PATHWAYS TO MENTAL HEALTH CARE, BARRIERS AND MANAGEMENT EXPERIENCES OF ADULTS LIVING WITH MENTAL ILLNESS IN KENYA

By

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DECLARATION

I declare that this dissertation is my original work and that it has not been submitted to any other
university.
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ACKNOWLEDGEMENT

I want to first and foremost thank my Lord for enabling me to complete this thesis. I would also like to acknowledge my supervisors Prof. Othieno and Prof. Mathai for their guidance in completing this thesis. Thank you.

DEDICATION

I want to dedicate this thesis to my late loving father Dominic Mwongela and my mother; Regina Mwongela. They inspire me to work hard. I also want to dedicate this thesis to my son Ethan.

APPROVAL

This thesis has been completed and reviewed under our supervision as University of Nairobi, Department of Psychiatry lecturers.

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LIST OF ABBREVIATIONS

KNH/UON ERC Kenyatta National Hospital/ University of Nairobi Ethics Research

Committee

WHO World Health Organization

OPERATIONAL DEFINITIONS

- 1. A traditional healer in this study will refer to one who uses powers passed down from one healer to treat various illnesses many of which are psychological underpinnings.
- 2. A herbalist in this study will refer to one who uses herbal medicine in treatment of mental illness.
- 3. A faith healer in this study will refer to one who uses spiritual powers in treatment of mental illness.

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1.0 CHAPTER ONE: INTRODUCTION

1.1. Background Information

Persons living with mental illness seek different pathways in accessing mental health care and experience different alternative—forms of management. The pathways can be broadly categorized as biomedical care and alternative care. The alternative—pathways include traditional healers, witch doctors, herbalists and religious healers among others. The choice of care mostly depends on the family's perceptions of the cause of the illness. If they feel the cause is witchcraft they seek care from a traditional healer or a witch doctor (Kisa et al., 2016). In Sub-Saharan Africa—the traditional healers and religious healers compete with the biomedical Mental Health Care (Ikwuka et al., 2016).

The pathways accessed in seeking mental health care most of the time depend on sociocultural and economic factors (Patel, Simunyu, & Gwanzura, 1997). Persons living with mental illnesses face difficulties and barriers which delay their treatment and most of the time lengthen the duration of the illness (Sorketti, Zuraida, & Habil, 2013;Ikwuka et al., 2016). The difficulties faced are multifactorial and include systemic, familial, cultural and individual factors. Some of them include, lack of awareness, economic burden, delay in family decision to seek care, myths and misconceptions regarding mental health problems, social stigma and discrimination, lack of social support, poverty, unwillingness of patients to take prescribed medicine (Kisa et al., 2016).

Research has shown that different communities of the world use different pathways. In the western world most persons with mental illness seek biomedical mental health care services while in African settings alternative care services are more likely to be sought (Sorketti et al., 2013). Global studies have also shown variations across countries which have been attributed to

differences in socio-cultural, religious and health care service contexts. The situation in Africa also depicts the variation as people with severe mental illness are more likely to seek alternative care as shown in Ethiopia but people with mental illness in Liberia, Uganda and Ghana are likely to first seek biomedical mental health care (Ibrahim, Hor, Bahar, Dwomoh, McKay, Esena, & Agyeponge, 2016a; Kisa et al., 2016). In Kenya, one study has been published that shows that people with mental illness are more likely to seek care in general hospitals before seeking care in mental health facilities (Guthua 2016). Also, an individual's ethnic background has been reported to influence decisions about whether and how to seek help as well as the array of services and supports that are available to the patient throughout the help- seeking process. Ethnicity has an impact on illness models and consequently care pathways (Henry Effiong & Kufre Albert, 2015). Education as well, has a mixed impact on pathway preferred to seek mental health care as educated people living with mental illness in Ghana are more likely to seek alternative non-biomedical care than biomedical mental health care (Ibrahim, Hor, Bahar, Dwomoh, McKay, Esena, & Agyeponge, 2016b).

1.2. Problem Statement

There is a treatment gap for people with mental illness. Access to care for mental disorders is inadequate for about 80% of people in low and middle income countries(Kisa et al., 2016)

Research findings have been mixed with regards to pathways sought and barriers to biomedical care and experiences in alternative care. These mixed findings do not favor an informed strategy in bridging the gap in access to biomedical care by persons living with mental illness.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Pathways to mental health care in this study refer to the avenues or facilities in which people living with mental illness seek care before seeking care in a psychiatric facility such as a mental hospital. Studies have documented that people living with mental illness tend to first seek care in alternative facilities where they are attended to by herbalists, witchdoctors and faith healers among other alternative care facilitators(Henry Effiong & Kufre Albert, 2015; Ibrahim, Hor, Bahar, Dwomoh, McKay, Esena, & Agyepong, 2016). These alternative care facilitators tend to use diverse management protocols which have been understudied. Indeed some studies have shown that some patients gained symptom remission after visiting these alternative care facilitators. However, some patients did not gain relief and their symptoms tends to grow in severity as documented in the case of schizophrenia (Henry Effiong & Kufre Albert, 2015). In sub-Saharan Africa, biomedical and alternative mental health care tend to be competing services with varying differential factors governing access and management. In Kenya, people with mental illness do seek alternative care before seeking biomedical care in mental health facilities. However, their experiences in alternative care have not been closely studied.

2.1 Pathways to Mental Health Care

2.1.1 Global Perspective

As much as countries outside Africa would be said to have high preferential rates for biomedical care, the situation is different in countries such as Nepal. In a study done in Nepal that involved patients living with mental illness as well as health workers and policy makers, traditional healers were preferred compared to biomedical care practitioners (Kisa et al., 2016). However,

the study participants reported that there were no biomedical care facilities that were near their community. Only the wealthy people could afford to travel outside the community or country and seek biomedical care treatment.

2.2.2 Africa Perspective

Studies conducted in Africa tend to vary in terms of care facilitators first contacted by people living with mental illness. While in some countries mental health specialists in biomedical care were first contacted by majority of people living with mental illness, in other countries the initial contact was with an alternative care practitioner (Henry Effiong & Kufre Albert, 2015; Patel et al., 1997).

In Nigeria, 76.8% of patients diagnosed with schizophrenia in Uyo Teaching and Referral Hospital had first been in contact with religious and traditional healers before seeking care at the hospital (Henry Effiong & Kufre Albert, 2015). The situation in Ghana was closely similar though not that high as 48% of patients with mental illness were likely to have first contacted either traditional healers, faith healers or general physicians (Ibrahim, Hor, Bahar, Dwomoh, McKay, Esena, & Agyepong, 2016). This means that a higher percentage had a mental health specialist as their first point of contact. This was also reflected in a study in Uganda and Liberia where a majority of people living with mental illness as well as people whose work is based on mental health preferred hospitals as opposed to alternative mental health care (Kisa et al., 2016). However, in Zimbabwe, though the first point of contact for people living with mental illness was biomedical practitioners, these people tended to consult traditional healers later when symptoms did not subside (Patel et al., 1997). In this study, three quarters of the respondents who had a previous consultation had had contact with both biomedical and traditional mental health care providers. It is important to understand the dynamics that would bring about differences in

who is sort first for mental health care and why in a bid to increase access to biomedical mental health care. As shown in the Ghana and Nigeria case, African countries do depict differences in pathways to mental health care hence there is likelihood that Kenya may present a different orientation to the pathway sort for mental health care.

2.1.3 Local perspective

Traditional healers are consulted for mental health and are able to recognize some of the mental disorders especially those relating to psychosis(Mbwayo, Ndetei, Mutiso, & Khasakhala, 2013).

2.2 Management Experiences in alternative Care

2.2.1 Global Perspective

Cultural beliefs are strongly held and used as indicators of places to seek treatment as shown in the study done in Nepal. The cultural beliefs are also used to deduce the cause of the illness consequently indicating who is best placed to manage the condition. If the cause is witchcraft, then a traditional healer is sort who in turn gives local medicines. In cases where the person is believed to have demons, then spiritual treatment in terms of prayers is sort from the church (Kisa et al., 2016).

