

PSYCHO-SOCIAL AND CULTURAL FACTORS ASSOCIATED WITH NON-ADHERENCE TO TREATMENTS AND FOLLOW UP AMONG OUTPATIENTS AT MATHARI HOSPITAL

A RESEARCH CARRIED OUT IN PART FULLFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF A MASTERS DEGREE IN PSYCHIATRY AT THE UNIVERSITY OF NAIROBI

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DECLARATION

I, Dr. Edith Wanjiku Kamaru-Kwobah, do hereby declare that this research is my original work, and that I have not presented it to any other institution of learning for an award of a degree or other certificate..

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ACKNOWLEDGEMENT

I wish to acknowledge my supervisors Professor David Ndeti and Dr. Anne Obondo for their intellectual input, guidance and support from the development of the proposal to the completion of this work.

I also would like to acknowledge Dr. Khasakhala of African Mental Health Foundation for his contributions and support.

I would like to acknowledge all the faculty in the department of psychiatry for impacting knowledge that led to the production of this work.

APPRECIATION

A big thank you to all the patients who took time to be interviewed, this work would not be done without your patience and cooperation.

Special thanks to my loving husband, Charles, for his intellectual input, financial and moral support, and to my lovely daughter Elsie for the patience she showed as I spent time away from her working on this study.

Much thanks to my colleagues, to my family members, to all my friends and especially Pangani bible study group for all the support and encouragement they provided.

DEDICATION

This work is dedicated to my dear parents, Mr and Mrs Kamaru for the great step of faith they took to educate me against all odds. This gave me a vital foundation without which I would never be here to do this work. I will forever be grateful for your sacrifice, courage and determination to give me what you never had.

DEFINITION OF TERMS

Adherence refers to the extent to which patient behavior, in terms of taking medications, attending follow-ups, or executing lifestyle changes, coincides with clinical prescription.

Nonadherence- For purposes of this study only, and due to the complexity of defining the same, non adherence refers to any number of missed doses of prescribed drugs since the previous visit.

Compliance refers to the extent to which patients follow doctors' prescription about medicine taking

Concordance refers to the extent to which patients are successfully supported both in decision making partnerships about medicines and in their medicines taking.

Caregiver/Carer- unpaid relatives or friends of a mentally ill individual who help that individual with his or her daily activities .

Culture- The set of shared attitudes, values, goals, and practices that characterizes an institution, organization, or group

Focus group - focus group is a small group of six to ten people led through an open discussion by a skilled moderator. The group needs to be large enough to generate rich discussion but not so large that some participants are left out.

Psychosocial Ones psychological development in, and interaction with social environment.

ABBREVIATIONS

ARVS – antiretroviral therapy.

DSM IV- Diagnostic statistical manual ,Fourth edition,

FGDs – Focussed group discussions

OPD- Outpatient department

SPSS- Statistical package for social sciences.

TB-Tuberculosis bacilli

WHO- World health organization

USA- United States of America.

ABSTRACT

Introduction; Non adherence is a major obstacle in delivery of healthcare services, because even the best medicine is not effective unless taken appropriately. According to WHO only about 50% of patients are compliant on treatment.

This study **aimed** at identifying the psychosocial and cultural factors that may be associated with nonadherence of outpatients on follow up at Mathari hospital

Methodology;This was a crosssectional descriptive survey . Data was collected using a structured questionnaire and focussed group discussions. Quantitative data was analyzed using SPSS version 17. Qualitative data was summarized in narratives.

Results: A total of 347 patients were conveniently sampled for face to face interview, and 4 focussed group discussions were held between July and December 2012. 57% were male and 43% female.The mean age was 36.8 years.The mean duration of illness was 9 years . 33.7% (n =117) reported missing medication since the previous visit, and 22.5% (n=78) missed a clinic in the previous one year. Nonadherence was associated with: not knowing the illness one suffered from (p 0.013), not knowing the names of the drugs one was taking (p value 0.030) , feeling the medication was not helpful, (p =0.002), feeling better hence no need for medication (p = 0.001), carelessness as a reason for missing medication (p value<0.0001), feeling one had used medication for too long and needed a break (p=0.026), unreliable source of information on the drugs and illness (p=0.0001), viewing the illness as different from other illness (P 0.048), fear that people will know about the mental illness (p =0.001) , discomfort with sharing about ones feelings with others (p=0.002), preference of herbal medication (P=0.004), high cost of drugs (p<0.0001) and feeling worse on taking medication(p=0.001). From the discussion groups, lack of awareness about medication featured strongly as a reason for missed medication.

Conclusion: Negative attitudes towards medication, lack of awareness, stigma , poor social support, use herbal medication ,high cost of medication and drug adverse effects are associated with non adherence. These factors need to be addressed at individual and institutional level in order to optimize the quality of care of the mentally ill. Psychoeducation programmes for patients and the community need to be emphasized in order to reduce these obstacles.

CHAPTER 1: INTRODUCTION

Adherence definition and assessment has remained a complex issue world over. Generally, it refers to the extent to which patient behavior coincides with clinical prescription. It is often used interchangeably with *compliance* and *concordance* although concordance is most preferred as it “emphasizes the role of appropriate doctor patient relationship and social support in appropriate use of medication” (De las Cuevas, 2011). Various methods have been used to assess adherence. These include self report, pill count, electronic refill, electronic monitoring and blood and urine analysis.

Whatever the definition, and the assessment method, it is clear that nonadherence levels are high and strategies must be put in place to reduce these levels. An understanding of factors that could contribute to the non-adherence is a vital step in reducing these high level of non-adherence.

1.1: BACKGROUND

Non-adherence is a common problem among patients with both physical and mental illness. According to WHO in the paper *adherence to long term therapies, evidence for action*, “adherence to therapies is a primary determinant of treatment success. Poor adherence attenuates optimum clinical benefits and therefore reduces the overall effectiveness of health systems”. In this paper it was reported that in developed countries only about 50% of patients with chronic conditions were compliant to medication. The situation is worse in developing countries, where poverty, limited facilities and poor human resources further complicates the situation. The full benefits of medications cannot be realized at currently achievable levels of adherence averaging at 50% (Haynes et al., 2002). These dismal levels are as a result of various factors working individually or in synergism with others.

1.1.1 BELIEFS: Adherence is highly associated with the patient's own beliefs which are influenced by personal knowledge and experience as well as that of family and friends (De Las Cuevas, 2011). Understanding the patient's perspective allows the provider to give treatment options in line with the patient needs and values. This then allows for a patient-centered approach, essential for promoting adherence. The current levels of non-adherence imply a failure to address patients' needs and preferences and represent a fundamental inefficiency in the delivery and organization of the public health systems. To achieve adherence, people must go through three nodes of adherence as shown in adherence loop **figure 1** below (Devorah et al 2006). This model was based on multiple sclerosis, erectile dysfunction, osteoporosis and weight

loss, and aimed at improving an understanding of the patient's journey with the conditions and the mental states that affect adherence. As demonstrated on the loop, patients must *believe* in the accuracy of diagnosis and the effectiveness of therapy if they were to adhere to it. They also need to *know* what to do, and when and how to do it. To complete the loop, they ought to physically, cognitively, emotionally and financially be able to *act towards achieving specified therapeutic goals*.

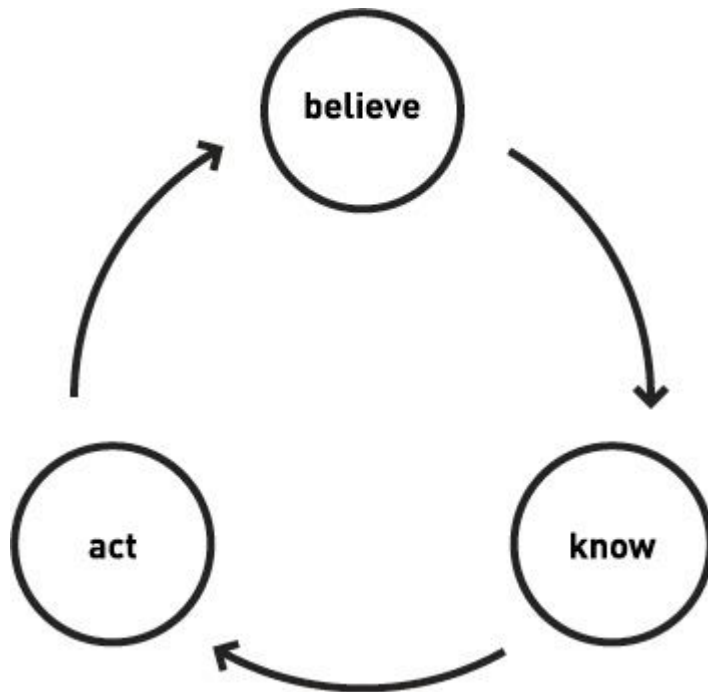


Figure 1 :**Adherence loop** (Devorah et al 2006,adapted from the paper Medication adherence,many conditions a common problem)

Several factors could affect or disrupt the loop and thus affect adherence among mentally ill patients (McDonald et al., 2002).

Factors relating to adherence could be explained using the health believe model (Perkins et al., 2006) as shown in **figure 2** below. At the center of the model is the likelihood that a patient will adhere to treatment recommendations. Factors that positively or negatively affect adherence, including the benefits of treatment, risks of illness, costs of treatment, barriers, and cues to act make up the rest of the model.

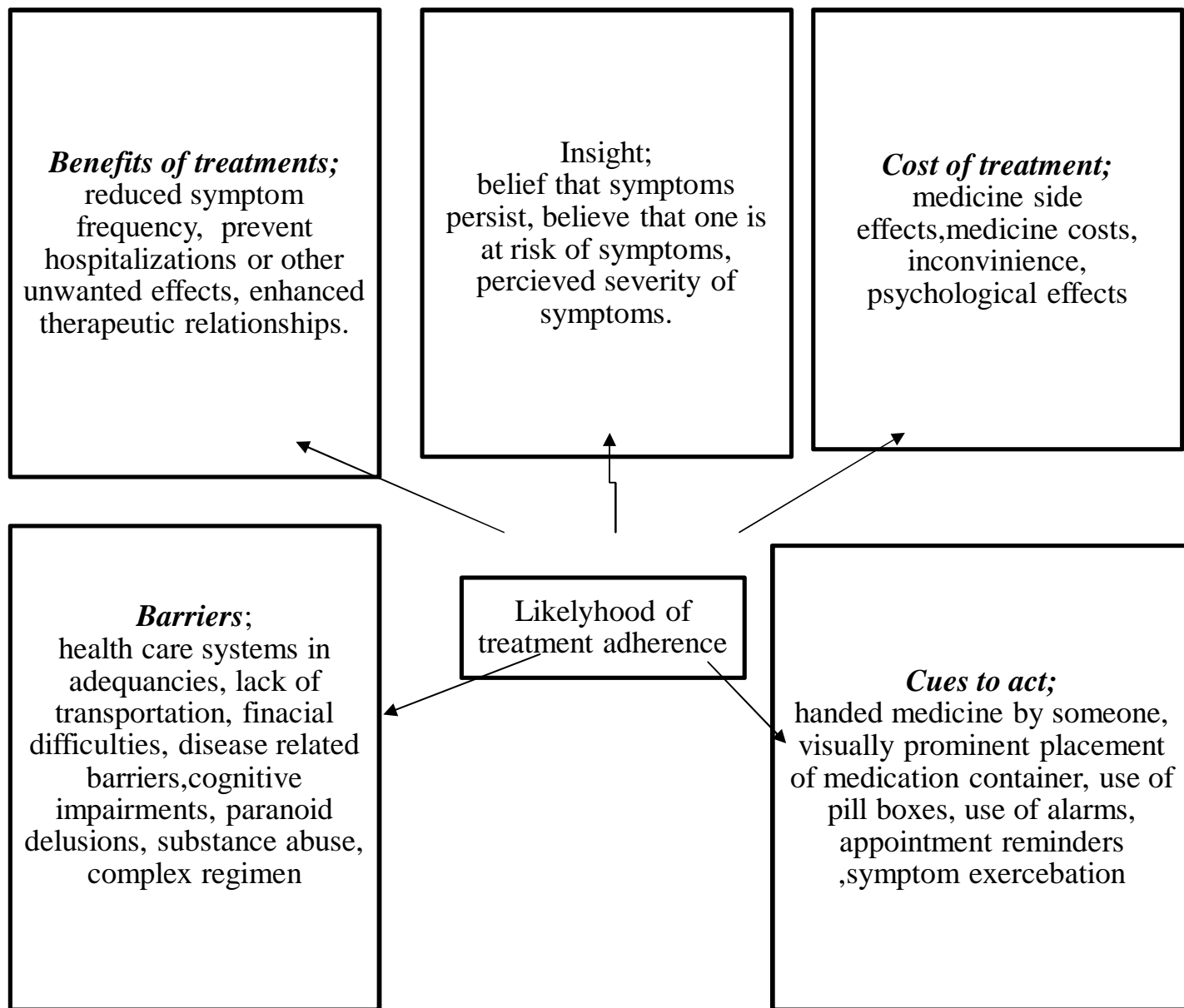


Figure 2 The health believe model showing the various factors that coul contribute to adherence (Adapted from Diana Perkins' paper on predictors of adherence)

1.1.2 ROLE OF KNOWLEDGE AND INSIGHT : Adherence to treatment depends on the ability of the patient to assess perceived benefits, potential risk of the illness and the cost of the

treatment even in terms of side effects (Perkins et al., 2006)The lack of awareness of the illness , its cause and course is characteristic of most mental illnesses, and therefore patients with these disorders may be unaware of their symptoms, the risk of relapse, and illness-related impairment of functioning (Svestka and Bitter, 2007). Such patients left of their own are unlikely to take medications as prescribed. Such patients need specific cues to act that would be provided by other people.

