

London School of Economics and Political Science

**Under-cover in Kenya:**

**The contribution of non-state actors to mental health coverage**

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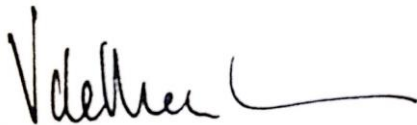
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## Preface

The findings from parts of this thesis (chapters 5 and 6) have been published or accepted for publication. The references to these articles are:

de Menil, V. and M. Knapp (in press). "Participation of psychiatric nurses in public and private mental health care in Kenya." International Psychiatry.

de Menil, V., M. Knapp, et al. (2014). "Service use, charge, and access to mental health care in a private Kenyan inpatient setting: the effects of insurance." PLoS One **9**(3).

de Menil, V., D. Ndeti, et al. (2014). "A hidden face of community mental health care in Kenya: specialist care from private providers " World Psychiatry **13**(1): 100.

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## Acronyms

CBR	Community Based Rehabilitation
CMD	Common mental disorders
DALY	Disability Adjusted Life Year
DFID	Department for International Development
EC	European Commission
EST	Economic Status Tool
GBD	Global Burden of Disease
GHQ	General Health Questionnaire
LAMIC	low- and middle-income countries
MHD	Mental Health and Development
MOU	Memorandum of Understanding
NACADA	National Authority for the Campaign Against Drug Abuse
NGO	nongovernmental organisation
QALY	Quality Adjusted Life Year
SMD	severe or serious mental disorder
SMR	standardised mortality ratio
UCT	University of Cape Town
WHOQOL	World Health Organization Quality of Life questionnaire

## **Abstract**

Half of health care in sub-Saharan Africa is privately provided, however, for mental health, the literature is all but absent on these services. Kenya provides a useful case-study, as it has a well-organized non-state sector and data are readily available. My thesis asks what contribution do non-state actors make to coverage for mental disorders in Kenya?

Non-state mental health care is conceived along two axes: for-profit vs. not-for-profit and formal vs. informal. Four empirical chapters use mixed-methods to examine: 1) not-for-profit NGO care; 2) for-profit inpatient care; 3) for-profit outpatient care; and 4) traditional and faith healing. Data were collected on 774 service users and 120 service providers from four primary sources, and two secondary sources, as well as from a wide range of key-informant interviews.

The first two chapters set the research question within the context of existing knowledge in the fields of health economics and health services research. The third chapter provides an overview of methods, focusing on cost-effectiveness analysis, case study method, and cross-cultural psychiatric epidemiology.

The first empirical chapter presents an NGO intervention called the model for Mental Health and Development, evaluated qualitatively and quantitatively, using cost-effectiveness analysis. The second empirical chapter offers a case study of a growing private psychiatric hospital, using regression analysis on the effects of insurance on charge and service use. The third chapter is a short descriptive analysis of a questionnaire completed by psychiatric nurses about their participation in mental health care, and structured interviews with specialist outpatient providers. The final empirical chapter contains qualitative and quantitative data on traditional and faith healing, analysed for similarities and differences. The conclusion ties together findings thematically according to capacity, access and cost, estimating the degree of mental health care coverage offered by non-state actors in Kenya, and offering lessons for policy and research.

## 1. Introduction: A Burden to Bear



Figure 1-1: Herbal advertisement in a Nairobi pharmacy, "Stressed? Get more out of life"

## 1.1 Background

“Stressed? Get more out of life.” So reads an advertisement for a herbal ginseng-based remedy at a pharmacy in a Nairobi mall (figure 1). The language of mental health and its inverse, mental distress, is making its way into urban middle-class Kenya, but to what extent is the country covering the need for treatment of mental disorders too severe to self-medicate? To begin addressing this question, we must take a step back in time and away from Kenya.

In the 1990s, research into mental disorders in low-income countries went from an exotic anomaly, studied mostly by anthropologists, to a field of public health with a growing evidence base. A major turning point for the field was the publication in 1994 of the first Global Burden of Disease study, which found that mental and neurological disorders accounted for a quarter of the burden of all disability (Murray and Lopez 1994). Depression alone was estimated to be the leading cause of disability worldwide and the fourth leading cause of disease burden. In what were loosely termed “developing countries,” neuropsychiatric disorders were estimated to cause 15% of years lost to disability, putting them on par in terms of their morbidity with the burden of infectious parasites.

The Kenyan government faces a number of competing priorities for development, and a tight overall budget, as a result of which mental health care receives little investment. With a Human Development Index ranking of 147 out of 177, Kenya is among the bottom 17% of countries in terms of education, life-expectancy and per capita income (US \$760) (United Nations Development Programme 2010). Every second person living in Kenya (46%) is living under the national poverty line (World Bank 2011). Economic growth and job creation are therefore high priorities of the State. Furthermore, nearly half (45%) of the country’s 39 million inhabitants are under the age of 15, making education and childhood illnesses among the leading concerns. Within the health sector, HIV is a high priority (Jenkins, Kiima, et al. 2010), driven in part by funds from donor agencies. Given these strong competing claims for a small budget, it is little surprise that Kenya’s public sector lacks the capacity to meet the population needs for mental health care.

In this introduction, I will start by outlining some of the evidence of why mental disorders matter in Africa and Kenya, from both a health and economic standpoint. Next, I will outline the landscape of Kenya’s mental health services – in both the public and non-state sectors. This brings me to a discussion of the treatment gap, and a return to my initial research question about service coverage. I will conclude with an overview of how the following chapters aim to answer that question.

## 1.2 What Are Mental Disorders and Do They Matter in Africa and in Kenya?

### 1.1 - a) Terminology

“Mental disorders” is a term commonly used in public health research referencing a diverse group of health conditions with differing prevalence rates. The Global Burden of Disease (GBD) nosology initially delineated fourteen conditions within the category “neuropsychiatric disorders” (table 1-1), which were further specified in the latest round to 20 conditions. By contrast, the World Health Organization (WHO) groups mental disorders into eight “priority conditions” (table 1-2) in their flagship Mental Health Gap Action Programme (mhGAP). The WHO’s classification includes a condition that is not, in fact, a condition, but an event to be prevented, namely suicide, as well as neurological disorders, such as epilepsy and dementia.

The study of depression is often widened in the literature to the term “common mental disorders,” which includes disorders on the anxiety spectrum (panic, obsessions, and traumatic stress, for example), termed ‘common’ because they are commonly (i.e. frequently) found in the general population. Schizophrenia and psychotic disorders, including bipolar disorder, are sometimes referred to in the literature as “SMI” or “SMD” short-hand for either serious or severe mental illnesses (Stobbe et al. 2014), or severe mental distress (Kinyanda et al. 2011). This terminology is misleading in that these disorders exist in mild, moderate and severe forms, and a mild psychotic disorder can be less “serious” or “severe” than a severe depression or phobia. The groupings are useful from the perspective of health service planning, however, as these conditions require different types of care. I will therefore adopt the terminology CMD and SMD at various points throughout the thesis.

Outside of the biomedical domain, the term “mental illness” is preferred by medical anthropologists. This term purposefully does not provide diagnostic specificity, choosing instead to capture the diversity of conditions under a single term. Instead, it highlights the concept of illness over disorder, or subjective experience over medical labelling. Still another term with currency among human rights activists is “persons with psycho-social disabilities”. This term implies that the conditions in question constitute a disability, and consequentially that people with these conditions are entitled to the rights enshrined in disability law. For the purposes of this thesis, I privilege the term mental disorders, as my work draws primarily from the field of health services research, however I also use the term mental illness in relation to traditional healing, as disease classification differs between biomedicine and traditional medical practice.

Table 1-1: Neuropsychiatric disorders in the Global Burden of Disease Study

1. Unipolar depressive disorders
2. Bipolar disorder
3. Schizophrenia
4. Epilepsy
5. Alcohol use disorders
6. Alzheimer and other dementias
7. Parkinson disease
8. Multiple sclerosis
9. Drug use disorders
10. Post-traumatic stress disorder
11. Obsessive-compulsive disorder
12. Panic disorder
13. Insomnia (primary)
14. Migraine

Table 1-2: Priority conditions in the WHO's Mental Health Gap Action Programme

1. Depression
2. Schizophrenia and other psychotic disorders
3. Epilepsy
4. Suicide
5. Dementia
6. Disorders due to use of alcohol
7. Disorders due to use of illicit drugs
8. Mental disorders in children

*1.1 - b) Health burden of mental disorders*

#### 1.2.a.i Globally

Whereas for most of the last century disease burden was calculated based on mortality, with the advent of the Global Burden of Disease study, morbidity and mortality merged together to form

a new metric, called the disability adjusted life year, or DALY. Since much of the burden of mental disorders is morbidity, resulting from sometimes chronic or recurring episodes of disabling illness, the DALY highlighted this spectrum of conditions for the first time as a global health priority. The Global Burden of Disease methodology underwent several revisions in its second and now third iterations in 2000 and 2010. As of the latest data, neuropsychiatric disorders account for 7.4% of disease burden worldwide (Whiteford, Degenhardt, et al. 2013). This represents a significant decline relative to earlier estimates of 14%, largely as a result of shifts in disability weights for mental disorders and adjustments for disease comorbidity. When the earlier data are analysed using the new method, results actually suggest an increase of 37.6% in mental disorders between 1990 and 2010. The change in epidemiological burden is driven by the demographics of ageing populations, rather than by an “epidemic” of mental illness, because mental and neurological disorders tend to strike most in the adult and later years.

The importance of mental disorders in causes of disability should not eclipse their place in causes of mortality. Deaths from mental disorders result from both suicide and premature mortality.<sup>1</sup> The World Health Organization estimates that 800,000 people die each year from suicide (World Health Organization 2001, 2014) – more than two and half times the number of women who die each year in childbirth. In sub-Saharan Africa, the suicide rate is 10 per 100,000 people per year with rates almost three times as high among men as among women. Measurement of pre-mature mortality is most advanced in high-income countries. People with schizophrenia, for example, have a life expectancy 15-20 years shorter than the general population in high-income countries (Nordentoft et al. 2013).

### 1.2.a.ii In Africa

There is reason to believe that the prevalence of mental disorders could vary from place to place, and therefore be different in Africa. For example, the most recent analysis of GBD data estimates that the burden from eating disorders is forty-fold higher in Australia and Asia than in sub-Saharan Africa (Whiteford, Degenhardt, et al. 2013). The variation may be lower, however, for more organic disorders, such as schizophrenia and bipolar disorder. While psychiatric epidemiology is highly advanced in Europe and other high-income countries, however, it remains in its infancy in low-income settings, making data on prevalence of mental disorders relatively thin. A recent systematic review of community-based prevalence studies for psychiatric disorders reported that no studies from Africa met their inclusion criteria (Baxter et al. 2013).

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<sup>1</sup> Premature mortality can result from untreated health conditions, side-effects of psychiatric medicines (especially the atypical antipsychotics which lead to type II diabetes and cardiac problems), and the negative effects of mental disorders on the progression of other diseases, including HIV



The best available evidence on prevalence of mental disorders in low-income settings pertains to common mental disorders. In a systematic review and meta-analysis published this year, covering the past thirty-three years of research, Zachary Steel and colleagues (Steel et al. 2014) found eight prevalence studies from six countries in sub-Saharan Africa. Pooling data across 15,211 individuals, they observed a 12-month prevalence of common mental disorders of 10.8% (with a 95% confidence interval of 7.2% - 15.9%). The lifetime prevalence of in sub-Saharan Africa was found to be 22% (CI 12.9% - 35.0%). Steel's review and meta-analysis raises puzzling findings on the varying prevalence of common mental disorders. It notes, for example, that these disorders are more common in English-speaking countries, though the authors qualify this finding, suggesting it may result from an age effect, because the English-speaking samples tended to be older (Steel et al. 2014). In addition, the study found that countries in North and South-East Asia had lower rates of depression relative to other countries.

Moving away from pooled data, which presents significant methodological challenges, one of the largest single studies of common mental disorders in Africa is from the South African Stress and Health study (SASH), which sampled over 4,000 people. The SASH study found a prevalence of 30.3% common mental disorders, of which 26% were severe, suggesting that the prevalence of severe common mental disorders is 7.9% (Herman et al. 2009). In addition, two community-based studies of the prevalence of depression in Rwanda (Bolton, Neugebauer, and Ndogoni 2002) and rural Uganda (Bolton, Wilk, and Ndogoni 2004) found rates of 16% and 21% respectively. Common mental disorders appear therefore to be widespread in sub-Saharan Africa.

The largest study of the epidemiology of schizophrenia-spectrum disorders in Africa was conducted in Ethiopia. In the town of Butajira, 68,378 people were interviewed, using the Composite International Diagnostic Interview (CIDI), and the lifetime prevalence of schizophrenia was found to be 0.47% (Kebede et al. 2003). A small study from Uganda examined the prevalence of "severe mental disturbances," which the authors defined in an original way composed of seven categories, using both Western and local nosology (Kinyanda et al. 2011). The authors found a prevalence of 0.9% SMD in the general population, which approximates the rate found by the study of psychotic symptoms in Western Kenya.

The evidence on cultural variation in psychiatric epidemiology, however, is riddled with methodological barriers (some of them addressed in chapter 3 on research methods), making it difficult to say with any certainty how much psychiatric epidemiology varies in Africa.

### 1.2.a.iii In Kenya

This thesis focuses on mental disorders in Kenya. The effort to measure the prevalence of mental disorders in the general population in Kenya is very recent – much of it published while this dissertation was being researched. The first documented prevalence measures were clinic-based (Ndetei, Khasakhala, Ongecha-Owuor, et al. 2009; Ndetei, Khasakhala, Kuria, et al. 2009), which are not representative of the population at large. For instance, one study sampled 2,543 patients from ten general health facilities, ranging from primary to acute care, and found that 23.2% of patients scored as depressed, using the Beck Depression Inventory (Ndetei, Khasakhala, and Mutiso 2010). Most of these (56%) had only mild depression. As this was a clinic-based sample, mild depression could be partially a response to being sick enough to seek health care. A further 10.1% of the clinic-based population, however, had moderate-to-severe depression.

A study published in 2012 by Rachel Jenkins and colleagues was the first of its kind in Kenya to undertake basic epidemiology using household-level data (Jenkins et al. 2012). Working in the rural town of Maseno, near the city of Kisumu in Western Kenya, the researchers found that 10.8% of the population had a common mental disorder (Jenkins et al. 2012). Surprisingly, no gender differential was found among those diagnosed, unlike in most other countries (Steel et al. 2014). In addition 0.6% of the sample reported two or more symptoms of psychosis (Jenkins et al. 2012). Symptoms do not equate with a diagnosis, so there are currently no data on the prevalence of SMD in Kenya. It is possible that the prevalence of psychosis is low in this rural setting, because of outward migration towards city centres with more opportunities for treatment, or because of severe neglect leading to premature mortality.

### 1.1 - c) *Economic burden of mental disorders*

#### 1.2.a.iv Poverty

In addition to the symptoms of illness, one of the burdens of mental disorders is ensuing poverty. One of the strongest studies bearing evidence of economic costs of mental disorders to individuals and families was conducted in India and Pakistan. Chisholm et al found that one month with depression was associated with costs equivalent to 7-14 days of agricultural labour in India and 20 days of agricultural labour in Pakistan (Chisholm et al. 2000). Direct costs of primary and hospital based care accounted for two-thirds and three-quarters of the costs measured by this study in India and Pakistan, including privately provided care, which comprised

88% and 70% of the direct costs. The remainder were indirect costs associated with time out of work and unpaid work caring for an ill relative, which constituted 20% and 38% of all costs in India and Pakistan respectively.

A systematic review by Crick Lund and colleagues from the Mental Health and Poverty Project tested the association between common mental disorders and poverty, measured by a number of indicators of deprivation (Lund et al. 2010). Using bivariate and multivariate analyses, they found that 73% and 79% of the 115 studies showed a positive association between poverty and common mental disorders: the poorer a person was, the more likely they were to experience a common mental disorder. Drilling down into which specific aspects of poverty created the greatest vulnerabilities, they found the strongest association with common mental disorders was lack of education. Strong associations were also found for socio-economic status, financial stress, housing, and food insecurity; however the number of studies with data on these indicators was small. Finally, low-income and unemployment were also associated with common mental disorders, though less consistently so. There were more studies analysing these two variables, however, creating opportunities for greater variability than for the other predictors.

A second systematic review by Lund and colleagues examined the effect of mental health interventions on economic outcomes, and inversely, the effect of poverty alleviation interventions on mental health outcomes (Lund et al. 2011). Counter-intuitively, the authors found no conclusive evidence that improving a person's economic status helped their mental health status. However, they did find that improving a person's mental health status was associated with an improvement in economic status. This improvement was statistically significant in half the studies, and no studies showed a reduced economic outcome. More evidence was available to address the effects of mental health interventions (9 articles) than to address the effects of poverty alleviation interventions (5 articles), which may have influenced the non-significance of the findings on poverty alleviation.

The Mental Health and Poverty Project review is informative about what the existing literature tells us and where its limitations lie. African countries were the setting for only 11 of the 77 community-based studies reviewed, and they concentrated on only four countries: Ethiopia (4), South Africa (3), Nigeria (3) and Zimbabwe (1). Moreover, the great majority of studies (85%) were cross-sectional, so they could not inform about the direction of association between poverty and common mental disorders. Does being ill make people poor, or does being poor make people ill? Only 11 of the 115 studies reviewed were longitudinal cohort studies with the possibility of distinguishing the direction of influence.

In the absence of strong quantitative data, qualitative data has shaped the prevailing opinion that the relationship between mental illness and poverty is reciprocal (Patel and Kleinman 2003; Lund et al. 2010; Saraceno, Levav, and Kohn 2005). On one side, the social causation hypothesis contends that conditions and events associated with poverty create stress and trigger mental disorders. On the other side, the social drift hypothesis asserts that people with mental disorders drift into poverty, because of the costs of health care and an inability to stay in work.

In addition to the two studies by Lund, a third study by Ernestina Coast and colleagues mapped the literature from low- and middle-income countries on the associations between poverty and a specific mental disorder, namely post-natal depression (Coast et al. 2012). The mapping exercise turned up 47 articles, both quantitative and qualitative, most of which explored whether poverty causes depression. The inverse causal link – whether post-natal depression engenders poverty – was not explored. Half of the African literature came from Nigeria alone, and only one study was from Kenya (Chersich et al. 2009). The Kenyan study was a cross-sectional survey of 500 women attending a paediatric immunization clinic in Mombasa. Five per cent of the women were diagnosed with depression using DSM IV criteria. Overall, the mapping paper found some associations between post-natal depression and variables relating to poverty – specifically income, socio-economic status and education – however, these associations were not consistent across studies. The authors noted that the studies focused almost exclusively on individual effects of poverty and that there is a gap in the literature on broader community-level effects.

Finally, a systematic mapping of the relationship between poverty and suicide was presented in a conference on global mental health (Iemmi et al. 2011). Valentina Iemmi and colleagues located 115 articles on this subject, hoping to discern whether suicide contributes to household poverty, and, inversely, whether poverty contributes to suicidality. Seventeen articles supported the latter association (poverty contributing to suicide), while no articles investigated the former association. Most of the literature (74% of articles) showed unclear associations between the two.

### *1.2.a.v* Social costs

Very limited research exists on the costs of mental disorders to society in Kenya or Africa. One study from Kenya calculated direct and indirect costs of mental disorders for all patients attending public hospitals (Kirigia and Sambo 2003). The cost per person hospitalised for a mental disorder in 1999 was US \$2,351, of which 19% was lost productivity, while the remainder

was the direct cost of treatment and care. The investigators concluded that people institutionalised for mental disorders cost the Kenyan economy US \$13.4 million, amounting to 0.1% of GDP in the same year. A serious limitation of this study is that the sample was hospital-based, and most people with mental disorders in Kenya never find their way to a hospital.

A cost-of-illness study was conducted in Nigeria examining the economic impact of schizophrenia on society (Suleiman et al. 1997). Suleiman and colleagues questioned a sample of 50 people with schizophrenia in an outpatient setting in Lagos and concluded that the total cost of schizophrenia was US \$268.50 (5,902 Naira) per patient per year, of which 15% were indirect costs. The bulk of the costs in this study (52%) were attributed to the purchase of medications. The main limitations of this study are that it relied on a sample of only 50 people with schizophrenia from a single treatment facility, and that the follow-up period was only six months long.

Efforts at measuring the societal costs of mental disorders in upper-income countries have focused predominantly on lost productivity –a form of indirect cost. A number of efforts have been made to measure indirect costs relating to the trio of unemployment, absenteeism, and presenteeism,<sup>2</sup> as well as early retirement. In Great Britain, 40% of people with enduring mental disorders are unemployed (Berthoud 2008) and mental disorders recently earned the dubious distinction of constituting the leading cause of absenteeism, surpassing back pain (McDaid, Curran, and Knapp 2005). It is presenteeism, however, (though challenging to measure) that is estimated to outstrip unemployment and absenteeism in terms of the social costs of mental disorders (Kessler and Frank 1997).

A systematic review of cost-of-illness studies for mental disorders from predominantly high-income countries found the negative economic impact of these illnesses far exceeds the direct costs of treatment (Hu 2006). The direct costs of treatment are trumped by indirect costs. In addition, mental disorders are associated with hidden costs, borne by social care, education, housing, criminal justice and the social security systems (Knapp 2003; Dewa, McDaid, and Ettner 2007). Indirect costs in high-income settings are estimated to account for upwards of two thirds of all mental health costs (McDaid, Curran, and Knapp 2005; Thomas and Morris 2003).

European measures of lost productivity are markedly higher than those found in the two African cost-of-illness studies. The African studies found that lost productivity amounted to 15% to 19% of the total costs of illness, as compared to two-thirds of costs in Europe. One explanation for this could be that the social welfare system in the two African countries studied is less well developed than in the European countries, so fewer costs are borne by social services.

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<sup>2</sup> Presenteeism is being present on the job, but under-performing due to illness.

But the explanation is more likely the inadequate measurement of non-wage agricultural productivity.

Upper-income country studies of the cost of mental disorders as a percentage of GDP range from 0.5% in the Netherlands (McDaid, Curran, and Knapp 2005) to 2.5% in the United States (Rice et al. 1990) and 3-4% in European member states of the International Labour Organisation (Gabriel and Liimataine 2000). A cross-country comparison found that in the United States and Finland 25% and 42% of disability claims were made for mental disorders (Dewa, McDaid, and Ettner 2007). Because of this economic impact, mental disorders in upper-income countries are perceived as an important agenda item not only for health care, but also for employment and for public policy broadly (Black 2008).

### **1.3 Kenya's Mental Health System**

#### *1.1 - d) The public sector*

Given the significant burden of mental disorders, in terms of both health and economic factors, what is the availability of treatment in Kenya? The government of Kenya has long recognised the importance of mental health care in its policies. In 1960, three years before independence, the national health policy called for the creation of provincial psychiatric units in each of the country's provinces (Kiima et al. 2004). These units continue to exist today in 6 of 7 provinces, located within general provincial hospitals (Kiima and Jenkins 2010). In 1982, the Kenyan government brought mental health from secondary into primary care, including it as one of nine essential elements guaranteed within primary care (*ibid*). The push for better mental health services continued with the passage in 1989 of the Mental Health Act, which called for a multi-disciplinary Kenya Board of Mental Health to supervise service provision, and which created the post of Director of Mental Health within the health ministry (Kiima et al. 2004).

In 1996 Kenya drafted its first national Mental Health Programme of Action, covering ten years, with an emphasis on community care and integration of mental health – within primary care and across sectors (Ministry of Health 1996). That action plan expired in 2006, and has yet to be replaced. Nonetheless, a commitment to provide mental health care was reaffirmed that year by its inclusion within the Kenya Essential Package of Health (Kiima and Jenkins 2010). Several new mental health documents are currently under negotiation including a new mental health act, and a national mental health policy (International Institute for Legislative Affairs 2011).

Kenya's relatively progressive mental health policies lack the financial backing, however, to be put into practice. No study has been conducted on the amount of funding available for

mental health within Kenya's public sector, and the WHO ATLAS database offers no data on this indicator from Kenya. The regional average for mental health spending is 0.5% of total health expenditure (World Health Organization 2011). If neighbouring Uganda is any indication, then the majority of Kenya's meagre mental health funding is being spent on mental hospitals (Raja et al. 2010), as is the case in most African countries (Saxena et al. 2007). In the absence of appropriate funding, the public mental health system is radically under-resourced and unable to implement its policies, particularly at the community level. Essential psychiatric medicines continually run out (Raja, Kippen, and Reich in press); psychiatric nurses move into general health care; and the Kenya Board of Mental Health has become inactive (Kiima and Jenkins 2010).

Despite a remarkable injection of funds into the general health system in the last decade, resources for mental health have not appreciably increased. Kenya's health spending grew by 50% from 2001 to reach Int\$ 3.2 billion in 2010 (Ministry of Medical Services and Ministry of Public Health and Sanitation 2011). The main driver of this growth was international funds from donors such as the Global Fund to fight HIV, TB and Malaria and the Global Alliance for Vaccines and Immunizations.

The inadequacies of public funding are revealed in a shortage of material and human resources for mental health care throughout Kenya. There is one psychiatric bed for every 200,000 members of the general population, and two thirds of those beds are located in Nairobi in the country's single public psychiatric hospital, Mathare Hospital (Kiima and Jenkins 2010). Outside of Nairobi, there are psychiatric units in six of the seven provinces, each with 22 beds, as per the 1960 health policy. The 1996 Mental Health Programme of Action called for psychiatric units to be created in each of the then 76 districts; at present, these units exist in only five districts.<sup>3</sup> David Kiima, Director for Mental Health, estimated in 2010 that having an inpatient unit in each district hospital would enable the treatment of 1% of people with psychosis during acute episodes (*ibid*). By extension, in the absence of those beds, outside of Nairobi 99% of cases of acute psychosis are left untreated by the public health system.

The supply of psychiatric medicines is little better than that of beds. Kenya's Essential Drugs List contains a wide array of psychiatric medicines (17 in total), but in reality only three are widely available throughout the health sector: one antipsychotic (chlorpromazine); one anticonvulsant (phenobarbitone); and one anxiolytic (diazepam, better known as valium) (Kiima and Jenkins 2010). Antidepressants were only available in hospitals until 2007, and today they are

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<sup>3</sup> The county is the new administrative unit of choice since the 2010 constitution, and Kenya has 47 counties.

rarely stocked in primary care. As a result, anxiolytics, which can be addictive, are inappropriately prescribed in place of antidepressants.

Human resources for mental health are similarly “extremely overstretched” in Kenya (*ibid*). In 2004, there were only 35 public psychiatrists, serving a country of 38 million. Furthermore, two out of every three public psychiatrists (69%) worked in Nairobi. Thus, despite a national ratio of 1 psychiatrist (public and private) per 500,000 people<sup>4</sup>, the picture is far worse outside of the nation’s capital, reaching 1: 3,000,000 in the provinces (Kiima and Jenkins 2010). By contrast, psychiatrists are relatively widespread in Nairobi, with a rate of 1: 63,000 people (Ndetei et al. 2007). The rate of psychiatrists in Kenya has been stable for the past ten years, thanks to a replacement level of psychiatrists graduating from local medical schools. Nonetheless, because of the “brain-drain” affecting many African health systems (Jenkins, Kydd, et al. 2010), there are as many Kenyan psychiatrists practicing in a public health facility in Kenya today as there are Kenyan psychiatrists practicing overseas (Ndetei et al. 2007). Kiima and Jenkins estimate that at current rates of medical diplomas, it would take 100 years to train enough psychiatrists so as to meet the 1996 policy target of one public sector psychiatrist per district.

The human resource shortage afflicting public psychiatrists also applies to psychiatric nurses and other allied mental health professionals. Many psychiatric nurses do not practice psychiatric nursing, but work instead in surgery, obstetrics and HIV clinics (Kiima and Jenkins 2010). One in four practicing psychiatric nurses are located in Mathare Hospital, leaving an estimated 180 public nurses to tend to the remaining 35.5 million Kenyans living outside of Nairobi. Unlike psychiatrists, psychiatric nurses are not graduating at a replacement rate, so these insufficient numbers are further dwindling. As with psychiatric nurses, so too with public medical social workers, who are present at a rate of one per province.

### 1.1 - e) *The non-state sector*

Stepping aside from the insufficiencies of the state sector, we turn to the capacity of the non-state sector to address the mental health treatment gap. It should be noted that “private,” as it is employed in this thesis, is not equivalent to for-profit. In keeping with key literature in this area, I use the term non-state and private interchangeably. Borrowing from a report by the International Finance Corporation (International Finance Corporation 2007), I conceptualize non-state or private care along two axes: 1) for-profit vs. not-for-profit; and 2) in the formal or informal sectors of the economy (table 1-3). The informal sector (or economy) is understood

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<sup>4</sup> By comparison, according to the WHO ATLAS, the ratio in the UK is 1 psychiatrist per 9,000 population.



here, using the definition of British anthropologist Keith Hart, as “economic activities which take place outside the framework of corporate, public and private sector establishments” (Hart 1987). Concretely, this refers to casual labour or unlicensed health care that goes untaxed and is not included in gross domestic product. As of the latest household survey data from 2006, over one third of Kenya’s working-age population (36%) participate in the informal sector, one half (50%) are self-employed farmers, and the remaining 14% work in the formal sector (Pollin 2009).

Formal for-profit providers include hospitals (small private hospitals are known in Kenya as “nursing homes”) and private outpatient clinics for both primary and specialist care. Formal not-for-profit providers refer to nongovernmental organizations (NGOs), faith-based organizations (FBOs) and social enterprises. The informal sector contains traditional and faith healers on the for-profit side (although some faith healers do not charge for services) and self-help groups, community-based organizations and families are on the not-for-profit side.

This thesis will sample care provided by all but the latter group of providers in the matrix of non-state actors, as it was not possible to collect data on community based organizations or self-help groups within the time and resource constraints of the field work. Some, though limited data are available about their influence within the context of an NGO intervention. This thesis will allocate a chapter to the intervention of the international NGO BasicNeeds, a chapter to for-profit hospital care, using a case study of Chiromo Lane Medical Center in Nairobi, a chapter to for-profit outpatient care, and a chapter to traditional and faith healers.

Table 1-3: Matrix of non-state actors in health care

	<b>For profit</b>	<b>Non-profit</b>
<b>Formal</b>	Hospitals, individual GPs, nurses, allied professionals	NGOs, faith-based organisations, social-enterprises
<b>Informal</b>	Traditional and faith healers	Self-help groups, community-based organisations, families

The lines between state and non-state care are sometimes blurred in Kenya. Many of the people working within the private health care sector also work in the public sector. In the words of a Kenyan health policy maker, “In Kenya now you cannot define a doctor as public or private. By day they are in the public sector, and at night, they are private.” Not only the people, but also the facilities are sometimes hard to define. The informant went on to note:

“The difference between private for-profit and not-for-profit is purely academic. Nairobi Hospital calls it surplus, not profit, but it’s the same. And Aga Khan is theoretically an FBO [faith based organization].”

Distinguishing between for-profit and not-for-profit, in the true sense, requires a set of criteria, not just one.” (KI 16, 7 October 2011)

This policy maker outlined three main criteria for defining a not-for-profit agency: 1) ownership; 2) incorporation status (e.g. liability trust or NGO); and 3) whether they are self-financing. The third criteria of self-financing seemed to him most essential: if a facility is self-financing then it functions as a for-profit business. I have adopted this definition of a for-profit as a self-financing entity.

#### **1.4 Treatment gap**

Despite the high clinical burden of mental disorders in Kenya, they remain largely untreated, although the precise treatment gap in Kenya is unknown. Treatment gap calculations are difficult to make, because they require precise, local epidemiological data. The largest undertaking in this regard is the ongoing World Mental Health Survey, which has sampled over 154,000 people across 28 countries, including two in Africa (Nigeria and South Africa). This study estimated that the treatment gap for “serious” mental disorders<sup>5</sup> across low-income countries is 76-85% (Demyttenaere et al. 2004). In Nigeria, they found only one in ten people with a diagnosable mental disorder was accessing treatment, making the treatment gap there 90% (Gureje and Lasebikan 2006). The gap was worse still for alcohol disorders, which were found to be entirely untreated. The proportion of people with mental disorders accessing specialist mental health services was only 1%.

A WHO-commissioned review of the treatment gap for mental disorders (Kohn et al. 2004) found in 2004 that only one study from Africa had been published on this topic amidst the 37 reviewed. The African study, from Zimbabwe, measured a treatment gap of 67% for major depression over the previous year (Abas and Broadhead 1997). More recently, the WHO examined the treatment gap for schizophrenia, drawing on data from the new WHO Assessment Instrument for Mental Health Systems (WHO AIMS) from 50 low- and middle-income countries. The authors found a treatment gap in low-income countries of 89% for schizophrenia. Epilepsy is among the neuropsychiatric disorders with the greatest treatment gap. A study in rural Kenya found that three in every four people with epilepsy had never been prescribed anti-epileptic medicine (Feksi et al. 1991). The gap in urban areas, however, is estimated to be less (Mbuba et al. 2008).

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<sup>5</sup> As opposed to severe mental disorders, serious mental disorders is a marker of severity of the condition and can encompass the common mental disorders.

## **1.5 Framework and questions**

### *1.1 - f) Literature gaps*

The literature on mental health in Africa remains in its infancy, however it has developed a growing evidence base over the past two decades. The literature is vocal about the treatment gap for mental disorders, although the data from Africa on disease prevalence and treatment coverage are thin. In addition, there is a growing evidence base about the economic burden of these illnesses. The literature gaps are as telling as the evidence itself that mental health is an area largely ignored by health care planners in Africa and Kenya, despite the significant burden of these disorders. Non-state provision of mental health care in low-income countries represents the largest gap in the literature and little, if anything, is published about its ability to provide mental health coverage not only in sub-Saharan Africa, but across low-income countries. The aim of this thesis is therefore to explore the ability of non-state actors to address the treatment gap in Kenya by providing service coverage for mental disorders.

### *1.1 - g) Theoretical framework*

In the last few years, a movement has been growing within global health policy to promote universal coverage, making “coverage” an essential concept to understand. In 2010, the World Health Organization’s annual World Health Report was titled “Financing health care: The path to universal coverage”(World Health Organization 2010). In 2012, the United Nations issued a declaration on universal coverage at the General Assembly (United Nations General Assembly 2012) and The Lancet medical journal published a special issue on universal coverage (Vega 2013). The following year, the WHO published another World Health Report titled: “Research for universal coverage”(World Health Organization 2013). Meanwhile, since the World Bank came under the direction of Jim Kim – a medical doctor and former leader of the HIV/AIDS 3 by 5 initiative at the WHO – it too has spearheaded the universal coverage movement, creating a Universal health Coverage (UNICO) study series, and defining joint targets with the WHO. The targets cover financial protection and service delivery, namely: 1) reducing by half the number of people impoverished by health care by 2020 and 2) doubling the proportion of people with access to health services by 2030 (World Bank 2014). Together, the World Bank and WHO are pushing to make universal coverage one of the new Sustainable Development Goals, which are to replace the Millennium Development Goals in 2015.

The interest in universal coverage is not new. It first came to the fore in the 1970s, coming to a head in Alma Atta in 1978 at an international conference on primary health care

with the slogan “Health for All” (World Health Organization 1978). It was therefore in the 1970s that the term coverage was first rigorously defined. This thesis adopts the framework of T. Tanahashi, published the same year as the Alma Ata conference. Coverage is conceived of along five dimensions: 1) availability; 2) accessibility; 3) acceptability; 4) contact; and 5) effectiveness (Tanahashi 1978). Availability refers not only to the physical presence of health care resources, but also to their characteristics and components. Accessibility relates to both the proximity of services to the prospective patient, and also, importantly, to their cost. Acceptability calls into question attitudes of patients to providers and vice-versa, including explanatory models of illness and their relationship to the care on offer. Contact coverage is what some researchers might dub “use” or “utilization” (Shengelia et al. 2005), meaning the degree to which patients actually come into contact with the service and how equitable those services are. Finally, effectiveness brings in a measure of care quality into the discussion of coverage. Tanahashi’s framework was originally set forth in 1978, and continues to serve as a reference point in discussions of health care coverage (Evans, Hsu, and Boerma 2013), including mental health coverage (De Silva et al. 2014).

Another framework I considered adopting was that of Penchansky on health care access. Penchansky’s five dimensions of access, published in 1981, mirror Tanahashi’s definition of coverage to a considerable degree, namely: 1) availability; 2) accessibility; 3) acceptability; 4) accommodation; and 5) affordability. Accommodation refers to the way in which a service organizes its services, for example appointment systems, hours of operation, and walk-in facilities. Affordability has been interpreted post-hoc to be contained in Tanahashi’s dimension of accessibility (De Silva et al. 2014), whereas the concept of effectiveness contained in Tanahashi’s framework is absent from that of Penchansky. Indeed, more recent theorizations around access and coverage note that a weakness of the focus on access is that it is overly reliant on supply-side analysis and neglects questions of quality (Shengelia et al. 2005).

### *1.1 - b) Research questions*

In response to the gaps in the literature, this thesis will address the question: *What contribution do non-state actors make to coverage for mental disorders in Kenya?* In other words, to what degree if any can non-state actors be considered part of the solution, or inversely part of the obstacle, to the problem of universal coverage within the context of mental health care?

Using Tanahashi’s definition of coverage, the over-arching research question is divided into sub-questions, reflecting the five dimensions of coverage:

1. What is the availability of non-state mental health services?
2. How economically accessible are non-state services?
3. How culturally acceptable are non-state services?
4. How many and which patients are in contact with non-state services?
5. How effective are non-state services?

The thesis will look at four main actors in non-state mental health care: 1) formal sector, not-for-profit providers (the NGO BasicNeeds); 2) formal sector for-profit inpatient providers (a psychiatric hospital); 3) formal sector for-profit outpatient providers (psychiatrists and psychiatric nurses); and 4) informal providers (traditional and faith healers, operating on both a for-profit and not-for-profit basis). These provider types form the basis of four empirical chapters. Each empirical chapter will focus on some, but not all, of the research sub-questions, as there are insufficient data to address them all.

The thesis uses mixed methods to analyse data from multiple sources, drawing on a combined sample of 939 people: 774 adults with mental disorders accessing treatment and 115 mental health service providers. Overall, I hypothesize that the non-state sector plays a significant role in providing health care in Kenya, despite being all but absent from the literature, but I hypothesize that the distribution of non-state care might not be equitable in terms of geography and income status.

## **1.6 Chapter overview**

First (**Chapter 2**), the context for this research is explored by reviewing the existing literature on effective mental health treatments in low-income countries and Africa, and on the debate surrounding the desirability of non-state actors in African health care. In the methods **Chapter (3)**, I explore questions surrounding the methodology of economic evaluation and case study, while also engaging with debates in the past century of cultural psychiatry. Methods of analysis in the ensuing empirical chapters include cost-effectiveness analysis (chapters 4 and 5), case study and multivariate regression (Chapter 6), descriptive statistics (Chapter 7), and qualitative framework analysis mixed with tests of binary association (Chapter 8).

The chapter on not-for-profit provision (**chapter 4**) describes the model for Mental Health and Development delivered by the NGO BasicNeeds in rural central Kenya, and analyses its cost-effectiveness in relation to treatment as usual. The MHD model offers community-based care for people with mental disorders in low- and middle-income settings. Using a pre-post design, 203 consecutively enrolled participants with mixed diagnoses were followed-up at 10 and

20 months. Costs are analysed from societal and health system perspectives. Comparison outcomes are drawn from the literature. Primary data are annualized for the sake of comparison.

The chapter on formal for-profit inpatient care (**Chapter 5**) uses a case study method to understand service use and charge in Chiromo Lane Medical Centre, a 30-bed psychiatric hospital in Nairobi, which forms part of one of the largest private psychiatric providers in East Africa. Nested within the case study, I use quantitative data shared with me by the hospital directors, to evaluate the effects of insurance on service use and charge, questioning implications on access to care. Data derive from invoices for 455 sequential patients, including 12-month follow-up. Multi-linear and binary logistic regressions explore the effect of private health insurance on readmission, cumulative length of stay, and treatment charge.

The chapter on formal outpatient care (**Chapter 6**) relies on two small datasets, one looking at the rate of participation of psychiatric nurses in mental health at large and in the private sector in particular, and the other querying the costs and access to specialist private practice clinics, using provider data. To address the first question, a simple questionnaire was delivered to 50 nurses attending the mental health meeting of the National Nursing Alliance of Kenya in 2012, including 40 with psychiatric nursing degrees. To address the second question about outpatient care, 11 private practitioners (8 psychiatrists, 3 psychiatric nurses) from Nairobi and Central Province were interviewed using a purpose-designed structured Private Psychiatric Practice interview.

In **Chapter 7**, I first examine the difference in characteristics between traditional and faith healers and the patients accessing their care. Next, I explore the capacity of these healers to diagnose and treat mental illness. Finally, I examine the relationship between the informal and formal health care system, questioning what it reveals about patient preference. The sample comprises 54 healers and 116 patients identified through snow-balling and purposive sampling. Data were gathered using three tools: the standardized Mini International Neuropsychiatric Interview and two purpose-designed tools, the Healing Interview and a socio-demographic questionnaire.

In the **conclusion (8)**, I explore the policy and research implications of these several pieces of research. Bringing together the findings from the five empirical chapters, I attempt to address the ability of non-state actors to address the mental health treatment gap in Kenya, based on the criteria of capacity, access and cost. In addition, I address the limitations of the thesis, chief among them the fragmentation of data sources, and I explore policy and research implications of the findings.

## 2. “Truths” About Mental and Private Health Care in Africa and Kenya



Figure 2-1: A man carrying home water in Nyeri

“My chief object is not to enter into controversial discussion with those who have attempted, or are attempting to describe the same things from outside observation, but to let the truth speak for itself.” – Jomo Kenyatta (Kenyatta 1961)

## **2.1 Introduction**

The study of private health care in Africa is full of controversy. Should private care exist? Does it undermine public care? Does it exacerbate inequalities? The same is true of the field of global mental health. Does mental illness exist in low-income countries? Does promoting treatment advance the cause of the pharmaceutical industry? Following the lead of Kenya’s first president, Jomo Kenyatta, whose dissertation on the customs of the Kikuyu tribe under British colonization was no less controversial, “my chief object is not to enter into controversial discussion.”

Instead, in this chapter I will look at the existing “truths,” in other words what is known from the literature about these topics, paving the way for a contribution to the knowledge through my empirical work. The chapter is divided in three sections. First, I will explore existing models of care for mental disorders in low-income countries. Next, I will review the evidence of what treatments are cost-effective. Finally, I will summarize the debate surrounding the role of non-state actors within African health care and provide facts and figures about their presence in Kenya. In each section, I will highlight gaps in the literature, where the “truth” has yet to be written.

## **2.2 Models of mental health care in LAMIC**

### *2.2 - a) Specialized services*

As we have seen, specialized services for mental health care are relatively rare in Kenya. Hospital care includes residential services for acute patients in designated psychiatric units, and some outpatient care at designated district hospitals with a psychiatric nurse on staff. In the public sector in Kenya, specialized care is almost exclusively available in hospitals. Within the non-state sector, there was no evidence on the availability of specialized mental health care when I began research into this topic. Two models of exclusively specialized care are studied in this thesis: 1) residential care in a for-profit psychiatric hospital; and 2) outpatient care from private practice psychiatrists and psychiatric nurses.



## 2.2 - b) *Integrated services*

Two of the main models for delivering mental health care in Africa are 1) through primary care and 2) through perinatal care. Proponents of primary care (Jenkins, Othieno, Okeyo, Aruwa, et al. 2013; Wright et al. 2013) note that this is the first resort for health care across all health systems, regardless of GDP, and that in a context of constrained specialised resources, it is all the more paramount. The rationale for focussing on perinatal care (Honikman et al. 2012; Nakigudde et al. 2013) is that childbirth is the single occasion when an woman is most likely to come in contact with the formal health system, and that it privileges access to care by women. A large-scale study funded by the UK Department for International Development is currently examining an intervention for mental health in both primary and maternal health care sites across five low-and-middle income countries including three in Africa: Ethiopia, Uganda and South Africa (Lund, Tomlinson, et al. 2012). Called the Programme for Improving Mental Health Care (PRIME), this study focuses on three priority conditions, namely depression, alcohol disorders and schizophrenia.

In a similar vein to integrating mental health within primary care, there is also a move in Africa to integrate mental health within chronic disease care (de-Graft Aikins et al. 2010; de Menil et al. 2012), which includes the treatment of HIV. The rationale for integrating mental health within chronic disease care is multiple. First and foremost, mental disorders are in many cases a form of chronic disease. Disorders like schizophrenia are sometimes accompanied by ongoing symptoms, such as paranoia or disorganized thinking. Other disorders, such as depression, can be cyclical and recurring. Chronicity is not a characteristic of all mental disorders, however, as some people experience full recovery from a single illness episode.

Another reason for integrating mental health within chronic disease care is because there can be a reciprocal relationship between mental disorders and chronic disease. The existence of a comorbid mental disorder tends to worsen the prognosis for chronic disease, and the existence of a comorbid chronic disease tends to aggravate symptoms of mental disorder. One example of this reciprocal association between mental health and chronic disease is that of comorbid depression and diabetes. A recent study by Leone and colleagues systematically mapped the evidence of associations between comorbid depression and diabetes with socio-economic status (Leone et al. 2012). Most of the 14 articles in the literature explored predictors of depression in people with diabetes. Some evidence was found to suggest that comorbid depression and diabetes were associated with lower socio-economic status, although the association was not found between comorbidity and education.

In response to the evidence on comorbidities, integrated treatments are being developed to address these illnesses more comprehensively. Integrated treatments can mean either established referral systems, or a combined treatment package delivered by a single provider. As one of the best-resourced illnesses, HIV has benefitted from the greatest amount of research into integrated care. As might be expected, treating HIV has been found to positively impact people's mental health (Okeke and Wagner 2013). Less intuitively, treating mental health problems has been found to improve HIV outcomes, among those on anti-retroviral therapy (Joska and Sorsdahl 2012). Mechanisms for this effect include improved medication adherence, and better access to and continuity of care. Specific mental health interventions have been developed for people with HIV, such as the "Friendship Bench" problem-solving approach, which has been shown to alleviate symptoms of common mental disorders in an HIV affected population in Zimbabwe (Chibanda et al. 2011).

In light of the clinical benefits of integration, recent research has focused on its potential economic benefits. Again, HIV research is the source of most of the literature on this topic, which has not yet been analysed for mental health care. A systematic review of the efficiencies of integrating HIV treatment and care with other health services found 35 peer-reviewed articles and 11 grey-literature articles on this topic (Sweeney et al. 2012). Only one of the articles compared integrated care with a non-integrated control, so it was not possible to estimate the cost-effectiveness of integration. The literature did, however, suggest that integrating care improved technical efficiencies, as demonstrated by lower unit costs of care. Furthermore, a study called Integra is underway, led by some of the same authors as the systematic review, to fill the literature gap on the cost-effectiveness of integrated care, and Kenya is one of its sites (Warren et al. 2012).

### *2.2 - c) Community-based interventions*

Also involving primary care, but not limited to it, are a broad range of strategies promoting "community mental health." The precise meaning of this term varies depending on the context (Hanlon, Wondimagegn, and Alem 2010). In addition to outpatient treatment, it can also include care within the community itself, which is to say in village streets, homes, religious venues, and schools (Raja 2009). Community mental health also involves a host of different actors, typically less-specialized in health.

In the context of increasing access to community mental health, considerable attention has been turned to the ability of lay-health workers to treat mental disorders, an approach referred to as "task-shifting." Most of the task-shifting literature comes from Asia (Rahman et al.

2008; Patel et al. 2010; Chowdhary et al. 2014). A systematic review of task-shifting in mental health suggests that the outcomes of this approach are, as yet, inconclusive, though they have shown signs of promise in certain contexts (van Ginneken et al. 2013). The review uncovered seven studies of task-shifting from low-income countries and fifteen from middle-income countries. Most of the studies focused on the influence of task-shifting on recovery from common mental disorders, particularly depression, anxiety and post-traumatic stress disorder. The study found that at two-to-six months post intervention, task-shifting appeared to increase the recovery rates from depression and anxiety. One of the studies reviewed came from Uganda (Bolton et al. 2003). The authors of the Cochrane review noted, however, that the data were subject to selection bias, small samples and high drop-out rates, making the findings inconclusive.

Another key type of community-based care takes the form of user-led, or “self-help” groups. Despite endorsement of service user involvement by global mental health policy makers (World Health Organization 2001, 2005), there is very limited research in this area from low- and middle-income countries. A trial from India demonstrated for the first time in a low-income setting that participation in user-groups (called self-help groups) was an independent determinant of good outcome for people with schizophrenia (Chatterjee et al. 2009). The groups constituted part of a community-based rehabilitation programme. In Africa, there is qualitative evidence of users forming networks at local, district and national levels in Ghana in order to influence health and development policies (Yaro and de Menil 2009). The work in Ghana was done with support of the NGO BasicNeeds, also active in Kenya. Papers have been written in Zambia (Katontoka 2007) and South Africa (Kleintjes et al. 2010; Kleintjes, Lund, and Swartz 2013) articulating the potential effects of increasing service user involvement within mental health, but no quantitative evidence exists on their outcomes.

In Kenya, a group calling itself Users and Survivors of Psychiatry Kenya (USP-Kenya), was established in 2007 to give voice to service users in policy debates and raise awareness among the general public about the nature of mental disorders. USP-Kenya was also supported with financing and infrastructure from BasicNeeds (USP-Kenya 2011). There appears to be a significant overlap, therefore, between the informal not-for-profit sector and the formal not-for-profit sector.

Among international NGOs working in mental health, there is a particular interest in displaced and brutalized communities as a consequence of humanitarian disaster (Betancourt et al. 2010). In Uganda, for example, the Peter Alderman Foundation set up training workshops and psycho-trauma centres to help overcome the effects of years of civil war between the Lord’s

Resistance Army, led by Joseph Kony, and the government of Yoweri Museveni (Nakimuli-Mpungu et al. 2013). A number of organizations aim to provide mental health care to refugees, such as International Medical Corps, working with Somalis in Ethiopia. Kenya shelters the world's largest refugee camp, Dadaab, which is home to some 500,000 mostly Somali refugees in the north-east of the country. Two international NGOs and a governmental organization – the International Rescue Committee, *Médecins Sans Frontières* and *Gesellschaft für Internationale Zusammenarbeit* (GIZ) – all have psychiatric nurses on-site providing mental health care to refugees. The effectiveness of these interventions is challenging to evaluate given the obvious constraints of conducting research in a context of acute insecurity. Some interventions for PTSD have shown benefit in adults, and group therapy and school-based supports have shown benefit for children with internalising symptoms, however the most commonly used humanitarian mental health interventions have not been subject to rigorous evaluation (Tol et al. 2011).

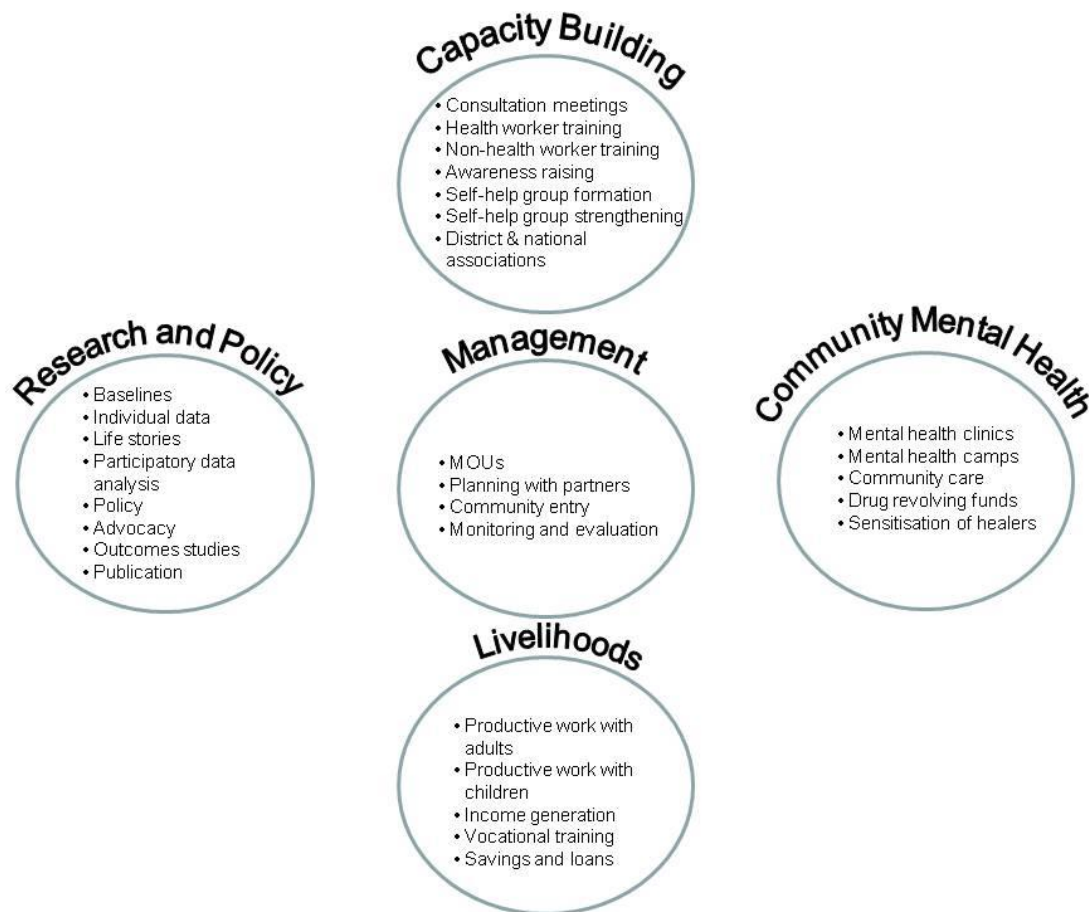
Community-based interventions in their truest sense involve people outside of the health sector, such as village leaders, religious leaders, traditional healers, teachers, and community workers, sometimes known as volunteers (de Menil and Underhill 2010). Community-based mental health care is widely promoted as best-practice in international policy documents. For instance, one of the four objectives of the new flagship Mental Health Action Plan 2013-2020 published by the World Health Organization is “to provide comprehensive, integrated and responsive mental health and social care services in community-based settings” (World Health Organization 2013). In middle-income countries, the emphasis of community mental health interventions is on de-institutionalizing existing mental health care, but in most of Africa, the emphasis is on creating new mental health services where there have been none. The leading providers of community-based care in Africa tend to be non-state actors rather than governments. Two models of community-based care stand out for having been most widely put into practice. These are the Mental Health and Development (MHD) model and the Community Based Rehabilitation (CBR) model.

#### **2.2.c.i Mental Health and Development (MHD) model**

The Model for Mental Health and Development was designed by Chris Underhill and field tested in India by DM Naidu and colleagues in 2000 (Underhill 2002). It is a rights-based intervention composed of five modules (figure 4-2): capacity building; community mental health; livelihoods; research and policy; and collaboration (formerly management). The MHD model, which is innovative for its inclusion of poverty-reduction strategies within a health care context,

was first described in detail within the handbook *Mental Health and Development: A Model in Practice (BasicNeeds 2008)*. A synthesis of its five modules follows.

Figure 2-2: Modules and activities of the MHD model



Source: BasicNeeds Operations Manual, 2010

*Capacity building:* Capacity building exists along three levels: users and carers, community leaders, and health and development workers (including community workers). The MHD model starts by consulting people with mental illness or epilepsy and their carers to assess their needs, as voiced by themselves. Listening to and sensitising key community leaders (village elders, police officers, government officials, religious leaders) takes place in parallel and is said to foster local ownership and adaptation of the intervention. Capacity building continues with health and development workers, who are trained in the aspects of mental health and development germane to their work. Emphasis is on diagnosis, treatment and prevention for health workers, and on recognizing mental illness or epilepsy and its links to poverty for development workers. One of the main outputs of the capacity building module is self-help groups of service users and carers, who are offered training in a number of topics, ranging from managing group dynamics and

techniques of self-advocacy to book keeping for income generation. The underlying principle of this module is to mobilize and empower communities to address the issues arising from or generating mental ill health.

*Community mental health:* Medical treatment in community health care settings is an essential component of the MHD model. Community mental health care is delivered principally in partnership with the national health service of a given country, as well as with private providers, such as charitable clinics. BasicNeeds also engages with practitioners of traditional medicine, who are often the first port of call for people with mental disorders seeking care. The main focus of the community mental health module is making care accessible in community settings (figure 4-1), as opposed to psychiatric hospitals, where it is typically found in low-income settings (Raja 2009). In the first instance, this involves creating outreach clinics in primary care centres, where psychiatric nurses or psychiatrists are brought in on regular occasions to provide treatment. Later, general health workers are often trained in mental health using national curricula (as per the capacity building module), and mental health clinics become integrated into primary care – offered alongside other standard health treatments, as per WHO policy (World Health Organization and World Organization of Family Doctors 2008). Community workers also form an essential ingredient to the community mental health module, supporting service users in their homes and neighborhoods, outside of the clinic (de Menil and Underhill 2010).

*Livelihoods:* In calling the organization BasicNeeds, Underhill chose to emphasise not only that mental health care is a basic need, but also that people with mental illness or epilepsy have basic needs that go beyond health care. BasicNeeds argues that engaging in a livelihood is one of the best means for overcoming the stigma surrounding mental illness and epilepsy. Income generating activities are mostly carried out in the context of self-help groups, but can also be the work of individuals, depending on the development services available in a given community. Livelihoods are grouped in two categories: 1) income generation; and 2) unpaid productive work, such as tilling soil, feeding animals, fetching water or cleaning.

*Research and Policy:* Including research within a community development model was a noteworthy decision on the part of those designing the MHD model, as community development workers sometimes resist data collection, arguing that it detracts time from important programme implementation. Research conducted in the context of the BasicNeeds model therefore has a clear practical application – for example, looking at causes of drug shortages (Raja, Kippen, and

Reich in press), or the public funding available for mental health in a given country or district (Raja et al. 2010). Much of the research aims to gather evidence for promoting or implementing health and development policies and improving practice. A sample of people with mental illness or epilepsy also engage in participatory action research to inform field staff of what is working and what needs changing in the model's application.

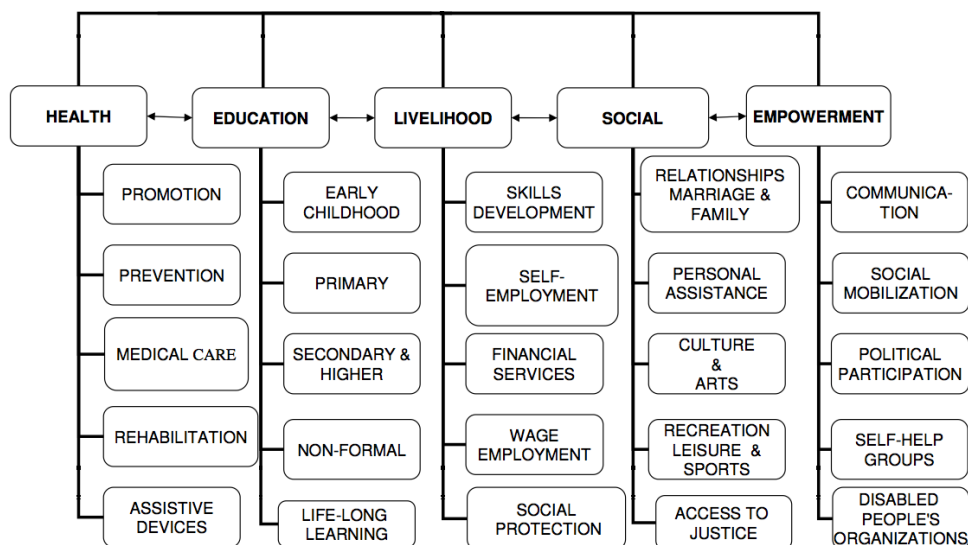
*Collaboration (formerly management):* The MHD model is managed and delivered through a web of public and private partnerships, numbering 88 in 2010 (BasicNeeds 2011). As a rule, BasicNeeds employs locals in their country of origin, rather than bringing in experts from abroad. In order to implement the BasicNeeds model, there must first be a partnership with government, so that the work is locally authorised. Partners must also meet a set of due diligence criteria, and are chosen on the basis of their interest in mental health and development, their standing in the community, and their organizational capacity, particularly as regards community workers and livelihoods. The Model for Mental Health and Development has been manualised by BasicNeeds to increase its dissemination and ensure standards of practice. The Operations Manual, which is regularly updated, breaks down each module into its component activities (figure 1) and is available for use by interested organizations by means of a license agreement.

#### 2.2.c.ii Community Based Rehabilitation

Within the field of disability the leading intervention model is Community Based Rehabilitation (CBR). The CBR model was developed in the 1980s by Swedish doctor Einar Helander, a specialist in rehabilitation medicine (Helander 1993). The model consists of five domains: health, education, livelihood, social, and empowerment, each further divided into five elements, as in the matrix above (figure 4-3). (World Health Organization 2010).

CBR was standardized in a 1994 policy paper, jointly authored by the International Labour Office, UNESCO, and the World Health Organization (International Labour Organization, World Health Organization, and United Nations Educational 2004). In 2004, the same group of international agencies updated their thinking in a strategy paper celebrating the twentieth anniversary of CBR's inception (International Labour Organization, World Health Organization, and United Nations Educational 2004). The paper defined essential elements for implementing CBR at national, district and community levels, and secured endorsements of the model from a panoply of sectors (social, health, education, employment, NGO, media and community).

Figure 2-3: Community Based Rehabilitation model



In addressing the use of CBR for the treatment of mental disorders, a word is called for on the position of mental disorders within the field of disability. (The language preferred by the disability community is “psycho-social disabilities,” as opposed to mental disorders.) Many mental health activists have lobbied to include mental illness within the definition of disability. The passage in 2007 of the Convention on the Rights of Persons with Disabilities was hailed as a great step forward in this respect in that it acknowledged that disorders of the mind constitute a disabling condition. Specifically, the convention defines persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.” (United Nations 2007). Not all mental health service users identify as disabled, however, particularly those from low-income countries (Lamichane 2014). The financial and resource benefit attached to this label in high-income countries is not present in low-income settings, and disability is typically viewed as a chronic condition from which there is no recovery. The term can therefore be seen by some as stigmatizing.

### 2.2.c.iii MHD in comparison

There is considerable overlap between MHD and CBR. Three of the five model areas show almost perfect overlap, namely health (CBR) and community mental health (MHD), education (CBR) and capacity building (MHD), and livelihoods (CBR and MHD). The two additional CBR branches, social wellbeing and empowerment, are also terms that cohere with MHD principles. Furthermore, preliminary research has shown signs of success for integrating mental health into CBR under certain conditions (Raja et al. 2008).



Some differences do stand out between these approaches, however. The main distinction between the three models is their genesis. Whereas CBR has its roots in the field of rehabilitation, the MHD model is the offspring of the field of development. BasicNeeds makes economic-based arguments – principally the reduction of poverty – for working in mental health (McDaid and al 2008). Indeed, BasicNeeds does not consider itself foremost as a health charity, but rather as a development organisation that happens to work with people with a health condition (Underhill 2011).

The development orientation of BasicNeeds is reflected in a more collectivist approach to intervention – starting with the community rather than with the individual. As opposed to CBR, which works principally at the unit of the individual, the MHD model works principally at the unit of groups, particularly self-help groups. The stated purpose of these groups is to encourage and capacitate people with mental illness or epilepsy to take charge of their lives (Yaro and de Menil 2009).

The development approach inherent in the MHD model is also reflected in the way that BasicNeeds engage in the discourse of human rights. The MHD model principally promotes the right of people with mental illness or epilepsy to development (United Nations General Assembly 1986) as distinct from their right to health care (United Nations 2007; United Nations General Assembly 1991). Both rehabilitation and psychiatric care are also conceived as fundamental rights, but they are framed as means to an end, which is development, rather than as ends unto themselves (Underhill 2011).

## *2.2 - d) Traditional and faith healing*

The informal sector for mental health care in Kenya is substantially larger than the formal sector, but less well documented. An estimated 80% of rural health care in Kenya is provided by traditional healers, and that rate may be higher in cases of mental health problems (Ndetei 2007). Healers come in many forms. Some healers are generalists, while others specialize in the treatment of certain disorders, including mental disorders (Okonji et al. 2008).

Psychiatrist Marx Okonji and colleagues shed some light onto mental health coverage by healers in a report on a healer workshop in Meson Division, Kisumu District. The 70 healers identified for the study were presumed to represent almost the whole population of healers in the division (population 50,000), making the ratio of healers to general population 1:714. The most appropriate analogue to the majority of healers is neither psychiatrists nor psychiatric nurses, but primary care providers. Kenya has approximately 2,000 primary care centres (Okonji et al. 2008), putting the ratio of primary care centres to general population at 1: 19,000. Healers

are considerably more prevalent than all types of formal health care providers, and up to 25 times more prevalent than primary care providers. Despite their pervasiveness, little is documented about the nature of care currently provided by healers to patients with mental disorders.

## 2.2 - e) *Literature gaps*

Despite the existence of several coherent models of care for mental disorders in low-income countries, evidence on their effectiveness is limited by the dearth of research in this area. Only 1% of all clinical trials on the treatment and prevention of mental disorders is conducted in low- and middle-income countries (LAMIC), where 80% of the world's population lives (Patel et al. 2007). If the literature is thin from low-income countries in general, it is thinner still from Africa. A systematic review conducted by Vikram Patel and colleagues for the first of two *Lancet* series on global mental health (*ibid*) found fifty-one studies from sub-Saharan Africa, but the majority were of limited generalizability, because samples were so small. Three quarters of trials conducted from LAMIC had fewer than 100 participants.

In 2010, the World Psychiatric Association commissioned a review of the literature on community-based mental health care in Africa and found “a conspicuous lack” of evidence (Hanlon, Wondimagegn, and Alem 2010). Of the 24 evaluations located in the published and grey literature, 70% were from South Africa, the only middle-income country in sub-Saharan Africa, and only five studies included any form of comparison (pre-post or comparison to another model). Not a single study evaluated clinical outcomes using standardised symptom scales. Equally, no evidence was found on the effectiveness of either traditional healing or user-groups, though both were noted as potentially promising interventions. In the Kenyan context, the MHD model has been widely implemented for the treatment of mental disorders, whereas CBR has not, so I have chosen to evaluate the MHD model, which is the subject of chapter four of this thesis.

## 2.3 **Cost-effectiveness of mental health care in LAMIC**

The literature on models of care focus primarily on two dimensions of Tanihashi's spectrum of coverage, namely availability and acceptability. However, in order for existing and emerging interventions to be implemented at scale in low-income settings and start redressing the treatment gap, they must be not only effective, but affordable. This is especially true in contexts of poverty, where, for example, running water is not the norm (figure 2-1). Two further dimensions that are critical to achieving full coverage, therefore, are economic accessibility and

effectiveness. Both dimensions can be addressed in combination through cost-effectiveness analysis.

Cost-effectiveness analysis allows for comparison between two different types of health service, for example mental disorders and malaria. “Where is your bed-net?” was the question once posed to psychiatric epidemiologist Vikram Patel by development economist Jeffrey Sachs (Patel 2011). To justify investment, mental health services must be of comparable cost-effectiveness to the leading alternative health interventions – such as bed-nets for malaria. Policy decisions require data on *avertable* disease burden, not *attributable* burden (Chisholm 2005), and economic evaluation is a leading way of measuring avertable disease burden.

Ideally, economic evaluations of mental health care in LAMIC should be based in empirical data and tailored to a country or region of focus (Chisholm 2005). However, a systematic review of economic evaluations of mental health in LAMIC (Shah and Jenkins 2000) found only ten empirical studies reporting on cost-effectiveness, and only one from Africa, conducted in 1989. The study, from South Africa, sampled 51 people with mental disorders and interviewed them before and after the introduction of home visits by psychiatric nurses (Gillis, Koch, and Joyi 1990). Hospital days decreased by half following the home visits, which led to estimated savings of Rd 786 (\$309) per patient per year: a promising result, but insufficient evidence for high-level policy making across the continent.

In the intervening years since the review was published, one economic evaluation was published using patient-level data from India. The study compared the cost-effectiveness of a lay-health worker intervention for depression with treatment as usual in public and private primary care clinics. Interestingly, the task-shifting intervention, devised by Vikram Patel and colleagues, was found to be more effective than treatment as usual in public facilities, but not in private practice (Patel et al. 2010). Effect was measured using the revised Clinical Interview Schedule, and scores in the public sector intervention group were 4.8 points better (20% of the baseline score) at 6 month follow-up than in the control group. Scores improved markedly for both intervention and control groups, particularly among private providers, where scores had fallen by approximately 60% across both intervention and control groups at follow-up. The researchers noted that recovery rates among the control group of private GPs was high, and they speculated that this could be the result of selection bias: private GPs who are interested in participating in a clinical trial are likely to be more motivated than the norm.

The cost-effectiveness results reflect these clinical findings (Buttorff et al. 2012). The intervention dominated in the public facilities – meaning it was lower-cost and had better effects – whereas costs and effects were almost equal between intervention and control in the private

facilities. The overall cost of the intervention was Int\$ 177 per person, divided evenly between direct health system costs and indirect opportunity costs. Intervention costs were lower than control costs, driven by lower indirect costs, specifically lost wages from sick days (Int\$ 108 in the control group vs Int\$ 64 in the intervention).

In the absence of patient-level data, the next-best alternative, which comes at little cost and can be performed rapidly, is economic modelling. Where possible, economic models are populated with data from a specific country, so as to more accurately reflect variation in costs relating to local context. The standard threshold for cost-effectiveness of an intervention is that it costs less than per capita GDP per Quality Adjusted Life Year gained (World Health Organization 2005). Two studies have used country-level data to design Markov models of mental health interventions: one from Chile and one from Uganda. Both studies estimate the cost-effectiveness of treatments for depression. The Ugandan model (Siskind, Baingana, and Kim 2008) used outcome data from a locally conducted study of interpersonal group therapy (Bolton et al. 2003; Bass et al. 2006), to which it added booster sessions. The primary outcome was number of episodes of depression, which were estimated to decrease by 16% with group therapy plus booster sessions. The incremental cost of this intervention was \$1,150 per Quality Adjusted Life Year (QALY) gained – which falls below the standard threshold of per capita GDP.