2.2.2 Africa Perspective

Medication was the prevalent mode of management in health facilities in Uganda and Liberia with the health facilities in Liberia citing lack of a diverse range of medication hence preferring Diazepam (Kisa et al., 2016). In Zimbabwe, however, injectable drugs and other oral treatment were mostly prescribed by general physicians though they were not specific to the mental problem diagnosis (Patel et al., 1997). Traditional healers in Zimbabwe gave spiritual explanations for causes of mental illness and gave spiritual management options. In Nigeria,

people living with schizophrenia were likely to have negative symptoms (p<0.001) and were seeking services of traditional and religious healers (Henry Effiong & Kufre Albert, 2015). These schizophrenia patients tended to have more contacts with the alternative care practitioners than contacts made ones they sort biomedical care (p=0.02). It is important to find out why the patient continued to seek care in the alternative care despite not gaining relief and what ultimately led to seeking biomedical care. In Nigeria, one of the reasons for seeking alternative care was due to the distance from the home area to a facility with specialized mental health care (Ikwuka et al., 2016). Understanding this help seeking behaviors will aid in awareness programs bent on increasing access to biomedical care. A common argument would be awareness. A study done in Uganda and Liberia showed that awareness as a barrier in terms of knowledge that mental illness is a health condition that can be treated in a health facility and awareness in terms of where the mental health biomedical facilities are located (Kisa et al., 2016). However, awareness may not be a standalone reason as a study done in Ghana showed people living with mental illness who had secondary education were less likely to seek biomedical mental health care than people without any form of education (uOR = 0.86; 95 % CI 0.18-4.08) (Ibrahim, Hor, Bahar, Dwomoh, McKay, Esena, & Agyepong, 2016). In Nigeria, the reality on the ground was that majority of people living with mental illness were more likely to seek mental health care from religious and traditional healers. However, when a non-clinical sample in the same county was interviewed on the same, 90.8% of them reported that they would seek care from a biomedical facility (Ikwuka et al., 2016). A majority of the respondents who supported this option were highly educated. However, the tables seemed to tip when spiritual was a consideration as Protestants were more likely to seek a spiritual form of healing than Catholics. Deep seated beliefs on what would work seem to tip the scales at the expense of awareness and

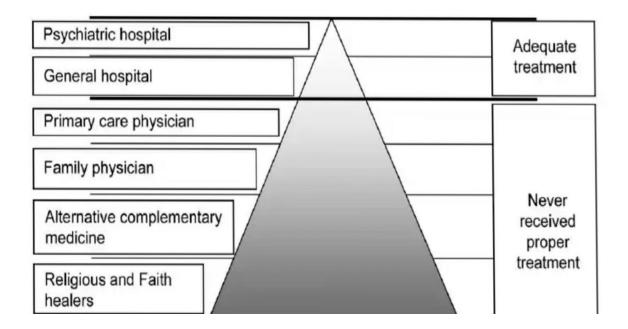
knowledge. In a study done across Uganda, Liberia and Nepal, respondents reported that they tended to be guided by beliefs (Kisa et al., 2016). A similar study in Zimbabwe found that the spiritual explanations that traditional healers gave for mental symptoms presentation won over the people living with mental illness (Patel et al., 1997). This is because they would consult traditional healers after their symptoms not remitting on consulting biomedical practitioners. Occupation is also significantly associated with path sort for mental health care as shown in a study done in Ghana ($\chi 2 = 6.91$; p < 0.033) (Roberts et al., 2014). Help seeking behavior tends to vary across certain socio demographic factors such as education, cultural beliefs and religion as shown in these studies though we are yet to study the Kenyan situation as keenly as the Ghana and Nigeria one. In understanding the Kenyan management trend, we can be able to attend to any social desirability bias and integrate mental health care systems that increase access to biomedical care and improve management outcomes.

2.2.3 Local perspective

In Kenya, individuals with mental illness admitted at Mathari National and Referral hospital were more likely to source treatment from general hospitals with medications being the prevalent form of management (Guthua, 2016).

2.3 Conceptual Framework

2.4 Theoretical Framework



Pyramid showing mental health care pathways in developing countries. It was developed as a result of a systematic review on psychiatric disorders and the outcomes of treatment sort from different care providers(Math & Srinivasaraju, 2010). As shown, treatment outcomes are inadequate when care is sort from non-specialists.

2.5 Rationale/Justification

There is little literature on studies done on pathways to mental health care services by persons living with mental illness within mental health facilities in Kenya. Moreover, studies done in Africa have shown mixed results as mentally ill persons from different countries may either first approach an alternative care setting or a biomedical one. Therefore there is need to research further on the topic and truly depict the Kenyan situation, more so since there is still a low rate of access to biomedical mental healthcare. Most studies done in Kenya were conducted

in a community setting whereas in this study the research will be conducted in a hospital setting. A few studies have been done in a Kenyan hospital setting but they fell short of depicting the management experiences and barriers in alternative care settings (Mbwayo et al.,2013 & Guthua, 2016).

2.6 Significance of the Study

This study will hopefully be of use in planning location of intervention sites and forms of treatment to be availed for people living with mental illness as it will depict the areas mentally ill persons are likely to first seek help and in what condition and for what reasons. Moreover, this study will show the underlying psychosocial factors that make patients first seek management in non-biomedical facilities as well as the forms of treatment they received and their experiences while in the care of non-biomedical care facilitators. In addition, the study findings may help policy makers to determine gaps in access to alternative mental health services hence fill this gap and give quality services whether it is in terms of financing; extending mental health care from primary care to alternative facilities; awareness and linkage through community mental health workers; as well as human resources such as clinical psychiatric officers among other necessities.

2.7 Study Question

What are the pathways to mental health care services, barriers and management experiences by persons living with mental illness aged 18 years and above before seeking biomedical mental health care in Machakos level 5 Hospital?

2.8 Objectives

2.8.1 Main Objective

To explore the mental health care pathways, barriers and experiences faced by persons living with mental illness aged 18 years before seeking biomedical Mental Health care in Machakos level 5 Hospital.

2.8.2 Specific Objectives

- To explore the barriers experienced by persons living with mental illness when seeking mental health care.
- 2. To explore patient's subjective experiences on management in both alternative and biomedical care.
- 3. To explore the different types of management offered to patients in alternative care settings.
- 4. To find out the places that patients with mental illness go to seek mental health care before seeking biomedical care.

CHAPTER THREE: METHODOLOGY

3.1 Study Design

This was a Qualitative Explorative study where the pathways, barriers and management experiences that people with mental illnesses go through before seeking biomedical mental health care will be studied.

3.2 Study Area

This study was conducted at Machakos level 5 Hospital which is located at Machakos County. The hospital has a general bed capacity of 500. The site was appropriate because the hospital has a mental ward with a bed capacity of 40. The mental unit serves as a referral center for patients with mental illness from other parts of the Machakos County.

3.3 Study Population

The study population were patients with mental illness attending Machakos level 5 Hospital's Psychiatric Unit and their care givers.

3.4 Exclusion and Inclusion Criteria

3.4.1 Inclusion Criteria

- Patients aged 18 years and above with a mental illness
- Patients able to give informed consent and information.
- Caregivers of patients for patients that were not stable enough to participate in the study(determined through a mental status examination)

3.4.2 Exclusion Criteria

- Patients that are not mentally ill
- Unstable mentally ill patient with no caregiver present

3.5 Sample Size Determination

The researcher interviewed 24 participants. Theoretical saturation was the basis of this study's sample size determination. As interviews were being conducted by the researcher, partial analysis of themes arising from the interviewees sentiments and experiences was continuously done. By the time the 24th respondent was interviewed, no new concept or linkage between concepts could be further established. None of the concepts established remained hypothetical and hence it was concluded that a point of saturation had been reached. As Moore (2002) posits studies show that there is a diminishing return to a qualitative sample as the study goes on that does not necessarily lead to more information(Mason, 2000)

3.5 Sampling Method

Patients being managed for different mental disorders at the Machakos level 5 Hospital mental unit and meet criteria were selected using a purposive sampling method. The participants were purposely selected depending on their capability to give information.

3.6 Data Collection Instruments/ Tool

A researcher designed questionnaire was used and it included socio- demographic factors such as age, gender, social economic status, religion, occupation, marital status, amount of fare used to reach the hospital as well as level of education among other variables.

A modified guide of the WHO Encounter form was also adapted for the interviews. The form was originally created to look at the number of mentally ill patients who seek care in psychiatric facilities. The researcher ensured that the form met the study objectives when it comes to exploring the management undertaken at the alternative care facilities as well as the experiences the patients had while in the facility.

