☐ Yes
2☐ No

14. In the last 3 months, how often did dialysis center staff check you as closely as you wanted while you were on the dialysis machine?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

15. In the last 3 months, did any problems occur during your dialysis?

1☐ Yes
2☐ No → **If No, Go to Question 17**

16. In the last 3 months, how often was the dialysis center staff able to manage problems during your dialysis?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Please remember that for these questions, dialysis center staff does <u>not</u> include doctors. Dialysis center staff means nurses, technicians, dietitians, and social workers at this dialysis center.

17. In the last 3 months, did dialysis center staff talk to you about what you should eat and drink?

1☐ Yes
2☐ No

18. In the last 3 months, how often did dialysis center staff explain blood test results in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

19. Has dialysis center staff ever told you what to do if you experience a health problem at home?

1☐ Yes
2☐ No

The Dialysis Center

20. In the last 3 months, when you arrived on time, how often did you get put on the dialysis machine within 15 minutes of your appointment or shift time?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

21. In the last 3 months, how often was the dialysis center as clean as it could be?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Treatment

The next few questions ask about your care in the last 12 months. As you answer these questions, think only about your experience at [FACILITY NAME], even if you have not been receiving care there for the entire 12 months.

22. You can treat kidney disease with dialysis at a center, or kidney transplant, or with peritoneal dialysis. In the last 12 months, did your kidney doctors or dialysis center staff talk to you as much as you wanted about which treatment is right for you?

1☐ Yes
2☐ No

23. Are you eligible for a kidney transplant?

1☐ Yes → **If Yes, Go to Question 25**
2☐ No
3☐ I don't know → **If Don't Know, Go to Question 25**

24. In the last 12 months, has a doctor or dialysis center staff explained to you why you are not eligible for a kidney transplant?

1☐ Yes
2☐ No

25. In the last 12 months, were you as involved as much as you wanted in choosing the treatment for kidney disease that is right for you?

1☐ Yes
2☐ No

26. In the last 12 months, were you ever unhappy with the care you received at the dialysis center or from your kidney doctors?

1☐ Yes
2☐ No → **If No, don't respond to 27 & 28**

27. In the last 12 months, did you ever talk to someone on the dialysis center staff about this?

[1]☐ Yes
[2]☐ No → **If No, don't respond to 28**

28. In the last 12 months, how often were you satisfied with the way they handled these problems?

[1]☐ Never
[2]☐ Sometimes
[3]☐ Usually
[4]☐ Always

29. What is your view on the care received from doctors in the dialysis unit?

……..

30. What is your view on the care received from staff (nurses, nutritionists) in the dialysis unit?

……..

31. Do you feel adequately informed about your current condition and the treatment you are undergoing?

Yes □ **No** □ **I don't know** □

32. In terms of the care you receive for hemodialysis, what do you feel is the aspect that needs to be improved the most? What improvement would you want to be made?

……..

Thank you for your participation.

APPENDIX IV: IN-DEPTH INTERVIEW GUIDE

I want to thank you for taking the time to meet with me today.

My name is Dr. Kariuki, and I would like to talk to you about your experiences in the provision of hemodialysis at this facility. Specifically, as one of the components of our overall program evaluation we are assessing program effectiveness in order to capture lessons that can be used in future interventions. The interview should take less than 20 minutes. I will be taping the session, as well as taking down some notes, because I don't want to miss any of your comments. Because we're on tape, please be sure to speak up so that we don't miss your comments. All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time. Are there any questions about what I have just explained?

Are you willing to participate in this interview? Yes □ No □

…….....

Interviewee Signature Date

1. What is your assigned role and duties in this dialysis unit?
2. How long have you been working in this unit?
3. What challenges do you experience in day to day care of patients on hemodialysis?
4. How do you overcome the challenges?
5. Do factors such as work shift hours, patient burden and working conditions affect the quality of care you provide to hemodialysis patients? If so, how?
6. In your opinion what gaps exist in the care of individuals undergoing hemodialysis?
7. What measures would you like put in place to improve the quality of care given to patients on hemodialysis at this facility?
8. Is there anything more you would like to add?

I'll be analyzing the information you and others gave me and submitting a draft report to the organization in two months. I'll be happy to send you a copy to review at that time, if you are interested.

Thank you for your time

APPENDIX V: CHECKLIST FOR RESOURCE AVAILABILITY

Staff

Number of Doctors: ……

Number of Nurses: ……

Number of dialysis stations: ……

Number of operational machines ……

Number of chronic patients: ……

Staff to patient ratio: ……

No. on 3 sessions/week: ……

No. on 2 sessions/week: ……

Vascular access (number)

AV Fistula: ……

Grafts: ……

Catheters: ……

Auxiliary facilities

Water assessment report ……

Facility for Chronic HBV patients Yes □ No □

Transplantation

Number on waiting list ……...

Number of transplants ……