The Chilean model (Siskind, Araya, and Kim 2010) used outcome data from a stepped-care intervention for women (Araya et al. 2003) and estimated intervention effects over the women's lifetime. The incremental cost-effectiveness ratio (ICER) of stepped-care versus treatment-as-usual was less than per capita GDP (\$9,900 at the time in Chile). The results were highly sensitive to the estimates of treatment coverage (relating to adherence), which ranged from 50% to 80%. Stepped-care became notably more cost-effective when modelled with higher adherence than usual care.

Because of a scarcity of data, the bulk of literature on economic evaluation of mental health in LAMIC is produced through economic modelling. There is a widespread lack of evidence on the costs of basic health services, particularly those provided by non-state actors. The WHO have devised their own method for estimating cost effectiveness within a given country or region by drawing on data from across multiple countries. The WHO CHOICE method for measuring cost-effectiveness (technically cost-utility) has two particularities: the comparison group is always 'no treatment' and outcome is measured in DALYs (World Health



health care, in this case mental and neurological disorders. Two papers have adopted a sectoral approach to model packages of care for priority mental health conditions (Chisholm 2005; Gureje et al. 2007). The first study of this kind by Dan Chisholm and colleagues modelled a package across the 14 WHO sub-regions, including Africa-E, which encompasses Kenya.

The package included treatments for two severe mental disorders (schizophrenia and bipolar disorder) and two common mental disorders (depression and obsessive-compulsive disorder) with coverage rates of 50% for all disorders except schizophrenia, which it estimated at 80% (Chisholm 2005). Chisholm concluded that, at a per capita cost of \$3-4, a minimum of 1,600 DALYs could be averted per million people living in sub-Saharan Africa. The interventions with the lowest cost-effectiveness in the package were for severe mental disorders, which amounted to two-thirds of the cost but only one-third of the gain. However, the author noted that other considerations than efficiency come into play in rational decision-making, in particular considerations of equity. (This point will be addressed in the following chapter on methods.)

Also adopting a sectoral approach, Oye Gureje and colleagues (including Chisholm) modelled a package of care for mental disorders in Nigeria (Gureje et al. 2007). The Nigerian package covered a different set of conditions at slightly different rates of coverage than the WHO regional study. In addition to schizophrenia and depression, the Nigerian package covered care for epilepsy and alcohol disorders, instead of for bipolar disorder and OCD. The modelled rates of coverage ranged from 40% for depression to 80% for alcohol disorders. Gureje concluded that the cost of such an intervention would amount to US \$0.77 per capita (80 Naira), which he deemed an affordable amount within the Nigerian context.

In conclusion, evidence from economic modelling suggests that several mental health interventions could be cost-effective at scale in Africa. In practice, however, few interventions are actually being put in place. The public health sector is over-stretched in terms of skilled workers, medical supplies and financial resources. What room is there then for the private sector to fill some of this gap?

## **1.2 Non-state health coverage in sub-Saharan Africa and Kenya**

### *1.2 - a) In sub-Saharan Africa*

Because of a shortage of public health resources across sub-Saharan Africa, attention is increasingly turning to harnessing the potential of the non-state sector (Smith, Brugha, and Zwi 2001; Marek et al. 2005; International Finance Corporation 2007; Bennett 2005). Discussions

around the role of non-state actors in global health often err towards principle rather than fact. The challenge of gathering evidence in this area is that its components are less well organised, and therefore harder to monitor. There is a lively debate around whether the non-state sector is contributing positively or negatively to health care coverage.

#### Positive contributions of non-state providers

The strongest argument in favour of the non-state sector (both for-profit and not-for-profit) is practical (Smith, Brugha, and Zwi 2001; Harding 2009; Harding and Preker 2003): non-state providers are delivering health care at a large scale with or without the endorsement of policy makers. Non-state actors provide an estimated 50% of formal health care in sub-Saharan Africa (International Finance Corporation 2007). To ignore them and focus exclusively on improvements in the public sector amounts to ignoring half of health care provision. Moreover, there is considerable overlap between state and non-state actors, since many doctors and nurses work in the public sector part-time and in the private sector for the other part.

An extension of the practicality argument is that non-state providers increase access to health care. A study by Joanne Yoong and colleagues made an effort to empirically measure this assumption by examining the association between private sector participation rates and health care consumption in 34 sub-Saharan countries (Yoong et al. 2010). Data were drawn from Demographic and Health Surveys in relation to two conditions: child birth and childhood respiratory diseases. Overall rates of medical service use were low (50% for people with health care needs), and a strong positive association was found between levels of private sector participation and use of health facilities: a 10% increase in private participation was associated with a 15% increase in use of health services. These results held when controlling for income and maternal education, two factors associated with higher levels of private participation. The main limitation of the study is that it is cross-sectional, so it is not possible to impute causality to the association.

A systematic review of the literature questioning the impact of non-state service provision on access to and quality of services concluded that “there is a need for much stronger evidence” (Patouillard et al. 2007). The review, which focused on the for-profit sector only, found 52 articles evaluating impact on a range of different private sector interventions. Half the studies were evaluations of training for private providers, while a third focused on social marketing and franchising, suggesting that these are the leading areas of study, if not activity within for-profit private health care.

Arguments are also found in favour of non-state health care among supporters of regulated market forces, who argue that provider competition and choice are good for consumers, and that health care is a good investment (International Finance Corporation 2007; Zwi, Brugha, and Smith 2001). This is the stance of a report commissioned by the International Finance Corporation and researched by McKinsey, titled *The business of health in Africa: Partnering with the private sector to improve people's lives* (International Finance Corporation 2007). Additional pro-market arguments include that the non-state sector is more innovative and that they can make available expensive services that wouldn't otherwise be offered (e.g. MRI machines). More ethically-oriented pro-market arguments can be found among proponents of user empowerment, since evidence from Asia suggests that service users prefer non-state provision: they perceive the non-state sector as having more flexible access, shorter waiting times, greater confidentiality, and greater sensitivity to their needs (Zwi, Brugha, and Smith 2001).

#### Negative contributions of non-state actors

For each point in favour of the non-state sector, a counter-point has been made by opponents, which I have summarized in the table below (table 2-4) (Hanson et al. 2008). They argue that high user fees (particularly in the for-profit sector) cause the private sector to decrease rather than increase access to health care, particularly among the poor (Oxfam 2009). The pro-private retort is that wealthier patients receiving care from the private sector lightens the public sector burden, enabling them to focus on the neediest (Marek et al. 2005). However, the strongest critics contend that, rather than increasing coverage, non-state providers act as substitutes for public providers, thereby undermining the public health system for no gain in overall population health (Marek et al. 2005; Oxfam 2009). Little evidence exists at the moment to confirm or deny these conflicting positions.

The most substantiated critique of the non-state sector is the uneven quality of services, resulting in part from a lack of appropriate regulation (Sauerborn 2001; Zwi, Brugha, and Smith 2001). There is considerable evidence to back this critique from a range of specialties including malaria (Kamat 2001), TB (Uplekar, Pathania, and Raviglione 2001), respiratory illnesses (Chakraborty and Frick 2002) and leprosy (Uplekar and Cash 1991). A host of problems were found in these studies, including failure to use appropriate diagnostic tests, and provision of drugs for inadequate lengths of time. Despite these serious short-comings, some researchers argue that comparable quality short-comings can be found in the public sector, and that the drivers of quality care are management and incentives, rather than whether the provider is publicly or privately owned (Hanson et al. 2008).



Table 2-1: Key points in the debate around non-state health care in LAMIC

<i>Keep in private care</i>	<i>Keep out private care</i>
<ol style="list-style-type: none"> <li>1. It is being widely used, so better to monitor than exclude.</li> <li>2. It increases access to health care.</li> <li>3. Users like it.</li> <li>4. It provides products and services that might not otherwise be available.</li> <li>5. Introduces competition and choice</li> <li>6. It is more innovative.</li> <li>7. There's overlap between the sectors.</li> </ol>	<ol style="list-style-type: none"> <li>1. It is costly and user fees reduce access to services.</li> <li>2. It is low quality, because unregulated.</li> <li>3. It is unequitable – caters to the rich and urban.</li> <li>4. It undermines the public sector.</li> </ol>

Beyond questions of quality, private sector service distribution also raises questions about equity. It is often assumed that private care serves wealthier populations to the exclusion of poorer people, who cannot afford the fees. While it is true that a greater proportion of those using non-state care is wealthy, the evidence does not bear out the hypothesis of exclusion of the poorest (Gwatkin 1999; Marek et al. 2005). A further critique around equity contends that private care focuses on urban populations to the exclusion of rural populations. Geographic distribution is, indeed, uneven, however, it is less so than suggested by critics. (I will address both of these challenges to equity within the context of Kenya in the following section.)

Thus, a more nuanced stance emerges placing emphasis on contextual factors in determining the strengths and weaknesses of non-state health provision in developing countries. This position, put forth by Kara Hanson and colleagues at the London School of Hygiene and Tropical Medicine (Hanson et al. 2008), notes great diversity among non-state actors, and contends that each should be examined separately, rather than conflating the performance of for-profit and non-profit, formal and informal actors alike.

### 2.3 - a) *In Kenya*

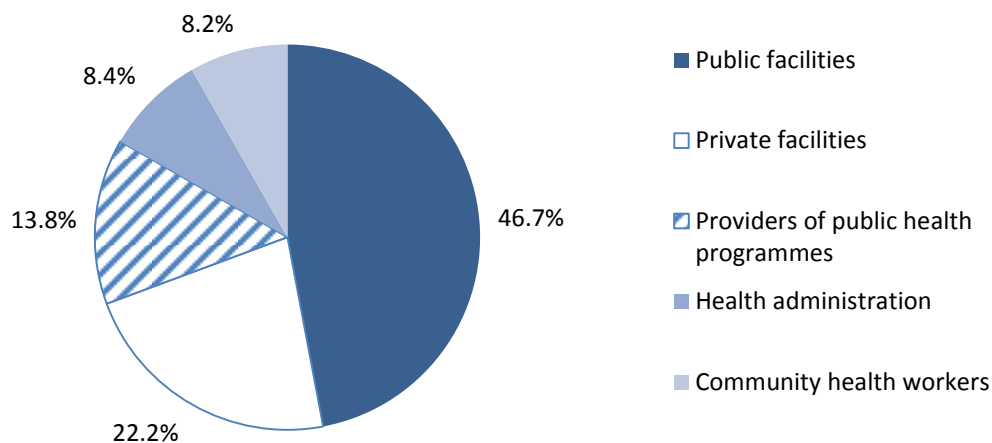
The relative shortfall of information about non-state mental health care in Kenya comes in stark contrast to the well-developed nature of Kenya's private health care sector in general. In 2010 the World Bank completed a rigorous Private Health Sector Assessment in Kenya, as part of the project Private Sector Partnerships-One (PSP-One) (Barnes et al. 2010). The assessment noted that Kenya's private sector is unusually well organized relative to other developing countries,

particularly around professional associations and trade groups. Moreover, pharmaceuticals represent a smaller segment of private sector spending in Kenya than in most other LAMICs, suggesting either that drugs are less over-prescribed, or that there are more providers relative to the number of drugs. Overall, private sector participation in Kenya’s health system was noted to be large and growing.

Indicators of the private sector’s size include the total market value, the number of providers, and the proportion of health visits made to those providers. According to the World Bank Assessment, the private health care market in Kenya is valued at Int\$ 542 million (Ksh 20.7 billion), two-thirds of which are spent on hospitals. As of the latest national health account data (Ministry of Medical Services and Ministry of Public Health and Sanitation 2011), nearly a quarter (22%) of total health expenditure goes to private facilities (figure 2-3), and half of that (46%) is spent on hospitals. Private hospital expenditure goes in majority (60%) to for-profit hospitals, in the form of out-of-pocket and insurance payments (figure 2-4).

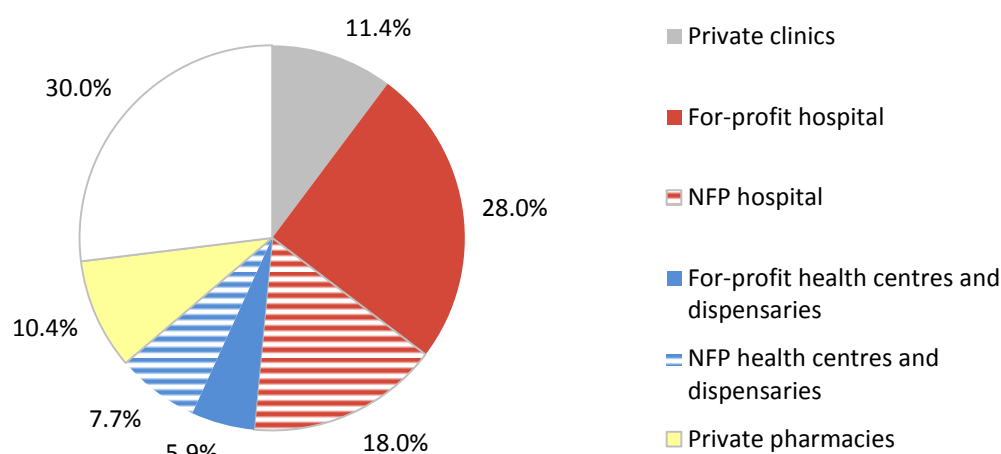
In terms of provider numbers, three-quarters of all doctors and two-thirds of nurses are estimated to work in the private sector – though not exclusively so (table 2-1). Furthermore, 59% of health facilities are privately owned, with faith-based organizations alone owning a quarter of hospitals and 15% of health facilities (table 2-2).

Figure 2-5: Distribution of Kenya’s total health expenditure in 2009/2010



Data source: National Health Accounts 2009/10

Figure 2-6: Distribution of Kenya's health spending to private providers



Data

source: National Health Accounts 2009/10<sup>7</sup>

On the demand side, 55% of urban health visits and 41% of rural health visits in Kenya are made to private providers (table 2-3). This suggests that the geographical spread is more equitable than might be expected. That being said, the bulk of rural provision may be from not-for-profit providers. Out-of-pocket (also called household) spending, which represents one third of health financing in Kenya, is split half and half between public and private providers. Data from 2005/6 national health accounts (figure 2-5) suggest that almost equal amounts of out-of-pocket funds are going to for-profit and not-for-profit hospitals (14.8% vs 11.2%). However, not-for-profit hospitals are likely to be seeing more patients, so this figure is potentially misleading.

Table 2-2: Estimates of Kenya's health personnel by sector, 2007-08

Cadre	Total Registered (2007)	Public Sector (2008)	Public Sector (% of total)	Private Sector*	Private Sector (% of total)
Doctors	6,271	1,605	26%	4,666	74
Dentists	631	205	32%	426	68
Pharmacists	2,775	382	14%	2,393	86
Pharmaceutical technologist	1,680	227	14%	1,453	86
Nursing officers	12,198	3,013	25%	9,185	75
Enrolled nurses	31,917	11,679	37%	20,238	63
Clinical officers	5,797	2,202	38%	3,595	62

Source: Barnes 2010<sup>8</sup>

<sup>7</sup> CHWs only accounted for 2% of private spending in the 05/06 NHA, as compared to 30% here. While CHW numbers have doubtless increased with the advent of a new strategy and their involvement in HIV treatments, this dramatic increase could also reflect a change in the definition or reporting of community health workers

Table 2-3: Distribution of Health Facilities in Kenya by Type and Ownership, 2006

Facility Type	MOH	FBO	Private	Total
Hospital	158	74	68	300
Nursing homes*			191	191
Health centers	459	172	21	652
Dispensaries	1,503	546	203	2,252
Clinics			1,734	1,734
Total	2,120	792	2,217	5,129

Source: Barnes 2010

MOH = Ministry of Health; FBO = Faith based organization; Private = for-profit

Table 2-4: Visits to health providers in Kenya by sector, 2007 (%)

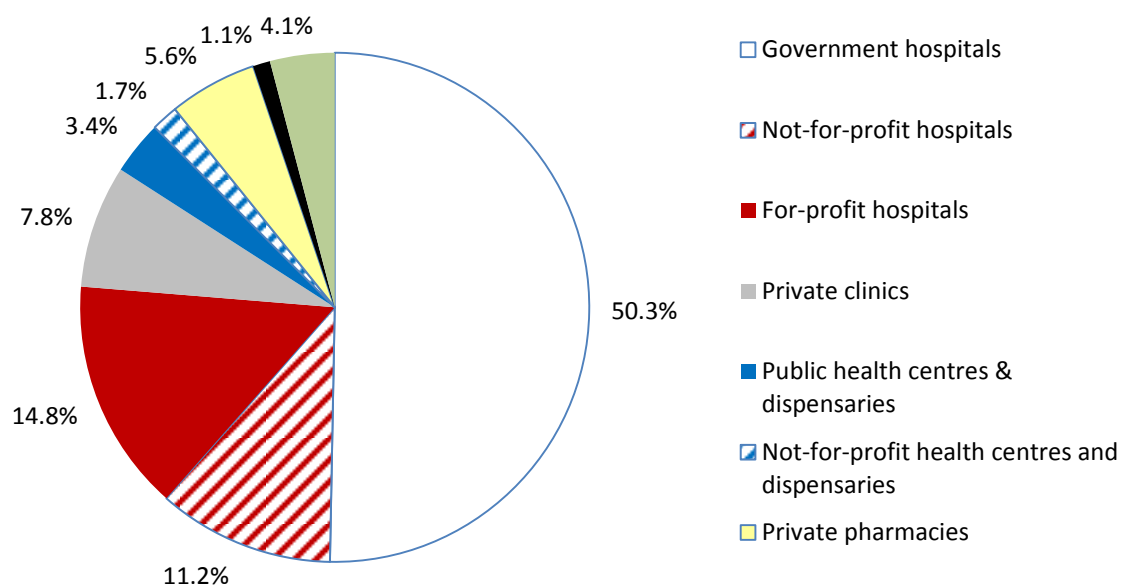
	Public	For-profit	FBO	Chemist	Other	Total
Urban	45.5	29	4.8	18.7	2	100
Rural	59.5	16.8	6.8	14.3	2.7	100

Source: Barnes 2010

The World Bank assessment coincides with increasing interest by the Government of Kenya in private sector provision of health care. The policy document *Vision 2030* (Government of Kenya 2007), which defines Kenya’s strategy for development over the next two decades, makes public-private partnerships one of the “key initiatives.” More broadly the policy states: “One of the basic strategies for achieving the health care goals of Vision 2030 is structural change. This will be achieved through an enhanced regulatory regime and the creation of an enabling environment to ensure increased private sector participation.” The World Bank report takes this further, arguing that “most government officials acknowledge that the public sector cannot provide for all of Kenya’s health needs, and recognize the importance of the private for-profit, not-for-profit and faith-based sectors” (Barnes et al. 2010).

<sup>8</sup> The World Bank report drew its data from the Ministry of Medical Services Strategic Plan, which is not publicly available. The Ministry of Public Health and Sanitation posted its plan online, however it does not contain data on human resources. I have therefore had to replicate tables 4-6 from the World Bank report. In addition, the 2009/10 national health accounts do not report on out of pocket spending, so I similarly had to replicate figure 7 from the World Bank report.

Figure 2-7: Out-of-pocket spending in Kenya by provider, 2005/06



Source: Barnes 2010

The distribution of non-state care between the poorer and wealthier segments of Kenyan society appears relatively even. Kenya's 1999 Demographic and Health Survey (Measure DHS 1999) reports that among the poorest quintile, 47% of health care for a sick child was received from a private provider, which was only somewhat lower than use by the wealthiest quintile (65%). The most recent DHS survey from Kenya unfortunately does not distinguish between public or private health care providers when examining rates of child health care attendance. It does, however, report on reproductive health. Over one third of contraceptives in Kenya are acquired from a private medical provider, plus an additional 6% from private non-medical sources, such as "shops" (unlicensed pharmacies) (Measure DHS 2009). Though high, this rate represents a decrease of 14% relative to 2003, when 41% of contraceptives were sourced from private medical providers.

The recent DHS report further reveals that private care is not equally used for all types of health care. Antenatal care, for instance, is 83% government provided. Since a majority (56%) of births in Kenya take place at the home, it may be that antenatal care is viewed as more optional, and that private care is used less for health services deemed optional.

The geographic distribution of private care between in Kenya appears slightly skewed towards urban care, but fairly even. According to the 1999 DHS data 49% of rural populations accessed health care through private providers as compared with 59% of urban populations

(Measure DHS 1999). A more recent household survey conducted by the Ministry of Health and reported on in the World Bank assessment found similar numbers with 49% of rural health visits and 55% of urban visits being made to private providers in 2003 (Barnes et al. 2010).

The quality of private health care has been evaluated in Kenya for reproductive health (Agha and Do 2008, 2009), malaria (Abuya et al. 2010), TB (Chakaya et al. 2008) HIV, and drug distribution (Liambila, Obare, and Keesbury 2010). In addition, some attention has been given to the use of franchises for malaria, reproductive health and primary care (Decker and Montagu 2007; Chiguzo et al. 2008; Fertig and Tzaras 2005).

Little evidence, however, exists for the use of private care for chronic diseases, such as cancer, cardiac disease and mental disorders. Indeed, the World Bank assessment notes the need to address this literature gap: “Analyzing the use of the private sector in the area of chronic illnesses was not part of this private health sector assessment’s original scope of work, but such an analysis would be an important contribution” (Barnes et al. 2010).

## **2.4 Conclusion**

There is a growing literature on the effectiveness of mental health interventions in low-income countries and some evidence – mostly from economic modelling – on the cost-effectiveness of some approaches. The literature is all but absent, however, on the topic of non-state provision of mental health care in low-income countries. For-profit care is a particularly unpopular area of research within mental health care, and other than doing head-counts of private psychiatrists, almost nothing is documented about its nature or costs. The four empirical chapters of this thesis will therefore aim to fill the gap in the literature on mental health coverage by non-state providers, looking at four models of care provided by different provider types: 1) the MHD model provided by an NGO; 2) inpatient hospital care provided by a for-profit provider; 3) outpatient specialized care provided on a for-profit basis; and 4) traditional and faith healing.

Further context surrounding these models will be provided within each empirical chapter that follows. But first, in the next chapter, I will explore three broad issues in methodology, namely concerns about the value of economic evaluation, the development of a new case study method for evaluating interventions in community mental health, and the cultural applicability of psychiatric diagnoses and research tools.

3. On Costs, Cases and Culture: An Overview of Methods



Figure 3-1: A drawing from art therapy at Chiromo Lane

### **3.1 Introduction**

The leading methodological challenge to conducting research into mental health care in Kenya is accessing data. The choice of methods used for analysis in this thesis was driven in part by the nature of available data, which in turn was informed by my personal trajectory and connections in the field of global mental health.

Prior to embarking on this thesis research, I worked for four years for the NGO BasicNeeds. BasicNeeds worked in four countries in Africa: Ghana, Uganda, Tanzania and Kenya. Ghana was the longest-standing programme, founded in 2002 and had the largest scale network of self-help groups. Uganda served for a time as the headquarters of the African Directorate, making it a center-point for the organization's international policy. Tanzania had a unique programme focusing on child carers. However, I chose to work in Kenya for a number of reasons.

Kenya is better resourced in mental health than its East African neighbours and the BasicNeeds programme there was the first I encountered. I spent two weeks in 2007 for my induction into the organization, meeting staff and learning about the programme model. My contact with the BasicNeeds Kenya office grew with time into a rewarding professional relationship. In 2009, BasicNeeds Kenya undertook an "impact study" of their work, in partnership with a leading mental health researcher from the University of Cape Town. The organization saw this as an opportunity to evaluate not only the health, but also the economic impact of their intervention model, however they did not have a health economist available to conduct that analysis.

I came to the LSE with the purpose of learning economic evaluation and with the BasicNeeds dataset more or less in hand. The data from the BasicNeeds impact study was not sufficient, however, to constitute a PhD dissertation. My broader interest was in the role of non-state actors within mental health care, and BasicNeeds had completed a study in 2008 on the role of traditional and faith healers in mental health service provision, together with their partner organization the Africa Mental Health Foundation. I therefore pursued contact with the Africa Mental Health Foundation, and entered into an agreement with them to analyse the data on healers.

There remained, however, a key missing area in the landscape of non-state care, namely the for-profit formal sector. As I looked into the question and spoke with my contacts, the name of Dr. Frank Njenga came up repeatedly. I contacted Dr. Njenga with no



previous ties to him and he kindly agreed to meet me. Over the course of a number of encounters, in which I described to him the case study method and the people supervising my work, he decided to open the doors of his hospital, the only private psychiatric hospital in Kenya.

In addition, I was interested in whether there was any market for specialist private outpatient care, not only provided by psychiatrists, but also by psychiatric nurses. I hired the Research Assistant from BasicNeeds Kenya to interview private providers, and I arranged myself to attend the Annual General Meeting of psychiatric nurses.

I have employed mixed methods of analysis, not only of necessity, but also of design. The qualitative data provide rich context and depth of understanding, while the quantitative data enable the measurement of scale, and offer potentially more objective measures of association, paving the way for causal analysis. Following the lead of Joanna Coast, I have combined qualitative and quantitative data in my approach to the economic evaluation of the BasicNeeds model for Mental Health and Development (Coast 1999). Chapter 4 approaches the evaluation qualitatively, while chapter 5 addresses it quantitatively, and each chapter provides different insights. In chapters 6 and 8, I weave qualitative and quantitative analysis together to examine for-profit hospital care and traditional and faith healing. Chapter 7 is the chapter with the most limited qualitative data.

The aim of this chapter is to first give an over-arching account of my data sources, ethical considerations and methods of analysis and then to address three issues pertaining to methodology. The methodological points emerge from analysis conducted in chapters 5, 6 and 8. First, I will explore the purpose, nature and ethics of cost-effectiveness analysis (chapter 5). Next, I will discuss my choice of the case study method and my contribution to its manualization (chapter 6). Finally, I will reflect on challenges posed to the validity of cross-cultural psychiatric epidemiology, particularly around the notion of “concept equivalence” and its absence, termed “category fallacy” (chapter 8). As this thesis uses mixed methods and analyses multiple datasets, the individual empirical chapters will provide more specific detail on the methods used therein.

### **3.2 Sources of Data**

This thesis combines primary and secondary data. Thanks to pre-existing ties I had from working for the NGO BasicNeeds, I was able to access data from two studies collected by BasicNeeds and its partner, the Africa Mental Health Foundation, which I used for secondary data analysis. In addition, I collected primary data with the help of the BasicNeeds Research

Officer, a Kenyan woman of Luo origin with a master's degree in public health, to collect primary data on private practice of mental health providers. Finally, I myself collected primary data from a private psychiatric hospital and from psychiatric nurses attending an annual general meeting of their professional association.

The planning stage of my field-work was made possible thanks to a Mobility Bursary of £2,500 from the London School of Economics and Political Science for travel and study in Cape Town. Crick Lund, head of the Alan Flisher Centre for Public Mental Health at the University of Cape Town (UCT), and co-principle investigator on the BasicNeeds-UCT Impact Study in Kenya, supervised my research in Cape Town from September through November 2011.

Looking across the empirical components, the thesis pieces together data from a complex web of sources (table 3-1). The data combine qualitative and quantitative material, synthesized in an inter-disciplinary approach for the purpose of greater comprehensiveness. Secondary data came from two sources: 1) the "MHD Impact Study" conducted jointly by BasicNeeds and the University of Cape Town, examining pre-post outcomes on 203 consecutively enrolled adult participants in the Mental Health and Development model in the districts of Nyeri and Meru; and 2) the "Healer Study" conducted jointly by BasicNeeds and the Africa Mental Health Foundation, examining the diagnosis and treatment of mental disorders by 54 traditional and faith healers and 116 adult patients in Kangemi, an informal settlement of Nairobi. The data from the MHD Impact Study were predominantly quantitative; whereas the data from the Healer Study were predominantly qualitative. I supplemented the secondary data from the MHD Impact Study with my own primary collection of costing data from the NGO BasicNeeds and direct observation of a self-help group and a mental health clinic.

In addition, I supplemented both the MHD Impact Study and the Healer Study with key informant interviews. I use the term key informant interviews in keeping with the definition of the United States Agency for International Development, namely "qualitative, in-depth interviews of people selected for their first-hand knowledge about a topic of interest. The interviews are loosely structured, relying on a list of issues to be discussed" (United States Agency for International Development 1996). Each key informant interview was conducted with a question guide, which I outlined ahead of the meeting. I took hand-written notes during the interviews and typed them up on the same day for electronic record keeping. On occasion, I noted verbatim speech. Some of the key informant interviews are referenced in the chapters of this thesis, whereas others informed the direction of my overall research

and research questions without eliciting specific citable references. Key informants provided oral consent to participate. They are referenced within the thesis as KI ## in chronological order of the interview. Key informant interviews were most central to the early stages of my research.

In addition to key informant interviews with 22 informants, I elicited opinion from 17 experts to assist with the analysis of data. Experts were approached from a range of disciplines including neurology, private health care, health policy, NGO management, nursing and research. Their information was used to guide specific methodological decisions within the chapters.

Primary data were also gathered from three additional sources: 1) a case-study of a private for-profit psychiatric hospital, including data from accountancy records of 455 adult patients; 2) a self-report questionnaire that I designed and administered to 50 psychiatric nurses; and 3) a semi-structured interview that I designed and administered to 11 outpatient providers.

The total number of people from whom or about whom quantitative data were collected is 944, including 774 people with mental disorders accessing services and 120 mental health service providers. Sampling methods ranged from snowballing (chapter 7) and purposive sampling (chapter 8) to convenience sampling (chapter 7) to sequential enrollment (chapter 5).

All photographs contained in the thesis were taken by me with permission of those photographed, with one exception (in chapter 8), which was reprinted with permission. The primary purpose of the photographs is to contextualize the findings, and occasionally to serve as a visual metaphor, as in the concluding chapter.

### **3.3 Site Selection**

Both urban and rural locations were included in this thesis. However, the population of Kenya is predominantly (76%) rural (Index Mundi 2011), whereas the sites in this thesis are predominantly urban, making the data not nationally representative. This is because site selection was based on the availability of data, and non-state providers are more present in urban areas. The sites represent three of the main Kenyan ethnicities: Kikuyu, Luhya and Luo. Data on the MHD model and on private practice were collected from the districts of Meru (figure 3-2) and neighbouring Nyeri, at the base of Mount Kenya – a traditionally Kikuyu land. Data from psychiatric nurses were also collected in Kisumu, a lake-town in Nyanza Province, of predominantly Luo ethnicity with a Luhya minority. The population

Table 3-1: Sources of data for thesis

**SECONDARY DATA**

<b>Chapter</b>	<b>Research method and tools</b>	<b>Title</b>	<b>Sample</b>	<b>Ethical approval</b>
4	Interview administered questionnaires: - General Health Questionnaire (GHQ-12) - WHO Quality of Life Questionnaire (WHOQOL Bref) - Economic Status Tool	MHD Impact Study	203 adult MHD participants	University of Cape Town (REC Ref: 098/2009) and Kenya Medical Research Institute (KEMRIRES 7/3/1).
7	Socio-demographic questionnaire In-depth Interview on Healing	Healer Study	54 healers 116 adult patients	Kenyatta National Hospital

**PRIMARY DATA**

<b>Chapter</b>	<b>Research method and tools</b>	<b>Title</b>	<b>Sample</b>	<b>Ethical approval</b>
4, 5, 6, 7, 8	Key informant interviews Meetings and correspondence with experts	N/A	22 informants 17 experts	
5	Case study of a private psychiatric hospital: - Staff interviews - Participant observation of clinical and non-clinical encounters - Review of patient accounts	Case study	1 hospital 11 staff interviews 455 patient accounts	Kenyatta National Hospital (P450/10/2011)
6	Self-report questionnaire administered to psychiatric nurses Semi-structured interview administered to private practice providers	Outpatient study	50 psychiatric nurses 11 private practice providers	
4	Focus group discussion with MHD participants Participant observation of MHD model NGO costs and hidden costs of the MHD model	MHD Impact Study	1 focus group (8 participants) 1 self-help group, 1 clinic N/A	Covered under the ethical clearance of MHD Impact Study above

Figure 3-2: Map of Kenya



from the informal settlement of Kangemi, where the healer study was conducted, were largely Kikuyu and Luhya. Together, the Kikuyu, Luhya and Luo represent 41% of the Kenyan population, however Kenya’s census lists over thirty ethnic groups, many of which do not figure in this thesis (Ambetsa Oparanya 2010). Greater detail is provided within the empirical chapters on the rationale for site selection from secondary data sources.

### 3.4 Ethics

In order to access both primary and secondary data, I entered into three data-sharing agreements with four organizations. The sometimes lengthy negotiations leading up to these agreements ensured that the interests of all parties were protected, including those of the research subjects. Contracts were agreed with BasicNeeds and the University of Cape Town (appendix 1), the Africa Mental Health Foundation (appendix 2) and Chiromo Lane Medical Centre (appendix 3). The data agreements outlined the conditions under which data would be analyzed, to what ends, and the parameters for their publication. While in Nairobi, my work was supervised locally by Professor David Ndetei, director of the Africa Mental Health Foundation and member of the Research and Ethics Committee of Nairobi University. With guidance from Professor Ndetei, I obtained a local research permit (appendix 4) and my primary data collection received ethical approval

from the joint committee on research ethics of Nairobi University and Kenyatta National Hospital (appendix 5).

The two secondary sources of data for this thesis were designed and collected by third parties, and came to me with existing ethical approvals. The BasicNeeds Impact Study design was approved by the Human Research Ethics Committee of the Faculty of Health Sciences (REC Ref: 098/2009) at the University of Cape Town (UCT) and by the National Ethics Review Committee at the Kenya Medical Research Institute (KEMRI/RES 7/3/1). Participants provided informed consent, or assent and their caregiver consented. The healer study was granted ethical approval by the University of Nairobi and Kenyatta National Hospital joint Ethical Review Committee. Both studies provided written informed consent, or assent from patients and their care givers (appendix 6, Impact Study consent form).

When I began field work for my primary data collection in November 2011, I was not planning on collecting any data from people with mental disorders. Instead, I intended to collect only data from hospital records. As a result, I read the LSE Research Ethics Policy and filled out the LSE Research Ethics Review Checklist (appendix 7) which formed part of my major review document, approved in September 2011. I did not proceed with a review from the LSE's Research Ethics Committee. Once in Kenya, I submitted my research protocol to the University of Nairobi and Kenyatta National Hospital, and received approval in October 2011 (P450/10/2011). In December, an opportunity arose for me to visit a private psychiatric hospital, and from there I was granted permission by the hospital board to study their practice. I therefore filed for an amendment to my original ethical clearance, which was granted in May 2012.

Obvious ethical concerns emerge in collecting primary data from a vulnerable population. During the case study and my field visit of the BasicNeeds programme, I interacted with people with mental illness or epilepsy at various stages of recovery. The most severely ill patients were those I spoke with at the Chiromo Hospital Group.

At Chiromo, I was introduced by a member of staff to those patients who attended a morning community meeting open to all patients. It was explained in English that I was a researcher trying to understand the model of care. A number of patients chose to approach me out of curiosity and with a desire to share their experience. Some patients, who did not attend the morning meeting, may have thought that I was associated with the staff and could affect change in their environment. For example, one woman led me to the washing

line, asking me where her clothes were. However, my inability to respond to queries like this made it quickly apparent that I did not play a role in treatment.

At no point was any patient required to interact with me. I was conscious not to approach patients in visibly acute conditions, so as not to risk interfering with their recovery or becoming part of a paranoid delusion about being observed. I mostly interacted with patients when they were at meals or in unstructured time outside in the courtyard. Some of my interactions were one-on-one, when a patient approached me, and others were collective, when I approached a group of patients talking amongst themselves. I did not ask to enter patients' rooms out of concern for their privacy. At one point, I was given the occasion to observe a session of E.C.T, however I chose not to do so, out of concern that the patient was not able to refuse my presence, and thus was unable to provide consent.

Ethical concerns also surrounded my collection of data from service providers at Chiromo. In the course of my field work, I held in-depth interviews with eleven members of the staff. Consent for these interviews was given orally. I explained the purpose of my research and noted that they were not required to answer any questions I asked. Preserving the confidentiality of the staff at Chiromo was essential. Any potentially negative information shared with me by staff could have put them at professional risk, as the findings were shared with the hospital board. To mitigate this risk, I interviewed and spoke with many members of staff and avoided including material that might be attributable to a specific individual.

A further concern at Chiromo was for the reputation of the facility itself, since there was no way to de-identify Chiromo Lane, as it is the only private psychiatric hospital in Kenya. Indeed, the hospital would not have wanted the research to be de-identified, as they explicitly stated that they were interested in participating partly because it would serve their brand as a progressive facility engaging with scientific evidence. To address the concern of the hospital's reputation, I asked the hospital director to review my analysis of the data, and made him a co-author on a paper I published based on this material. The director did not change any of the content, contributing only further insights about the reason for findings pertaining to low occupancy rates.

For the study of the Mental Health and Development model, I collected some, though minimal, primary data from staff and patients. All patients with whom I spoke were consenting participants in the BasicNeeds and University of Cape Town study to which my research was an addendum. My verbal interactions with these patients were in two groups:

a focus-group of patients attending a clinic, and a self-help group meeting. The MHD patients were all in advanced stages of recovery. Our interactions were mediated by a translator. In addition, I held one-on-one in-depth interviews with seven members of staff implementing the MHD model. Consent for these interviews was given orally and confidentiality of staff has been preserved.

Finally, I collected primary data from psychiatric nurses and psychiatrists using two tools: a semi-structured interview and a questionnaire. Respondents to the interview provided signed informed consent (appendix 8), while those completing the questionnaire were given both a written and oral explanation of its purpose, as well as the opportunity not to participate. In the case of psychiatric nurses, I was told they were not supposed to work in public and private simultaneously (KI 19, October 5, 2011). That rule appears to have been more enforced in Nairobi, however, than in rural areas where the shortage of health professionals encouraged a more practical approach. Nonetheless, disclosing information about their private practice could have put the nurses at some risk of chastisement, so maintaining confidentiality was essential. I did not record the names of the psychiatric nurses completing the questionnaire, and I de-identified the data from the interview respondents.

### **3.5 Positionality and Influence of Gate-Keepers**

The choice of subjects for my research was largely influenced by gate-keepers. I borrow this term from Robert Burgess, among others, who uses it to describe a person, usually an authority, who has the ability to grant a researcher access to a subject or group of subjects (Burgess 1982). Recent discussion of gate-keepers has focused on their ability to control research subjects, and therefore impede true consent. Tina Miller, for example, notes that gate-keepers have the “power to sanction access to less powerful individuals,” and alludes to several forms of that power, including cultural, hierarchical, paternal and therapeutic (Miller and Bell 2002). In my case, a number of powerful gate-keepers both threatened and ultimately enabled the progress of this PhD research. The gate-keepers took the form of both individuals and institutional structures, for example the senior management team at BasicNeeds, and the Board of Chiromo Lane Medical Center.

My choice of the case study method for the study of Chiromo Lane was informed by my relationship with the lead author of that manual, Alex Cohen, who had supervised my master’s thesis at the Harvard School of Public Health. He co-authored the manual in 2011, just as I was exploring the design for my thesis research. In December 2011, on



meeting the Director of Chiromo Medical Center, I first considered using his case study method within my thesis. Other methods were also available for learning about the extent of mental health coverage provided by Chiromo Lane. One alternative, for example, was to focus only on quantitative data drawn from medical records. To do so, however, would have required prior knowledge about how records were kept at Chiromo and what they contained. In addition, the medical record approach would have missed valuable pieces of context about the orientation, history and place of Chiromo within the wider system of private residential care for mental disorders. Another alternative method was to focus only on qualitative data from informant interviews with patients, their family, clinical and support staff. Qualitative research of this nature, however, was not an active interest of the hospital Director – a key gate-keeper – and the study had to be of mutual interest to me and him in order to be carried forward. The Director was foremost interested in questions of health economics, making a mixed methods approach more appropriate. Furthermore, the case study approach allowed for flexibility and an iterative approach to formulating questions in a context where very little was known ahead of the initial research.

The impetus for conducting an economic evaluation of the model for Mental Health and Development came initially from the senior management team of the NGO BasicNeeds, who were eager to determine how their model compared to other health care interventions. I was employed by BasicNeeds for the four years prior to embarking on my thesis research, working in various capacities, including raising funds, supporting the senior management team to develop their strategic framework, and interviewing programme directors and implementing staff to draft their Operations Manual. This work gave me a unique insight into the nature of BasicNeeds' work, and the principles and history underlying the Model, allowing me to delve into my PhD research with the benefit of what would ordinarily have required many months of observation and background reading. In addition, my previous employment earned me the trust of BasicNeeds staff, such that they spoke with me candidly, rather than measuring their words out of concern for what I might think. The quality of my data and my ability to analyze them were therefore considerably aided by my precedent with the organization.

BasicNeeds also played a role in introducing me to the director of the Africa Mental Health Foundation. The two organizations were joint principle investigators on the study of traditional and faith healers, which forms the basis of my data in chapter seven. Although the funding for that research came from a service delivery grant to BasicNeeds, the funding had expired by the time I researched the data – five years after the study's

completion – and there were no constraints posed on me by the funders, nor by the two NGOs.

In addition to collaborating with BasicNeeds to share data, I hired one of its employees, Milka Waruguru, to serve as a research assistant on my thesis. Milka interviewed the private practice mental health providers for the chapter on outpatient care, she set up my site visit to Nyeri and Meru, and she was in continual correspondence with me answering specific questions about the nature of the MHD intervention and of the Impact Study protocol. Milka's involvement helped me clean the data from the Impact Study and improved my analysis. The choice of patients with whom I conducted a focus group in Meru was made by Milka and BasicNeeds partner staff, as a result of which it highlighted examples of successful outcomes. I did not, however, rely heavily on the focus group data, and the selection bias on that part of my data was offset by explicit effort to elicit feedback from staff on areas where the intervention and the research had been most challenging. Milka is likely to have shared a similar bias to me in favour of BasicNeeds. Her principal role on this thesis, however, was independent of BasicNeeds, in collecting data from private practice psychiatrists and psychiatric nurses (the subject of chapter 6). It is possible that some of the individuals approached to participate would have known of her affiliation with BasicNeeds and been influenced either to participate or not to participate on the basis of their opinion of the NGO. It is not possible, however, to verify this hypothesis.

That being said, my previous employment with BasicNeeds also raised a question of conflict of interest in terms of evaluating their outcomes. No doubt, I wanted their intervention to prove cost-effective. I did not, however alter the data in any way, and I subjected the analysis to review by my two supervisors, as well as presenting it on two occasions, once in a public conference on global mental health, and once in a workshop of health economists at the LSE. At no point were my methods called into question for being biased. Furthermore, the NGO placed no constraints on the independence of my research. They asked only to be included as co-authors on any publications that might emerge from this data in the scientific literature. The flip-side of conflict of interest is interest, and research into the area of global mental health cannot be done in the absence of interest. As it stands, interest in this field remains limited, and therefore community mental health interventions such as that of BasicNeeds are as yet under-researched. I believe the merit of undertaking this research, albeit cautiously, well outweighs the potential risk of conflict of interest.

### 3.6 Context-specific challenges

Conducting research in a context of international war and domestic instability raises significant challenges, as demonstrated in Kenya. The relatively short duration of my field work and the absence of comparison data from the public sector were the result of the insecurity and a health sector scandal that took place as my research unfolded.

On October 16 2011, the Kenyan military launched Operation *Linda Nchi* (Swahili for “Protect the Country) jointly with Ethiopia and the Transitional Federal Government of Somalia. The object of the offensive was to eliminate al-Shabaab, a Somali-based Islamic fundamentalist group with links to al-Qaeda. In the previous month, Shabaab had claimed responsibility for the kidnapping of two *Medecins Sans Frontieres* workers in the Dadaab refugee camp, and the kidnapping and killing of three tourists (a disabled French woman and a British couple) in the coastal resort towns of Lamu and Kiwayu. There ensued a war that continues to this day.

On November 6th 2011, a month and ten days after Kenya declared war on Shabaab, I arrived in Nairobi to start my fieldwork. While I was conducting a case study of a private inpatient psychiatric facility, on May 28<sup>th</sup> 2012, an explosion wracked a popular shopping complex on Moi Avenue in the central business district of Nairobi, injuring 30 and killing one. Almost weekly throughout this time, grenades were thrown into churches at Sunday worship.

In July 2012, 5,000 troops from Kenya joined 12,000 troops from other parts of Africa to form the African Union Mission in Somalia (AMISOM). Together, they sought to overthrow the Shabaab-dominated port town of Kismayo, a mission that was accomplished in September 2012. A four-day siege of Nairobi’s Westgate shopping mall took place in September 2013, leaving 72 dead (including a young, female foreign health worker). The Westgate mall attack was reportedly a retaliation by Shabaab for the taking of Kismayo. Had I not felt at personal risk throughout this time, I might have extended my fieldwork in Kenya. Instead, I spent only three months there, predominantly in Nairobi, avoiding public transportation and public meeting places as much as possible.

At the same time as international conflict was raising security threats, domestically health worker strikes and a scandal within the public health care system absorbed much of the attention of Ministry of Health. The scandal surrounded the National Health Insurance Fund (NHIF), an entity that came into being in 1966 offering coverage for inpatient health

care for all people working in the formal sector. At the end of April 2012, the Parliamentary Committee on Health blew the whistle on NHIF disbursements being made to “ghost clinics.” They noted that the fund had paid half of their quarterly disbursements (USD 3.8 million) to only two companies, Clinix Healthcare Ltd and Meridian Healthcare Centres, both of which used the money for capital investment to expand their clinics, rather than to provide services (Mureithi 2012). Clinix Healthcare came under the closest scrutiny, as it was 99% owned by a foreign company, registered in the British Virgin Islands. Furthermore, it was discovered in late May that an unexplained transfer of Ksh 900 million (USD 10.7 million) was made from the NHIF to the Isle of Jersey. Half of the quarterly budget was missing.

There ensued a political drama. The head of Civil Service, Francis Kimemia, sacked the entire NHIF board on Saturday May 5th. At the opening of the work week on Monday May 7, the Minister of Medical Services, Anyang Nyong’o, reinstated the board. Later that same day, Prime Minister Raila Odinga overruled Nyong’o, sacking the board once again. The Parliamentary Health Committee issued a report, which the MPs tabled, and then a hearing was held with the Director of Pharma Investment Holdings. In mid-June, Clinix and Meridian were removed from the NHIF roster of providers (Karongo 2012).

The Ministry of Health was so consumed by the drama unfolding with the NHIF that it had little space for external requests such as my own. In May 2012, I contacted the Ministry on a daily basis for a period of two weeks, trying to access data about hospitalization of people with mental disorders within public facilities. In the subsequent weeks I made multiple visits to the headquarters, met with members of the nursing staff and received oral agreements. But the data were never made available.

In addition to the challenges of war and government corruption, the more mundane day-to-day challenges of conducting research in a low-income country are manifold. They include the absence of electronic medical records, slow or broken internet connections, which sometimes cause emails to disappear, power outages that make work come to a halt, old computers crashing and irretrievably losing data, research assistants not fully trained in data entry using quantitative databases to enter qualitative data, key contacts changing mobile phone numbers, and people not showing up to meetings because of grid-lock traffic or road accidents. This is just a selection of the challenges, but lends some idea of why it is a great privilege to have had access to the data that I did for this thesis.

### **3.7 Methods of Analysis**

The empirical chapters of this thesis employ several different methods of analysis. Chapter 4 renders a qualitative description of an intervention model for mental health care. Chapter 5 on non-profit care uses economic analysis. Chapter 6 on for-profit inpatient care combines case method with regression analysis. Chapter 7 on for-profit outpatient care employs descriptive statistics. And chapter 8 on traditional and faith healers uses framework analysis and simple quantitative tests of binary association (chi-square, logistic regression). I will enter into further detail on two of these methods – economic evaluation and case study – to explore their limitations and innovations. Then I will take a step back and question the validity of cross-cultural research into mental health care.

#### *3.7 - a) Economic Evaluation*

##### 3.7.a.i Why undertake economic evaluation?

A provocative series of tweets by of Richard Horton, editor of the Lancet, recently challenged the discipline of health economics at large, and the use of economic evaluation in particular (Parkin, Appleby, and Maynard 2013). In his first tweet, Horton lamented, “The promise economics offers is seductive: how to allocate scarce resources in society. It’s a false promise.” He went on to attack economic evaluation, observing, “Rationality, for the economist, means subjecting every thought/decision to a cost-benefit analysis. A wholly narrow view of humanity.” And further, “The assumption is that human beings make cost-benefit decisions based only on self-interest. No.”

Horton’s Twitter manifesto against health economics reveals his misunderstandings of the field, but nonetheless highlights the “ethical minefield” (Williams 1992) in which this method sits and incites a justification of these methods. Economic evaluation is not appropriate for “every thought,” as it is itself a costly undertaking. Indeed, the limitations in many studies – including in this thesis – relate to limitations in resources for research. Only interventions that may be rolled out widely or are particularly costly are worthy of economic analysis. More importantly, Horton’s observation that “self-interest” is the main (indeed “only”) guide to economic evaluation is mistaken. The purpose of economic evaluation within the context of health economics is to guide decisions for social, not individual benefit.

The “seductive” rationale for economic evaluation is to guide resource allocation in situations of scarcity. As a method, it therefore lies at the heart of debates around distributive justice. By enumerating costs and consequences, economic evaluation proposes to make more transparent the implicit trade-offs that individuals and societies often make blindly (Drummond, Sculpher, and Torrance 2005, chapter 2). As the costs of health care have been spiralling in industrialised economies, and as data collection and analysis methods become increasingly sophisticated, the supply and demand for economic evaluation have rapidly escalated. In the early 1990s, the proportion of clinical trials incorporating economic analyses jumped from 2.5% to over 25% (Kim, Morris, and Schulman 2000), plateauing at that level in subsequent years (Glick, Polsky, and Schulman 2001).

Horton is not the first to raise riot at the idea of introducing cost as a criterion in decisions about medical practice. In 1980, a scientist writing for the *New England Journal of Medicine* charged that “a physician who changes his or her way of practising medicine because of cost rather than purely medical considerations has indeed embarked on the “slippery slope” of compromised ethics and waffled priorities” (Loewy 1980). A prominent health economist from the University of York, Alan Williams, retorted years later that the alternative to economic evaluation is “the lottery.” More specifically:

“Judgments about the value of another person’s life ... are inescapable in a system which is expected to behave in a non-capricious manner in discriminating between the well and the ill, between the severely ill and the slightly ill, and between those likely to benefit from a particular treatment and those unlikely to do so, in order that some systematic priority-setting can take place. The supposedly more ethical alternative of making these decisions by lottery ... seems to me quite inhuman and uncaring” (Williams 1992)

Moving beyond the question of whether economic evaluation is evidence of “compromised ethics” or of being “human and caring,” the next pertinent question becomes what methods of analysis are used. We move then from whether economic evaluation is worth undertaking to how to go about it.

### 3.7.a.ii Types of economic evaluation

Though employed in common parlance as a synonym for all economic evaluation, cost-benefit analysis is but one of several types of economic evaluation. Three types of economic evaluation dominate the literature, namely cost-benefit analysis, cost-

effectiveness analysis and cost-utility analysis. The definition of an economic evaluation used here, that of Michael Drummond, is “the comparative analysis of alternative courses of action in terms of costs and consequences” (Drummond, Sculpher, and Torrance 2005, chapter 2). The particularity of cost-benefit analysis, as the term is used in health economics, is to value consequences in terms of monetary benefit, which raises challenging ethical questions about how to value life, as well as practical questions about how to attach a monetary value to improvements in health.

A more widely used evaluation method is cost-effectiveness analysis, which measures consequences using disease-specific outcomes, such as depression-free days. Cost-effectiveness is designed to answer the question, “Which of two treatments is preferred for the *same* condition?” In economic rhetoric this is a question of technical efficiency (Dolan and Olsen 2002), meaning the transformation of inputs into outputs without waste.

Health policy makers are often more interested, however, in allocative efficiency, meaning how to optimally distribute goods or services based on a population’s preferences. Allocative efficiency addresses the question: “Which of two treatments is preferred for *different* conditions?” Answering that question quantitatively requires a means of comparing outcome across different health states. Broadly, the generic outcome of interest to economists is utility. Within the field of health care, however, utility is often assumed to be interchangeable with health, wellbeing, or quality of life (Dolan and Kahneman 2008). Some economists, such as Paul Dolan, have noted that this assumption could exaggerate the place that health actually occupies in a person’s individual utility function (*ibid*). In practice, the most common generic measures used in economic evaluations of health care are the Quality Adjusted Life Year (QALY) (Fanshel and Bush 1970; Williams 1996) and the Disability Adjusted Life Year (DALY) (Murray and Acharya 1997). Together, these two measures form the basis of a third kind of economic evaluation, known as cost-utility analysis.

Cost-utility analysis compares cost to the QALYs gained or DALYs averted by an intervention. A QALY is one year of perfect health, whereas a DALY is one year of life lost. The QALYs generated by a health care intervention are calculated by multiplying the number of years of life remaining (or time to follow-up in the study) by a utility weight associated with a given condition. Utility weights range from 0 for death to 1 for perfect health. DALYs are calculated by aggregating death and disability caused by an accident or illness, weighted by the estimated burden of that disability. DALYs were first designed as

a measure of disease burden, but they have subsequently been used as an outcome measure.

Much of the debate around QALYs and DALYs has pivoted on the methods used to value the utility of a given health state. The four most common methods for valuing health states are the visual analogue scale, standard gamble, time trade-off, and person trade-off (Drummond, Sculpher, and Torrance 2005, chapter 10). The time trade-off method was principally used to devise QALY utilities, whereas the person trade-off was used to devise DALY weights. The time trade-off method asks respondents to choose between a certain amount of time in good health versus a longer period of time unwell. The person trade-off method, instead, assumes the position of a public health planner, asking respondents to choose between saving a certain number of people with one health condition versus a smaller number of people with a worse health condition.

Among the issues surrounding methods of valuation is whose utility is valued? QALY valuations were made by surveying thousands of individuals in the community for their perceptions (Billingham, Abrams, and Jones 1998). While democratic in approach, it tends to skew utility values in the direction of severity: people living with a disability often adapt to their condition and find it less problematic than imagined by those without the condition (Dolan and Kahneman 2008). DALY weights, not initially concerned with being democratic, were first calculated by a group of medical experts, who were forced to collectively arrive at a consensus (Arnesen and Nord 1999). In 2010, however, a new series of DALY weights was issued, which took account of responses from over 30,000 members of the general population using online and household surveys across several countries, including Tanzania (Salomon et al. 2013).

Another key methodological challenge surrounding DALYs and QALYs pertains to age-weighting (Barendregt, Bonneux, and Van der Maas 1996). Original DALYs use age discounting to reflect that a year lost to someone of working age is more economically costly than a year lost to a child or an elderly person. Subsequent attacks of this approach have led the Global Burden of Disease team, who make these DALY calculations for the World Health Organization, to offer several varieties of DALY, including one without age discounting. Finally, questions arise over whether health benefits, such as DALYs and QALYs, should be discounted at the same rate as capital (Claxton et al. 2011; Goodin 1982). This debate is more relevant to long-term modelling projections, however, which are not within the scope of this thesis.



Despite the challenges levelled against the DALY and QALY methods, the advantage they procure of offering a single generic unit of outcome that allows comparison across a vast array of different conditions, is argued by proponents to outweigh their shortcomings, making them an attractive tool of economic analysis.

I chose to use DALYs in my evaluation of the cost-effectiveness of the Model for Mental Health and Development (chapter 5), because it was not feasible to cross-over between the outcome measures used in my data and the QALY. Despite its name, the WHO Quality of Life instrument (WHOQOL Bref) is not convertible by any evident means to a QALY. The most common tool for measuring a QALY in Europe and some other countries is called the EuroQol (EQ-5D), which scores quality of life along five dimensions: mobility; self-care; usual activities; pain/discomfort; anxiety/depression (EuroQol 1990). Two iterations exist, one with three levels of response (no problem, some problem, a lot of problem), and the other with five levels of response. The number of permutations of answers is therefore in the hundreds. Each permutation has been allocated a utility based on preferences stated by different populations predominantly in Europe, but also including some in Africa (Jelsma et al. 2001). The utility weight is then transformed into a QALY by means of a simple calculation, not dissimilar to that of the DALY, weighting the time spent in the health state with the utility associated with that health state. In the absence of the EQ-5D or similar bespoke measure, however, it is challenging to calculate a QALY. By contrast, the General Health Questionnaire (GHQ-12) has established cut-off points for defining health states, which can be translated with relative publicly available disability weights used to calculate DALYs.

### 3.7.a.iii Ethics and limits of cost-effectiveness analysis

Although cost-effectiveness and cost-utility analyses increase the transparency of key factors involved in an intervention, they do not provide an automatic algorithm for decision-making. Some people have drawn up league tables of incremental cost-effectiveness ratios (ICERs) in the effort to compare interventions (Gerard and Mooney 1993). While such tables are useful at categorizing interventions into broad levels of efficiency, they cannot be used as a means of abdicating the process of prioritization. In the words of Michael Drummond, “None of the approaches is intended to be a magic formula for the removal of judgment, responsibility or risk” (Drummond, Sculpher, and Torrance 2005, chapter 2). Or, to paraphrase the stance of Allan Williams, there is more to economic decision making than accountancy (Williams 1979).

One of the chief limitations of economic evaluation is that it does not take into account how benefits are distributed, which is paramount to those concerned with equity.

In fact, economic evaluation is imbedded with implicit assumptions about equity. Principally, cost-utility analysis reflects egalitarian ethics, meaning that life has the same value for all people at all times, or “a QALY is a QALY is a QALY” (Williams 1992). While instinctively this notion rings true, there may be reasons to argue otherwise:

“As a society, we may prefer to give a QALY to someone who is in very poor health, compared with someone who is close to full health, or to someone who has not experienced much good health during their lifetime, compared with someone who has experienced “fair innings” (Drummond, Sculpher, and Torrance 2005)

Building on this observation, Dolan and Olsen tease apart six factors influencing a person’s understanding of equity (table 3-2) (Dolan and Olsen 2002). In addition to illness severity and a person’s previous health profile – the two factors mentioned by Drummond – Dolan and Olsen introduce several new dimensions, touching on questions of personal responsibility and social knock-on effects. Many people intuitively believe that if a health condition stems from a lifestyle factor within their control, for example smoking or skiing, that said person should be held responsible and therefore less entitled to treatment than if he or she were an innocent victim, for example of a car accident (Williams 1992). In addition, Dolan and Olsen contend that some people, for example armed forces veterans or indigenous people, may be thought to have a claim on priority treatment. Finally, some illnesses, for example dementia, cause more impact on other members of a family or social network than others, such as hip replacement.

Table 3-2: Dolan’s six factors of equity

1. Distribution of benefits
2. Severity of illness
3. Previous health profile
4. Lifestyle
5. Compensation or reward
6. Impact on others

Dolan and Olsen furthermore observe that a key dimension to assessing equity is age. In discussing the previous health profile of a hypothetical patient, they outline three types of “ageism”(Dolan and Olsen 2002). The first ageism is health-maximising, which tends to prioritize younger people. The second ageism is productivity maximizing and

tends to prioritize the working-aged. The third ageism revolves around the notion of “fair innings” (Williams 1997), which suggests that those who have lived a number of years in good health should allow priority to those who have not. The age-based dimensions of equity are even more relevant in a low-income country like Kenya, where approximately half of the population is under the age of twenty.

Another limitation of economic evaluation – or perhaps more accurately of the role of economic evaluation in supporting decision-making – is that it is possible for an intervention to be cost-effective, but not affordable. Indeed, within an African context, where health budgets are squeezed dry, many interventions fall within this category. Defining affordability is challenging. The short-hand solution applied by many global health economists is to use per capita GDP as the ceiling for an affordable cost per DALY (Edejer et al. 2003). This method, however, does not take into account that the affordability of an intervention depends on the prevalence of an illness or condition. Interventions such as vaccines, which must be delivered to entire populations, quickly become costly despite very high rates of efficiency. An economic evaluation should therefore be accompanied by an impact assessment, to determine, among other things, questions of affordability and acceptability.

A final key limitation of economic evaluation is that it is based in utilitarian logic, and therefore subject to a non-consequentialist critique. Philosophically, the roots of non-consequentialist thought, such as libertarianism, lie in the 18<sup>th</sup> century writings of Immanuel Kant (Kant 1785) and his followers, including John Rawls (Rawls 2001) and Robert Nozick (Nozick 1981). Broadly summarized, the counterpoint to utilitarian thinking is that moral actions rely on a “categorical imperative”—an unconditional principle that is an end unto itself – rather than on ends justified by means. In application, this line of reasoning is found within the field of health and development predominantly among proponents of human rights. So, for example, interventions to reduce the chaining of individuals with mental illness may not be cost-effective (in practice, no such studies exist), but may be pertinent from a human rights perspective, which finds that chaining a human being defies a categorical imperative for treating people with dignity (United Nations General Assembly 1991).

Discussion of economic evaluation would not be complete without considering the cost of conducting such an economic evaluation itself. Drummond et al quip, “Even economic evaluations should be subject to economic evaluation” (Drummond, Sculpher, and Torrance 2005, p. 355). Again, this is especially true in the African context where

conducting a randomized controlled trial may mean diverting funds from needed treatments to research. Given the resource constraints, economic evaluations in an African setting must sometimes resort to imperfect study design, for example using observational studies rather than randomization, as is the case in the economic evaluation employed in this thesis.

### *3.7 - b) Case Study Method*

In the context of limited resources for research, a pragmatic method of evaluation is the case study. I chose the case-study method as a principal means of gaining access to data on for-profit hospital care, because it is a practical and flexible method that accommodates the unpredictabilities of collecting data in East Africa. Prior to my initiating this thesis research, I did not have pre-existing ties with the for-profit mental health sector in Kenya, and the case study also enabled me to collect data without having a large pre-existing professional network.

As defined by Robert Yin, case studies are a method of social inquiry that address contemporary phenomena and seek to answer the questions *how* and *why* (Yin 2014). Yin distinguishes case studies from ethnography, noting that they are conducted over shorter periods of time and do not necessarily involve participant observation. The case study is a useful technique within a context where little is known about the topic prior to its study, as is the case of private mental health care in Africa. Yin refers to this type as a “revelatory case”, as compared to other types, such as the common case, the unusual case, the longitudinal case or the critical case.

Defining the case was more complex than I originally anticipated, because the psychiatric hospital in which I chose to conduct my work was part of a large and growing network. When I began the study, the network contained three mental health facilities in and around Nairobi. On my second visit, a fourth facility was being newly initiated. As I proceeded, a fifth institution was launched in Mombasa. Some of the facilities had closer links with one another than others. For example, two facilities shared a name and a board of directors, although they were located in different parts of Nairobi, while three other facilities had a slightly different ownership arrangement, although many of the directors were the same. Operationally, referrals between the five facilities were common. I chose to focus on one of the five facilities, as it was the oldest and had electronic records. However, I visited all four of the five facilities that were open to the public, all of which served as data points with which to contextualize my case.

While conducting the case study, I was also testing a case method manual (Cohen et al. 2012). The “Case Study Methodology to Monitor & Evaluate Community Mental Health Programs in Low-Income Countries” complements existing case study textbooks with specific questions important to consider when evaluating mental health programmes in resource-poor settings. It sets out seven domains of inquiry, namely: 1) context; 2) history; 3) programme model; 4) programme organization; 5) client population; 6) intervention; and 7) information systems. For each domain, the manual proposes a series of questions, some to be asked, and others simply to guide observation. My contributions to modifying these questions and updating the manual earned me a position as co-author on the second edition of the manual. The methodological contribution of the manual is modest and consists principally of formulating a set of domains of inquiry and articulating a series of question guides (appendix 9) specific to the practice of mental health care in low-income settings. The authors of the manual did not ask me to use their method, however. It was I who approached them with the desire to test it, as the focus on mental health made it more relevant to my research than other case study manuals.

I conducted a single case study, as opposed to multiple comparative cases, with the intent of using it as a method of evaluation. Chief among the principles of data collection for case studies is the collection of multiple sources of data to triangulate findings. My case study drew on data from: 1) direct observation of therapeutic and non-therapeutic environments; 2) interviews and informal conversation with patients and staff; 3) physical and electronic archives; and 4) operational documents, such as pharmacy records and accounts. At the end of each day of visits, I compiled my direct observations and photographs electronically into field notes.

As Yin observes in his methodology, at the outset “the specific information that may become relevant to a case study is not readily predictable.” In my case, I obtained access to a tremendous wealth of quantitative data from a newly implemented electronic accountancy system. These individual accounts became the basis for rigorous quantitative analysis with both a descriptive and an explanatory focus. The data provided information about length of stay, readmission and charge over the course of one year, as well as documenting the presence of third-party payers, namely private insurance. Ultimately, I conducted regression analysis to examine the relationship between who financed care and the quantity and price of that care. This level of quantitative analysis within a case study is unusual and constitutes a strength of this thesis.

### 3.7 - c) *Cross-Cultural Epidemiology*

#### 3.7.c.i Cultural equivalencies

Taking a step back from the specifics of economic evaluation and the case study approach, a more fundamental question exists about the validity of any and all cross-cultural research by a European concerning mental health care in Africa. A key methodological concern surrounding health-related research in an African setting is that of cultural translation. Cultural translation can be particularly contentious in the area of mental health research, where categories of inquiry are arguably more socially constructed than other areas of health. In 1988, Joseph Flaherty and colleagues published a seminal article defining five key principles when adapting research instruments for cross-cultural use in psychiatry (Flaherty et al. 1988). The quality of cross-cultural adaptation was outlined in terms of five equivalencies: 1) semantic; 2) content; 3) technical; 4) criterion; and 5) conceptual. I will examine each in turn.

*Semantic equivalence* is the most straightforward of Flaherty's five, and it relates to the appropriate translation of idioms. Since mental health symptom checklists often use colloquial idioms of distress, such as "down in the dumps," or "blue," they can be easily mis-translated. The best practice method for avoiding mis-translation is that of back-translation (World Health Organization 2014), which requires that a tool be translated into the local language and then translated back into the original language (often English), by a different set of translators, to see if the original meaning was preserved. This method is time-consuming and costly, however, as a result of which many studies do not employ best-practice (Prince 2013).

In evaluating semantic equivalencies, I would stipulate that the data in this thesis are of average quality. The only symptom checklist used in my data was the Mini International Neuropsychiatric Interview (Sheehan et al. 1998) used among patients of traditional healers. The tool was formally translated by researchers from the Africa Mental Health Foundation into two local languages (Kiswahili and Kikuyu) and it was spot-translated into Luhya and Luo for a small number of patients who struggled to understand either of those two languages. This does not represent best-practice in translation, as resources were not available for a more thorough process of back-translation. Nonetheless, the MINI has been widely used in East Africa, including by the researchers who designed the study and collected the data, so their familiarity with the tool may have improved the delivery of questions.

*Content equivalence* exists when each item on a questionnaire is relevant to the phenomenon of study. Existing research in cross-cultural mental health, for example, reveals that symptoms of guilt and worthlessness are rarely endorsed among people with depression in Asian cultures, particularly in China (Kleinman 1987). It could be argued, therefore, that a depression symptom check-list with an item for guilt or worthlessness would not meet content equivalence. I am not in a position to comment on the content equivalence of my data, as there are no comparable locally derived tools against which to measure it.

*Technical equivalence* is achieved when the method of data collection does not distort the response. This is of particular concern in less literate societies, where filling out a questionnaire could lead to random responses, or to responding in a way deemed desirable, because it evokes a context of test-taking. In order to preserve technical equivalence in this thesis, two self-report checklists were interviewer-administered when evaluating the model for Mental Health and Development (chapter 5). Both tools were from the BasicNeeds Impact Study, namely: the General Health Questionnaire and WHO Quality of Life Questionnaire.

The presence of an interviewer introduces another source of potential bias, namely social desirability. This is all the more true in that the interviewers were mostly the clinicians themselves, so participants may have wanted to demonstrate that they were improving to please the health care providers. There might equally, however, have been an incentive for participants to under-report their health, if they thought that doing so would lead to greater benefits. The social desirability bias was offset, however, by the fact that participants did not necessarily see the same clinician from one period to the next and therefore did not necessarily establish a significant therapeutic bond. Moreover, responses varied considerably between time two and time three, whereas if the responses were guided predominantly by social desirability, one would have expected them to improve after the first period of follow-up and then plateau. The main concern raised by the interviewers themselves was around the question about sexual wellbeing in the WHOQOL, to which a number of participants preferred not to answer. That question did not carry much weight, however, in the overall analysis.

Determining *criterion equivalence* requires establishing the relationship of the tool with existing and established measurements of the same phenomenon. Within the context of psychiatric diagnosis, the gold standard tools are often clinician-administered (Prince 2013), such as the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) (Wing

et al. 1990) or the Structured Clinical Interview for DSM Disorders (SCID) (First et al. 1995). The General Health Questionnaire (used in chapter 5) has been validated in Africa using the DSM-IV as a gold standard (Chipimo and Fylkesnes 2010). The MINI diagnostic assessment (used in chapter 8), serves as a gold-standard measure against which to validate other tools, suggesting that meets standards for criterion equivalence (Breuer et al. 2014) As there are no gold-standard measures that have been locally developed, a higher level of criterion equivalence cannot be attained at present. However, both of these tools are based on biomedical (often considered Western) nosologies, raising concern over the fifth and last of Flaherty's equivalencies.

It is *conceptual equivalence* that has raised the greatest debate and fostered the most critique in relation to global mental health research. The question raised by conceptual equivalence is whether the tool is measuring the same theoretical construct in the new cultural environment as in the culture of origin. The most strident critique of conceptual equivalence is raised by Derek Summerfield (Summerfield 2012; Summerfield 2008), though more moderate positions are also frequently expressed in the literature (White and Sashidharan 2014).