1.1.3 SOCIAL SUPPORT: The cognitive deficits, and the poor social and occupational status often renders mentally ill patients incapable of taking care of themselves. These patients are dependent on others for material and emotional support. This often requires that health seeking behavior and adherence to medication is supervised or even facilitated by another person. The success of this support depends on the availability of a caregiver, their understanding of the illness and their attitude towards the illness (Nosé et al., 2003). Families that do not understand the illness or have negative attitudes towards mental illness or stigmatize their mentally ill relative are unlikely to assist in the care seeking, follow up and adherence to medication.

1.1.4 STIGMA: Discrimination directed to mentally ill patients may negatively affect healthcare seeking behavior and adherence to treatment (Baumann, 2007),(Sirey et al., 2001).In Kenya, anecdotal experience indicate that the mention of Mathari Hospital instills negative feelings and stigma. The anecdotal information by relatives to a patient with severe mental disorder often confess delay in seeking services at Mathari hospital as they do not want anyone to know that their loved one is “mad” and must be seen at the institution. The relatives often come to the facilities after trying to access mental health services from other general health facilities. This profound stigma towards Mathari hospital is likely to negatively affect future follow-ups of affected patients and their family.

1.1.5 ALTERNATIVE TREATMENTS: Ideologies that associate mental illness with curses, punishment or even witchcraft are likely to negatively affect any trust of drugs or other forms of therapies prescribed in the hospitals (Ofori-Atta et al., 2010). These patients are likely to prefer miracle working preachers and witchdoctors and other traditional healers, and not western medicine (Adewuya and Makanjuola, 2009). The issue of herbal medication both modern and traditional may influence a patient’s decisions to abandon conventional medicines. A significant number of patients depend on these herbal and traditional medicines and often have their safety at stake in case of counterfeit, poor quality or adulterated products (WHO traditional medicine strategy 2002-2005). The main challenges with these remedies is that few or no mechanisms are put in place to test safety and effectiveness and those who administer them have no training that would be essential for the administration of these treatments (Akerlele, 1984).This is especially a threat to patients with persistent symptoms or severe adverse effects who are frustrated and are desperate for a solution, which most herbalist and other traditional healers claim to guarantee. T

1.1.6 COST OF TREATMENT: The cost of buying medication, the cost of transport to a health facility can greatly impact on compliance to treatment. This is worsened by the fact that

most mentally ill patients are not able to work and depend on others to provide for their financial needs. In places where poverty is prevalent, food shelter and coltings, and not medication then becomes a priority.

1.1.7 DRUG RELATED FACTORS: Most neuroleptics have side effects that range from mild to severe and debilitating effects. Effects like drowsiness may interfere with normal functioning and patients may opt not to take these medications. Other effects like the extrapyramidal side effects may be very incapacitating and once experienced a patient may be hesitant to take subsequent drugs.

1.2 STATEMENT OF THE PROBLEM

Poor adherence to treatment prolongs and worsens symptoms or delays remission of all forms of mental illnesses. About 42 % of patients with bipolar disorder are not adherent to prescribed treatments (Rakofsky et al., 2011), while about 50% of patients with schizophrenia do not adhere to treatment (Zygmunt et al., 2002). These trends are true for other mental illnesses and this is a major barrier to favorable treatment outcomes, which remain poor despite advances in methods of management that include new drugs, various forms of psychotherapy and family interventions. Suboptimal adherence to psychotropic medications have grave consequences. These include relapses, significantly more psychiatric hospitalizations and emergency room visits. These patients have poorer mental functioning, lower life satisfaction, more disability-related absences from work, greater substance use, increased suicidal behavior, poorer adherence to medications for comorbid medical conditions, and higher cost of health care (Lambert et al., 2010). Appropriate interventions depend on a clear understanding of the problem and the contributing factors (McDonald et al., 2002). This study aimed to document psychosocial and cultural factors that may be associated with poor adherence at Mathari Hospital. Such knowledge would be a guide to finding appropriate interventions in order to improve the quality of care and an overall improvement in quality of life for the patients.

1.3: STUDY OBJECTIVES

MAIN OBJECTIVE: To establish the psychosocial and cultural factors that affect adherence to prescribed therapies and follow up among out patients at Mathari hospital.

SPECIFIC OBJECTIVES.

- I. To determine the social demographic characteristics associated with poor adherence.
- II. To establish socialcultural factors that affect adherence
- III. To establish psychological factors affecting adherence.

Based on the findings of the study, suggest ways of curbing non adherence to treatment and follow up of mentally ill patients.

1.4: HYPOTHESIS

There are identifiable psychosocial and cultural factors associated with non adherence to psychiatric treatment and follow up among patients on follow up at Mathari hospital.

1.5: JUSTIFICATION OF THE STUDY.

No medication is effective unless it is taken appropriately (WHO 2003) and non adherence is a major hindrance to the management of mental illness .Dr Mareko in his dissertation, established that there is a very high rate of non-adherence (64% compared to the world average of about 50%) among patients at Mathari hospital (Mareko, 2005 not published). In his study, non-adherence was strongly associated with type of DSM-IV diagnosis, comorbid substance use and adverse effects of the drugs. This study aimed at seeking more information on the contribution of such factors as insight into illness, knowledge, attitudes, beliefs, stigma, and alternative medicines . This understanding would aid in looking for ways to overcome the obstacles and thus improve the outcomes of available treatments .

CHAPTER 2: LITERATURE REVIEW.

Adherence to treatment is one of the keys to optimal health care delivery. Several authors have explored different aspects of adherence, and the factors associated with it.

2.1. WORLD

2.1.1 ADHERENCE AND CULTURE.

The role of culture in adherence has been demonstrated by various studies around the world. In China mental illness was believed to be caused by evil spirits and a lot of mentally ill patients were taken to witch doctors for treatment (Li and Phillips, 1990). This trend may be changing but still has a long way to go (Fan and Holliday, 2006), with a lot of patients still using the traditional medicines. This situation is not unique to China as different countries experience different cultural challenges in the care of the mentally ill. A study including 20 African Americans and 30 Whites was done to examine the rates of non adherence, self perceived reasons for non adherence and attitudes associated with non adherence. It was found that 50% of both races were non adherent and that illness and medication factors were similar in both groups. However there was a difference in patient related factors such as fear of addiction and medication as a symbol of illness, pointing to effect of culture and attitudes on adherence (Fleck et al., 2005). In Haiti, Haitian, African-American, and non-Latino White youth in a community mental health setting, were compared on adherence to treatment guidelines for attention-deficit/hyperactivity disorder (ADHD) and depressive disorder. It was found that Haitian youth use outpatient mental health services in similar proportion to African-American youth and at lower rates than White youth. Guideline-adherent treatment for ADHD and depression was limited by low retention in care for Black youth. Low insurance coverage was reported as a likely contributor to reduced use of services, especially for Haitians (Carson et al., 2011).

2.1.2 ATTITUDES AND BELIEVES.

The role of attitudes and believes has also been demonstrated. In a study done in Scotland on patients on various types of antidepressants, it was established that attitudes and behavior are better predictors of adherence than adverse effects (Scott and Pope, 2002). The conclusion was that clinicians needed to enquire a lot more about adherence. Perkins et al found out that the likelihood of becoming medication non-adherent for one week or longer was greater in subjects whose belief in need for treatment was less, or who believed medications were of low benefit (Perkins, 2002). Other similar studies emphasizing the role of attitudes have been done in Ireland (Hill et al., 2010). It is also important to note that negative attitudes of the clinicians has a bearing on how well a patient takes their medication (Taj and Khan, 2005). Care givers must be able to positively and effectively communicate with patients in order to have trust and confidence in the medication. This will allay fears in case of delayed response and also guide patients on how to handle any adverse effects.

2.1.3 KNOWLEDGE AND INSIGHT.

The understanding one has on their illness has a major bearing on their adherence. Lack of knowledge could be due to the psychopathology, general poor understanding of mental illness in the community, and poor communication from the clinicians to both the patient and the care givers . Lack of insight has a strong contribution to non-adherence (Hill et al., 2010), ((Buckley et al., 2007). A study conducted in the United States (Kessler et al., 2001) on prevalence and correlates of untreated severe mental illness, found that majority of the patients with untreated mental illness felt that they had no emotional problem requiring treatment. The others who knew of a possible problem preferred to solve the problem on their own thus did not seek help. This is also seen in a study done in France which indicated that patients with poor insight were 1.7 times more likely to discontinue medication, suggesting a need for psycho education programs in order to improve adherence(Droulout et al., 2003). Awareness of illness contributes to medication adherence via patients' perceived necessity of antipsychotics. Studies have demonstrated a direct negative relationship between concerns regarding antipsychotics and adherence and an indirect negative effect of a general distrust regarding pharmacotherapy and adherence via antipsychotic specific attitudes(Beck et al. 2011). In Pakistan also, one of the commonest reasons for non-compliance was unawareness of the benefits of treatment (Taj and Khan, 2005).

The lack of awareness could be associated with degree of psychopathology. In a study in Pakistan, the commonest illnesses leading to non-compliance were major depressive disorder, schizophrenia and bipolar affective disorder. This study concluded that compliance is directly related to prognosis and all medical practitioners must look for these for better outcomes (Taj and Khan, 2005). Lower global functioning especially due to prolonged untreated psychosis is likely to translate to poor adherence (Hill et al., 2010)

2.1.4 COST OF TREATMENT.

In most of the world the cost of treatment is met by the patient and their care givers. Unfortunately this has a negative impact on adherence as poverty may dictate that basic needs take priority over medication, especially worse in mental illness where except in cases of aggression, symptoms can be easily assumed as there is no pain. Studies done across have reported cost as a significant obstacle to adherence(Taj and Khan, 2005). This has further costs implications as these patients are likely to have more frequent hospitalization and emergency treatments which are generally expensive. In San Diego a study to establish the relationship between adherence to antipsychotic treatment and expenditure, found that rates of psychiatric hospitalization were lower for those who were adherent (14%) than for those who were non-adherent (35%), partially adherent (24%), or had excess fills (25%). Those who were adherent had significantly lower hospital costs than the other groups (Gilmer et al., 2004). This means that while cost is a hindrance to adherence, non-adherence further increases the cost thus worsening

the situation (Sun et al., 2007). This is because it increases the emergency and inpatient care required which is more expensive than outpatient management of stable patients (Marcus and Olfson, 2008)

2.1.5 DRUG RELATED FACTORS .

Drug factors have also been associated with adherence. A study was done on schizophrenics to find out if dosing frequency had any effect on adherence. Adherence was compared among patients who experienced an increase or decrease in dosing frequency and among patients on stable regimens of once-daily or more than once-daily dosing. This study found that reduced dosing intervals lead to a modest increase in adherence (Pfeiffer et al., n.d.). In a 2-year prospective study of 254 patients recovering from a first episode of schizophrenia, schizophreniform, or schizoaffective disorder, Perkins et al examined the relationship between antipsychotic medication non-adherence. Subjects randomized to haloperidol were more likely to become medication non-adherent for one or more weeks than subjects randomized to olanzapine (Perkins et al., 2006). There are however other studies that differ in this argument. One example is the cross-sectional study of patients' perspectives on adherence to antipsychotic medication: depot versus oral which was done on 73 patients in London with schizophrenia and schizoaffective disorders. The findings were that beliefs and attitudes are more important than side effects in predicting self-reported adherence and influencing factors thereof. The conclusion was that prescribing a depot medication to enhance relapse prevention will not in itself ensure adherence and therefore must also be accompanied by discussion regarding adherence and associated personal benefits (Patel et al., 2008). Drugs adverse effects like weight gain, drowsiness and other extra pyramidal effects have also been associated with poor adherence (Taj and Khan, 2005)

2.16 COMORBID SUBSTANCE USE.

There is comorbidity of various mental illnesses and substance abuse. It is likely that during times of intoxications patients may not take their medication as required. Addicted patients may prefer to use their money on substances that make them feel good other than on health care. Predictors of future non-adherence were substance misuse and duration of untreated psychosis (Hill et al., 2010). In a prospective study done in the United Kingdom on predictors and clinical consequences of non-adherence, baseline predictors of non-adherence were alcohol dependence and substance abuse in the previous month, hospitalization in the previous 6 months, independent housing and the presence of hostility. Non-adherence was significantly associated with an increased risk of relapse, hospitalization and suicide attempts. The conclusion was that non-adherence is common but can partly be predicted. (Novick et al., 2010)

2.2 AFRICA

While a lot has been written on adherence in mental illness in the western countries, the situation is different in Africa. This is despite the high likelihood of contextual barriers that would be

unique to our continent that has high levels of poverty, fewer resources and high levels of crime (Breen et al., 2007). The symptomatology may vary in different ethnicities (Masłowski and Oosthuizen, 1993) and abnormal behavior characteristics of mental illness is likely to be interpreted differently in different cultures resulting in varying solutions being sought (Niehaus et al., 2004).