3.7 Recruitment and Data Collection Procedure

Study participants were recruited from patients receiving management for different mental disorders at the Machakos level 5 psychiatric ward.

The study participants were recruited using purposive sampling method. In both the wards and in the clinics patient's files were used to find out the first admission or visit to the facility as well as the condition and severity of the condition they were first admitted with. This involved the nursing officer in charge to find out which patient was stable enough to participate in the study with regards to their ability to communicate coherently. For those who could not do so and had their caregiver present, the caregivers were interviewed instead.

Screening was done to determine whether they met the inclusion criteria. This included offering informed consent document with details of the study and given opportunity to ask any question they may have regarding the study.

The 24 study participants who met the criteria and were willing to participate in the study were asked to sign an informed consent form. The interview then commenced using questionnaires and an audio recorder with the help of the WHO 'pathway study' encounter form guide

3.8 Quality Assurance Procedures

- This research proposal was reviewed by the University Of Nairobi Department of
 Psychiatry and Kenyatta National Hospital Ethics and research committee which ensured
 that the proposal passes the quality threshold.
- The researcher received training on research methods and administration of the study
 questionnaires to be used at the University Of Nairobi and worked under the guidance of
 supervisors; Proffesor Caleb Othieno and Dr. Mathai from the University Of Nairobi
 Department of Psychiatry.
- 3. Emphasis was put on explaining the consent form to ensure that the study participants fully understood the questions being asked and what the study is about.
- 4. Results of research were presented formally to the University of Nairobi Department of psychiatry and Kenyatta National Hospital –University of Nairobi Ethics and Research committee for peer review, hence further ensuring high-quality research.

3.9 Data Management, Anticipated Analysis and Presentation

The data/ interview recorded were translated from Kiswahili and Kamba to English and transcribed. The data was then analyzed along predetermined themes using Atlas Ti 8 software for Qualitative analysis. The themes were determined through coding. The data was then presented in terms of themes which were supported by verbatim quotations which were basically extracts from the transcriptions.

3.10 Ethical Consideration

- Approval to carry out the study was requested from the University of Nairobi/ Kenyatta
 National Hospital Ethics Research Committee. Also, written authority and clearance was
 obtained from the Machakos county chief officer of health and Machakos level 5
 Hospital medical superintendent.
- 2. Participants were informed that participation in the study was voluntary and that the information obtained would be used only for the purpose of the study. Those who refused to participate or withdrew at any stage were not to be penalized and would continue to get treatment from Machakos level 5 Hospital.
- 3. Once the respondent agreed to participate in the study, they were taken to a quiet office which was provided by the hospital administration where the interview took place. First, Proper explanation of the study process and objectives and purpose of the study was given to all patients who are legible and were offered a chance to participate without coercion.
- 4. Confidentiality was observed. All information collected in this study was confidential.
 Serial numbers instead of names were used to ensure this confidentiality. Soft copies stored in computer systems that are password protected. Information obtained were recorded and stored in locked cabinets only accessible to the researcher.

3.11 Potential Benefits to Study Participants

The data from the study may help the patients and health workers to understand better the pathways and experiences faced by persons living with mental illness in accessing mental

health care services which can help in betterment of their treatment and close follow up at the clinic.

3.12 Potential Risks

There was no physical harm to the respondents that was anticipated from participation in the study. However, discussion of potentially sensitive topic was anticipated to probably make participants uncomfortable with relieving traumatic experiences in the past. In case of psychological distress, the study participants were offered psychological support. In cases where patients were overwhelmed emotionally while retelling their experiences they were referred to the hospitals counselor for counseling.

CHAPTER 4: FINDINGS

4.1 Introduction & Data Analysis Strategy

In this chapter; summative content qualitative analysis of the collected data has been represented as per the specific objectives which were to explore the different types of management offered to patients in alternative care settings, to find out the places that patients with mental illness go to seek mental health care before seeking biomedical care, to explore the barriers experienced by persons living with mental illness when seeking mental health care and finally to explore patient's subjective experiences on management in both alternative and biomedical care. This chapter basically entails the exploration of themes underlying respondents' sentiments on key issues being investigated. After transcription of in depth interviews was undertaken; transcripts were then coded as per the emerging themes in the study. This involved identifying of passages of text (verbatim quotations) that helped create a framework of thematic ideas during analysis by Atlas Ti 8 software.

4.2 Socio-Demographic Profile of the Respondents

The study first sort to determine the socio-demographic profile of the respondents in this study and as shown in the summary frequency Table 4.1; the gender of the respondents was equally distributed with both male and females being 12 in number. Most of the respondents were between the ages of 30 years and 39 years. As for whether the respondents were married, single, separated or divorced; 12 respondents were single followed by the ones who were married. The study also sought to find out the highest level of education that the respondents had attained and it was noted that majority of the respondents 12 had only managed to undergo primary education.

Only 1 respondent had managed to reach tertiary level of education. Finally, all the respondents were Christians.

Table 4.1: Summary of Socio-Demographic Profile of the Respondents

Frequency		Frequency
	Marital Status	
12	Single	12
12	Married	7
	Separated	3
	Divorced	1
1	Separated	3
5	1	
9	Religion	
4	Christians	24
3	Others	0
2		
1	Secondary	10
12	T. college/ university	1
	12 1 5 9 4 3 2	12 Single 12 Married Separated Divorced 1 Separated 5 9 Religion 4 Christians 3 Others 2

4.3 First Visits for Seeking Treatment For Mental Illness

4.3.1 Biomedical Care

The respondents were asked where else they had sought for treatment before coming to the hospital and it was established that most of the respondents actually did not seek alternative treatment as a first resort and instead they preferred going to the hospital for biomedical treatment. Actually 13 respondents indicated this. 11 of the respondents indicated that they sought alternative treatment by going for prayers and being taken to traditional healers. 6 respondents indicated that they had been taken for prayers. Only 5 out of the 24 respondents had been taken to traditional healers. It's important to indicate that two respondents indicated that they went for prayers as they sought biomedical treatment too.

As illustrated in the verbatim quotations sampled, it is clear that the emergent theme is "preference towards biomedical treatment for mental illness". It is illustrated that biomedical treatment whether sought through one's own volition or persuasion from individuals, was the preferred choice. The first quotation illustrates that the patient himself first of all sought treatment at a small dispensary on his own and from there he was later referred to Machakos level 5 hospital. A few respondents indicated the same experience as this respondent for example caregiver interview 5 in these extracts. The second verbatim quotation shows that the respondents' wife decided that he was to be taken to hospital and nowhere else to seek treatment, a sentiment he shared. Though self awareness of the respondent could be put into question at the particular point of decision making well before treatment, the obvious conclusion is that biomedical treatment was preferred. The third extract clearly illustrates a father's struggle to get treatment for his son which he started from Kakamega hospital to Agakhan and finally ended up at Machakos Level 5. At no time did the parent seek alternative care for the mental illness the son suffered from. This is also illustrated in other interviews. Finally in the final interview, the respondent was forced to seek biomedical treatment by the courts and was admitted at Mathari and later referred to Machakos Level 5 hospital. Since the treatment was working, they never sought alternative treatment. It is also important to note that all the respondents finally ended seeking bio-medical treatment despite other having sought for alternative treatment initially. The emergent theme are best illustrated by these verbatim quotations:

"Personally, I didn't go anywhere else, I just went to hospital only in Mitamboni and then I was written for a letter to come here"...P_Interview 3(56yr old, married male Patient _pg. 3)

"when I was sick, I wasn't taken to another place, I wasn't taken for prayers anywhere else, people from our home said that I should be taken to hospital and that's how I was taken to hospital. I wasn't taken for treatment elsewhere. we never went to look for treatment elsewhere, me and my wife decided that I should come to hospital, so I came to hospital..." P_ Interview

4(44yr old, married male Patient) _pg. 1

"I was referred here by...when we went to Kakamega hospital he was treated, we came this way. when we came here, we came to...I took him to Agakhan mission hospital. In Agakhan, he was treated, now...when I came to Machakos, I came here and found Dr. Wazome and Dr. Wazome treated him and understood his problem, now he is so much better ..." Caregiver_Interview5

(53yr old, married male, the father to the Patient) _pg. 2

"but, eeh...we went to some other place called Kisau health clinic, Kathiani and we saw that he was not getting any help from there and therefore we decided we go further ahead..."