Summerfield's critique of the validity of cross-cultural mental health research centres around the process of identifying and diagnosing mental disorders. He attacks the very fundamentals of what constitutes a mental disorder, labeling claims that half of people experience one in their lifetime as "disease mongering."

We face an epidemic of false positive diagnoses of mental disorder. [...] There is now no more bloated category than "depression," threatening to all but expunge the nuances of language denoted by "distress," "sadness," "despair," "gloominess," "pessimism." (Summerfield 2012)

Summerfield further notes that "Western psychiatry is but one among many ethno-psychiatries" (Summerfield 2008) equating it to systems of traditional healing (Summerfield 2012) both in terms of the soundness of its diagnostic labels and the bravado of its treatment claims. Summerfield's own bravado reveals itself, however, as he treads on uncertain ground suggesting that mental disorders in low-income settings are "normal responses to a social world that is no longer coherent or functional" (Summerfield 2008). Masking his opinion behind the work of Amartya Sen, he later notes: "It was only when people were more comfortably off, freed from the everyday imperatives of poverty and food insecurity that they acquired the "luxury" of generating concerns about their health" (Summerfield 2012). To suggest that mental disorders are a luxury flies in the face of



existing empirical data on the relationship between poverty and mental distress (Lund et al. 2010; Lund et al. 2011). Nonetheless, Summerfield's critique of validity raises a valid point, worthy of further exploration.

### 3.7.c.ii Origins of cross-cultural psychiatry

A more nuanced picture of the validity of mental health research can be found by contextualizing Summerfield's arguments within a 100 year-old debate on the objectives of cross-cultural psychiatry. The debate has been framed in the literature in three phases: the old cross-cultural psychiatry; the new cross-cultural psychiatry (Kleinman 1977); and beyond to the age of global mental health (Kirmayer 2006).

The positions of the old school of cross-cultural psychiatry – though they did not know themselves by that name – can be found in the writings of Emil Kraepelin (Engstrom 1908) and K. Singer (Singer 1975). As described by its critics, the older generation viewed cultures as “closed, self-contained worlds in homeostasis or a steady state, with a substantial degree of homogeneity across individuals” (Kirmayer 2006). Culture was understood to be the handmaiden of biology, a universal substratum that determined the expression and course of disease. Conceptually, biology was thought to give form to disease (pathogenesis), while culture merely shaped the content (pathoplasticity) (Littlewood 1991; Kleinman 1987). In the playful language of Geertz, quoted by Littlewood “culture is icing, biology cake [...] difference is shallow, likeness deep” (Littlewood 1990).

Concretely, the old generation of cross-cultural psychiatry scholars focused their attention on the research question, “What similarities exist in psychiatric diagnosis across cultures?” Thus, they set out with their diagnostic manuals in hand to find the prevalence of psychiatric disorders in other settings. Kraepelin was one of the first, venturing to Java in 1904 to look for *dementia praecox* and manic-depressive illness – disease categories he had defined himself just a few years earlier in the first symptom-based classification of psychiatric disorders (Engstrom 1908).<sup>9</sup> Kraepelin's research launched a new line of study into cross-cultural epidemiology of mental health. On close examination of 100 patients in

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<sup>9</sup> Kraepelin's legacy has been overcast by the eugenicist underpinnings to his concern with cross-cultural psychiatry. Underlying his desire to canvass the world and document the epidemiology of his newly coined disease categories, lay a concern that the German race was declining in quality – a problem that could be off-set with practices of “racial hygiene,” such as limiting alcohol consumption and preventing syphilis (Engstrom 1908).

a psychiatric asylum near present-day Jakarta, he found – through a process of multiple translations from Javanese to Dutch to German – that there was a specific condition in Java known as *amok*, characterised by an unexplained violent rampage, (Carr 1985) (which subsequently lent itself to the English expression “running amok”). Later critiques of Kraeplin note that the emphasis was on searching for universal symptoms or syndromes and translating them into familiar concepts. Thus, applying Western nosology to the Javanese context, the culture-bound syndrome *amok* would later be “translated” as brief reactive psychosis (Littlewood 1991).

### 3.7.c.iii The “new” cross-cultural psychiatry

Proponents of the “new cross-cultural psychiatry” argued that translations of disease categories from one language and culture to another constitute an error of “category fallacy” (Kleinman 1987; Kleinman 1977). Category fallacy can be understood as a form of selection bias, only the selection relates to symptoms rather than to individuals in a sample. The underlying observation, first articulated by Arthur Kleinman, is that a researcher tends to “find” or “see” what he or she is looking for, with disregard to whether what is found is meaningful (1977). “A category fallacy is the reification of a nosological category developed for a particular cultural group that is then applied to members of another culture for whom it lacks coherence and its validity has not been established” (Kleinman 1987). The concept is most convincingly described when Kleinman inverts the direction of cross-cultural research. He imagines researchers from Latin America questioning New Yorkers to detect “soul-loss” (*falta de animo*), an illness category that is meaningful within certain Latin American cultural contexts, but has no referent in the streets of Manhattan (outside of Latin neighbourhoods).

The direction of category fallacy is more commonly that Western researchers apply their (biomedical) illness categories onto other cultures. Some categories may have a broad application – this is particularly true of the so-called serious mental disorders, such as schizophrenia-spectrum and bipolar disorders. Others, however, may seem as irrelevant as soul-loss is to a New Yorker. Kleinman evokes dysthymia, characterized by chronic poor affect not severe enough to warrant a diagnosis of depression, as one example of a Western disorder without cross-cultural application.

“Dysthymic disorder ... may hold coherence in the more affluent West, but it represents the medicalization of social problems in much of the rest of the world (and perhaps the West as well), where severe economic, political and health constraints create

endemic feelings of hopelessness and helplessness, where demoralisation and despair are a response to real conditions of chronic deprivation and persistent loss, where powerlessness is not a cognitive distortion but an accurate mapping of one's place in an oppressive social system." (Kleinman 1987)

Kleinman's critique is not dissimilar to that of Summerfield; however he takes aim at a subset of the spectrum of depressive disorders rather than at the entire condition.

The crux of the "new cross-cultural psychiatry" is the relationship between biology and culture, and which is determinant. In his defining article, Kleinman points to a key distinction between disease and illness (Kleinman 1977). The former is defined as biological, while the latter is a cultural construct. Kleinman, and his colleague Roland Littlewood, contest the notion that "disease is taken to be "real" and hidden by the illness" (Kleinman 1987). In their view, illness matters more than disease, as it shapes not only meaning, but also help-seeking behaviours and in turn the course of illness.

"Depression experienced entirely as low back pain and depression experienced entirely as guilt-ridden existential despair are such substantially different forms of illness behaviour with different symptoms, patterns of help-seeking, course and treatment responses that, though the disease in each instance may be the same, the illness rather than the disease is the determinant factor." (Kleinman 1977)

The new cross-cultural psychiatry saw culture as open-ended and heterogeneous, focusing on "local worlds" rather than on national identities. It took active interest in individuals' illness experiences and explanatory models. By repositioning biology (disease) and culture (illness), the new cross-cultural psychiatry furthermore sought to contextualize medicine within politics. Thus, neurasthenia, for example, a condition characterized by chronic fatigue, was understood as an expression of demoralization in response to the Cultural Revolution in China (Kleinman 1982). The solution proposed by the new cross-cultural psychiatrists to the problem of validity was to start with local idioms of distress and work from the bottom up, rather than starting with biomedical categories and working down.

### 3.7.c.iv Beyond the cross-cultural: global mental health?

Thirty years after Kleinman's launch of the new cross-cultural psychiatry, Lawrence Kirmeyer boldly sought to reappraise the field, ushering in the age "beyond the new cross-cultural psychiatry" (Kirmeyer 2006). This newest phase might better be dubbed the age of global mental health. The term global mental health is problematic, in that mental health is

inherently social and individual; however it extends from the popularly employed term global health, which replaced international health to convey that health and disease travel beyond national borders. In the last ten years, a Movement and a Centre were created in the name of global mental health.(Movement for Global Mental Health 2010; Centre for Global Mental Health 2008)

Kirmeyer notes that the current age of global mental health has polarized the field of cross-cultural psychiatry. On the one hand lie clinicians and public health practitioners, who “assume the cross-cultural portability of psychiatric theory and practice in order to achieve practical outcomes,” with little self-reflection. On the other hand lie medical anthropologists, embarked on what “has seemed to be an exclusively critical enterprise that does not consider the exigencies of clinical practice and the legitimate efforts of patient and clinician to wrest something helpful from their encounter.” Indeed, the discussions between clinician-scholars and social scientists are too few, and often beleaguered (Summerfield et al. 2012). At the heart of the debate is the contention that “psychiatry itself is an agent of globalization” (Kirmeyer 2006).

The concept of category fallacy is now familiar to most researchers in global mental health; and a few studies have addressed this methodological challenge. In Zimbabwe, Vikram Patel conducted a free-listing exercise in the Shona language to arrive at locally appropriate descriptions of a depression-like condition known as *kufungisisa*, or thinking too much (Patel, Simunyu, and Gwanzura 1995). Theresa Bettancourt undertook a similar process to arrive at local idioms for depression-spectrum disorders among children surviving war in Uganda. One of the local idioms she found in Rwanda, *two tam*, interestingly, also translates as thinking too much (Betancourt et al. 2009). Professor Ndeti, who supervised this thesis in Kenya, contributed to the development of an East-African symptom checklist for common mental disorders (Ndeti et al. 2006). Moving from diagnosis to measurements of outcome, Paul Bolton designed a symptom checklist to evaluate functionality in relation to the real tasks undertaken by people in rural Uganda (Bolton, Wilk, and Ndogoni 2004).

For the most part, however, research has continued much as before in using tools designed in the West and attempting their translation into local language (semantic equivalence), without questioning the validity of the disease constructs (concept equivalence). As Kirmeyer laments:

“To establish the cross-cultural validity of diagnostic constructs [...] demands [...] detailed ethnography aimed at establishing

symptom, syndrome and illness meaning, as well as culturally valid indicators of sickness, disability and outcome. This methodological program has only been attempted in a few areas, yet one often hears psychiatrists doing international work confidently claim that many of the disorders in our nosology are universally valid.” (Kirmayer 2006)

The main justification for not undertaking more of these ethnographies has been one of limited resources. Martin Prince observes, “If [the] resources are limited, then the local assessment may not live up to expectations, and adaptation of an existing measure from another culture may be more cost-effective” (Prince 2013). Indeed, poorly developed local measurements may be worse than carefully constructed foreign ones, which have benefitted from years of application and stood the trial of sophisticated statistical tests of reliability and internal consistency.

The emphasis of this age of global mental health may be more on designing interventions and evaluating their outcomes than on scrutinizing the accuracy of diagnosis. A shift towards more practical and less theoretical arguments was first announced by proponents of the new cultural psychiatry. For example, Roland Littlewood observed: “As it is possible to employ a concept without having a term for it, we can, alternatively, pay greater attention to what people actually do pragmatically in cases of sickness. Illness categories are strategies as well as explanations” (Littlewood 1991). Diagnosis within a clinical context serves primarily as a first step in a strategy for treatment. Thus, researchers have tended to focus on large umbrella-categories of diagnosis, which are less contestable than more specific classifications. For example, the latest edition of the Diagnostic and Statistical Manual (American Psychiatric Association 2013) catalogues approximately 300 illnesses, including “dependent personality disorder” and “intermittent explosive disorder,” whereas the World Health Organization’s flagship programme, the Mental Health Gap Action Programme (World Health Organization 2008) defines only eight priority conditions: 1) depression (which includes anxious depression); 2) schizophrenia; 3) bipolar disorder; 4) alcohol and substance abuse; 5) epilepsy; 6) suicide; 7) childhood disorders; and 8) dementia.

The challenge posed by anthropologists to health services researchers, such as myself, resides as much in the appropriateness of interventions as in that of diagnosis. In particular, questions arise in relation to the extent to which medical solutions are offered to social problems. As Kirmayer observes, “Psychiatry tends to have one answer for all these complex social ills – more mental health services” (Kirmayer 2006). Kirmayer’s chief

concern is the potential manipulation of research agendas by pharmaceutical companies, whose primary objective is to expand their market. If pill-popping becomes the globalized response to social suffering, then the field of global mental health must indeed question its legitimacy. Returning to Summerfield, there is “a question as to whether non-Western societies do need “mental health services” at all, as we understand them in the West, and if so, which bits?” (Summerfield 2012).

The only international intervention studied in this thesis was the model for Mental Health and Development, by BasicNeeds. The singularity of this model is that it is implemented through local community structures and integrates social and economic activities in addition to psychiatric care. Thus it cannot be said of BasicNeeds that they are a conduit for pharmaceutical companies.

### 3.7.c.v Relationship of this thesis to the cross-cultural debate

Where does this debate about the validity of cross-cultural mental health research leave us in relation to the research undertaken in this thesis? The critiques levelled by medical anthropologists on the tools of health services research are relevant throughout this thesis and serve as a reminder to temper the conclusions drawn from the data. They are most relevant, however, in the chapter on traditional and faith healing (chapter 8), where the challenge of category fallacy holds the most ground.

The first category that could be called into question by research into mental illness within Kenyan tribal cultures is that of illness. Traditional healing in Kenya does not only address illness, but also misfortune. According to Charles Good, problems of misfortune for which people in Kenya seek traditional and faith healing include “disaffection of a close relative, a broken marriage, loss of a job or lack of success in obtaining one. One woman asked a traditional medical practitioner to provide her with herbal medicine that would keep thieves away from her shop” (Good 1987). Jean Comaroff coined the term “affliction” to account for the combination of physical and non-physical complaints, illness and misfortune, addressed by healers (Comaroff 1980).

The second category in question in the term mental illness is that of the mind. Existing literature on the cosmology of traditional healing in Kenya suggests that affliction is understood to stem from three broad causes. Within the Luhya cosmology, the causes of affliction are: 1) human (witches); 2) spiritual (especially ancestral spirits); and 3) environmental (air, water, food) (Wandibba 1995). Luo cosmology adds to that trio affliction that is inherited and affliction resulting from breaking of social taboos (Sindiga

1995). In both Luhya and Luo cultures, mental affliction is not seen to sit only within the individual, but more broadly within the community and the environment.

Yet another category in question is that of diagnosis. Anthropologists have observed that traditional African cosmology does not distinguish between cause and effect, etiology and symptom. In an often-cited passage from Jean Comaroff, describing the Tshidi tribe of South Africa and Botswana, she explains:

“No fixed relationship exists between specific causes and symptoms. Particular causal metaphors (such as sorcery) can be applied to a wide range of sensations and, conversely, similar sensations may be associated with various etiologies. Indeed, symptoms and causes are not logically separated in Tshidi perceptions; the former are merely tangible expressions of the latter. ... Thus, a broken leg is both fracture and sorcery.” (Comaroff 1980)

Diagnosis within a context of traditional and faith healing is not about labelling a condition, so much as it is about identifying the cause, which is inseparable from treatment. If all afflictions are either natural, human or spiritual, or some combination thereof, the question is less about which of those categories caused the affliction, but rather which human, or which spirit has intervened.

Biomedical diagnosis may be less distinct from traditional diagnosis, however, than Comaroff would imply. Many disease labels, such as depression, are understood to have a heterogeneous origin, and its symptoms – fatigue, headache, sleeplessness or sleeping too much – are often non-specific. The biomedical diagnosis relies on a clustering of non-specific symptoms into a category that becomes specific. I will further address the specific tensions between emic and etic categories – those developed from within a given culture, and those imported from abroad – within the context of the chapter itself. However, if health services researchers were to surrender to the threat of category fallacy, nothing comparative could be said about traditional versus conventional medicine. It is therefore important to acknowledge this limitation, but not allow it to prevent thoughtful research.

In conclusion, this thesis pulls together a considerable amount of data from multiple sources, presenting both strengths and weaknesses in research method. Although the samples and variables differ tremendously in size and scope, they are nonetheless unified by the overarching research question about the capacity, access and economic impact of non-state mental health care. Moreover, the six sources of data from rural and urban settings have unearthed rich new material on a topic that is little studied in a context of considerable challenge to research.

#### 4. Evaluation of the Model for Mental Health and Development

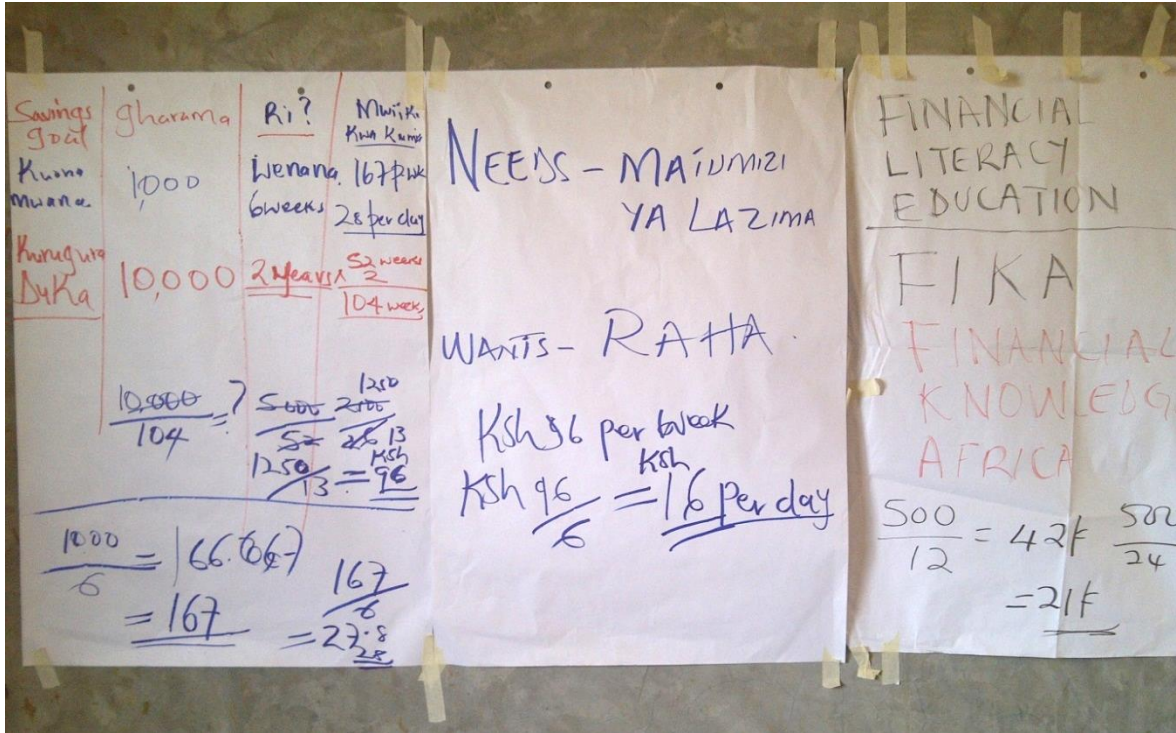


Figure 4-1 Photo of needs versus wants from a financial literacy training for BasicNeeds participants, provided by Financial Knowledge for Africa (FiKA)



## 4.1 Introduction

An estimated 5,000 nongovernmental organizations (NGOs) in Kenya purport to work in the field of health. However, according to the umbrella organization Health NGOs Network (HENNET), only 250 of them are “viable,” meaning they have been operational for at least 3 years, meet a minimum required annual budget, and have a reliable management structure, described as “a Board that is more than husband and wife” (KI 03, July 17 2011). Eighty five of these NGOs are members of HENNET, and a key informant from that organization speculated that a dozen of them do some work in mental health. However, most of the work that qualifies as mental health related is predominantly “psycho-social support,” or “life-skills,” in other words prevention rather than treatment. The leading NGO provider of mental health treatment in Kenya is the HENNET member BasicNeeds.

BasicNeeds, started operations in 2000 and has a mission “to enable people with mental illness or epilepsy to live and work successfully in their communities.” The NGO, which is headquartered in the UK, has delivered its intervention model in 14 countries – 4 countries in Africa (Ghana, Tanzania, Uganda, Kenya), 7 in Asia (India, Pakistan, Sri Lanka, Lao PDR, Nepal, China, Vietnam), 1 in Latin America (Colombia), and 2 in high-income countries (Australia and the UK). The NGO targets both adults and children who self-identify as having a mental illness or epilepsy. The latest numbers published by BasicNeeds suggest that in 2013 their intervention reached close to 175,000 people, including through direct contact with services by 42,469 people with a mental disorder and 32,549 care-givers. The BasicNeeds intervention model, called the model for Mental Health and Development (MHD), stands out among mental health interventions in that it simultaneously addresses problems of ill-health and poverty through a user-based approach, involving multiple members of the community.

With an annual turn-over of £2 million, funded largely by international aid, BasicNeeds makes a sizeable investment in mental health, but the social returns on that investment have not yet been evaluated in relation to the programme’s cost. Given that economic arguments are at the core of BasicNeeds’ rationale, it is particularly germane to subject their work to economic evaluation. At present, there is evidence that the MHD model is effective at improving the quality of life of people with mental disorders in Kenya (Lund, Waruguru, et al. 2012), but the question remains how effective they are relative to treatment as usual and whether it is worth the additional investment.

In 2009, researchers from the University of Cape Town (UCT) partnered in Kenya with the NGO BasicNeeds to evaluate MHD model in Nyeri North and Meru South. The

MHD model was funded in the two districts by two international funders: the UK Department for International Development (DFID) and the European Commission (EC). The research was funded with residual money from DFID. Both donors funded BasicNeeds for three years, contributing approximately £500,000 each for the duration of the grant, though only a small fraction of that was allocated to research. The impetus for the impact evaluation came from BasicNeeds, as well as from the lead UCT researcher, Crick Lund, rather than from donors, who would have been satisfied with mid-term and end-of-project programme evaluations. At that time, no prior study of community mental health in Africa had ever used standardized outcome scales (Hanlon, Wondimagegn, and Alem 2010). The study employed a pre-post design and followed 203 consecutively enrolled participants in the MHD Model for 20 months. Measures of wellbeing, service use and economic impact were administered at baseline with two follow-up periods at 10 and 20 months. The descriptive outcomes of that study were published in 2012 (Lund, Waruguru, et al. 2012).

In this chapter, I will evaluate the BasicNeeds model using a mixture of qualitative and quantitative data and methods. First, I will describe the MHD model in practice in Kenya, having outlined its broad principles in chapter two. Next, I will undertake an economic evaluation of the MHD model compared with treatment as usual, using one- and two-year time frames and adopting both societal and health systems perspectives. Finally, I will put those quantitative results in the context of qualitative findings about successes and challenges in delivering the model. This chapter primarily addresses two categories from within Tanahashi's framework of coverage, namely accessibility (including affordability) and effectiveness. It does not seek to address the availability, acceptability or contact coverage of the MHD model.

## **4.2 Methods**

This chapter combines primary and secondary data both qualitative and quantitative in kind, however it relies most heavily on quantitative data from a secondary source. The majority of the quantitative data come from a pre-post study with follow-up at 10 and 20 months led jointly by the University of Cape Town and BasicNeeds. My principal role was in collecting supporting qualitative data and cost data, preparing the quantitative dataset for analysis, and analysing the data. Participant outcomes from the UCT-BasicNeeds study have been analysed in a published paper (Lund, Waruguru, et al. 2012), but the data on user costs have not previously been analysed, nor has any attempt at a cost-effectiveness analysis been undertaken. As the study had no control group, I devised a method for estimating comparison

costs and outcomes from the literature for the purpose of cost-effectiveness analysis. In complement to the UCT-BasicNeeds secondary data, I collected primary data on NGO costs and estimated comparison group outcomes from the literature.

With generous support of an LSE Mobility Bursary, I spent Michaelmas Term of 2011 in Cape Town under supervision of Crick Lund, one of the principal investigators of the BasicNeeds-UCT Impact Study. Together, we addressed issues arising from cleaning the data (appendix 21). In addition, I worked closely with the director, research officer and accountant at BasicNeeds Kenya. Finally, I collected qualitative data during a site visit to Central Kenya in July 2011. I will first describe the methods used to collect and analyse qualitative data, then I will turn to the measurement and analysis of quantitative data on outcomes and costs.

The study design was approved by the Research and Ethics Committee at the University of Cape Town and by the Ethical Review Committee at the Kenya Medical Research Institute (KEMRI). Participants provided informed consent (appendix 5), and if they were unable to do so their caregiver did. The right to refuse participation was clearly explained by the BasicNeeds Research Officer and held no consequences. Data were shared with me according to a signed Memorandum of Understanding between the University of Cape Town, BasicNeeds and the LSE (see chapter three for further detail on ethics). All additional data that I collected were covered under the ethical clearance of the original study.

#### *4.2 - a) Location*

The BasicNeeds-UCT Impact Study was funded by a DFID project operating in Meru, Laikipia, Nyeri and Nyandarua counties. Laikipia was not selected as a research site, because the Ministry of Public Health declined to participate. Nyandarua and Nyeri have similar population characteristics, so the principal investigators felt they could be selected interchangeably, whereas Meru is slightly wealthier, making for a useful contrast. The principle investigators therefore chose Meru and Nyeri as the study sites. The European Commission also funded the work of BasicNeeds in these two counties, though they did not fund the research.

Meru County has population of 1.4 million and an area of 7,000 km<sup>2</sup>, while Nyeri County is about half the size of Meru with a population of 700,000 and covers an area of 3,300 km<sup>2</sup> (Ambetsa Oparanya 2010). The 2009 Census (*ibid*) reports that in Central province, 80% of people have primary or pre-primary education. In terms of household wealth, 40% have access to running water, 91% use pit latrine toilets, 85% own a radio and 75% own a mobile phone. The economies of Nyeri and Meru rely mostly on unmechanized farming,

produced largely for subsistence. The main cash-crops are coffee and tea, while maize, potatoes, beans, tomatoes and kale are produced for local consumption. The stimulant khat (known locally as *miraa*) is also a main product of the region. In addition, livestock rearing is common, particularly cattle, sheep, goats and chicken.

Describing the programme location is complicated by the shifting boundaries of government districts in Kenya between 2007 and 2010. The number of districts escalated from 70 in 2006 to a peak of 256 in July 2009, and plummeted to 47 in September 2009 (Nyasato 2010). Once the new constitution passed in 2010, districts were discarded in favour of counties. For the purpose of this study, the 2006 district unit approximates the coverage area better than the county unit; so I used the districts of Nyeri North and Meru South as the geographical borders. The population and geography of these districts is approximately half that of the counties of Nyeri and Meru, however for fluency of reading, I refer to them in the chapter as Nyeri and Meru.

#### 4.2 - b) *Qualitative Data*

The qualitative data are descriptive, arising from a number of conversations with BasicNeeds staff in Kenya and the UK, a two-day site visit to Nyeri and Meru counties on 19-20 July 2011. On the site-visit (appendix 10), I interviewed seven members of the implementing staff: the lead representatives of two implementing partners; a psychiatric nurse; a clinical health officer; a community worker, and the BasicNeeds research and policy officer. In addition, in Meru I attended a mental health clinic in a primary care facility (Kajuli dispensary), where I held a focus-group discussion with service users (five men, two women), translated from Kitharaka by the community worker. Because of the issues of translation, I have paraphrased the responses from focus group participants rather than quoting them, as they are unlikely to represent verbatim speech. In Nyeri, I attended a self-help group meeting of the *Mugunda* group, which had 22 participants (14 women, 8 men). Discussion was conducted in Kikuyu and translated for me into English by the group treasurer. I chose not to record these sessions, out of concern that doing so would cause participants to be less forthcoming. Instead, I took detailed field notes, which I typed up at the end of each day. The main goal of this data was to better understand the challenges arising in the delivery of the MHD model and to witness examples of positive outcomes.

In addition to this primary data, I also drew data from two unpublished external programme evaluations commissioned by donors (O'Connell, Musomi, and Mwangi 2011; Ntulo, Musomi, and Mwangi 2011). The authors of the DFID evaluation were Helen

O'Connell, Johnson Musomi and Judy Mwangi, each coming from differing areas of expertise, covering mental health, general health and programme evaluation. O'Connell is a PhD trained clinical psychologist specialized in early intervention and based in Ireland. She had previously evaluated the work of BasicNeeds in Tanzania. Musomi is a Kenyan medical doctor and Mwangi a Kenyan public health specialist, trained at the London School of Hygiene and Tropical Medicine. Both were employed by the NGO AMREF, the former as the Outreach Coordinator and the latter as a Regional Programme Officer in charge of Research, Monitoring and Evaluation. The European Commission evaluation was a mid-term evaluation, rather than an end-of-project evaluation, as a result of which one of the authors (Christina Ntulo) was an employee of BasicNeeds, though in Uganda rather than in Kenya. The other two authors were Musomi and Mwangi, the same evaluators who would see through the project's completion in the DFID end-of-project evaluation. With backgrounds mostly in the NGO sector, these evaluators are likely to have been sensitive to the challenges of programme delivery in Kenya. I was given access to these evaluations thanks to my pre-existing ties with the NGO. I know that they were not selected on the basis of being favourable evaluations, because I had access to all evaluations of the Kenya programme through an internal list-serve. These two evaluations were the most thorough and relevant to the research study in terms of timing and geographic coverage.

Four years working with BasicNeeds provided me with a pre-existing depth of knowledge of their practice in Kenya. I first visited the BasicNeeds programme in Kenya in the spring of 2007, where I met the programme staff – most of whom continued to be employed in 2011 – and visited their programme in Nairobi. During that trip, I witnessed the opening of a new clinic in the informal settlement of Kangemi, and I observed the first meeting of a service user group with aspirations of national representation, called Users and Survivors of Psychiatry Kenya. Over several years working with the organization, I held numerous skype meetings and interviewed staff about their practices in view of writing them up into the organization's Operation Manual. The knowledge I amassed of the organizational model, in rhetoric and practice, enabled me to evaluate its work in Kenya more expediently than would a newcomer and with greater access to people and supporting literature. At the same time, it made me less neutral to the outcomes of the data. I had reason to hope that the intervention would prove effective and cost-effective. To counter-act that bias, of which I was aware, I explicitly inquired about challenges to the model's delivery and tried to reach beyond positive messages.

I used thematic analysis to analyse the qualitative data from Nyeri and Meru. The a priori themes were defined by the activities of the MHD Model. In the first round of analysis, I read through the field notes and grey literature and grouped comments according to MHD activities. Then I created new categories for observations that did not fit into an activity, which I later labelled overarching comments.

#### *4.2 - c) Scope of Outcomes and Costs*

##### **4.2.c.i Outcomes Tools and Measures**

Since the MHD Model is holistic, and seeks to address not only health, but also social and economic outcomes, the principal investigators chose outcome tools that measured not only health, but also quality of life. The primary outcome measure was the General Health Questionnaire 12-question version (GHQ-12, appendix 11) and the secondary measure was the WHO Quality of Life Questionnaire, short-form (WHOQOL Bref, appendix 12). Clinical data were collected by three male health professionals: a psychiatric nurse, a clinical officer for health and an occupational therapist. Data were collected at three intervals: baseline (time 1), 10 months (time 2), and 20 months (time 3).

##### **GHQ 12**

Despite its name, the General Health Questionnaire was designed as a screening tool for detecting mental distress in a general population. It has been widely used in international research, including in Africa (Gureje 1991; Abiodun 1993; Amoran, Lawoyin, and Lasebikan 2007; Chipimo and Fylkesnes 2010). The tool exists in various formats, ranging from a long-form of 60 questions to a short-form of 12 questions, which was used for this study. Usually, the GHQ is self-administered, but since the Impact Study population were not highly literate, the tool was interview administered. Respondents were asked to rate how they felt in relation to their “normal self,” and responses were coded on a 4-point Likert scale from “much less than usual” to “much more than usual.” There are two methods for scoring the GHQ-12: the Likert scoring method (0,1,2,3) gives rise to scores from 0-36, while the bi-modal scoring method (0,0,1,1) gives rise to scores of 0-12. Since most of the literature reports on the bi-modal scores, we adopted that method. Higher scores indicated worse symptoms.

The GHQ-12 has established cut-off points, which enable a continuous outcome measure to be converted into a binary outcome of sick or healthy, which is useful for economic evaluation. The thresholds differ, however, in different cultural contexts (Goldberg,

Oldehinkel, and Ormel 1998). Literature from Kenya (Njenga 2000) suggested using 2/3 as the cut-off point for sickness (ie scores lower than 3 were coded as healthy). This is more conservative than the literature from Nigeria (Gureje and Obikoya 1990), which uses a 1/2 cut-off, but is consistent with the cut-off used in Zambia (Chipimo and Fylkesnes 2010).

The GHQ has not widely been used for cost-effectiveness analysis. A number of studies calling themselves cost-effectiveness studies have used the GHQ, but they are not true cost-effectiveness analyses in the standard economic sense (Drummond, Sculpher, and Torrance 2005). Some studies (Aracena et al. 2009; Glass and Goldberg 1977) compare mean GHQ scores between intervention and control groups to determine which is more effective and then separately analyse costs; but they fail to bring the two measures together into an incremental cost-effectiveness ratio or net monetary benefit, and thus never define a unit of cost-effectiveness. Other studies are true cost-effectiveness analyses, however they either employ the GHQ as a secondary measure of outcome, unassociated with cost (McIntosh et al. 2009; Woods et al. 2012), or they use it to screen study participants (Noordik et al. 2009), or as a predictor of outcome (Kendrick et al. 2006). I located a single cost-effectiveness study from 1998 (Morriss et al. 1998), using the GHQ as a primary measure of effectiveness for an intervention training GPs to recognize mental disorders in somatising patients. The authors, Morriss and colleagues, used the same analytic approach as I have adopted, namely translating patients with scores of 2 or less on the GHQ as recovered, and calculating the cost per recovered patient. David Goldberg, who designed the tool, is a co-author on the outcome paper from that study (Morriss et al. 1999), suggesting he deems this an acceptable way to use the tool.

### WHOQOL Bref

The 26-item WHOQOL Bref, a shortened form of the WHOQOL 100, measures quality of life along four domains: physical health, mental health, social relationships, and the environment. Questions are asked on a Likert scale of 1-5, resulting in a maximum total raw score of 130 points. (Three questions are reverse coded.) Domains are built from a range of 3-7 questions, and are scored by taking the mean of responses multiplied by 4 (World Health Organization 1996). The result is a score from 4-20, which can then be converted to a score out of 100, for ease of interpretation (Chou et al. 2013). Transformation to a score out of 100 does not follow a simple multiplication by 5. According to the guidelines, the score out of 100 is calculated as follows:

$$\text{WHOQOL domain (100)} = (\text{WHOQOL domain (20)} - 4) * (100/16)$$

The WHOQOL scale also includes two general questions, one about quality of life in general (“How would you rate your quality of life?”) and one about health (“How satisfied are you with your health?”).

Unfortunately, there is no agreed method for aggregating the four domains and two general questions into a single measure of quality of life. Drawing from the literature, I summed all items on the scale (reverse coding, where required) to create a continuous raw score, as done by Deribew and O’Connell and others (O’Connell, Skevington, and Saxena 2003; Deribew et al. 2013; Gassmann et al. 2013, ). While it remains close to the data, the challenge with this approach is that it weighs more heavily the quality of life domains with more questions attached to them, and it is hard to interpret the meaning of a one point increase. Because of the challenges related to aggregating and interpreting WHOQOL scores, I did not use the WHOQOL for the cost-effectiveness analysis. Instead, I used it as a way of triangulating the GHQ outcome scores, to test the accuracy of that data. I therefore have analysed WHOQOL outcomes at 10 and 20 months without extrapolating the data to one and two years.

#### Healthy days and DALYs

Outcome tools were transformed in several ways. First, an analysis was done of the change in score on the WHOQOL and the GHQ. Next, the cut-off point for health in the GHQ enabled translating the outcomes into a binary outcome of sickness or health. Health was then further specified into a number of healthy days, based on a linear trend between the baseline and follow-up scores. Finally, healthy days were translated into an estimate of DALYs using disability weights. Death was also reported as an independent outcome.

#### 4.2.c.ii Scope of Costs

Cost data were identified from multiple sources. NGO costs were assembled from expenditure data reported to grant donors (the European Commission and the UK Department for International Development). Government costs were drawn from World Health Organization unit cost estimates for Kenya. User costs were measured as part of the BasicNeeds-UCT Impact Study and comes from the Economic Status Tool, an adaptation of a tool by Murthy et al. (Murthy et al. 2005). Comparison group costs were held constant, using baseline data from before the intervention.



I used baseline data to estimate the costs of a no-treatment control. Follow-up data were designed to be collected at 9 and 18 months. In practice the mean time to follow-up was 294 days (s.d. 36) and 593 days (s.d. 39) respectively, which amounts to approximately 10 and 20 months of 30 days (9.8 and 19.8 precisely). I have reported the descriptive outcomes using the data as they were collected; however for the purpose of cost-effectiveness analysis, I extrapolated the data to estimate costs at 1 year and 2 years.

Costs were calculated from two perspectives: societal and health system. The societal perspective, which includes indirect costs to society such as changes in productivity and unpaid labour, is the most commonly adopted in economic evaluation. However, the health system perspective, which reports on direct costs only, is more often the interest of policy makers. Costs were calculated per person per year in keeping with the conventions of economic evaluation (Drummond, Sculpher, and Torrance 2005). Cost data were analysed in Kenyan shillings converted to international dollars using the 2011 IMF implied PPP conversion rate, equal to 42.479 Kenyan shillings per dollar (International Monetary Fund 2013).

A key methodological question around costing related to how to define the intervention being costed. Should I include the MHD Model as a whole, or only those activities that directly impacted on the measured outcomes? Including the whole Model has the advantage of preserving the intervention as BasicNeeds conceived of it and promoted it to the funders; however, it also runs the risk of inflating the cost per effect by incorporating elements of the model that do not influence the immediate measured outcome. I chose to include almost all costs, excluding only the costs of research studies, since they have no immediate measurable effect on the clinical outcomes of the intervention; however I included monitoring and evaluation, audits and participatory data analysis (which involves programme participants) as well as overhead costs associated with the office in the U.K. All other costs were included.

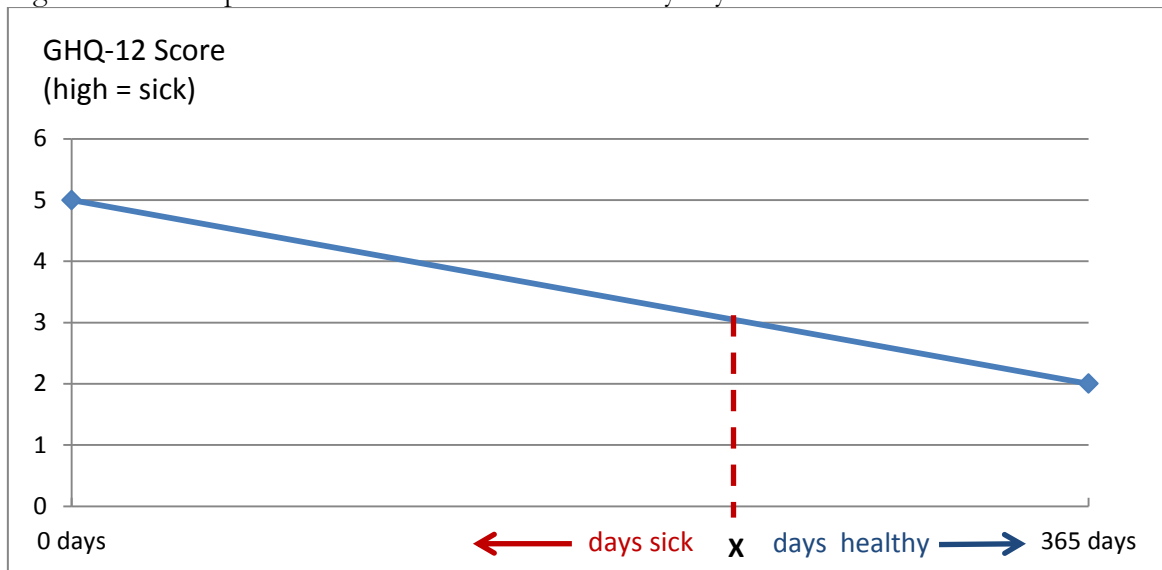
#### *4.2 - d) Measurement Issues around Outcomes*

##### **4.2.d.i GHQ-12**

As GHQ outcomes were measured at approximately ten month intervals, they had to be annualized to match the comparison outcomes. For the first year of data, I took into account the outcomes at both 9 months and 18 months, adjusting for the exact number of days

between interviews. To annualize the GHQ at one and two years, I assumed the trend between time 2 and time 3 was linear (figure 4-2).

Figure 4-2: Example of a line used to calculate healthy days



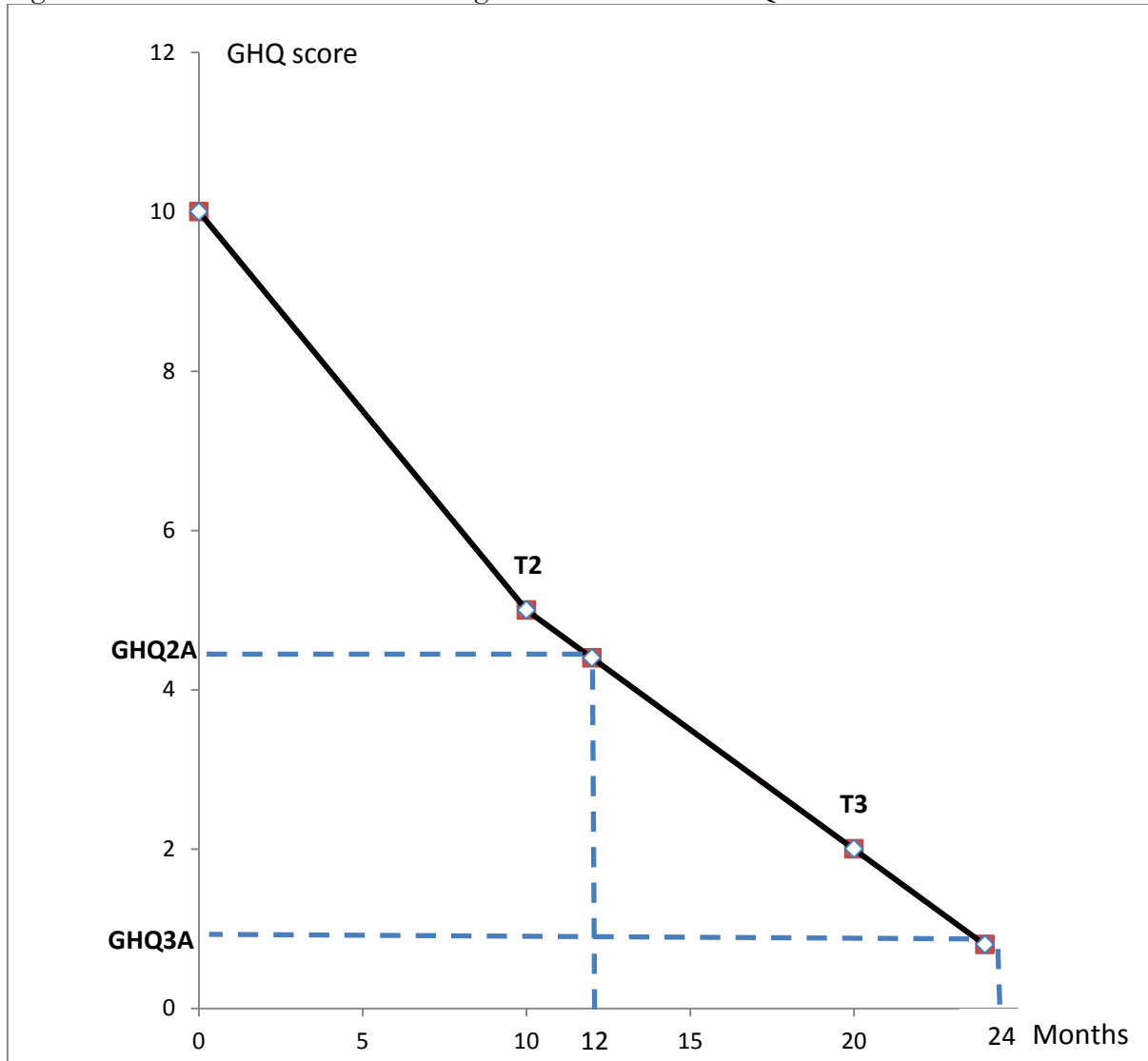
I created linear equations for each person in the sample with  $x$  equal to days since baseline and  $y$  equal to GHQ score (figure 4-3). The linear assumption is supported by precedent from the literature (McCrone et al. 2004). Then I solved for the value of  $x = 365$  days, or at two years for  $x = 730$  days. Since I did not know the  $y$  axis intercept value for the line between time 2 and time 3, I used the linear equation  $y - y_1 = m(x - x_1)$  which translates for one-year outcomes to:

$$GHQ_{365} - GHQ_{T_2} = \frac{\Delta GHQ_{T_2-T_3}}{\Delta days_{T_2-T_3}} \times (365 - days_{T_2})$$

$$GHQ_{365} = \frac{\Delta GHQ_{T_2-T_3}}{\Delta days_{T_2-T_3}} \times (365 - days_{T_2}) + GHQ_{T_2}$$

For the 20 subjects lost at time 3 but with data at time 2, I used the same linear equation, but drew the line between baseline and time 2. There was no significant difference in mean GHQ score at baseline between those lost at time 3 and the rest of the sample ( $t_{201} = -1.16$   $p=0.25$ ), suggesting that the values imputed were missing at random.

Figure 4-3: Linear method for estimating 12 and 24 month GHQ outcomes



To annualize the *change* in GHQ score, I used a slightly different equation, so as to take into account all three data points in a non-linear fashion. I added the first change in score by a fraction of the second change to arrive at an estimated change in 365 days. The equation at year one looks as follows:

$$\Delta GHQ_{365} = \Delta GHQ_{T1\_T2} + \Delta GHQ_{T2\_T3} \times \frac{(365 - \text{days}_{T2})}{\Delta \text{days}_{T2\_T3}}$$

The second half of the equation represents the number of missing days to complete the year  $(365 - \text{days}_{T2})$  multiplied by the change per day (GHQ change divided by the number of days between time 2 and time 3). To estimate the two year outcomes, I multiplied the change in score from baseline to time 3 by a fraction of that same number, representing the change per

day for the number of missing days. The equation, a variant on the previous one, looks like this:

$$\Delta GHQ_{730} = \Delta GHQ_{T1-T3} \times \frac{730}{days_{T3}}$$

#### 4.2.d.ii Healthy days

I assumed the same linear trend between follow-up points to estimate the number of days spent in health. Figure 4-2 shows a sample linear equation using a baseline score of 5 and a follow-up score of 2. Time was mapped on the x axis in days and the GHQ score was mapped on the y axis. The number of days sick was defined as the  $x$  value when  $y$  equals three – the cut-off score for health. The number of healthy days in a year was therefore 365 minus the number of sick days. Since research interviews were not conducted exactly 365 days apart, the numbers were adjusted by 365 divided by the difference in time between interviews to estimate the number of days healthy per year. The number of healthy days between baseline and year one was determined by the following equation with  $x$  equal to sick days, baseline GHQ score equal to the  $y$  intercept, and the estimated 12-month GHQ score for the second value of  $y$ .

$$y = \frac{|\Delta GHQ|}{\Delta Time}(x) + GHQ_1$$

$$x = (y - GHQ_1) * \frac{\Delta Time}{\Delta GHQ}$$

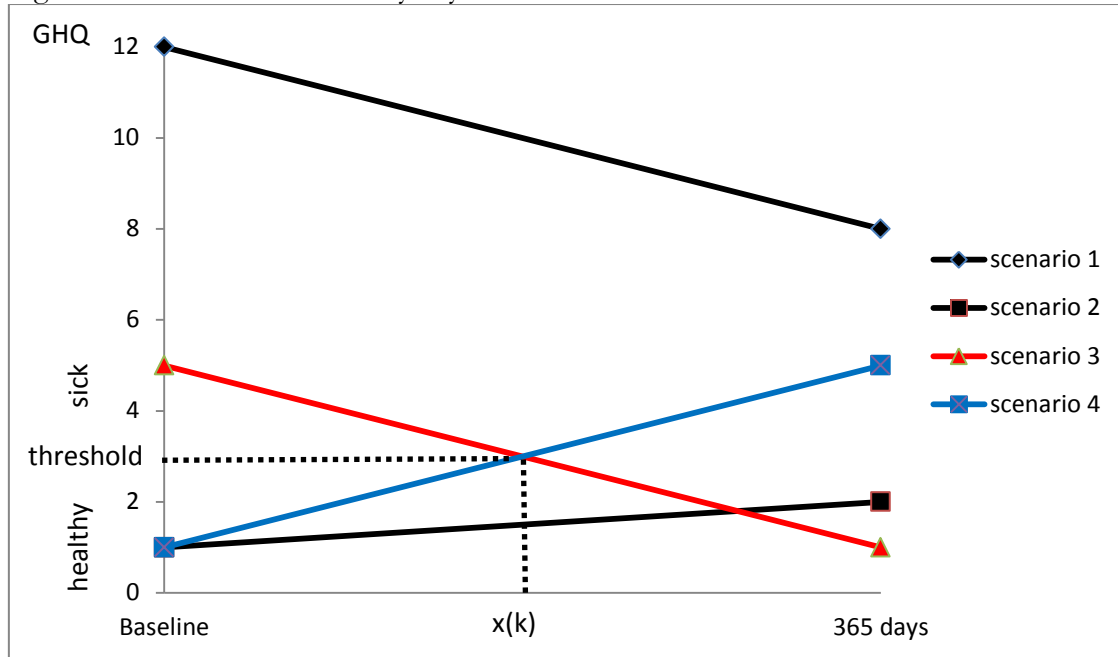
If  $y = 3$ , then the number of sick days  $x$  in the first year is:

$$x = (3 - GHQ_1) * \frac{365days}{|\Delta GHQ|}$$

Next, I outlined four scenarios (figure 4-4):

1. The person started and ended sick
2. The person started and ended healthy.
3. The person started sick and got better.
4. The person started healthy and relapsed.

Figure 4-4: Scenarios for healthy day calculations



In the first scenario, the number of healthy days in the first year were equal to 0. The second and fourth scenarios were excluded, since the cases that did not meet baseline criteria for illness were excluded from analysis. In the third scenario, where the person started sick, healthy days = 365 - x, using the equation above for x at y = 3.

Two year outcomes relied as much as possible on raw data, rather than on extrapolation. The total number of healthy days in two years was calculated as the sum of healthy days in the first 10 month follow-up, plus the estimated healthy days in the remaining time. To estimate the second part of the equation, a line was drawn between between time 2 and the extrapolated 2 year GHQ score –an extension of the line between times 2 and 3 (figure 4-3). The equation for this line was calculated as follows:

$$y_1 - 3 = m(x_1 - x_k)$$

$$x_k = x_1 - \frac{y_1 - 3}{m}$$

$$x_k = x_1 - (y_1 - 3) \times \frac{\Delta x}{\Delta y}$$

Plugging in the values at time 2 for  $x_1$  and  $y_1$  we get:

$$x_k = \text{days}_{T2} - (\text{GHQ}_2 - 3) \times \frac{730 - \text{days}_{T2}}{\text{GHQ}_{3A} - \text{GHQ}_2}$$

Next, I used the same scenarios as for year one (figure 4-4).

1. The person started and ended sick

If GHQ2 and GHQ3A > 3  $\Rightarrow$  Healthy days = 0

2. The person started and ended healthy.

If GHQ2 and GHQ3A < 3  $\Rightarrow$  Healthy days = 730 – days at time 2.

3. The person started sick and got better.

If GHQ 2  $\geq$  3 and GHQ3A < 3  $\Rightarrow$  Healthy days = 730 – days at time 2 – x

4. The person started healthy and relapsed.

If GHQ 2 < 3 and GHQ3A  $\geq$  3  $\Rightarrow$  Healthy days = x when y = 3.

#### 4.2.d.iii DALYs

In order to increase the generalizability of the study results, I converted the GHQ outcomes into Disability Adjusted Life Years averted (DALYs). A DALY is defined as the sum of death and disability, referred to as Years of Life Lost (YLL) plus Years Lost to Disability (YLD). Typically, a DALY is measured over the lifetime of an individual, however I chose not to project my disability outcomes forward, as the long-term outcomes of mental health interventions are uncertain. I therefore calculated DALYs per year for the two years covered by the evaluation. The most basic equation for DALYs set out by Christopher Murray and colleagues (Murray and Lopez 1996) is:

$$\text{DALY} = \text{YLD} + \text{YLL}$$

$$\text{YLL} = \text{N} * \text{L}$$

With N = number of deaths and L = age-specific life expectancy at death

Life expectancy was time-discounted using the equation for present value of annuities:

$$\frac{1 - (1 + r)^{-t}}{r}$$

The discount rate r was set at 3% based on conventional DALY calculations, for the purpose of comparison with other studies.<sup>10</sup>

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<sup>10</sup> This is lower than the 7% discount rate than I adopted for unit costs, because there is precedent arguing for adopting a higher discount rate in a low-income African context.

$$YLD = P * DW * L$$

With P = prevalence; DW = disability weight and L = duration of the illness in years

As the sample was entirely sick, P was equal to 100%.

Projecting the YLL outcomes to 24 months was challenging, because it is not possible to predict death for a given individual. So rather than using N as the number of deaths, the data were aggregated into a single mortality rate for the sample. I used observed deaths (table 4-1) to calculate the 10-month mortality rate<sup>11</sup> for the two follow-up periods, disaggregated by diagnosis (appendix 14). The mortality rates for SMD were 0.02 and 0.05 at 12 and 24 months, while for epilepsy they were 0.00 and 0.02 and for CMD they were 0.04 in the first year. The age-specific life expectancy at death was calculated based on the observed deaths at 20 months, using Kenyan life tables (Global Health Observatory 2011). I did not adopt age weighting, since that technique has been critiqued on grounds of equity. The mean years of life lost per person who died, using a 3% discount rate per year, was 16.47 years for the whole sample, but it was higher for epilepsy (25.95 years) than for schizophrenia (15.28 years), as epilepsy tends to affect people starting at a younger age. As there was only one death of a person with epilepsy, however, these numbers are far from certain.

I calculated two-year DALYs for serious mental disorders and epilepsy, but not for common mental disorders, as there is insufficient literature with which to estimate two-year counter-factual outcomes. To calculate DALYs at two years, it is not possible to simply add the change in DALYs in year one to the change in DALYs in year two, because that would miss the DALYs averted from maintaining the good health of those who improved in the first year. Neither is it possible to subtract the year two DALYs from the baseline DALYs, because that would assume that no one would have spontaneously improved in the first year. So, I made the same assumption of spontaneous recovery in the first year as for the treatment as usual group.

DALYs averted in the 1st year = DALYs at baseline – DALYs at 12 months

DALYs averted in the 2nd year = DALYs at baseline – DALYs at 24 months - spontaneous recovery in year 2

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<sup>11</sup> Mortality rate is defined as deaths divided by person years.

Table 4-1: Observed deaths and years of life lost at 20 months in the MHD sample

	<b>SMD deaths</b>		<b>CMD deaths</b>		<b>epilepsy deaths</b>		<b>Total deaths</b>		<b>Age-specific life exp.</b>		<b>YLL</b>	
	M	F	M	F	M	F	M	F	M	F	Raw	Discount
15-19	0	0	0	0	1	0	1	0	51	53	51	25.95
20-24	0	0	0	0	0	0	0	0	47	49		
25-29	1	0	0	0	0	0	1	0	43	45	43	23.98
30-34	1	1	0	0	0	0	1	1	39	41	80	30.20
35-39	0	0	0	0	0	0	0	0	35	37		
40-44	1	0	0	1	0	0	1	1	32	34	66	28.60
45-49	0	0	0	0	0	0	0	0	28	30		
50-54	0	0	0	0	0	0	0	0	24	26		
55-59	0	0	0	0	0	0	0	0	20	22		
60-64	0	1	0	0	0	0	0	1	17	18	18	13.75
65-69	0	0	0	0	0	0	0	0	13	15		
70-74	0	1	0	0	0	0	0	1	10	11	11	9.25
75-79	0	0	0	0	0	0	0	0				
80-84	0	0	0	0	0	0	0	0				
<b>Total</b>	<b>3</b>	<b>3</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>4</b>	<b>4</b>			<b>269</b>	<b>131.74</b>
<b>Mean YLL</b>	<b>15.28</b>		<b>14.30</b>		<b>25.95</b>						<b>33.63</b>	<b>16.47</b>

I calculated disability (YLD) using recently published Global Burden of Disease (GBD) 2010 disability weights, which range from 0-1 for 230 health states (Institute of Health Metrics and Evaluation 2010). A challenge in DALY conversions was determining which of the 203 disability weights to apply to my sample (table 4-2).

Table 4-2: Disability Weights used for DALY Conversions

<b>Health state</b>	<b>GHQ-12 score</b>	<b>DALY weight</b>
Schizophrenia	3-12	0.689
Bipolar disorder	3-12	0.480
Common mental disorder, moderate	3-7	0.406
Common mental disorder, severe	8-12	0.655
Epilepsy, moderate (treated)	3-7	0.319
Epilepsy, severe	8-12	0.657

Two health states exist in the GBD study for schizophrenia: acute (0.756) and residual (0.576). Acute schizophrenia, as defined by GBD researchers (Ferrari et al. 2012), is associated



with positive symptoms (hallucinations, delusions) and applies to 63% of cases, while residual schizophrenia is associated with negative symptoms (catatonia, flat affect) and is found in 37% of cases. Since the two states are qualitatively different, rather than reflecting a difference in severity, it was not possible to estimate the proportion of the sample with acute versus residual schizophrenia. Instead, I calculated an average disability weight for schizophrenia by multiplying the weight for acute and residual schizophrenia by their respective prevalence, which amounts to a weight of 0.689 for all those with a GHQ score of 3 or more.

Two GBD health states exist explicitly for bipolar disorder – manic (0.480) and residual (0.035) – while bipolar depression falls into one of the three health states associated with depression: mild (0.159); moderate (0.406); and severe (0.655). The diagnosis of bipolar disorder was coded into the data with the additional information “manic disorder,” so I coded all those with bipolar disorder scoring above the case threshold with the disability weight for manic.

Common mental disorders were rare in this sample, and consisted almost exclusively of depression. The GBD study divides depression into three different health states each with their own disability weight: mild (0.159); moderate (0.406) and severe (0.655). The BasicNeeds-UCT Impact Study did not contain a severity measure; however the distribution of GHQ scores for people with common mental disorders (appendix 17) is skewed towards the more sick end of the spectrum.

Several possible methods exist for estimating illness severity of the sample. One approach is to look to the literature on severity cut-offs used for the GHQ-12, most of which comes from high-income countries. Researchers from New Zealand adopted a cut-off of 8 in the GHQ-12 to estimate severe depression (Bushnell et al. 2005), drawing on scoring guidelines provided by Goldberg, who designed the tool (Goldberg and Williams 1988).

Another approach is to map the GHQ scores onto a comparable tool with defined severity parameters. The Patient Health Questionnaire nine items (PHQ-9) is a widely used screen for depression, including by the UK’s National Health Services (Spitzer, Kroenke, and Williams 1999). The PHQ-9 is scored on a scale of 0-27 with scores of 15 or higher indicating moderate-to-severe depression. Research from India demonstrates high correlation ( $r=0.72$ ) between the PHQ-9 and the GHQ-12 (Patel et al. 2008), suggesting that a cross-over between the two scores may be possible. If correlation were perfect, then one unit on the GHQ-12 would be equivalent to 2.25 units on the PHQ-9, resulting in a cut-off of  $6/7$  ( $15/2.25 = 6.67$ ) for moderate-to-severe depression.

Yet another approach to coding severity is to isolate the top quartile or the population scoring one standard deviation above the sample mean. While this statistical approach offers a marker of severity relative to other cases within the sample, it does not account for the possibility that the entire sample is severely ill – a realistic possibility in Kenya where only the most ill reach treatment. The statistical cut-off is therefore a less attractive approach. I opted for the more conservative of the literature-based approaches, and coded as severe all those with a score of 8 or higher.

For epilepsy, the GBD study allocated disability weights to four different health states: 1) treated, seizure free (0.072); 2) treated with recent seizures (0.319); 3) untreated (0.420); and 4) severe (0.657). This essentially breaks down into two levels of severity – moderate and severe – with a different weight for those on treatment as opposed to those not on treatment. The distribution of baseline GHQ scores for people with epilepsy in our sample appears bimodal (appendix 17), which supports the division of outcomes into moderate and severe. As with common mental disorders, I coded as severe those with a score of 8 or higher.

In computing DALYs, those with a diagnosis of “other” (n=6) were excluded from the analysis, as there is no associated disability weight. Those with baseline GHQ scores below the cut-off for health (n=4) were also excluded from the analysis of DALYs, as there was no possible change in health status.

#### 4.2.d.iv Estimated comparison outcomes

Comparison outcomes were estimated from the literature (tables 4-4 and 4-5), using a treatment as usual comparison. In the Kenyan context, for the majority of individuals with mental disorders, treatment as usual is equivalent to no treatment from conventional medicine. Those few who do receive medical treatment receive limited hospital based care, while others receive traditional healing. For common mental disorders data were only available from a multi-site study from mostly high-income countries, which employed a no-treatment control.

## Remission

*Common mental disorders* – A study by the researchers who designed the GHQ proved useful in estimating outcomes for a putative no-treatment control. Simon, Goldberg and colleagues analysed data from a WHO study (Simon et al. 1999) using the GHQ-28 across fifteen countries of varying income levels, including Nigeria. Out of 948 people diagnosed with depression, 545 had unrecognized – and therefore untreated – depression. The GHQ-28 scores of these untreated depressed people dropped a mean of 7 points between baseline and one-year follow-up. The equivalent drop on a GHQ-12 score, assuming the two scales are proportionate, would be 3 points ( $7/28 = 3/12$ ). I therefore estimated the GHQ-12 scores of the BasicNeeds depressed population, had they been untreated, by subtracting 3 from their baseline GHQ scores. I then transformed the continuous score into a binary outcome of sickness or health, based on the 2/3 cut-off point used in Kenya.

*Severe mental disorders* – Several studies exist reflecting on the outcomes of untreated populations of people with schizophrenia in low-income countries and are reported in table 4-4 (Haro et al. 2011; Kebede et al. 2003; Ran et al. 2001; Ran et al. 2007; Teferra et al. 2011; Thirthalli et al. 2009). The most culturally comparable population to our Kenyan sample was that of a study conducted in rural Ethiopia. Kebede and colleagues followed a cohort of 307 individuals with schizophrenia over four years. They measured natural course using, among other tools, the Short Form 36 (SF-36), a questionnaire with 36 items scored on a Likert scale across eight domains, including a mental health domain (Ware et al. 1993).

At baseline, 89% of the sample were treatment naïve; however 28% of follow-up time was spent on treatment. The sample had 23% recent onset schizophrenia, while the remainder had long-standing disorder. The mean SF-36 mental health score increased in the first year by 9.2% for those with long-standing schizophrenia and by 18.3% for those with recent onset schizophrenia. It increased from baseline to year two by 12.4% for those with long-standing disorder and by 20.3% for those with recent onset schizophrenia. The mean increase over the whole sample was therefore 11.3% in the first year and 14.2% in two years.

The literature indicates that there is good correlation between the SF-36 and the GHQ (Romppel et al. 2012; Failde, Ramos, and Fernandez-Palacin 2000), particularly in relation to the mental health subscale of the SF-36, which has a Spearman rank correlation of 0.73 (McCabe et al. 1996; Kelly et al. 2008). An improvement of 11.3% and 14.2% on the SF-36 mental health scale translates to a decrease in GHQ-12 of 1.4 and 1.7 points respectively. I then transformed the continuous score into a binary outcome of sickness or health, based on the 2/3 Kenyan cut-off point for the GHQ.

*Epilepsy* – The literature on the natural course of epilepsy offers widely diverging estimates of spontaneous remission, ranging from 20% to 57% (Hesdorffer 2010; Kwan and Sander 2004; Nicoletti et al. 2009; Placencia et al. 1992; Schmidt and Sillanpää 2012; Wang et al. 2003). I met with Ley Sanders, an expert on epilepsy research in low-income countries at the University College of London, who noted that the literature on natural remission of epilepsy has overlooked the high rates of mortality among those lost-to-follow-up. He believes that spontaneous remission rates are lower than previously estimated (including by himself), and that mortality from epilepsy-related accidents is higher. Recent data from Kenya, however, suggest that spontaneous remission rates from epilepsy are in fact much lower than previously estimated, ranging from 6-8% per year (Newton 2013). Since the Kenyan estimate is based on empirical data from the same place and time, as opposed to non-empirical estimates, I chose the rate of 7% spontaneous remission for my analysis.

### Mortality

To estimate death in the comparison group, I used disease-specific standardized mortality ratios (SMR). The SMR is the ratio of deaths in a designated cohort, over that in the general population with the same age and sex distribution in a given year. It is more accurate to use the SMR than the simple mortality rate, because SMR is standardized to the age and sex of the population. For common mental disorders, I used a conservative estimate of 1.6 from a recent meta-analysis (Cuijpers et al. 2013). For severe mental disorders, I used an SMR of 5.98 from an Ethiopian study, which also formed the basis of estimates of remission (Teferra et al. 2011).

For untreated epilepsy, I used new data collected in Kenya between 2007 and 2008 (Ngugi et al. 2014). The study draws on data from 754 individuals with active convulsive epilepsy and over 230,000 members of the general population to derive an SMR of 6.5 for active convulsive epilepsy. Those not taking anti-epileptic drugs (over half the sample) had a death rate of 48.8, as compared to a rate of 33.3 in the total sample. The implied SMR for untreated active convulsive epilepsy is therefore the all-epilepsy SMR times the rate ratio of those untreated as compared to the whole sample:  $(48.8/33.3)*6.5 = 9.5$ . However, following communication with Charles Newton, I have chosen to use the more conservative SMR rate of 6.5, because of concerns he has about the accuracy of data on treatment adherence. This number may be subsequently modified when new biometrically verified adherence data is made public by Newton and his team at the Wellcome Trust centre in Kilifi Kenya.

Table 4-3: Expected deaths in a matched sample with untreated mental disorders

General population			SMD				CMD				Epilepsy				All
mortality rate			male		female		male		female		male		female		
Age	Male	Female	N	deaths	N	deaths	N	deaths	N	deaths	N	deaths	N	deaths	Total
15-19	0.002	0.003	5	0.07	0	0.00	1	0.00	0	0.00	5	0.08	3	0.062	0.22
20-24	0.003	0.004	5	0.10	2	0.05	0	0.00	1	0.01	4	0.09	4	0.106	0.35
25-29	0.005	0.005	14	0.41	4	0.13	0	0.00	0	0.00	11	0.35	4	0.137	1.02
30-34	0.007	0.007	15	0.60	7	0.28	2	0.02	1	0.01	3	0.13	3	0.130	1.17
35-39	0.010	0.009	11	0.63	10	0.56	1	0.01	3	0.04	2	0.12	3	0.182	1.55
40-44	0.010	0.011	7	0.41	7	0.47	0	0.00	2	0.03	2	0.13	0	0.000	1.03
45-49	0.011	0.013	5	0.32	10	0.78	0	0.00	4	0.07	0	0.00	3	0.254	1.42
50-54	0.010	0.014	1	0.06	3	0.25	0	0.00	1	0.02	0	0.00	1	0.090	0.42
55-59	0.012	0.019	0	0.00	5	0.55	0	0.00	2	0.05	0	0.00	1	0.121	0.73
60-64	0.017	0.024	2	0.21	2	0.29	0	0.00	0	0.00	2	0.23	2	0.315	1.04
65-69	0.030	0.037	0	0.00	0	0.00	0	0.00	2	0.10	1	0.19	0	0.000	0.30
70-74	0.047	0.056	0	0.00	2	0.67	0	0.00	3	0.24	0	0.00	0	0.000	0.91
75-79	0.074	0.085	0	0.00	0	0.00	0	0.00	0	0.00	1	0.48	0	0.000	0.48
80-84	0.120	0.134	0	0.00	0	0.00	0	0.00	1	0.19	0	0.00	1	0.869	1.06
<b>total deaths</b>			<b>65</b>	<b>2.81</b>	<b>52</b>	<b>4.02</b>	<b>4</b>	<b>0.04</b>	<b>20</b>	<b>0.76</b>	<b>31</b>	<b>1.80</b>	<b>25</b>	<b>2.265</b>	
<b>1 year</b>			<b>6.83</b>				<b>0.79</b>				<b>4.06</b>				<b>11.68</b>
<b>2 years</b>			<b>13.66</b>				<b>1.59</b>				<b>8.12</b>				<b>23.37</b>
<b>mortality rate</b>			<b>0.058</b>				<b>0.033</b>				<b>0.073</b>				<b>0.059</b>

To convert the disease-specific SMRs into a probability of death for the study sample, I multiplied the number of people in my sample (N) by the expected death rate for a normal population with the same age and sex distribution as mine, using Kenyan life tables (Global Health Observatory 2011). The equation for calculating years of life lost for a given age and sex cohort was:  $YLL = \text{mortality rate} * N * SMR$

Next, I aggregated the total expected deaths by diagnosis and calculated a mortality rate (appendix 14), which I used to calculate a mean number of Years of Life Lost, as was done for the MHD group, described in the section on DALYs. The mortality rates thus calculated were 58 per 1000 for severe mental disorders, 33 per 1000 for common mental disorders and 73 per thousand for epilepsy (table 4-3).

### DALYs

Estimating DALY outcomes for the comparison group was done in different ways, depending on available data. DALYs for common and severe mental disorders were calculated in the same way as for the intervention group. YLDs for common mental disorders and epilepsy were calculated using GHQ scores, to determine the severity of disability weight, multiplied by time spent sick (1 – healthy days). A single mean YLL was calculated for the whole sample, by multiplying expected mortality by the estimated time spent dead, which was assumed to be 50% of the year (the midpoint). Two-year DALYs were not calculated for common mental disorders as insufficient data were available in the literature on the natural course of these disorders beyond 12 months.