There is limited data on specific factors associated with adherence to treatments among the mentally ill in Africa. One study done in South Africa showed that patients had significantly fewer all-cause discontinuations for injectable risperidone (26.0%) compared to oral haloperidol and risperidone (70.2%) at 24 months (Emsley et al., 2008).

The concepts of spirits and witchcraft and its associations with mental illness is common especially in this part of the continent. This association has been demonstrated in Zimbabwe by a study that involved community members, primary care givers, the traditional and faith healers. Case vignettes were used to represent real situations. Angered ancestral spirits, evil spirits and witchcraft were seen as potent causes of mental illness. (Patel et al., 1995). Many viewed mental illness symptoms as social problems and that accordingly, the treatment for these was social, rather than medical. These findings are similar to those of a study done in Ghana to assess common understanding of mental illness among women (Ofori-Atta et al., 2010). Respondents attributed mental illness in women to women being the weaker sex, hormones, witchcraft, adultery, abuse and poverty. In a study in Nigeria causes of epilepsy were believed to include brain disorder, witchcraft, destiny, and demonic possession. Traditional medicine was the first preferred treatment option in 80.5% of participants; treatment approaches included herbal preparations, spiritual exorcism, special cultural diets, charms, and sacrificial offerings (Osungbade and Siyanbade, 2011). In a study on preferred treatment for mental illness among southwestern Nigerians, majority preferred spiritual and traditional healers to western medicine (Adewuya and Makanjuola, 2009)

2.3 KENYA

In Kenya like the rest of Africa, little has been written on adherence in mental health. This is despite the high likelihood of a lot of cultural influence on health care seeking behavior and adherence to prescribed treatments.

Dr Mareko in his master of medicine dissertation (2005) did a study on non adherence. In his study 171 patients and their 171 care givers in Mathari hospital found an absolute non compliance of 66.45%. When non compliance was less absolute (0-25% missed medications) the rate was of 43.7%. This study found a higher rate of noncompliance in psychotic disorders compared to other diagnoses. Higher rates were also found in patients with longer relapse duration when off treatment, poly pharmacy, those experiencing side effects of drugs, inadequate

information on illness and medication, and in comorbid substance use. Other factors that were positively associated with noncompliance in this study included unemployment and low income (Mareko . 2005).

In general health, witchcraft, evil spirits and charms have been reported as possible factors that affect health seeking behaviour (Mwenesi et al., 1995).The use of traditional herbs is not rare among various communities. Among the Samburu who associate most illnesses with pollutants that interfere with digestion, more than 80 plant species have been identified for medicinal purposes (Bussmann, 2006).The Masaai community in addition to pollutants, associate illnesses with witchcraft and also have several plants for medicinal use (Bussmann et al., 2006). Other communities also have herbalist and other traditional healers(Kareru et al., 2006) which implies that any illness viewed as having cultural origin is likely to be referred to them before seeking conventional medicines. There is no documented relationship between these factors and mental health and this study may establish any correlation.

While not much has been written about adherence to neuroleptics, there has been some work done in other medical fields which may also suggest what to expect in psychiatric care. Cost, ignorance, substance abuse and herbal medicines have been associated with poor adherence to drugs given for TB (Muture et al., 2011) while lack of time and forgetting were associated with poor adherence to ARVS (Wakibi et al., 2011).

CHAPTER 3: METHODOLOGY

3.1: STUDY DESIGN

This was a cross-sectional descriptive study.

3.2: STUDY SITE

The study was carried out at Mathari Hospital, the largest psychiatric referral and teaching hospital in Kenya. It is located in Nairobi County. It has a bed capacity of 600 patients and about 250 patients are seen in the outpatients departments (OPD) every week. It serves a big population with majority from Nairobi, Central and Eastern regions due to proximity. However, patients are referred from various health facilities across the nation due to the limited capacity of handling extremely disturbed patients in the peripheral hospitals, most of which have no psychiatric inpatient facilities.

The hospital outpatient department is open every day, for twenty four hours. Patients seen includes new patients referred from general hospitals around the country and those walking in to seek psychiatric services. Those who missed their clinics, and those who relapsed before their appointments are also seen here.

Every mentally ill patient seen in Mathari hospital is assigned to a ward, even if they are not admitted. Patient follow-up is done in the respective wards in the outpatient clinics that run every Tuesday morning with the exception of public holidays.

3.3: STUDY POPULATION

The study involved patients seen in the outpatient departments of Mathari hospital. These mostly consisted those attending the Tuesday clinics and in smaller numbers those who came on other days having missed their Tuesday clinics or for reviews for one reason or the other.

3.4: SAMPLE SIZE CALCULATION AND SAMPLING PROCEDURE

The sample size for the face to face interview was calculated using the formula by Naing et al (2006) as shown:

$$n = \frac{Z^2 pq}{d^2}$$

Where n is the sample size, Z is the standard normal deviation set at 1.96 to correspond to 95% confidence interval. p is the prevalence estimate set at 66.45% which was the absolute rate of non compliance at Mathari hospital (Mareko, 2005), q is $1-p$ and d is the degree of precision set at 0.05(5%).

The sample size after substituting the values was as follows;

$$n = \frac{1.96 \times 1.96 \times 0.66 \times 0.34}{(0.05)^2}$$

$$n = 344.$$

A total of 347 patients were interviewed.

In addition to these, 4 focused group discussions were conducted. Each group consisted of seven to nine participants.

3.5 RECRUITMENT PROCEDURE

Participants were recruited from the OPD. Any patient seen at the OPD during the period of study was given a chance to participate in the study. The patients were briefly assessed by the researcher as they waited to go in for their consultation or after they had been seen by the attending doctor. The stable patients were given an explanation of the study. Those who accepted to participate were further screened to ensure they fulfilled the required criteria and an informed consent was taken.

For participation in the focused groups, patients were recruited on Tuesday mornings, before the start of the clinics. Those who accepted to participate were put in groups of seven to nine for the focused discussions. The choice of Tuesday was informed by the large numbers of patients seen on this day that made it easier to get the required numbers. This also meant that these participants did not need to be given a different appointment for the study to avoid the cost implications of such an appointment. After the discussion the participants were able to continue with their clinic schedule therefore reducing inconveniences caused.

3.6 INCLUSION CRITERIA

1. Clinically stable patients, defined as not having florid symptoms of psychosis, disturbed mood or severe anxiety symptoms, as assessed by the researcher, that would affect understanding, reasoning and concentration.
2. Patients who had been on follow up for at least 6 months.
3. Patient who were aged 18 years or above.
4. Those who consented to participate.

3.7 EXCLUSION CRITERIA

1. Clinically unstable patient, defined as having florid psychotic, mood, anxiety, or other symptoms, as assessed by the researcher, that would interfere with understanding, reasoning and concentration.
2. Patients who were less than 18 years of age.
3. Patients who had been followed up for less than six months.
4. Those who failed to give consent to participate.

3.8: SAMPLING METHOD

Convenient sampling method was applied to get the desired sample size. Each patient who came to the hospital during the period of the study had a chance to participate. This was done because in the outpatient departments a good number of patients were likely to be disturbed a factor that could make getting the desired sample size take unnecessarily too long if a given randomization was done.

3.9: STUDY INSTRUMENTS

Three instruments were used;

1. Researcher designed Social demographic questionnaire which provided information on age, gender, level of education, social economic status and the details of social support network.
2. Researcher designed Adherence questionnaire with questions developed with reference to drug adherence questionnaire by Hogan et al, (2000), Moriskys 8 item self reported medication adherence rating scale, and Medication Adherence Rating Scale; MARS (Thompson et al, 2000).
3. Researcher designed FGDs guide.

3.10 : DATA COLLECTION, MANAGEMENT AND ANALYSIS

Data was collected on all working days between 8 am and 6 pm between the months of July 2012 and December 2012. This was done in two different ways. First, individual patients had face to face interview using the structured questionnaire. Data collected this way was entered into a password protected Microsoft Office Access Database while the original forms were kept in a lockable cabinet. After data entry was completed, entered data was checked against the hard copy questionnaires and any inconsistencies and errors identified were corrected. Data was analyzed using the statistical Package of social sciences (SPSS) version 17.

Secondly, four focussed group discussions were held on four different Tuesday mornings. These were facilitated by the researcher with an assistant to take notes and operate a tape recorder. Each FGD had seven to nine participants. The focus group discussions were audiotaped and the transcriptions typed out. These were compared with notes taken and harmonization of the responses was done. The discussions were organized into the following key themes.

1. Knowledge of the illness
2. Attitudes towards the prescribed medicine.
3. Reasons for non adherence
4. Beliefs and practices related to spiritual healing
5. Beliefs and practices related to spirits/ curses /and witch craft.
6. Beliefs and practices related to alternative treatments.

3.11: ETHICAL CONSIDERATIONS

After approval by the department of psychiatry, the science and ethical clearance was sought from the Kenyatta National Hospital Research and Ethics committee.

Patients had a brief explanation of the study by the investigator. They were allowed to make any clarifications and voice their concerns. Those who accepted to participate were screened to ensure they fulfilled a given criteria. Those who fulfilled the criteria were taken through informed consent explanation process and upon verbal consent, signed the written consent form.

There were no anticipated risks in the study apart from psychological invasiveness of assessing psychosocial and cultural factors associated with non-adherence. The participants benefited from this study by being educated on the negative effect of non adherence to psychiatric treatment. They were also allowed to ask any questions about their illness.

There was no material compensation for participating in the study as the patient did not suffer any pain or loss except for the time spent during the interview.

The participants were allowed to withdraw at any time before or during the study process without losing any benefits.

Confidentiality was maintained at every stage of the research. This was achieved by using numbers and not the names of the patients and locking all research materials in a private place until analysis was done.

3.13: TIMELINE

November 2011-February 2012	Proposal development
March-July 2012	Ethical clearance
July- December	Data collection
January- February	Data cleaning and analysis
March	Report writing
April	Report presentation

3.14: BUDGET (Amount in Kenya shillings)

Stationery	25 000
Computer services	20 000
Transport and communication	15 000
Data cleaning and analysis	35 000
Miscellaneous	10 000
Total	105 000

All the above expenses were met by the researcher.