Caregiver_Interview 5(53yr old, married male, the father to the Patient)_pg. 2

"at that time, he destroyed the neighbours property and he was caught and prosecuted and when he was brought by the police, the court saw that he had a mental problem and so he was referred to Mathari..." Caregiver_Interview 11(63yr old, married male, the Brother to the Patient)_pg.

3

4.3.2 Traditional Healers

Despite the fact that the emergent theme is preference towards the biomedical management of mental illness, other pathways were also identified to manage mental illness by the patients. The following verbatim quotations illustrate the respondent's choices to seek alternative mental illness treatment; particularly traditional healing methods:

"when Beth started being sick, we took her to a traditional healer and we saw that we were not getting help and instead she continued being affected by her illness until we decided to come here and when we came here she had even been tied using ropes because she had become very very ill ..." Caregiver_Interview 7(68yr old, married female, the sister to the 63yr old female Patient) pg. 2

"Previously, we used to seek for help from traditional healers but it was dead, we never got anything..." Caregiver_Interview 10(59yr old, separated female, the mother to a 33 year old male Patient)_pg. 3

"I went to the traditional healers" "I was taken there because I was not even self aware. so I was taken there..." Patient_Interview 16(33yr old, female Patient)__pg. 4

"I took Martin to two traditional doctors back then ..." Caregiver_Interview 18(69yr old, widowed female, the mother to the 35year old male Patient) ___pg. 4

"I was taken to the traditional doctor and I said..." Patient_ Interview 20(41yr old, widowed female Patient)_pg. 3

These five extracts clearly illustrate that the respondents were taken to the traditional healers or witchdoctors by their relatives to seek for treatment when they were experiencing serious manifestation of their mental illness symptoms.

4.3.3 Prayers / Faith Healers

Other respondents sought prayers as treatment for their mental illnesses before seeking biomedical treatment. As mentioned earlier, they were slightly more than those that went to the traditional healer but nevertheless significant. One sub-emergent theme that was related to seeking prayers for treatment was "acceptance". Prayers seemed generally accepted and expected from these respondents especially considering the fact that they were all Christians.

"yes, being prayed for in the church, we have gone...every time she gets sick, I always take her to hospital and even when I met with this friend, she told me to go to hospital..." Caregiver_
Interview 9(35yr old, sister to 24yr old female Patient) pg. 3

"Yes, I went for prayers..." Patient_Interview 15(31yr old, Single female Patient)_pg. 3

"Yes we went to be prayed for..." Patient_Interview 17(53yr old, separated male Patient)_pg.

5

4.3.4 Culture Linked To Seeking Traditional Healers/ Faith Healers For Treatment

It is also important to note that seeking of bio- medical and traditional healers or faith healers was seemingly related to their understanding of what could have caused the mental illness. The other emergent theme based on their responses particularly among the respondents who sought traditional or faith healers first was *culture and belief system of the patients*. This is because of their ingrained belief that there is existence of and belief in evil spirits which is passed down from one generation to the next. Nearly all the caregivers who took their mentally ill relatives to the traditional healers or witchdoctor were convinced that the mental illness was caused by evil spirits and they were brought about by individuals who were evil.

Only one respondent believed that her sins against God brought about her mental illness. It was however interesting that she did not seek help from faith healers. On the other hand, the probability of getting a respondent that actually was brought up in the church also seeking prayers as a form of treatment and believing it worked or it helped in improving his/her condition was very high. These verbatim quotations illustrate these sentiments:

"(chuckles)...I was thinking that the child had been bewitched..." Caregiver_Interview 10(59yr old, separated female, the mother to a 33 year old male Patient)_pg. 3

"It was brought by sins...particular sins that I had committed against God..." Patient_
Interview 16(33yr old, female Patient)_pg. 4

"I think my son was wronged, I believe he was thrown for evil spirits while he was in school long time ago when he was in class 5 and that's why his illness started. This is because my son left home well and he was brought back very sick and since then her son has not been normal...

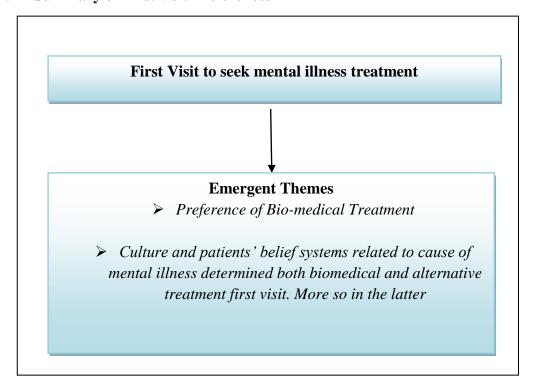
Caregiver_Interview 18(69yr old, widowed female, the mother to the 35year old male Patient)_pg. 3

"I don't know if it came from wherever I was married or what...But I believe so because after I got married things just started happening" Patient _ Interview 20(41yr old, widowed female Patient)_pg. 3

"It was just the family that decided to take me to the traditional healer and this is because they felt that I had suffered a lot from the bewitching that they felt had been done to me..." Patient_
Interview 15(31yr old, Single female Patient)_pg. 4

"Yes, being prayed for in the church, we have gone...every time she gets sick..." Patient_
Interview 15(31yr old, Single female Patient)_pg. 4

Table 4. 2: Summary of First visit Preferences



4.4 Patient's Subjective Experiences On Management in both Alternative and Biomedical Care

4.4.1 Experiences Related To Alternative Medical Care

An integral part of the study objective was to determine the subjective experiences of the respondents who sought treatment at alternative treatment places and biomedical care. So far the study has established that the respondents basically sought treatment at two alternatives places; at the churches and the traditional healers. As illustrated by the verbatim quotations from the transcripts; the emerging theme related to this objective was "overwhelming negative experiences". First and foremost, there was an overwhelming response of no improvement being clearly observed by patients and their caregivers specifically with reference to patients getting healed or better after being prayed for or treated by the traditional healers. Other negative experiences that were reported ranged from rejection and stigmatization and being harmed both physically, emotionally and socially because of seeking alternative treatment. Some of these sentiments were best illustrated by these verbatim quotations:

"where we went for treatment we didn't get any help but we used a lot of money as she was being treated by the traditional healer until we decided to come to hospital..." Caregiver_
Interview 7(68yr old, married female, the sister to the 63yr old female Patient)_pg. 2

"those herbs that she was given, didn't give her any problems and she used to take them, however, they didn't help her because she was not improving..." Caregiver_Interview 7(68yr old, married female, the sister to the 63yr old female Patient)_pg. 3

"first of all, we were prevented from getting into the church and many a times, people don't seem to understand us and they think that we are the ones with the problem, and that's its us who know her problems...they don't understand us completely. but those that understand us a little,

just pray. At long last, they just pray and we see that it reduces and continues to reduce..."

Caregiver_Interview 9(35yr old, sister to 24yr old female Patient)_pg. 4

"the experience we got from there was not good, the treatment that my son got was not the best and he was not improving even a little bit..." Caregiver_Interview 18(69yr old, widowed female, the mother to the 35year old male Patient) _pg. 3

"we were given many different things that I couldn't understand. I was to use them on my child for example things that I was supposed to put on him but they didn't help him and he also didn't receive any healing from those things and he didn't change. I also spent a lot of money, I sold my cows, my things so that I could take him to the traditional healer and he didn't get well..."

Caregiver_Interview 18(69yr old, widowed female, the mother to the 35year old male Patient)

_pg. 5

"and he said that I was a witch and so I bought traditional healers kamba clothes and set them on fire and I said that I was a Christian and that I didn't have any witchcraft and then when I went to my home, I went for prayers..." Caregiver_Interview 20(41yr old, widowed female Patient)_pg. 4

"I stopped seeing those things that I was seeing at night..." Patient_Interview 23(25yr old, married female, Patient)_pg. 4

"previously, we used to seek for help from traditional healers but it was dead, we never got anything..." Caregiver_Interview 10_pg. 3... "Yes, we lost 8 people..." Caregiver_Interview 10(59yr old, separated female, the mother to a 33 year old male Patient)_pg. 5

4.4.2 Experiences Related To Bio-Medical Care

Unlike the emerging theme related to alternative treatment care, the emergent theme related to bio-medical treatment was "positive experiences". There was an overwhelming response or a

general consensus on the better quality of treatment and actual visible results where the patients actually got better. There was also no report of stigmatization or refusal of treatment. These sentiments were shared by all the respondents except one respondent who was not sure where the positive results could be attributed to; the prayers or biomedical treatment and this was mainly because she went for both simultaneously.