Epilepsy outcomes had to be estimated at the aggregate, rather than by imputing patient level data, as there was no way to estimate GHQ outcomes. Untreated epilepsy has its own GBD disability weight of 0.42, regardless of severity, and seizure-free epilepsy carries a low-level disability weight of 0.072, presumably reflecting sequelae of the disease. Those estimated to be sick were presumed sick the whole year, and those in remission were presumed healthy the whole year – since the definition of remission was two years seizure free. As with the intervention group, DALYS averted in two-years were calculated by comparing the DALY state at year two with baseline. The mean DALYs for people with epilepsy were calculated as follows:

DALY = YLD + YLL with:

YLD = (disability weight) \* (% year sick) (population proportion sick)

= (disability weight 1) \* (% year sick) (1- remission rate – mortality rate) + (disability weight 2) \* (% year sick) \* (remission rate)

YLL = 1 \* (mortality rate) \* (50% year dead)

$DALY_{epilepsy} = (0.42 * 1 * (1 - 0.3 - 0.057)) + (0.0072 * 1 * 0.3) + (1 * 0.057 * 0.5)$

$DALY_{epilepsy} = 0.301$

Table 4-4: Literature on natural course of mental disorders in low-income settings

Study	Location	Condition	Sample	Outcome measure	Follow-up	Results
Kebede 2005	Ethiopia	schizophrenia	N= 307 with follow-up data, age 15-49; 28% of follow-up time was spent on treatment as usual	SF-36, SANS & SAPS (Scales for assessment of positive and negative symptoms)	4 years	SF-36 mental health score increased from a mean of 52.1 to 61.3 at year 1 and 64.5 at year 2, ie an increase of 9.2% in one year and of 12.4% in two years
Alem 2009	Ethiopia	schizophrenia	N=307 (82% male)	SF-36	5 years	Throughout follow-up 30.8% of cases were continuously ill, while 5.7% enjoyed a near-continuous complete remission. In the final year, 54% were in psychotic episode, while 17.6% were in partial remission and 27.4% were in complete remission. Odds of remission were 4.55 higher for those on antipsychotics than those not.
Teferra 2011	Ethiopia	schizophrenia	N=307 (82% male)	Standard Mortality Ratio (SMR)	5 years	SMR was 5.98. The mortality rate was 8,661/100,000 for men and 5,006/100,000 for women.
Thirthalli 2009	India (Karnataka)	schizophrenia	N= 215, 33 untreated at follow-up, 58% untreated at baseline	IDEAS (Indian Disability Evaluation and Assessment Scale), PANSS (Positive and Negative Symptoms Scale)	1 year	Mean score statistically unchanged in those untreated. IDEAS mean score at baseline and follow-up 8.9 (0.67) 8.8 (0.58) PANSS mean score at baseline and follow-up 81.46 (7.42) 78.18 (5.04) According to the 7-point cut-off used for the IDEAS, all of them remained disabled at one year follow-up
Haro 2011 (SOHO study)	Algeria, Egypt, Saudi, Turkey	schizophrenia	N=701 from Africa & Middle-East, Only 8.9% never treated	Clinical Global Impressions – Schizophrenia (CGI-SCH)	3 years	In the Middle East & Africa, 17.8% achieved functional remission, while 79.6% achieved clinical remission over 3 years
Ran 2001	China (Sichuan)	schizophrenia	N=510 total, 367 active cases	Social Disability Screening Schedule (SDSS)	2 years	9.6% of those untreated achieved complete remission and 8.3% achieved partial remission

Ngugi 2013	Kenya	epilepsy	N=752 with epilepsy – all prescribed anti-epileptics, but not all adherent	Clinical assessment by neurologist	3 years	Overall SMR was 6.5, mortality rate for those non-adherent to anti-epileptic drugs was 48.8 vs 33.3 overall.
Nicoletti 2009	Bolivia	epilepsy	N=103, 71 with data on seizures, only 10.5% had taken an antiepileptic drug for more than 2 months	Standardized questionnaire conducted by neurologists using ILAE definitions of seizure	2 years 5 years 10 years	10/103 had died in 10 years; 2-year remission for those not on treatment was 57.7% (30/52) 5-year remission for those not on treatment was 44.2% (23/52), but if you include those who died and assume they were symptomatic, then the numbers drop to 48% and 37% respectively.
Hesdorffer 2010	N/A	epilepsy	N/A – commentary	N/A	N/A	A 1–2 year spontaneous remission occurs in 20% to 44% of prevalent epilepsy
Wang 2003	China	epilepsy	N=387, 130 untreated	N/A	N/A	41% remission
Placencia 1992	Ecuador	epilepsy	N=1020, 643 untreated	Clinical assessment by doctors & a neurologist using ILAE definitions	N/A	49% of those untreated and 31% of the whole population entered into spontaneous remission
Kwan 2004	Lit review	epilepsy	N/A	N/A	N/A	Spontaneous remission estimated at 30%.
Simon 1999	Multi-site	common mental disorders	545 unrecognized (untreated) cases	GHQ-28	1 year	Mean score dropped 7 points from baseline.
Whiteford 2013	Lit review	common mental disorders	adults in primary-care settings	Multiple tools	1 year	53% remit spontaneously within 12 months.
Cuijpers 2013	Lit review	Common mental disorders	22 studies	Multiple tools	Multiple years	Relative risk of death for major depression is 1.58



Table 4-5: Parameters used to calculate DALY outcomes

	SMD		CMD		Epilepsy	
	MHD	Comparison	MHD	Comparison	MHD	Comparison
<b>Mean healthy days</b>	55 in 1 year 456 in 2 years	8 in 1 year 33 in 2 years	9 in 1 year	26 in 1 year	53 in 1 year 436 in 2 years	26 in 1 year 77 in 2 years
<b>Source</b>	Impact study (GHQ-12)	Kebede 2003	Impact study (GHQ-12)	Simon 1999	Impact study (GHQ-12)	Newton 2013
<b>Mean duration of disability (years)</b>	0.849 in 1 year 0.375 in 2 years	0.978 in 1 year 0.955 in 2 years	0.975 in 1 year	0.928 in 1 year	0.855 in 1 year 0.402 in 2 years	0.929 in 1 year 0.895 in 2 years
<b>DALY weight</b>	schizophrenia 0.689 bipolar 0.480		severe (GHQ $\geq$ 8) 0.655 moderate (GHQ $<$ 8) 0.406		severe ((GHQ $\geq$ 8) 0.657 moderate (GHQ $<$ 8) 0.319	
<b>Source</b>	Institute of Health Metrics and Evaluation 2010					
<b>Mortality rate</b>	0.02 at 10 months 0.05 at 20 months	0.058 per year	0.04 at 10 months	0.033 per year	0.00 at 10 months 0.02 at 20 months	0.059 per year
<b>Source</b>	Impact Study	Teferra 2011 & Global Health Observatory 2011	Impact Study	Cujpers 2013 & Global Health Observatory 2011	Impact Study	Ngugi 2014 & Global Health Observatory 2011

## 4.2 - e) *Measurement Issues around Costs*

### 4.2.e.i Government costs

The principal government inputs into the MHD Model in this setting were clinical health care in the form of inpatient and outpatient care. Government costs were valued using the WHO CHOICE unit cost estimates for a public outpatient health visit in rural Kenya and for a public hospital bed day (World Health Organization 2011). The cost of a single outpatient visit was valued at Ksh 84 (Int\$ 2.42), which includes all costs (building, staff, operation costs) except medicines and diagnostics. There are typically no diagnostics associated with outpatient mental health visits in this setting, and medicine costs were entirely born by users, as measured by the EST. The EST questionnaire assessed the use of outpatient mental health services, but not of outpatient health care overall. Outpatient mental health services were only available at follow-up, so no costs are associated with the control. The cost of a single inpatient bed day was valued at Ksh 375 (Int\$ 10.7), covering the “hotel” costs, ie personnel, capital and food (World Health Organization 2011).

### 4.2.e.ii NGO Costs

NGO costs (table 4-6) were calculated top-down for the first year of the study from the expenditure records filed with the two donors funding the MHD model in these districts, using the costing methodology set out by Creese and Parker for the World Health Organization (Creese and Parker 1994). Donor financial reports had to be aligned to the research calendar and converted into the same currencies. The Impact Study research year started on July 31<sup>st</sup> 2009; whereas the DFID project reported on the UK fiscal year, starting April 6, and the EC project reported on the calendar year. In addition, EC expenditures were reported in Kenyan shillings, while DFID expenditures were reported in pounds sterling. I requested the monthly exchange rates that had been used for the DFID conversions and averaged them per twelve month period of study. The exchange rate used was 118.42 and 124.46 per GBP in the first and second year. All cost calculations were done in Kenyan Shillings and converted after analysis into international dollars. All costs were calculated using 2011 currency values. Inflation from December 2009 (midpoint of the first year of study) to December 2011 was 18.93%, and from December 2010 (second year) to 2011 it was 14.42% (Kenya National Bureau of Statistics 2012).

It was not possible to derive unit costs from the NGO expenditure sheets. Spending was reported in some instances by activity and in some instances by output, but never by

quantity. So, for example “training of teachers for promotion of school mental health” was listed as an item on the EC expenditure, but it did not report on the number of trainings nor in which districts, nor was it possible to determine post-hoc from records.

The most accurate way of calculating costs per person from grant expenditures was first to distribute them by district and then to divide them by the number of people seen in that district. This is because participants were tracked by location rather than by grant, since some locations were covered by several grants. So it was not possible to divide the total EC expenses, for example, by the number of participants in the EC project. The EC project operated in four districts of roughly equal size, only one of them (Nyeri) in the research area, so EC expenses were divided by four. The DFID project operated in seven districts, including the two study sites, so DFID expenses were multiplied by 2/7. Not all BasicNeeds participants within the districts of Nyeri North and Meru South participated in the study. A total of 429 individuals with mental disorders participated in the MHD in Nyeri North and Meru South during the first research year, so I further divided the combined EC and DFID expenses for the two districts by 429 to derive a mean cost per person.

There were no hidden costs from volunteer work or use of donated items. In keeping with local rhetoric, the NGO called community workers “volunteers,” but they were in fact paid a per diem, which corresponds with a market value for their time, so no additional costs were associated with them.

Table 4-6: Measurement of provider costs

Unit	Quantity
<b>NGO Capital Costs</b>	
car	1
motorbike	1
computer	3
desk & chair	3
mobile phone	3
camera	2
<b>NGO Start-up Costs</b>	
Staff recruitment	5 BasicNeeds staff & 2 partner staff
Signing partnership agreements	4 MOUs
<b>NGO Recurring Costs</b>	
<i>Personnel:</i>	
- BasicNeeds Programme Manager	1 person full-time
- BasicNeeds Accountant	1 person full-time

- BasicNeeds Administrator	1 person full-time
- BasicNeeds Community Animator	1 person full-time
- BasicNeeds Research Officer	1 person half-time
- Maendeleo & Caritas Coordinators	2 people full-time
- Health workers	3 people, per diem
- Community workers	77 people, per diem
Supplies	stationary and printing
Building operation & maintenance	1 office in Nairobi Westlands
Vehicle operation & maintenance	1 car & 1 motorbike
<i>Trainings:</i>	
- For health workers	1 five-day workshop, Kenya Medical Training Ctr
- For SHGs	7 trainings offered to 32 groups in clusters
- For partner staff	1 at start-up
<i>Social mobilization:</i>	
- Community consultation meetings	1 per village at start-up
- Operating Mental Health Action Groups	1 group per district, quarterly
- Meetings with District Health Coordinators	N/A
- Advocacy with local media	N/A
<i>Monitoring &amp; evaluation:</i>	
- External programme evaluations	2
- Participatory data analysis	Quarterly in each district
- Partner review meetings	Quarterly with each partner
UK support costs	N/A
<b>Government Costs</b>	
Inpatient bed days	variable
Outpatient clinic visits	1/month

N.B. The source of all NGO costs was grant expenditure sheets, and the source of government costs was WHO CHOICE 2011.

Capital costs and were amortized over their useful life to determine their present value (in 2011), employing a linear discounting method, described by Damian Walker (Walker and Kumaranayake 2002, p. 60). The equation for amortization was:

$$A = P * \frac{r(1+r)^n}{1+r^n-1}$$

With A = cost per year

P = initial investment (principal)

r = interest rate

n = number of years

Start-up costs were similarly amortized. The capital goods purchased for or used by the project were: a used 4x4 car; a new motorbike; a laptop; a desktop computer; a printer; a desk; a chair; a camera and three mobile phones. December 2011 replacement values were located

for capital costs from website retailers and by phoning dealerships. The useful life of capital goods in the Kenyan context was deemed by the accountant at BasicNeeds Kenya to be considerably higher than in a standard European context. Whereas the conventional useful life of a computer and car are deemed 3 and 5 years respectively, he valued them at twice that rate – 6 and 10 years respectively, which is in keeping with other African analyses (Sinanovic et al. 2003). Mobile phones were estimated to have 3 years, desk chairs 10 years, and cameras 5 years of useful life. The Central Bank Rate of Kenya in December 2011 was 0.07 (Central Bank of Kenya 2011), which is about twice the conventional discount rate of 3% used in economic analyses (Sinanovic and Kumaranayake 2006), but less than the 8% rate that was recommended in South Africa in the 1990s (Sinanovic et al. 2003).

#### 4.2.e.iii User Costs

User costs (table 4-7) were calculated from patient-level data collected in the BasicNeeds Impact Study, using the Economic Status Tool (EST, appendix 13). The EST is a 19-item multiple-choice and short-answer questionnaire, which is interview administered, with the aim of assessing health service use and costs to the service user and household. Mean values were adjusted to a one year time-frame. Data were managed using SPSS 19.

Cost data were cleaned by looking for outliers, by clarifying the terms of the questions asked, and by determining hidden costs where questions were not asked. In one instance, the costs recorded for medicines during hospitalization proved very high; but it was revealed that additional treatment costs, such as labs and scans, were included in the response, because they were not asked about elsewhere. I recoded the scans under hospital fees. User fees associated with mental health clinics were not recorded, but were added to the data post-hoc.

The EST questionnaire asks about a range of time-frames, from one week to nine months. To calculate annual costs, I assumed a linear trend, for example multiplying 9 month costs by 4/3 to derive 12 month costs. This assumption is unlikely to be accurate on the level of the individual; but it may hold true on the aggregate level and is in keeping with costing conventions. When reporting descriptive results, the original time frame was preserved, and means were given only for those who responded positively to the question.

Table 4-7: Measurement and valuation of user costs

<b>Direct costs</b>	<b>Source</b>	<b>Unit</b>	<b>Value (Ksh)</b>
Hospital	EST* 9f, 9g, 9j	Hospital bed fee Doctor's consultation fee Travel cost	variable

Medicines	EST 9i/18g	Monthly expenditure on psychiatric medicines	variable
Healer	EST 10d, 10f, 10g	Healer fee Travel cost per session Number of sessions in 9 months	variable
Outpatient clinic visit	Research Assistant	Travel cost User fees	50 first visit 20 follow-up
<b>Indirect costs</b>			
Change in patient productivity	Kenya Ministry of Labour 2011	One month minimum wage of unskilled agricultural worker	3,765
Patient days out of role	EST 8e, 9d, 9h	One day out of role	162
Carer days out of role	EST 12e, 13b	One day out of role	162

\* EST = Economic Status Tool

#### Direct costs

Direct, or out-of-pocket user fees included: 1) hospitalization; 2) outpatient treatment; 3) medicines; and 4) traditional healing. The assumption was made that doctor's fees for hospitalization were one-off rather than daily recurring, based on information provided by my research assistant. Transportation costs were included in each of the treatments and were doubled where the question asked about the cost getting to the clinic, to account for round-trip. Money spent travelling to the hospital (EST 9f) was assumed to be round-trip and include the cost of travel of a carer. Economic evaluations in high-income countries often use running costs published by the Automobile Association to calculate the economic cost of vehicle travel, which includes wear and tear and servicing (Association 2013). In our study, travel by vehicle was rare. It was assumed on the basis of their income levels that those travelling by vehicle for treatment were using collective transportation and that none of the participants owned their own vehicle. Since collective transportation is a private for-profit service in Kenya, I used the price of travel as a proxy for the economic cost.

Estimating the yearly cost of medicines was somewhat complex. Since baseline interviews were conducted from the clinic, just after the participant had enrolled in treatment, all participants were on medicines at baseline. The recorded data therefore did not reflect a treatment-as-usual control. I assumed that only participants who had been hospitalized in the months prior to baseline were on medicines at baseline.

#### Indirect costs

Indirect costs for participants were calculated by aggregating time spent in hospital and in transportation to treatment. These were offset against the productivity gains resulting from return to work. Indirect costs for carers included days of work lost (EST 13) and hours spent care-giving (EST 12) within a normal day. Days of hospitalization were not counted as a loss to carers, since patients with mental disorders in Kenya do not require accompaniment by a carer, as is the case in some resource-poor settings. Nonetheless, the local researchers leading this study confirmed that it is customary for a carer to visit a patient once to twice a week in a district hospital and once a month in Mathare national hospital. Additional hidden costs to carers include making and bringing food, since hospital food is often insufficient. As data were not collected on these hidden costs to carers, I did not capture food costs and assumed weekly visits to district hospitals and monthly visits to Mathare, which I costed for travel expense and a day of lost productivity.

A key methodological question is how to value carer and participant productivity in a largely non-wage economy. I chose to apply a flat rate, based on the current minimum wage rate, which is a variant of the human capital approach (Su, Sanon, and Flessa 2007), also referred to as an opportunity cost approach (Faria, Weatherly, and van den Berg 2012). Change in productivity among participants was determined from change in occupational status, and I valued paid and unpaid work equally. Examples of unpaid work include household work and subsistence farming. Two reasons for valuing unpaid work on par with paid work are: 1) that most activity in this poor, agricultural setting is unpaid subsistence work; and 2) this approach ensures gender equality, since more women in the sample worked in unpaid activities than men, especially in household work.

The flat rate I chose for valuing carer and participant time is the monthly minimum wage of the lowest paid unskilled agricultural worker in Kenya. This flat wage rate was more appropriate than the patient-level data, because the sample of participants earning income was very small with a wide variance, and therefore potentially less accurate. I consulted with a health economist at UCT (Edina Sinanovic) to confirm the appropriateness of this method. The lowest agricultural wage in 2011, according to the Kenyan Ministry of Labour was valued at Int\$ 98.0 (3,765 Ksh) per month (Kenya Ministry of Labour 2011), which amounts to a daily wage of Int\$ 4.2 (162 Ksh), based on 23.3 work days per month. The following assumptions were made in calculating monthly income: a) a year was coded as 280 work days, equal to 52 weeks of 6 days, minus 21 days annual leave and 11 public holidays, as per Kenya's labour law (ILO 2011); b) a month was coded as 23.3 work days, which equals the official

work year divided by 12; c) a season was considered four months, based on the usual farming seasons in Kenya: February-May; June-September; October – February.

Change in productivity among MHD participants was measured using EST question 7. As there were no data on changes in productivity for a treatment as usual control, I held productivity constant at baseline levels for the control group. Those who moved from unemployment (codes 1 or 2) to full-time house work, unpaid work, or paid work (codes 4, 5, 6) were valued at the minimum wage described above (Int\$ 98.0/ 3,765 Ksh per month). Part-time work, be it paid employment or household work (codes 3 and 7) was arbitrarily assumed to be 50% (the midpoint) of annual minimum wage. Thus, those moving from unemployment into full-time productivity were valued at 45,180 Ksh (the full annual wage rate) while those moving from unemployment to part-time, or from part-time to full-time productivity were valued at 22,590 Ksh. Students were valued as unemployed. Productivity loss from change in occupational status was calculated in the same manner as productivity gain. For the 20 cases lost to follow-up in year two, I used data from 10 month follow-up. Change in productivity was annualized to one and two years using the following equation with “days” referring to days until follow-up at time T:

$$\Delta prod_{365} = \Delta prod_{T1\_T2} + \Delta prod_{T2\_T3} \times \frac{(365 - days_{T2})}{days_{T2\_T3}}$$

$$\Delta prod_{730} = \Delta prod_{T1\_T3} \times \frac{730}{days_{T3}}$$

Kenya’s most recent data on employment and wages comes from the Kenya Integrated Household Budget Survey (KIHBS) of 2005/06. An analysis of that data (Pollin, wa Githinji, and Heintz 2008) asserts that in the formal sector (where the most complete data was available), close to half of the working population earned beneath the statutory minimum wage. The minimum wage may, therefore, be an exaggeration of the actual average monthly income in the agricultural sector in the Central region.

### 4.3 Results: Description of the MHD in Practice

#### 4.3 - a) Partners

The main implementing partners of the MHD model in Nyeri and Meru were, respectively, the Catholic NGO Caritas and the local chapter of a national women’s organization, *Maendeleo ya Wanawako*, together with district departments of the Ministry of Health (figure 4-4). In



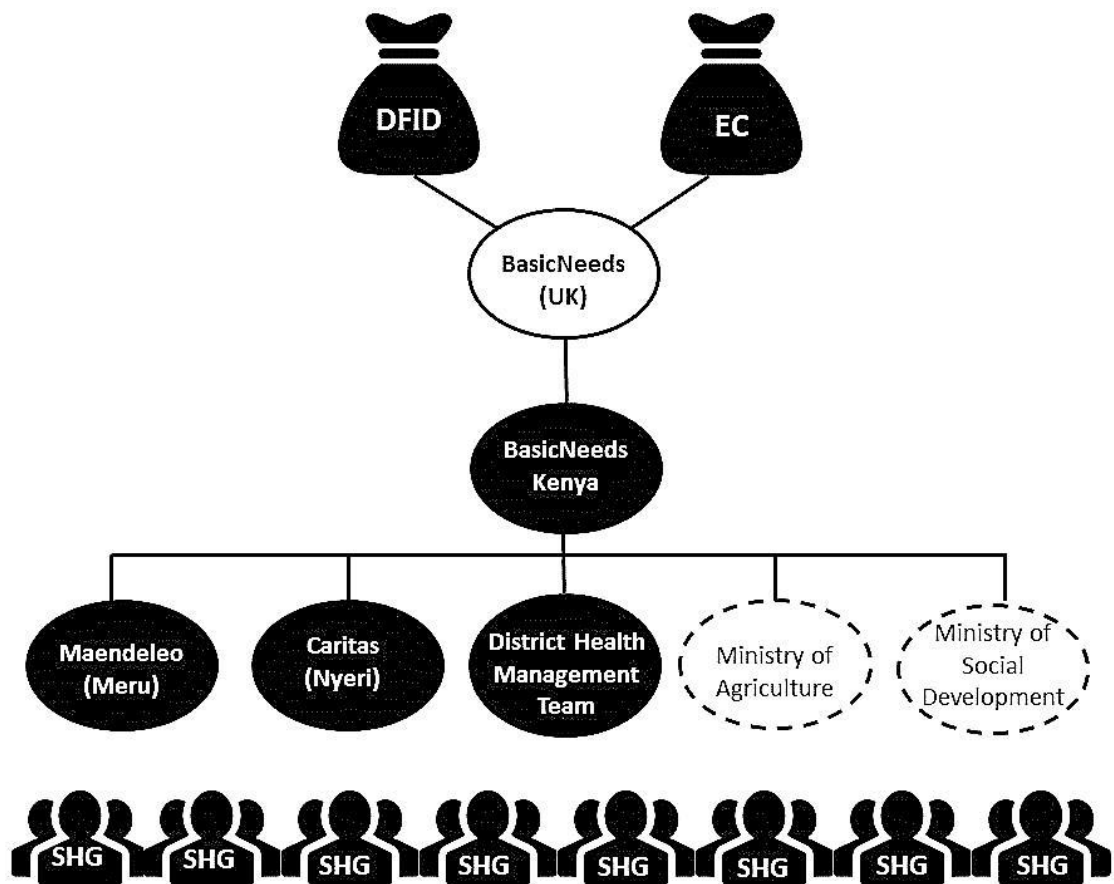
addition, BasicNeeds engaged several resource partners, which are organizations providing services or skills in support of the MHD model, but are not accountable for the model's delivery. The resource partners in these two counties were the Ministry of Gender, Children and Social Development, who registered self-help groups, and the Ministry of Agriculture, who provided livelihood training to the groups.

*Maendeleo ya Wanawake* (Women's Development) is a volunteer-based community organization. BasicNeeds hired one person full-time to implement the MHD model, but prior to that the organization functioned without any revenue. The specialty of *Maendeleo* is to oversee self-help groups of women, and it has 400 such groups within its network in Meru. For the purpose of the MHD model, *Maendeleo* employed 25 part-time community workers: 16 women and 10 men, reimbursed at a rate of Int\$ 7.1 (Ksh 200) per activity. Each community worker devoted an estimated 5 full days a month on the intervention.

Caritas is the department of social development within the Secretariat of the Catholic diocese of Nyeri. Each of the 45 Catholic diocese in Kenya has an independently financed and operated Caritas, and their directors meet annually to coordinate policy and practice. The Catholic diocese do not cover the same administrative boundaries as the Kenyan government, so Caritas Nyeri covers the counties of Nyeri and parts of Laikipia. Other departments of the Catholic Secretariat include education, youth, law and spirituality. Caritas Nyeri was founded in 1993 and currently runs 8 programmes: 1) mental health (since the partnering with BasicNeeds in 2007); 2) agriculture; 3) water and sanitation; 4) health (focusing on home-based care for people with HIV and care for orphans and vulnerable children); 5) drought and famine relief; 6) governance; 7) peace-building; and 8) faith and empowerment (including training youth leaders). Each programme has an independent coordinator and staff, so BasicNeeds employed one full-time person at Caritas to lead the MHD model's implementation in Nyeri. In addition, Caritas employed 52 of their 253 community workers on the MHD model. Community workers at Caritas were paid Int\$ 10.8 (Ksh 300) per activity to work on mental health.

The Ministry of Health supported the MHD model in Nyeri and Meru through the District Health Management Team by providing the services of psychiatric nurses and the venue of their health facilities free of charge. In exchange, BasicNeeds coordinated the clinics, ensured there were patients and medicines, and paid a per diem for the nurses' time.

Figure 4-5: Organigram of BasicNeeds in Nyeri and Meru



Legend: dotted ovals refer to resource partners, while solid black refers to implementing agencies.

#### 4.3 - b) Activities

The activities involved in the MHD model often cross-over between different modules, so I will present them by activity rather than by module.

*Consultation meetings* – These were meetings held for all community members to discuss mental health symptoms and to sensitize the public to mental illness. Community members, including people with mental disorders, discussed the experience of living with a mental disorder and facts about mental illness, prompted by the following questions, which are standard throughout all MHD programmes: 1. What is my/their life like? 2. What are my/their needs? 3. What can I do to meet my/their needs?

*Outpatient mental health clinics* – Prior to the arrival of BasicNeeds, the only public outpatient mental health services in the area were found at Nyeri Provincial General Hospital and Nanyuki District Hospital. In Meru, the MHD model put into operation five outpatient mental health clinics: one open daily at Chuka District Hospital, and four outreach clinics

open once a month in Mukuni, Kajuki, Kaanwa and Mpukoni health centers or dispensaries – the lowest level public health facilities. In Nyeri, seven outpatient clinics were put into operation: in the towns of Endarasha, Naromoru, Gakawa, Mugunda, Karemno, Bellevue and Warazo. Nurses drove to the clinics by motorbike at considerable personal risk: indeed one psychiatric nurse lost a finger in an accident driving to one of the outreach clinics. Public health clinics in Kenya are not free of charge, so users paid Int\$ 0.5 (Ksh 20) per visit and Int\$ 1.3 (Ksh 5) on their first visit in keeping with general practice.

*Home visits* – Home visits were made by community workers once a month in Nyeri and once a quarter in Meru. The purpose of home visits was to: a) check up on treatment adherence and medication side-effects; b) assess relationship dynamics within the family; c) discuss particular needs; and d) collect programme data. Patients with particular needs, for example a physical illness or experiencing particular distress, received additional visits, as needed. Research from India found that home-visits by community health workers were reported by service users to be stigmatizing in that context, because they were delivered by someone from outside the village, thereby calling attention to the fact that someone within the home was sick (Chatterjee et al. 2014). In the BasicNeeds, context, however, home-visits were delivered by community workers who lived within the villages they served.

*Self-help group formation and training* – Self-help groups were established with the primary purpose of creating livelihood activities for participants, as well as offering psycho-social support and being vehicles for self-advocacy. Almost everyone in the study participated in a self-help group: the baseline rate of participation in self-help groups was only 7%, while by year one, it had grown to 94% (n=181). *Maendeleo* and Caritas oversaw 32 self-help groups between them (O’Connell, Musomi, and Mwangi 2011). Groups averaged 15-25 people in size (30 maximum), and they met once to twice a month and they contained both users and carers. Many groups had user fees of approximately 50 Ksh per month; however if a member could not pay they were nonetheless welcome to attend.

In the set-up phase, a community worker (in some instance a recovered service user), referred to as a facilitator, supported the group activities, but this person had decreasing levels of involvement over time. Groups registered with the Department of Gender, Children and Social Development at a cost of Int\$ 17.9 (Ksh 500), and several of them set up bank accounts. Twenty of the groups (63%) had received a loan or small grant of approximately Int\$ 200-400 (Ksh 7,500 – 15,000) by the end of the project in 2011 (O’Connell, Musomi, and Mwangi 2011), but there are no data on loan repayments. Examples of livelihood activities

conducted by the groups in Nyeri and Meru include potato farming, soap making, and knitting and selling sweaters.

The two partner organizations offered slightly different training to the self-help groups, depending on local resources and group demand. BasicNeeds and the partner staff collaborated to deliver five core trainings, each lasting 1-2 days, as follows: 1) group formation and management; 2) book-keeping; 3) livelihoods training; 4) advocacy; and, optionally for groups having trouble cohering 5) group dynamics. In addition, the MHD model coordinators arranged for two external trainings: 1) financial skills, a one-day programme delivered by Equity Bank and Financial Knowledge for Africa (figure 4-1); and 2) livelihood skills training from a Ministry of Agriculture extension worker, in particular livestock rearing in Meru and soap-making in Nyeri. Groups received these trainings at different times in their development, according to their need – either expressed or observed. In addition, a support group was created for community workers in both Meru South and Nyeri as a strategy to ensure that they detach from the groups they were facilitating.

*Mental Health Action Groups* – In each county the MHD model led to the creation of a group of community leaders advocating for mental health, called a Mental Health Action Group. These groups had approximately 7-10 members including lawyers, priests, a user and carer, a youth representative and the MHD coordinator from the local partner organization. Groups met quarterly and addressed issues raised by the user and carer, or by the MHD partner. For example, a case was brought up in Nyeri about the rape of a woman with mental disorder; while in Meru the groups responded to problems of shortages in psychiatric medicines at the health centre and petitioned the clinic to waive user fees.

#### **4.4 Results: Analysis of Costs**

##### *4.4 - a) Demographics*

The population at baseline consisted of 203 individuals: 104 from Meru and 99 from Nyeri. Median age at baseline was 35 years (range 18-81) with half the population 25–45 years old (interquartile range 19), and a quarter 18–25 years old. The population was evenly divided by sex (50.2% men). Half (53.7%) were never married. The mean household size was 6 people (range 1-17). Over half the sample (57.2%) were diagnosed with a severe mental disorder, and over a quarter (27.6%) had epilepsy (figure 4-6). Relatively few people (10.3%) had a common mental disorder. Half of participants (53.4%) were educated to less than a primary school level; a third (33.0%) had primary school education; and 20% had secondary education or

above. The education profile of the sample suggests a lower socio-economic status than the regional norm. According to the 2009 Census, only 14.7% of the population of Central province have pre-primary education and two-thirds (65.9%) have primary education (Ambetsa Oparanya 2010). Population demographics are reported by Lund et al in a table (4-8) reproduced here (Lund, Waruguru, et al. 2012).

Figure 4-6: Sample diagnoses at baseline

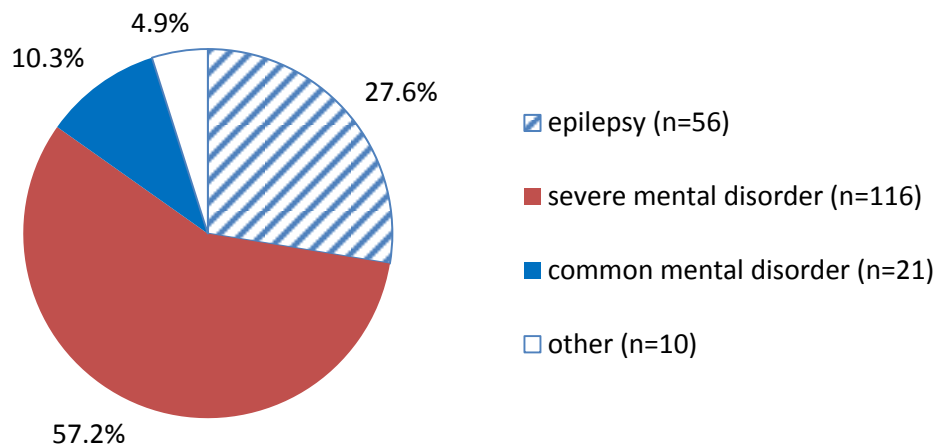


Table 4-8: Population demographics of MHD participants (Reproduced from Lund et al 2012)

Median age	35	
% Male	103	50.7%
<b>Diagnosis</b>		
Epilepsy	56	27.6%
Schizophrenia	67	33.0%
Bipolar	32	15.8%
Depression/anxiety	21	10.3%
Psychosis	17	8.4%
Other	10	4.9%
<b>Education</b>		
Never been to school	12	12.0%
Some primary school	84	41.4%
Completed primary school	67	33.0%
Completed secondary school	28	13.8%
College +	12	5.9%
<b>Marital status</b>		
Unmarried	109	53.7%
Married	69	33.5%

Divorced	13	6.4%
Widowed	13	6.4%
<b>Prior work</b>		
No	125	61.6%
Yes	78	38.4%
<b>Occupational status</b>		
None	111	54.7%
Productive	69	34.0%
Income generating	23	11.3%
<b>Household income source</b>		
Casual labour	62	30.5%
Family farming	130	64.0%
Salaried job	7	3.5%
Business or other	4	2.0%

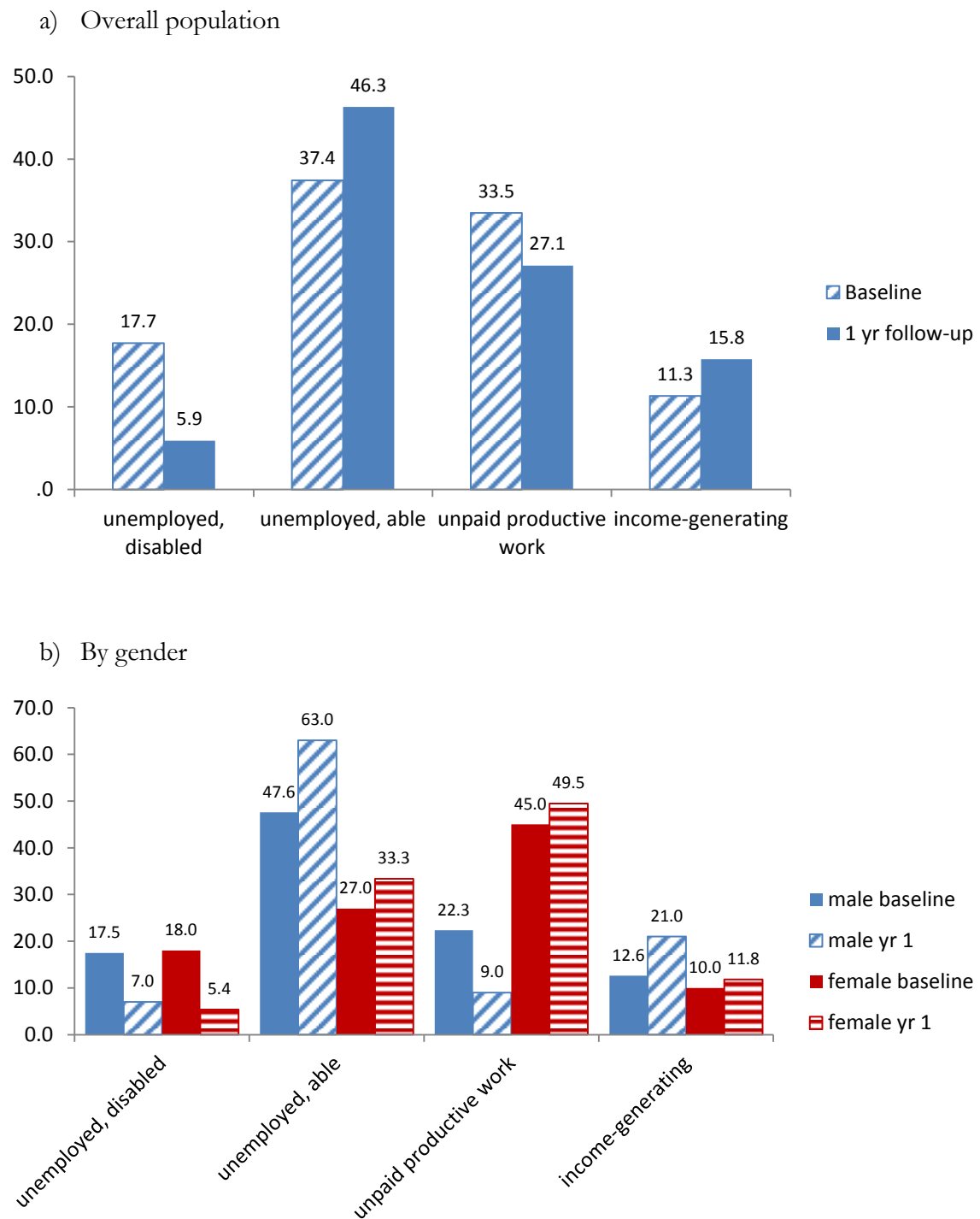
#### 4.4 - b) Change in productivity

*Household* – The main source of household income for two-thirds (64.0%) of participants was farming, and for close to a third (30.5%) casual labour. Household income was understood as cash revenue. Since subsistence farming does not translate into cash, the income level reported per household was very low, at a median of Ksh 700 (Int\$ 18.5) per month (mean Ksh 1,321, Int\$ 35) for an average sample household size of 6 people.

The average inflation rate over the study period, calculated from the monthly consumer price index (inflation =  $CPI_2 \div CPI_{base} * 100$ ), was 3.4% for the first ten months of follow-up and 11.4% over 20 months. After adjusting for inflation, household income remained unchanged over the first ten months of intervention, but it almost doubled between baseline and 20 month follow up: the mean in Ksh at baseline, time 2 and time 3 was 1,321, 1,374 and 2,517 (s.d. = 1,755, 1,387, 2,806,  $t_{175} = 6.4$ ;  $p < 0.001$ ). Nonetheless, the mean income at 20 months translates to Int\$ 59.2, which is far beneath the agricultural minimum wage, and provides little on which to support a 6-person household. This potential intervention-related savings could not be included in the cost-effectiveness analysis, because there is no way to estimate the equivalent savings for the comparison group.

*Participants* – Two thirds of participants had no prior work experience at baseline, and only 11.3% of participants were generating income. After ten months of intervention, 15.8% of the population were earning income (figure 4-7a), a significantly greater amount than at baseline (single sample two-tailed Z-test:  $Z=1.975$ ,  $p=0.049$ ). Those who were unemployed shifted from being disabled (decrease of 11.8% in 10 months) to being able to work (increase of 8.9%). In addition, the number of people in unpaid productive work slightly decreased, while those in earning income increased.

Figure 4-7: Change in occupational status after one year, overall and by gender



The association between occupational outcomes and the intervention appears to have been mediated by gender (figure 4-7b). The occupational status of men and women differed significantly at both baseline and follow-up (chi-square  $p=0.003$  and  $p<0.001$  respectively). Women tended to increase their engagement with unpaid productive work, while men did less unpaid work and generated more income after the intervention.

Few participants generated income (n=22 at baseline, 36 at 10 months), making statistical analysis of that variable challenging. The median income of those earning did not change from baseline to follow-up: it was 2,000 Ksh (Int \$ 52.7) at both times.

*Gains and losses* – In the course of 20 months, half of participants changed their productivity: 34.7% (n=61) experienced a gain and 13.6% (n=24) experienced a loss in productivity. It is possible that there is some measurement error in the estimation of productivity, since there is a subjective element to whether someone is coded as unemployed versus doing household work or working without monetary benefit. However, there is no reason to believe that the measurement error would be biased towards gains or losses in productivity, so it should cancel out on aggregate.

#### 4.4 - c) *Out of pocket expenses*

*Hospitalization* – The number of people hospitalized in the previous nine months dropped from 9 at baseline to 2 at ten-month follow-up. At baseline, the majority (n=5) attended the provincial general hospital; two attended the district hospital; and two attended the national referral hospital. The mean distance travelled to hospital was 99 km at a mean cost of Int\$ 12.3 (Ksh 467) per admission. All but one of those hospitalized were admitted once, and one was admitted twice. The average length of stay per admission was 26 days. Mean hospital fee was Intl \$ 10.1 (Ksh 386) and mean doctor consultation fee was Int \$ 15.2 (Ksh 575).

*Traditional Healing* – At baseline, 7% of the sample (n=15) attended a traditional or faith healer, while at follow up only 1% (n=2) attended a healer. Those ever attending a healer (n=18) was used for analysis of descriptives, so as to increase the sample. More people (60%) attended faith healers than traditional healers (n=11 and 7 respectively). All traditional healers were herbalists, and one practiced a combination of herbs and prayer. Slightly more men than women attended healers (n=10 and 8 respectively), and their age distribution was comparable to that of the rest of the sample. The average number of sessions attended was 1.5 in the previous nine months and did not appear to differ in quantity by type of healer.

One in five of those attending healers did so in Nairobi. None of them were attending hospital in Nairobi, so they may have travelled purposefully to attend a specialist healer. One third of those attending healers (n=5) walked to their appointment, taking 10-30 minutes, while the remainder were transported in a vehicle averaging three hours (127 minutes) one-way. The mean round-trip transportation fee was Int \$ 7.5 (Ksh 282, sd 306).

None of the faith healers charged for their service, neither in cash nor in kind. The herbalists all charged cash on a fee for service basis, though none asked for in-kind payments.



The mean fee per session with a herbalist was Int \$ 14.7 (Ksh 558, sd Ksh 356, range Ksh 60-1,000) – the equivalent of three days of agricultural labour on minimum wage (Ministry of Labour Kenya 2012). Aggregating the consultation fees, transportation and opportunity cost of participant time, the mean cost of seeing a herbalist was Int \$ 24.0 (Ksh 909) per session, or Int \$ 53.3 (Ksh 2,021) per year.

*Community mental health clinic* – No patient paid for community mental health services prior to the BasicNeeds intervention, as none existed outside of the hospital. BasicNeeds coordinated clinics cost Int\$ 1.3 (Ksh 50) for the first visit, which went towards the purchase of a medical record book, and Int\$ 0.5 (Ksh 20) on all subsequent visits, in accordance with standard public health fees in Kenya. Additional costs were associated with travel and time. The mean fee spent on travel to the community clinic per month was Int\$ 1 (Ksh 37) and the mean amount of time was 40 minutes (0.67 hours).

*Sale or loan of property* – At baseline one in five participants (n=40, 19.7%) reported having had to sell property or take out a loan in the previous nine months to cover treatment costs. At ten-month follow-up, the proportion of those needing loans or a sale dropped four fold to one in twenty (n=10, 5.2%). Moreover, the mean cost of the sale or loan dropped from Int \$ 183.2 (Ksh 6,942) to Int \$ 40.6 (Ksh 1,539). The largest reported sale or loan to cover treatment was Int \$ 633.2 (Ksh 24,000) at baseline.

#### 4.4 - d) *Unpaid care*

At baseline, just over a third (36.9%) of users reported receiving help from a carer, while after 10 months of intervention only 8% received help from a carer. In addition, among those offering care, the mean time per week spent caring dropped from 14.7 hours at baseline to 7.5 hours at 10 months.

Out of concern that user self-report might not accurately reflect care-giver burden, in July 2012, three years after baseline, I collected additional data from 25 users and 25 carers with the help of the same research assistant who had overseen the original data collection. Users and carers were questioned independently of one another about whether they had received or given “help in performing any activity” (EST question 12a). There was perfect agreement between users and carers in terms of which users received help (n=12 or 42.9%), although users slightly under-estimated the number of hours of help they received relative to carers: the mean reported by users was 15.9 hours, whereas by carers it was 17.0 hours per week. For the purpose of costing, I preserved the original data unchanged.

Table 4-9: Costs before and after the MHD Model, all diagnoses

	Before					After 1 Year					After 2 Years							
	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)
<b>NGO Costs</b>	1	0	0	0	0	0	1	22,941	22,941	22,941	0	540	1	23,708	23,708	23,708	0	558
Capital	1	0	0	0	0	0	1	200	200	200	0	5	1	200	200	200	0	5
Start-up	1	0	0	0	0	0	1	587	587	587	0	14	1	587	587	587	0	14
Personnel	1	0	0	0	0	0	1	10,659	10,659	10,659	0	251	1	11,277	11,277	11,277	0	265
Supplies	1	0	0	0	0	0	1	884	884	884	0	21	1	767	767	767	0	18
Building & vehicle operation	1	0	0	0	0	0	1	2,078	2,078	2,078	0	49	1	2,441	2,441	2,441	0	57
Training	1	0	0	0	0	0	1	999	999	999	0	24	1	1,063	1,063	1,063	0	25
Social mobilization	1	0	0	0	0	0	1	1,060	1,060	1,060	0	25	1	1,003	1,003	1,003	0	24
Clinic operation	1	0	0	0	0	0	1	878	878	878	0	21	1	883	883	883	0	21
Monitoring and evaluation	1	0	0	0	0	0	1	764	764	764	0	18	1	1,552	1,552	1,552	0	37
Sub-grants to partners & SHGS	1	0	0	0	0	0	1	4,831	4,831	4,831	0	114	1	3,935	3,935	3,935	0	93
<b>Government Costs</b>	203	0	45,000	550	3,683	13	193	1,010	10,010	1,071	674	25	173	2,021	58,271	2,565	4,839	61
Inpatient bed days	203	0	45,000	550	3,683	13	193	0	9,000	60	674	1	173	0	56,250	544	4,839	13
Outpatient clinic visits	203	0	0	0	0	0	193	1,010	1,010	1,010	0	24	173	2,021	2,021	2,021	0	48
<b>Direct user:</b>	203	0	95,382	2,019	10,528	48	193	549	52,593	1,445	3,824	34	173	924	105,417	2,412	9,012	57
medicines	203	0	42,815	1,035	5,934	24	193	0	8,135	624	827	15	203	0	15,961	1,224	1,623	29
traditional healing	203	0	10,466	171	959	4	193	0	0	0	0	0	193	0	0	0	0	0
outpatient clinic	203	0	0	0	0	0	193	549	549	549	0	13	193	1,078	1,078	1,078	0	25
hospital	203	0	52,567	814	5,274	19	193	0	49,475	270	3,565	6	173	0	118,966	1,062	10,179	25
<b>Indirect user:</b>	203	0	77,112	7,532	12,766	177	193	-58,271	52,021	215	22,027	5	172	-64,924	62,229	-12,492	35,671	-294
change in productivity	203	0	0	0	0	0	193	-58,271	52,021	-410	21,766	-10	173	-69,581	62,229	-13,676	34,813	-322
time sick	203	0	43,416	1,355	5,462	32	193	0	50,544	432	4,085	10	173	0	50,544	1,005	6,259	24
informal care	203	0	52,650	6,177	10,506	145	193	0	8,424	190	1,155	4	173	0	676	7	68	0
<b>Total user</b>	203	0	119,341	9,551	19,065	225	193	-57,008	53,855	1,664	21,999	39	172	-62,458	96,017	-10,072	36,394	-237
<b>Total cost</b>	203	0	133,216	10,102	21,286	238	193	-33,057	77,806	25,676	22,021	604	172	-13,788	200,937	39,145	37,853	922

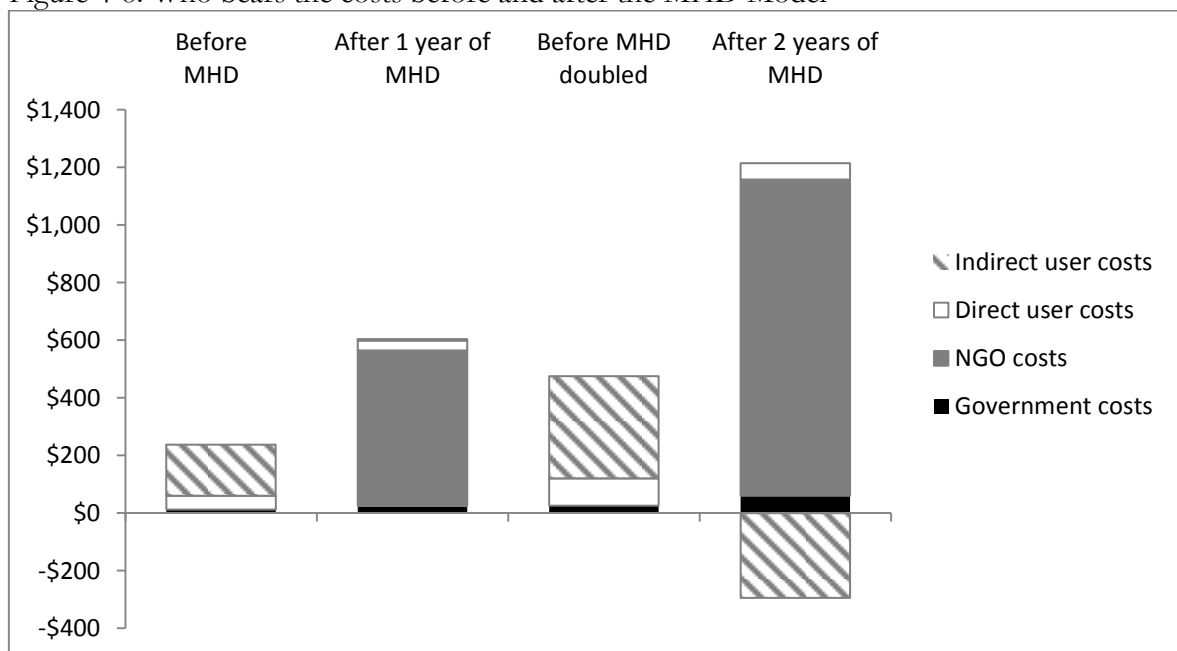
#### 4.4 - e) Total costs

Total costs of the MHD Model in the first year were higher than the treatment-as-usual costs recorded at baseline. From the societal perspective, the intervention cost Int\$ 604 per person in the first year versus Int\$ 238 for no intervention (as measured by baseline costs). At two years, the intervention cost Int\$ 922, while the comparison is estimated to have cost Int\$ 476 per person (table 4-9). The relatively lower cost of MHD in the second year was largely the result of the savings from a return to productive work among those in the MHD Model.

Not only did total costs change, but so too did their components, in other words who bore the costs (figure 4-8). Before the intervention, 94% of costs were born by the service user, whereas after two years of the MHD Model, the average user made savings of Int\$ 237. The majority (85% in the first year) of intervention costs were born by the NGO. Government costs doubled over the course of the intervention, as increasing numbers of people accessed care in the community; however they remained modest throughout, amounting to only 6% of total costs before and in the first year after the intervention.

The cost profile changed considerably by diagnosis (appendix 15). Severe mental disorders were associated with the lowest total costs before the MHD intervention amounting to Int\$ 250 versus Int\$388 for common mental disorders, primarily because people with common mental disorders received twice as much informal care as those with SMD (Int\$251 per year per person with CMD versus Int\$ 101 per person with epilepsy)

Figure 4-8: Who bears the costs before and after the MHD Model



After two years of intervention, epilepsy was the most costly illness at Int\$ 995, as compared with Int\$ 876 for SMD. This is largely because the savings from a return to productive work proved more modest for people with epilepsy than for those with severe mental disorders (Int\$ 208 versus Int\$ 398).

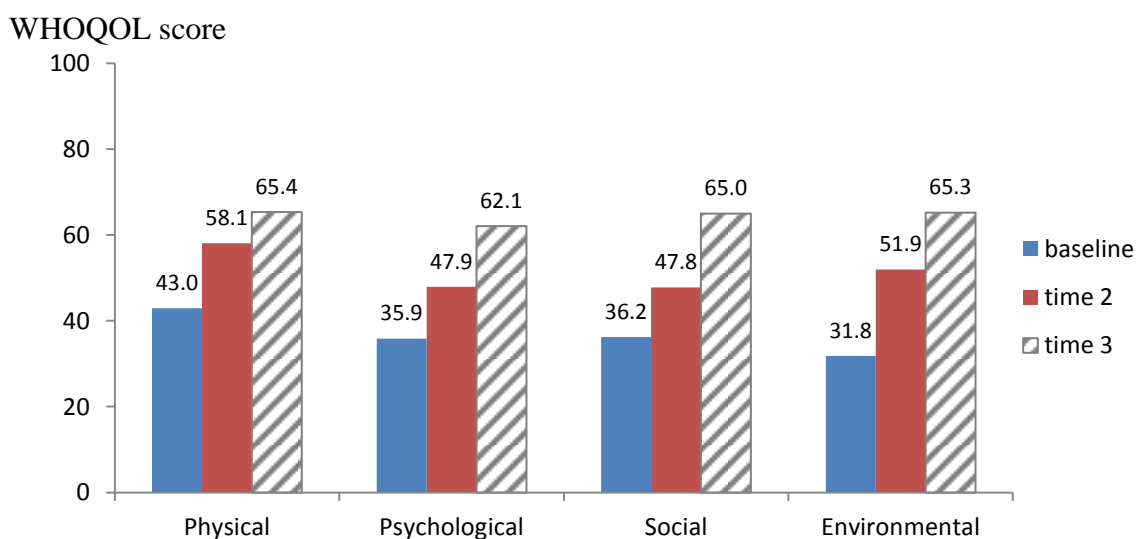
#### 4.5 Results: Analysis of Outcomes

A preliminary analysis of outcomes has been published for this data (Lund, Waruguru, et al. 2012), but this section expands on the published findings. The only repetition is the presentation of the population demographic profile. Outcomes are analysed in the following ways: 1) by change in absolute score on the GHQ and the WHOQOL; 2) by converting the GHQ score into an estimate of healthy days; and 3) by converting healthy days into DALYs averted.

##### 4.5 - a) Change in WHOQOL Scores

The distribution of WHOQOL domain scores at baseline (appendix 19) appeared normal for physical, social and environmental domains, but were skewed toward the sick in the psychological domain, as might be expected in a population with mental disorders. WHOQOL domain scores showed a linear trend in improvement from baseline to twenty month follow-up (figure 4-9). Baseline scores were lowest for the environmental (mean 31.8) and highest for physical domains (mean 43.0).

Figure 4-9: Mean WHOQOL domain scores over time, whole sample



The average change across WHOQOL domains (appendix 20) was an increase of 15% in 10 months and 28% in twenty months. The greatest change appears to have been in the environmental domain, which improved 20% in the first follow-up period and 34% in twenty months. The other domains performed comparably to one another, although the social domain appears to have improved more in the second year than in the first, jumping from an 11% increase in the first year to a 29% increase in the second year. The difference in improvement between the environmental and all other domains was significant in both the first year and over two years, using one-way ANOVAs and the Tukey post-hoc test ( $F_{3,748} = 12.29$   $p < 0.001$ ;  $F_{3,688} = 13.10$   $p < 0.001$ ). The change in domain scores were comparable across diagnoses (figure 4-10) with the exception of common mental disorders, which saw a greater increase in the social domain and less in the environmental domain.

The change in total raw WHOQOL score (appendix 20) was 17 points out of 130 (13%) in the first ten months and 28 points out of 130 (21.5%) over twenty months. The change appears relatively constant across diagnoses, but those with epilepsy appear to have benefitted more in the second year, as compared to those with other diagnoses: they had the smallest change in the first ten months (13 points) and the largest change by twenty month follow-up (30 points).

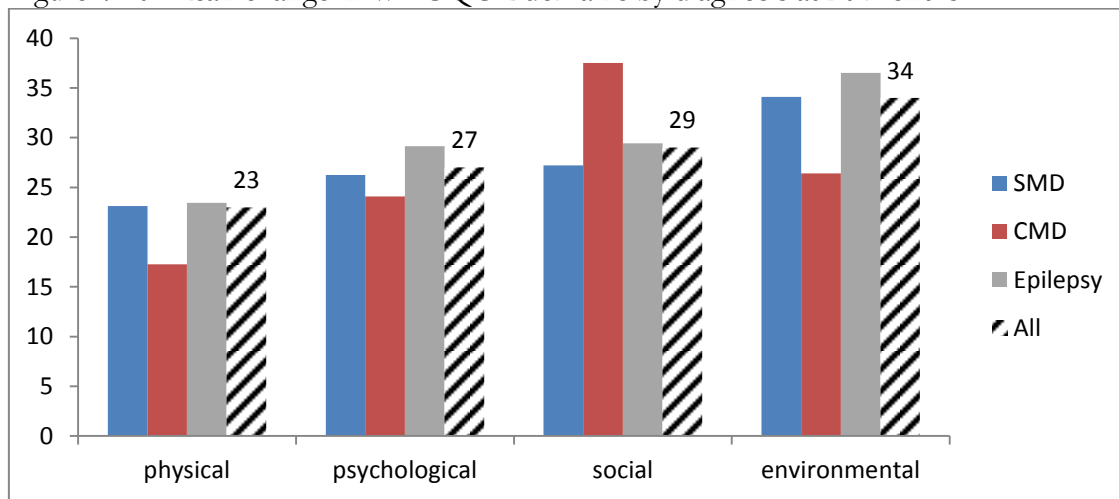
#### *4.5 - b) Change in GHQ-12 Scores*

Mean GHQ score decreased from 8.6 to 5.7 and finally 1.5 at baseline, ten months and twenty months. The distribution was heavily skewed to the right (sickness) at baseline and skewed to the left (health) at twenty months (figure 4-11), but developed a slight u-shape at ten months (appendix 16), indicating that some people were getting well, while others remained sick. The mean change in GHQ-12 score from baseline to ten months (appendix 16) was a decrease of 2.9 points (24.0% of the 12 point GHQ score) whereas from baseline to 20 months it decreased 7.0 points (s.d 3.0) (58% of the GHQ) (figure 4-11).

Despite the majority positive outcomes, the GHQ scores of 12.8% of participants (n=26) got worse between baseline and the first follow-up. The mean increase in score for those whose health got worse was 3.1 (s.d. 2.0), and one third of them (n=8) increased by only one point. In year two, the proportion of people whose scores worsened diminished to only 3.4% (n=7). The counts were too small to analyse statistically, however it appears there was no apparent correlation between diagnosis and worsening scores (50% SMD, 15% CMD and 35% epilepsy).

Comparing across diagnoses (appendix 18), there was no statistical difference in GHQ scores at baseline between those with serious mental disorders, common mental disorders or epilepsy (one-way ANOVA,  $F_{2,23} = 2.058$   $p = 0.15$ ). There was also no significant difference in the change in GHQ scores by diagnosis in the first ten months, nor over twenty months (one-way ANOVA,  $F_{2,23} = 0.325$   $p = 0.72$  and  $F_{2,20} = 1.464$   $p = 0.26$ ). Nonetheless, I have reported on outcomes by diagnosis, as the conditions described are clinically and biologically different and therefore do not warrant conflating.

Figure 4-10: Mean change in WHOQOL domains by diagnosis at 20 months



#### 4.5 - c) Correlation between WHOQOL and GHQ-12

There was considerable correlation between the WHOQOL and GHQ-12 scores at times 2 and 3, but less so at baseline. The raw WHOQOL total had a Pearson's correlation of  $-0.669$  at time 2 and  $-0.606$  at time 3. Correlation was also strong by domain at times 2 and 3, with the strongest correlations being with the environmental domain at time 2 ( $r = -0.663$ ) and with the physical domain at time 3 ( $r = -0.690$ ). The social domain showed higher levels of correlation at baseline ( $r = -0.426$ ) than other domains, but lower correlation at time 3 ( $r = -0.356$ ). These high levels of correlation support the validity of the GHQ as a measure of quality of life, or wellbeing in this population. On that basis, the subsequent analysis relies on the GHQ to estimate healthy days and DALYs averted.

#### 4.5 - d) Healthy days

The health outcomes showed a positive, linear trend over the two years of study. After 10 months of intervention, a third (34.0%) of participants were healthy, while after twenty

months three quarters (75.8%) of all participants were healthy, using the GHQ-12 cut-off of 3. Healthy day outcomes appear to have been better on average for those with severe mental disorders or epilepsy than for those with common mental disorders ( $t_{164} = 1.85$   $p=0.066$ ). The difference in outcomes was not statistically significant at the alpha = 5% level, but it was significant at the alpha = 10% level ( $t_{182} = 1.62$   $p=0.10$  at ten months and  $t_{160} = 1.65$   $p=0.10$  at twenty months). No significant difference was found between outcomes of those with epilepsy and those with severe mental disorders.

The annualized average number of healthy days gained in the first year of the MHD intervention was 50, but the benefits appear to have increased dramatically in the second year, bringing the two year average to 455 healthy days across all diagnoses (figure 4-13). The stark contrast between year one and two year outcomes (figure 4-12 b and c) is partly attributable to the method for measuring healthy days. Since a healthy day is determined by a threshold value (in this case 3), any improvements made above that threshold are not observed by this measure. Returning to the raw data of change in GHQ score, we observe that the increase in benefits in the second year were considerably less marked than they appear with the healthy day measure. The mean increase was 4.1 points in the second ten months, as compared to 2.9 in the first ten months – using the projected data, this amounts to 3.9 points in the first year versus 4.5 in the the second year. It is also important to note the wide standard deviation of 202 days around the two-year intervention outcomes.

Figure 4-11: Mean change in GHQ score, whole sample, from baseline to 20 months

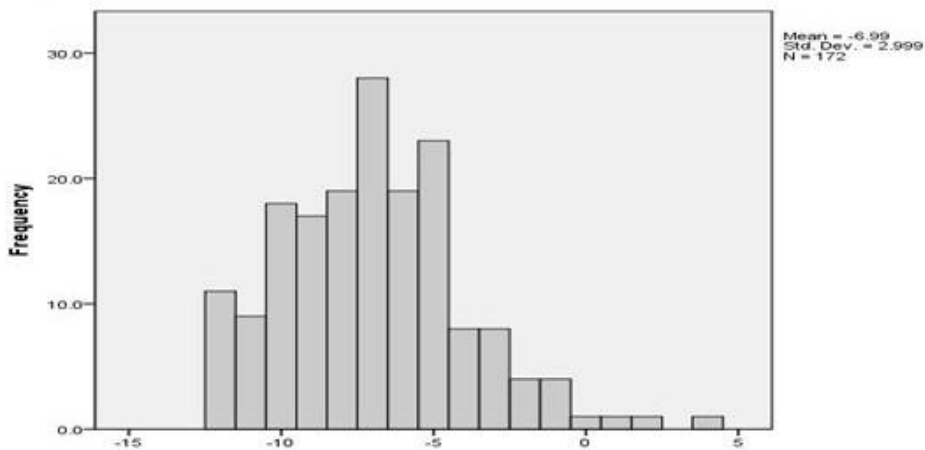


Figure 4-12: GHQ-12 distribution, whole sample

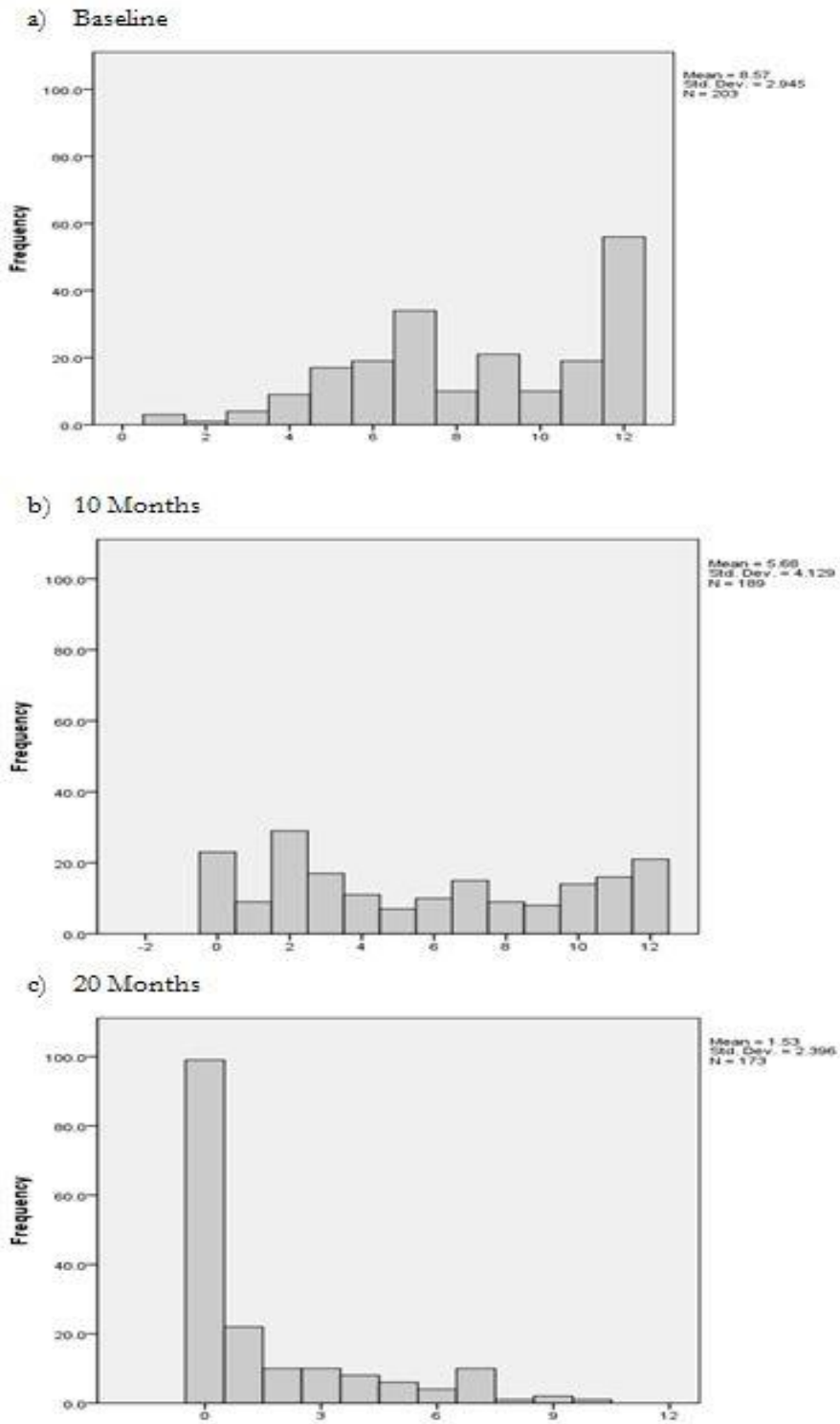
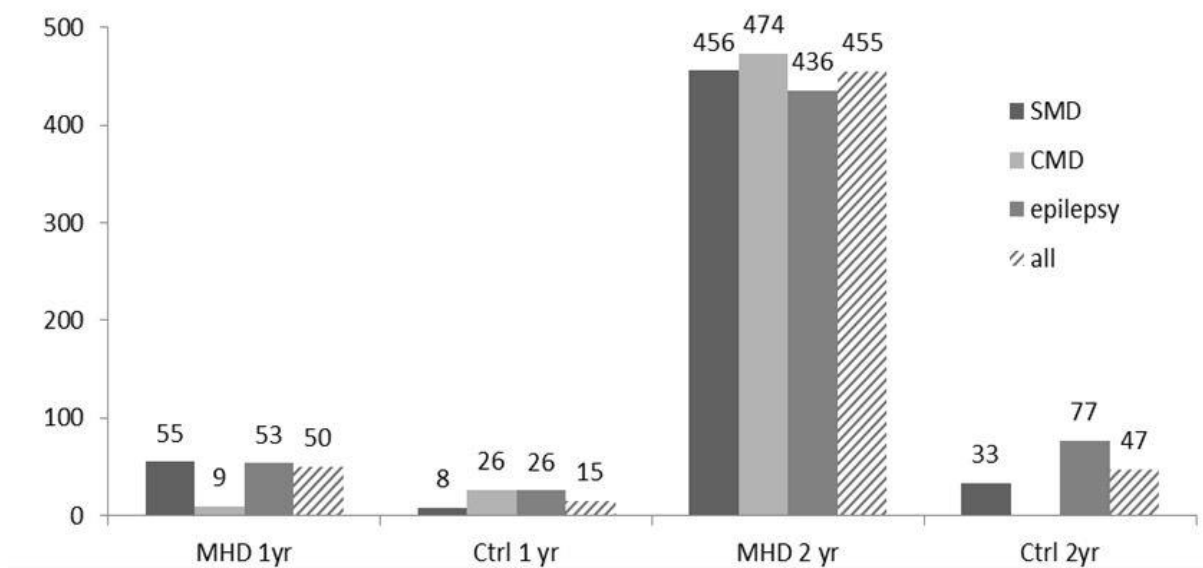




Figure 4-13: Mean annualized healthy days in MHD and comparison, by diagnosis



#### 4.5 - e) Change in DALYs

The change in DALYs between baseline and follow-up was positive in the first year but negative in the second year (0.005 and -0.077 DALYs respectively) for those in the MHD group. This means that the health of the group as a whole deteriorated over time, despite the intervention. The driver of this result is death. Those who were alive improved markedly between year one and year two, as demonstrated by the mean change in GHQ score shifting from 4.2 to 8.4 points from one year to two years. The number of deaths also increased markedly, however, in the second round of follow-up: whereas only two people died in the first ten months of the study, six people died in the second ten months. The mortality rate in the first ten months of the study was significantly lower than standardized mortality rates for populations with these illness profiles (it was 2% for the MHD cohort as a whole, compared with figures from the literature of 6.3% for SMD and 5.98% for epilepsy). The mortality rate of 5% in months 10-20, however, though slightly lower than expected, nonetheless approximated the SMR from the literature, given the small sample size. As most of the deaths happened in the SMD diagnosis, their DALY outcomes are most affected, whereas the group with epilepsy experienced a positive change in DALYs in two years.