CHAPTER 4: RESULTS

4:1 STRUCTURED INTERVIEW

4.1.1 SOCIAL DEMOGRAPHIC CHARACTERISTICS

TABLE 1: Social Demographic characteristics		N	%
Sex	Male	196	57.0%
	Female	148	43.0%
Marital Status	Married	118	34.2%
	Single	189	54.8%
	Widowed	18	5.2%
	Divorced	18	5.2%
	Other	2	0.6%
Religion	Muslim	14	4.1%
	Christian	325	94.5%
	Other	5	1.5%
Employment	None	209	60.8%
	Part-time	39	11.3%
	Full-time	96	27.9%
Reason for unemployment	Illness	106	84.1%
	Retirement	20	15.9%
Living with	Alone	62	18.0%
	Spouse	79	23.0%
	Parents	121	35.2%
	Sibling	41	11.9%
	Other	41	11.9%
Where lives	Rented	129	37.3%
	Own house	84	24.3%
	Family house	120	34.7%
	Other	13	3.8%
Income	None	3	2.1%
	< 1000	26	18.4%
	1000-10000	59	41.8%
	10000-20000	30	21.3%
	20000-50000	20	14.2%
	Over 50000	3	2.1%
Education	None	15	4.4%
	Primary	135	39.5%
	Secondary	136	39.8%
	University	24	7.0%
	Other	32	9.4%

A total of 347 patients were interviewed between the months of July and December 2012. The mean age was 36.8 years with the youngest being 18 years and the oldest 83 years old. The mean duration of illness for those interviewed was 9 years with a medium of 6 years, a minimum of 6 months and a maximum of 40 years. Most of the participants were male. Almost half of the respondents were single. Most of the participants were unemployed with only 27.9% in full time employment. The commonest reason given for unemployment was the illness. See table 1 above.

4.1.2: SELF REPORTED MISSED MEDICATION AND MISSED CLINICS

117 out of 347 of the patients reported missing medication since the previous visit, and 78 out of 347 had missed a clinic in the previous one year. See figure 1 below.

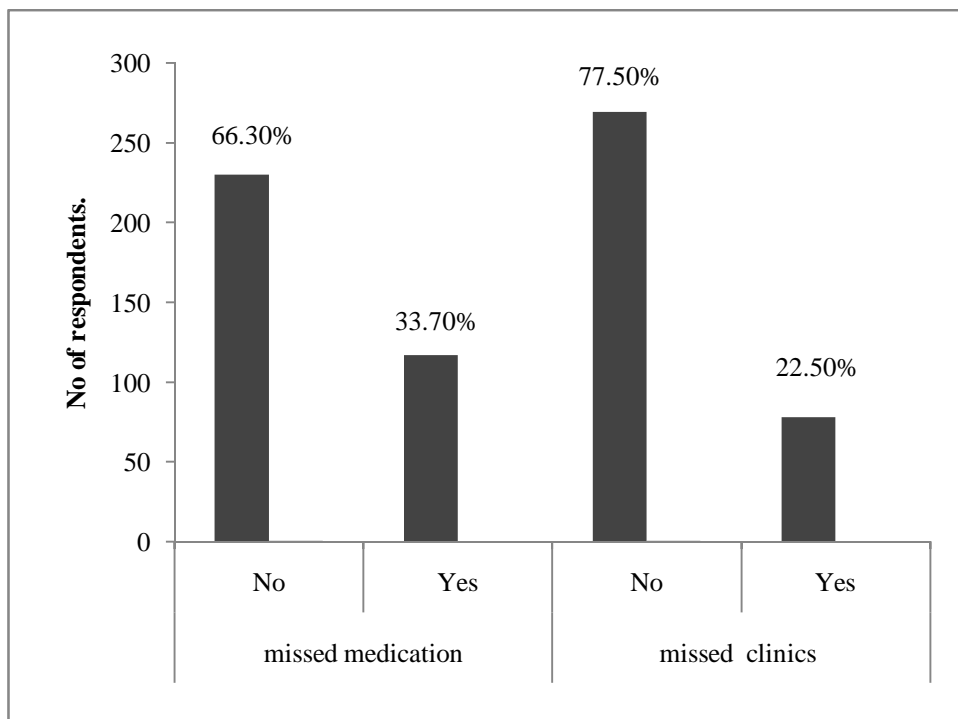


Figure 3 Number of patients missing clinics and medication.

As shown on table 2 below, the most frequent reason given for not taking medication was the drugs making the patient feel weird. This was followed by carelessness and feeling like one was better hence needed no drugs.

Table 2: Various Reasons for missing medication and clinics.

	No		Yes	
	N	%	n	%
Feeling medication is not helpful because illness is not medical	278	80.1%	69	19.9%
Feeling that have taken meds for too long and it is time to break	273	78.7%	74	21.3%
Feeling that have taken too long to get relief	244	70.3%	103	29.7%
Medication makes them feel wierd like a zombie	195	56.2%	152	43.8%
Fear of addiction to medication	248	71.5%	99	28.5%
Felt better and did not see need to continue	236	68.0%	111	32.0%
No good reason, I was just careless	223	64.3%	124	35.7%
Fear that people will know have mental illness	306	88.2%	41	11.8%
Preferred herbal medication or suppliments	306	88.2%	41	11.8%
Preferred or was directed to traditional healer or wotch doctor	319	91.9%	28	8.1%
Preacher prayed and proclaimed healing	272	78.4%	75	21.6%
Clan members conducted some rituals to cast out spells that were believed to be cause of illness	318	91.6%	29	8.4%
The clinic was too far from home	299	86.2%	48	13.8%
The medicine was too expensive	294	84.7%	53	15.3%
There was no one to accompany you to the clinic	304	87.6%	43	12.4%
The medication makes you feel worse	296	85.3%	51	14.7%

4.1.3:FACTORS ASSOCIATED WITH NONADHERENCE

SOCIAL DEMOGRAPHIC ASSOCIATIONS WITH MISSING MEDICATION

Sex , marital status , religion and employment did not affect non adherence. Although not statistically significant ($p > 0.05$) those who were living alone or with non close relatives (“others”), those who had lower income, and those who had lower levels of education had higher non adherence rates, see table 3 below.

Table 3: Association of Non adherence and Social demographic characteristics

		Have you missed any of your medications since last visit?				Chi-square	P value
		No		Yes			
		N	%	N	%		
Sex	Male	125	63.8%	71	36.2%	1.278	0.258
	Female	103	69.6%	45	30.4%		
Marital Status	Married	80	67.8%	38	32.2%	4.442	0.349
	Single	123	65.1%	66	34.9%		
	Widowed	13	72.2%	5	27.8%		
	Divorced	12	66.7%	6	33.3%		
	Other	0	0.0%	2	100.0%		
Religion	Muslim	9	64.3%	5	35.7%	0.118	0.943
	Christian	216	66.5%	109	33.5%		
	Buddhist	0	0.0%	0	0.0%		
	Hindu	0	0.0%	0	0.0%		
	Atheist	0	0.0%	0	0.0%		
	African traditional	0	0.0%	0	0.0%		
	Other	3	60.0%	2	40.0%		
Employment	None	142	67.9%	67	32.1%	4.446	0.108
	Part-time	20	51.3%	19	48.7%		
	Full-time	66	68.8%	30	31.2%		
Living with	Alone	37	59.7%	25	40.3%	6.424	0.170
	Spouse	52	65.8%	27	34.2%		
	Parents	88	72.7%	33	27.3%		
	Sibling	28	68.3%	13	31.7%		
	Other	22	53.7%	19	46.3%		
Income	None	0	0.0%	3	100.0%	7.374	0.194
	Less than 1000	17	65.4%	9	34.6%		
	1000-10000	38	64.4%	21	35.6%		
	10000-20000	17	56.7%	13	43.3%		
	20000-50000	12	60.0%	8	40.0%		
	Over 50000	3	100.0%	0	0.0%		
Education	None	9	60.0%	6	40.0%	1.871	0.759
	Primary	86	63.7%	49	36.3%		
	Secondary	92	67.6%	44	32.4%		
	University	16	66.7%	8	33.3%		
	Other	24	75.0%	8	25.0%		

ATTITITUDES AND BELIEFS

Non adherence was associated with: Feeling that the medication was not helpful ($p < 0.002$), feeling better and therefore no need of medication ($p < 0.001$), feeling that one had taken medication for too long and it is time to break ($p = 0.026$) and carelessness ($p < 0.0001$). See table 4 below.

Table 4: Association of attitudes, beliefs and non adherence

		Have you missed any of your medications since last visit?				Chi square	P value
		No		Yes			
		N	%	N	%		
Feeling medication is not helpful because illness is not medical	No	195	70.1%	83	29.9%	9.328	0.002
	Yes	35	50.7%	34	49.3%		
Feeling that have taken meds for too long and it is time to break	No	189	69.2%	84	30.8%	4.979	0.026
	Yes	41	55.4%	33	44.6%		
Feeling that have taken too long to get relief	No	166	68.0%	78	32.0%	1.127	0.288
	Yes	64	62.1%	39	37.9%		
Fear of addiction to medication	No	172	69.4%	76	30.6%	3.672	0.055
	Yes	58	58.6%	41	41.4%		
Felt better and did not see need to continue	No	170	72.0%	66	28.0%	10.920	0.001
	Yes	60	54.1%	51	45.9%		
No good reason, I was just careless	No	167	74.9%	56	25.1%	20.678	<0.0001
	Yes	63	50.8%	61	49.2%		

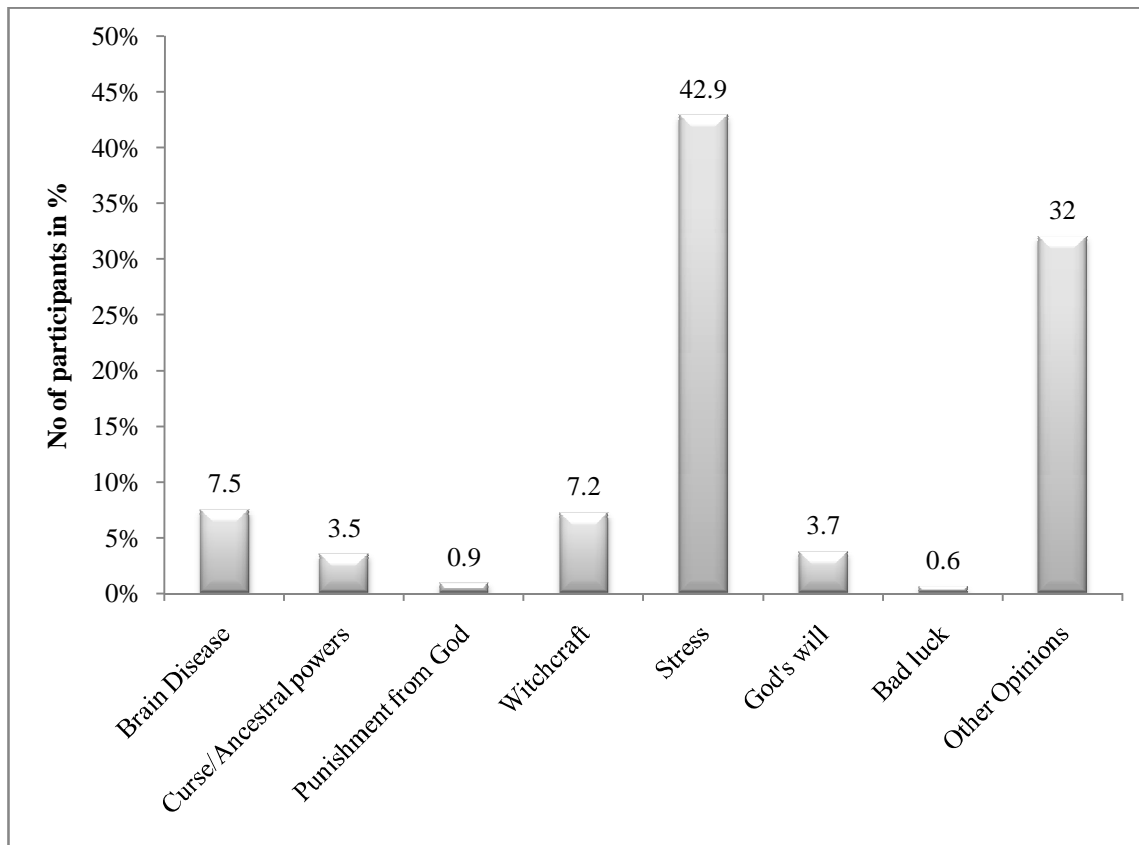


Figure 4 Patient's understanding of the illness.

KNOWLEDGE AND INSIGHT

Figure 4 above shows that majority of the patients (67%,) knew the illness they suffered from. However, probed further on their understanding of the illness, 42.5% reported the cause of their illness was stress and only 7.5% thought it was a brain disease.