"Even as we were coming to this hospital, we were also going to be prayed for and so we would be prayed for and then we would go to hospital and we were not seeing the difference between being prayed for and going to the hospital, it was like they were all the same..." Caregiver_
Interview 2(47yr old, female, the sister to a 41 year old female Patient)_pg. 3

Table 4. 3: Summary of Patient Subjective Experience on Management in Both

Treatment Setting

Patient's Subjective Experiences on Management in both Alternative and **Biomedical Care Emergent Themes (Biomedical) Emergent Themes (Alternative)** Overwhelming Positive Experiences Overwhelming Negative Experiences ✓ No improvement in ✓ Positive Results patients condition ✓ Better quality of ✓ Exposure to harmful treatment & actual visible results procedures ✓ No stigma ✓ Unnecessary procedures ✓ No denial of treatment ✓ Rejection when seeking treatment from faith healer

4.5 To Explore The Different Types Of Management Offered To Patients In Alternative Care Settings

The study also sought to find out the type of management that was offered to patients at alternative care settings. The emergent theme here was "presence of unorthodox treatment methods". The study findings show that generally, the traditional healers and witchdoctors used unorthodox treatment methods like making incisions on patients head and putting medicine. They also treated the relatives of the patients among other methods. They also used animals as they insisted they were critical for treatment. As for the faith healers it was noted that most of them just prayed and applied anointing oil on their patients and may be occasionally gave them some holy water to drink. Some of these observations were best illustrated by these verbatim quotations:

Wherever we were going to be prayed for, we were simply being prayed for and nothing else was given to us whether it was for application or for drinking...no...we were just prayed for...

Caregiver _ Interview 2(47yr old, female, the sister to a 41 year old female Patient)_pg. 3

"no, she was prayed for and applied anointing oil because they also thought that it was evil spirits..." Caregiver _ Interview 9(35yr old, sister to 24yr old female Patient)_pg. 5

"We didn't get any treatment; we were prayed for but didn't get any treatment and was not successful..." Patient _ Interview 17(53yr old, separated male Patient)_pg. 5

those herbs that she was given, didn't give her any problems and she used to take them, however, they didn't help her because she was not improving...Caregiver_Interview 7(68yr old, married female, the sister to the 63yr old female Patient)_pg.3

"but when they would enter the homestead, they would cleanse the homestead and evil spirits but he himself, he would run away..." Caregiver_Interview 10_pg.4. ... "goats used to be slaughtered..." Caregiver_Interview 10_pg.5... "and chicken used to be slaughtered..."

Caregiver_Interview 10_pg.5

"he gave me medicine...he made incisions on my stomach with a razor blade and there was blood..." Caregiver_Interview 10(59yr old, separated female, the mother to a 33 year old male Patient)_pg.5

These verbatim quotations from the interviews brought out the sub-emergent theme depicting lack of similarities between treatment methods. Clearly the prayer treatment method was quite simple unlike the traditional healer treatment method which varied from issuance of herbs to prayers for evil spirits and accusations of presence of the witchcraft trade as a cause of mental illness in patients. Clearly the experiences varied depending on whatever method the traditional healer chose to use. In biomedical treatment, the experience was straight forward, the respondents saw the clinicians and were treated with medicine and they actually felt better.

Table 4.4: Summary of Methods of Alternative Treatment

Emergent Theme		
Presence of unorthodox treatment methods		
Harmful Traditional Practices	Traditional Practices considered NOT	
	Harmful	
Cutting or Making Incisions on the body i.e.	Prayers from faith healers	
head by Traditional healer		
Giving the relatives medicines to help the	Being given holy water to drink	
Patient while the individual is not sick		
Use of animals for cleansing by the traditional	Application of anointing oil by the faith healers	
or witch doctors		

4.6 The Barriers Experienced By Persons Living With Mental Illness When Seeking Mental Health Care

4.6.1 Poor Socio-Economic Status

With regards to the barriers that are faced by persons living with mental illness when seeking treatment; the emergent theme was poor socio-economic status. There was an overwhelming response indicating that money or finances was the biggest challenge the patients and their families faced. The cost for seeking treatment was mostly related to the bus fares they used to reach the hospital and the money they paid to obtain the medicine that they were given in the hospital. As for those respondents who were first taken to traditional healers, they indicated that they used considerable amounts of money and wealth to get treatment and never really saw any improvement. As for prayers, most of the respondents indicated that they did not spend money at all while seeking to be prayed for and instead the would only offer a token to the pastor as thanks giving. These sentiments are clearly shown in these verbatim quotations below...

"the other challenge I was getting was coming from Mwala to Machakos; the fare. The fare that I need to come and go back was a real challenge..." Patient_Interview 1(26yr old, single male

"we were given many different things that I couldn't understand. I was to use them on my child for example things that I was supposed to put on him but they didn't help him and he also didn't receive any healing from those things and he didn't change. I also spent a lot of money, I sold my cows, my things so that I could take him to the traditional healer and he didn't get well..."..."

Patient)_pg.5

Caregiver _Interview 10(59yr old, separated female, the mother to a 33 year old male Patient)_pg.3

4.6.2 Stigmatization

One of the sub emergent themes was stigmatization. Stigmatization was mentioned as a major challenge because some respondents were rejected by the church and society because of their mental illnesses or as a consequence of visiting a traditional healer or witchdoctor. This verbatim quotation illustrates this sentiment:

"for example the last Saturday, there were prayers and we were prohibited from entering the church...it is true...yes, true...until it reached a point when she ran away and went to the pulpit where they had to pray for her and after being prayed for, we were told to go back the same way we came..." Caregiver_Interview 9(35yr old, sister to 24yr old female Patient)_pg 4 & 5

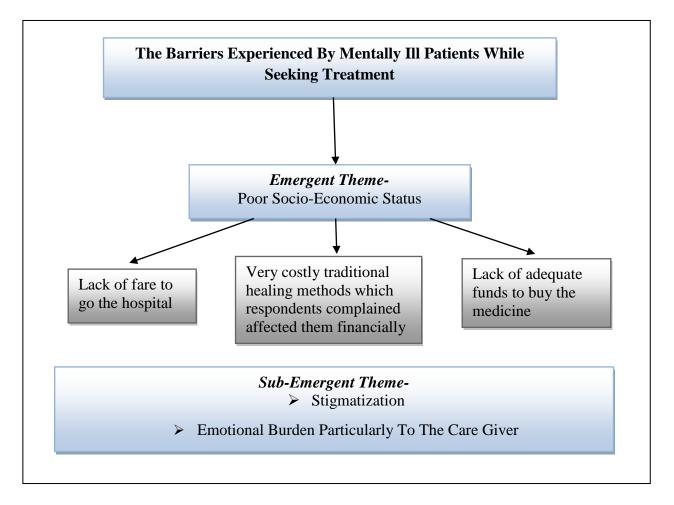
4.6.3 Emotional Burden

Another sub-emergent theme was emotional burden especially of the caregivers. The challenge that the respondents reported was emotional burden they faced and particularly when related to caring for the mentally ill patient. These also included their view on how the society rejects them and associate the illness with evil. One respondent said,

"I have also had emotional problems because my son has stayed ill for a long time and I also have sadness that when I am no longer there, I don't know who will take care of my son and that really makes feel anguish in my heart...I have received a lot of help from the hospital compared to where I had gone to the traditional healers..." Patient_Interview 1(26yr old, single male

Patient)___pg.5





CHAPTER 5:DISCUSSION, CONCLUSION AND RECCOMENDATION

5.1 Discussion

5.1.1 Places That Patients with Mental Illness Go To Seek Mental Health Care before Seeking Biomedical Care

The study established that most of the respondents basically preferred biomedical treatment given at the hospital however; quite a number of respondents also sought treatment from faith healers who were mostly religious leaders from the respondents' regular churches and also from the traditional healers and witchdoctors establishments. Similar results have been reported in studies done in Africa; for example in studies done in South Africa to determine the level of involvement of traditional healers in the treatment of common mental disorders, it was established that 18 percent of respondents with mental illness actually sort biomedical treatment while only 4 percent of the respondents actually went to be helped by traditional healers exclusively. It was however noted by the researchers that most of the mentally ill patients actually never sought for treatment from any place. Hence their health seeking behavior was notably poor. The study also notes that there were those who sought treatment from both places; the biomedical and alternative treatments (Sorsdahl, et al., 2009). A study done in Tanzania also showed that more of the mentally ill patients actually sought biomedical treatment. The researchers attributed their choice of treatment to the progression in Education and improved knowledge on mental health and treatment (Ngoma & Prince, 2003). Studies done in Liberia, Uganda and Ghana also indicated that mentally ill patients were more likely to first seek biomedical mental health care (Ibrahim, Hor, Bahar, Dwomoh, McKay, Esena, & Agyeponge, 2016; Kisa et al., 2016).