In the comparison group, health deteriorated more over two years, as reflected by a greater negative change in DALYs. The average change in DALYs was -1.052 in the first year and -2.250 in two years (table 4-10). The greater deterioration in health in the comparison group than in MHD implies that the MHD intervention is averting disability.

Table 4-10: Outcomes in MHD and comparison, by diagnosis

GHQ	SMD				CMD				epilepsy				All			
	N	max	mean	sd	N	max	mean	sd	N	max	mean	sd	N	max	mean	sd
MHD 1	111	5.6	<b>-4.2</b>	3	19	4.8	<b>-2.8</b>	4	49	3.7	<b>-3.6</b>	3	184	5.6	<b>-3.9</b>	3
Comp 1	116	-1.1	<b>-1.1</b>	0	23	-3.0	<b>-3.0</b>	0	0	.	.	.	139	-1.1	<b>-1.4</b>	1
MHD 2	104	2.6	<b>-8.3</b>	3	17	5.1	<b>-9.4</b>	4	44	1.2	<b>-8.1</b>	3	169	5.1	<b>-8.4</b>	3
Comp 2	116	-1.5	<b>-1.5</b>	0	0	.	.	.	0	.	.	.	116	-1.5	<b>-1.5</b>	0
<b>Healthy days</b>	N	max	mean	sd	N	max	mean	sd	N	max	mean	sd	N	max	mean	sd
MHD 1	111	364	<b>55</b>	79.76	19	112	<b>9</b>	29.19	49	364	<b>53</b>	79.55	184	364	<b>50</b>	77.22
Comp 1	116	365	<b>8</b>	48.06	23	243	<b>26</b>	63.08	56	26	<b>26</b>	.00	195	365	<b>15</b>	43.56
MHD 2	104	729	<b>456</b>	201.67	19	721	<b>474</b>	213.48	46	634	<b>436</b>	208.30	173	729	<b>455</b>	202.26
Comp 2	116	730	<b>33</b>	128.18	0	.	.	.	56	77	<b>77</b>	.00	172	730	<b>47</b>	107.08
<b>DALYs</b>																
MHD 1	111	.38	<b>.002</b>	.34	19	.08	<b>-.464</b>	.26	49	.60	<b>.196</b>	.19	179	.60	<b>.005</b>	.35
Comp 1	116	-.20	<b>-.839</b>	.18	23	-.07	<b>-.358</b>	.17	54	-1.60	<b>-1.805</b>	.17	193	-.07	<b>-1.052</b>	.52
MHD 2	108	.41	<b>-.173</b>	.47	16	.72	<b>.107</b>	.42	43	.51	<b>.096</b>	.29	167	.72	<b>-.077</b>	.45
Comp 2	116	-.39	<b>-1.653</b>	.35	0	.	.	.	54	-3.14	<b>-3.533</b>	.33	170	-.39	<b>-2.250</b>	.94

#### 4.5 - f) Loss to follow-up and death

Subjects lost to follow-up appear to have had a mix of both good and bad outcomes, comparable to the rest of the cohort. There was no statistical difference in age, sex, diagnosis or any other variables studied between those lost to follow up and those retained in the study. At 10 months, ten subjects (4.9%) were lost to follow-up, and at 20 months, 30 subjects (14.8%) were lost (table 4-12). The main reason for loss to follow-up after two years was moving (n=11, 36.7%), and whereabouts being unknown (n=8, 26.7%). Among those who moved and were traced, six moved for marriage, employment or both. Two of those lost to follow-up were found to have negative outcomes: one was arrested and the other had developed acute psychosis (though originally diagnosed with epilepsy).

Eight people died in the course of the study (3.9% of the sample). Among those who died, causes of death were available for three cases and reflect a mix of natural causes and illness-related mortality: asthma attack, assault, and suicide. As stated previously, two of the deaths occurred in the first ten months of study and the remainder occurred between ten and twenty months. Projecting the data to two years, we would expect that 10 people might have died (table 4-3). The number of deaths observed and projected is markedly less than the expected deaths (table 4-1) in this population.

Table 4-11: Reasons for Loss to Follow-Up

<b>Reason Lost</b>	<b>N</b>	<b>Percent Sample</b>	<b>Percent Lost</b>
Died	8	3.9	26.7
Declined interview	1	0.5	3.3
Moved	11	5.4	36.7
Whereabouts unknown	8	3.9	26.7
Defaulted on treatment	1	0.5	3.3
Other	1	0.5	3.3
<b>Total</b>	<b>30</b>	<b>14.8</b>	<b>100</b>

The expected number of deaths in two years of a Kenyan population with the age, sex and disease profile of our sample was 23 – 14 with serious mental disorders, 1 to 2 with common mental disorders and 8 with epilepsy. The eight people who died in this study were 6 with serious mental disorders, 1 with common mental disorders and 1 with epilepsy (table 4-1). The deaths averted appear to have been greatest for those with epilepsy, however the small size of the sample and the rarity of death as an event make it challenging to test this association statistically. Nonetheless, the deaths in our sample exceeded the expected deaths among a comparable healthy sample of Kenyans, which would have been 4.6 in two years. The excess mortality may be linked to the relative poverty as well as to the illness of the population.

## 4.6 Cost-Effectiveness and Cost-Utility Analysis

### 4.6 - a) Incremental cost effectiveness ratios (ICERs)

The incremental cost-effectiveness ratio of the MHD Model is defined as follows:

$$ICER = \frac{C_i - C_c}{E_i - E_c}$$

With C = costs, E = effects, i = MHD intervention and c = comparison.

Table 4-12: Costs, effects and incremental cost-effectiveness ratios, by diagnosis

Diagnosis	GHQ unit	Healthy day	change in DALY from baseline	Total Cost (Ksh)	Total Cost (Int\$)	Base Case Direct Cost (Int\$)	Sensitivity 2 Direct Cost (Int\$)
<b>SMD</b>							
MHD 1yr	4.2	55	0.002	25,217	594	602	649
Comp 1yr	1.1	8	-0.839	9,360	220	80	80
<b>ICER 1yr (soc)</b>	<b>120.0</b>	<b>7.97</b>	<b>444</b>				
<b>ICER 1yr (hs)</b>	<b>167.6</b>	<b>11.12</b>	<b>620</b>				
MHD 2 yr	8.3	456	-0.173	37,220	876	1,236	1,321
Comp 2 yr	1.5	33	-1.653	18,719	441	161	161
<b>ICER 2 yr (soc)</b>	<b>64.4</b>	<b>1.03</b>	<b>294</b>				
<b>ICER 2yr (hs)</b>	<b>64.4</b>	<b>2.54</b>	<b>726</b>				
<b>CMD</b>							
MHD 1yr	2.8	9	0.120	28,188	664	587	635
Comp 1yr	3.0	26	0.137	14,285	336	77	77
<b>ICER 1yr (soc)</b>	<b>-1681</b>	<b>-19.2</b>	<b>-18,987</b>				
<b>ICER 1yr (hs)</b>	<b>-2621</b>	<b>-29.9</b>	<b>-29,605</b>				
<b>Epilepsy</b>							
MHD 1yr	NA	53	0.196	25,152	592	602	649
Comp 1yr	NA	26	-1.805	10,312	243	19	19
<b>ICER 1yr (soc)</b>	<b>NA</b>	<b>12.54</b>	<b>175</b>				
<b>ICER 1yr (hs)</b>	<b>NA</b>	<b>20.92</b>	<b>291</b>				
MHD 2 yr	NA	436	0.096	42,271	995	1,167	1,238
Comp 2 yr	NA	77	-3.533	20,625	486	37	37
<b>ICER 2 yr (soc)</b>	<b>NA</b>	<b>1.42</b>	<b>140</b>				
<b>ICER 2yr (hs)</b>	<b>NA</b>	<b>3.15</b>	<b>311</b>				
<b>All dx</b>							
MHD 1yr	3.9	50	0.005	25,676	604	599	647
Comp 1yr	1.4	15	-1.052	10,102	238	60	60
<b>ICER 1yr (soc)</b>	<b>145.4</b>	<b>10.55</b>	<b>347</b>				
<b>ICER 1yr (hs)</b>	<b>213.7</b>	<b>15.5</b>	<b>510</b>				
MHD 2 yr	8.4	455	-0.077	39,145	922	1,216	1286
Comp 2 yr	1.5	47	-2.250	20,203	476	121	121
<b>ICER 2 yr (soc)</b>	<b>64.8</b>	<b>1.09</b>	<b>205</b>				
<b>ICER 2yr (hs)</b>	<b>159.1</b>	<b>2.69</b>	<b>504</b>				

\*soc = societal perspective; hs = health systems perspective; comp = comparison group; ICER = incremental cost-effectiveness ratio

The total costs were composed of the sum of provider costs (NGO and government) and user costs (direct and indirect). As described earlier (see “scope of costs”), for the counter-factual intervention I assumed that costs were held at the baseline values of the study population. Thus, the costs for “comparison, 1 year” refers to the baseline costs, while “comparison 2 years” refers to the baseline costs times two. Effects were modified according to published rates of spontaneous remission and standardized mortality ratios described in the previous section on measurement of outcomes. Using this equation, I derived several ICERS, differing by unit of outcome and by diagnosis (table 4-12).

The average cost per healthy day (figure 4-14) was Int\$ 10.55 in the first year, but decreased to Int\$ 1.09 in two years. From the societal perspective, across all diagnoses, the incremental cost of the MHD intervention was Int\$ 347 per DALY averted in the first year, and Int\$ 205 per DALY averted over two years. However, these averages mask considerable variation by diagnosis.

The data suggest that common mental disorders were not cost-effective to treat using the MHD Model. This is partly because the natural course of untreated common mental disorders is very good, with roughly half of people with depression remitting spontaneously in a year (Whiteford, Harris, et al. 2013). That being said, the estimates of spontaneous remission are based on primary care samples, whereas one might assume that those entering treatment in Kenya would be suffering from more severe depression, so spontaneous remission in this group might have been lower than estimated. In addition, outcomes improved more in year two than in year one; however, since it was impossible to estimate control group outcomes in year two, it wasn't possible to estimate cost-effectiveness for common mental disorders at two-years in this sample. Finally, the sample size was very small (n=24 at baseline), making analysis of this data more subject to error.

Treating epilepsy with the MHD Model proved slightly more cost-effective in two years than in one, costing Int\$ 140 vs. \$175 per incremental DALY respectively (figure 4-15). The healthy day outcomes (figure 4-14), which do not carry disability weights, reflect much better outcomes over two years (Int\$ 1.42 per day) than in the first year (Int\$ 12.54 per day). The main driver of this finding is the reduced number of deaths of people with epilepsy relative to expectation. Only one person with epilepsy died in the 20 months of observation, whereas the expected number of deaths in a population with the same age distribution with epilepsy is greater than 5 in 20 months (appendix 14). The disability weights for epilepsy are lower than for severe mental disorders, thereby lending the changes in mortality more effect than the changes in disability with regard to DALY outcomes.

Figure 4-14: ICER per healthy day at one and two years, societal perspective

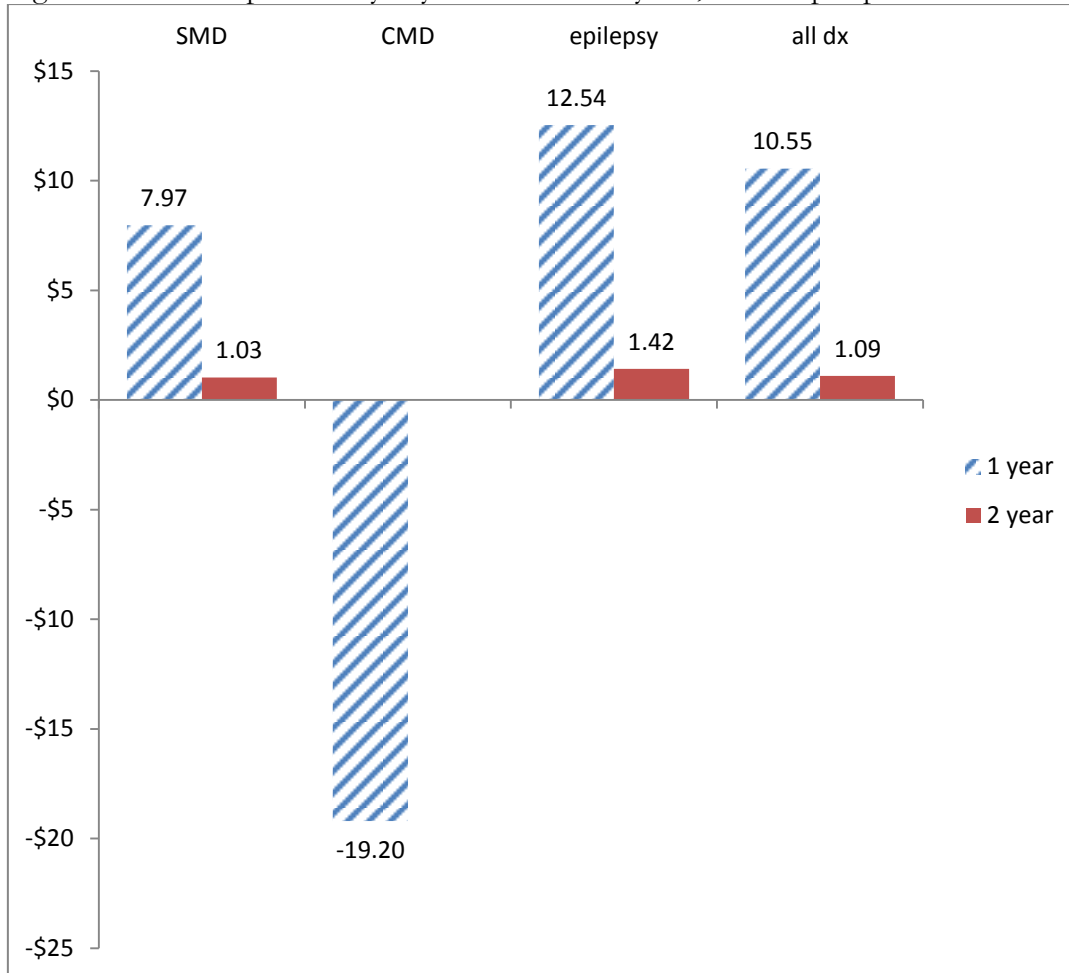
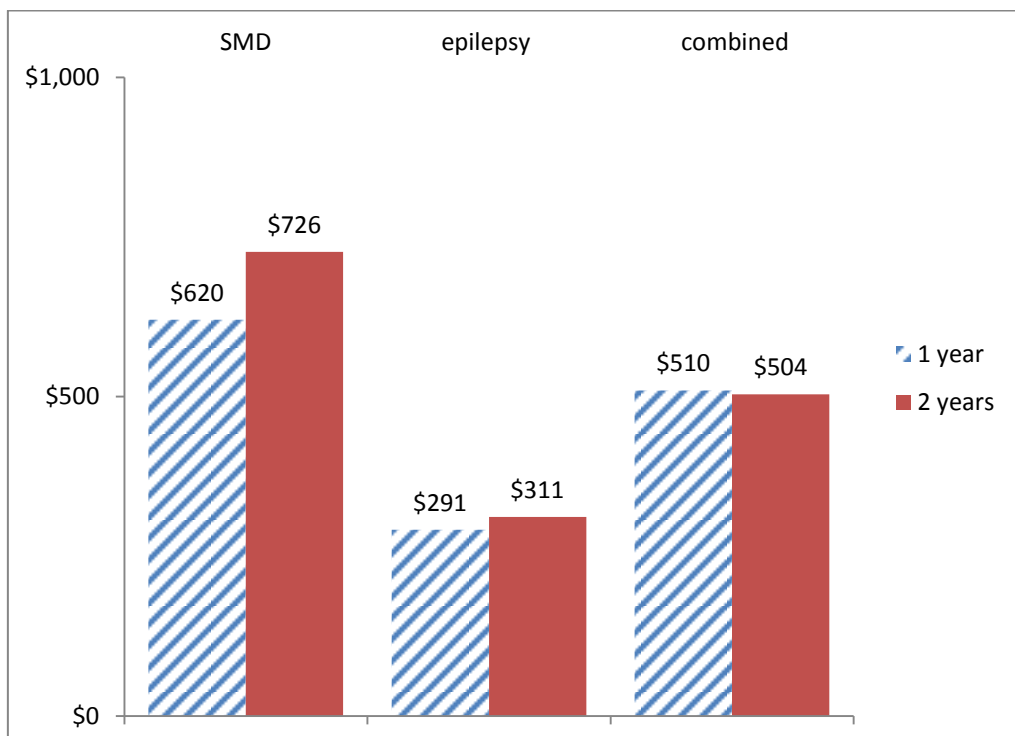


Figure 4-15: ICER per DALY at one and two years, health systems perspective



By the end of two years, severe mental disorders appear to have been the most cost-effective diagnostic group to treat using the MHD Model, although epilepsy was more cost-effective in the first year. SMD cost Int\$ 444 per DALY in one year and Int\$ 294 per DALY in two years. The reason for the sharp increase in cost-effectiveness between the first and second year is that many people with SMD returned to productive work in the second year, having been previously disabled. The cost per incremental healthy day in year one was Int\$ 3.47, which is less than the minimum daily farming wage of Int\$ 4.2 (162 Ksh), used to calculate indirect costs. Over the course of two years, the cost per incremental healthy day dropped to only Int\$ 1.05. A dollar a day represents the living expense of an estimated half of Kenyans (UNICEF 2014).

#### *4.6 - b) Health systems perspective*

From the health system perspective, each healthy day cost Int\$ 9.6 in the first year and Int\$ 1.65 in two years, all diagnoses combined. Severe mental disorders were the most cost-effective to treat, costing Int\$ 15.5 per incremental healthy day in the first year, and dropped to Int\$ 2.69 over two years. Epilepsy cost Int\$ 12.54 in the first year and Int\$ 1.42 in two years. Common mental disorders did not appear cost-effective to treat, since they cost more and produced approximately the same effect as no treatment.

The health system ICER per DALY averted was stable between the first and second year. Across all diagnoses, MHD cost Int\$510 and Int\$504 per DALY averted in one and two years. The treatment for severe mental disorders was less cost-effective than for epilepsy from the health systems perspective, because this perspective excludes the notable productivity gains made by people with SMD in the second year of MHD. SMD cost \$620 per DALY in the first year and Int\$726 per DALY in two years. The reason MHD appears less cost-effective in the second year is because the death rate increased among the population with SMD during that time. Epilepsy cost \$291 and \$311 per DALY averted in one and two years from the health system perspective. The conventional threshold for cost-effectiveness acceptability used in low-income settings is per capita GDP per DALY (Chisholm 2005). Kenya's PPP adjusted gross national income in 2011 was Int\$ 1,710 (World Bank 2011), making the MHD model appear cost-effective at one and two years for severe mental disorders and for epilepsy from the health system perspective.

#### 4.6 - c) Sensitivity Analysis

It is necessary to test the robustness of the findings relative to key assumptions included in the analysis. The most significant assumptions in this study are the values estimated for the treatment-as-usual comparison group, and the cut-off point used to convert the GHQ score into a healthy day. I therefore tested the ICER sensitivity using two alternative scenarios for measuring healthy days (table 4-13). Another source of uncertainty surrounds the measurements of cost, so I also altered the assumptions about costs.

The greatest uncertainty around costs is the valuation of productivity, particularly the assumption that the productivity of a comparison group would have remained constant. The uncertainty in measuring productivity, however, is addressed through the health systems perspective analysis, which does not include any measure of productivity, and is discussed in the results section above. A further source of uncertainty around costs is in the WHO CHOICE unit costs for government inputs. An outpatient clinic visit is costed based on a primary health care visit, which typically lasts approximately 3 minutes. By contrast, a mental health visit is likely to last closer to ten to fifteen minutes for a visit (with first visits being the longest). I therefore tested the sensitivity of results to this cost by tripling the estimate for outpatient government-run clinics.<sup>12</sup>

Scenario two, the worst-case scenario, adjusts assumptions by improving the comparison group outcomes and increasing government costs. It assumes that spontaneous remission from epilepsy is 20%, as previously published (Kwan and Sander 2004), and not 7% per year as indicated by as-yet unpublished data from Kenya (Newton 2013). In addition, it estimates comparison outcomes for severe mental disorders by using the published rate of 5.7% for complete remission (Alem et al. 2009), instead of using the cross-walk technique previously described from the SF-36 to the GHQ-12. Furthermore, it increases the discount rate on DALYs from 3% to 7% to match the discount rate used for capital. Finally, it triples the government cost of outpatient clinics.

Scenario two (figure 4-16) demonstrates that the findings for epilepsy are highly sensitive to the control group estimate in the first year, but considerably less so over two years. In the first year, treatment as usual appears *better* than the MHD Model (73 healthy days vs 53), while over two years, the MHD Model substantially outperforms treatment as usual (436 healthy days vs 146). The two-year ICER is \$2.14 cents per healthy day as compared with Int\$ 1.09 per healthy day in the base case. The shift in assumption for SMD control outcomes

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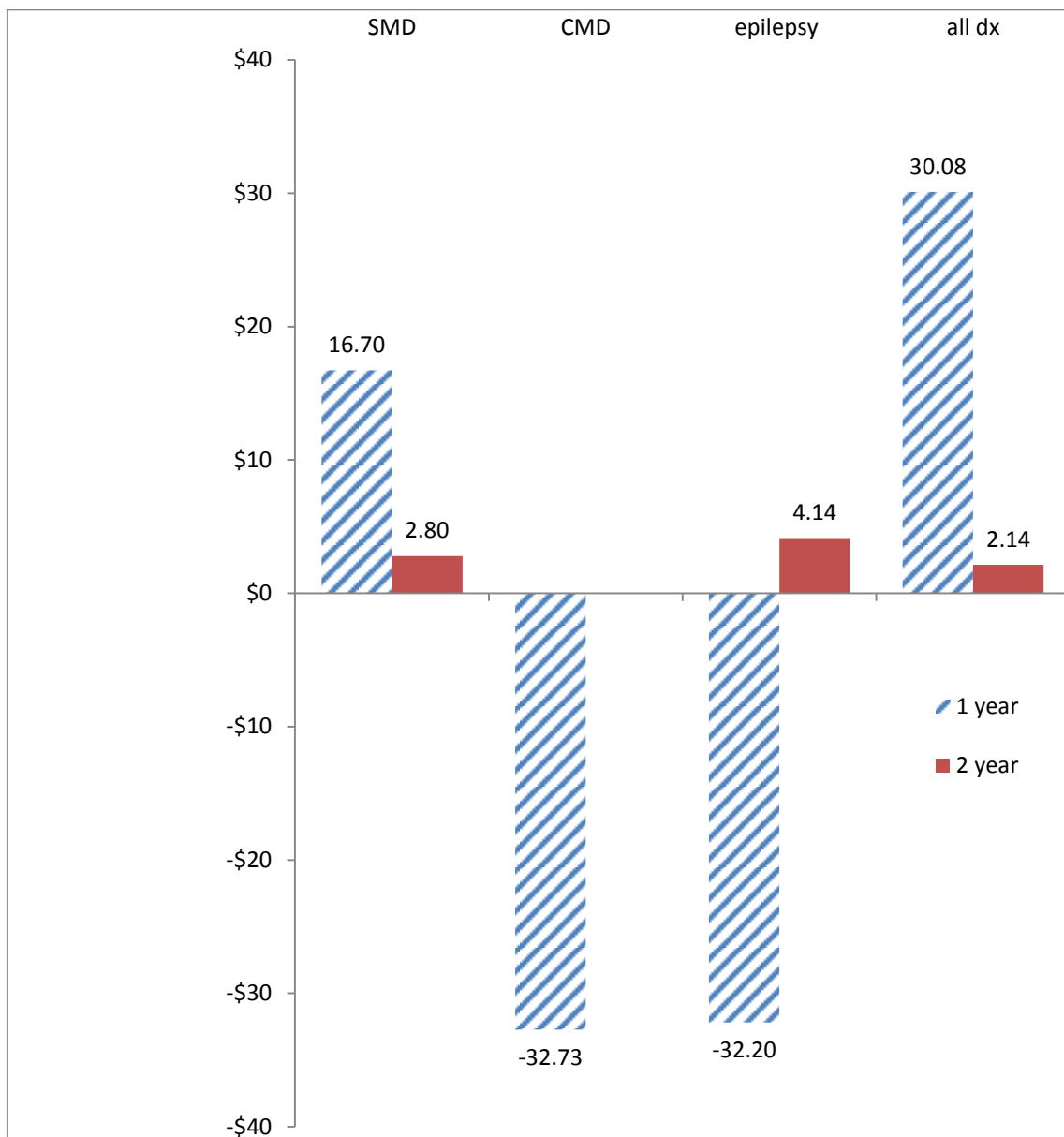
<sup>12</sup> The clinician's time is not the only input to the unit cost of a clinic, so tripling the cost is equivalent to more than tripling the clinician's time.



leads to a three-fold improvement in those outcomes (from 6 healthy days per year to 21). Again, one-year outcomes are more sensitive than two-year outcomes. At one-year, the ICER for SMD increases to Int\$ 16.70 per healthy day, up from Int\$ 7.97 in the base case. Over two-years, however, the ICER decreases to Int\$ 2.80 per healthy day as compared to \$1.03 in the base case. For all diagnoses combined, the ICER is highly sensitive in the first year – jumping to a mean of Int\$ 30.08 per healthy day, up from Int\$ 10.55 – but much less sensitive over two years, shifting from Int\$ 1.09 cents per incremental healthy day to Int\$ 2.14 cents per day.

Figure 4-16: Sensitivity Analysis, Case 2 (Worst Case)

a) ICER per healthy day



a) ICER per DALY

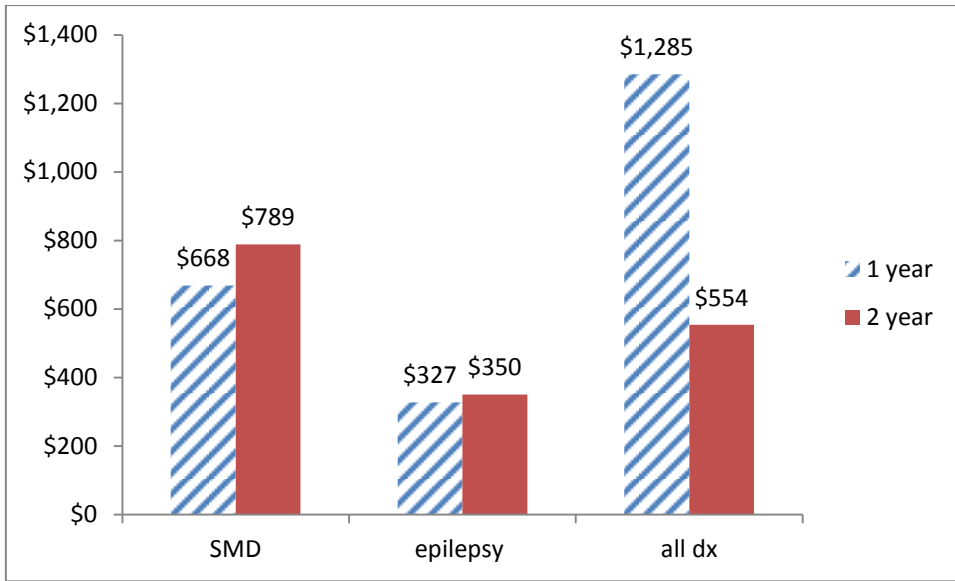
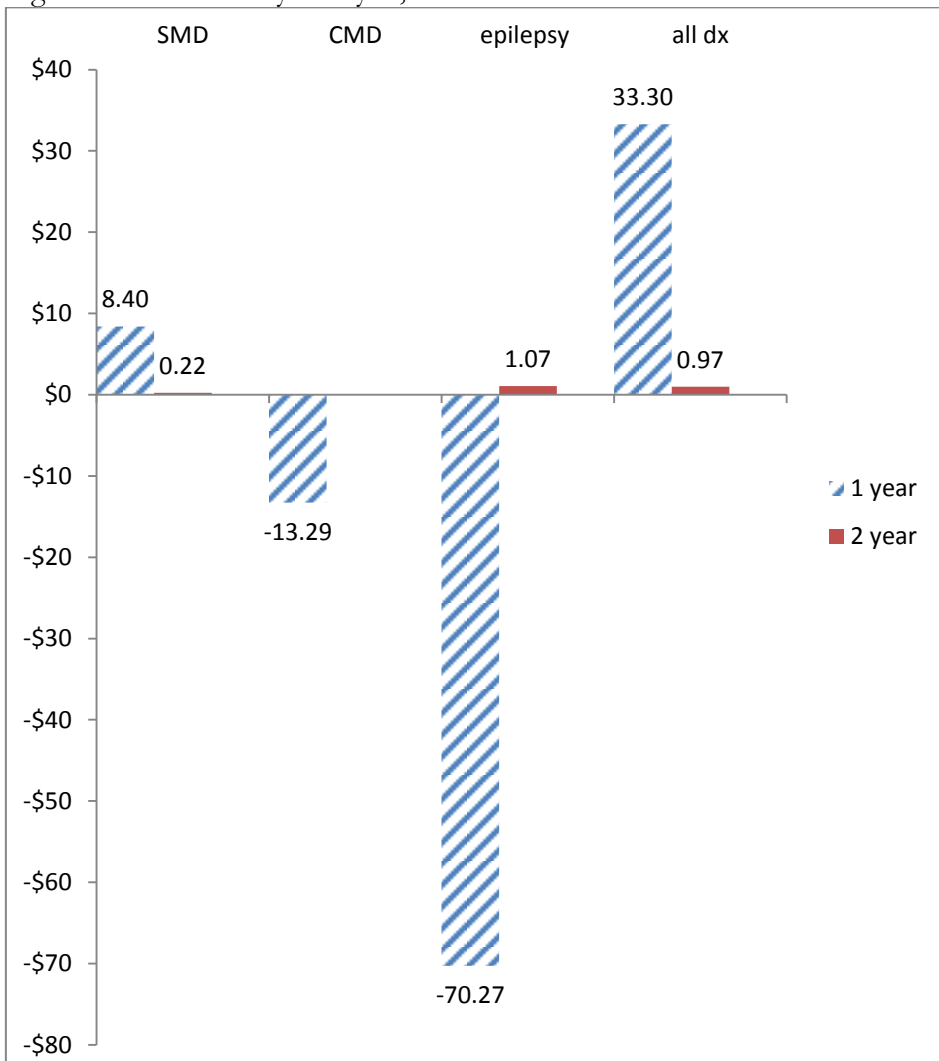


Figure 4-17: Sensitivity Analysis, Case 3



Scenario three (figure 4-17) adjusts assumptions for the GHQ cut-off. Since the GHQ measure relies on count data, the cut-off of 3 established in Kenya means a score of 2 indicates health and 3 indicates sickness. However, my techniques for annualising outcomes required turning the GHQ into a continuous measure, including values between 2 and 3. In the base case scenario, scores of three or more indicated sickness, and anything less than 3 indicated health. In scenario three, however, I tested using 2 as a cut-off, meaning anything greater than 2 indicated sickness and anything 2 or less indicated health.

As with scenario 2, the results of scenario 3 proved sensitive in the first year, but less so over two years. The number of healthy days in the first year decreased across all diagnostic groups, including for control groups, where these outcomes were estimated using the GHQ (all cases except epilepsy). The number of healthy days among people in the MHD Model dropped by half in all three diagnostic groups in the first year: from 55 to 25 for SMD, from 9 to 5 for CMD, and from 53 to 21 for epilepsy. Over two years, however, the results were fairly comparable, as a result of which the overall ICER remained unchanged at Int\$ 1.12, just 3 cents more than the base case per incremental healthy day.

The results set out above rely on mean values and do not account for variance around those means, which creates further uncertainty in the parameters. Drummond outlines several approaches to managing uncertainty in economic evaluation (Drummond, Sculpher, and Torrance 2005). The first is standard hypothesis testing, using t-tests. The challenge with this method is that the p-value does not reflect effect size, and moreover I cannot anticipate the desirable p-value for this context. The second method for managing uncertainty is to define a confidence region, creating a 95% confidence interval around costs and effects. The challenge with this method is that it assumes no association between costs and effects, which is rarely the case.

A third method, which allows for the measurement of covariance is the incremental net benefit (INB) approach. Net benefit is defined as willingness to pay times the mean change in effects minus the mean change in costs (Nixon, Wonderling, and Grieve 2005):

$$INB(K) = K\mu_{\Delta e} - \mu_{\Delta c}$$

where K = willingness to pay for 1 unit gain in health, c = costs and e = effects.

Table 4-13: Healthy days, scenarios 2 & 3

	<b>SMD</b>				<b>CMD</b>				<b>Epilepsy</b>				<b>All dx</b>			
	N	max	mean	s.d	N	max	mean	s.d	N	max	mean	s.d	N	max	mean	s.d
<b>Scenario 2</b>	epilepsy 20% and SMD 5.7% remission															
MHD 1	111	364	<b>55</b>	80	19	112	<b>9</b>	29	49	364	<b>53</b>	80	184	364	<b>50</b>	77
Comp 1	117	21	<b>21</b>	0	23	243	<b>26</b>	63	56	73	<b>73</b>	0	196	243	<b>36</b>	31
MHD 2	104	729	<b>456</b>	202	19	721	<b>474</b>	213	46	634	<b>436</b>	208	173	729	<b>455</b>	202
Comp 2	117	42	<b>42</b>	0	0	.	.	.	56	146	<b>146</b>	0	173	146	<b>75</b>	49
<b>Scenario 3</b>	GHQ cut-off of greater than 2															
MHD 1	111	243	<b>25</b>	46	19	62	<b>5</b>	16	49	122	<b>21</b>	37	184	243	<b>22</b>	42
Comp 1	116	33	<b>1</b>	4	23	122	<b>30</b>	20	56	26	<b>26</b>	0	195	122	<b>11</b>	15
MHD 2	103	701	<b>404</b>	219	16	638	<b>469</b>	191	42	666	<b>427</b>	184	165	701	<b>419</b>	205
Comp 2	116	398	<b>7</b>	52	0	.	.	.	56	51	<b>51</b>	0	172	398	<b>21</b>	47

If the intervention is cost-effective, then  $INB > 0$ . Unlike with the ICER, which is a fraction, it is possible to run regressions using the INB as a dependent variable, and thereby to test for covariance. A standard way to display the results of these regressions is in a cost-effectiveness acceptability curve (CEAC), which plots the willingness to pay on the x-axis and the probability that  $INB(K) > 0$  on the y-axis. Since the BasicNeeds-UCT study design is pre-post and control outcomes were estimated using the same sample as the intervention, analysis of variance and covariance is problematic. I therefore chose not to undertake a probabilistic analysis of uncertainty.

#### **4.7 Discussion and Limitations of the Quantitative Outcomes**

Compared with other health interventions modelled by the World Health Organization's CHOosing Interventions that are Cost-Effective (WHO CHOICE) (Tan Torres Edejer et al. 2003), the MHD model appears an attractive choice for policy makers. As the WHO CHOICE costing method does not include valuations of productivity (Johns, Baltussen, and Hutubessy 2003), WHO CHOICE results are best compared with those of MHD from the health system perspective. Viewed thus, the MHD model performs in the same range of cost-effectiveness as HIV treatments. Highly active anti-retroviral therapy (HAART) combined with Directly Observed Treatment Short-Course (DOTS) for TB in the Africa E region costs Int\$ 596 per DALY averted for simple HAART and Int\$ 1,977 for HAART Plus, while the MHD costs Int\$ 503 over two years. Furthermore, the MHD substantially out-performs WHO CHOICE models for old mood stabilizers and psychosocial treatment for bipolar disorder (Int\$ 2,165 per DALY)(Chisholm et al. 2005), and "first generation" antipsychotics with psychosocial treatment for schizophrenia (Int\$ 1,670 per DALY)(Chisholm et al. 2008).

Based on these results, there is an argument for scaling up the MHD model more broadly in Kenya. To do so, however, would require a significant investment of external funds, as the majority of direct costs are currently born by the NGO BasicNeeds, by way of international donors. In a country where per capita spending on health is Int\$ 37 per year (World Health Organization 2012), an intervention costing Int\$ 599 per person per year in direct costs to deliver is not readily affordable to the public sector. The returns on that investment are significant in terms of return to productive work; however they are not returns that would be monetized by the government.

The quantitative data in this cost-effectiveness analysis are limited in their ability to inform about the challenges of programme delivery, as they reduce complex outcomes to a single number. The cohort in the BasicNeeds Kenya Impact Study consisted of a mixed diagnostic group, which constituted a challenge in the choice of an appropriate outcome measure. The GHQ, which was selected as the primary measure of outcome, is designed to assess psychiatric symptoms, rather than diagnosis, particularly symptoms of common mental disorders, but not psychoses or epilepsy.

Very few studies (Caqueo and Lemos 2008; Wilkinson et al. 2000) have made use of the GHQ 12 in a population of people with severe mental disorders. In studies of severe mental disorders, the GHQ is more commonly used to measure the psychological strain on care-givers. One of the challenges in relation to the measurement of severe mental disorder is that the tool is designed to measure illness episodes, so it asks how a person is feeling in comparison to their “usual” self. In contexts of chronic disease, however, the usual self may be a sick self, which poses a risk to the validity of the responses. That being said, several items on the GHQ12 reflect symptoms of psychosis – in particular, items 1 (ability to concentrate), 4 (decision making) and 6 (ability to perform daily activities). It may, therefore, be a meaningful measure of disease morbidity.

The GHQ is also a poor measure of symptoms for epilepsy, as it does not ask about seizures. A study from Nigeria, however, found the GHQ-30 to be significantly correlated with a measure of quality of life among people with epilepsy (Mosaku et al. 2006). Indeed, the GHQ functions predominantly in this study as an indicator of quality of life rather than as a marker of symptom suppression: as such, the tool measures recovery in the broader sense than clinical symptom alleviation. The challenge remains, however, whether the cut-off used for common mental disorders is meaningful for severe mental disorders and epilepsy. Findings for SMD and epilepsy at two-years, however, proved relatively insensitive to the cut-off.

Furthermore, a limitation of the data is the accuracy of self-report. Problems in self-report can occur from recall bias – especially where periods of recall are long, such as nine months in many of the questions on the EST – or from a perceived desire to please the interviewer or provide socially acceptable answers, such as around income. For example, attendance of traditional healers may have gone under-reported, since the interviewers were clinicians with conventional medical backgrounds.

In addition, converting to DALYs required making assumptions, which come with uncertainty. In particular, assumptions about the sample severity are potentially problematic. While it is customary to use cut-offs of the top quartile or one standard deviation above the

mean to measure extremes within a given distribution, which does not inform us about whether the entire sample is severe. It is possible that in a Kenyan context, those reaching treatment may all have severe symptoms. That being said, the GHQ is a continuous measure, and the distribution of GHQ scores did not all cluster at the extreme of sickness, so the data appear to support the notion that some patients were more severe than others. Nonetheless, the choice of cut-off for severity remains untested in a wider Kenyan cohort, creating some uncertainty about the DALY weights.

Even at its best, DALY methodology has been subject to considerable criticism, particularly in relation to the selection of disability weights. The 2004 GBD study data used weights derived from a group of health experts, from mostly high-income countries, using a person trade-off method. That approach was deemed by many a poor indicator of actual disability weight, because it neither accounts for the preferences of the person in the condition, nor those of the general public, nor is it representative of expertise from low-income countries. In response to this critique, the 2010 GBD update reassessed its disability weights, using two sources: a population-based survey conducted in Bangladesh, Indonesia, Peru, Tanzania and the USA; and an internet survey (Salomon et al. 2013). An ongoing critique of DALYs relative to the Kenyan context is that by weighting disability equally across all settings, DALYs undervalue the burden of disability in low-income settings, where the environment is less accommodating than in higher-income settings (Reidpath et al. 2003). The response to this claim is that weighting diseases uniformly is an expression of egalitarian values (Institute of Health Metrics and Evaluation 2010).

Another potential weakness is that our study provides no measure of treatment adherence. An intervention check-list provided some indication of the degree to which people had participated in the programme, but it did not ask about medication adherence. It is possible that outcomes differed according to a person's level of adherence to the MHD Model. That being said, the literature suggests that self-report of adherence is highly inaccurate (Mbuba et al. 2012), so the absence of this information may not be such a weakness. Moreover, since the cost-effectiveness analysis is interested in mean aggregate outcome, rather than in individual outcomes, the absence of adherence measure is less problematic in this context than it would be for an outcome study.

Finally, and most importantly in the context of an economic evaluation, the absence of a control group is a severe limitation to this study, making it impossible to know what aspect of the changes observed are attributable to the intervention as opposed to external factors. For example, a part of the change in occupational status could simply be the result of the

ageing of the population – as participants get older, they are more likely to contribute to the workforce, especially since one quarter were 25 years old or younger. Inversely, loss of productivity could be the result of the economic down-turn, making part-time income generating jobs less available.

The choice of literature for comparison group raised a number of challenges. The Ethiopian study consisted almost entirely of men, making it an imperfect predictor of outcomes for women. There was no literature on mortality rates of depression in a low-income setting, so our data come from high-income countries where populations have better access to treatment, which could make the excess mortality an under-estimation of what it would be in a low-income setting. And estimated outcomes for untreated epilepsy vary tremendously, creating a substantial source of uncertainty. Nonetheless, the cost-effectiveness results remained robust over the course of two-years, despite sensitivity to individual assumptions in the first year.

#### *4.7 - a) Insights from the Qualitative Data*

Given the multiple limitations to the quantitative data, qualitative data offer a rich resource in unpacking some of the complexities underlying the MHD model's outcomes. Discussions with patients and programme staff and review of documents by external evaluators revealed that delivering the MHD model was not without challenge. I will present two over-arching challenges, followed by specific challenges associated with certain activities, namely community consultation, outpatient clinics, home-visits and forming self-help groups.

##### 4.7.a.i Overarching issues

A key over-arching concern was that of leadership, which powerfully affects the delivery of the MHD model. The model is only as good as the partners and people delivering it. Shortly before the onset of the evaluation research, BasicNeeds had to fire one of its implementing partners, because it was failing to adhere to its commitments. Furthermore, both the DFID and EC evaluators observed that the government authorities were not equally committed to the MHD project across all districts. EC evaluators remarked, “There was more suffering in the communities where the government entities are not delivering reasonable mental health services, (e.g. Laikipia North)” while DFID more discretely echoed, “In areas where government staff were not very involved or supportive, the delivery of programme outputs was very difficult and had limited impact.” Nyeri and Meru appear to have been areas where



the MHD model was functioning well, thanks to the engagement of partners and local government. However, it is apparent that the MHD model differs in content depending on the local partners. A greater adaptability to local contexts is the trade-off for potential inconsistencies from place to place.

A further over-arching issue is that neither the EC nor the DFID grant was explicitly intended for the delivery of the MHD model. Instead, the EC grant supported democratic governance, while the DFID funding stream sought to promote human rights. Specifically, the EC funded BasicNeeds from the beginning of February 2009 through the end of January 2012 in a project titled “Strengthening the capacity of people with mental disorders to hold government to account for mental health and development in Kenya” (contract DCI-NSAPVD/2008/156-918). DFID funded BasicNeeds from the beginning of January 2008 through the end of March 2011 in a project titled “Respecting the rights and needs of people with mental illness in Nyeri, Laikipia, Nyandarua and Meru South” (CSCF 450). BasicNeeds therefore sought to deliver their MHD model in such a way that emphasised the governance and rights focus of their donors. That meant emphasising user-based advocacy through self-help groups instead of health care delivery. The donor evaluations reflect this emphasis, and raise the question of what is to be evaluated when evaluating a multi-dimensional intervention model.

Further issues that emerged from the reports of patients, staff and evaluators relate to the capacity of the health-system and of service-users, coordination (particularly with HIV programmes) and resource constraint. These topics are most clearly addressed in describing the delivery of MHD activities.

#### **4.7.a.ii Issues by activity**

*Community consultation* – The chief challenge raised with regards to the community consultation meetings relates to the broader culture of NGOs and was variously dubbed by programme staff as an “issue of handouts,” or “dependency syndrome.” NGOs are known to hand out free goods to participants, and in some cases people come to depend on those hand-outs. The local HIV programmes, for example, offered samosas and tea when people attended their activities, while Caritas offered relief food through a different programme from the MHD intervention. A number of people would therefore come to the MHD consultation meeting in the words of one member of the programme staff primarily to “see what’s on offer.” In addition, MHD participants sometimes behaved with a sense of entitlement. The same staff member observed that when participants were receiving relief food from Caritas: “The food

was for all people in the locality, so they [MHD participants] had to queue with everyone else. They didn't understand why they weren't being given priority. They asked, "Why are you mixing us with them?" MHD participants appear to have felt a sense of superiority over the other villagers because of their sense of belonging in the MHD programme run by the BasicNeeds partner, Caritas.

The MHD model aspires to teach people to pro-actively address their needs, rather than passively receive benefits; however not all partner organisations appear to have assimilated that approach. The DFID evaluation noted:

"The success of the programme ... requires an ability [of programme staff] to have a clear understanding about rights-based approach vs. a service provision or a charity-based approach. While many organizations have adopted a rights-based approach, in reality the transition from service provision, particularly in the case of church-based organisations, can be slow." (O'Connell, Musomi, and Mwangi 2011)

The term "rights-based" is opposed to "charity", implying that recipients of the MHD model should act as participants rather than as beneficiaries of the intervention. This distinction between charity and rights, or between passive and active participation also comes to play in the distinction made between "wants" and "needs," illustrated on the flip-chart of a financial training session offered through the intervention (figure 1). Want implies personal involvement, whereas need implies an absence: "I will" versus "I lack." Ironically, the name BasicNeeds evokes the language of passivity that the organization is trying to fight. As noted by the DFID evaluators, the spirit of dependency may be driven as much by partner agencies as by programme participants.

Absence of coordination between different NGO programmes also raised an issue in organizing the community consultations. It sometimes happened that the community workers organized a consultation meeting on the same day as an activity of one of the local HIV programs, such as Afya+ or the International Centre for AIDS Care and Treatment Program (ICAP). In addition, NGOs competed amongst each other to hire the best community workers, but they did not have the same means. The HIV programmes were able to pay up to KSh 800 (Int\$ 19) per activity, whereas BasicNeeds partners only paid a quarter of that (KSh 200, Int\$ 5). While it was not possible to directly compare the amount of time required for an HIV activity as compared to an MHD activity, I was told that they were comparable. That being said, money was by no means the only incentive for community workers, who were referred to by the NGO as "volunteers." Other incentives included: 1) not having to queue for treatment at the clinic; 2) receiving free drugs at the clinic; and 3) getting priority for casual

labour around the clinic, such as cleaning jobs. Social prestige was also cited as an incentive by partner staff.

*Outpatient clinics* – Absence of coordination and the issue of hand-outs were similarly flagged as barriers to the delivery of the mental health outpatient clinics. Nyeri has a relatively high prevalence of HIV, and patients with both a mental disorder and HIV had to attend both the mental health clinic and a “comprehensive care centre” for HIV. Little communication existed between those two facilities. In relation to hand-outs, the same people who attended the consultation meetings to “see what’s on offer” would sometimes show-up at the clinic. As described by one health care provider, “Some clients were brought by a relative, because the relative wanted to see what assistance was available. But when they found it was only drugs, the person refused to take the drugs. Even the relative said ‘You are not sick, do not take.’” Fake patients were quickly routed out through the process of self-selection just described.

As diagnosis and prescription were the main activities undertaken in the outpatient clinics, medication side-effects and shortages were the main source of challenge in this activity. Drowsiness was a common complaint from those taking medicines. A member of the programme staff recounted how a female patient had recovered and stopped taking her medicines after getting married. She reportedly said: “They make me sleep a lot, and now I am married, I need to get up, cook, clean...” A man in the focus-group echoed, “I used not to know myself, but now I do. The only problem is the drugs make me very sleepy.” Another member of the focus group noted frustration with the repetitive nature of maintenance drug treatment: “Will the drugs ever change? It’s always the same drugs.” The novelty appeal of the MHD intervention wore off over time. Finally, a key problem highlighted in relation to medicines is that they were supposed to be taken with food, and food was not always available, because of extreme poverty.

Shortages of psychiatric medicines at the mental health clinics were equally cited as a problem. Since the clinics were government-run, they relied on government drug-supply systems. However, the drugs supplied to clinics were typically rationed on the basis of precedent, and in the past there had been no demand for psychiatric medicines. Clinics would often run-out of drugs, particularly carbamazepine for epilepsy. Some participants would be sent to the provincial general hospital, where supplies were better, but the distance and inconvenience reportedly led some participants to drop-out of the programme. BasicNeeds’ position was that they did not want to create a parallel system of health care, and that the demand for drugs should come from service users, rather than from their staff, otherwise they would fall into the trap of the dependency syndrome.

In addition to a shortage of medicines, the capacity of the public health system was stretched in terms of the ability of primary care providers to diagnose and treat mental disorders. As observed by the DFID evaluators:

“Primary care often struggles to deal with complex psychiatric cases. It deals with epilepsy very well but there may be a need for more specialized treatment at a district level for more complex cases. The balance between, on the one hand, increasing the local demand for local services and, on the other, working to ensure that such services are improving in their capacity to meet such demands, can be difficult. There is always a risk that the creation of demands, which cannot realistically be met, may have negative long-term consequences.”  
(O’Connell, Musomi, and Mwangi 2011)

DFID’s observation was corroborated by a comment made to me that some health staff got “discouraged” because they found the mental health training inadequate. In particular, no treatment was available for the management of drug-abuse. One young-man with a drug-abuse problem in the MHD programme hanged himself. His suicide caused the programme staff to raise the need for specialist treatment of substance use disorders, but resources were lacking to pursue this need.

Home-visits – The absence of psychological therapies within the MHD as practiced in Kenya was seen as a short-coming by both programme staff and the evaluators. Home-visits are conceived of as the primary means through which psychological support is given to MHD participants. They also serve as a form of follow-up for patients who have not shown up to their clinic appointment. Home visits do not, however, constitute formal counselling. As observed by DFID, “Research into brief psychological treatments, or group therapies should be explored. ... brief psychological interventions could reduce their reliance on medication and give them new skills for managing themselves” (O’Connell, Musomi, and Mwangi 2011). One of the health care providers noted that there was a perception that all that the clinics consisted of “Come, take your drugs and go.” The absence of psychological therapies is partly an issue of financial constraints but also of limited local capacity. There are not many trained therapists in Kenya, although there is a cadre of trained counsellors. Counsellors typically live and work in the cities, however, and hiring them can be costly.

Self-help groups – One of the main challenges raised in relation to forming self-help groups was the slow pace with which people became interested. As described by one of the programme staff, “Groups are like Christianity: you preach, and preach, and preach, but when you ask who wants to join, only five people raise their hands. It takes time for the idea to catch on. Only once people see how it helps others, then they get interested.” In the context

of grants that last only three-years, it can be difficult to demonstrate the effects of self-help groups, which took about two-years to get running.

The slow-pace of membership uptake was contrasted to an impatience among group members with the outcomes of their livelihoods projects. “People are not used to waiting for results from investments.” The example was given of a group that was given a grant of KSh 10,000 (Int\$ 235) that was invested on a group project between 10-15 members. In addition, the sense of entitlement observed during the community consultation also plays out in the livelihood activities. One of the programme staff observed, “Some people were given a small loan to make income, for example a plot of land to plant with potatoes. They would say, ‘It is too small what you give us.’” The grants and loans provided to self-help groups raised a further question of sustainability, as did the technical support provided to them from community workers and programme staff. The DFID evaluator commented “Self-help groups ... will need ongoing support and advice for the foreseeable future, particularly in relation to advocacy and micro-finance” (O’Connell, Musomi, and Mwangi 2011)

The verdict was mixed on the ability of self-help groups to serve as vehicles for advocacy. EC evaluators noted, “Caritas led meetings between users and government; [but] users did not have skills to use ongoing government projects, policies or even the new constitution as a basis for advocacy” (Ntulo, Musomi, and Mwangi 2011) At the same time, however, they reported that “the district health management team accused BasicNeeds Kenya and Caritas Nyeri of putting them on a collision course with people with mental illness, because of sensitization on their rights” (Ntulo, Musomi, and Mwangi 2011) *Ibid*. If district government officials were complaining of a “collision course,” then surely the user-led advocacy had some potency. Taking a step back, we can observe an inherent tension in the structure of the MHD model whereby the government serves both as a partner and as an adversary, or at the very least as a target of user-led advocacy.

These qualitative findings reveal uncertainties that cast into doubt the definitive nature of the quantitative results. The principle uncertainty is that Nyeri and Meru may not be representative of all MHD programmes, in that they appear to have been best-case scenarios. In addition, the programme delivery may have been positively influenced by the research process itself: the requirements of locating patients who had dropped-out in order to conduct research interviews, may have led to greater follow-up than in standard programme delivery. Finally, the fact that the activities of BasicNeeds were financed by donors interested in governance and human rights may have skewed the delivery of MHD in this setting less towards the health components and more towards advocacy. Nonetheless, the material

presented here reflects the reality of programme delivery through an NGO, where the “messiness” of resource constraints and donor demands inevitably shapes the practice of service delivery.

The testimonies of the select group of patients participating in the focus-group illustrated ways in which the MHD model succeeded in bettering the lives of some Kenyan men and women. One man, observed his transformation from a perpetrator of domestic violence to a supportive father in the three years since he had begun participating in the MHD activities. He described having beaten his wife and chased his children under the influence of auditory hallucinations, and noted that he was no longer disturbed by voices. The only noises that continued to disturb him were those of motorbikes, and his main preoccupation had become the wellbeing of his wife and the education of his children. A man with epilepsy reported how prior to receiving treatment with anti-convulsants he needed to be accompanied at all times by a care-giver. He spoke with visible pride about his ability to walk on his own to the clinic, to wash his clothes, fetch water, and help out farming lentils and maize. His account revealed not only signs of his own recovery, but also the implicit relief on his care-giver, who no longer had to shadow his movements.

Women in the programme reflected in their own way on how the intervention had helped them, emphasising their ability to participate once again in their family. A pregnant woman, who had received treatment for psychosis, recounted that she used to wander around the village unclothed, as a result of which her family tied her up at home. Her experience of illness had been as a victim of abuse rather than a perpetrator, albeit from possibly well-intentioned family members. Another woman told of how her children were taken from her by her parents, after she went wandering and slept in the forest. When asked how the intervention had changed her life for better or worse, her clear emphasis was on having her children back. Her experience of recovery emphasized the shift from a person being cared for to a care-giver, through mothering. The focus-group sample was skewed towards those who benefited most from the intervention; however the testimonies of those individuals are as relevant as the discussion of challenges in reflecting on the effectiveness of the MHD model in practice.

## 4.8 Conclusions

In conclusion, based on a combination of the quantitative and qualitative data, the MHD model could arguably do more or do better, but it appears in its present form to be doing considerable good. The areas of greatest potential improvement are in the provision of psychological therapies, possibly through counsellors or by training lay-workers, as has been done successfully in Asia (Patel et al. 2010) and in working with service users to improve drug-supply. The question of how to improve the sustainability of the livelihoods activities, which currently involve small grants, also merits further exploration. The strengths of the MHD model are the centrality of user-led advocacy, the equal emphasis on non-medical aspects of recovery (especially livelihoods), and partnership with local governments. The model offers specialised mental health care in a community setting, thus addressing a major gap in treatment for a vulnerable population.

This study suggests that the MHD model is cost-effective and equitable. However, for this intervention to be affordable, international donors must continue to finance mental health. Moreover, at the country-level, the model's sustainability requires dynamic, multi-sectoral participation from government, civil society and local communities – taking the clinic into the community and the community into the clinic. This robustness of findings from this study is limited by the absence of comparison group, and its generalizability outside of the setting of rural, Central Kenya has yet to be determined, making it difficult to infer conclusively the appropriateness of this model across the board. The results here would suggest that scaling up the MHD model might be worthwhile, starting by spreading to neighboring counties. Despite the limitations of this research, the study remains valuable in that it draws from patient-level data and provides rigorous economic analysis in a context (East Africa) and for a set of conditions (mental disorders) that are not typically subject to economic evaluation.

**5. A Case Study of Mental Health Coverage in a For-Profit Psychiatric Hospital**



Figure 5-1 A session of art therapy at Chiromo Lane



## 5.1 Introduction

One third (36.7%) of health expenditure in Kenya comes from out-of-pocket payments (World Health Organization 2012), and out-of-pocket expenditures goes predominantly (76.3%) to hospitals, including private for-profit hospitals, which consume 14.9% of them (Barnes et al. 2010). Understanding the drivers of private hospital expenditure is therefore key to containing health costs. Out-of-pocket expenditures are associated with catastrophic loss in low-income countries (McIntyre et al. 2006), so policy makers have been vying to create social health insurance in Kenya and elsewhere in sub-Saharan Africa (Hsiao, Shaw, and Fraker 2007; World Health Organization 2010).

In 2004, Kenya's parliament passed a promising bill to create a National Social Health Insurance Fund, which would fund both outpatient and inpatient care for all Kenyans using a sliding scale of contributions (Hsiao, Shaw, and Fraker 2007). Disappointingly, the bill was not signed into law, because of concern over the feasibility of its financing. Now, the only operational social insurance is the National Hospital Insurance Fund (NHIF), which is under investigation by Kenya's Ethics and Anti-Corruption Commission, and which allocates only 22% of funds towards benefits (Hsiao, Shaw, and Fraker 2007). NHIF pays a flat-fee of Ksh 800 (Int\$ 20.8) for inpatient stays and enrolment is mandatory for all formal sector employees; but currently it covers only 5.5% of the population (Barnes et al. 2010).

In this context of barriers to national insurance, private health insurance remains one alternative to user fees for financing health care, among those who can afford it. In Kenya, private health insurance is used by 2% of the population and accounts for 4% of total health expenditure (Barnes et al. 2010; Drechsler and Jütting 2007). Critics of private health insurance argue that it benefits only the rich and leads to spiralling use and costs of services, while proponents suggest that it provides financial protection, increases early access to services, and mitigates problems of wait-time and quality (Preker, Scheffler, and Bassett 2007). The debate remains largely theoretical in low-income settings in the absence of evidence. A systematic review of randomised controlled trials and observational studies about the impact of health insurance in Africa and Asia found only one study of private health insurance, and it was from Asia (Spaan et al. 2012).

Within the field of mental health, the main area in which private service provision dominates is in the treatment of substance abuse. Kenya's National Authority for the Campaign against Alcohol and Drug and Abuse (NACADA) lists 59 accredited services for drug and alcohol abuse nationally, including 36 with residential facilities (NACADA 2014).

Information on the date of origin is available online for 37 services, and 75% of them were founded in the last ten years (figure 6-2). Only four of the services (7% of all services, 11% of residential services) are public, namely: 1) Mathare Hospital and 2) Kenyatta National Referral Hospital in Nairobi<sup>13</sup>; 3) Coast Provincial General Hospital in Mombassa; and 4) the newly opened rehabilitation at Moi Referral Hospital in Eldoret (Rift Valley).

Figure 5-2: Growth in Kenyan Drug Treatment Centres, 1996-2012

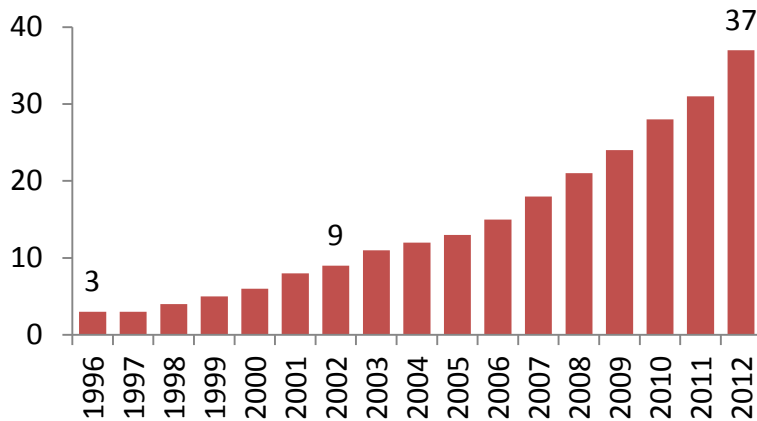
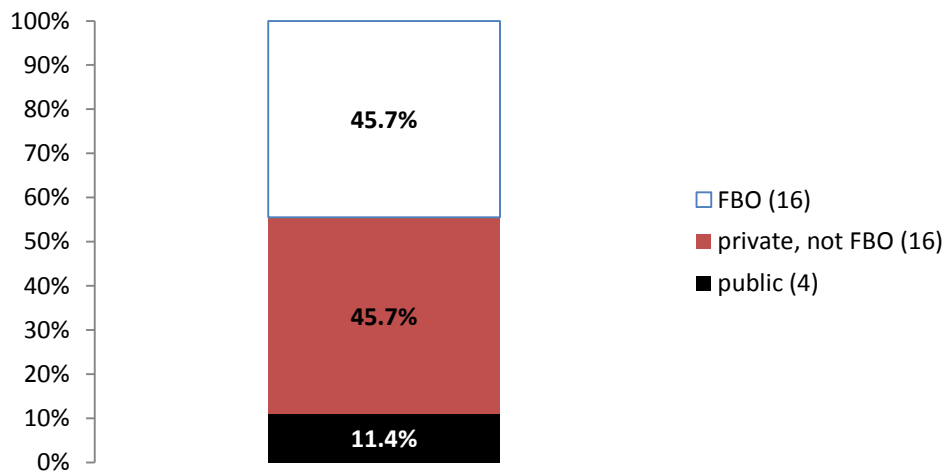


Figure 5-3: Residential Alcohol and Drug Rehabilitation Centres by Type



Among the private services, it can be challenging to determine which are for-profit and which are not-for-profit, as a number of the services have not-for-profit status but function as self-financing entities. Most of the truly not-for-profit services are faith-based, and faith-based services accounted for 42% of services listed by NACADA, suggesting that the remaining half of all alcohol and drug abuse services in Kenya are for-profit entities (figure 6-

<sup>13</sup> Kenyatta has a special para-statal status and controls its own budget; but functions as a public facility.

3). Based on online information, the mean number of beds in the twelve residential rehabilitation centres providing that information was 30 (s.d. 10), and the mean target length of stay in the sixteen facilities providing that information was 4 months (122 days). The standard deviation on target length of stay was large (99 days) because of a single outlier, which accommodated people for up to two years.

Outside of alcohol and drug abuse treatment, inpatient non-state mental health care exists in two varieties: 1) in designated psychiatric wards of three private hospitals, all in Nairobi; or 2) in general wards or private rooms of general private hospitals, found all over the country. In both cases, psychiatrists, like other medical specialists, are not on the staff of the hospital; but pay visits to the patients they have admitted. Nurses on non-specialised wards may or may not have specialized psychiatric nursing training. Of the three private hospitals with psychiatric wards, two (Nairobi West and Avenue Hospital) are general hospitals with locked psychiatric wings; and only one – Chiromo Lane – is a designated psychiatric hospital.

This chapter looks in detail at Chiromo Lane, a set of facilities to which I was granted rare access to conduct a case-study. The study comes at a pivotal time in the trajectory of the institution, as it is in the process of rapid expansion. The Chiromo Hospital Group now constitutes five facilities, with a total of 100 beds, making it the largest provider of private psychiatric services in Kenya and, to my knowledge, in East Africa. This chapter examines three types of mental health service coverage provided by Chiromo from Tanahashi's framework: availability coverage; contact coverage and accessibility coverage with an emphasis on the latter. The chapter seeks to answer the following research questions:

1. What health treatment is available to people with mental disorders at Chiromo?
2. Who is contacting services at Chiromo? How many people and what are their characteristics?
3. How financially accessible are these services? Does insurance increase access coverage?

The chapter does not address the effectiveness of services at Chiromo, as no outcome data were available for analysis.

## 5.2 Methods

### 5.2 - a) Case study method

My fieldwork was guided by the *Case Study Methodology to Monitor & Evaluate Community Mental Health Programs in Low-Income Countries* developed by Alex Cohen and colleagues (Cohen et al. 2011). The case study method is a manualized mixed method drawing from the fields of medical anthropology and health services research, and incorporating participant observation with collection of basic quantitative data. The method is a practical means of describing programs that cannot readily be captured by randomized controlled trials (Cohen, Kleinman et al. 2002), and it emerged with an eye towards evaluating the work of non-state actors, especially NGOs. This is the first time the method is being put to use with a for-profit provider.

Broadly, research using this method asks how well the programme responds to its local context, as defined by health policy, human and other resources, alternatives for care, and type of need. Data collection is conceptualized along seven topic areas: 1) context; 2) history; 3) programme model; 4) clients; 5) interventions; 6) organization and 7) information systems. In preparing the site visits and interviews, I revised the list of interview topic guides, which I submitted to the lead author of the case study manual together with comments on the contents of the manual. As a result of this contribution, I have been made a co-author on the second edition of the Case Study manual (Cohen et al. 2012).

I chose the case method from among other available research methods for reasons of practicality. The case method allows for an iterative process of posing questions, getting answers and posing more questions, which is ideal in a context about which almost nothing is publically known. Furthermore, the case method made it possible to integrate both quantitative and qualitative inquiries and to do so in a way that was minimally threatening to the institution being studied. It allowed the institution to jointly define the area of research interest and for them to gradually gain trust through contact with me during my field work. The strength of the case study method for community mental health, as compared with other case study methods, is that the questions outlined in the question guide (appendix 9) were particularly germane to mental health care, for example addressing electro-convulsive therapy and self-help groups, thereby ensuring that I did not miss key areas of importance.

I made my first visit to Chiromo Lane on December 13, 2011 to assess the feasibility of the case method in that context. In May 2012, I received formal consent of Chiromo's Board to conduct the research. Formal ethics approval for the research was granted by Kenyatta Hospital and the University of Nairobi joint Ethical Review Committee on May 18, 2012 in an amendment to the original ethical approval of my PhD fieldwork, granted on November 14, 2011.

#### 5.2.a.i Qualitative Data

Over the first two weeks of June 2012, I conducted daily visits to the four facilities in operation within the Chiromo Hospital Group so as to observe the environment and talk with patients and staff about their experiences. During that time, I conducted eleven interviews with members of staff: two directors, three nurses, four counsellors, the pharmacist, and the accountant. Interviewees were selected on the basis of who would be best equipped to answer the questions posed in the case manual question guide. The response rate to interviews was 92% with one director refusing on the grounds that he had too many patients to see. He invited me, instead, to observe his patient sessions with permission from patients. Please see the section on ethics in chapter three for a review of the ethical considerations of this research.

In addition to the formal interviews, I held informal conversations with a dozen patients, as well as with a nurse's aid, the kitchen, maintenance and security staff, and I observed clinical practice during consultations of three psychiatrists (all directors), two group therapy sessions, and three community meetings. Finally, I held a key-informant interview with a person in charge of insurance for chronic disease at AAR, a health maintenance organization. It was not possible within the time constraints to interview an employer in charge of one of the employer-run insurance schemes.

I took hand-written field notes throughout the course of the day, and at the end of each day, I typed them up. Much of the field notes consist of observations, but occasionally I recorded verbatim speech from my notes, when the language used seemed singular or noteworthy. The complete field notes constitute a 16,000 word record of my observations. I also took photos and collected supporting documents from the pharmacist, accountant and nurse in charge, as well as gathering publically available data from the internet on the landscape of providers of residential care.

I used thematic analysis to analyse the qualitative data collected during my site visit. I started with an analytic framework using the domains defined by the case study (see appendix)

and I categorized my field notes according to those themes. Next, I sorted the themes according to what they revealed about my three research questions. The process of data collection and analysis were iterative in the first instance, as what I observed in the hospital helped to shape the set of questions I posed next.

The purpose of the qualitative data analysis was to contextualize the quantitative data and to provide a depth of understanding and insights that could not be captured through the variables in the dataset. In addition, the qualitative observations helped guide what data I collected quantitatively. For example, I was not initially planning to find out rates of involuntary admission, until the question of patient rights emerged from observing the consequences of a patient refusing medication. Indeed, at the outset of the research, I did not anticipate having access to a relative abundance of quantitative data. It was only through the process of interviews and probing that the quantitative data were made available. The research question addressing availability coverage is better addressed by the qualitative data than by quantitative data, as these data provide insight into the inception of the service, and contextualize it within the wider landscape of services.

#### 5.2.a.ii Quantitative Data

The primary quantitative dataset was compiled from detailed invoices from Chiromo Lane, which serve as a record of service use, cost of care, length of stay and readmission. These data were available thanks to a new hospital management information system, instituted in March 2011. The accountant at Chiromo was forthcoming in sharing data, and went so far as to bring in the computer engineer who designed the HMIS in order to add the functionality of exporting data into Excel. Unfortunately, the Excel export function did not work for the detailed accounts, which were the main source of my quantitative data analysis. The accountant provided detailed invoices for all patients discharged from 28 March 2011 through 27 March 2012. In addition, twelve months of follow-up data were made available for 317 patients. Data were provided in Notepad (3,000 pages) and I re-entered selective components into SPSS 19. Data on medicine use were entered for a subset of the first 100 unique patients.