Table 5: Association of knowledge of illness with nonadherence

		Have you missed your medication since last visit.					
		NO		YES		Chi square	P Value
		N	%	N	%		
Knows what they illness they are suffering from	No	64	57.1%	48	42.9%	6.181	0.013
	Yes	166	70.6%	69	29.4%		

Those who knew the illness they suffered from missed medication less (29%) than those who did not know the illness they suffered from 42.9%, and the difference was statistically significant (p 0.013) as shown on Table 5 above.

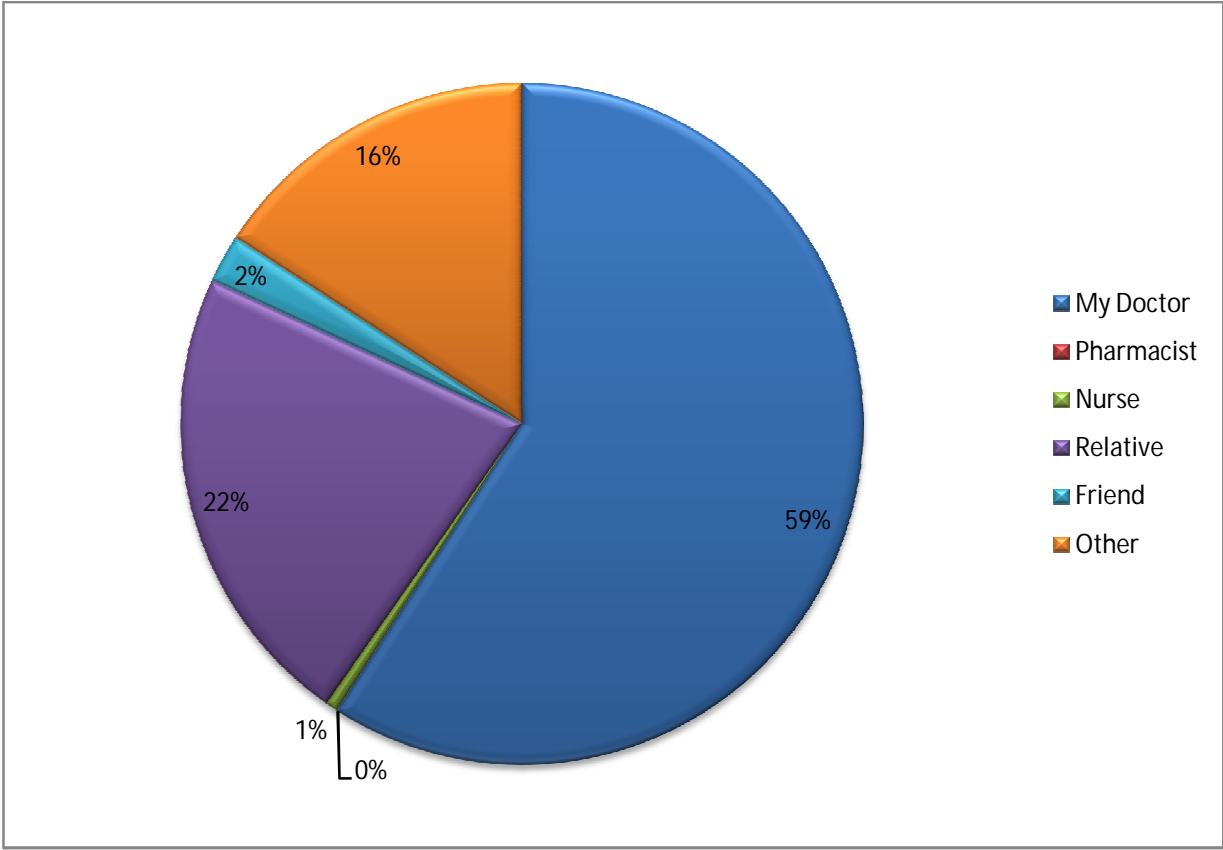


Figure 5: Source of information on the illness.

The figure above shows that doctors were the leading source of information about the illness and the drugs.

Table 6: Association of source of information with non adherence

		Have you missed any of your medications since last visit?				Chi square	P value
		No		Yes			
		N	%	n	%		
Who informed you about your illness?	My Doctor	149	73.8%	53	26.2%	34.272	<0.0001
	Relative	55	72.4%	21	27.6%		
	Friend	2	25.0%	6	75.0%		
	Other	20	37.0%	34	63.0%		

Those who got information from the doctors or relatives missed medication less than those whose source of information were either friends or ‘others’, and the difference was significant ($p < 0.0001$) as shown on Table 6 above

KNOWLEDGE OF THE DRUG

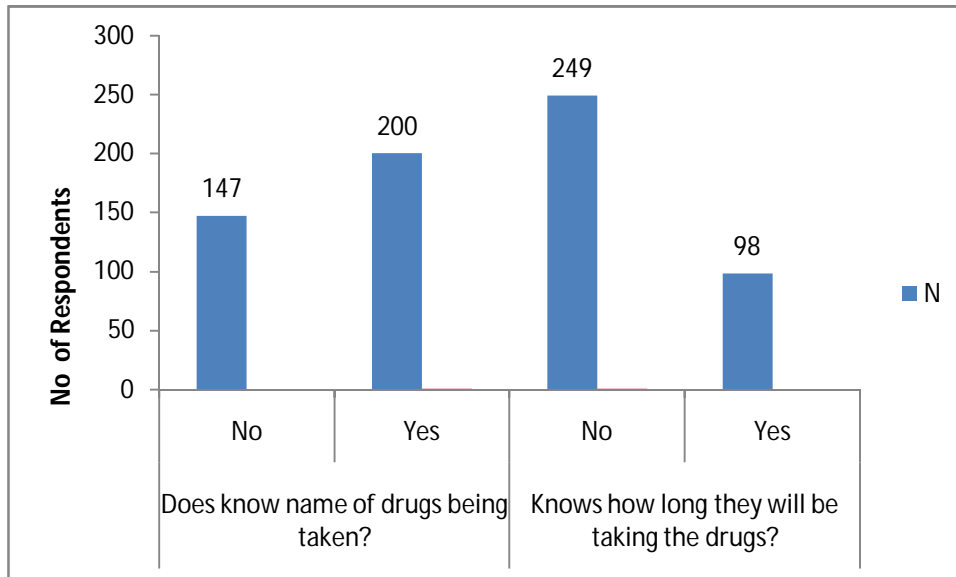


Figure 6 Knowledge of the drug.

Figure 6 above shows that 57.6% of the respondents knew the names of the drugs they were taking while only 28.2% (98/ 347) knew the duration they would be taking the drugs.

Table 7: Association of knowledge of the drugs with nonadherence

		Have you missed any of your medications since last visit?				Chi square	P value
		No		Yes			
		N	%	N	%		
Does know name of drugs being taken?	No	88	59.9%	59	40.1%	4.701	0.030
	Yes	142	71.0%	58	29.0%		
Knows how long they will be taking the drugs?	No	167	67.1%	82	32.9%	0.244	0.622
	Yes	63	64.3%	35	35.7%		

Those who did not know the names of the drugs missed medication significantly more than those who knew(p value 0.030) .

STIGMA

Table 8: Responses of perceived or experienced Stigma

	Have you missed any of your medication since last visit?		
		N	%
In your opinion is your illness different from other illnesses such as Asthma, Hypertension, Diabetes	No	183	52.7%
	Yes	164	47.3%
Would you disclose your nature of illness to your friends, or employer?	No	100	28.8%
	Yes	247	71.2%
Have you ever been denied anything at work or at your home or anywhere else because of your illness?	No	293	84.4%
	Yes	54	15.6%
Have you or you family member been ill treated because of the nature of the illness you are being treated for	No	321	92.5%
	Yes	26	7.5%

47% of the patients viewed the mental illness as different from other illnesses and majority (71.2%) would comfortably disclose the nature of their illness to other people. Very few patients reported being discriminated against either as an individual or as a family

Table 9: Association of stigma with non adherence

		Have you missed any of your medications since last visit?				Chi square	P value
		No		Yes			
		N	%	N	%		
In your opinion is your illness different from other illnesses such as Asthma, Hypertension, Diabetes	No	130	71.0%	53	29.0%	3.919	0.048
	Yes	100	61.0%	64	39.0%		
Would you disclose your nature of illness to your friends, or employer?	No	60	60.0%	40	40.0%	2.481	0.115
	Yes	170	68.8%	77	31.2%		
Have you ever been denied anything at work or at your home or anywhere else because of your illness?	No	200	68.3%	93	31.7%	3.293	0.070
	Yes	30	55.6%	24	44.4%		
Have you or you family member been ill treated because of the nature of the illness you are being treated for?	No	211	65.7%	110	34.3%	0.581	0.446
	Yes	19	73.1%	7	26.9%		
Fear that people will know have mental illness	NO	212	69.3%	94	30.7%	10.420	0.001
	YES	18	43.9%	23	56.1%		

Higher rates of non adherence was found among those who felt their illness was different from other illness (P 0.048) and those who reported missing medication for fear of others knowing they have a mental illness (p = 0.001). See Table 9 above.

SOCIAL SUPPORT

Figure 7 below shows that most patients did not have to be reminded by others to attend the clinic or take medication. Parents were the leading payers of the medical expenses. Most of the patients shared with their parents feelings of unwellness. 27.3% reported that they would not tell anyone that they were ill.

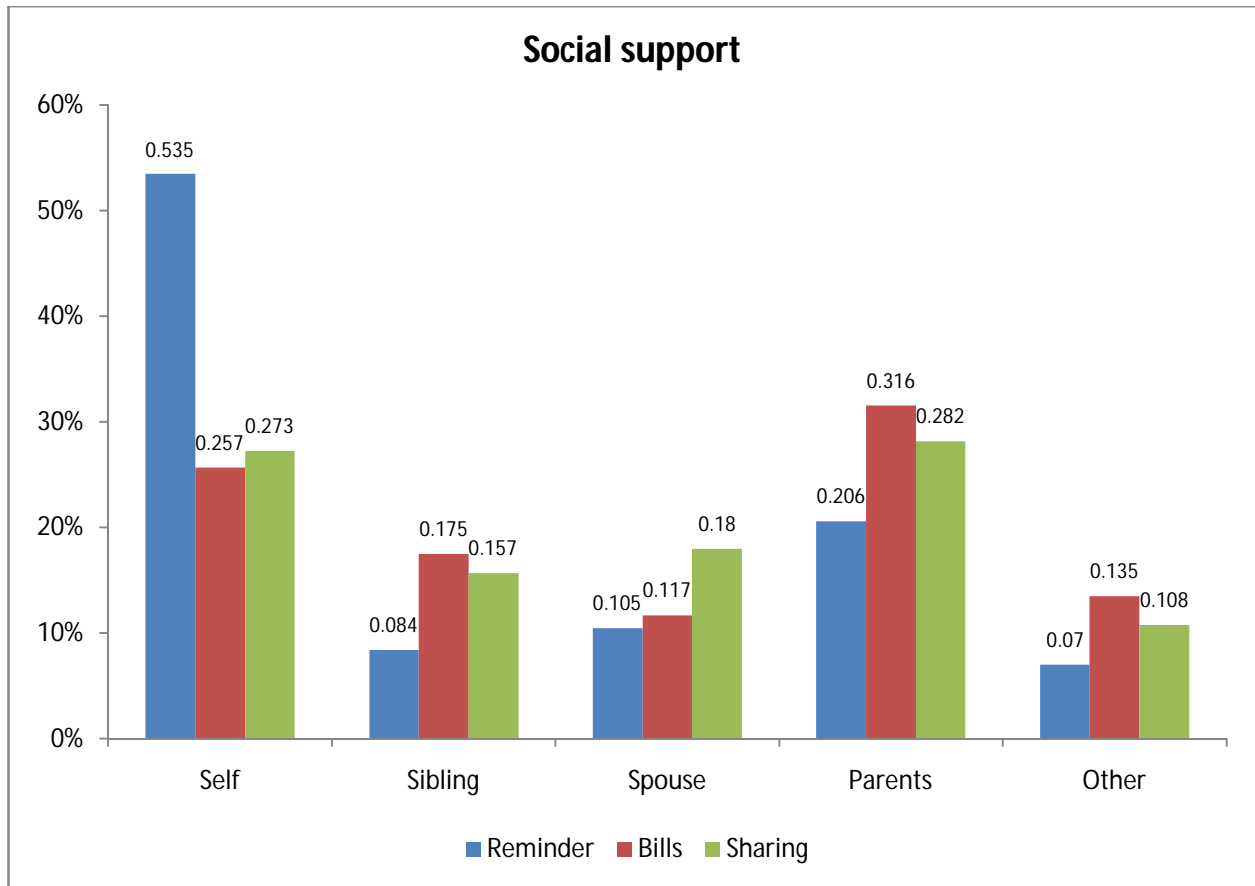


Figure 7: financial and emotional support

Table 10 below shows that those who did not have close relations to remind them to take medication had higher rates of missing medication (p 0.032). The highest rates of missed medications were among those who either told non close relations at 51.4% (“Others”) or no one at 43.6% when they felt low or unwell. There were significantly lower rates of missed medication among those who shared their feelings with either parents, siblings or spouses (P =0.002)

Table 10: Association of social support and adherence.