Contrary to this current study which was carried out in a hospital, it has been noted that more mentally ill patients stemming from Africa actually embrace traditional healers which in this case also includes faith healers who combine their cultural belief and religion. For instance in a study done in two districts in Eastern Uganda in 2011 to determine the profiles and outcomes of traditional healing practices for severe mental illnesses, it was established that over 80 percent of the respondents who were involved in the study actually went to traditional healers before going to the hospital for biomedical treatment (Abbo, 2011). Another study conducted in Ghana reported that only 6% of patients consulted a traditional healer prior to presenting themselves to mental health care services (Appiah- Poku et al., 2004) Previous studies done in South Africa also indicate that most of the mentally ill patients or at least almost half them had been to a traditional healer for alternative treatment (Freeman et al., 1994; Ensink and Robertson, 1999) Finally to further contextualize the study findings, in a study that was conducted in Kenya to determine the complementary role of traditional and faith healers and whether there could be a potential liaison with biomedical mental health services in Kenya; it was found that their roles were accepted and appreciated by communities (Mbwayo, Ndetei, Mutiso, & Khasakhala, 2013). Basically most individuals sought help from them and reported significant improvement hence they were considered complimentary to biomedical treatment. This particular study reveals different results contrary to the ones stated but nevertheless it has been further supported by Math & Srinivasaraju (2010), who stated that treatment outcomes for mentally illness are inadequate when care is sought from non-specialists.

5.1.2 Patient's Subjective Experiences On Management In Both Alternative And Biomedical Care

The study determined that the respondents only sought alternative treatment at two places; the church and at the traditional healers. Contrary to published studies especially those done in Africa, this particular study revealed that no improvement was witnessed after seeking help at these alternative care facilities. Respondents describe a difficult search for treatment that could actually help with some describing the incidents as upsetting because they caused negative experiences ranging from rejection and stigmatization and being harmed both physically, emotionally and socially. Unlike other studies which imply that there are similarities between faith healers and traditional healers with regards to methods employed during treatment (Mbwayo, Ndetei, Mutiso, & Khasakhala, 2013). This current study shows no similarities between the two methods where one involved normal prayers and application of anointing oil and drinking of holy water done by pastors and the other involved incisions and application of herbs or treatment of relatives or even performing cleansing homes rituals to chase away evil spirits by traditional healers and witchdoctors. Again, contrary to other studies that indicate that faith healers and traditional healers play a complementary role to bio-medical treatment, this current study brought out the notion that faith healers were more accepted as opposed to traditional healers and witch doctors a factor that should be further explored. Finally negative experiences ranging from rejection and stigmatization and being harmed physically, emotionally and socially because of seeking alternative treatment were also expressed. Though a study done on traditional healers which in this case also included faith healers, it was established that even though they participated significantly in the management of mental illness, they did cause harm to their patients. (Vikram, 2011).

5.1.3 Types of management offered to patients in alternative care settings.

The study revealed that generally, the traditional healers and witch doctors used unorthodox treatment methods like making incisions on patients head and putting medicine. They also treated the relatives of the patients among other methods. They also used animals as they insisted they were critical for treatment. As for the faith healers it was noted that most of them just prayed and applied anointing oil on their patients and may be occasionally gave patients some holy water to drink. As earlier mentioned and unlike other studies, they did not offer more or less the same treatment methods. The traditional healers methods in this study were not particularly complimentary to the biomedical treatment and were notably not helpful. On the other hand most patients considered going for prayers very helpful in their healing process.

In a study that was conducted in Nigeria however, it was noted that the traditional healers' methods were complimentary to bio-medical treatment and the 80 percent of the patients that actually sought their help and also went for bio-medical method of managing mental illness actually showed significant improvement after treatment (Abbo, 2011). However, this conclusion begs the question; which treatment method actually worked for the patient to exhibit overall improvement? Our current study is more objective with this regard as it ways outcome independently and based on patients subjective experiences prior to seeking bio-medical help.

5.1.4 The Barriers Experienced By Persons Living With Mental Illness When Seeking Mental Health Care

With regards to the barriers that are faced by persons living with mental illness when seeking treatment; there was an overwhelming response indicating that money or finances were the biggest challenge the patients and their families faced. These were mostly related to fares they

used to reach the hospital and the money they paid to obtain the medicine that they were given in the hospital. As for those respondents who were first taken to traditional healers and witchdoctors indicated that they used considerable amounts of money to get treatment.

It was also noted that the distance to the hospital was also challenge that could not be ignored. This was concluded from the cost of transport incurred by most respondents. Most of them seem to spend quite a bit of fare to get to the hospital. Stigmatization was also mentioned as a major challenge because some respondents were rejected by the church and society because of their mental illnesses or as a consequence of visiting a traditional healer or witchdoctor. This was also related to the emotional burden that the patients and especially because of dealing with caring for a mentally ill patient. Other studies have also shown similar results indicating that financial burden and stigma are a major concern for mentally ill patients and their relatives (Ramin, 2005).

5.2 Conclusion

The research question of the study was; what are the pathways to mental health care services, barriers and management experiences—by persons living with mental illness aged 18 years and above before seeking biomedical mental health care in Machakos level 5 Hospital? According to the findings and hence the conclusion arising from the study; it can be assumed that the biomedical treatment method is the best treatment method for mental illness and this is because of the most of the respondent didn't seek alternative treatment. That said, to conclusively answer the research question, it can be concluded that faith healing or prayers was the most preferred alternative pathway for mental health treatment. It was found to actually compliment bio-medical treatment as opposed to traditional healing methods which was associated with negative experiences. A fact that needs to be explored further with regards to assessing a number of key

factors that could explain the finding especially considering the fact that as mentioned earlier; studies in Africa strongly support the inclusion of traditional method of healing or treating of mental illness which supposedly has positive results..

5.3 Recommendations

The study recommends that

- More funding should be invested in helping more patients' access biomedical treatment.
 Being that this type of treatment clearly shows improvement. This will alleviate the cost of transport for the patients and the respondents every time they have to go for their appointments. It will also with costs related to acquisition of medication.
- 2. Traditional medicine has been associated with successful treatment of mental illness in different parts of Africa, therefore more training should be done to these traditional healers to ensure that they do understand how to treat mental illness. It is surprising that no respondent was actually helped or felt better after seeking treatment at a traditional healer
- 3. There should be devolution of health services on a larger scale to help prevent long journeys that are made to seek treatment for mental illness. Small dispensaries run by the county governments should consider hiring mental health specialists which will help improve the experiences of the caregivers and the patients seeking treatment
- 4. Stigmatization of mentally ill patients and their caregivers should be addressed through education and creating awareness about mental illness up to the grass root levels. This way individuals who coexist together with mentally ill patients can have a better

understanding of what they need and how they should treated socially. This could be well achieved by discussing causes and treatment of mental illness

5.4 Suggestion for Further Studies

The study yields findings that contrast with similar studies with similar studies done in Africa. It is therefore important to further look into factors that could have contributed to such results for instance whether the sample size, though allowed in qualitative analysis; was truly a representative of the mental ill patients or caregivers hence a true picture of their views. Whether indeed traditional healing has no impact on mental illness and if so what are the factors surrounding this? Is it related to a belief system that currently is being influenced by progressive ideologies and education? This is of course owing to the fact that studies have indicated the importance of liaison between biomedical and traditional healing treatment to tackle mental illness; this current study seems to imply that it is not necessary at all.

The study had one limitation; it was carried out in a hospital setting hence data collected was on patients who were attended at the psychiatric unit leaving out other patients in the community and therefore another study should be done where all the mentally ill in the community are included. The interview venue lacked neutrality.