I entered 33 variables from the detailed invoices (appendix 22), describing demographics (age, sex, religion, marital status, occupation, address) and costs of care (bed fee, counselling, group therapy, doctors' fees, medicines, labs, ECT). In the raw data, each case was a discharge. I restructured the dataset from long to wide so that each case was a unique patient, thereby enabling analysis of follow-up data over 12 months. I also transformed the costs of care into binary variables to indicate whether different types of treatment had been

received. Finally, I computed additional variables of interest, such as length of stay per discharge, total length of stay, charge (per day, per stay, per year) and number of readmissions, (table 5-2)

Quantitative data were also given to me from two other facilities within the Chiromo Hospital Group, called Bustani and the Retreat. These facilities provided patient admissions logs in Excel and Word, identifying all patients treated since they began operation (10 years and 2 years respectively), as well as their diagnosis, age and sex. Dates of admission and discharge were also recorded, so it was possible to calculate length of stay, however there was no documentation of readmission. In addition to these datasets, I collected my own data on involuntary admissions, reviewing the clinical records of the 50 most recent patients hospitalized at Bustani and Chiromo Lane.

### *5.2 - b) Data cleaning*

I went to great lengths to verify the accuracy of the data, cross-referencing cases between datasets, and conversing on several occasions with the accountant, Musa Korir. I will describe the data cleaning methods I used on a variable by variable basis.

#### **5.2.b.i Editing**

I calculated length of stay in three ways: 1) by subtracting the date of arrival from the date of discharge; 2) by dividing the total cost of bed fees by the unit cost of bed fees; 3) where applicable, by dividing the total NHIF claim by the fixed daily claim amount of 800 Ksh. Where there were discrepancies, I relied on the total bed fee as the most accurate measure of length of stay, on advice from the accountant. I checked the variable for sex against patient names and found a number of discrepancies. So, I asked the accountant to re-enter all the data on sex and resolved all the ambiguities. I searched for duplicate names with different patient IDs and found three. In two cases, I determined from the address that the patients were the same and I merged the data, and in one case, I determined that the patients were distinct and kept them separate.

#### **5.2.b.ii Coding**

I transformed the string variable for primary diagnosis into a categorical variable testing multiple categorizations. Conversations from my site visit revealed that the term “mood disorder” refers to bipolar disorder, and MDP, short for “manic-depressive psychosis,” refers to schizo-affective disorder, so I recoded those conditions as such. I first categorized

diagnosis with as much specificity as possible. In keeping with Kenyan literature (Ndetei, Khasakhala, Ongecha, et al. 2008), I merged the diagnoses of “psychosis,” “paranoid psychosis,” “psychotic” and “acute psychotic episode” with schizophrenia. Thus, the first categorization was in 8 parts: 1) alcohol disorder; 2) substance disorder; 3) bipolar disorder; 4) schizophrenia or non-affective psychosis; 5) schizo-affective disorder; 6) common mental disorder (depression/anxiety); 7) comorbid condition; 8) other.

Using the categories from the WHO’s flagship Mental Health Gap Action Programme (mhGAP), I then reduced the number of diagnoses into six, five, four and three categories. The mhGAP defines eight priority conditions: 1) depression (and anxiety); 2) schizophrenia and other psychotic disorders; 3) alcohol disorders; 4) drug disorders; 5) childhood disorders; 6) epilepsy; 7) dementia and 8) suicide (World Health Organization 2008). Suicide is a consequence rather than a disorder, and thus does not apply here; nor do childhood disorders, since Chiromo’s population is adult. Dementia was too rarely the primary diagnosis and epilepsy was never the primary diagnosis, so neither condition warranted a category of their own. That left the first four conditions, to which I added categories for comorbid conditions and other, to capture sleep disorders. The resulting classification had six categories. Next, I created a five-category model, which conflated alcohol with substance disorders. Then I created a four-category model, which conflated comorbid and other disorders. Finally, I created a three-category model: 1) substance use disorders; 2) severe mental disorders; 3) common mental disorders; comorbid conditions and other. In my regression analysis, I tested different diagnostic groupings, using three, four and five categories. The diagnostic grouping had no significant effect on outcomes. So, I chose the three category diagnosis, since it has the most statistical power.

In addition to diagnosis, I explored various ways of transforming occupation from a string into a categorical variable. The Population Council, which conducts extensive research in Kenya on health and demographics, codes occupation into thirteen categories: 1) unemployed looking; 2) unemployed, not looking; 3) informal sector; 4) self-employed; 5) employed professional; 6) employed clerical; 7) employed manual, skilled; 8) employed manual, unskilled; 9) disabled; 10) casual skilled; 11) casual unskilled; 12) student; 13) other. The information in my dataset was not comprehensive enough, however, to be able to back-code the data in that way. Next, I looked to the International Standard Classification of Occupation (ISCO), published by the International Labour Organization and widely used in economics (International Labour Organization 2012). This categorizes workers into ten major groups, each of which can be sub-divided into one of four skill levels. My data lacked



specificity on skill level, ruling-out the ISCO classification. Finally, I looked to an analysis of the 2006 Kenya Integrated Household Budget Survey (KIHBS) (Pollin 2009). This study divided occupation along three main lines 1) agricultural self-employed, 2) informal sector and 3) formal sector, each of which was associated with a mean income. I adopted this classification, adding categories for unemployed, student, and house-wife.

### 5.2.b.iii Imputing

A significant amount of data was missing on some of the key predictor variables, in particular doctors' invoices, diagnosis and occupation. For diagnosis and occupation, I asked the accountant to return to the clinical files and locate the data on 133 missing cases. Occupation was not possible to retrieve, however, so it remained missing for 20% of cases (n=90).

The invoice for doctors' fees was missing from 30.7% of cases (n=182), three quarters of them (n=148) from patients with third party payers (chi square 1df  $p < 0.001$ ), so I imputed the missing data. The reason for much of the missing data is that invoicing for insured patients is often done directly to the insurer. Fees differed significantly by attending doctor, so I imputed values based on the attending doctor and whether the patient was insured. I imputed six different values, five for out-of-pocket patients according to their doctor and the sixth for patients with third party payers. There were not enough data points to vary the fee for insured patients by doctor.

### 5.2 - c) *Quantitative Analysis*

To explain variations between patients in amount and components of care, linear and binary logistic regressions were run in SPSS 19 on four dependent variables: 1) readmission; 2) cumulative annual length of stay; 3) charge per day; and 4) cumulative annual charge. Covariates examined were age, sex, diagnosis, insurance, attending doctor, and whether the patient was earning income prior to hospitalization. Since the distribution of total length of stay and total charge were highly skewed, I took the natural log of those variables and ran log-linear regressions. Regressions were run on the 317 patients with 12 months of follow-up data. However, because of missing values, complete data were available for only 244 patients.

For each of the regressions, I tested three models, using forward selection with four, five and six covariates. Model 1 used age, sex, diagnosis and insurance as covariates. Model 2 added whether the patient was earning prior to hospitalization; and Model 3 added the attending doctor. Since 69 cases were missing data on occupation, the sample size for model 1 was originally higher than models 2 and 3, so I reran the regressions with the same 244 cases as the other models, so as not to distort significance because of differing sample power. In the

following section, results of the qualitative and quantitative analysis are combined in order to answer the research questions.

The terms cost and charge are used interchangeably at some points in the chapter for ease of reading, however it should be noted that the values reported are technically charges, not costs. Since bed fees changed during the period of study, the unit bed fee was held constant using March 2012 rates. Int\$ were converted using the IMF rate of 38.4 Ksh to 1 Int\$.

### **5.3 Results: Availability Coverage**

#### *5.3 - a) Origins and Growth of the Institution*

Founded in 1996, Chiromo Lane offers acute private psychiatric care in a small-scale (30-bed), low-level hospital with comfortable accommodation, aspiring to the motto “recovery in dignity.” The founding staff are a social worker and three psychiatrists, the latter trained at the Maudsley hospital in London, UK, prior to establishment of psychiatric training in Kenya (1971). The impetus to its creation, as described by one of the founding directors, was demand.

“I used to be the Medical Supervisor at Mathare and people would ask me, “Where else can we go?” because of the conditions there. First, I would send them to Aga Khan or Nairobi Hospital, where the general wards accept psychiatric patients. But the other patients couldn’t manage being next to psychiatric patients with erratic behaviour and the nurses were not trained in management of mental illness. So then we would send them to Avenue Hospital, which has a locked psychiatric ward with about 20 beds, but it became congested.”

The founding directors put up their own money and took out loans to buy the land on which Chiromo sits.

The building in which Chiromo is housed was a private home, not a purpose-built psychiatric hospital. Located in a former private home in the wealthy Westlands neighbourhood of Nairobi, it maintains the structure and feel of a home – with open doors, small rooms and a garden. Downstairs in the two-story building are five shared rooms for three to four people each, called “general wards.” Three of the general wards are designated for men and one for women. Upstairs are seven additional rooms, five of which are private and often unoccupied. There is also a living room area with a television. Meals are served downstairs in an inner courtyard of the building, and the food is good local fare (*ugali*, *sukumawiki*, *meat*).

At any given time (other than meals) about half of patients can be found in the courtyard, sitting in chairs, reading the paper, or talking with one another. The garden area is closed off by a metal gate, guarded by an *askari*, a typical form of security for well-to-do Nairobi residents. The *askari* protect not only the patients from getting out, but also potential robbers from forcing their way in.

Despite its convivial feel, signs of restriction are nonetheless present in Chiromo, as might be expected within a psychiatric hospital. As you enter the building, a sign reads in English, “Kindly hand over all your money and valuables to the nurse on duty for safe-keeping.” On a bulletin board inside another sign reads “Notice to all: glass bottles not allowed. For safety reasons.” One room on the ground floor is reserved for solitary confinement of patients who become unmanageable. The staff refer to the room as “the obs room,” while patients call it “the cell.” One patient noted, “It’s not even a cell, it’s a mortuary.”

Chiromo first expanded in 2001 (table 5-3), when the Board responded to a request from “stable” patients (non-violent, non-psychotic) to be separated from “unstable” patients. **Bustani**, meaning resting place, was created for that purpose with a focus on younger people. Though located in a different (equally wealthy) neighbourhood in Lavington, Bustani functions like a second 15-bed unit of a single hospital. Chiromo and Bustani are owned and managed by the same Board, medicines are supplied by the same source, nurses wear the same logo-ed uniforms, and patients are readily transferred between the two facilities, although they maintain separate patient identification numbers.

A single story brick house, Bustani is surrounded by a large and well-tended garden. The living-dining room area is appointed with comfortable chairs and couches with plastic coverings and a large 8-seater dining table. Against the walls are two desks, one with a computer, although it is not working, and a very new-looking TV with satellite reception and a DVD player. The walls are hung with patient art as well as with supposedly calming images, such as flowers and swans. Bathrooms are the same for patients and staff and are clean. A water dispenser offers cold and hot water at all times.

Table 5-1: Chiromo Hospital Group Overview

Facility Name	Chiromo Lane	Bustani	The Retreat	Havilah House	Retreat Pwani
<b>Purpose</b>	Acute psychiatry ("unstable" patients) & detox	Acute psychiatry ("stable" & younger patients) & detox	Alcohol & drug rehab	Alcohol & drug half-way house	Acute psychiatry, detox & rehab
<b>Year established</b>	1996	2001	2010	2012	2012
<b>Location</b>	Nairobi, Westlands	Nairobi, Lavington	Limuru	Nairobi, Upper Hill	Mombasa
<b>Beds</b>	30	13	25	15	17
<b>Patients at time of visit</b>	20	7	20	4	NA
<b>Target length of stay</b>	2 weeks	2 weeks	6-8 weeks	3 months	NA
<b>Average length of stay in days (s.d.)</b>	11.8 (10)	15.9 (32)	52 (35)	NA	NA
<b>Average LOS per year</b>	16.7 (18.5)	NA	NA	NA	NA
<b>Admissions in last recorded year</b>	450	129	91	NA	NA
<b>Occupancy rate</b>	56.6%	37.5%	51.9%	NA	NA
<b>Involuntary admissions</b>	70%	22.9%	0%	0%	NA
<b>% male</b>	66.4%	63.8%	87%	NA	NA
<b>Mean age (s.d.)</b>	36.3 (13.7)	30.7 (11.2)	33.1 (10.4)	NA	NA

The environment at Bustani is much less restrictive than at Chiromo. Patients are allowed to keep their phones and belongings. Instead of the “Smoking highly prohibited” signs found around Chiromo, here a sticker on the bulletin board reads, “Hot chicks don’t smoke.” The bulletin contains other inspirational quotes, where Chiromo’s contains rules and public health messages. The four bed-rooms bear name plates over the doors with floral names: Mulberry (3 beds), Snow-drop (3 beds), Dahlia (2 beds), Balm (5 beds).

The second expansion was from acute care to rehabilitation with the aim of improving continuity of care. In 2010, the Board of Chiromo (slightly modified) set-up **The Retreat**, a rehabilitation located in Limuru, one-hour’s drive from Nairobi. The Retreat is indeed physically a retreat: you approach the facility down four kilometers of “rough road” (dirt), passing a flower farm along the way. The facility was built from a stately home, so “huge,” in the words of one staff member, that “If I lived here, I would get myself five wives!” The spacious building is one story tall, and rooms are laid out in two gendered wings – four in the

male wing, two in the female wing, with up to six beds per room. The maximum capacity of the building is 25 “residents,” all recovering from alcohol or drug abuse. The shift in language used by programme staff from patients to residents reflects both the longer stays and also possibly a different concept they have of a person recovering from substance use problem, as compared with a person recovering from psychosis.

Unlike Chiromo and Bustani, and despite being a converted home, The Retreat has a more institutional feel than the other two facilities. This is largely a result of the layout and decors. The walls are mostly hung with framed posters describing the mission, core values, philosophy and other key corporate or didactic principles. It has considerably less artwork or otherwise personal touches, and the large scale lends a feel of student hall to the living-room – which features a fish tank and a television with satellite reception. The bathrooms also have numerous stalls and showers side by side, unlike the other facilities, which have individual bathrooms. It is possible that the atmosphere of The Retreat reflects the influence of American rehabilitation clinics, as discussed below in the section on the programme model.

In 2012, the year of my fieldwork, the Chiromo Group expanded in two more directions: functional and geographic. With a continuing emphasis on improving continuity of care in addiction treatment (figure 6-4), the Chiromo Board opened a half-way house in the centre of Nairobi, called **Havilah House** with a capacity of 13 people for expected stays of three months. The name Havilah refers to a biblical place, rich in gold and onyx, which may have been on the East African Coast. The house is rather more prosaically located in the center of Nairobi’s Upper Hill neighbourhood on bustling Ngong Road, a major bus and *matatu* thoroughfare. It is also down the street from Dr. Njenga’s private outpatient practice (Upper Hill Medical Centre) and from Nairobi Hospital, one of the city’s pre-eminent private hospitals. The target population at Havilah House is people graduating from rehabilitation programmes, such as The Retreat, and re-integrating into work and life, but still wanting a structured environment that is substance-free. “Residents” meet as a “family” each evening for community meetings and can participate in two psycho-education groups on weekends. Random room checks ensure that the environment remains substance-free.

The two-story building is converted from four private apartments, separated by two staircases in the front and back. Each apartment holds at least three rooms, a kitchen and a living room featuring wooden floors and big windows. They are comfortable without being luxurious. One apartment hosts the counsellor’s office and a large living-dining area with a television that is on at all times and a menu of meals posted at the entrance. Nonetheless, the environment bore physical signs of the distress that brings people to live at a place like

Havilah House. In the counsellor’s office, a broken window marred an otherwise scenic view of the courtyard. I was told that “a patient” had thrown a stone, because he was angry, without further explanation. Clients of Havilah House are typically referred to as “residents,” but the shift in language to “patient,” serves as a reminder that they remain in a treatment setting.

Finally, June saw the opening in Mombasa of the newest member of the Chiromo Group, the **Retreat Pwani**, Swahili for Coastal Retreat. This 17-bed facility has a joint function of acute psychiatry and drug and alcohol rehabilitation, acting like a small-scale combination of Chiromo and The Retreat located on the coast, which is a main channel for the international drug trade.

Figure 5-4: Care pathway for a person with substance use disorder in the Chiromo Group



### 5.3 - b) Programme Model

The programme model in the Chiromo Hospital Group combines bio-medicine with elements of the therapeutic community approach. In terms of the biomedicine, the programme distinguishes itself by specializing in comorbidity between substance use and other psychiatric disorders. In addition, the programme adopts a secular orientation, despite accommodating many religious patients. Until recently, the majority of rehabilitation centres in Kenya were faith-based, so facilities like The Retreat and Havilah House fit a niche market for secular care with an emphasis on psychiatric comorbidity. The Retreat, for example, offers daily visits by a psychiatrist, whereas most rehabilitation programmes in Kenya rely exclusively on non-medical personnel. The secular care model, however, appears indissociable in this Kenyan context, from for-profit provision.

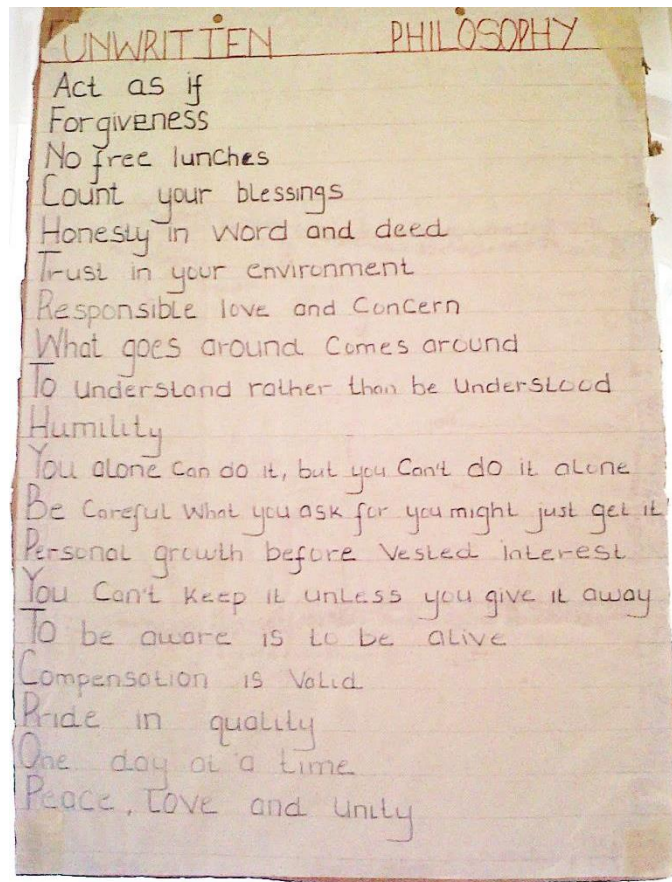


Figure 5-5: The “unwritten philosophy” at The Retreat

Despite its secular approach, elements of Christian culture are nonetheless apparent throughout the Chiromo Hospital Group. In the Retreat, for example, an “unwritten philosophy” – which is in fact hand-written and posted on the wall (figure 6-6) – contains 19 principles, some of them with Biblical overtones. The “philosophy” mixes idioms of common sense (“No free lunches,” “Count your blessings”), with Biblical phrases (“Honesty in word and deed,”), and apparent virtues (“Forgiveness,” “Humility”). The origins of the unwritten philosophy are unclear, although I was told they were compiled by staff. Rooms at the Retreat are named after parts of the unwritten philosophy, for example Forgiveness, which has six beds. Elements of the Christian prayer of St. Francis of Assisi is found both on the unwritten philosophy at the Retreat (“To understand rather than be understood,”) and also in Bustani, where “Lord make me an instrument of thy peace” appears on the bulletin board.

The presence of religion at the core of treatment is evocative of the 12-steps approach to substance use care, popularized through alcoholics anonymous (AA) and narcotics anonymous (NA) (Ferri, Amato, and Davoli 2006). The second of the twelve steps, after admitting powerlessness over alcohol, is to acknowledge that there is “a higher power,” sometimes referred to as God. The schedule of AA and NA meetings is posted on the bulletin

board in Chiromo Lane, suggesting that the 12-step model forms part of the network of continuing care available to patients in the community. Religion is also a central part of life for most Kenyans, however, so even a secular approach to treatment might be expected to include allusions to religion if it is to be culturally grounded. So, for example, a group meeting at Chiromo Lane started with a prayer and a song (“This is the day that the Lord hath made”), but patients are not asked to make professions of faith, nor are they told that their recovery will depend on God.

The therapeutic community (De Leon 2000) found in Chiromo is a peer-based approach to treating substance use disorders. Evidence of the therapeutic community approach was most visible throughout the hospital group in the form of daily community meetings in which patients were encouraged to voice “compliments and complaints.” These meetings were held in all facilities including Chiromo Lane, where they took place every other morning for about a half hour. The meeting I observed was attended by eight patients and three members of staff (two nurses, one counsellor), and it was not initially clear who were the patients and who were the staff. The meeting was run by a woman who turned out to be a patient and it opened with a prayer and a song. The list of compliments included that: the TV was on regularly; the food was delicious; the place was clean and didn’t smell; and some of the staff were good at listening. Complaints included that: the hot water had run out; one of the nurses had been rude; the food was too salty; it was deemed excessive to put someone in the observation room because they smoked; and the bed sheets in the observation room needed changing.

Chiromo’s therapeutic community or “TC” orientation was brought to the hospital group in the form of two large-scale trainings organized by NACADA and run by an American organization called Day Top. According to its website, Day Top has 13 residential centres in the United States, and has provided training overseas in Sri Lanka, Ecuador and Yunan, China. The first Day Top training in Nairobi took place in 2007 and lasted 6 weeks. It was open to all professionals with experience working with addiction, including psychologists, counsellors, and teachers. The second training, which took place in 2010, was more targeted, covering three core components of the TC approach: morning meetings, conflict resolution, and relapse prevention. The TC acronym suggests an intellectual product for sale and resonates with the more corporate approach of the Retreat, which was established the same year as the second training from Day Top.



### 5.3 - c) *Psychological Therapies*

Patients were admitted to Chiromo by their psychiatrist. Fourteen psychiatrists admitted patients in 12 months; however 87% of patients were admitted by only four psychiatrists, three of them hospital directors. The range of interventions offered included visits with psychiatrists, group therapy, psychiatric medicines, labs and scans and electro-convulsive therapy (ECT) (table 5-4). The hospital staff operated three shifts, morning (7.30am-2.30pm), afternoon (1.30pm – 8.30pm) and evening (7.30pm-8.30am). At each shift there were two care assistants and one qualified nurse on duty. Status reports were written about patients throughout the course of the day, every 4 hours (10am, 2pm, 6pm, 10pm, 2am and 6am). Any member of staff could add to the patient notes, which were read aloud in morning rounds.

In addition to daily consultations of approximately 15 minutes with a psychiatrist, two-thirds of patients received either individual counselling (60.2%) or group therapy (36.9%). Counselling was given by one of four full-time counsellors, predominantly young university-educated women. Patients receiving individual counselling averaged 1.2 sessions per week, each lasting up to an hour. Group therapy existed in various forms, including psycho-education, art therapy and (rarely) family therapy. Patients receiving group therapy averaged 1.4 sessions a week.

Group therapy is eclectic in orientation. Counsellors asked selected patients to join the group, on the basis of whom they thought capable of group participation. Then they selected a group topic relating to the issues of the day, sometimes influenced by what has been voiced in the community meeting. On the day I attended, the topic was violence and fear, since a female patient raised a complaint during the community meeting about having been hit by another patient.

Art therapy was held every other day at noon for one hour (figure 6-1), in alternation with group therapy. The session I attended was led by two counsellors and attended by ten patients (eight male, 2 female). The task at hand was to draw on an A4 paper in answer to the question “How are you feeling?” (chapter 3, figure 3-1). Patients each talked about their drawing and then counsellors elicited feedback from other patients. The discussion was lively and patients seemed engaged.

Other potential non-therapeutic activities for patients included playing board games amongst themselves or with counsellors. However, games were not out in the open; they had to be requested by patients. Basketball was also an option in theory, although the ball was lost when I visited. On one occasion, I saw two patients playing badminton outside. But many of the patients were too ill to play games.

### 5.3 - d) *Biomedical care*

One of the main forms of intervention at Chiromo, but by no means the only one, is medication. Patients are not allowed to refuse medication. In the words of one member of staff:

“Sometimes we say, ‘If you refuse to swallow, we will give you an injection. Still, we have to make sure that they swallow and haven’t hidden the pill, so we sometimes open their mouth and check the tongue. If a person refuses medicines, you are wasting a whole day that is payable.’”

Staying in hospital without taking medicines is viewed as a “waste,” because medicines are understood as the primary means of treatment – the main thing being paid for. The focus on value for money expressed by this member of staff may partially be a response to her realization that I was interested in the economics of care, as much as a reflection of her own concern with cost-saving. Not surprisingly, some patients objected to forcible treatment. One of them observed:

“In Europe they don’t inject you so much. Here it’s injections all the time. If they say, ‘Take this med,’ you must take it. If you refuse, they inject you with a ‘stopper.’ That’s what they call what they use to calm you down. It’s a thick white liquid.”

During my visit I observed a man being forcibly sedated and put into the observation room. The origin of the episode that he refused to take his antipsychotic medication and became belligerent. He had a record of beating someone up so badly that the man was sent to hospital.

At the site visit, 70% (n=14/20) of patients were admitted involuntarily, as compared to 23% (n=8/35) at Bustani, and therefore had limited choice in their treatment, including medication. (Kenya’s mental health law requires authorization from one doctor and one family member for involuntary admission.) Some said they received injectable medicines more than they would like. Indeed, three quarters (76.7%) receive an injection. Doctors and nurses preferred injection because it circumvents problems of adherence.

From the HMIS data, I found that nearly all (91%) patients were prescribed a psychiatric medicine (mean 3.3 medicines). The rates of medicine consumption by category were: antipsychotics 81%; sedatives 70%; antidepressants 21%; anticonvulsants 17%; drug or alcohol medicine 9%; lithium 5%; and methylphenidate (Ritalin) 2%. A wide range of medicines was available, including six antidepressants (4 SSRIs, 2 SNRIs and an adrenergic receptor antagonist) and nine antipsychotics (4 typical, 5 atypical).

In general, doctors at Chiromo prescribed branded drugs, and the pharmacist was required to fill the prescription as written. Two thirds (n=6) of antipsychotics and five of six antidepressants were prescribed in only brand form. Among patients taking antipsychotics, half (50.6%, n=42) were given only branded medicines. For olanzapine, given in both forms, the brand cost 15 times the generic. Reasons for preferring brands included: 1) preferable means of administration (eg soluble drops for olanzapine); 2) some patients prefer brands; 3) greater quality assurance. In the words of one doctor, “The greater price than the branded medicine is the price of not getting better, which people don’t calculate. If you stay for an extra three days inpatient because your medicine didn’t work, that is expensive.”

Chiromo’s pharmacy is a small room that is very well stocked. Eighty-seven medicines were prescribed to the patients in the HMIS sample, all of which were stocked locally. Chiromo even has a supply of some medicines that are not registered for use in Kenya (Ritalin, Naltrexone, Solian), having requested and been granted specific permissions to use them by the medical authorities. Most of the medicines (85%) come from a single local distributor called Krishna. Drugs that need to be imported are sourced directly from the manufacturer. Drug orders are placed once a week, on Wednesdays, and should supply run out, they can be restocked within the day. The only reason for shortage is when the suppliers run out, which happens rarely. The pharmacy tops up its wholesale prices by 33%, which is the maximum legal top-up controlled by a law on exploitation. It is not mandatory, however, for patients to buy their medicines from the Chiromo pharmacy.

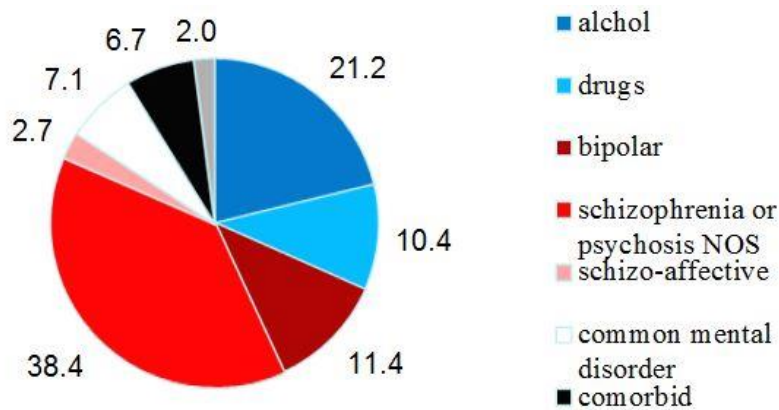
In addition to receiving medicines, over half of patients received a lab test (55.6%) or a scan (9.9%). The most common lab tests were blood tests, liver and thyroid functions, urinalysis, and diagnostics for infectious disease (e.g. HIV, malaria). Tests were also conducted to verify blood levels of medications, such as lithium. Scans included x-rays, electroencephalograms (EEG)s for epilepsy, computerised tomography (CT) head scans, magnetic resonance imaging (MRIs) and ultrasounds.

Lastly but significantly, sixteen per cent of patients (16.2% n=74) received electroconvulsive therapy (ECT), averaging 4.9 sessions (max12, s.d. 1.8). E.C.T. was administered bilaterally and modified with the muscle relaxant suxamethonium. On one of the afternoons of my visit, E.C.T sessions were scheduled with three patients. They took place upstairs in one of the private rooms. I did not observe an E.C.T. session out of concern for the vulnerability of the patients and a difficulty they may have felt in declining my request.

#### 5.4 Results: Contact Coverage

455 unique patients were seen at Chiromo Lane in a period of 12 months from March 2011 to March 2012. Two thirds (66.4%) were male with a mean age of 36.3 years (range 14-82). The population was Christian (90.6%), Muslim (8.0%) and Hindu or undeclared (1.4%), in proportions reflecting the national population (Ambetsa Oparanya 2010). Three-quarters (77.7%) lived in Nairobi; and during the site visit, 20% were foreign, from the Congo, Somalia and Sudan. It was not possible to get accurate data on addresses from the HMIS because the address noted was used for accountancy purposes so Kenyan addresses were preferred. Half (50.6%) were employed in the formal sector, a quarter (26.7%) were students, 13.5% unemployed or retired, 4.6% house-wives, and 4.6% farmers or informally employed.

Figure 5-6: Patient diagnoses, Chiromo



In 2010, 130 patients were seen at Bustani, two thirds (n=83) male, with an average age of 31 (sd 11). The mean length of stay was 15.9 days (sd 32.3, maximum 297). Readmissions were not recorded in this dataset. One third of patients in Bustani carried comorbid diagnoses. Over one half (n=66) were diagnosed with depression (with no sex differential). Just over a third (n=47) had a substance use disorder, the majority alcohol-based. In addition, just under a third of the population were diagnosed with ADHD (n=39), which was not found in Chiromo. Finally, a quarter (25%) of the population had a severe mental disorder, half of them (n=17) schizophrenia and the other half (n=16) bipolar disorder.

The population of the Retreat was mostly male (87%), and alcohol dependence was the problem affecting most of the residents (59%), while the remainder were affected by drug dependency or alcohol-and-drug dependency. In 2011, 107 people were treated for a substance use disorder at The Retreat, staying an average of 52 days (range 1-198, sd 35).

The patients at Chiromo were well-educated and often well-travelled. Several of them spoke in fluent English of experiences in Canada, China, Dubai and beyond. On one occasion, a patient was looking for a word, and another one offered “egotistical.” Signs posted around the facility were also in English, the language of educated Kenyans and also an international language. The staff I met, however, were all fluent in Swahili, with one exception (a counsellor), and clinical encounters were often conducted in Swahili.

Not all patients were articulate in English, however, nor were they all wealthy. I listened uncomprehendingly to a Somali man talk tearfully and imploringly, while holding my hand. And a woman, who appeared psychotic, spoke to me in agitated sentence fragments, mixing Swahili and English, about wanting to see her two children and asking where her underwear had gone. The lowest income patients appeared to be from among those whose care was paid for by an employer, as was the case, for example of a man who worked lifting cement bags.

Two male patients on detox shared with me their observations about the quality of care. They started by saying it was good: “You eat well and sleep well here.” And then that it was “50/50 – neither so good, nor so bad.” One man complained that some nurses are less experienced than others and assume that all health problems relate to mental health.

“I had an upset stomach because of some food that I ate and a bad smell was coming from my mouth. The nurse, he said it was the effect of the medicines I was taking, but me, I knew it wasn’t. Then I vomited a lot, and another nurse who was more experienced said that it could not be coming from those medicines, and he gave me a syrup and I felt better.”

The distinction between health and mental health is of both clinical and personal significance: clinical, because people with mental disorders often receive worse physical health care than the general population, and personal because the man in question did not want all his behaviours to be explained by the single factor of his psychiatric diagnosis. A further distinction was noted by another patient, who wanted not to be identified with patients with different diagnoses. “Having a mental illness doesn’t mean you are mad. But they treat us all the same, like we are all mad.” Indeed, not all patients were “mad,” although approximately half were diagnosed with a psychotic disorder (figure 6-5). One third of patients had a primary diagnosis of alcohol (21.2%) or drug disorder (10.4%), and half had a psychotic disorder, namely schizophrenia or non-affective psychosis (38.4%), bipolar (11.4%) or schizo-affective disorder (2.7%). Only 7% had depression or anxiety; and a further 7% had comorbid psychiatric diagnoses.

Table 5-2: Population characteristics and services used at Chiromo Lane Medical Center  
 March 2011-March 2012  
 Source: patient accounts

Demographics:		N
Male	66.4%	302
Mean age	36.3 (sd 13.6)	N/A
Nairobi address	77.7%	284/358
Religion:		(Total N: 79)
Christian	90.6%	74
Muslim	8.0%	4
Hindu or undeclared	1.4%	1
Occupation:		(total N: 326)
Formal sector employment	50.6%	165
Students	26.7%	87
Unemployed or retired	13.5%	59
House-wives or unpaid work	4.6%	15
Farmer or informally employed	4.6%	15
Earning income	55.2%	180
Financing:		(total N: 454)
insurance (100% of fees)	15.8%	72
employer (100% of fees)	12.7%	58
out-of-pocket	71.5%	324
NHIF (Int\$20 co-pay)	29.0%	133
Services:		(total N: 585)
Individual counselling	60.2%	352
group therapy	36.9%	216
lab tests	55.6%	325
scan	9.9%	58
ECT	16.2%	91
psychiatric medicine	91.0%	532
Medicines		(total N: 101)
antipsychotic	81.0%	83
sedatives	73.3%	74
antidepressants	21.0%	25
anticonvulsants	17.0%	21
alcohol or drug medicine	9.0%	9
lithium	5.0%	5
methylphenidate (Ritalin)	2.0%	2
Received only branded antipsychotics	50.6%	42
Received an injection	76.7%	77

## 5.5 Results: Accessibility Coverage

### 5.5 - a) Insurance coverage

One of the factors that stands out from the qualitative analysis of patients is that the services at Chiromo are reaching a predominantly wealthy population of sick people; and one of the primary means of broadening access to services across a wider population base is through health insurance. AAR, a health-maintenance organization chaired by Dr. Frank Njenga, one of Chiromo's Directors, is reportedly the first insurance provider to cover mental health care in Kenya. As described by one of the hospital Directors, Dr. Okonji, "It used to be that insurance wouldn't pay for psychiatric services, period. It was an exclusion, despite the 1994 Mental Health Act, which states that it is an offense to discriminate on insurance. I helped to write that Act, so I know."

An interview with a member of staff at AAR confirmed that they provide 100% coverage for inpatient mental health services up to a ceiling of Int\$ 6,600 (Ksh 250,000). The ceiling had increased 2.5 fold in the past decade from a starting point of Int\$ 2,600 (Ksh 100,000). Suicidality and substance use disorders were excluded from all AAR coverage. However in cases of comorbidity, Chiromo sometimes submits the comorbid diagnosis to the insurer to obtain coverage. Pre-existing conditions were also excluded from individual plans, but not from corporate plans. The pre-existing condition policy had recently changed, however, to introduce limited coverage for people with chronic disease.

Whereas inpatient hospital stays were well covered by insurance providers, I was told that none of them covers substance use rehabilitation. Only the National Hospital Insurance Fund contributes to rehabilitation costs, and its total contribution, making a flat payment of Ksh 3,000 (Int\$ 70) – hardly enough to cover a single day of the two-month rehabilitation.

AAR prided themselves on being an insurer aware of mental health problems. Every February, designated Mental Health Month, all patients who come into the clinic are screened with the Patient Health Questionnaire (PHQ-9). Furthermore, throughout the year, anyone who makes more than four visits to the doctor within 12-months is given an evaluation, which includes the PHQ-9. The screening has been said to locate "*hapa na hapa people*" – literally "here and there people" – referring to people with unexplained medical conditions. I was told of one patient who had had seven stomach operations in the previous year, though nothing had been found. Treating mental health problems was justified economically by the insurer as a means of keeping down unneeded medical costs.

Many companies that don't have a formal medical insurance scheme nonetheless have an ad hoc scheme. Companies view that they have a social responsibility to their employees, so they set aside a certain budget for medical expenses like any other company expense. Examples of companies that fall into this category are Kenya Power, KenGen and Portlands. Individual staff members do not usually contribute to the scheme.

According to the HMIS data, a quarter of patients (28.5%, n=130) had their care paid in full by an insurance provider (n=72) or employer (n=58). Twenty-one insurers and 29 companies provided coverage, in all cases without co-payment. There was no association between diagnosis and being insured (chi square p=0.54). The association between being insured and being employed was not significant at the 0.05 level (chi-square, p=0.08). In addition, NHIF partially reimbursed 29% of patients (n=133) with Int\$ 20/day (Ksh 800). A third (36.8%) of those receiving NHIF paid for the rest of their care out of pocket.

#### *5.5 - b) Charges and components of care*

Chiromo charged fee-for-service with lower fees for patients paying out-of-pocket. Patients paid a flat "bed fee" per night for accommodation and hired staff, which amounted to nearly half (45.8%) the total charge (table 5-5). A minority (11.8%) had private rooms, while the remainder stayed in general rooms of 3-4 people. Those paying out-of-pocket paid an upfront deposit of Int\$911 (Ksh 35,000) to cover approximately one week of "bed fees." The second leading component of charges was psychiatric consultations, which represented one third (30.2%) of fees. Medications were the third highest expense, amounting to 10.0% of the invoice. The lowest-cost intervention was non-medical psychological therapies at only 1.6% of charges. Mean charge per patient day in the general ward was Int\$ 266 (Ksh 10,218). The distribution of total yearly charge was skewed with mean Int\$ 4,262 (Ksh 163,648) and median Int\$ 2,821 (Ksh 108,333).

#### *5.5 - c) Length of stay and readmission*

Mean length of stay (LOS) at Chiromo was 11.8 days (max 93, s.d. 10.0). One quarter (22.2%) of patients were readmitted within 12 months (mean 1.4 readmissions). Mean cumulative length of stay over 12 months (figure 6-7) was 16.7 days (median 10.6, max 153, s.d. 18.5).



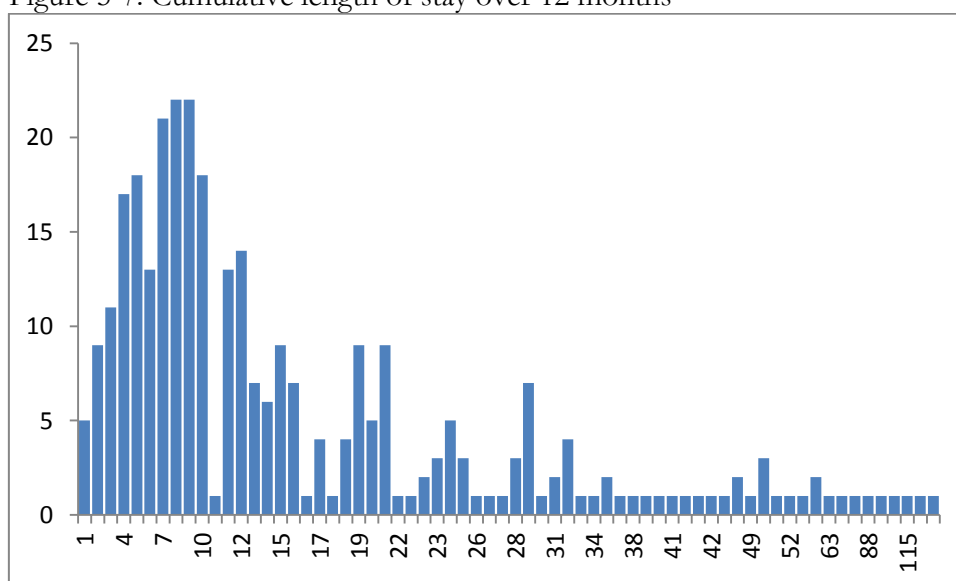
Table 5-3: Component and aggregate charges

Mean Component Charge	Int\$	Ksh	% Total
"Bed fee" (hotel fee) - out-of-pocket	117	4,500	45.8%
"Bed fee" - third-party payer	130	5,000	
Psychiatrist	78-104	3,000-4,000	30.2%
Medication per day	32	1,220	10.0%
E.C.T	299	11,500	7.9%
Labs & scans	151	5,800	3.6%
MRI	234	9,000	
x-ray	39	1,500	
Talk therapy			1.6%
art therapy	5	200	
psycho-education groups	13	500	
individual counselling	26	1,000	
Other (eg external consults)			0.9%
Total			100.0%

Aggregate Charge	Int\$	Ksh	S.D.
Mean charge per day	266	10,227	2,625 (Ksh)
Mean charge per year	4,276	164,215	167,927 (Ksh)
Median charge per year	2,821	108,317	71,622 (Ksh)

Figure 5-7: Cumulative length of stay over 12 months



	Mean	Median	S.D.	N
Annual LOS (days)	16.7	10.6	18.5	316
LOS per stay (days)	11.8	9	10.0	585

### 5.5 - d) Regression outcomes

*Readmission* (table 5-7): All three models show having a third-party payer (insurance or employer-based) as a robust positive predictor of readmission, although the significance weakens to the 0.06 level in model three. Concretely, having a third-party payer increases the odds of readmission by 2-3 (the exponentiated betas of models 1-3). When model one was run on the larger sample (n=301), severe mental disorder also became significant. Severe mental disorder appears associated with risk of readmission, but complicated when employment is introduced. This may be because those with severe mental disorder are somewhat less likely to be earning income (although there is no significant association between these variables – see diagnostics below). The third model shows care by a particular doctor being preventative of readmission. It is possible, however, that the doctor has a diagnostic speciality and therefore that this is an effect stemming from the influence of diagnosis.

*Annual length of stay* (table 5-8): Model one shows both having a third party payer and a diagnosis of severe mental disorder (compared with substance use disorder) are both predictive of longer cumulative stays. When controlling for earning (model two), however, the effect of diagnosis disappears. Earning income becomes a significant predictor when controlling for doctors in model 3, with those earning income staying less long in hospital.

*Daily charge* (table 5-9): The regression results confirmed that having a third-party payer predicted the daily charge, as was known from the two-tiered pricing system. What it revealed, however, is that patients with a severe mental disorder were also more likely to pay more per day than those with substance use disorders, controlling for insurance coverage, age, sex and the doctor. The effect size of this finding is quite small, however. Finally, the attending doctor was also found to predict charge in model 3.

*Annual charge* (table 5-10): As for daily charge, annual charge was predicted by having a third-party payer and a diagnosis of severe mental disorder. When doctor was added into the equation (model three), all doctors appeared to have patients with higher charges than the reference doctor (not named here for confidentiality).

Table 5-4: Predictors of readmission

Readmission Predictor	Model 1 (n=301)			Model 2 (n=244)			Model 3 (n=244)		
	Exp(B)	S.E.	Sig.	Exp(B)	S.E.	Sig.	Exp(B)	S.E.	Sig.
Age	1.00	0.02	0.88	0.99	0.02	0.65	0.99	0.02	0.64
Sex	1.00	0.45	0.99	1.14	0.46	0.78	1.30	0.48	0.64
Payer	2.81	0.44	<b>0.02</b>	2.47	0.44	<b>0.04</b>	2.40	0.47	<b>0.06</b>
Diagnosis									
* severe mental disorder	1.97	0.52	0.19	1.98	0.52	0.19	1.53	0.54	0.32
* common mental disorder & other	1.54	0.70	0.53	1.63	0.70	0.48	1.20	0.73	0.62
earning income				2.22	0.49	0.11	2.40	0.51	0.11
doctor									
doctor 1							0.57	0.74	0.44
doctor 2							0.18	0.69	0.31
other doctors							0.59	0.51	0.01
Log likelihood ratio	158.70			155.90			148.20		

Reference group for diagnosis is substance use disorder, for payee is out of pocket

Table 5-5: Predictors of annual length of stay

Cumulative LOS (ln) Predictor	Model 1 (n=244)			Model 2 (n=244)			Model 3 (n=244)		
	B	S.E.	Sig.	B	S.E.	Sig.	B	S.E.	Sig.
Age	0.00	0.00	0.28	0.01	<0.01	0.11	0.01	0.00	0.10
Sex	-0.02	0.12	0.89	-0.05	0.12	0.67	-0.06	0.12	0.64
Payer	0.27	0.12	<b>0.03</b>	0.31	0.12	<b>0.01</b>	0.34	0.13	<b>0.01</b>
Diagnosis									
* severe mental disorder	-0.15	0.12	0.23	0.14	0.12	0.70	0.13	0.12	0.85
* common mental disorder & other	-0.07	0.15	0.66	0.06	0.16	0.24	0.03	0.16	0.31
Earning income				-0.21	0.11	<b>0.06</b>	-0.23	0.11	<b>0.05</b>
doctor									
doctor 1							-0.04	0.20	0.85
doctor 2							-0.10	0.14	<b>0.06</b>
other doctors							-0.27	0.14	0.47
R <sup>2</sup>	0.03			0.04			0.06		

Reference group for diagnosis is substance use disorder, for payee is out of pocket

Table 5-6: Predictors of charge per day

Charge per day Predictor	Model 1 (n=242)			Model 2 (n= 242)			Model 3 (n=242)		
	B	S.E.	Sig.	B	S.E.	Sig.	B	S.E.	Sig.
Age	0.00	0.00	0.95	0.00	0.00	0.73	0.00	0.00	0.93
Sex	-0.05	0.03	0.16	-0.05	0.03	0.13	-0.04	0.03	0.23
Payer	0.22	0.03	<b>&lt;0.01</b>	0.22	0.04	<b>&lt;0.01</b>	0.19	0.03	<b>&lt;0.01</b>
Diagnosis									
* severe mental disorder	0.07	0.03	<b>0.04</b>	0.07	0.03	<b>0.04</b>	0.08	0.03	<b>0.02</b>
* common mental disorder & other	0.03	0.05	0.58	0.02	0.05	0.62	0.02	0.04	0.67
earning income				-0.03	0.03	0.37	-0.02	0.03	0.44
Doctor									
*doctor 1							0.40	0.05	<b>&lt;0.01</b>
*doctor 2							0.15	0.04	<b>&lt;0.01</b>
*other doctors							0.15	0.04	<b>&lt;0.01</b>
R <sup>2</sup>	0.15			0.15			0.32		

Reference group for diagnosis is substance use disorder

Table 5-7: Predictors of annual charge

Total Charge (ln) Predictor	Model 1 (n=242)			Model 2 (n= 242)			Model 3 (n=242)		
	B	S.E.	Sig.	B	S.E.	Sig.	B	S.E.	Sig.
Age	0.00	0.00	0.24	.007	.004	.073	0.01	.004	.074
Sex	-0.06	0.11	0.62	-.095	.115	.408	-0.09	.115	.459
Payer	0.49	0.12	<b>0.00</b>	.537	.121	<b>&lt;0.001</b>	<b>0.53</b>	.123	<b>&lt;0.001</b>
Diagnosis									
* severe mental disorder	0.21	0.12	<b>0.07</b>	.210	.119	.079	0.20	.119	.097
* common mental disorder & other	0.11	0.16	0.48	.092	.160	0.56	0.06	.160	.718
earning income				-.241	.111	<b>.031</b>	-0.25	.111	<b>.025</b>
Doctor									
*doctor 1							0.36	.205	.078
*doctor 2							0.05	.135	.697
*other doctors							-0.12	.138	.393
R <sup>2</sup>	0.08			0.10			0.12		

Reference group for diagnosis is substance use disorder

Figure 5-8: Residuals for LOS regression, Model 1

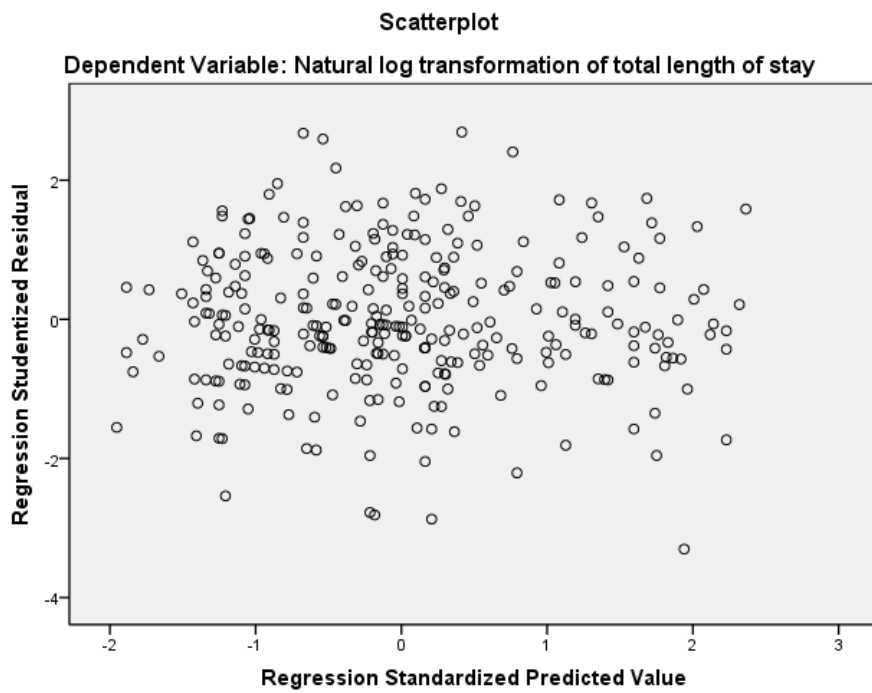


Figure 5-9: Residuals for Total Charge, Model 1

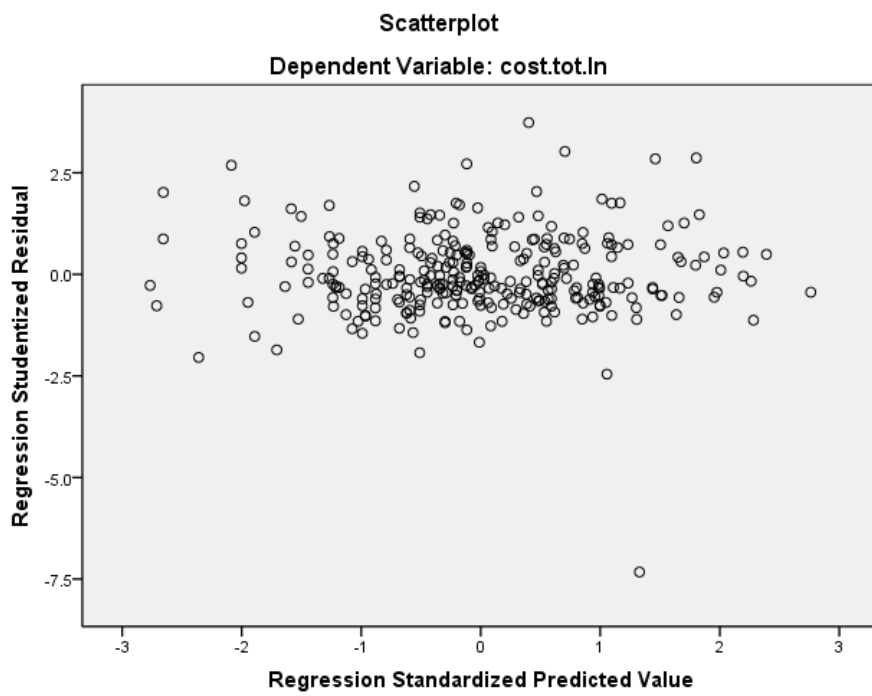


Figure 5-10: Residuals for Total Charge, Model 2

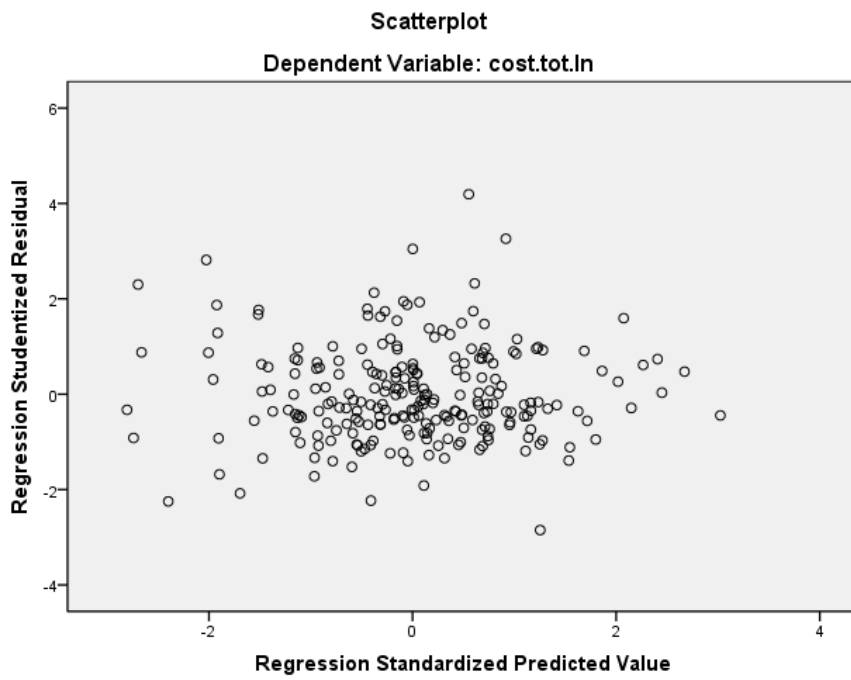
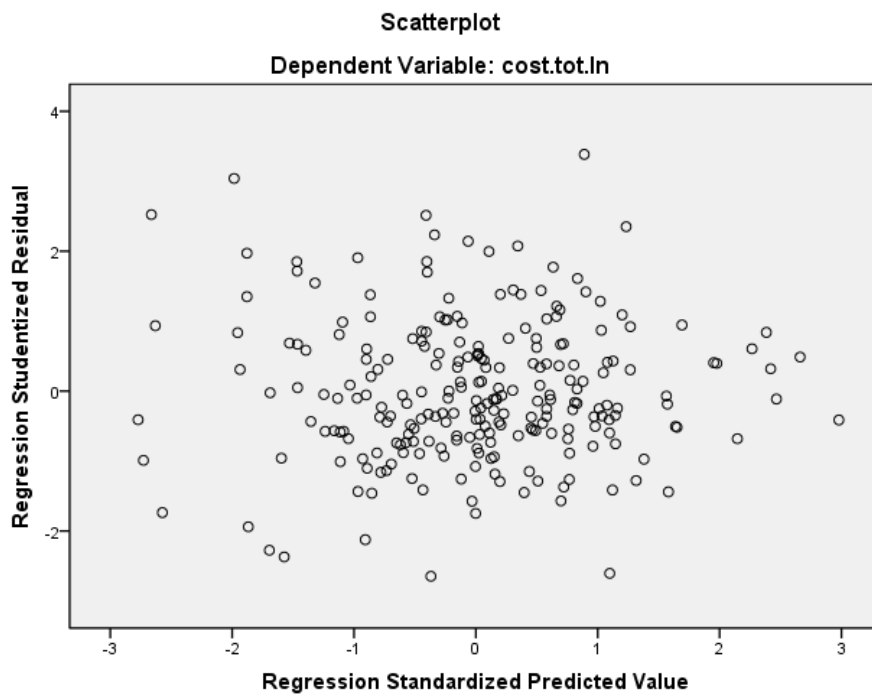


Figure 5-11: Residuals for Total Charge, Model 3



*Diagnostics:* I tested the assumption of homoscedasticity (homogeneity of variance) by plotting studentised residuals. The residuals for the regression on total length of stay were clearly homogeneous (figure 6-8). For the regression of total charge, the residuals grew more homogeneous with each additional independent variable (figures 6-9 through 6-11), suggesting that the third model may be the best.

I also tested the models for multicollinearity (table 5-6). In theory, having a third-party insurer and being in paid employment might be collinear, as insurance is often employer provided, but the chi square test of association was not significant at the 0.05 level ( $p=0.09$ ). Indeed, since some insurance covers family members, the insured party is not necessarily employed. Next, I tested the association between diagnosis and payer, because most insurance companies explicitly do not cover substance use disorders; but the association was insignificant (chi square,  $p=0.36$ ). In addition, I tested the association between diagnosis and employment, hypothesizing that people with severe mental disorders might be less likely to be in employment than those with substance use disorders. There was no association, however, between these two variables (chi square,  $p= 0.51$ ).

Table 5-8: Tests of collinearity (chi square)

Variables	p-value
Diagnosis (3 categories) and payer	0.09
Employment and payer	0.36
Diagnosis (3 categories) and employment	0.51

Finally, I examined the goodness of fit of the models, as suggested by the R squared statistic. The R squared figures were relatively low in all the regressions, as outcomes are likely to be driven largely by illness severity, a variable for which we had no measure. R squared was particularly low for length of stay (0.03-0.06), but the models were better at predicting daily charge (R squared 0.15-0.32). Annual charge was driven in part by length of stay, so its R squared falls between those for LOS and for daily charge (0.08-0.12).

## 5.6 Discussion

With eighteen psychiatrists admitting patients to the facility, Chiromo is a treatment facility for half of Kenya's total population of psychiatrists. Moreover, given the small amounts of money invested into mental healthcare broadly in Kenya, the relatively large amount of spending in Chiromo makes it an important subject of study within Kenya's mental healthcare system.

### *5.6 - a) Availability coverage*

The expansion of Chiromo over the past decade has largely served the purpose of improving continuity of care. The combination of facilities creates a single continuous service from hospital admission to home – but only for patients with substance use disorders at present. The conceived pathway of care for a patient with substance use disorder in the Chiromo Group in Nairobi is two weeks of acute care at Chiromo or Bustani, followed by six weeks of rehabilitation at The Retreat, then three months at Havilah halfway house, and finally a return home. The hospital group has yet to offer comparable continuous services for patients with non-substance related psychiatric disorders. Indeed, this appears to be a gap in service provision within both public and private mental health service provision in Kenya. The singularities of Chiromo within the larger context of residential services are its secular model, based on the therapeutic community approach, and the emphasis on comorbidity between substance use disorders and other psychiatric disorders.

### *5.6 - b) Accessibility coverage*

The most salient finding from the regression analysis is the positive association between private health insurance and both quantity and cost of care. In terms of cost, it is possible that the higher cost of care to insured patients constitutes a mild form of cross-subsidy towards the out-of-pocket patients. That being said, out-of-pocket charge to the uninsured remains high, making this only a very partial cross-subsidy at best. In terms of quantity, in the absence of data on health outcomes, it cannot be rigorously determined whether additional days of hospitalization and readmission indicate moral hazard of insurance or greater access to needed treatments. However, the literature provides some benchmarks of quantity of care against which to begin to assess quality in this setting.

Literature from other parts of the world on the effects of insurance on service use for chronic disease suggest that insurance may be associated with more care. On the side of quantity, a small study from Argentina found the odds of anti-depressant use were 7.2 times higher among the insured than the uninsured (Machnicki, Dillon, and Allegri 2011). A study examining insurance effects among 3,824 participants with common mental disorders in Santiago, Chile, found that half were privately insured, and they had 2.7 times higher odds of receiving a mental health consultation than those publicly insured, adjusting for the more severe symptoms found among the publicly insured (Araya et al. 2006). Health insurance was therefore associated with more coverage in a context of low overall coverage (20% of those with disorders received any consultation), but also with increased inequality. Health outcomes



for those on insurance may also be better, as suggested by findings from a large-scale study of a general population in China where having health insurance (of unspecified type) was associated with lower severity of depressive symptoms (Tian et al. 2012).

In a higher-income context, the inverse relationship was found in relation to quantity of care and private insurance. A study from Israel observed that when insurance was associated with fee-for-service (i.e. a fee per inpatient day), it resulted in lower length of stay for mental disorders than in public health care, where provider payments were made based on an annual global budget (Bodner et al. 2010). The modality of provider payments may be as important as insurance in determining the quantity of care.

In the African context, Chiromo has considerably shorter stays than most psychiatric hospitals, suggesting there is not an evident over-consumption of care. A general teaching hospital in Johannesburg has a mean psychiatric LOS of 15.4 days (van Rensburg 2011), which approximates the LOS in Chiromo. However, the Johannesburg hospital has a readmission rate of only 7.5%, suggesting better continuity of care after discharge (van Rensburg and Olorunju 2010). A public general hospital in South Africa, found a mean LOS for psychotic men of 43.9 days (sd 39.4) (Niehaus et al. 2008). And a general public teaching hospital in Nigeria had a mean psychiatric LOS of 28.7 days (n=371) (Oladeji, Ogundele, and Dairo 2012).

It is somewhat challenging to interpret Chiromo's use of ECT in the absence of a severity marker for the population. Chiromo's ECT rate, is high by global standards, but lower than among inpatient psychiatric populations elsewhere in Africa. According to a recent systematic review, African ECT rates range from 21-28% at hospitals in Malawi, Nigeria and South Africa (Leiknes, Schweder, and Hoie 2012). It could be argued that a country with less accessible mental health treatment might have a more clinically severe population that warrants more ECT; however it could equally be argued that a country with a better health care system offering more community-based care would reserve hospital treatment for only the most severe.

Beyond the question of its frequency is how ECT is administered. ECT in Africa is generally performed unmodified (without muscle relaxants) (James et al. 2010; Selis, Kauye, and Leentjens 2008), because of resource constraints, whereas Chiromo follows international guidelines, modifying ECT with a relaxant. The mean number of sessions at Chiromo (5) approximates the 6 session dose recommended by the UK's National Institute for Clinical Excellence (NICE) (National Institute for Clinical Excellence 2003). Patients receiving ECT at Chiromo are predominantly diagnosed with schizophrenia or bipolar disorder. NICE

guidelines do not recommend using ECT for schizophrenia; however, Royal College of Psychiatry guidelines specify cases where ECT is recommended, particularly for catatonic schizophrenia (Royal College of Psychiatrists 2005). On the basis of what can be measured, it appears Chiromo is performing ECT within the realms of appropriate use.

### *5.6 - c) Contact coverage*

At 57.6%, occupancy rates at Chiromo were low at the time of study. I was told that one reason for keeping beds empty is that staffing capacity was not on par with infrastructural capacity, so that while the hospital could physically accommodate more patients, it could not do so to desired levels of quality. Another potential reason for low occupancy was the financial barrier to treatment.

With a per-capita GDP of Int\$ 1,015 (Ksh 38,970) (Kenya National Bureau of Statistics 2007), treatment at Chiromo lies well beyond the reach of most Kenyans, making charge the main barrier to access. By comparison, the World Health Organization's method for Choosing Programmes that are Cost-Effective (WHO CHOICE) estimates the "hotel cost" (personnel, capital, food) of an inpatient bed/day in a public, urban hospital in Kenya at Int\$ 14.49 (Ksh 505) (World Health Organization 2011). A comparable figure at Chiromo is the daily "bed fee" of Int \$119 (Ksh 4500), considerably above the public sector estimate. Anecdotally, the lowest-income patients observed during the site-visit (eg someone employed lifting cement) were among those with employer-based insurance. Increasing insurance therefore may be a means of providing access to care from a broader population base.

Despite being unaffordable to most Kenyans, Chiromo may be economically justified to the population it serves. With 50.6% of patients in formal employment, Chiromo's occupational profile departs markedly from the national norm, in which only 9% of working age people (14% of those employed) work in the formal sector (Pollin 2009). The average yearly income in Kenya's formal sector in 2011 (adjusted from 2007) ranged from Int\$ 2,767 (Ksh 9,000) for a private employee to Int\$ 4,959 (Ksh 16,132) for a public employee (Pollin 2009). If treatment were to enable people to return to employment, then the median cost of treatment at Chiromo would be cost-neutral for formally employed patients.

Moreover, if Chiromo patients have better outcomes than those in the public sector, the additional cost of care could be justified for all patients from an economic perspective. There are insufficient outcome data to rigorously compare; however some process indicators provide insight into the relative quality of care. The diagnostic profile at Chiromo mirrors that in Kenya's public psychiatric hospital, Mathare, where 34.4% have a substance use disorder;

and 51.0% have schizophrenia or psychosis (Ndetei, Khasakhala, Maru, et al. 2008). Chiromo's readmission rate of 22.2% is also in keeping with the that of 24.6% found in Mathare hospital (Ndetei, Khasakhala, Maru, et al. 2008); however comparison on readmission is limited by the absence of published data on length of stay at Mathare.

A more meaningful comparison may be along the lines of human rights. In February 2011, CNN released a scathing documentary about Mathare (McKenzie and Formanek 2011) showing a dead body beside a live patient in an isolation cell. In response, the Kenya National Commission on Human Rights audited public mental health care, noting "systemic neglect" (Kenya National Commission on Human Rights 2011). The Commission inspected three public psychiatric inpatient units, finding staff-to-patient ratios of 1:80, and occupancy rates from a low of 105% to a high of 200%. Hygiene was poor, and hospitals lacked basic resources and equipment, like a functioning ECT machine. By comparison, Chiromo has a qualified nurse-to-patient ratio of 1:20, hygiene is good, the pharmacy is stocked without shortage, and the ECT functions.

The patients at Chiromo tend to be wealthy and well-educated, although that was not true of all patients. Some patients expressed the desire to distinguish themselves from other patients on the basis of diagnosis – a request which was taken into account in the creation of Bustani for the treatment of people with non-psychotic disorders. In addition, patients wanted it to be recognized that not all their experiences were the result of their psychiatric condition. The majority of patients at Chiromo Lane were involuntarily admitted, whereas at Bustani most were voluntary, reflecting in part that there were more people with psychotic conditions at Chiromo Lane, who may have lacked insight into their condition, but also that Chiromo was viewed as the highest security treatment facility, and therefore also treated people with problems of anger control.

Chiromo delivers acute psychiatric care each year to approximately 450 people, to quality and human rights standards higher than its public counterpart, but at considerably higher price. If there were more efficient (lower-cost) ways of delivering care, Chiromo might expand its services and increase its occupancy. Means of lowering inpatient costs include: 1) using more generics; 2) shifting the mix in staff to reduce reliance on psychiatrists; and 3) reducing readmissions, possibly through developing more outpatient psychosocial interventions and intermediary care, thus improving continuity of care. Incentives for cost-cutting could be built into insurance, for example by mandating the use of generics. These lessons extend beyond the provision of mental healthcare specifically and are relevant to all inpatient care for chronic disease. Furthermore, if Chiromo wanted to make their services

available to a wider population in need, they could cross-subsidize care between their insured and uninsured patients to a far greater degree than is apparent.

## **5.7 Limitations and Reflexivity**

My quantitative findings are limited by the absence of clinical outcome measures and of comparable data from the public sector. Comparison is also challenged by a lack of indicator of illness severity. Indeed, the regression analysis is subject to an omitted variable bias, as the model was driven by the available data. Illness severity is likely to be the largest predictor of length of stay, but there was no available measure to test that assumption. The low r-squared values of the regression results indicate that the variables in the model are not the primary factors that explain variance in outcomes.

Furthermore, generalizations on the overall quality of private versus public care cannot be made on the basis of this single case. Indeed, the Chiromo model is not currently generalizable, because its concentration of qualified professionals would be unsustainable at scale in this low-income setting. Where it is more comparable is to the 36 other facilities in Kenya with residential care for substance abuse, although Chiromo offers hospital based care, whereas the others are residential facilities with little or no medical supports. It nonetheless represents one extreme of the continuum of care for mental disorders and substance abuse in Kenya (a continuum lacking in continuity), namely acute care.

In exploring the limitations of the data, it is important to reflect on how my personal characteristics may have influenced my findings. My position as an unmarried, foreign white woman entering an African-populated hospital, dominated by male patients and female nursing staff is likely to have influenced the response I received. I might have been seen as a subject of interest in my own right, just as the patients and staff of Chiromo were subjects of interest to me. Having been invited to conduct the study by one of the hospital directors, I am likely to have been associated in the minds of patients with a member of staff, despite having presented myself as an independent researcher. Patients spoke to me openly, including voicing criticisms, but these criticisms may have been partially influenced by the impression that I could be instrumental in improving their situation, by reporting problems to staff. Nonetheless, having conducted a case study of an Argentine inpatient facility for mental disorders (de Menil and Cohen 2009), I was attuned to the challenges of rendering oneself accessible to both staff and patients, and I actively elicited conversations with patients.

Furthermore, having worked for four years with a not-for-profit mental health NGO, my bias is towards care that is affordable and serves all social groups, not only the wealthy. My implicit bias against expensive care may have led some members of staff to over-emphasise

efforts at cost-containment. That being said, the quantitative data, which are more objective in this respect, support the claims made by physicians, that if a patient was paying out of pocket and seemed to struggle financially, they would try to reduce the length of the inpatient stay.

Being an outsider to Kenya served as both an advantage and a disadvantage in conducting this case study. As I did not master Swahili, the subtleties of what was said when discussions shifted into that and other East African languages were lost on me. However, were it not that I was an outsider, particularly from a well-reputed London university, I most likely would not have been given access to the hospital to conduct the study. A high degree of uncertainty surrounded my initial request, as the relationship between academia and the private sector in Kenya is sometimes fraught. This concern was ultimately resolved by drafting a non-disclosure agreement, a legally bounding document defining under what circumstances data could be shared and with whom.

The relationship of Chiromo's director to the board of the AAR health management organisation constitutes an apparent conflict of interest insofar as he sits on the side of both provider and financer of his service. As the insurer, he would presumably want to contain consumption, whereas in the role of provider, he would want to increase it. When I posed this question to him directly, he refuted the conflict of interest, noting that from both perspectives the goal is to treat more people. From the insurance perspective he observed, "It's a numbers game," meaning the more people who are covered, the cheaper it becomes to treat, whereas from the provider perspective, early detection and treatment are the way to lower the cost of care. He concluded, "I have said, and I will always say, that with mental disorders not to treat is more costly than to treat."