		Have you missed any of your medications since last visit?				Chi-square	P value
		No		Yes			
		n	%	N	%		
Who reminds you to attend clinic and take medication	Self	128	69.6%	56	30.4%	10.552	0.032
	Sibling	17	58.6%	12	41.4%		
	Spouse	28	77.8%	8	22.2%		
	Parents	45	63.4%	26	36.6%		
	Other	10	41.7%	14	58.3%		
Who pays for your medical bills?	Self	60	68.2%	28	31.8%	3.076	0.545
	Sibling	39	65.0%	21	35.0%		
	Spouse	29	72.5%	11	27.5%		
	Parents	74	68.5%	34	31.5%		
	Other	26	56.5%	20	43.5%		
Who do you tell when you feel low/or when you feel like you are unwell?	No one	53	56.4%	41	43.6%	16.659	0.002
	Sibling	35	64.8%	19	35.2%		
	Spouse	45	72.6%	17	27.4%		
	Parents	76	78.4%	21	21.6%		
	Other	18	48.6%	19	51.4%		

ALTERNATIVE TREATMENTS

Table 11: Traditional/alternative medicines

	No		Yes	
	N	%	N	%
Preferred herbal medication or suppliments	306	88.2%	41	11.8%
Preferred or was directed to traditional healer or witch doctor	319	91.9%	28	8.1%
Preacher prayed and proclaimed healing	272	78.4%	75	21.6%
Clan members conducted some rituals to cast out spells that were believed to be the cause of illness	318	91.6%	29	8.4%

Few patients reported seeking alternative treatments, inform of herbal medications, miraculous healing or cultural rituals as shown in Table 11 above.

Table 12: Association of alternative medication and nonadherence

		Have you missed any of your medications since last visit?				Chi square	P value
		No		Yes			
		N	%	N	%		
Preferred herbal medication or suppliments	No	211	69.0%	95	31.0%	7.272	0.004
	Yes	19	46.3%	22	53.7%		
Preferred or was directed to traditional healer or wotch doctor	No	215	67.4%	104	32.6%	2.202	0.138
	Yes	15	53.6%	13	46.4%		
Preacher prayed and proclaimed healing	No	176	64.7%	96	35.3%	1.400	0.237
	Yes	54	72.0%	21	28.0%		
Clan members conducted some rituals to cast out spells that were believed to be cause of illness	No	214	67.3%	104	32.7%	1.748	0.186
	Yes	16	55.2%	13	44.8%		

Those who used herbal medication missed medication significantly more than those who did not use them (P value of 0.004).

COST OF TREATMENT

Table 13: Cost and non adherence

	No		Yes	
	N	%	n	%
The clinic was too far from home	299	86.2%	48	13.8%
The medicine was too expensive	294	84.7%	53	15.3%

Cost of medication and long distance of clinic from home was cited as a reason to miss medication by a few patients as shown in table 13 above.

Table 14: Association of cost of treatment with nonadherence

		Have you missed any of your medications since last visit?				Chi square	P value
		No		Yes			
		N	%	N	%		
The clinic was too far from home	No	201	67.2%	98	32.8%	0.858	0.354
	Yes	29	60.4%	19	39.6%		
The medicine was too expensive	No	206	70.1%	88	29.9%	12.343	<0.0001
	Yes	24	45.3%	29	54.7%		

As table 14 above shows ,those who felt the medication was too expensive missed medication more than those who did not view cost as a hindrance (P<0.0001).

DRUG FACTORS

Table 15 Adverse effects of drugs as a reason for missed medication

	Have you missed any of your medication since last visit			
	NO		YES	
	n	%	n	%
The medication makes you feel worse	296	85.3%	51	14.7%
Medication makes them feel wierd like a zombie	195	56.2%	152	43.8%

43% of the patients reported missing medication because of feeling wierd like a zombie .

TABLE 16: Drug factors.versus non adherence

Have you missed medication since last visit							
		No		Yes		CHI Square	P value
		N	%	N	%		
Medication makes me feel wierd like a zombie	No	139	71.3%	56	28.7%	4.979	0.026
	Yes	91	59.9%	61	40.1%		
The medication makes you feel worse	No	207	69.9%	89	30.1%	12.006	0.001
	Yes	23	45.1%	28	54.9%		

The rate of missing medication was higher among those who felt worse on taking medication (P = 0.001) and those who reported feeling lika a zombie on taking medication (p = 0.026).

4.2 RESULTS II- FOCUSED GROUPS.

Four groups were recruited for discussion on four different Tuesday mornings. The discussions were held within the wards between 9am and 10am. All participants were adults comprising 16 males and 17 females.

GROUP NO	NUMBER OF PARTICIPANTS	GENDER	WARD
1	9	Male	6 M
2	7	Male	5M
3	8	Female	6F
4	9	Female	2F

REASONS FOR NOT TAKING MEDICATION

Participants were asked to give some of the reasons for not taking medication as prescribed. The reasons were varied and included ; side effects of drugs, stigma, cost and lack of understanding of the illness. Some of the responses given are

Group 1

“I hate being associated with madness. People treat me very badly because I take these drugs. Its like having HIV. I feel bad when they tie me down and bring me to hospital”.

“To avoid being stigmatized, people underrate you when they know you are taking the drugs for mental illness. They can tell because you gain weight and look sleepy”

“The drugs make my tongue heavy and I start drooling saliva”.

“There are times I feel I am healed, there are no hallucination so there is no need of continuing with the drugs”.

“I sell clothes in Gikomba market and have to wake up very early. Sometimes I forget to take medication and remember when I am at the market”.

“Money to buy the medicine is a problem. There is no one at home to buy me and I have to ask the social worker to help”

Group 2

“The drugs have a lot of side effects, especially shaking of the hands and drowsiness”.

“I feel I am cured so I do not see the need for more medication”.

“Some drugs are very expensive. Currently the doctor prescribed a drug worth 1800 Kenya shillings and I cannot afford it”.

Group 3

“When the symptoms go ,I feel cured so I do not see the need for daily medication”

“I have once been prayed for and was told I am cured so I stopped taking medication”

“Peer pressure affects young people like me. My friends think its strange to take medication daily so I sometimes stop to avoid feeling the odd one.”

“ I had been cured and was well for 17 years (between 1995 and 2012). I was not taking any medication all those years and I did not have any problems”.

Group 4

“I feel very sleepy I even get late to work. To avoid losing my job I just avoid taking medicine unless I feel very bad”.

“ I have taken the drugs for too long and sometimes a just need a break”.

“I have been healed for the last one year so I should not take the medication every day. I only take them when getting sleep is a problem”.

“I was well for 4 year and I believed I had been cured so I stopped medication. I did not expect to be sick again.”

KNOWLEDGE AND INSIGHT

The respondents were asked to describe what they understood as the illness they suffered from. The commonest responses given for this was Malaria, stress and depression. Few patients gave the scientific names . Its important to note that in each of the four groups there was atleast one patient who confessed not knowing the very reason they were taking medication.

Some of the representative responses include;

GROUP 1

I suffer from stress”

“I don’t know what I suffer from, they said I was behaving funny so they brought me here and I was put on medication”.

“I have cerebral malaria”

GROUP 2

“I have an alcohol problem, I am not a mental case”

“I have cerebral malaria”.

“I don’t know, my people bought me here out of malice”.

“They want to get my piece of land because they say I am a mental case”

Group 3

“I know I have a mental illness but I do not understand the scientific name”.

“I was told it is depression because I feel hopeless”.

GROUP 4

“I have never been told; I just come and get medication”.

“There is a stranger that lives in me; I take medication to remove her”.

BELIEFS ABOUT THE CAUSE OF ILLNESS

The respondents were asked to say what in their opinion caused the illness they suffered from. Stress, inheritance, witchcraft and evil spirits were the commonest causes given by the participants. Substance abuse was also frequently named with alcohol and cannabis being dominant. Some of the representative responses include.

Group 1

“I was bewitched by a neighbor. I was doing well financially and they were jealous of me”.

“It is hereditary; my family has a history of mental illness. A brother and an uncle had been affected”.

“There are a lot of problems in the family that bring stress to me. I think a lot about them”.

“Bacteria from the cement industry I was working in must have clogged the brain”.

Group 2

“Excess alcohol and cannabis use abuse”

“I think it is angry spirits from our ancestors because my brothers and father also had the same illness.”

Group 3

“Family conflicts, there is a lot of disharmony at home”.

“May be its being too religious, I talked too much about salvation when they first brought me here”.

“I was arrested and the life in prison was traumatizing. By the time I left I was confused and they said I am mad”.

Group 4

“Family conflicts, my husband drinks and comes home late. He is very harsh to me”.

“I used to abuse cannabis and Miraa. These must have damaged my brain”

“Some evil spirits planted some stranger in me”.

May be it's a curse or witch craft. I have never known”.

ATTITUDES TOWARDS MEDICATION

The respondents were asked what they thought about the drugs they were currently taking and whether they felt the drugs were helpful to them.

Most of the patients felt that the drugs were very helpful. However a good number reported that although the drugs were helpful, the drugs had side effects that created discomfort. A few patients however did report that the drugs did not help them as they were still experiencing their initial symptoms. Some of the responses given were;

Group 1

“Sometimes they help reduce the voices that I used to hear. Sometimes they do not seem to help”.

“I have taken them for so long and am not healed so I cannot say they work”

Group 2

“Yes the drugs are good, there is a time I was so sick I could not go to work. I am a teacher and am back to work. I would recommend them to someone with a mental illness”.

“I have taken these drugs for so long but I think I have become resistant. They don’t seem to work on me. I still hear voices talking to me”

Group 3

“The drugs have really helped me, I am a civil servant and I am able to continue with work. My bosses understand that I have to come to clinic and they are supportive. I would not stop using these drugs”.

“Of course the drugs are good. I was not able to sleep and now I sleep like a child. Though they have some side effects they are very helpful”.

“I have taken the drugs for one year and I do not feel any different. For me the drugs do not help”.

Group 4

“They make me feel bad, tired and without energy. Am not sure they are helping me”.

PRAYERS AND SPIRITUAL HEALING

Participants were requested to give their thoughts and practical experience regarding prayers and spiritual healing in mental health, There were mixed feeling spiritual healing.. Most of the patients preferred combining prayers and medication. Others felt that there is no such thing as miracle healing while others reported being healed through prayers.

Some representative responses are;

Group 1

“Prayer can be helpful if it is combined with medication. I do not believe in total spiritual healing”

“I have been prayed for and I got well so I believe in prayers. This is true because demons make you hear voices”

“I have been prayed for by a prophet and was told I am healed but I still came back here so in my opinion those prayers do not work”

Group 2

“Well I think God is powerful and real prayers work. I have never had an opportunity but if it came I would go for the prayers.”

“I have tried going to those preachers but I did not get well so I doubt they work. Those guys are after money.”

“I haven’t seen anyone cured of mental illness from prayer but I have seen drugs work so I go for medicine.”

Group 3

“I used to think that Satan brought the disease so I had to go for prayers. The preacher claimed he had removed the demons but the disease persisted. This healing thing is a hoax.”

“My people insisted I should be prayed for but I did not see any help. May be it depends on a person’s faith.

“I have gone for those prayers because the drugs were taking too long. The prayers gave me some peace but I was not cured so I have continued with medication”

Group 4

“I tried those prayers at one point, I even paid money because they promised I would be healed. I learnt these preachers are in business and they just want to exploit us because they know we are desperate.”

“Yes it worked for me and I was healed for one year. If you believe ,you will be cured.”

“I have no experience with that kind of healing, I have never heard anyone who was prayed for and got healed.”

WITCHCRAFT, SPIRITS AND CURSES.

Participants were asked to give their opinion about mental illness being linked to witchcraft, spirits and curses.and where possible to give a personal experience.