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APPENDICES

1. Participant Consent Form

Pathways to Mental Health Care and Experiences of Adults Living With Mental Illness in

Machakos Level 5 Hospital

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Introduction

This is study intends to find out management practices that patients experience before going to seek help in a hospital. During this study you can ask about anything that you want including risks and benefits, your rights and what as a participant you need to do. This process is called informed consent. As a participant you need to know that your participation is entirely voluntary and you can withdraw from the study at any time. Refusal to participate in this study will not affect the services offered in this hospital in any way.

What is the purpose of the study?

The researcher will be interviewing patients with mental illness to find out the different types of care they accessed before coming to hospital. The participants will have a choice to go through counseling if need be. The researcher is therefore asking for your consent to participate in this study.

What will happen if you decide to participate in this study?

If you agree to participate in this study the following will take place. You will be interviewed by a trained interviewer in a private space where you will feel free and comfortable answering the questions. The interview will take approximately 45 minutes. The topics to be covered will be like, 1) where did you seek help for your mental disorder before coming to hospital? 2) What are some of the experiences you had as you sought help? 3) What are the barriers you encountered in seeking help?

Psychological therapy / counseling will be offered if need be.

Are there any risks harms, discomforts associated with the study?

Medical research has the potential to introduce psychological, social and emotional risks; intrusion of privacy is one of the risks. The researcher will keep everything as confidential as possible. A code number will be used to protect your identity in a password protected computer data base. All paper work will be kept in a locked file cabinet. Answering certain questions in the interview may be uncomfortable, if there are questions you do not want to answer you can skip them.

Are there any benefits of being in this study?

No. there will be no benefits in participating in this study.

Will your participation in this study cost you anything?

No.

Will you be given a refund for any money spent as being a participant in this study?

No

What if you have any questions in the future?

If you have more questions or concerns about participating in this study please contact the researcher on the number 0725068273 or her supervisors, Prof. Othieno, on 0724879111 and Dr. Muthoni Mathai 0727329904.

For more information about your rights as a research participant you can contact the secretary/chairperson Kenyatta National Hospital- university of Nairobi Ethics and Research Committee. Telephone No.276300 Ext 44102 email uonknh_erc@uonbi.ac.ke

The researcher will pay back for call charges to those numbers if he call is for study related communication.

What are your other options?

Your decision to participate in this study is voluntary. You are free to decline from participating in this study or withdrawing at any point without intimidation or loss of benefits.

2. Statement of Consent

Participant's statement

I have read this consent form or had the information read for me. I have had the chance to discuss this study with the researcher. I have had my questions answered in a language that I understand the risks and benefits have been explained to me. I understand that my participation in the study is voluntary and that I may opt to withdraw any time. I freely agree to participate in this research study. I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form, I have not given up any of the legal rights that I have as a research participant.

I agree to participate in this research study	Yes	No
Participant printed name		
Participant signature/thumb stamp	D	Date
Researcher's statement		
I the undersigned have fully explained the relevant d	letails of this researc	ch to the participant
named above and believe that the participant has unc	derstood and that is	willing to freely give
his/her consent.		
Researcher's name		Date
Signature		

If you have more questions or concerns about participating in this study please contact the researcher on the number 0725068273 or her supervisor, Prof. Othieno, on 0724879111. You can also contact KNH/UON-ERC on 276300 Ext 44102 email uonknh_erc@uonbi.ac.ke

3. Participant Kiswahili Consent Form - Fomu ya Ridhaa ya Mshiriki

Njia za Afya ya Akili huduma na Uzoefu wa Watu wazima wanaoishi na ugonjwa wa akili katika Hospitali ya Machakos Level 5

Mwongela Ann^a, Othieno Caleb^b, Mathai Muthoni^b

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Utangulizi

Huu ni utafiti unaolenga kujua mazoea ya huduma na uzoefu wa wagonjwa kabla ya kutafuta msaada hospitalini. Wakati wa utafiti huu unaweza kuuliza kuhusu kitu chochote unachohitaji kujua ikiwa ni pamoja na hatari na faida za utafiti, haki yako na nini kama mshiriki unahitaji kufanya. Mchakato huu unaitwa ridhaa. Kama mshiriki unahitaji kujua kwamba ushiriki wako ni hiari kabisa na unaweza kujiondoa wakati wowote. Kukataa kushiriki katika utafiti huu hakuathiri huduma unazopatiwa katika hospitali hii kwa njia yoyote ile.

Nini lengo la utafiti?

Mtafiti atakuwa akiwahoji wagonjwa wa akili ili kujua aina mbalimbali za huduma wanazopitia kabla ya kuja hospitalini. Washiriki watakuwa na uchaguzi wa kupitia ushauri nasaha ikiwa ni lazima. Hivyo mtafiti anaomba idhini yako ya kushiriki katika utafiti huu.

Nini kitatokea kama utakubali kushiriki katika utafiti huu?

Kama utakukubali kushiriki katika utafiti huu yafuatayo yatafanyika. Utahojiwa faragha na mtafiti aliefunzwa ambapo utakuwa huru kujibu maswali. Mahojiano yatachukua takribani dakika 45. Mahojiano yatahusu vitu kama, 1) Ni wapi ulitafuta msaada kwa shida yako ya ugonjwa wa akili kabla ya kuja hospitali? 2) Je, ni uzoefu gani uliupitia wakati ukitafuta msaada? 3) ni vikwazo gani ulipitia wakati ukitafuta msada?

Je, kuna athari au madhara yoyote yale kuhusiana na utafiti huu?

Utafiti wa matibabu unaweza kusababisha madhara ya kisaikolojia, kijamii na kihisia; uingizaji wa faragha ni moja ya hatari. Mtafiti atatunza kila kitu kwa usiri mkubwa kadri iwezekanavyo. Nambari ya utambulisho itatumika kulinda utambulisho wako katika komputa inayolindwa na nywila . Kazi zote za karatasi zitatunzwa katika kabati lililofungwa . baadhi ya maswali katika mahojiano yaweza yasiwe mazuri kwako, iwapo kuna maswali hutajisikia kuyajibu wawezakuyaruka.

Je, kuna faida yoyote ya kuwa katika utafiti huu?

Hapana, hakutakuwa na faida kwa kushiriki katika utafiti huu.

Je, ushiriki wako katika utafiti huu itakugharimu kitu chochote?

Hapana.

Je, utarudishiwa fedha yoyote utakayotumia kwa kuwa mshiriki katika utafiti huu?

Hapana.

Vipi iwapo una maswali yoyote katika siku zijazo?

Kama una maswali zaidi au dukuduku kuhusu kushiriki katika utafiti huu tafadhali wasiliana na mtafiti kwa namba 0725068273 au msimamizi wake, Prof. Othieno, kwa namba 0724879111.

Kwa habari zaidi kuhusu haki zako kama mshiriki unaweza kuwasiliana na katibu / Mwenyekiti kamati ya maadili ya utafiti ya pamoja ya chuo kikuu cha Nairobi na Hospitali kuu ya Kenyatta. Namba No.276300 Ext 44102 email uonknh_erc@uonbi.ac.ke

Mtafiti atakurudishia gharama zote utakazotumia iwapo utapiga namba hizo kwa masuala yanayohusiana na utafiti huu.

Je, chaguzi zako zingine ni zipi?

Uamuzi wako wa kushiriki katika utafiti huu ni wa hiari. Uko huru kukataa kutoshiriki au kujitoa wakati wowote ule bila kunyanyapaliwa au kukosa huduma

4. Statement of Consent (Kiswahili Version) – Maelezo ya Makubaliano Kauli ya mshiriki

Nimesoma/nimesomewa fomu hii ya ridhaa. Nimekuwa na nafasi ya kujadili utafiti huu na mtafiti. Maswali yangu yamejibiwa katika lugha ninayoielewa, nimeelezwa juu ya faida na hasara za kushiriki kwangu. Naelewa kwamba ushiriki wangu katika utafiti hu ni wa hiari na nawezachagua kujiondoa wakati wowote. Kwa uhuru wangu nakubali mimi mwenyewe kushiriki katika utafiti huu. Naelewa kwamba juhudi zitafanywa kuweka taarifa na utambulisho wangu kwa siri. Kwa kutia saini fomu hii ya ridhaa, sijaondoa haki yangu yoyote ya kisheria niliyonayo kama mshiriki wa utafiti.