Despite its limitations, this study is notable as a first analysis of insurance effects on mental health care in Africa, and provides a useful benchmark of private inpatient practice against which to measure alternatives and future change.

## 6. Psychiatric Nurses and Outpatient Private Practice



Figure 6-1: Private psychiatric outpatient clinic in Nyeri, Central Province, Kenya

## 6.1 Introduction

Despite a growing interest in community mental health care in Africa (Hanlon, Wondimagegn, and Alem 2010), the literature is relatively silent on outpatient private practice. A systematic review of community mental health care on the continent found that “in the low-income countries of the Africa region, community mental health care is largely restricted to mental health care delivered by primary care workers, with specialist mental health workers (usually psychiatrists and psychiatric nurses) tending to provide care through hospital-based outpatient clinics” (Hanlon, Wondimagegn, and Alem 2010).

Outside of Africa, in India, private outpatient psychiatry is known to be flourishing. The Indian Association of Private Psychiatry counts 1,890 members, a number deemed large and growing (Patil et al. 2011; Kala 2003). In Africa, however, private mental health care remains a hidden face in the landscape of literature on community care. The main discussion of private psychiatry in Africa comes from South Africa (Colin 2012), reflecting on changes since the introduction of managed care (Hanlon, Wondimagegn, and Alem 2010). What little the literature tells us about private psychiatric care in Africa is mostly limited to counting psychiatrists. Other cadres of private practitioners go un-enumerated, and the nature of their services is unexplored.

In Kenya, 44% of psychiatrists work in private practice (Ndeti et al. 2007). Their geographic distribution is less equitable than that of public psychiatrists: one in nine private psychiatrists practices in rural areas, as compared with one in five public psychiatrists (ibid). In addition to psychiatrists, there are an estimated 30 practicing clinical psychologists, all of whom operate privately, as they are not part of a government service scheme (Khasakhala 2011, October 5).

The bulk of specialist psychiatric care in Kenya is delivered by psychiatric nurses. Psychiatric nurses in Kenya have prescribing rights, and thus can, and do, perform most of the functions of a doctor, as is done elsewhere in Africa (Chetty and Hoque 2013). There are two types of psychiatric nursing certification: certificate and diploma, requiring 1 and 1.5 year(s) of specialized training. General nurses in Kenya also receive some psychiatric training, but it is minimal. All nurses receive one unit in mental health, which translates to 60 hours of training. It used to be that all nurses would do a rotation in Mathare Hospital, the 600 bed public psychiatric hospital in Nairobi. More recently, however, some nurses rotate through the psychiatric units in the 13 provincial and district hospitals that have one.

The shortage of psychiatric specialists in Africa is frequently attributed to outward migration to wealthier countries (Padmanathan and Newell 2012; Jenkins, Kydd, et al. 2010);

but less attention is turned to their migration internally to other fields of health. Kenya's Chief Nursing Officer reports that, with a ratio of one nurse to 1,345 people, the country has a shortfall of 66,782 nurses to meet the norms recommended by its own Ministry of Health (Rakuom 2010). The Kenyan Ministry of Health estimates there to be 500 practicing psychiatric nurses (Kiima and Jenkins 2010); however, because of the general nursing shortage, not all of them work in mental health. Reliance on psychiatric nurses to deliver mental health care is greatest outside of Nairobi, especially in rural provinces, where there averages one psychiatrist per 3-5 million people (Kiima and Jenkins 2010).

From a health systems perspective, it is essential to know the rate of participation of psychiatric nurses in mental health care in order to plan for appropriate levels of service coverage. This includes not only their participation in public health services, but also in private practice (figure 6-1), since two thirds (63%) of enrolled nurses are estimated to work in the private sector (Barnes et al. 2010). This chapter addresses three of Tanashi's five types of coverage, namely availability, contact and (to a lesser degree) financial accessibility.

Specifically, it addresses the questions:

- 1) How many mental health specialists are available to offer mental health services? And what type of outpatient services are available in private practice?
- 2) How many patients come into contact with mental health specialists and what are their characteristics?
- 3) How financially accessible are outpatient services in private practice?

Data are drawn from three sources: questionnaires; structured interviews; and key-informant interviews collected in Kisumu, Nyeri and Nairobi.

## **6.2 Methods**

### *6.2 - a) Tools*

I designed two simple tools for this study: The Mental Health Nursing Questionnaire and the Private Psychiatric Practice Questionnaire. Prior to designing those tools, I intended to collect data on availability, accessibility and contact coverage by conducting a telephone interview with administrators at private hospitals. I designed a Hospital Questionnaire to that end, asking how many specialized mental health staff they employed, how many mental health patients were admitted in the previous month, whether they had psychiatric medicines in supply and a functional E.C.T machine and so forth. An experienced Kenyan researcher who piloted the initial questionnaire ruled out that method, saying that telephone interviews would



not be possible and that administrators would not answer such questions, even if they knew the answers, because they would need to receive personal authorization from someone in the hospital hierarchy. I concluded that personally administering questionnaires or interviews was a more promising approach in Kenya.

I chose to conduct interviews with nurses in private practice, because I was interested in learning in detail about the nature of their services, which have never before been researched. I chose questionnaires for the psychiatric nurses attending an annual general meeting because I wanted to maximize the number of respondents in limited time and was interested in relatively simple quantitative answers.

The *Mental Health Nursing Questionnaire* (appendix 23) is a 25-item multiple choice numerical answer survey (appendix 12), which was delivered to all psychiatric nurses attending the annual meeting of the mental health chapter of the National Nursing Alliance of Kenya (NNAK) in April 2012. The purpose of the tool was to determine 1) the proportion of psychiatric nurses working on mental health, and 2) the rate of participation of psychiatric nurses in the private sector. The membership in 2012 of the NNAK mental health nursing chapter stood at 53 nurses. Their annual general meeting was opened to both registered and non-registered nurses, however. A total of 50 nurses attended the meeting in Kisumu, and the response rate was 100% of attendees (n=50).

The *Private Psychiatric Practice Questionnaire* (appendix 24) was developed to understand the nature of services offered by private practitioners and to estimate treatment coverage. It is a structured interview with sections on: a) patients (number, sex and diagnoses); b) treatment (duration, medicines prescribed); c) fees; and d) clinic operation (mental health vs general, hours, relation to public sector). The interview was delivered to psychiatrists and psychiatric nurses in person (with two exceptions) between July and September 2012 by my Kenyan research assistant, an employee of BasicNeeds with a master's degree in public health.

Both newly designed instruments were piloted in London and in Kenya. The Mental Health Nursing Questionnaire was piloted at London's Institute of Psychiatry with an expert on Kenyan mental health and with a doctorate level Kenyan health researcher working in London. In Kenya, it was piloted with one clinical psychologist and one psychiatric nurse. Issues were raised in relation to the sensitivity of declaring locum work, and certain rephrasing was suggested.

The Private Psychiatric Practice Questionnaire was piloted in Kenya with three private providers: a psychiatrist, a psychiatric nurse and a clinical psychologist. Concerns were raised about the length of the questionnaire, the formulation of questions regarding patient

characteristics, and the need for the questions about prescription practice. Adjustments were made and the revised questionnaire was re-reviewed by the same individuals. The sites selected were Nairobi and Nyeri – Nairobi because of the preponderance of private providers there, and Nyeri because the snowballing technique started with a contact there through the NGO BasicNeeds.

Ethics approval for this data collection was granted by Kenyatta National Hospital and the University of Nairobi's joint Ethical Review Committee (see appendix). Interview respondents signed informed consent (see appendix). Questionnaire respondents were given oral and written information about the purpose of the research and their right not to participate or to desist from participating. Names were not recorded and all responses were kept confidential.

### 6.2 - b) *Sampling*

I distributed the Mental Health Nursing Questionnaire on April 24, 2012 to all nurses attending the annual general meeting of the mental health nursing chapter of the National Nursing Alliance of Kenya (NNAK). Fifty people attended out of the 77 registered members, and all of them self-completed the survey.

Sampling for the Private Psychiatric Practice Questionnaire was purposive, so as to acquire an equal number of respondents from Nairobi and the Central province. Psychiatrists were selected from the *Kenya Medical Directory*, which lists 39 professionals under the category “psychiatrists and psychologists” (Express Communications Ltd 2011). Psychiatric nurses were identified using snowball sampling, where subjects refer other subjects. The response rate was 40%: 27 people were approached (22 psychiatrists, 5 psychiatric nurses, one third female), 11 responded (8 psychiatrists, 3 psychiatric nurses) and 16 refused. Reasons for refusal included: 1) absence of compensation, resulting in opportunity cost of income forgone from private practice; and 2) concern about confidentiality, particularly around earnings. There was no detectable bias in respondent uptake. Some respondents chose not to answer questions about prescription practice, but all other questions were completed.

### 6.2 - c) *Ethics*

Signed informed consent was received from all research subjects (appendix 11). The research methods were approved by the Kenyatta National Hospital's Ethics and Research Committee. For further discussion of the ethics of this research, see chapter 3.

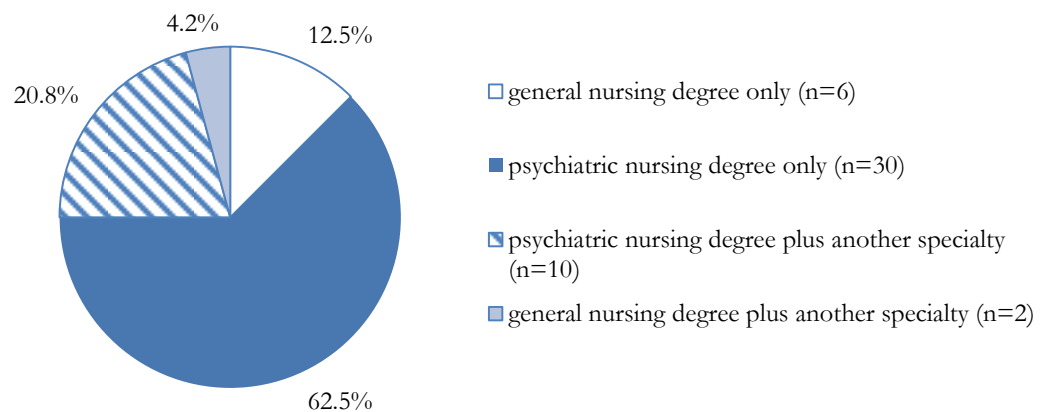
### 6.2 - d) Analysis

Data were entered into two databases in SPSS 19 and analysed using simple frequencies and descriptive statistics. Data from psychiatric nurses in private practice were pooled across the two data sets to increase the sample size. There was no overlap in participants from the two studies, so no double-counting.

### 6.3 Results: Availability of Psychiatric Nurses in Mental Healthcare

Nurses were 54% female with a mean age of 46 years (sd 6.5), and 40% worked in Nairobi. Forty nurses had a psychiatric nursing degree (diploma n=33, certificate n=7), eight had none (general nursing only n=2, midwifery n=2) and two did not respond (figure 6-2). One quarter of those with a psychiatric nursing degree (n=10) had at least one other nursing degree: 12.5% (n=5) in community health, 7.5% (n=3) in midwifery, and 5.0% (n=2) in two or more specialties.

Figure 6-2: Nursing degrees held by the sample



Half (47.5%) of those with psychiatric nursing degrees (n=19), worked specifically as mental health nurses, while the other half were employed either as general nurses (20.0%, n=8), as other specialty nurses (15.0%, n=6), in administration (12.5%, n=5) or as nursing teachers (5.0%, n=2) (figure 6-3). Among those employed as non-psychiatric clinical nurses, half (46%) their caseloads were mental health patients. The eight nurses without a psychiatric nursing degree worked mostly as general nurses (n=5), but also as administrators (n=2) or teachers (n=1).

Figure 6-3: Employment functions of those with psychiatric nursing degrees

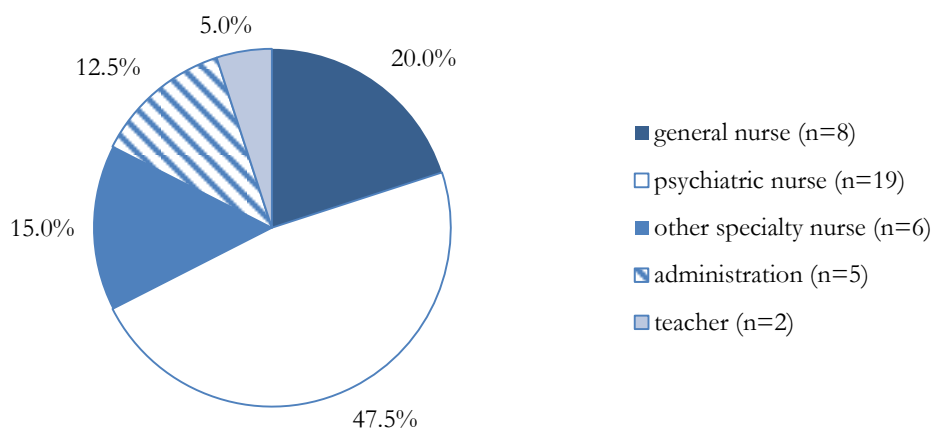


Table 6-1: Employment of those with psychiatric nursing degrees

	Psychiatric nurse		Non-psychiatric, clinical		Non-clinical		Total	
	%	N	%	N	%	N	%	N
Sampled	100%	19	100%	14	100%	7	<b>100%</b>	<b>40</b>
Employed by the public sector	40%	13	33%	12	17%	5	<b>75%</b>	<b>30</b>
Employed by the public sector only	44%	12	37%	10	19%	5	<b>68%</b>	<b>27</b>
Participating in the non-state sector	64%	<b>7</b>	36%	4	0%	0	<b>28%</b>	<b>11</b>
Doing additional locum work	0%	0	100%	6	0%	0	<b>15%</b>	<b>6</b>
Private practice, ever	50%	2	25%	1	25%	1	<b>10%</b>	<b>4</b>

Among the 47 psychiatric nurses in clinical practice, all but one held a public sector job (table 6-1). Two thirds (66% n=33) worked exclusively in the public sector, while a quarter (28% n=14) worked partially in the non-state sector. Those in non-state care worked for not-for-profit hospitals (n=6), for-profit facilities (n=4) or a combination of providers (n=4).

Ten per cent of nurses (n=5, including 4 with psychiatric nursing degrees) reported ever having managed a private clinic, and 6% (n=3) currently did so. All private practice nurses worked simultaneously in the public sector. Private clinics operated on average two days (14 hours) per week. The majority (n=4) operated general health clinics rather than mental health clinics. On average, five mental health patients were seen each week (range 3-10), occupying one quarter of the patient caseload.

Outside of private clinics, psychiatric nurses also participated in private practice doing locum work at for-profit hospitals or NGOs. Fourteen per cent (n=7) reported doing private locum work in the previous month, largely (n=5) in for-profit hospitals. Only one locum was employed for mental health services. The amount of time spent in locum work differed widely across respondents from a minimum of a half day to a maximum of 9.5 days in the previous month.

#### **6.4 Results: Coverage of Private Outpatient Mental Health Services**

##### *6.4 - a) Availability coverage*

Half of the eleven respondents (n=6) to the Private Psychiatric Practice Questionnaire were from Central province, but all the psychiatric nurses were from the province. A quarter of respondents (n=3) were women, and the average age was 46 years old (s.d. 9) (table 6-2). Respondents had worked on average 9 years (s.d. 5) in the private sector. A quarter of respondents (1 psychiatrist and 2 psychiatric nurses) operated general clinics, serving physical and mental health needs jointly. All those operating general clinics were located in the province. The general clinics run by psychiatric nurses served on average only 5% patients with mental health problems, whereas the general health clinic run by a psychiatrist served 65% patients with mental health problems.

A wide range of medications was prescribed. Three quarters of respondents offered atypical antipsychotics as their usual clinical response for psychosis. The two respondents offering only the older typical antipsychotics were both psychiatric nurses. One quarter of respondents sold medications at their clinic; while the remainder sent patients to local pharmacies. There appeared to be no association between the type of professional or their location and whether or not they sold medicines.

Three quarters of private providers (n=8) split their time with the public sector. The preferred time for working in the private sector was weekday afternoons and Saturdays. Private clinics operated a mean of 24 hours per week (range 12-40, s.d. 7.8). Two respondents operated clinics at two different locations. Three quarters of those practicing in both public and private sectors (n=6/8) said the care they offered in a private clinic was different from what they offered in their public service. The main distinction was a greater choice of drugs, particularly the option of atypical antipsychotics in private practice. One respondent noted: "At the government clinics, prescriptions are dictated by the available psychotherapeutic medications." Continuity of care was also highlighted as an area of difference. "I am able to

constantly follow the client,” in private practice, whereas follow-up was deemed poor in public practice. A psychiatrist from Nairobi, however, asserted that treatment in public and private was the same, saying, “All patients are equal.”

Table 6-2: Private Outpatient Practice Descriptives

<b>Provider Profile</b>	<b>Mean</b>	<b>Range</b>
Age	46	34-65
% female	27%	
Time in private sector	9.2 years	4-19
% also working in public	73%	
<b>Patient profile</b>	<b>Mean</b>	<b>S.D.</b>
% female	56%	
common mental disorders	56%	0.18
severe mental disorders	25%	0.16
substance use disorders	15%	0.08
epilepsy	2.5%	0.05
childhood disorders	2.5%	0.03
intellectual disability	<1%	0.02
<b>Treatment</b>	<b>Mean</b>	<b>Range</b>
Duration of first visit	60 min	50-90
Duration of standard visit	30 min	15-45
Wait-time	20 min	3-60
Use atypical antipsychotics	75%	
<b>Coverage</b>		
Active case load in 6 months	128	22-360
Patients seen per clinic day	5	2-10
Clinic operation per week	24	12-40
<b>Fees for standard visit</b>	<b>Int\$</b>	<b>Ksh</b>
Psychiatric nurse	13.0	500
Psychiatrist	55.3	2,100
–Nairobi psychiatrist	62.5	2,400
–provincial psychiatrist	43.4	1,700

#### 6.4 - b) Contact coverage

Respondents had an active case load of 128 mental health patients on average, but the number ranged widely from 22 – 360, depending on whether they were full-time or part-time in private practice and whether they operated a general or specialized clinic. (Active patients were defined as those seen in the past 6 months.) One quarter of patients seen each week were

new to the clinic. The mean number of mental health patients seen per clinic day was 5. Slightly over half of all patients (56%) were women.

The majority of mental health patients (55%) were seen for common mental disorders. Another quarter (25%) were seen for severe mental disorders (schizophrenia, bipolar, psychosis). The third most frequent condition was alcohol and substance disorders, experienced by 15% of patients. Epilepsy (3%), childhood disorders (2%) and intellectual disability (less than 1%) were rare in private outpatient settings.

Private practitioners saw their patients for an average of one hour on the first visit (range 50-90 minutes) and half an hour on follow-up visits (range 15-45 minutes). Psychiatrists reported seeing patients for 10 minutes longer than psychiatric nurses on both the initial and follow-up visit. All providers endorsed a typical wait time of 20 minutes (range 3-60 minutes). Patients were followed-up on average monthly (maximum, every 8 weeks). In the previous month, the professionals referred a mean of 12 patients (13% of their clients) to inpatient services.

#### *6.4 - c) Access coverage*

The mean fee of a standard consultation by a psychiatric nurse was Int\$ 13 (Ksh 500), whereas for a psychiatrist it was four times that a Int\$ 55.3 (Ksh 2,100). There was also an apparent difference in fees between doctors in Nairobi as compared with those in Central province. The mean follow-up fee for a Nairobi psychiatrist (n=5) was Int\$ 62.5 (Ksh 2,400), while the provincial psychiatrists (n=3) charged Int\$ 43.4 (Ksh 1,700) – a difference of Int\$ 18.2 (Ksh 700 Ksh). The duration of the consult was comparable across these two groups of respondents. Nearly two thirds of respondents (63%, n=7) modulated fees on the basis of a patient's ability to pay, judged in part by their occupation. Fees also depended on the length of the session, which, for some, was flexible.

### **6.5 Pooled Results**

By pooling the findings from psychiatric nurses in private practice in the two questionnaires, we increase the sample to eight individuals – five from the Mental Health Nursing Questionnaire and three from the Private Psychiatric Practice Questionnaire (table 6-3). Most psychiatric nurses in private practice were male (88%), whereas overall psychiatric nurses were half (54%) women. Psychiatric nurses saw a mean of 2.6 patients per working hour and worked on average 12.6 hours in private practice.

The majority of patients seen by psychiatric nurses were not seen for mental health. On average two in every five patients (39%) were mental health patients. That being said, there was considerable variance in the extent to which these providers engaged in private practice. The number of hours in which their private clinics operated, for example, ranged from 2 to 28, resulting in a wide weekly range of patients seen.

Table 6-3: Pooled results of coverage by psychiatric nurses in private practice

	N	min	max	mean	s.d
age	8	39	55	46.5	6.6
per cent male	8	0	1	87.5%	35.4%
hours per week in private practice	7	2	28	12.6	10.0
patients seen per week	8	5	40	19.8	13.2
patients seen per working hour	7	0	6	2.6	1.8
mental health patients seen per week	5	0	18	7.2	7.0
per cent mental health patients	8	0	100	39.4	41.3

## 6.6 Discussion

### 6.6 - a) Availability coverage

The data from the Mental Health Nursing Questionnaire demonstrates one way in which the mental health treatment gap in Kenya is adversely affected by the overall health treatment gap, as rare skilled labour is being drawn away from the practice of psychiatry to other areas of health. I found that half of those with psychiatric nursing degrees in Kenya are employed for functions other than delivery of mental health care. This finding is consistent with previous estimates, (Kiima and Jenkins 2010) but had never before been measured.

A contributing factor to the “drain” of psychiatric nurses to other services is that one quarter of those with psychiatric nursing degrees also hold other specialty nursing degrees. Two specialties in particular – community health and midwifery – have particularly high overlap with psychiatric nursing. Inversely, however, it should also be noted that not all nurses who have worked in a mental health setting have psychiatric nursing degrees, as was the case of 17% of our sample.

If the sample of nurses participating in this modest survey is representative, the results would imply that only 238 of the estimated 500 practicing psychiatric nurses in Kenya work specifically with mental health patients, which amounts to a ratio of 0.62 psychiatric nurses per 100,000. Though low, this nonetheless amounts to higher than the average for low-income



countries, which are estimated to have an overall mean of 0.42 psychiatric nurses per 100,000.(World Health Organization 2011) Moreover, in response to the demand for mental health services, roughly half of the people on the caseloads of psychiatric nurses in general practice are patients with mental health needs. The training of a nurse is often known by colleagues, as a result of which a psychiatric nurse will commonly be referred psychiatric cases, even when employed for other functions.

Kakuma et al argue in *The Lancet* that the necessary ratio of specialist human resources to achieve desirable coverage for mental disorders in low-income countries is 22.3 health workers per 100,000 population: 6% psychiatrists, 54% nurses in mental health settings, and 41% psychosocial care providers.(Kakuma et al. 2011) This works out to a ratio of 12 mental health nurses per 100,000. To achieve that ratio, Kenya would need 4,650 nurses working in mental health settings – 20 times the estimated number of psychiatric nurses currently practicing mental health care. Policy efforts to address this wide gap in human resources are focused on two strategies: 1) task-shifting counselling to lay health workers;(Kakuma et al. 2011) and 2) integrating mental health into primary care by training clinical officers.(Jenkins, Kiima, et al. 2010; Jenkins, Othieno, Okeyo, Kaseje, et al. 2013) The latter strategy is also applied in settings with higher densities of specialised providers, such as the UK.

The findings from this survey also point to a significant role played by psychiatric nurses in the private sector – through private outpatient practice, inpatient locum work, and with NGOs. One nurse noted that the Ministry of Health has a policy prohibiting simultaneous work in public and private facilities, out of concern that private work compromises public work: *'If people work two jobs, they do it quietly.'* Nonetheless, 14% of nurses reported doing locum work. A further 10% of psychiatric nurses have managed a private practice, and a quarter of their patients come seeking mental health services. Psychiatric nurse-run clinics tend to operate outside of Nairobi, as the competition from private psychiatrists is high in the capital. Despite their significant involvement in private practice, the participation rate of psychiatric nurses in private practice was found to be lower than that of other types of nursing.(Barnes et al. 2010)

#### 6.6 - b) *Contact coverage*

Data from the Private Psychiatric Practice Questionnaire provide insight into who is accessing private mental health care in Kenya. The leading diagnosis for which people attended private mental health clinics was common mental disorders, which is a departure from the clinical profile of patients in psychiatric hospitals. The majority of patients in both public and private hospitals in Kenya are affected by psychosis (Ndeti, Khasakhala, Maru, et al. 2008). In a

context where the term “mental” is associated with psychotic behaviour, a private clinic located in the community may offer a less stigmatizing option of care for non-psychotic patients. Privately owned clinics are more “private” to service users in that they are less visible and care can be sought with greater confidentiality.

Another key factor that distinguishes patients accessing private outpatient care from those in public inpatient settings is that more of them are women. It is frequently found that women experience common mental disorders at higher rates than men (who are diagnosed more frequently with substance use disorders)(Whiteford, Degenhardt, et al. 2013), so the higher preponderance of women in these outpatient clinics is linked to the higher prevalence of common mental disorders in this setting. It is not possible to say from these data whether being female or having a common mental disorder is the driving factor in seeking care from a private provider. In theory, it would seem likely that having a common mental disorder might lead a person to seek care in a setting that is free of psychotic patients; however it is also true that women seek health care more than men. So either could be true. Regardless, the finding remains that outpatient private practice clinics increase access to mental health services by women.

#### *6.6 - c) Access coverage*

The fee of Int\$ 13.0 (Ksh 500) charged by psychiatric nurses represents approximately two and a half days work by an unskilled agricultural labourer earning an average monthly income of 4,258 Ksh (Ministry of Labour Kenya 2012). This is a significant, but not unattainable sum. By comparison, the average fee of a psychiatrist (whose consultation runs on average 10 minutes longer) represents half a month’s salary for the same agricultural worker, making it inaccessible to most.

Higher costs among psychiatrists are driven not only by provider fees, but also by choice of medicines. Psychiatric nurses appear to adopt different prescription practices than psychiatrists, relying more on typical antipsychotics than on newer more expensive medicines. This may be the result of an effort to keep prices down, or a carry-over of practice from the public sector. The shortage of specialized human resources for mental health compounds the fee structure to make psychiatric nurses a more realistic means of expanding access to specialist mental health care than psychiatrists – as is also the case in the public sector.

## 6.7 Limitations & Conclusions

### 6.7 - a) Limitations

A limitation of the Mental Health Nursing data is the potential for sampling bias, as the sample represents only those attending the annual general conference on mental health in Kisumu. Residents of Western Kenya would have had an easier time attending the conference than those from other provinces. In addition, those with psychiatric nursing degrees who are no longer practicing mental health would probably be less inclined to attend such a meeting. It is also possible that those in private practice would be less likely to be members of the mental health nursing chapter. One reason for this is that there is a separate chapter of the NNAK for private practice nurses. The private nursing chapter of NNAK has 45 members, and when I met with the chair, she could not name any members who were psychiatric nurses (Sikobe 2011, October 5), so I chose not to pursue that avenue of inquiry.

A key informant interview with the chair of the mental health nursing chapter supports the idea that the sample may be skewed towards the public sector. She noted that seven years prior, when she became chair, “*you couldn’t separate the mental health nurses chapter from Mathare Hospital*” (KI 19, November 17, 2011). (Ngungiri 2011, November 17) All the members were from the national referral psychiatric hospital, the mainstay of public mental health care, and all their meetings took place in Nairobi. She herself worked full-time in a private hospital, and she managed to gradually shift the centre of focus of the professional association outside of Nairobi. Hosting the 2012 AGM in Kisumu, in the Rift Valley, was a testimony to that shift towards greater inclusiveness of psychiatric nurses outside of Mathare. The question is whether the bias towards Mathare Hospital reveals the actual nature of where psychiatric nurses practice in Kenya or a metropolitan-centred dynamic of the professional nursing association.

Unfortunately, the registries of the Nursing Council of Kenya do not shed any light onto the matter, as they are not up to date: the national registries include all nurses ever registered, whether alive or dead, practicing or retired, thus inflating the figures for psychiatric nurses. The registries stated that there were 1,545 psychiatric nurses in July 2011 (KI 12, July 22 2011), which is three times the number of practicing psychiatric nurses estimated by the Ministry of Health (Kiima and Jenkins 2010). In the absence of reliable figures on the number of practicing psychiatric nurses, it is not possible to say whether my sample was representative of the true number employed in the private sector. If it is the case that the mental health

nursing sample was biased towards public workers, then my estimate of the shortfall of psychiatric nurses is conservative, as is the estimate of their participation in private practice.

A further limitation is that my nursing data do not address the treatment of mental disorders by non-specialist providers. One of the tasks of psychiatric nurses is to supervise primary care providers in questions relating to mental health treatment. The chair of the private nursing chapter noted that general nurses also see patients with mental disorders: *“If a mental case walks in here, I’m not going to walk away and panic. I am calming the person down.”* General nurses in Kenya have two and half to three and a half years of post-university training (for certificate and diploma levels respectively), which includes a unit of training on mental health. By limiting the study to specialist care, the present analysis misses a major component of the treatment of mental disorders; however time and resource constraints did not permit widening the inquiry.

The Private Psychiatric Practice Questionnaire also has a potential for sampling bias in that individuals willing to respond to a research interview may be more likely to participate in the public sector than those who refuse to participate in research. Snowballing as a sampling method is also subject to sampling bias in that individuals refer others whom they know, making it more likely that they share similar characteristics. Snowballing, however, is an effective and low-cost strategy when the population being sampled is small and hard to reach, as is the case of private practice specialist mental health providers in Kenya.

The greatest limitation faced by this chapter is that of data accessibility. Obtaining data from private health care providers is challenging in any setting, but even more so in a low-income context. It is possible that my choice of research assistant, who is affiliated with the NGO BasicNeeds, may have dissuaded some private providers from participating, be it because they thought she was trying to influence them in some way, or because she might not approve of their for-profit work. On the other hand, she was local and had good connections in the area, making it possible for her to find potential subjects and persist in contacting them. The small sample sizes in this chapter limit the interpretability of the findings, as numbers are too small for statistical analysis of association. However, if the published number of 24 psychiatrists working in the private sector is accurate (Kiima and Jenkins 2010), then by interviewing 8 private psychiatrists, I sampled one third of the national cadre.

For future research, offering compensation for participation might lead to higher response among private providers. In addition, future research should seek the perspective of patients visiting private clinics to better understand their preferences. Finally, an additional source of private outpatient mental health care in Kenya comes from the growing cadre of

university graduates trained as counsellors, sometimes loosely referred to as “psychologists.” Counselling psychologists are employed by both the public and private sectors predominantly for HIV, substance use disorders, and non-pathological emotional strain; but they are rarely self-employed, working mostly within larger health care facilities. Further research would be useful on the capacity of counsellors to address the mental health treatment gap in outpatient settings.

#### *6.7 - b) Conclusions*

In conclusion, it appears that psychiatric nurses are migrating internally to nursing positions in other areas of health care, aggravating the existing “brain drain” on mental health. The specialized skills of psychiatric nurses are largely being used for general medical practice and other specialties, including midwifery and community health. The tendency of psychiatric nurses to work in general medicine applies to both public and private practice. At least ten per cent of psychiatric nurses have experience running a private practice, though the real number may be higher depending on the representativeness of the sampled population.

The study of private practice providers demonstrated a large cross-over between private and public sectors. Three-quarters of private mental health providers split their time with the public sector. Private providers were often not a different category: they were the same people working in different settings. In fact, some private professionals asserted that the private sector pay helped them continue working in the public sector. In a context of under-paying public health providers, private employment may be seen as a form of cross-subsidy for public health care.

**7. Mental Health Coverage from Traditional and Faith Healers in a Nairobi Settlement**



Figure 7-1 Traditional healer demonstrating inhalation of herbs  
(source: BasicNeeds Kenya)

*“In most developing countries [...] the alternative to consulting traditional practitioners for mental health problems is not consulting anyone at all, as mental health professionals are not readily available.” (Jilek and Wolfgang 1993)*

*“TM [traditional medicine] is sometimes also the only affordable source of health care — especially for the world’s poorest patients.”(World Health Organization 2002)*

## 7.1 Introduction

It has previously been said within health policy documents that traditional healing is the only accessible form of care for mental illness in many low-income settings (Jilek and Wolfgang 1993; World Health Organization 2002). While true in some respects, this claim suggests there is no alternative to traditional care, or at best only a binary alternative between receiving care and receiving none. By extension, one is led to believe that Kenyans “take what they can get” when it comes to mental health care, without much in the way of choice. The reality in Kenya is that traditional practitioners come in many forms, and thus open the door to many alternatives from which an individual must choose. Furthermore, healers differ in type and denomination according to ethnic group. With over thirty ethnic groups recognized in Kenya’s census, this creates considerable variation in the notion of a healer.

Table 7-1: Categories of traditional healer in Gusii  
Source: (Sindiga 1995)

English translation	Gusii
1. herbalist	<i>omonyamete</i>
2. diviner	<i>omoragori</i>
3. “witch smeller”	<i>omoriori</i>
4. traditional birth attendant	<i>omorabi</i>
5. surgeon (includes dentist)	<i>omobari</i>
6. circumcisor	<i>omosari</i>
7. blood-letter	<i>omoromeki</i>
8. dealer in love-medicines	<i>omoebia</i>
9. undertaker of autopsies	<i>omwati</i>
10. rain maker	<i>omonyibi embura</i>
11. one who uses medicine to prevent disease & misfortune	<i>omokireki</i>
12. fortune teller	<i>omobani</i>
13. sorcerer	<i>omonyamosira</i>

A book titled *Traditional Medicine in Africa* provides a useful anthropological overview of healing practices by tribe in Kenya (not, in fact, across Africa) (Sindiga, Nyaigotti-Chacha, and Kanunah 1995), and it underscores the heterogeneity of healers. Among the Gusii tribe of Western Kenya, the authors found as many as thirteen different terms for traditional healer (table 7-1). These terms reflect specializations related not only to health, but also to general welfare, for example rain-making and fortune-telling. The catch-all term in Kiswahili for a traditional healer is *mganga*. Two of the most common specialties of healer that come in contact with people with mental illness are herbalists (*mukimi wa miti*) (figure 7-1) and diviners (*mundu mue*). Herbalists use plant remedies to heal sickness, while diviners reportedly have a supernatural power to see and heal (Jilek and Wolfgang 1993). A third category of healer that is popular among people with mental illness is a faith healer (*muombaji*, meaning person who prays). Faith healers are members of a religious congregation and use aspects of religious worship to heal.

In practice, a considerable overlap has been observed between different types of healers. In his study of Luhya healing practices, Simiyu Wandibba contends, “Today traditional medicine has a new expert. This is a man or woman who combines the Bible and herbs to diagnose and treat a wide range of diseases” (Wandibba 1995). A recent case study of a Luhya faith healer in Western Kenya, who calls himself a *mtumishi* (servant of God) confirms this assertion. The healer held church services and used the Bible to heal, however the Bible served less as a text than as a piece of ritual paraphernalia. To diagnose problems of his clients, this healer placed a Bible on the floor and voices of witches were said to emerge from it. To rid the individual of the witches, the *mtumishi* later dramatically set the Bible alight with kerosene, while “The congregation listen[ed] to the voices of the witches crying and screaming that they [were] burning, and begging for mercy” (Okwaro 2010). The study’s author, Ferdinand Okwaro, observes the following:

“For the Christianised Africans, the use of the Bible and the seemingly Christian procedures reassured them that they were participating in a Christian ritual although they might not agree with all aspects of the rituals, especially the burning of Bibles.” (Okwaro 2010)

The key term in this description is “seemingly Christian.” Okwaro’s case study illustrates what he calls a “hybridization” and a “complex fusion of African and Christian cosmologies.” The Bible serves as a stand-in for what might formerly have been a more traditional tool of divining: “While his grandfather used a buffalo’s switch to divine, he uses the Bible.” The focus of Okwaro’s article is on the relationship between faith healing and modernity, and he



denotes this practice as a “strategy,” which succeeds in “appealing to a wider clientele.” Christianity appears to be associated with modernity in this East-African setting, and modernity has wide appeal. The question is how representative this case is of the general practice of faith healing in Kenya.

The religious profile of Kenya has changed substantially over the years, with the population becoming increasingly Protestant, especially evangelical Protestant. The 2009 Census found that Nairobi was 74% Christian and 47% Protestant (Kenya National Bureau of Statistics 2009). The spread of evangelical churches is a trend noted across Africa, beginning in the 1980s (Teuton, Bentall, and Dowrick 2007). The evangelical church largely replaced in popularity the African Independent Churches (Zionist, Ethiopian, Apostolic for example), which formed a central research interest for anthropologists in the 1960s (Meyer 2004; Jilek and Wolfgang 1993). A syncretism between Christianity and traditional religion was established in Zionist and Apostolic churches in South Africa. Karl Peltzer described faith healing rituals involving tying wool around the wrist, applying ashes to the skin, and blood-letting through the nose (Peltzer 1999). Little information exists, however, on the nature of faith healing within the more contemporary evangelical churches in East Africa.

The leading piece of anthropological research on traditional medical practices in Kenya was conducted by Charles Good from 1977-1979 (Good 1987). The focus of Good’s work was the contrast between rural and urban practitioners of traditional healing and he placed a special emphasis on mental illness, which was one of the conditions most commonly addressed by the healers he observed. His urban population was drawn from the Mathare settlement, consisting of a predominantly Kikuyu population, but largely Kamba group of healers, while his rural site was southern Machakos, a Kamba dominated area. He carefully documented the symptoms, diagnostic categories and healing practices associated with mental illness, including a thorough description of the physical spaces in which healing took place – in keeping with his background in medical geography. Good’s rich description provides an invaluable benchmark for understanding traditional healing practices in Kenya. He notes of urban healers that they are entrepreneurs driven by “economic opportunity,” and that they adapt to changing circumstances. This suggests that the nature of urban healing practices is likely to have changed substantially in the three decades since Good’s study.

Historically, research into traditional and faith healers has been highly politicized around the question of whether they are helpful contributors to the health system or harmful detractors. Early missionaries and colonists in Kenya, seeing traditional healing as a threat to the social order, labelled these practices as “witchcraft,” and banned them in the Witchcraft

Oridnance of 1925. In the 1950s, when Kikuyu armed forces, known as *Mau-Mau*, tried to overthrow the British colonial administration, the hunt against witchcraft became more acute, featuring ceremonies to burn healing paraphernalia. The *Mau-Mau* required their members to swear oaths as part of initiation into the group, and this oath-taking was associated in the mind of the British with sorcery. Women, however, were more often the targets of these witch-hunts than men. In 1955, 1,800 women and 150 men are reported to have had objects confiscated in three districts alone (Nottingham 1959 quoted in Good).

In contrast to the colonial “civilizing” agenda, in the 1960s and 1970s, mostly Western medical anthropologists upheld the value of what they called traditional medical practice, or ethno-medicine, occasionally even romanticising it (Edgerton 1966; Peltzer 1999; Good 1987). Up into the 1990s, articles were written simply to note that “traditional medicine has much to offer” (Patel 1993). Over time, practitioners of conventional medicine have become more engaged with the idea of collaborating with traditional healers, spurred in part by an under-supply of skilled medical professionals and also by the acknowledgement that the two systems of medicine have different things to offer. Nonetheless, current research suggests that a disciplinary divide remains alive today with anthropologists expressing openness towards the benefits of traditional healing, and biomedical practitioners more often remaining sceptical (with some exceptions) (Campbell-Hall et al. 2010; Asante 2012; Sorsdahl, Stein, and Flisher 2010).

As a result of this disciplinary divide, most of the research into traditional medical practice has been qualitative. A small exception exists around studies of help-seeking, where national household surveys have included quantitative questions about attending traditional care (Sorsdahl et al. 2009). The distinctions between the categories of traditional and faith healer are nowhere clearly delineated. Researchers from Ghana, quoting other researchers and even drawing from the World Health Organization, offer this by way of definition:

“Traditional healers (in Twi, *okomfoo*) are trained to administer locally prepared herbal medicine for the treatment of diseases (Crawford & Lipsege, 2004; WHO, 2002). Faith healers or pastors/imams are religious leaders who base their treatment on the powers of God to heal sickness (Kale, 1995). The major difference between traditional and faith healers in treatment practices is that the former pour libation (sacrifice to the gods) to the ‘small gods’ (*obosom*) at the shrines and also use herbs for treatment of mental disorders, whilst the latter employ prayers, fasting and the sprinkling of holy water as the major means of treating diseases (Puckree et al., 2002).” (Ae-Ngibise et al. 2010)

What little quantitative evidence exists, suggests that faith healers are becoming more preponderant than traditional healers (Read and Doku 2013), particularly since the rise of Pentecostal churches (Ae-Ngibise et al. 2010). A recent study from Ghana, drawn from a sample of people attending a public mental health clinic, found that only 6% reported having previously attended a traditional healer for the problem, whereas 14% had consulted with a pastor (Appiah-Poku et al. 2004). Thirty years earlier in Ghana, a study of patients at the national psychiatric hospital found that 64% had consulted a herbalist and 26% had attended faith healing (Lampsey 1977).

South Africans reporting using healers at the same rate as Ghanaians. According to a large-scale household survey, among those with a diagnosable psychiatric disorder, 9% attended traditional healers and 11% attended faith healers (Sorsdahl et al. 2009). Attendance of healers is not, however, equally distributed across the population. Peltzer found rates higher among Black South Africans, including a prevalence of up to 38% consultation with healers in one setting (Peltzer 2009). It is possible, moreover, that people under-report attendance with traditional practitioners when queried by health researchers, because it is frowned upon by many conventional medical providers.

In 2007, nearly thirty years after Charles Good conducted his ethnography, the NGO BasicNeeds paired with the Africa Mental Health Foundation to update knowledge of traditional and faith healing practices for mental illness in Kenya. The study is based in an informal settlement of Nairobi, where alternatives for health care are relatively abundant. Starting from the observation that individuals living in Nairobi have a choice about what sort of informal care to seek, the study focused on two broad classes of provider: traditional healers (herbalists and diviners) and faith healers (evangelical Protestants).

Using their data for secondary analysis, I will address three of Tanahashi's five types of coverage, namely availability, contact and acceptability. This is the only empirical chapter to address the question of acceptability coverage, thus touching on questions of culture that draw partially from the literature, if not the methodology, of medical anthropology. First, I will compare the socio-demographics of traditional and faith healers and the patients in contact with their services. Next, I will explore the nature of services made available by these two classes of healer, in particular diagnosis and treatment. Finally, I will examine the acceptability of conventional medicine to patients and providers of healing, as well as the acceptability of different healing types between one another.

## 7.2 Methods

This chapter constitutes a secondary analysis of data collected in 2007 by researchers from the Africa Mental Health Foundation (David Ndetei and Lincoln Khasakhala) and from BasicNeeds Kenya (Allan Oginga). A small team of community health workers and research assistants affiliated with the Africa Mental Health Foundation supported them with the data collection, cleaning and management. Secondary analysis of qualitative data is problematic in that the person doing the analysis is divorced from the original context and relationship of the researcher to the subject of research (Parry and Mauthner 2005). This is particularly the case when a number of years have intervened between collection and analysis as was the case here. The principal arguments for conducting this re-analysis are: 1) that healers constitute an “elusive” population (Long-Sutehall, Sque, and Addington-Hall 2010), for which I could not collect data myself, given my parallel priorities and constraints, and 2) that the existing data had not been fully exploited and therefore warranted further analysis. In addition to examining the secondary data, I spoke with two of the co-investigators on the original study and conducted two key informant interviews to contextualize my understanding of healers.

### 7.2 - a) *Research questions*

The objective of the original study was to serve as a “benchmark of practice” of traditional and faith healing in relation to mental illness in Kenya. The study triangulated self-report from providers with that of service users. Five descriptive research questions were defined by the principle investigators:

1. What are the socio-demographic characteristics of faith healers, traditional healers, mentally ill persons and their carers?
2. What are the traditional names of the different types of mental illness that are managed by traditional and faith healers?
3. What are the different symptoms of mental illness identified by traditional healers, faith healers, mentally ill persons and carers in the community?
4. What are the procedures of identifying and treating different mental disorders by the traditional and faith healers?
5. What are the clinical types of psychiatric disorders among the patients who are seen by faith and traditional healers?

The study was written into a 72 page descriptive report by the three principle investigators and published in the grey literature by the NGO BasicNeeds (Ndetei, Khasakhala, and Oginga 2008). The analysis on that report is not repeated by the contents of this chapter.

My own research objectives departed from those of the principle investigators. The chapter seeks to address the following research questions:

1. (Availability) Who are traditional and faith healers, and do they differ in terms of socio-demographics? What type of healing (diagnosis and treatment) do they offer people with mental disorders?
2. (Contact) Who are the patients coming into contact with traditional and faith healers? Do they differ in terms of socio-demographics or illness profiles?
3. (Acceptability) What is the relationship of healers and their clients to conventional medicine? What do patients express about the acceptability of these different types of care?

### *7.2 - b) Data collection and tools*

Qualitative and quantitative data were collected from providers and patients of traditional healing between July and August 2007. Data were collected by a small team of university educated research assistants, trained by the Africa Mental Health Foundation, as well as by the Research Officer at BasicNeeds. The interviews were predominantly held in Kiswahili. Research assistants also spoke Kikuyu, Luhya and Luo and could alternate with those languages as needed.

A total of five instruments were used in the study (table 7-2), three were administered in slightly modified forms to patients and healers, and two additional instruments were administered to patients alone to measure diagnosis and stigma. Three of the tools were standardized, namely the Mini International Neuropsychiatric Interview (MINI) (Sheehan et al. 1998), The Stigma Scale, and the Systems of Belief Inventory (Sheehan et al. 1998; King et al. 2007; Kash et al. 1995). Two additional tools were designed and piloted by the Africa Mental Health Foundation and BasicNeeds for the purpose of the study: a structured interview, which I am calling the Healing Interview, and a socio-demographic questionnaire. To address my research questions, I have focussed on the data from three tools: the MINI; the Healing Interview and the socio-demographic questionnaire.

The MINI Plus is a structured diagnostic interview designed by researchers in France and America (Lecrubier et al. 1997; Sheehan et al. 1998), which diagnoses conditions found in the Diagnostic and Statistical Manual (DSM IV) and the International Classification of Diseases (ICD 11). Screen questions detect symptoms, and follow-up questions are asked if the screen is endorsed. The tool has demonstrated validity and reliability on par with the

Structured Clinical Interview for DSM IV (SCID-R) and the World Health Organization's Composite International Diagnostic Interview (CIDI) (Amorim et al. 1998), the two widest-used diagnostic instruments, and it takes less time to administer (on average 22 minutes). The tool has been widely used in East African populations (Abbo et al. 2013; Ayazi et al. 2012; Rukundo, Musisi, and Nakasujja 2013; Warfa et al. 2012), and has been used as the referent against which to validate another diagnostic tool in Rwanda (Scorza et al. 2013).

Table 7-2: Tools used in the original healer study

<b>Tool</b>	<b>Respondent</b>	<b>Author (Date)</b>
Mini-International Neuropsychiatric Interview (MINI Plus 5.0)	patients	Sheehan (1998)
The Stigma Scale	patients	King (2007)
Systems of Belief Inventory	patients & providers	Kash (1995)
Semi-Structured Healing Interview	patients & providers	Africa Mental Health Foundation
Socio-demographic questionnaire	patients & providers	Africa Mental Health Foundation

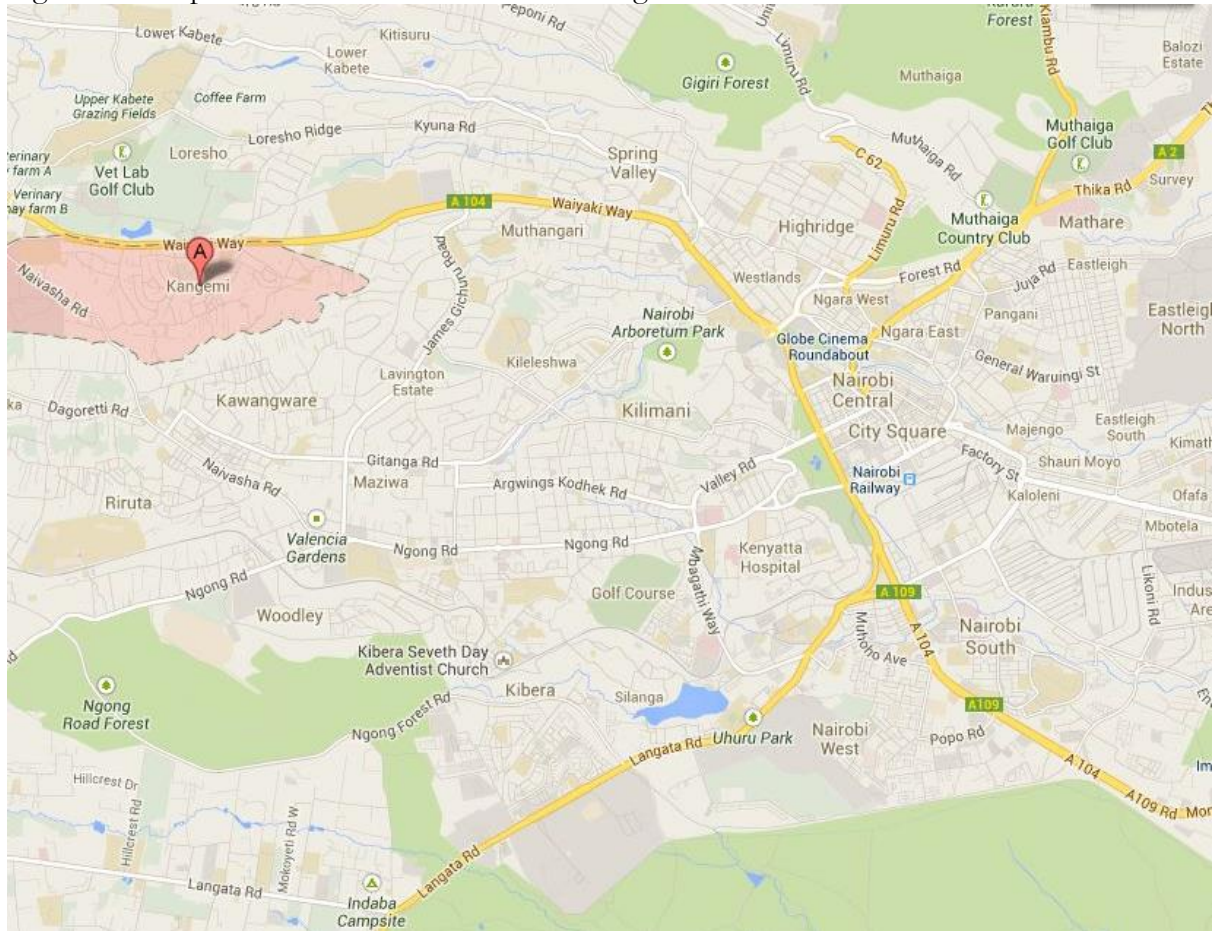
The current study used 12 out of 26 modules of the MINI, choosing to eliminate questions about disorders less commonly found in Kenya, such as anorexia, bulimia, and body-dysmorphic disorder, with the aim of reducing the research burden on subjects. The conditions screened for were: depression; dysthymia; suicidality; bipolar disorder; panic; agoraphobia; OCD; PTSD; alcohol and substance disorders; schizophrenia and generalized anxiety. In addition, a diagnosis of epilepsy was coded by the research assistant based on information provided by the patient and carer. The MINI is designed to be clinician-administered, but can also be administered by a lay-researcher with the benefit of additional training.

The Semi-Structured Healing Interview asked 19 mostly open-ended questions about the nature of diagnosis, treatment and referral (appendix 25). The interview asked about types of treatment and elicited attitudes towards conventional medicine. It employed a free-listing technique that has been effectively used to elicit culturally sensitive data for the purpose of diagnosis of mental disorders in other parts of East Africa (Betancourt et al. 2009; Bolton and Tang 2002). The socio-demographic questionnaire (appendix 26) is a 13-item questionnaire with multiple choice answers about age, sex, marital status, education, religion, accommodation and employment.

## 7.2 - c) Location

The study took place in Kangemi (figure 7-2), an informal settlement in the West of Nairobi with an estimated population of 64,000 (United Nations Habitat 2010). Kangemi is one of five wards in Nairobi Westlands, and its small area of 1.6 km<sup>2</sup> is tucked between the wealthy neighbourhoods of Westlands, Lavington and Loresho. An estimated one in five people in the slum has access to running water (da Cruz, Sommer, and Tempra 2006). Kangemi was selected because BasicNeeds was running its MHD model there and had opened a clinic in one of the government health services. They chose Kangemi because it is one of the poorest of the informal settlements around Nairobi and they were able to access a space in which to open a mental health clinic.

Figure 7-2: Map of the informal settlement of Kangemi



### *7.2 - d) Sampling*

Purposive sampling was used to select the 54 healers and 116 patients who were interviewed. First, the researchers paired with government administrators and local leaders to conduct a mapping of Kangemi. The settlement was divided into six divisions (Kichagi, Warugu, Kawangware, Marenga, Warugu, Kaptigat), and leaders associated with each division were asked to identify the traditional and faith healers within their community. Several group meetings were organised by community health workers with the local leaders and traditional and faith healers to explain the nature of the study and its objectives. In addition to healers identified by community leaders, others were located by research assistants by following up on advertisements for healing posted around the settlement area. To identify patients, the traditional and faith healers were each asked to propose three patients with a mental illness, whom they had seen on at least three occasions.

The inclusion criteria for patients were that a) they self-identified as having a mental illness, b) sought care from a traditional or faith healer, and c) were willing to participate in the research. Inclusion criteria for providers were that a) they practice traditional or faith healing, b) they report to have treated mental illnesses, and c) they be willing to participate in the research. There were no exclusion criteria, though if an individual was not in a state of mind to be interviewed, it was agreed that the carer could respond to questions. Both children and adults were interviewed in the original study, but data in this chapter come exclusively from adults. In-depth interview data were missing from four patients, so the sample size for most of the patient analysis is 112. Descriptive data about healing procedures was available from 90 patients and 50 healers.

### *7.2 - e) Data cleaning and management*

Researchers from the Africa Mental Health Foundation and BasicNeeds cleaned and managed the data upon collection. Interview responses were documented on paper and tape-recorded. The interviews were then transcribed and translated from Kiswahili and other local languages by research assistants from the Africa Mental Health Foundation. Qualitative data were preliminarily analysed by a research assistant at the Africa Mental Health Foundation using Desk Smart software. He created codes using techniques informed by Grounded Theory (Corbin and Strauss 1990). Preliminary analysis consisted of open-coding, an inductive process by which categories emerged from the data, and selective coding, a deductive process by which material was selected and discarded in relation to the core variables of interest. The selective coding categories were guided by the initial research questions.



In November 2011, I signed a data sharing agreement with the Africa Mental Health Foundation, who are in possession of the data. The agreement gave me permission to analyse the data contained in two separate databases, one of providers and the second of patients. The databases were transferred to me in SPSS 14. A large number of variables contained extensive string data, however, so I extracted the string data into Word and then into NVivo, assembling all qualitative responses by individual and by theme.

Original transcriptions were not available, as the computer containing them had crashed in the intervening five years between the study's completion and my analysis. The resulting qualitative data is therefore a mix of coded categories (as evidenced by repetition of words and phrases) and pieces of transcription translated into English. The transcription often shifted from first-person into third-person narrative, presumably a license taken by the research assistants entering the data. There was approximately twice as much qualitative data from each provider as from each patient: the combined data from the 54 providers was of equivalent length to that from the 112 patients (approximately 5,000 words for each group). Though imperfect in form, the qualitative data are nonetheless rich in content.

I cleaned the provider data by verifying the accuracy of key variables, such as the healer type. I checked healer type against the qualitative data provided and found two providers (H5 and H55) mis-coded as faith healers, who self-described as traditional healers, and one provider (H44) coded as a traditional healer, who self-described as a faith healer. I also checked sex against name. As the study IDs were not unique, I allocated a unique ID to each provider and patient.

## 7.2 - f) *Analysis*

In addition to cleaning the data, I also created a variable for ethnicity. Two Kenyan researchers, one Luo and one Luhya, separately coded the ethnicity of healers and patients based on their names. There were only two discrepancies and in both cases one of the ethnicities named was Luhya and none were Luo, so I chose the ethnicity given by the Luhya researcher, on the basis that he would know best what were Luhya names. Ethnicity was not attributable for five subjects out of the sample of 170.

I calculated patient diagnoses using the algorithms provided in the MINI questionnaire. The data provided to me were raw, so diagnosis had not been analysed. Lifetime rather than current diagnosis was used in the analysis, as there was no information available on when in the course of treatment these interviews were held, and some patients may have recovered since commencing treatment.

I used thematic analysis to code qualitative data from respondents, in keeping with the techniques outlined by Bryman (Bryman and Teevan 2004). First, I restructured the qualitative data so that it was sorted by healer type and by broad theme – diagnosis, treatment, referral. Next, I discerned sub-themes from the data and grouped responses according to those sub-themes. Finally, I wrote up the thematic analysis from those groupings.

When referring to subjects in the thematic analysis, I have used the labelling H##T or H##F short for healer, ID number, and traditional or faith, and P##T, P##F and P##B short for patient, ID number, and attending a traditional healer, faith healer or both. Five patients reported on visits to both traditional and faith healers.

I coded the qualitative data numerically, so as to be able to perform simple tests of statistical association. I used the original codes handed to me by researchers from the Africa Mental Health Foundation as a starting point for quantitative analysis. For example, in response to questions about treatment, the following codes appeared in the original dataset: prayers; Bible-reading; counselling; fasting; herbs; drugs; medicines; advice; encouragement; food/money; therapeutic incision; witchcraft; body or anointing oil; sprinkling water; and blessings. Next, I combined some codes to create broader categories – for example herbs, drugs and medicines into one theme (coded herbs), counselling and advice into another theme (coded counsel). Each of these broader categories was made into a binary yes/no variable, which could be counted, and compared across healer types. Binary variables were also created for referral procedures (any referral, referral to conventional medicine, referral to faith healing, referral to traditional healing) and for symptoms (headache, talking a lot and so forth).

Because of the small sample size, I started by looking at two-way associations (chi-square and t-tests), using healer type as the dependent variable. I used the Fishers Exact statistic when the cell count was less than 5, for example when analysing diagnoses. If the two-way association proved significant, I tested its correlation with other variables by way of a logistic regression. The 5 patients seeing more than one type of healer were excluded from these tests of association.

### *7.2 - g) Ethics and funding*

Informed consent was sought from and signed by healers, patients and carers participating in the study. Patients whose condition was such that they could not consent provided assent and a carer provided consent. The study was granted ethical approval by Kenyatta National Hospital Ethical Review Committee. The sample size was doubled in response to the ethical review by Kenyatta, so as to be able to run statistical tests of association.

The study was funded as part of a three-year (2005-2008) grant to BasicNeeds from the Department for International Development titled “Mainstreaming poor mentally ill people in the informal settlement of Kangemi in Nairobi Kenya.” The total grant amounted to approximately £400,000, but the research study constituted a small component of the larger project.

### **7.3 Results: Availability and Contact Coverage**

For the sake of comparison, I will juxtapose responses from patients and providers, mixing the topics of availability and contact coverage, and structuring the results instead along the lines of socio-demographics, diagnosis and treatment. A separate section will be devoted to acceptability coverage.

#### *7.3 - a) Socio-demographics*

##### **7.3.a.i Healers**

There was a preponderance of faith healers ( $n=31$ ) over traditional healers ( $n=23$ ) represented in the study, suggesting that faith healers may be more prevalent in Kangemi than traditional healers, since the sampling aimed to be comprehensive. Clear demographic distinctions appeared between the traditional and faith healers (table 7-3). With a mean age of 49 years, traditional healers were older on average than faith healers, who averaged 41 years ( $t_{52} = 2.078, p = 0.043$ ). Faith healers were also more likely to be women ( $X^2(1, N = 54) = 5.562, p = 0.018$ ): while only one in five traditional healers were women, faith healers were evenly divided between men and women (table 7-4). In terms of religion, faith healers were exclusively Protestant, suggesting that they were Pentecostal healers, while a quarter ( $n=6$ ) of traditional healers were Muslim, and 13% ( $n=3$ ) were Catholic.

In terms of ethnicity, the sample of providers were mostly Luhya (43%) and Kikuyu (31%), but there were also some Luo (12%), Kamba (6%) and Ugandans (8%). Faith healers were significantly more likely to be Kikuyu than traditional healers ( $X^2(1, N = 51) = 5.653, p = 0.017$ ) with almost half (45%) of faith healers being Kikuyu, as compared to only 14% of traditional healers. By contrast, one in five traditional healers was of Ugandan origin, whereas no faith healers were Ugandan. Luhyas constituted approximately half of both traditional and faith healers.

Economic distinctions were also apparent between the two healer types. Faith healers were more likely to have achieved more than primary education ( $X^2(1, N = 54) = 5.468, p = 0.019$ ): two-thirds (n=19) of faith healers had more than primary education, whereas only 22% of traditional healers had gone beyond primary school and a further 22% had not completed primary school. Income levels also reflected a disparity between the two groups. Faith healers were more likely to be formally employed than traditional healers ( $X^2(1, N = 54) = 5.332, p = 0.032$ ), and they were more likely to earn more than 5,000 Ksh (Int\$ 132) per month ( $X^2(1, N = 50) = 7.484, p = 0.006$ ). Whereas 40% of faith healers earned more than 10,000 Ksh (Int\$ 264) per month, only 10% of traditional healers earned a comparable amount, and 25% of healers earned less than 1,000 Ksh (Int\$ 26) per month. Unfortunately, no information was available on the fee structures of these healers. The difference in income may partially account for a difference in housing between the two groups, with faith healers appearing slightly more likely to own a house than traditional healers, although the sample size is too low to confirm statistically. Using chi-square and logistic regression to test association between socio-demographics and provider type (table 7-4), gender, income and employment were significant at the alpha 5% level, and education at the alpha 7% level.

Table 7-3: Association between provider socio-demographics and healing type

	<b>X2</b>	<b>p-value</b>	<b>β</b>	<b>p-value</b>
Female	5.562	0.018	3.736	0.053
More than primary education	5.468	0.019	3.311	0.069
Income > 5,000 Ksh	7.484	0.006	7.484	0.006
Employed	5.332	0.032	4.160	0.041
Kikuyu	5.653	0.017	NA	NA

### 7.3.a.ii Patients

One hundred twelve patients responded to the Structured Healing Interview. Three quarters of patients (73%, n=82) were attending faith healers and one quarter (27%, n=35) were attending traditional healers (table 7-5), including 4% (n=5) who were attending both types of healers simultaneously. In terms of religion, the patient sample were 100% Christian and predominantly Protestant (80%) with a mean age of 33 years. The majority (72%) were women. Half (47%) were cared for by a parent, spouse or child, while most of the remainder were cared for by other family members. Just over half were married and 70% were educated to primary level or less.

Table 7-4: Socio-demographic characteristics of traditional and faith healers

	<b>Traditional</b>		<b>Faith</b>		<b>All</b>	
	23		31		54	
	N	%	N	%	N	%
Age	48.8 (sd 11.4)		40.6 (sd 10.4)		43.3 (sd 11.2)	
Female	4	17.4	15	48.4	19	35.2
Married or cohabitating	17	73.9	23	74.2	40	74.1
Ethnicity						
Luhya	11	50.0	11	37.9	22	43.1
Kikuyu	3	13.6	13	44.8	16	31.4
Luo	2	9.1	4	13.8	6	11.8
Kamba	2	9.1	1	3.4	3	5.9
Ugandan	4	18.2	0	0.0	4	7.8
Education						
less than primary	5	21.7	0	0.0	5	9.3
primary	13	56.5	12	38.7	25	46.3
more than primary	5	21.7	19	61.3	24	44.4
Religion						
Protestant	12	52.2	0	0.0	43	79.6
Catholic	3	13.0	0	0.0	3	5.6
Muslim	6	26.1	31	100.0	6	11.1
Employment						
None	22	95.7	22	71.0	44	81.5
part-time	1	4.3	1	3.2	2	3.7
full-time	0	0.0	8	25.8	8	14.8
Income (monthly)						
< 1,000 Ksh (Int\$ 26)	4	20.0	1	3.2	5	10.0
1,000-4,999 Ksh (Int\$ 162)	12	60.0	13	41.9	25	50.0
5,000 -10,000 Ksh (Int\$ 264)	1	5.0	8	25.8	9	18.0
> 10,000 Ksh (Int\$ 264)	2	10.0	9	29.0	11	22.0
Rents house	22	95.7	27	87.1	49	90.7

Table 7-5: Socio-demographic characteristics of patients

	<b>Traditional</b>		<b>Faith</b>		<b>All</b>	
	<b>N=35</b>		<b>N=82</b>		<b>N=116</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
Age	31.7 (sd 9.0)		34.1 (sd 10.7)		33.4 (sd 10.2)	
Female	19	54%	65	79%	83	72%
Married or cohabitating	24	71%	41	53%	63	57%
Ethnicity						
Luhya	23	79.3	26	34.7	51	44%
Kikuyu	4	13.8	37	49.3	48	42%
Luo	2	6.9	6	8.0	9	8%
Kamba	0	0.0	3	4.0	4	3%
Other	0	0.0	3	4.0	3	3%
Education						
less than primary	5	14%	10	12%	14	12%
primary	21	60%	50	62%	67	58%
more than primary	9	26%	21	26%	34	30%
Religion						
Protestant	29	83%	63	79%	90	80%
Catholic	6	17%	17	21%	23	20%
Employment						
None	18	53%	53	69%	70	64%
part-time	12	35%	19	25%	30	28%
full-time	4	12%	5	6%	9	8%
Income (monthly)						
<1,000 Ksh (Int\$ 26)	10	48%	33	51%	41	48%
1,000-5,000 Ksh	9	43%	31	48%	41	48%
> 5,000 Ksh (Int\$ 132)	2	10%	1	2%	3	4%
Living in rented house	33	94%	73	89%	106	91%
Carer's relation						
Spouse	3	16%	13	21%	16	22%
Parent	4	21%	14	22%	18	25%
Child	1	5%	5	8%	6	8%
Other relative	11	58%	25	40%	36	49%
Friend or neighbour	0	0%	3	5%	3	4%
No carer	0	0%	3	5%	3	4%

Indicating low socio-economic status, most respondents (91%) rented rather than owned their home, and two-thirds (64%) were unemployed. The remainder were mostly employed part-time. Half of patients reported earning less than Ksh 1,000 (Int\$ 26) per month, while approximately another half earned between Ksh 1,000 and 5,000 (Int\$ 132). However, the response-rate to questions about income was relatively low (72%), making this data potentially less accurate. Indeed, there was poor correlation between responses to the questions about employment and income: 29% of those unemployed (n=20) responded that they were earning more than 1,000 Ksh per month. It is possible that they earned money through casual labour rather than through formal employment, but nonetheless the responses around income and employment merit further attention.

The ethnicities of patients matched those of healers almost identically. The patient population were almost evenly split between Luhya and Kikuyu (44% and 42% respectively), with a remainder of Luo (8%), Kamba (3%) and a scattering of other tribes. Patients of faith healers were considerably more likely to be Kikuyu (49%) than patients of traditional healers (14%), suggesting that ethnicity may play a role in their choice of provider.

The patients of traditional and faith healers appeared relatively similar in socio-demographic profile (table 7-6) with two exceptions: patients of faith healers were more likely to be women ( $X^2(1, N = 112) = 7.032, p = 0.008$ ) and they appeared more likely to be employed ( $X^2(1, N = 112) = 2.672, p = 0.102$ ), though the latter was only significant at alpha 10%. Since being female and employed are often negatively correlated, I ran a logistic regression using those two variables as covariates of treatment type. Being female remained significant ( $\beta=1.213, p=.014$ ), but employment became insignificant ( $p=.214$ ) as predictors of attending a faith healer.

Table 7-6: Test of association between patient socio-demographics and healer type

	$X^2$	p-value
Female	7.032	.008
Married or cohabitating	2.007	.157
More than primary education	0.042	.838
Protestant	0.105	.293
Employed	2.672	.102
Income > 1,000 Ksh	4.153	.125

### 7.3 - b) *Diagnosis*

#### 7.3.b.i Healer Perspective

When asked what types of mental illness (*akili isiyo timamu*) they treat, healers responded with a wide spectrum of answers (table 7-7). Because the data were coded in English by Kenyan research assistants with backgrounds in public health, the diagnostic labels applied were mostly drawn from conventional medicine, though it is unlikely that the healers would have used those words in many cases. For example, healers are reported to have said they treat epilepsy, depression, anxiety, schizophrenia, psychosis, bipolar (and “manic”), addiction, autism and cerebral palsy. Epilepsy was the most common condition cited by traditional healers (76%), while depression was the most common condition cited by faith healers (72%). In addition, the healers enumerated medical diseases not traditionally associated with mental illness, in particular HIV, cerebral malaria, sexual dysfunction and infertility.

Despite the intrusion of researcher bias with regards to diagnosis, the data nonetheless preserved several local idioms of distress. Both traditional and faith healers alike used local terms meaning “demon-possessed”: 29% of traditional healers and 38% of faith healers used this term (table 7-8). A person possessed by demons was described as “talking to oneself, being sometimes sad and other times jovial, feeling as if being followed by unseen beings, sleeplessness” (h9f), as well as by being “irritable [and] fighting” (h39t) or “violent” (h49t) and “very afraid of people” (h43t). These descriptions evoke common symptoms of what conventional medicine might call psychosis, but they could equally be related to acute mood disorders or anxiety. In the absence of comparative data between diagnostic systems, it is impossible to say whether demon-possession maps onto a single conventional medical diagnosis.