A good number of patients associated their illness with witchcraft, some evil spirits and unresolved cultural demands. Some had been taken to the witch doctors while others had some cultural rituals performed to cure them. Those who had actually been subjected to such rituals and then brought to the hospital were strongly opposed to them, especially when such practices did not improve their symptoms. Representative responses are given below.

Group 1

“The voices that one hears could be coming from evil spirits”.

“I believe that I was cursed and that is why I am here. I used to be well and I cannot say am sick because I do not feel pain anywhere”.

“I used to think I was bewitched but when I was taken to the witch doctors I did not get well. It’s a lie. I don’t believe the witchcraft has anything to do with my illness”.

“It is possible ancestral spirits can contribute. Sometimes when I did not seem to improve my parents thought it was something to do with my grandparents, they even tried taking some goats. After that I improved”.

“There is a connection between mental illness and evil spirits because a neighbor of ours was jealous that we were doing well financially. I believe she must have thrown some evil spirits to our home that caused me the mental illness”.

“I don’t believe in those things. An illness is an illness. There is no need of looking for explanations”.

Group 2

“I think mental illness is a normal illness and to associate it with witchcraft is to give the devil credit”.

“There is witchcraft but it is not the one that causes mental illness.”

“The evil spirits can be sent to you by evil people who do not want you to succeed. I believe that is why I am here today. The world is evil.”

“I do not know about witchcraft, I have never see it being practiced near me so I do not think it exists”

Group 3

“The abnormal behavior that one has during the illness may be misinterpreted as evil spirits. Until a doctor explained that it’s an illness, I believed I was bewitched.”

“It is stigma that makes people say that mental illness is witchcraft, just because they do not understand the mental illness does not mean some evil spirit is at work”.

“In my case I feel like there are unresolved family conflicts that have made the ancestral spirits unhappy. We have even gone to take some goats to my maternal home to appease them.”

“We have done a lot of rituals at home because my people believe that I have some evil spirits. I have not felt any benefit of those rituals. The medication is better because my sleep has improved”

Group 4

“Evil spirits and witch craft are there even in the bible. The thing is they are not the cause of mental illness. Mental illness is just like any other disease.”

“Some people strongly believe that mental illness is too strange to be a normal illness. My family initially believed in it so much. They took me to the witch doctors severally. It cost a lot of time and money. I did not get well. When I became worse they decided to bring me to Mathari”.

“ According to our traditions (Kikuyu) if a woman like me gets a strange illness they associate it with dowry or curses. For me we had to take some money to my father because my husband’s family believed it’s because they have not completed paying my dowry.”

HERBAL AND OTHER TRADITIONAL MEDICATIONS

Participants were asked to give their views and personal experience on use of herbal or traditional medication as opposed to the conventional medicines given in hospital.

The use of herbal medication was not very popular with most patients. A good number had tried them without improvement. Others continued to use them in combination with the prescribed medicine. The general feeling was that the hospital medication was superior to the herbal medication.

Group 1

“Yes the herbs work, I have used them and they cured me. Unfortunately due to stress I became unwell again.

“I do not think they work because the herbalists do not even know what they contain”.

“I have been given some traditional medicine from the village before I was brought here. They did not help and that is why I was brought to the hospital.”

“One herbalist gave me some liquid to use and told me to stop taking the drugs you gave me. I became so sick I was admitted into the hospital soon after. I would not take them again”

“Sometimes we get desperate when these drugs do not seem to work well and we go for any other alternative hoping it will help. You cannot blame us.”

Group 2

“I have used some for such ailments like headache but I would not dare use them for mental illness. I fear going back to the way I was before I was given the drugs am currently on.”

“I was given one called MURUGU .I used it for one year and I was ok. I can say they work”.

“Some are so expensive yet they do not work. I would call it business to exploit us because they know we are desperate”.

“I have used some traditional medicine and I combined with the drugs am given here without any complication. I think its ok to use them ”

Group 3

“I have combined them with the drugs am used but I did not see any additional benefit. They were expensive so I stopped using them”.

“It’s a bad idea to use them without knowing the contents. At least I read about the drugs am given for my Bipolar disorder and understand how it works. Those herbs have no clear description of content and dosing. I would not advise anyone to take them”.

“I visited a herbalist because I felt the drugs I was given in hospital were taking long to work. He told me to take his herbs with half the dose of the medication I was given here. I relapsed soon after. I am confident that they do not work.”

Group 4

“They do not work. When I got ill my people went to Kisii, my home village to get some roots. I took them. They did not help me. I even got worse. They do not work”

“I had taken drugs for 4 years so when I was told the herbs will cure my illness I decided to try. They were very costly but I was desperate for a cure. The herbalist kept encouraging me to take them but while taking them I had a very bad attack and had to be admitted. I discovered the hard way that these guys are con men. I will never try that again”

“I have used them and they helped me a little. I have to combine them with the medicine I am given here”

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATION

5.1: DISCUSSION

High nonadherence rates have been demonstrated among mentally ill patients. This study found a nonadherence rate of 33.7% which is slightly lower than rates that have been found in other studies, and is likely to be due to the indirect, self reporting method of assessment used in which many patients are likely to under report their failure to take medication. Studies in USA among schizophrenics found rates of 41.2% (Lacro et al., 2002a) and 60% among patients with bipolar mood disorders (Lang et al., 2011). Any rate of non adherence is unacceptable as it results in recurrent admissions, longer hospital stays and greater cost of care (Offord et al., 2013), therefore reducing the quality of life of these patients (Adelufosi et al., 2012).

5.1 1: FACTORS ASSOCIATED WITH ADHERENCE

SOCIAL DEMOGRAPHIC FACTORS.

Although this study did not find an association between employment status and non adherence, its important to note that majority of the patients were unemployed and majority of them related this to their illness. This finding is not unusual given the social occupational impairments that results from common mental disorders, the lower educational attainment, unfavourable market dynamics and poor legislative laws to protect them against discrimination by employers, as demonstrated in a study in USA to establish employment barriers for persons with psychiatric illness (Cook, 2006). Most participants in this study who were employed had low salaries and this low economic status is likely to result in dependence on others for healthcare expenditure and other material needs. This study, found no significant relationship between non adherence and age, sex or marital status, findings that were similar to a study done in USA (Lacro et al., 2002b) implying that such characteristics often do not affect how well one takes medication. While this study did not find an association between non adherence and level of education, another study (Hudson et al., 2004), showed that low education level was significantly associated with non adherence.

KNOWLEDGE AND INSIGHT

Knowledge of the illness increases adherence as patients understand the need for using medication (Beck et al., 2011). In this study most of the participants did not fully understand the illness they suffered from. Majority thought they suffered from stress and only few thought they had a brain disease. This was demonstrated by the focused group discussions where most patients thought they had stress, depression and malaria. One patient best described the lack of awareness when they said, *“I don’t know what I suffer from, my family said I was behaving funny so they brought me here and I was put on medication”* and another one who said, *“I don’t know, my people brought me here out of malice. They want to get my piece of land because they*

say am a mental case". In this study lack of knowledge of the illness and of the drugs they were taking resulted to higher levels of non adherence . Interestingly the source of such information was important, with those whose source of information was relatives and doctors being associated with the lower levels of non adherence possibly because a clinician or a close relative is likely to give more accurate information. These results compares with a study done in Pakistan in which God's will' (32.3%), 'superstitious ideas' (33.1%), 'loneliness' (24.8%) and 'unemployment' (19.3%) were given as the cause of mental illness (Zafar et al., 2008). A study done in France among patients with psychosis showed that poor insight was associated with poor adherence (Droulout et al, 2003) and an expert consensus in Texas endorsed poor insight and lack of awareness as important factors leading to poor adherence (Velligan et al., 2009).

ATTITUDES AND BELIEFS

The opinion one holds about the illness and the drugs is likely to have a bearing on compliance to any form of therapy offered. A positive attitude would act as a drive to take medication even when it doesnot seem very necessary as during remission. In this study negative attitudes towards medication and the illness were associated with higher non adherence rates. Feeling the medication is not helpful because the illness is not medical, not seeing the need to continue with medication and even carelessness had statistically higher rates of nonadherence. Such attitudes were exemplified in the focused group discussions when one patient said *"I hate being associated with madness. People treat me very badly because I take these drugs. Its like having HIV. I feel bad when they tie me down and bring me to hospital"* Another one said *" I have taken the drugs for 1 year and I do not feel any different. For me the drugs do not help"* Such patient are highly unlikely to take medication outside the hospital . The importance of patient's attitudes in nonadherence was demonstrated by a study done in Austria (Rettenbacher et al., 2004) , emphasizing the need to include the patient in prescription decision process in order to enhance adherence.

STIGMA

Most of the patients in this study did not feel discriminated against. These findings contradict other findings which have showed that mental illness is highly stigmatized . This is likely to be due to the fact that the various aspects of prejudice were not exhaustively explored in this study. A survey on the global pattern of experienced and anticipated discrimination, against people with schizophrenia done in 27 different countries revealed that negative discrimination was experienced by 47% of the participants in making or keeping friends, 43% from family members, 29% in finding a job, 29% in keeping a job, and 27% in intimate or sexual relationships. Anticipated discrimination affected 64% in applying for work, training, or education and 55% in looking for a close relationship; 72% felt the need to conceal their diagnosis. Over a third of the participants anticipated discrimination for job seeking and close personal relationships when no discrimination was experienced (Thornicroft et al., 2009) . In Canada a survey on employment discrimination showed that mentally ill patients experience

direct discrimination because of prejudicial attitudes from employers and workmates.(Stuart, 2006) thus resulting in poor participation in labour force (Cook, 2006).

When one is discriminated against because of the mental illness or the effects of the drugs they take, they are likely to developed resentment and bitterness, may find it difficult to comply to prescribed therapies. In this study feeling that the illness was different and fear of other people knowing that one had a mental illness resulted in significantly higher levels of nonadherence. One of the patient sexemplifies this by saying that the reason they did not take medication was *“To avoid being stigmatized, as people underrate you when they know you are taking the drugs for mental illness. They can tell because you gain weight and look sleepy”*.

SOCIAL SUPPORT

Mentally ill patients require a good support net work to cater for their emotional and material needs. In this study a high number of patients were not able to share their feelings when they felt low a factor that was significantly associated with higher levels of nonadherence. The ability to share negative feelings would reduce any negative feelings about the drugs and would provide an avenue for encouragement. Sharing such feelings with those who care can lessen the impact of disease on ones emotion and promote feeling of well being that would then enhance compliance. Depending on friends or distant relatives as reminder to take medication resulted to higher non adherence rates as such are likely to be unstable and inconsistent.. These findings are similar to the findings of a study done in Nigeria (Adewuya et al., 2009) which have showed that poor social support is associated with non adherence and this results in poor quality of life (Adelufosi et al., 2012). The fact that taking drugs daily is cumbersome requires that one has support that ensures that compliance is maintained. During relapse a patient requires someone who can be accountable in order to give a reminder or literally administer the drugs. Lack of such support will be detrimental to adherence.

Although this study did not show an association between financial support and non adherence, it is common knowledge that financial support is important especially where insurance cover is limited This is complicated by the fact that many of the mentally ill patients are often unable to participate in income generating activities, or if they do, it is to a smaller scale compared to healthy individuals, making them relatively dependent on others.

ALTERNATIVE TREATMENTS

Witch craft,

In this study witchcraft did not significantly contribute to higher rates of non adherence. This is despite the fact that mental illness is often thought to be caused by magical powers and patients may seek help from withdoctors before seeking psychiatric services. In this study few patients reported seeking witchdoctors as reason for missing medication or follow up. This is not surprising as such practices are not widely accepted and would rather remain a secret to avoid

embarrassments. However, in the focused group discussion some participants reported having experiences with the witch doctors. One participant said *“Some people strongly believe that mental illness is too strange to be a normal illness. My family initially believed in it so much. They took me to the witch doctors severally. It cost a lot of time and money. I did not get well. When I became worse they decided to bring me to the hospital”*, demonstrating that such practices are not very rare in this set up. Findings of a study done in Tunisia showed that 43% of relatives of schizophrenic patients believed the disease was caused by witchcraft and 30.8% believed in such practices as exorcism.(Bouhlef et al., 2012).