Ninakubali kushiriki katika utafiti huu	Ndio	Hapana	
Jina la mshiriki			
Sahihi/dole gumba la mshiriki		Tarehe	
6. Kauli ya mtafiti			
Mimi niliyetia sahihi hapa chini nimemue	elezea mshirik	i tajwa hapo juu taarifa zote zinazoh	ust
utafiti huu na ninaamini mshiriki ameelev	va na yuko tay	yari kwa uhuru wake kutoa ridhaa ya	
ushiriki wake.			
Jina la mtafiti		Tarehe	-
Signatura			

Kama bado una maswali zaidi au dukuduku juu ya ushiriki wako katika utafiti huu tafadhali wasiliana na mtafiti katka namba zifuatazo 0725068273 au msimamizi wake, Prof. Othieno, namba 0724879111.pia unaweza wasiliana na KNH / UON-ERC kupitia namba 276300 Ext 44102 email uonknh_erc@uonbi.ac.ke.

Socio-Demographic Data Form 1. What is your sex? Male Female 2. What is your age? < 20 20-29 30-39 40-49 50-59 >60 3. What is highest education level? No/some education Primary education Secondary education Tertiary education 4. What is your marital status? Single/never married Widowed Separated Divorced 5. What distance do you cover on your way to this psychiatric hospital (in amount of the bus fare paid in Kshs.) _____ 6. What is your religion?

English Questionnaire

7.

Christian	
Islam	
Others	

Pathway Encounter Form/Interview Guide for patients

- 1. Could you please explain to me how you came to be in this hospital?
 - a. Were you referred from somewhere else? If yes,
 - b. Where were you referred from?
- 2. What was the main problem that you presented with?
- 3. How long ago did the main problem begin?
- 4. What do you think might have caused your mental illness?
- 5. Where else did you seek mental health care from before coming to hospital?
 - a. How long ago was this?
 - b. What are the experiences you had at the alternative care setting(s) that you visited?
- 6. Did anyone suggest that you should seek help or it was your own initiative?
 - a. What were the reasons as to why you decided to seek help from the alternative care setting?
- 7. What were the forms of treatment that were offered to you at the alternative care settings?
 - a. How did you find the different treatment methods that were offered at the alternative care settings?
 - b. What were the effects of treatment? Did your condition change after the different forms of treatment that were offered?
 - c. What were the costs of treatment at the alternative care settings?

- d. Were there any harms experienced at the alternative care settings? If yes what were the harms and how did you deal with them?
- 8. What are the problems that you might have encountered when you were accessing mental health care?
- 9. What is your take on both biomedical and alternative mental health care services?

Pathway Encounter Form/Interview Guide for care givers

- 1. Could you please explain to me how your patient came to be in this hospital?
 - a. Was she/he referred from somewhere else? If yes,
 - b. Where was she/he referred from?
- 1. What was the main problem that your patient presented with?
- 2. How long ago did the main problem begin?
- 3. What do you think might have caused your patient's mental illness?
- 4. Where else did your patient seek mental health care from before coming to the hospital?
 - a. How long ago was this?
 - b. What are the experiences your patient had at the alternative care setting(s) that he/she visited?
- 5. Did anyone suggest that your patient should seek help or it was their own initiative?
 - a. What were the reasons as to why your patient decided to seek help from the alternative care setting?
- 6. What were the forms of treatment that were offered to your patient at the alternative care settings?

- a. How did you find the different treatment methods that were offered at the alternative care settings?
- b. What were the effects of treatment? Did your patient's condition change after the different forms of treatment were offered?
- c. What were the costs of treatment at the alternative care settings?
- d. Were there any harms experienced at the alternative care settings? If yes what were the harms and how did you deal with them?
- 7. What are the problems that you might have encountered when you were accessing mental health care?
- 8. What is your take on both biomedical and alternative mental health care?

8. Dodoso (Kiswahili Questionnaire)

Maswali ya Kijamii na Idadi ya Watu

1. Jinsia yako ni ip	oi?
Kiume	\Box
Kike	_
2. Umri wako?	
<20	
20-29	
30-39	
40-49	$\overline{\Box}$
50-59	
> 60	

3. Elimu yako ya juu?	
Sijasoma / nimesoma kidogo	
Elimu ya msingi	
Elimu ya sekondari	
Elimu ya juu	
4. Hali yako ya ndoa?	
Sijaoa/sijaolewa/sijawahi kuoa/kuolewa	
Mjane	
Tumetengana	
Nimetalikiwa	
5. Ni umbali gani toka kwako hadi kwa ho	ospital hii ya huduma ya magonjwa ya akili (unatumia
nauli kiasi gani Kshs.)	
6. Dini yako?	
Mkristu	
Uislamu	
Nyingine	

9. Mwongozo wa Mahojiano ya Mgonjwa

- 1. Tafadhali neieleza ni vipi ulifika katika hospitali hii?
 - a. ulitumwa kutoka mahali pengine? Kama ndio
 - b.ulitumwa kutoka wapi?
- 2. Tatizo kubwa uliokua nayo ni ipi?
- 3. Umekua na hii tatizo kwa muda gani?
- 4. Ni nini unafikiria ilisababisha ugonjwa wako wa akili?
- 5. Ni mahali wapi pengine ulipoenda kutafuta huduma ya ugonjwa wa akili kabla kuja hospitalini?
 - a. ulikua ni wakati gani uliopita?
 - b. Ni uzeofu gani ulipata katika vituo vya mbadala ambavyo ulitembelea?
- 6. Kuna mtu yeyote aliyekueleza uende kutafuta matibabu ama yalikua maamuzi yako mwenyewe?
 - a. Ni sababu zipi zilizokufanya kwenda kutafuta huduma za matibabu kutoka kwa vituo vya mbadala?
- 7. Ni aina zipi za matibabu ulizopata Katika vituo vya mbadala?
 - a. Ulizipata vipi aina za matibabu ambazo ulipewa kwenye vituo vya mbadala?
 - b. ulipata mabadiliko yapi baada ya matibabu uliyo pewa?
 - c. Ulipata Gharama zipi za matibabu katika vituo vya mbadala?
 - d. Ulipata madhara yoyote ulipokua ukipata matibabu ya vituo vya mbadala? Kama ndio yalikua ni madhara yapi na ulikabiliana nayo vipi?
- 8. Ni matatizo yapi ulipata wakati ulipokua niatafuta matibabu ya ugonjwa wa akili?
- 9. Maoni yako ni yapi kuhusu njia za matibabu ya hospitalini na yale ya mbadala?

10. Mwongozo wa Mahojiano ya Mtuo Huduma

- 1. Tafadhali neieleza ni vipi mgonjwa wako alifika katika hospitali hii?
 - a. Alitumwa kutoka mahali pengine? Kama ndio
 - b.Alitumwa kutoka wapi?
- 2. Tatizo kubwa mgonjwa wako aliokua nayo ni ipi?
- 3.Mgonjwa wako amekua na hii tatizo kwa muda gani?
- 4. Ni nini unafikiria ilisababisha ugonjwa wa akili wa mgonjwa wako?
- 5. Ni mahali wapi pengine mgonjwa wako alipoenda kutafuta huduma ya ugonjwa wa akili kabla kuja hospitalini?
 - a. ulikua ni wakati gani uliopita?
 - b. Ni uzeofu gani mgonjwa wako alipata katika vituo vya mbadala ambavyo ulitembelea?
- 6. Kuna mtu yeyote aliyemweleza mgonjwa wako aende kutafuta matibabu ama yalikua maamuzi yake mwenyewe?
 - a. Ni sababu zipi zilizomfanya mgonjwa wako kwenda kutafuta huduma za matibabu kutoka kwa vituo vya mbadala?
- 7. Ni aina zipi za matibabu ulizopata mgonjwa wako Katika vituo vya mbadala?
 - a. Mgonjwa wako alizipata vipi aina za matibabu ambazo ulipewa kwenye vituo vya mbadala?
 - b. Alipata mabadiliko yapi baada ya matibabu aliyo pewa?
 - c. Mlipata gharama zipi za matibabu katika vituo vya mbadala?
 - d. Alipata madhara yoyote ulipokua ukipata matibabu ya vituo vya mbadala? Kama ndio yalikua ni madhara yapi na ulikabiliana nayo vipi?
- 8. Ni matatizo yapi alipata mgonjwa wako wakati ulipokua akiatafuta matibabu ya ugonjwa wa akili?
- 9. Maoni yako ni yapi kuhusu njia za matibabu ya hospitalini na yale ya mbadala?