Spiritual healing

The fact that mental illness presents as behavioral disturbances as opposed to pain or visible injury creates room for many to think of it as a spiritual affair and not normal illness. The concept of demon possession is not rare and many seek spiritual healing for what they believe is a spiritual illness. In this study however, few reported seeking such healing, and those who had sought prayer and healing did not have higher rates of nonadherence. Nevertheless spirituality and religion has been shown to have a role in the management of mental illness and has been associated with better sense of self and coping with illnesses (Mohr et al., 2012). In addition mentally ill patients seek help from churches before visiting psychiatric facilities as was shown by a study on the pathways to mental health delivery in Nigeria (Erinosho, 1977). Any benefits from prayers may be reversed when patients are promised healing and urged to abandon their medication. When the cure does not happen the results can be despair and suffering. This was best demonstrated by a participant in the discussion group who had this to say; *“I tried those prayers at one point, I even paid money because they promised I would be healed. I learnt these guys are in business and they just want to exploit us because they know we are desperate”*. As this participant said, the chronicity of mental illness and the not too rare poor response to treatment may put one in a desperate position. These patients may be victims of miracle workers, who promise instant healing and a drug free life. In the focused group discussion many patients did not believe in abandoning the treatments but would not hesitate to combine the prayers and the medication.

Herbal medication

The chronicity and distress of living with mental illness can result in a search for promising herbal or food supplements (Chiappedi et al., 2012). Studies have been conducted to establish the effectiveness of specific plants in psychiatric practice (Sarris and Kavanagh, 2009) with issues of dosing, tolerability and efficacy still at large (Sarris, 2007). In this study use of herbal medication was reported by the minority, and a good number combined them with the prescribed medication. As put across by one participant, *“I had taken drugs for four years so when I was told the herbs will cure my illness I decided to try. They were very costly but I was desperate for a cure. The herbalist kept encouraging me to take them but while taking them I had a relapse and had to be admitted. I discovered the hard way that these guys are con men. I*

will never try that again “, most patients seek the herbs as an alternative when they don't seem to get well as fast as they would wish. As demonstrated in this study, this significantly affects the use of conventional medication as herbalist, unlike clinicians promise cure, making them “a better option”.

COST

This study found that inability to buy a prescribed drug significantly contributed to nonadherence. Asked why they missed medication, one focused group participant said “*Some drugs are very expensive. Currently the doctor prescribed a drug worth 1800 and I cannot afford it*”. While this may not seem like a lot of money to the clinician it is a lot to an unemployed patient without other financial support. Results of a crossnational survey including Canada and USA showed that people with low income and inadequate insurance were more likely to miss medication due to cost. (Kennedy and Morgan, 2006) The non adherence that results from this then leads to a worsening situation as the cost of managing relapses become even higher, (Sun et al., 2007) and results in other indirect costs like loss of productivity and disability compensation (Bagalman et al., 2010),

DRUG FACTORS

Patients take drugs to relieve distress. When the prescribed drugs cause more distress, the patient would have no reason to take them. This is the reason why in this study adverse effects of drugs were mentioned as one of the leading causes of failure to take medication. In the focused group discussions one of the participant said “*I feel very sleepy I even get late to work. To avoid losing my job I just avoid taking medicine unless I feel very bad*” demonstrating the distress side effects of drugs can cause. Feeling worse after taking medication was significantly associated with nonadherence. These finding concurs with other studies that have shown association of nonadherence with adverse effects of drugs (Dibonaventura et al., 2012) and pointing to a need to consider tolerability of drugs during prescription to improve adherence (Masand and Narasimhan, 2006).

5.2: STUDY LIMITATIONS

1. The use self reporting to determine non adherence is likely have created bias as patients reports what they feel is acceptable.
2. The associations of various factors with nonadherence did not factor in the type of diagnosis and comorbid substance use, both of which have a bearing on nonadherence.
3. Convenient sampling method may have created a bias.

5.3:CONCLUSION

Lack of awareness about the illness ,negative attitudes towards mental illness and the drugs prescribed, perceived stigma , poor social support,high cost of medication, negative effects of drugs and preference of herbal medications are associated with nonadherence to prescribed medications. These must be addressed in order to improve the quality of lives for all our patients.

5.4 RECOMENDATIONS

1. Put in place psycho education programmes for individual patients ,relatives and the community,to demystify mental illness .This includes provision of trained personnel and material resources to facilitate this.
2. Clinicians must go out of their way to provide basic information regarding a mental illness and medication in a simple way and avoiding confusing jargon. The education should include name of illness, expected outcomes, drugs prescribed and the anticipated adverse effects.
3. Strengthen psychiatric social work departments through adequate training and laying down infrastructure to ensure that the patients social assets are wholistically assesed and utilized appropriately to enhance adherence and thus improve quality of life.
4. Put in place mechanisms of reducing cost of care. Clinicians must involve the patient in the prescription process.If an expensive drug must be used in the cases of resistance, or intorelance to cheaper options, the clinician must discuss with the patient other sustainable means of acquiring the drugs.
5. Put in place policies to provide a variety of drugs at a subsidized cost to enable clinicians affordable options to switch to incase of side effects.

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APPENDICES

APPENDIX 1: CONSENT DETAILS

CONSENT EXPLANATION

My name is Dr. Edith Kwobah, a postgraduate student at the University of Nairobi. I wish to carry out a research on psychosocial and cultural factors associated with non adherence to treatment and follow up among outpatients being seen at this hospital.

This information will help us understand the difficulties our patients face in the course of follow ups and in taking their medications. The understanding will help us look for ways of solving it. This will help improve the services that we offer to our patients.

The information you give me is confidential. You will not be identified by your names but by a number you will be assigned once you accept to participate in the study.

It is optional to participate in this study and you can opt out at any point during the interview. There are no material gains. However, you will benefit by getting advice concerning your illness and the drugs you take and the advantages of adherence. You also have a chance to ask any questions and get detailed answers and guidance. There are no risks involved except for psychological invasiveness as personal questions will be asked.

The interview will take 20 to 45 minutes of your time.

For any questions or clarifications you can contact my supervisors Dr. Obondo on 0721849686 and Professor Ndeti on 0722518365. You can also contact the department of psychiatry, college of health services, using the address P.O Box 19676, 00202, or call 254-020 2726300 ext44355. You can also reach the Kenyatta National Hospital ethics board using the address P.O Box 20723 00202, or call 726300-9.

Thank you

CONSENT FORM

I together with my caregiver..... after having understood the explanation given to me by Dr. Edith Kwobah about the study, do hereby accept to freely participate in the study on psychosocial and cultural factors affecting adherence being carried out at Mathari Hospital.

Signed.....(Patient) Date.....

Signed.....(Carer) Date.....

Signed.....(researcher) Date

APPENDIX 2:STUDY INSTRUMENTS.

SOCIAL DEMOGRAPHIC QUESTIONARE

PARTICIPANTS IDENTIFICATION NO.....

1. Age.....
2. Sex.....
 - A)Male.....
 - B)Female.....
3. Marital status..
 - A) Married
 - B) Single
 - C) Widowed
 - D) Divorced
 - E) Other.
- 4.Religion..... (Tick one)
 - A) Muslim.....
 - B) Christian.....
 - C) Buddhist.....
 - D) Hindu.....
 - E) Atheist.....
 - F) African traditional
 - G) Others(specify).....
- 5.Employment.....
 - A) None.....
 - B) Part time.....
 - C) Fulltime.....
- 6.Reason for unemployment (Where applicable)...
 - A) Illness.....
 - B)Retirement.....
 - C)Others.....
- 7.Whom do you live with.....
 - A)Alone.....
 - B)Spouse.....
 - C) Parents.....
 - D) Sibling.....

E) Others(specify).....

8. Who owns the house that you live in?

- A) Rented.....
- B) Own house.....
- C) Family house.....
- D) Other (specify).....

9. Estimated income per month.

- A) Less than 1000.....
- B) 1000 - 10 000.....
- C) 10000-20000.....
- D) 20000-50000.....
- E) Above 50000.

10. Level of education.

- A) None.....
- B) Primary.....
- C) Secondary.....
- D) University.....
- E) Other specify.....

STRUCTURED FACE TO FACE INTERVIEW QUESTIONARE

(knowledge and insight)

1. Do you know the kind of the illness you suffer from.....YES.....No.....
How long have you suffered this illness(years)
2. What in your opinion is the cause of your illness.....
 - A) Brain disease,like any other illnesses.
 - B) Curse/ancestral powers
 - C) Punishment from God
 - D)Witchcraft
 - E) Stress
 - F) Gods will
 - G) Bad luck
 - H) Others specify.....
3. Do you know the name of the drugs you are taking.....YES.....NO.....
4. Do you know for how long you will take your medicationYES.....NO.....
5. Who informed you about your illness?
 - A) My doctor
 - B) A pharmacist

- C) A nurse
- B) Relative
- C) Friend
- D) Others specify.....

Attitudes

6. I) In your opinion, is your illness different from other illnesses like asthma, hypertension, diabetes
- A) Yes
 - B) NO

II) In which ways is it different.....

7. Would you comfortably disclose your nature of illness to your friends ,or employer
- A). Yes.....
 - B) No.....Reasons.....

Stigma

8. Have you ever been denied anything at work or at your home or anywhere else because of your illness?

- A) Yes.....Explain.....
- B) No

9. Have you or your family ever been ill treated because of the nature of the illness you are being treated for?

- A) Yes..... Explain.....
- B) No

Social support.

10. Who reminds you to attend your Clinics and/ take medication?

- A) Self....
- B) Sibling.....
- C) Spouse
- D) Parents.....
- E) Others (Specify).....

11. Who pays your medical bills?

- A) Self....
- B) Sibling.....
- C) Spouse
- D) Parents.....
- E) Others (Specify).....

12. Who do you tell when you feel low/or when you feel like you are unwell?

- A) No one....
- B) Sibling.....
- C) Spouse
- D) Parents.....

E) Others (Specify).....

Level of non adherence.

12. Have you missed any of your medications since the last visit

Yes

No

If yes .. How many doses have you missed.....

13. Have missed any clinics in the last one year.

Yes.

NO..

13. When is the last time you took your medication?(fill the exact or approximate number)

A) - Today.....

B) _ days ago.....

C) _ weeks ago.....

D) _ months ago

E) _ years ago.

14. Have you ever postponed or failed to take medication or attend clinic for any of the following reasons? (Answer Yes or No)

(Attitudes and believes]

A) Feeling that the medication was not helpful because your illness is not medical and cannot be cured by conventional medication.....

B) Feeling like you had taken the medicine too long and it was time you took a break despite the doctor advising otherwise.....

C) The medication was taking too long to relief your symptoms.....

D) The medication made you feel weird, like a zombie.....

E) Fear of addiction to the medicine.....

F) You felt better and did not see the need for continued medication.....

G) No good reason, I was just careless.....

(Stigma)

H) Fear that people will know you have a mental illness.....

(Traditional /alternative medicines)

I) You preferred herbal medication or supplements.....

J) You preferred /or was directed to visit to a traditional healer/witchdoctor.....

K) After a preacher prayed for you and proclaimed you were healed.....

L) After clan members conducted some rituals to cast out spells that were believed to be the cause of your illness.....

(cost)

- M) The clinic was too far from your home.....
- N) The medicine was too expensive.....

(Social support)

- O) There was none to accompany you to the clinic

(Drug adverse effects)

- P) The medication makes you feel worse.....

PART 11 : FOCUSED GROUPS DISCUSSION GUIDE

INTRODUCTION

Welcome to today's discussion. Thank you all for the willingness to participate. My names are Edith Kwobah, I am a post graduate doctor pursuing a master of medicine in psychiatry. As a part of my studies, I am holding this discussion in order to gain more knowledge on your views on the illness you are being treated for, the drugs you take and reasons why you may not take the drugs. You are the experts in this. There are no right or wrong answers. What you say is of great value so feel free to discuss with me. Be honest but don't say something that may make you feel uncomfortable.

The discussion will be tape recorded and also notes taken verbatim. This will enable me write a good report of our discussion.

We have 45 minutes to hold our discussion, kindly allow other people to give their opinion.

At the end of our discussion I will allow us to ask any questions regarding your illness.

GROUP NO.....

1. What do you know understand is the illness you suffer from.
2. What in your opinion caused this illness that you suffer from.
3. What do you think about the drugs you are currently taking for the illness? (Do they help you)
4. What are some of the reasons you may not take medications as prescribed.
5. What do you think of prayers and spiritual healing in mental health, (give your own experience where possible).

6. What is your opinion about mental illness being linked to witchcraft, spirits/curses (give your experience where possible).
7. What is your opinion (or personal experience) on use of herbal or traditional medication as opposed to the conventional medicines given in hospital.

APPENDIX 3

FLOW CHART OF STUDY IMPLEMENTATION