The term “madness” (madmen are *wazimu* in Kiswahili) was also loosely used by traditional and faith healers alike in association with severe psychosis mixed with destitution. For example, a faith healer described a madman as “walking aimlessly... eating his stool... eating anything in sight... very rough and dirty” (h01f). A Luhya traditional healer echoed elements of this description, noting that a madman is “poorly groomed, wears dirty clothes and runs around all day along the road, making incomprehensible speech and thoughts” (h35t). A distinction was drawn by a Kamba traditional healer between “a disease you are born with” and “demon-possessed” (*kenpagma*), which is acquired, with the former characterized by the affected people “at times [being] very good people, until a given season or time” (h49t).



A lesser used but nonetheless prevalent diagnosis was “bewitched”: 10% (n=3) of faith healers and 5% (n=1) of traditional healers used the term. This diagnosis appears to be associated with a wide range of complaints, including, but not always, being demon-possessed. Other local idioms of distress included “feeling tired in the head” (h35t) and suffering from “emptiness” (h34t), or “being quiet and over-thinking” (h17f), which are suggestive of the spectrum of anxiety and depression within conventional medical nosology. Finally the term “delayed milestones” was commonly used to refer to a developmental delay, not only in the form of mental retardation, but also a delay of life-events, such as marriage or child-bearing.

Table 7-7: Kiswahili words for mental illness and traditional practitioners

<b>English</b>	<b>Kiswahili</b>
<b>Illnesses</b>	
Mentally ill	<i>akili isiyo timamu</i>
Mad person	<i>mwenda wazimu</i>
Demon-possessed	<i>kupagawa</i>
Bewitched	<i>kurogwa</i>
Epilepsy	<i>kifafa</i>
<b>Traditional practitioners</b>	
Traditional healer	<i>mganga</i>
Faith healer	<i>muombaji</i>
Herbalist	<i>akimi wa miti</i>
Diviner	<i>mundu mue</i>

The process of arriving at a diagnosis was similar in some respects between faith and traditional healers. Both categories of provider based their assessments largely around direct observation, questioning, and listening. “They tell me their problems” (h43t) “I ask the history” (h17f). Experience was noted as an important element contributing to the skill of diagnosis. “I identify the problem by observation, through experience, as taught by my grandfather” explained a traditional healer (h49t), while a faith healer asserted, “I am able to know by seeing them, due to experience” (h1f).

Table 7-8: Mental illnesses treated by traditional and faith healers

Diagnosis	Traditional		Faith	
	N	%	N	%
epilepsy	16	76.2%	17	58.6%
depression	8	38.1%	21	72.4%
“demon possession”	6	28.6%	11	37.9%
mania	3	14.3%	7	24.1%
schizophrenia	3	14.3%	5	17.2%
“madness” or psychosis	3	14.3%	2	6.9%
suicidality	1	4.8%	4	13.8%
“bewitched”	1	4.8%	3	10.3%
thinking too much	1	4.8%	0	0.0%
stress or anxiety	0	0.0%	3	10.3%

In addition to these factors, which also shape the diagnostic practices of conventional medical providers, traditional and faith healers both observed that they were helped by an additional super-natural force. For faith healers, the added power took the form of “God’s guidance” (h28f). A Luo faith healer observed “Through the holy spirits, I receive guidance on the type of person before me. After prayer, the demons in a possessed person start talking” (h1f). The plural of “spirits” is significant here, in that typically Christian doctrine refers to a single Holy Spirit. The plural suggests a synchronism between Christian and traditional cosmologies, since Luos traditionally believe in multiple ancestral spirits (Sindiga 1995). Also of note is that the external force assisting in diagnosis is not only that of the “holy spirits,” but also that of “the demons.” The agency of demons in diagnosis is echoed by another faith healer, who asserted: “Demons are manifested through a strong prayer and worship, and the patient starts to jump and talk non-stop” (h9f). Not all faith healers invoked demons, however. A number (n=5) of them noted instead that diagnosis was made through a process of repentance. Implicit in this approach is that the cause of mental illness is not demons but sin.

Reference to a super-natural power distinguished two types of traditional healer from one another, namely herbalists and diviners. Whereas a pure herbalist relies on symptoms that can be directly observed or recounted, the diviner (or herbalist-diviner) connects with an external force – be it a divinity or ancestral spirits – and receives a revelation. One traditional

healer described having “powers to see and identify” (h39t), and several others explained that burning herbs helped them to connect with the spirits (h34t, h47t, h49t). “I light herbs mixed in a pot – different herbs are crushed and mixed with some ash and a fire is lit – and I ask the patient to sit next to it, and the demon starts to talk, identifying himself” (h49t). A shared imagery of talking demons is evident between this traditional healer and the faith healers quoted previously. Some diagnostic codes, however, are specific to traditional healers. For example, after lighting herbs on fire, one healer noted: “The smoke must be vertical. If it goes horizontal, it means bad luck and the patient must make an offering” (h34t). In another case, also without a Christian analogy, diagnosis was made by communicating with spirits through a mirror.

“I use a traditional way of looking into the mirror to see the problem and the causative agent. The client comes to my work place and I ask him how he feels. Using the mirror, I hold his right hand and I am able to translate the message I receive” (h33t).

On the basis of these descriptions, we can deduce that at least seven of the traditional healers, about a third of the sample (30%), were diviners. Over half (56%) were herbalists, and the specialty of the remainder (n=2) could not be determined.

### 7.3.b.ii Patient Perspective

Data on symptoms were available from 76 patients. Unfortunately, patients were not asked to list their own symptoms, but rather general symptoms of mental illness (*akili isiyo timamu*), so it was not possible to associate idioms of distress with diagnosis. As with healers, the term “demon possession” was used by patients, though much less frequently (n=2, 3%).

“Witchcraft” (or being bewitched) was only reported by one patient.

Patients also enumerated many common symptoms of psychosis and depression. Symptoms of psychosis included “talking to self,” “laughing to self,” “walking aimlessly,” “talking without meaning,” “being unkempt,” as well as more unusual symptoms like being “naked,” “garbage collecting,” and “eating from garbage.” Recognized symptoms of depression described by the patients included “crying,” “feeling low,” “quarrelling,” “losing sleep” and “no appetite,” and wanting to end one’s life. In addition, two non-descript symptoms appeared commonly in patient descriptions, namely “headaches” (14%) and “thinking a lot” (11%).

Table 7-9: Patient diagnoses, using the MINI, by healer type

Diagnosis	Traditional		Faith		All	
	N	%	N	%	N	%
Any diagnosis	30	86%	67	82%	92	82%
Mood disorder	24	69%	50	61%	74	66%
Anxiety disorder	3	9%	7	9%	10	9%
Bipolar disorder	1	3%	15	18%	16	14%
Schizophrenia	1	3%	0	0%	1	1%
Alcohol disorder	1	3%	2	2%	3	3%
Epilepsy	6	17%	2	2%	8	7%
Suicide attempt	7	20%	11	13%	18	16%
No diagnosis	5	14%	15	18%	20	18%

Note that the five patients of both traditional and faith healers are counted in both the traditional and faith columns, but only once in the “all” column.

Table 7-10: Tests of association between patient diagnosis and healer type

	Chi square statistic	p-value	df
Common mental disorder	0.748	0.387	1
Suicide attempt	1.263	0.261	1
Serious mental disorder	2.653	0.143	1
Alcohol disorder	0.043	1.00	1
Epilepsy	9.451	0.006*	1
No diagnosis	1.022	0.312	1

Turning to the biomedical diagnoses resulting from the MINI assessment (table 7-9), I found that diagnostic profiles were somewhat similar between patients of traditional and faith healers. Eighty two per cent (n=92) of those identified by healers as having a mental illness had a disorder diagnosable by the MINI. Among those with a diagnosable mental disorder, 80% (n=72) had a common mental disorder. All of the ten cases diagnosed with anxiety had comorbid depression. A further 17% (n=16) of those with a diagnosable disorder met criteria for bipolar disorder, while only a single patient of one traditional healer was diagnosed with schizophrenia. Alcohol dependence was also rare with only 3% of patients (n=3) meeting criteria, while epilepsy was present among 7% of the patient population (n=8). As alcohol

disorders are more prevalent than epilepsy in the general population, we can observe that individuals with an alcohol problem are seeking care from healers with considerable less frequency than those with epilepsy. Interestingly, one in five patients (18%) did not meet criteria for any mental illness using biomedical categories, though they were presumably experiencing distress.

A relatively large number of patients (n=18, 16%) had a history of attempted suicide. There was an association between having attempted suicide and attending a traditional healer, significant at the alpha 10% level though not at the alpha 5% ( $p = 0.069$ ) (table 7-10). If a past suicide attempt indicates illness severity, then it is possible that patients attending traditional healers may be on average slightly more ill than those attending faith healers. This hypothesis is supported by the greater proportion of patients with no diagnosable illness found among faith healers, although the latter association is not statistically significant.

### 7.3 - c) *Treatment*

Treatment did not vary systematically by diagnosis, although some healers reported having a system of treatment connected with diagnosis.

#### 7.3.c.i Faith Healing

Faith healing existed in different forms, the greatest distinctions being whether it was individual or collective and whether it took place in the patient's home, the healer's space, or in the church. Half the patients of faith healers acknowledged receiving home visits. In general, when healing took place in the church it was collective, but in some instances, one-to-one counsel was given in the church (p102f). Healing was sometimes performed by the pastor or priest, but also by self-appointed members of the congregation believed to have special healing powers (p77f); however data were not collected on the healer's role within the church, so that wasn't possible to quantify. Further differences existed in terms of the combination of different procedures undertaken. Several different procedures were described by providers and patients of faith healing, namely: 1) prayer; 2) Bible-reading; 3) counselling or encouragement; 4) cleansing; 5) anointment and 6) offerings.

Prayer was the most ubiquitous component of all faith-healing, endorsed by 100% of providers and patients alike. Prayer took place in different ways, sometimes with the patient kneeling (p37f, p96f), sometimes with the healer laying hands on the head (p29f, p37f), often with the person prayed for closing their eyes (p8f). Usually the healer would utter the prayer and the person being healed would repeat the words (p93f). Prayer took place most commonly

in the church or home, however one Luo healer noted: “We pray for them at the church and in their homes and even at their birth places” (h1f). Going to the birth place to pray is suggestive of a traditional practice, which gives weight to the homeland because it is the resting place of ancestral spirits (Sindiga 1995).

A number of patients healed in church noted that at the “praise and worship” part of the service, people were called forward to the altar to be prayed for collectively (p23f, p29f, p74f, p92f, p95f). One person mentioned that the church ran collective support-groups “to encourage each other” (p102f). As part of the collective nature of healing, patients were often asked to announce their problem publicly (p37f, p77f). Sometimes prayer was preceded or followed by singing (p78f).

In other instances, however, prayer was viewed as a more individual act. Several respondents remarked that they were asked to pray for themselves “severally” (p24f) or “pray at home ‘til next meeting” (P37f). And in one case, the healer noted that he was “praying for strength” (h32f), possibly strength for himself to heal, as well as strength for the patient to endure.

The second most common component of faith healing was counselling or encouragement, described by 59% of providers and 31% of faith patients. The most frequent emphasis of the counselling was providers telling faith patients to “trust [they] are healed” (p74f), “believe the demon has been cast out” (p92f), “have faith that God will heal” (p78f), or “believe God will answer the prayers” (p37f) – 22% of patients reported this emphasis on belief in a cure as part of the healing process. Providers confirmed the centrality of belief in the healing process. In the words of one faith healer, part of his technique is to “make the person believe in the Bible and the Holy Spirit” (h2f), while another healer described it as a “boosting of faith” (h7f). A smaller number of patients (n=3) observed that they were asked to repent their sins (p36f, p106f, p116f). One patient noted that she was “advised not to feel guilty” (p95f). Another reflected that she and the healer were “talking about the homestead” (p86f). And a healer stated that in his counselling, “the patient is encouraged morally and taught to accept” (h9f).

Use of the Bible was the third most frequently noted component of faith healing, mentioned by 38% of healers and 11% of patients. It is possible that some patients view Bible reading as part of praying and therefore did not mention it separately. Neither patients nor providers elaborated on which passages of the Bible were read. The Bible was not only used for reading, however. A Luo faith healer observed “I make them kneel down and bang them with the Bible as I sprinkle water on the head” (h17f).

Though less frequently noted, faith healing was also accompanied by a process of cleansing. A Luo healer observed, “I cleanse the patient, the inhabitants and the whole house by spraying holy water” (h1f). A Luhya healer echoed this practice and described purifying the water first by boiling it and adding salt (h18f). Water was not the only form of cleansing. Fasting was also mentioned by four faith healers (14%) as part of their instructions to patients for ritual healing. There was a discrepancy, however, between healers and patients in his regard, since no patients reported having fasted.

The most dramatic form of cleansing was “casting out of demons,” also described as “driving away” and “chasing” demons. This form of exorcism was reported by one Luo healer (h4f) and four patients (p36f, p71f, p92f, p96f), which represents about 5% of respondents in each group. Unfortunately, no further detail was provided in our data about this procedure.

After cleansing, several healers and patients mentioned anointment with oil (described in one instance as olive oil). Four patients and four providers reported use of oil. One patient explained that she was asked to buy anointing oil costing 100 shillings (Int\$ 2.6) and told to “put it in some water and let the oil stay for 7 days before use” (p23f). Though less explicitly monetary, the language of “offerings” was used by six patients, who noted that gifts of food or money constituted part of the proceedings. By contrast, none of the faith healers alluded to offerings. One healer noted, inversely, that she “provides for the [patient’s] need with food or money” (h21f).

### 7.3.c.ii Traditional Healing

The most common component of healing provided by both herbalists and diviners was herbs. (The term herbs refers here to all plant remedies, including roots and tree bark.) All of the traditional healers reported administering herbs, and all of their patients reported receiving them. Herbs existed in many varieties, the details of which exceed the scope of this study. A number of healers noted that the purpose of the herbs was to expulse material from within the body, be it through sneezing and salivating, or vomiting and diarrhoea (h38t). As described by one healer, “Those who appear mad are given a herb through the nose, and the patient drinks and then sneezes while drooling saliva and mucus, then calms down” (h49t).

Herbs were given in many forms (table 7-11). The most common form of administration (reported by 67% of providers) was to serve a drink with crushed or powdered herbs. Usually the base of the drink was water, sometimes boiled to extract the substance, for example with tree bark (p11t). One patient described that the water was brought all the way from the East Coast of Kenya, “*maji ya Mombasa*” (water from Mombasa) (p12t). For bitter

herbs, the substrate was sometimes soda, for example Coke (p113t) or Fanta orange (h50t). Another means of ingesting herbs was to mix it in food, for example in mutton (h39t) or in the liver of a young dog (h50t).

A second mode of administering herbs was air-born, through the nose or mouth. This included sniffing herbs, inhaling their smoke (h35t, h53t) or breathing in their vapour with a steam bath. One healer described that for psychosis, “the patient is put in a blanket with steam” (h35t). Patients were also covered when inhaling smoke, according to one healer (h53t).

Still another means of administering herbs involved placing them on or in proximity to the body. Sometimes (n=4 providers, 1 patient) herbs would be mixed into oil and massaged into the body. At other times (n=3 providers, 2 patients), the herbs would be steeped into a bath in which the patient soaked (h38t, h47t, h53t, p9t, p65t). As described by one patient, “You remove clothes and enter into water. Then you are covered with a blanket and *sufuria* [cooking pot]” (p9t). Finally, some healers advise putting herbs and roots in contact or near the body while sleeping. A healer remarked, “a special concoction is tied on the patient’s head as he or she sleeps” (h35t). While a patient confirmed that she was “given some roots to put under the pillow” (p65t), and another remembered that herbs were placed “under the head at night” (p62f).

A form of treatment practiced exclusively by diviners involved making small incisions across the body. One in three of the traditional healers interviewed (n=7) noted that they used incisions among their array of remedies. The process, according to one healer, is intended to produce bleeding and pain. “For persistent headaches, I make skin cuts on the temporal and frontal areas of the head until one bleeds. Then I apply traditional medicines on and in the wounds until the patient feels pain” (h35t). Another healer suggested that the incisions are a means of administering protective herbs. “Using a blade, I cut part of the body and insert the herbs in the body” (h55t).

Table 7-11: Traditional and faith healing procedures

	TRADITIONAL				FAITH			
	Provider		Patient		Provider		Patient	
	N	%	N	%	N	%	N	%
Prayer	2	10%	4	16%	29	100%	64	100%
Counselling or encouragement	1	5%	1	4%	17	59%	20	31%



Asked to believe he/she is cured	0	0%	0	0%	0	0%	15	23%
Asked to repent	0	0%	0	0%	2	7%	2	3%
Use of the Bible	0	0%	1	4%	11	38%	7	11%
Fasting	0	0%	0	0%	4	14%	0	0%
Cleansing with water	0	0%	0	0%	4	14%	1	2%
Anointment with oil	2	10%	2	8%	4	14%	4	6%
Offering (food, drink, money)	0	0%	1	4%	0	0%	6	9%
Casting out demons	0	0%	0	0%	1	4%	4	6%
Herbs, roots or medicines	21	100%	26	100%	0	0%	0	0%
Data on mode of herb delivery	16	100%						
Drink	10	67%						
Rub in (incisions)	7	44%						
Sniff or inhale	6	38%						
Apply externally (oil, bath)	5	31%						
Chew, lick or eat	4	25%						
Incisions	7	33%	5	19%	0	0%	0	0%
Massage	4	19%	1	4%	0	0%	0	0%
Chains	1	5%	0	0%	0	0%	0	0%
Home-visits	18	86%	13	50%	27	93%	25	45%

One in five patients of traditional healers (n=5) reported receiving incisions. The proportion of patients who reported receiving incisions was lower than that of the healers who performed it, so it appears not to be a treatment of first resort for the most prevalent conditions. One patient described the procedure as follows. “He cut parts of the body then smeared with ashes in these parts. [...] Then he mixed boiled water from barks of trees with crushed leaves and then poured it into the cuts” (p11t). A second patient reported that the healer “put the ashes where they act with a razor blade” (p100t). Another patient noted, “You are cut with a blade all over the body and they apply the herbs. Then they give you herbs to swallow and shower with” (p62t). For another patient, the cuts were focused on the stomach. She was “locked up in the house with the traditional healer. He poured out some liquid and grains as an offering to the ancestors and prayed to drive away demons. Then he cut my stomach and poured some liquid drugs” (p71t). The purpose of the cuts as described here is to “drive away demons” is is therefore presumably a treatment for the diagnosis of “demon possessed” (*kepagna*) and possibly also “bewitched” (*keurogwa*).

The patients receiving incisions were predominantly male (n=4/5). There was no clear pattern of biomedical diagnosis visible in terms of who received incisions, however epilepsy predominated. Those receiving incisions had the following biomedical diagnoses: mood disorder (n=3); epilepsy (n=2); comorbid alcohol dependence (n=1). Since epilepsy was less prevalent than mood disorders among traditional healers, the rate of incisions amongst people with epilepsy was considerably higher than for mood disorders: one-third of patients with epilepsy received incisions as compared to 1/8<sup>th</sup> of those with mood disorders. One of those receiving incisions had previously attempted suicide, which is in keeping with the 20% prevalence of suicide attempt among those attending traditional healers. All of those receiving incisions had a diagnosable disorder, suggesting they may be more severely ill on average than other patients.

In addition to the use of herbs and incisions, some traditional healers used prayer. Four patients of traditional healers (16%) described prayer being part of their treatment. Several healers prayed over the herbs rather than over the patient, with the aim of helping them to be more potent: one patient described that the healer “prayed over some herbs and asked me to drink it” (p89t), another that the healer said a “prayer for the herbs to be blessed” (p115t). One patient noted that she was “prayed for in language [she] did not understand” (p82t), but that appears to have been rare. Another healer “prayed to drive away demons” (p71t), as part of the act of making incisions. Two healers reported praying as part of their practice (h33t, h34t), one of them in combination with use of a mirror, arguably as much for diagnosis as for treatment.

A final and highly contentious technique for managing mental disorders was the use of chains. One traditional healer noted that if a person exhibited *aliyetumi wa majini* (possession by Djinn), “The patient is violent, and at times they are chained, when seen for the first time” (h49t). Djinn are an evil spirit that form part of a Muslim belief system, and they play a role not dissimilar to demons within a Christian context. This traditional healer was Muslim, and blended elements of that system of faith into his practice. No patients reported having been chained. However, as chaining appears to be reserved for patients who are psychotic and only one patient in our sample had a history of psychosis, our data may not be a good source for testing the prevalence of this practice.

### 7.3 - d) *Follow-up care*

Follow-up procedures varied a great deal from healer to healer, though not ostensibly between traditional and faith healers. Traditional healers often gave their patients herbs to take for a

certain duration of time, ranging from two days (p46t) to two-months (p21t) and even up to three years (p60t). The majority of traditional healers reported following up after one or two weeks on the progress of herbal remedies (h41t, h42t, h54t). In rare instances, however, for both traditional and faith healing, treatment was viewed as one-off: “they just give the medication once,” reported a patient of a traditional healer (p33t), while a patient of a faith healer noted, “after prayers, that’s the end of everything” (p14f). A number of healers performed home-visits to check on the progress of healing. Since half of patients are seen in their homes for the initial treatment, this is a natural form of follow-up.

Faith healers also performed frequent home-visits for follow-up care, according to their patients (p29f, p31f, p84f). One patient reported that the faith healer visited her home “every three days in the beginning, then every one week, when [I got] stronger” (p64f). A week seemed to be the standard period of follow-up, as reported by the healers themselves (h13f, h9f, h17f), which corresponds with the frequency of standard church services. Some patients, however, noted that there was no follow-up (p8f, p35f). Several faith healers noted that it was the choice of the individual being healed whether or not to return (h16f, h22f, h28f). Patient choice did not figure among the factors mentioned by traditional healers.

## **7.4 Results: Acceptability Coverage**

### *7.4 - a) Referral*

Although traditional and faith healers tended to be accepting of conventional medicine, they were not equally accepting of one another. Several providers of faith healing expressed distrust of traditional healers, although the reverse was not overtly expressed. “There is need for linkage with hospitals, but not with the traditional healers, because they are not honest” (h32f), claimed one faith healer. Another stated more diplomatically, “people should only use prayers and hospital medicine” (h14f).

Responses about referral practices (table 7-12) differed notably between providers and patients, however the low response rate from patients (26%, n=33) makes their data less robust on this question than on other topics. The majority (three-quarters) of providers, both faith and traditional, reported coordinating care with other providers, however a minority of patients (one-third) reported having been referred for care, or been the recipient of coordinated care.

Table 7-12: Referral practices according to providers and patients

	TRADITIONAL				FAITH			
	Providers		Patients		Providers		Patients	
	N	%	N	%	N	%	N	%
Refers to other providers	16	76%	4	31%	22	79%	7	35%
Refers to conventional medicine	15	75%	3	23%	21	75%	7	35%
Refers to faith healers	4	20%	2	15%	6	21%	0	0%
Refers to traditional healers	3	15%	0	0%	1	4%	0	0%

The most common referral, reported by providers and patients alike, was in the direction of conventional medicine. A quarter to a third of patients reported being referred to conventional medicine, with referral rates slightly higher among patients of faith healers (35% versus 23%). It was rare that a traditional healer referred to a faith healer (n=4 providers, 20%), and it was even more rare that a faith healer referred to a traditional healer (n=1 provider, 4%). Faith healers more commonly reported referring to other healers of the same type, whereas traditional healers appeared as likely (relatively unlikely) to refer to a faith healer as to another traditional healer. A few healers noted that referral should be the initiative of the patient. “Linkages are not necessary. Let the patient decide on his own” (h29f), noted one provider, while another advised, “Let patients choose where to go” (h53t).

#### 7.4.a.i From the perspective of faith healing

Faith healers saw an intrinsic connection between their work and the work of conventional medical providers, because both were perceived to be doing the work of God (table 7-13). “It is God who gives doctors wisdom, [...] both doctors and patients need God” (h3f), said one provider, while another echoed, “God gave men the ability to know medicine; but we should also believe that God will heal us when prayer is involved” (h9f). Another faith provider noted that conventional medicine and healing are two means to a similar end: “Both prayer and medicines are powerful. God works in many ways” (h17f).

Patients raised the same arguments as faith healers for the overlap between faith healing and conventional medicine: “Conventional medicine is very important, but God has to be involved for it to work” (p1f), stated one patient, while another noted the dictum: “Doctors treat, but God heals” (p57f). Implicit in the idea that God heals is the supposition

for some that conventional medicine addresses symptoms, whereas faith healing provides a cure. As voiced by one patient, “prayers only can heal completely” (p4f).

Some providers and patients alike noted that faith healing served a different, yet complementary, function to conventional medicine. Doctors and faith healers were seen as two parts of a whole: “They work hand in hand,” (p6f) observed one patient. Another patient noted a synergy between the two types of care: “Prayers can heal alone, but when combined with medical treatment they do better” (p37). A faith healer understood the specificity of her work as providing interpretation and meaning to the illness experience: “It is good to take drugs and also be taught about God's purpose for life” (h9f). Several patients noted that faith healing provided an element of encouragement or “uplift” that was absent from conventional medicine. One patient observed that she “prefers hospital medication, but combines with prayers for uplifting” (p3f), while another mentioned that “the hospital can provide drugs but the church is better at counselling and encouragement. Both work in their own ways” (p103f). Still another patient observed that faith healing, delivered through the community of the church, had the appeal of a more holistic approach: “I need the community support... [faith healing] looks at the individual as a whole” (p41f).

Despite the widespread view that faith healing and conventional medicine are complementary, a number of faith healing patients did not hesitate to state a need for hospital-based care for acute episodes of psychiatric illness. “If you are sick, go to Mathare Hospital” (p10f) said one patient, while another person responded to the question of how mental illness should be treated, “they should be institutionalized, then revealed [sic], when they are better, back into society” (p27f). Another patient noted the financial obstacle to hospital-based care, arguing “They should have some funds with which they can send one to hospital” (p80f). Hospital-based care was not seen as distinct from faith care, however. One patient recommended, “pastors should be going to the hospitals of mentally ill and pray for the patient” (p36f).

A practical argument made by providers in favour of medical pluralism was that not everyone believes in God, or not with equal fervour. “There’s a need for both faith healing and hospital drugs – for those who don’t believe” (h15f). And again, “medical treatment works well for those with little faith; prayers work for believers” (h28f). Or, “It all depends on the individual's faith” (h29f). A patient added to this conviction that without faith even conventional medicine is ineffective. In her words: “you can take drugs, but because of lack of faith you don’t get well” (p5f).

A number of healers and patients felt that faith healing was more effective than conventional medicine, and some even thought conventional medicine was best avoided. Patients expressed the view that there is an order of operations and prayer should come first: “Both are good, but prayer should come before hospitals” (h10f). Or, “Prayers are supreme, but they may be combined with conventional medication” (p31f). Explanations for the superiority of faith healing differed. One patient commented that prayers are better because they offer a single solution for all problems, whereas medicine is different for each illness: “The same medicine can’t heal all diseases, but prayer can heal all the diseases. It doesn’t work always, unlike prayers, which work always” (p24f). Another patient thought faith healing had longer-lasting effects: “after prayer it takes [more] time before a relapse” (p113f). Whereas another person noted that the effects were more immediate: “It lifts my spirit and I feel the burden has reduced even before healing” (p32f). A healer concurred, arguing “faith healing works faster than drugs” (h26f).

A few patients (7%, n=5) of faith healers stated that prayer had replaced medication: “I don’t even use drugs, prayers are more powerful” (p19f), and “I stopped taking drugs because I believe more in prayers” (p69f). One person asserted that “conventional medicine made me to be worse than I was” (p115f) – possibly the result of medication side-effects. Two individuals explained that the reason for stopping conventional medicine was the cost. “I prefer prayers as they are not requiring money, but with modern medicine I require medicine” (p26f), stated one patient. While another person resigned from future use of medication, declaring, “This is the last time I will use medication, I believe so. So I won’t buy more” (p118f).

A single patient of a faith healer expressed a distaste for faith healing, saying “I prefer medical treatment, because in faith healing you can be misled and gotten into things you don’t want to be in” (p28f). Money was not mentioned by any of the patients of faith healers, neither as part of their care nor as an obstacle to it.

Table 7-13: Patient preferences for care

	<b>Traditional</b>		<b>Faith</b>		X2	p-value
	N	%	N	%		
Healing and conventional medicine are equal	4	14%	30	42%	6.966	0.008
Faith healing is better	5	18%	33	46%		
Traditional healing is better	3	11%	0	0%		

Conventional medicine is better	15	54%	7	10%	22.20	<.001
It depends on the condition	1	4%	1	1%		
Conventional medicine is bad	1	4%	1	1%		
Traditional healing is bad	5	18%	1	1%		
Faith healing is bad	0	0%	1	1%		

#### 7.4.a.ii From the perspective of traditional healing

As with faith healers, some traditional healers saw their work as the other face of conventional medicine. “All drugs are from herbs, it’s only that they make them into tablets and injectable” (h37f), noted one healer. Another observed, “After all, conventional medicine came from traditional medicine” (h49f).

A pragmatic concern, expressed by a traditional healer, but not by faith healers, was the need to maintain clients. “People have left traditional treatment. We need to act also with the western convention and assist one another” (h34t). Money was also a factor in the preferences of patients of traditional healers. One person complained, “When there’s no response after a long time, it’s good to be told to go to hospital instead of wasting money when you can’t be cured” (p21t). Another patient, however, took an opposite stance, stating that traditional healing was the economical option: “Conventional medicine is better, but it is expensive” (p59t).

Not surprisingly, several providers of traditional medicine felt their services were more effective than conventional medicine. In one case, efficacy was attributed to the potency of the remedy: “herbs are stronger than traditional medicine” (h38t) – note that “traditional” here refers to conventional. One respondent argued that the higher quality of traditional herbs was due to their being natural rather than artificially engineered: “Traditional herbs are good since they have not been mixed with some chemicals that may destroy body tissues. They are natural products” (h54t). One traditional healer made the caveat, however, that “conventional medical treatment to clients has a faster positive response, while mine takes a bit some time” (h33t). A different explanation for preferring alternative medicine (also found among faith healers) was that conventional medicine only suppresses symptoms: “Hospital drugs only reduce pain but don’t cure” (h50t).

A few patients (n=3) also took a stance in favour of traditional healing compared with conventional medicine, though they were fewer in number than those espousing faith healing alone. One person stated, “You can’t mix traditional medicine with medical treatment” (p107)

without offering an explanation. Another patient argued that traditional remedy “is far much better, because it has no side effects” (P65).

Some patients (n=5, 18% of those attending traditional healers), however, turned against traditional healing. One respondent based his opinion on outcomes, “I have been well since stopping herbal medicine and starting conventional medicine” (p12t). Two patients expressed concern about the quality of the herbs: “herbal drugs may be any fake leaves” (p39t), cautioned one, while another advised to “avoid traditional healers, since some of them fake medication” (p81t). Another patient distrusted healers more broadly than for the quality of their herbs: “I prefer doctors, because they tell the truth. Traditional healers may lie sometimes” (p60t). Several patients preferred conventional medicine, because they felt it was more systematic: “They assess you to confirm the illness, before treatment is given, unlike traditional medicine” (p21t), stated one patient, while another concurred “They [doctors] know how to recognize the illness, but the traditional healers just try [things] out” (p33t). One patient resolved “never [to] go back to traditional medicine” (p52t).

#### 7.4.a.iii Specificity of mental illness

There was a perception amongst a number of traditional and faith healers alike that some conditions are better treated by conventional medicine – especially HIV, malaria and cancer – and others are better treated by traditional or faith healers. “There are problems that can only be taken care of by drugs, and others only by prayer” (h18f), stated a faith healer. A traditional healer said it differently: “Each day has its own disease to cure. Herbs treat demon-possessed people well, and malaria can be cured by hospital pills.” (h42t).

Mental illnesses fell into the category that many healers thought were better treated outside of conventional medicine. One faith healer stated “conventional medicine doesn’t work for disturbances of the mind.” (h4f). Similarly, a traditional healer asserted, “for mental illness, we should try herbal medicine, where conventional medicine has failed” (h36t). Interestingly, a traditional healer, also observed that “some conditions are spiritual” (h5t) explaining that he refers patients to faith healers for that reason. That attitude did not apply to the majority of healers, however.

Patients shared the notion that certain illnesses responded better to certain types of care. One faith patient remembered, “When I had cerebral malaria, the drugs really helped; but now I am leaning towards prayers” (p68f). Another faith patient noted, “Some [conditions] can only be cured by prayers and some by medicines. From hospital, you should be taken to a faith healer, because some illness might require faith, for example [being] demon-possessed”



(p106f). A herbalist patient echoed, “Sometimes medicine works and the traditional treatment doesn’t” (p16t). While another herbalist patient stated, “medical treatment reduced the pain, but traditional healers made the wounds and swellings go away” (p46t).

For a number of patients, their view of conventional versus traditional healing was shaped by the concrete outcomes of care – both positive and negative. Stated succinctly, “All of them [types of healing] are good as long as they help” (p116f). This was particularly evident in patients with epilepsy. One patient asserted, “I think drugs are not as potent as prayers, because when I sought medical intervention for my problem it worked through prayers: I no longer have seizures” (p18f). For a second patient the absence of effect of conventional medicine was enough to promote faith healing, although the latter appears not to have had better effect: “Prayers are better, as I have seen them function in my life. I have been on medication, but there has been no difference – without fail I still have the seizures” (p30f). Inversely, a third patient with epilepsy pronounced himself in favour of conventional medicine: “medication is better since it has stopped all the episodes of convulsion” (p61f).

## 7.5 Discussion

### 7.5 - a) *Different categories of illness*

The study confirms that traditional and faith healing remain widely used services for addressing common mental disorders. The forms of traditional healing represented by our sample were herbalists (*akimi wa miti*) and diviners (*mundu mue*). The labels used to diagnose patients differed from Western biomedical categories. In particular the terms “demon possessed” (*kupagna*) and “bewitched” (*kurogna*) were common across both traditional and faith healers. Birgit Meyer offers some insight into the significance of the devil or demon within Christian and traditional religion in Ghana. Studying the conversion to Protestantism of members of the Ewe tribe in the early 20<sup>th</sup> century, Meyer asserts: “The Ewe were classified as belonging to the general category of “heathens” [meaning devil-worshippers]... It was the task of the mission to lead them away from Satan back to the Christian God” (Meyer 1996). The devil became a cross-over symbol between Christianity and their traditional religion, another term for the spirits they worshipped. The traditional African religious structure, or cosmology, was therefore preserved within the Protestant church in Ghana. It is possible that a similar process took place in Kenya. The fact that the term “demon possessed” is equally shared by traditional and faith healers suggests that underlying concepts may be shared about the origins of illness.

The notion of “witchcraft” or “bewitching” appears to remain active in Kenya, despite the Witchcraft Ordinance of 1925 banning the practice, which was renewed and updated in 1961 and 1977. Charles Good describes the belief clearly:

“Belief in witchcraft and sorcery was and is an inseparable element of virtually all African systems of disease etiology... Acting from jealousy, greed, or a desire for vengeance, the perpetrators are believed to call on evil powers to bring misfortune and harmful agents that induce mental distress and physical harm to the victim.” (Good 1987)

The idea of witches was explicitly captured in our sample in the term “bewitched,” but the term “demon” was more popular, and appears to encompass a similar idea. Demons were said to be “cast-out” by faith healers and their patients in the same way that witches and their curses or hidden charms were traditionally driven out of people’s body’s by diviners and other healers specialized in that area.

In addition to these two terms, the language used by patients and providers to describe symptoms on the spectrum of depression and anxiety was in keeping with findings from neighbouring countries in Africa. In Rwanda, “having lots of thoughts” was also a common trope for a form of depression, known in the local language as *two tam* (Betancourt et al. 2009), and in Zimbabwe “thinking too much,” or *kefungisisa*, was equally associated with a depressive state (Patel, Simunyu, and Gwanzura 1995).

Shifting from an emic to an etic perspective, based on the biomedical diagnoses contained in the MINI assessment, the large majority of patients (66% of the sample, 80% of those with a diagnosable disorder) attended healers for common mental disorders. The patients appeared relatively severe, as indicated by the fact that 16% had previously tried to end their lives. No comparable data is available from Kenya on the prevalence of attempted suicide in a clinical setting. Bipolar disorder was more commonly found among faith healers, while people with epilepsy appeared more likely to attend traditional healers. It is possible that patients with epilepsy attending faith healing would be referred to conventional medicine, or alternatively that patients perceive traditional healing as more effective than faith healing in addressing epilepsy.

The notable under-representation among patients of both types of healers was from individuals with alcohol problems. Although less prevalent on the whole in Kenya than in many industrialized countries, alcohol disorders are widespread, particularly among men. While a large portion of the Kenyan population abstains from alcohol altogether, among those who drink, problem drinking is prevalent. The best data on alcohol consumption come from Western Kenya. In a study of over 4,000 people using demographic and health surveillance

data, 60% of men and 80% of women reported lifetime abstinence from alcohol, but 30% of men were using actively in the prior month (Bloomfield et al. 2013). A second study attempted to capture problem drinking using census data from over 72,000 individuals and found that only 7.2% of people (male and female combined) reported drinking in the prior month, but 60% of them did so to drunkenness on half or more occasions (Lo et al. 2013). Combining these numbers, the census data would suggest that 4.4% of the general population may engage in problem drinking. Actual numbers could be higher than reported to census officials, because of reluctance to admit to problem drinking.

Moreover, the prevalence of alcohol problems is typically higher in clinical settings than in the general population. Ndetei and colleagues found a prevalence of problem drinking of 25% among 2,770 patients across ten general medical facilities (Ndetei, Khasakhala, Ongecha-Owuor, et al. 2009). By comparison, in the Kangemi healer sample – a treatment setting – only 3% had an alcohol disorder. This suggests that many low-income individuals with an alcohol problem in Nairobi are not seeking care from traditional or faith healers, which leads one to ask whether they are receiving any form of care.

#### *7.5 - b) Hybridization of treatments*

Despite a heterogeneity of treatment practices, patterns of care were readily visible between faith healers and traditional healers. The principal difference in treatment procedures between faith and traditional healers appeared to be that traditional healing was more biological in origin, focusing on the body – vomiting, diarrhoea, sneezing, drooling, eating, drinking, massaging, bathing – whereas faith healing was less material, focusing instead on the spirit through prayer, reading, talking, singing and sprinkling with water or anointing with oil. There was particular emphasis in faith healing on verbal counselling. Examples of faith counselling included advising an individual not to feel guilty, talking about the “homestead,” and speaking optimistically about the future and possibilities of recovery. Patients responded to these procedures expressing feelings of “uplift,” hope and encouragement. In some instances the church offered support groups and even professional counselling, thus filling a similar role to a conventional mental health care provider.

Despite these differences, some aspects of treatment were shared across traditional and faith healers. Prayer was the most commonly shared technique, used universally by faith healers, but also employed by traditional healers. One faith healer even alluded to praying “at the birth place,” a practice suggestive of deference to ancestral spirits. More broadly, some traditional and faith healers in this study showed evidence of a shared cosmology, or

understanding of causality. Indeed, several descriptions of faith healing were evocative of traditional practice, suggesting that the hybridization observed by Okwaro in his single case-study in Western Kenya is not idiosyncratic. For example, faith healers using the Bible to “bang” on people’s heads is more suggestive of a traditional practice that transforms the Bible into a ritual object, rather than a typically Christian practice of using the Bible principally as a source of text. Similarly, practices such as “chasing out of demons” are evocative of expelling witches, underscored by references to plural “holy spirits.” Witchcraft and its treatment have long been a cornerstone of one branch of traditional African medicine.

This cross-over between traditional and faith healing practices reflects a shift in healing techniques since the time when Charles Good first described them. An illustration of divination as it was practiced in 1979 can be found in the case of Kamau and his healer “K.”

“K. revealed correctly and to Kamau’s amazement that he was involved in a land dispute that included his sister and two unrelated parties. Following the divination, which K accomplished by playing the “magic bow” (*ota*) and making numerous counts of small colored pebbles shaken from her special divining gourds (*ketti*), K. instructed Kamau to write down the names of all people who might bewitch him. [...] K’s diagnosis also determined that Kamau was suffering from a nearly fatal illness caused by the witchcraft. To symbolize the seriousness of his illness, Kamau had to be ritually “resurrected” from his graveside. [...] K revealed that Kamau had not had sexual relations for the past 5 months, and he agreed. K said this was a further sign of [the evil neighbour’s] nefarious deeds. Ceremonies included the use of a baby chick “less than 10 days old! Whose blood, drawn from a small cut made on its crest, was rubbed into small cuts K had made on Kamau’s back with a razor blade. The chick was also made to ingest some of Kamau’s blood, thus transferring the evil power of the witchcraft from Kamau to itself.” (Good 1987)

Chicken blood and ritual resurrections are far from the descriptions provided by the respondents in this study. The practices enumerated by this sample often mimicked biomedical practice – with herbs administered like medicines. Although incisions continue to be made to “transfer the evil power of witchcraft,” the procedure has been somewhat “sanitized” by eliminating the chicken.

Thus traditional practice in urban Kenya appears to have shifted in two main ways, first by a cross-over of some practitioners from *mganga* to *mtumisbi* (traditional to faith healer) and secondly from a change in ritual objects of the farm (a chicken, for example) to objects drawn from biomedical or religious practice (herbs, the Bible). These changes may have been influenced by the Witchcraft Ordinance, which was updated in 1977, just two years before Charles Good conducted his research. Good noted the pragmatism of healers, stating: “urban

traditional medical practitioners adapt by diagnosing and treating problems in terms of causes and methods that are possible and credible for them to manage in the urban setting”. The symbols of biomedicine and the Bible appear to have become more “credible” to the Nairobi clientele than the previous language of mock-resurrection and chicken blood. Thus traditional healing has “modernized” by fusing cultural trends into a new, but related web of ritual and meaning.

### *7.5 - c) Potentially negative practices*

A few procedures documented by traditional healers and their patients raise concern in terms of patient rights. Cutting the skin with a razor to pull out demons or spirits and deliver protective herbs (often in the form of ash) was a particularly prevalent practice, and one associated with pain. One patient observed that he had been locked up when the procedure took place, suggesting limited choice. One in three traditional healers mentioned using incisions among their healing procedures, while one in five patients of healers had experienced it. The highest prevalence of incisions was for patients with epilepsy (one in three); and all patients receiving incisions were male. However, the small sample (n=6) creates uncertainty around these figures. Though not widely documented, the literature on incisions suggests that this practice is also not uncommon in other parts of Africa. Articles from Nigeria (Adelekan, Makanjuola, and Ndom 2001) and South Africa (Peltzer 1999) refer to practices of “scarification” and “protective incisions,” however it is unclear whether these practices are seen to serve the same purpose as skin cutting in Kenya.

A second alarming practice associated with traditional healing was chaining. It was mentioned by only one traditional healer, however, who noted it as a form of containing psychosis. Since psychosis was rare in our patient population, it was not possible to estimate the frequency of this practice. Chaining and binding with ropes, however, are known to be relatively common practice for containing acute psychosis across Africa. They are viewed as an intervention of last resort in contexts where sedatives and appropriate medication are not available. Chaining is not only practiced by healers, but also by family members. Ndetei (2010) notes the poignant case of a young man who was chained on both hands and both legs by his mother, while in the psychiatric facility in Puntland State, Somalia. The literature also documents cases from Sudan (Ndetei David and Mbwayo 2010), Ghana (Roberts 2001), and South Africa (Peltzer 1999). In Kenya, the practice of physical restraint is long-standing: a study conducted in the 1960s notes that 121 out of 126 (96%) Kamba people interviewed in south-central Kenya responded to the question "what should be done with a psychotic

person”, by saying "tie them, then have a doctor treat them" (Edgerton 1966). The practice has raised concern of human rights agencies in many parts of the world, including recently in Ghana (Human Rights Watch 2012).

It is notable, however, that certain alarming practices that have been documented in relation to healing of mental illness in other parts of Africa were not found in this urban population from Nairobi. In particular, beating or whipping patients, including with palm fronds (Agara, Makanjuola, and Morakinyo 2008), is a well-documented intervention in Nigeria (Adelekan, Makanjuola, and Ndom 2001) and in Ghana (Roberts 2001; Ae-Ngibise et al. 2010). Flagellation is delivered by traditional and faith healers alike in these West African contexts, but was not found in our Kenyan sample.

Possible negative effects were also apparent in descriptions of faith healing. The idea that mental illness is caused by sin is particularly problematic, especially for those who do not recover, because it implies that they continue to be at fault. In addition, there are potentially stigmatizing consequences to the idea that the outcomes of healing depend on one’s degree of faith. By extension, those who do not improve are implicitly lacking in faith – again, a case of blaming the victim. Poor health outcomes become doubled with poor spiritual outcomes. Only one patient spoke negatively about faith healing, saying that “you can be misled and gotten into things you don’t want to be in” (p28f), so this observation of potential stigma is not borne out by this data, but it deserves to be tested in future studies.

#### *7.5 - d) Acceptability*

The outcomes of care and its costs were the principle factors influencing patient preference. Where patients improved, they preferred the type of care associated with that improvement, and when possible they sought to reduce costs. Literature from South Africa suggests that the cost of a consultation with a traditional healer is the same as for a conventional primary care provider (Sorsdahl 2009) with the average cost of traditional healing amounting to Int\$ 72 (R321) at the 2008 PPP conversion rate. Another study from South Africa, using data from a national household survey, found a median cost of care for a traditional healing consultation of Int\$ 33.7 (R150) (Nxumalo et al. 2011). A study on a much smaller sample of 51 patients from Nigeria calculated that traditional healing cost three times as much as conventional medicine, although the author expressed a clear bias in favour of conventional medicine (Makanjuola 2003).

Mbwayo and colleagues in Kenya, also researching in Nairobi informal settlements, observed that the economics of traditional healing are not only a question of cost, but also of

how payments are made. They noted that some healers accept in-kind payments, payments by instalment, and even deferred payments based on treatment outcome (Mbwayo et al. 2013).

Patient satisfaction appeared lower for traditional healers than for faith healers. A number of patients (18%, n=5) expressed discontent with traditional healing, some of them because it came at significant cost with no perceived benefit. Some faith healers and patients perceived traditional healers to be “fakes” or “liars,” however the majority of patients did not speak poorly of traditional healers. One patient spoke ill of faith healers.

Both providers and patients of faith and traditional healing adopted a widely accepting stance towards conventional medicine. From a principled argument, faith healers and their patients observed that God governs doctors and healers alike, whereas traditional healers observed that herbs form the basis of both conventional and traditional medicine. More practical arguments for adopting a pluralist approach from the perspective of providers included that some people have less faith, and the providers’ need to maintain a client base.

This relatively accepting stance on behalf of healers aligns with the literature on referral between traditional and conventional medicine, which suggests that traditional medical practitioners are more likely to be accepting of conventional medicine than vice-versa (Campbell-Hall et al. 2010; Asante 2012). One study from South Africa, however, found that within the field of psychiatry conventional practitioners were more open to traditional healing than in other areas of medicine (Mokgobi 2013). Another study from South Africa suggests that traditional healers turn to conventional medicine only as a last resort and for temporary measures, such as tranquilizing injections, which they view as a physical rather than psychiatric intervention (Sorsdahl, Stein, and Flisher 2010).

## **7.6 Limitations**

The principle limitation of this study is the use of secondary qualitative data that could only partially be reconstituted. The partial coding of the qualitative data made rigorous qualitative analysis challenging. Furthermore, as the data were not designed with the purpose of answering my research questions, they did not permit me, for example, to answer questions about the economic accessibility of healing or to estimate the proportion of patients seen for mental health reasons. Some data on the cost of healing, however, can be found in chapter four in the section documenting direct costs of care.

Not only were the data partial, but the initial process of data collection may have been influenced by the mission of the NGO BasicNeeds, who were co-investigators on the study and who were responsible for distributing the funds that paid for the research. As seen in

chapter four, the MHD model involves community mobilization, including through involvement of traditional and faith healers. The main intent of BasicNeeds' engagement with healers has tended to be ensuring that the rights of people with mental disorders are respected, and encouraging referral to conventional medicine when traditional remedies are not demonstrating an effect. This background agenda may have influenced the responses given about referral, particularly on the part of providers. That being said, the research assistants doing most of the data collection were employed by the Africa Mental Health Foundation rather than by BasicNeeds, and did not necessarily share the same purpose. Moreover, research is understood to be a separate activity from the service delivery modules of the MHD model, such as community mental health, capacity building and livelihoods. Nonetheless, the results must be read with an awareness of the potential hidden influences resulting from the funding and implementation of the research.

The generalizability of these findings is constrained by the specificity of healing practices to a given ethnic group. It was clear that ethnicity was of importance in the choice of healer by patients in that the ethnic composition of the two samples was closely matched. The informal settlement of Kangemi represented Luyha and Kikuyu most prominently, making this study most relevant to healing practices within that group. Nonetheless, the urbanicity of these healers may have a somewhat homogenizing effect on their traditional practices. Moreover, some healers may have idiosyncratic practices that have no bearing on their ethnic traditions.

A further limitation to the quantitative analysis of this data is that the questions elicited free-listed responses. Rather than asking a person whether they had received a certain kind of treatment, for example, the question asked what types of treatment they had received. This technique allows for unpredicted responses, but it is likely to be less accurate in terms of enumeration. In addition, because of the purposive sampling strategy, it is unclear whether the sample is representative of the actual patient population attending healers. Nonetheless, the quantitative data are more accurate than no numbers. Moreover, from a qualitative perspective, free-listing is preferable in that it does not guide respondents towards pre-elicited responses.

A more substantial limitation to this research is the risk of category fallacy, as described in chapter three. By applying biomedical diagnoses from the MINI assessment to a context of traditional healing, the research stands the risk of finding what it is looking for while missing the point. The concept of a mental illness does not neatly map onto the diagnostic system – referred to by anthropologists as “cosmology” – of traditional healing.



Against this backdrop, asking traditional and faith healers to enumerate the mental illnesses they treat, and furthermore inquiring how they diagnose them could seem absurd.

Countless articles have set about similarly problematic tasks, trying to translate traditional practices into the language of Western medicine. Speaking of traditional healing in East Africa, David Ndetei noted in 2007:

“Of course, they do not call it psychotherapy, but in practice it is psychotherapy as we psychiatrists understand it today. ... Compare this with Freud’s and others’ psychodynamic procedures at the end of 1800s and early 1900s and ask yourself who really invented psychotherapy and when!” (Ndetei 2007)

Other scholars are more nuanced in their assertions, such as Marian Tankink who states about born-again churches in Western Uganda, “Many aspects of the churches’ activities can also be found in western trauma therapies”(Tankink 2007). Joanna Teuton, researching healers in Uganda, notes that faith healers are more inclined to use Western psychiatric terminology than traditional healers, especially the term “counselling,” suggesting “greater exposure to a biomedical concept of mental health” (Teuton, Bentall, and Dowrick 2007).

James Dow responds to the epistemological challenge of claims of equivalency between traditional medical practice and conventional mental health care. As if in response to Ndetei (though written well before), he jibes:

“Can we really accept the idea that a shaman, chanting and singing over a prostrate patient, is analogous to Sigmund Freud sitting back in his chair and musing over a patient recounting her dreams? ... Shamanism and faith healing are types of magical healing, a type of symbolic healing that involves the ritual manipulation of super-human forces. Its contrasts with psychoanalysis are dramatic enough to illustrate that psychoanalysis does not provide a universal model.”(Dow 1986)

While Dow speaks against using psychoanalysis or Western biomedicine more broadly as the “model” on which to map traditional practice, he does not shy away from drawing parallels between the different medical systems. Indeed, Dow sets out to establish a “universal structure” of healing. Central to his thesis is that all healing involves a “cultural myth,” used to define the problem, and “transactional symbols” that are attached to emotions.

Without delving further into the complexity of Dow’s tenets, we can simply observe that cross-cultural parallels are not anathema to anthropology, and that traditional and biomedical practices can be compared. Furthermore, the healers were able to identify people who were “mentally ill” (*akili isiyo timamu*). Eighty per cent of the sample purposively chosen by the healers had a diagnosable biomedical mental disorder, suggesting a good rate of

correspondence between their categories and those of biomedicine at the broadest level of diagnosis.

In addition to the challenge of category fallacy, this study faces numerous limitations in relation to the quality of data. Most significantly the absence of full transcriptions is a great short-coming. As a result, the qualitative analysis had to rely on fragments of transcription and pre-coded material. Nonetheless, these fragments lent a greater richness to the analysis than purely quantitative analysis of this data would allow.

The study's strengths balance its limitations. In particular, the triangulation of data between patients and healers allows for a more accurate depiction of practices than studies engaging with only providers or only patients. In addition, bringing quantitative analytic skills to bear on the topic of traditional and faith healing, as I have done here, is a relatively rare undertaking. Finally, given the difficulty of obtaining access to this understudied group of providers and patients, the data available for analysis were quite rich.

Looking forward, if traditional and faith healing are to be conceived of on the same plane as Western medicine, then they ought to be evaluated along the same principles. In order for this to be acceptable to healers and biomedical practitioners alike, it would be desirable that diagnostic tools be developed that reflect local understandings of illness, as has been done in a elsewhere in Africa (Patel and Mann 1997). No studies exist at present evaluating the effects of traditional or faith healing on mental health outcomes in Africa. Further research is essential in this area to move discussion forward from whether to how to invest in collaboration between these two systems of care.

**8. Conclusion: Where to From Here?**



Figure 8-1 Woman herding goats, Chuka, Meru district

## 8.1 Introduction

In this thesis I set out to establish what contribution non-state actors make to coverage for mental disorders in Kenya. Drawing on the theoretical framework of Tanahashi to define health care coverage, I posed the following questions:

- What is the availability of non-state mental health services?
- How economically accessible are non-state services?
- How culturally acceptable are non-state services?
- How many and which patients are in contact with non-state services?
- How effective are non-state services?

The dissertation was structured according to different types of actors working outside of the public sector – in the formal and informal sectors, on a for-profit and not-for-profit basis. Overall, I hypothesized that the non-state sector was playing a significant role in providing health care in Kenya, despite not being appropriately recognized by the literature, but I imagined that the distribution of non-state care might not be equitable in terms of geography and income status.

Using mixed methods allowed me to address these questions from multiple angles and gave greater depth to my findings. In chapter four qualitative data from interviews with programme staff and patients unearthed some of the complexities in delivering the MHD model, which could not be detected from the quantitative measures used in the cost-effectiveness analysis. Inversely, the quantitative measures were more impervious to claims of anecdotal evidence, which could be made of qualitative data. In chapter five on Chiromo Lane, the qualitative data provided a rich description of the services available and the patients coming into contact with them, as well as shaping the questions to be asked of the quantitative data. In the first instance, the quantitative data from the hospital were to be descriptive, providing a measure of the amount and costs of services provided, but through discussion and observation, the question emerged about the effects of insurance on those costs and quantities of care. In chapter six different sampling strategies – snowballing and convenience sampling – offered different approaches to answering questions about outpatient care: in the former, providing access to a small and elusive population and in the latter providing access to a greater number of respondents. Finally, re-analysing qualitative data on healing in chapter seven allowed me to call into question existing categories of traditional and faith healer, while triangulating between patient and provider perspectives and challenging the strength of findings through simple tests of statistical association. The many methods and sources of data in this thesis make the exercise of synthesising the findings more complex – comparable to

herding goats (figure 1) – however, jointly they provide a more complete picture of a topic that rarely comes to light.

I will shape my research conclusions around for-profit versus not-for-profit care. First I will present a summary of the findings by chapter, and then I will group the findings thematically according to the five types of coverage in Tanahashi's framework, namely: availability, contact, accessibility (including affordability) acceptability and effectiveness. Next, I will discuss the limitations of these findings, and finally I will explore their implications on future policy and research.

## **8.2 Main Findings**

### *8.2 - a) Summary of findings*

In **chapter 4**, examining the cost-effectiveness of the MHD model, results were most definitive for people with schizophrenia-spectrum or bipolar disorders (the majority of the sample). MHD cost Int\$ 594 per person in the first year and Int\$ 875 over two years from the societal perspective. The difference in the second year was largely the result of savings from a return to productive work among those in the MHD model. The two year cost per healthy day gained was and Int\$ 1.09 and Int\$ 2.69 from the societal perspective – less than agricultural minimum wage. The cost per DALY averted over two years was Int\$ 205 and Int\$504 from the societal and health system perspectives – on par with antiretrovirals for HIV. Findings proved sensitive at one-year follow-up, but robust over two years to two alternative scenarios investigated. MHD achieved increasing returns over time. The model appears cost-effective and equitable, especially over two-years, though its affordability relies on multi-sectoral participation locally and internationally. The qualitative data called attention to challenges in delivery of the model, particularly in coordination with other NGOs, capacity of health care providers to diagnose and treat, variations in leadership from place to place, and the influence of funders on the content of the model. Overall, the MHD model appears to be improving the quality of life of the majority of its participants, though it could arguably be improved by offering psychological therapies and improving medication supply.

Patients at Chiromo Lane (**chapter 5**) were 66.4% male with a mean age of 36.8 years. They were diagnosed with substance use disorder (31.6%), schizophrenia-spectrum and bipolar disorder (49.5%), common mental disorders (7%); comorbid disorders (7%), and other diagnoses (4.9%). In addition to daily psychiatric consultations, two-thirds received individual counselling or group therapy; half received lab tests or scans; and 16.2% received ECT. Most took a psychiatric medicine. Half of those on antipsychotics were given only brands.

Insurance paid in full for 28.8% of patients. The mean length of stay was 11.8 days per admission and, in 12 months, 16.7 days (median 10.6). 22.2% were readmitted within 12 months. Patients with PHI stayed 36% longer than those paying out-of-pocket and had 2.5 times higher odds of readmission. The mean annual charge per patient was Int\$ 4,262 (median Int\$ 2,821). Insurers were charged 71% more than those paying out-of-pocket - driven by higher fees and longer stays.

The qualitative data depicted a facility with a relatively non-restrictive and welcoming physical environment, employing a therapeutic community approach to treatment in which patients were given a voice. Nonetheless, the majority of patients (70%) were involuntarily admitted and did not have a choice about whether or not to take the medicines prescribed. The preferred method of medication administration, to avoid problems of adherence, was injection. Mandating medications was justified as a cost-saving procedure. The human rights standards at Chiromo were visibly higher than in its public counter-part, Mathare National Referral Hospital. In 2011, Chiromo delivered acute psychiatric services to approximately 450 people, to quality and human rights standards higher than Mathare, but at considerably higher cost. With more efficient delivery and wider insurance coverage, Chiromo might expand from its occupancy of 56.6% to reach a larger population in need.

The chapter on formal outpatient services (**chapter 6**) revealed that only half (47.5%) those with psychiatric nursing degrees worked specifically as psychiatric nurses. Those employed as general nurses nonetheless saw on average half (46%) mental health cases. Ten per cent of psychiatric nurses had run a private clinic (75% of them general clinics), and 15% were doing private locum work alongside salaried employment. Kenya would need to increase the number of psychiatric nurses 20 times in order to achieve the internationally recommended ratio of 12 psychiatric nurses per 100,000 in low-income countries. It appears psychiatric nurses are migrating internally to nursing positions in other areas of health care, aggravating the existing “brain drain” on mental health.

Among psychiatrists and psychiatric nurses running private clinics, a quarter ran general health clinics, while the remainder focused on mental health. Respondents had a mean active case load of 128 mental health patients. The majority of patients (55%) were seen for common mental disorders; 25% for severe mental disorders; and 15% for substance use disorders. Three quarters of providers split their time between public and private practice. Use of atypical antipsychotics and better follow-up were reported in private practice. Wait-times in private outpatient clinics were relatively short, estimated by providers to be 20 minutes. The mean fee for a standard consultation by a psychiatric nurse was Int\$ 13 (Ksh 500) and by a

psychiatrist Int\$ 55.3 (Ksh 2,100) – equivalent to 2.5 days and half a month respectively of a typical agricultural worker’s income. In a context where mental is associated with psychotic behaviour, a private clinic in the community may offer a less stigmatizing, more “private” (in the sense of confidential) option than hospital-based care, to those who can afford it. In addition, where public health providers are underpaid, private employment may act as a cross-subsidy for public health care.

Finally, the chapter on healers (**chapter 7**) found socio-demographic differences between traditional and faith healers, but considerable overlap in their interpretations of the cause of illness. Faith healers (all Protestant) were better educated and had higher incomes than traditional healers. They were also more likely to be women than traditional healers, as were their patients. The mean age of healers was 43 years, while for patients it was 33 years. Traditional and faith healers alike diagnosed patients as “bewitched” or “demon-possessed”; however their patients were less likely to use those terms. According to biomedical diagnoses, 75% of patients had a common mental disorder and 7% had epilepsy, while 18% did not meet biomedical criteria for a mental disorder. Patients with epilepsy appeared to attend traditional healers more than faith healers, while those with bipolar disorder were more likely to attend faith healers. There was a notable under-representation of individuals with alcohol problems among patients of healers (3%).

The practice of traditional healing (herbalism and divining) was more biological than faith healing. Traditional healers focused on the body – vomiting, diarrhoea, sneezing, drooling, drinking, bathing – whereas faith healing was less material, and focused on the spirit through prayer, reading, talking, singing. Some aspects of treatment, particularly prayer, were shared across traditional and faith healers. A few procedures raise alarm in terms of patient rights, most notably a practice common among herbalists of cutting the skin with a razor to free demons. Faith healing also presented potentially stigmatizing principles in the idea that illness results from sin and that the outcome of healing depends on one’s faith. Both of these principles imply that those who do not improve are either sinful or lack faith – both cases of blaming the victim. Providers and patients of faith and traditional healing adopted a widely accepting stance towards conventional medicine. The outcomes of care and its costs appeared to be the principal factors influencing patient acceptance of a given model of care.

### 8.3 Thematic Findings

#### 8.3 - a) Availability Coverage

How do these findings address the over-arching theme of coverage raised by my thesis? To address this question, first I will first look at coverage in terms of service availability, followed by accessibility and contact coverage, and finishing with acceptability and effectiveness coverage. In measuring the availability of mental health services provided by non-state actors, I will look at the number of human resources to estimate the number of patients treated.

##### 8.3.a.i For-profit care

*Outpatient care* – My research revealed a hidden face of community mental health care in the form of private practice specialists providing outpatient care (de Menil et al. 2014). In Nairobi, the private practice market for mental health care appears to be cornered by psychiatrists, whereas outside of the capital, there are a significant number of psychiatric nurses running private clinics. Nurse-run clinics tend to be for general health care, but they include mental health and a quarter of patients are seen for mental health reasons. My sample of nurses attending the annual general meeting of the mental health chapter of the National Nursing Alliance of Kenya revealed that 10% had experience running a private practice. All of them also worked in the public sector. In addition, 14% of the nurses were working in part at other for-profit health facilities.

*Inpatient care* – Private hospital care for mental health is mostly centred around Nairobi. In Nairobi, three hospitals provide inpatient psychiatric care in specialized units: Nairobi West, Avenue Hospital and the Chiromo Lane Hospital Group. Collectively, these three hospitals offer approximately 100 psychiatric inpatient beds, which is one sixth of the number of beds in the public national referral hospital, Mathare. Outside of Nairobi, there are no psychiatric units on any hospitals in the non-state sector.

In addition to these hospital beds on specialized mental health units, many general private hospitals offer inpatient psychiatric services in non-specialized units. Psychiatric patients in general hospitals can be seen either in general wards or in private rooms. According to Kenya's Private Sector Health Assessment, there are 259 private hospitals in Kenya (Barnes et al. 2010). A further form of residential care provided on a for-profit basis is found in substance use rehabilitation centres. Data from NACADA suggest that there are 16 such facilities operating on a for-profit basis throughout Kenya.

Because of the scarcity of health specialists in Kenya, psychiatrists (and other health specialists) are not salaried hospital employees on private hospitals. Instead, they operate as



consultants, who are given admitting rights at various hospitals. Private hospitals themselves do not track the number of psychiatric patients seen within their facilities. Instead, these patients are tracked and followed-up by their psychiatrist. The best way to estimate the number of mental health patients seen on an inpatient basis in the non-state sector is therefore to interview psychiatrists. This is what I did, and on average private specialists (who numbered 24 in 2010 (Kiima and Jenkins 2010)) referred 12 patients per month to inpatient care.

Aggregating data from the chapters on outpatient and inpatient care, and combining it with pre-existing numbers from other sources, we can start to estimate the number of patients receiving specialized mental health care from private for-profit providers. Using the occupancy rates from Chiromo Lane and The Retreat rehabilitation centre, together with data on target length of stay from the websites of NACADA accredited facilities, I estimated the number of patients treated in specialized inpatient facilities. By combining the number of patients referred per psychiatrist with the number of private hospitals, published in the World Bank Private Sector Health Assessment (Barnes et al. 2010), we can estimate the number of patients seen in general hospitals.

Patients treated in specialist facilities =  $N(\text{facilities}) * \mu(\text{beds}) * \text{occupancy} * (1 \text{ year}/\text{LOS})$

Patients treated in general facilities =  $N(\text{referrals}/\text{year}) * N(\text{private psychiatrists})$

The most complete information available is on for-profit inpatient care, which is treating an estimated 5,721 people with mental and substance used disorders each year – 3,456 in general hospitals and 1,517 in specialized psychiatric units (table 8-1). For rehabilitation centres, which have an estimated occupancy of 52% and a target length of stay of 4 months, the predicted number of patients seen per year is 750. The data from this thesis do not enable us to estimate the coverage of traditional healers in the treatment of mental disorders. It is, however, apparent that many people with mental disorders attend traditional and faith healers, especially women with common mental disorders.

### 8.3.a.ii Not-for-profit care

*Outpatient care* – It is harder to quantify the coverage of not-for-profit mental health care by the non-state sector. According to my findings from the annual general meeting of psychiatric nurses, 20% of Kenyan psychiatric nurses work in part for not-for-profit facilities. Combining that with for-profit participation, we find that 28% of psychiatric nurses work part-time or more in the non-state sector. This number is markedly lower than the statistic cited in the World Bank’s “Private Health Sector Assessment for Kenya,” which found that 67% of

enrolled nurses work for the non-state sector. It is possible that my sample was skewed towards the public sector, because private sector providers may have more barriers or less incentive to attend an annual general meeting of a professional association. It is equally possible, and indeed likely, however, that the field of mental health is less privatised than other areas of health care. One reason for this could be that the private mental health market remains dominated by traditional and faith healing.

Outpatient specialist mental health services are offered in selected areas of Kenya by NGOs. Only three of the fifty nurses questioned (6%) worked on an outpatient basis for not-for-profit agencies. Unfortunately, the umbrella organization for health-related NGOs, HENNET, does not track which of its 85 members work in mental health. The NGO BasicNeeds is the leading mental health provider in Kenya and it organizes service delivery jointly with the state sector. BasicNeeds estimates that it enabled outpatient treatment for 1,770 people with mental illness through their programme in 2010 (BasicNeeds 2011). Other NGOs also operate within the field of mental health in Kenya, in particular providing counselling to refugees. Such is the case of the International Refugee Committee, and MSF. Data on the number of people treated are unfortunately not publically available for these and other small-scale mental health programmes.

*Inpatient care* – At the inpatient level, the only specialist not-for-profit mental health services are rehabilitation centres for alcohol and drug abuse. No not-for-profit hospitals were found with a specialized psychiatric unit. Indeed, the non-state sector dominates treatment for alcohol and drug abuse; without this sector, there would be almost no services available for people with these disorders. Ninety per cent of residential rehabilitation centres are privately run, and approximately half of them (16 facilities) are not-for-profit, faith-based organizations. Collectively, these not-for-profit rehabilitation centres treat an estimated 750 individuals with substance use disorders each year (table 1).

Table 8-1: Estimated national coverage of non-state specialist mental health care

<b>Inpatient care (hospitals)</b>	<b>For-profit</b>			<b>Not-for-profit</b>		
	<b>Facilities</b>	<b>Psych Beds</b>	<b>Patients/yr</b>	<b>Facilities</b>	<b>Psych Beds</b>	<b>Patients/yr</b>
General inpatient facilities	259	0	3,456	74	0	NA
Psychiatric inpatient facilities	3	100	1,517	0	0	0
Alcohol and drug rehabilitation centres	16	480	749	16	480	749
Total inpatient			5,721			
<b>Outpatient care (human resources)</b>	<b>Providers</b>	<b>Caseload/yr</b>	<b>Patients</b>	<b>Providers</b>	<b>Caseload/yr</b>	<b>Patients</b>
Psychiatrists	24	298	7,152	0	0	0
Psychiatric nurses	30	144	4,320	30	NA	NA
Psychologists	30	NA	NA	0	0	0
Counsellors	NA	NA	NA	NA	NA	NA
			11,472			
<b>Total</b>			<b>16,445</b>			<b>NA</b>

## 1.2 - b) *Contact Coverage*

### 8.3.a.iii Treatment gap

What percentage of the Kenyan population in need are in contact with mental health services? Measuring treatment coverage requires knowledge about prevalence rates of mental disorders in the community. The most complete data available are on the treatment of substance use disorders. There are no community-based prevalence data from Kenya on these disorders; the only community-based evidence is on substance use – pathological or otherwise (Atwoli et al. 2011). Data on misuse (abuse, dependence) come from a clinic-based convenience sample (Ndetei, Khasakhala, Ongecha-Owuor, et al. 2009). The best available community-based prevalence data are from Nigeria (collected as part of the World Mental Health Survey): the 12-month prevalence of substance use disorders was 0.8% (0.6% alcohol-related, 0.2% drug-related) (Gureje et al. 2006). Applying this prevalence to the Kenyan population of 38 million, we would estimate that 304,000 people experience a substance use disorder in a given year. The prevalence of substance dependence, as opposed to abuse, was found to be only 0.1% in Nigeria, which would translate to 38,000 people in Kenya. By that measure, the 1,500 people receiving substance use treatment from non-state actors represents only 4% of the population in need.

Although the non-state sector is meeting only a small fraction of the treatment gap for substance use disorders, it nonetheless is providing markedly more treatment than the public sector for these same disorders. If we assumed that the four public facilities operated at 100% occupancy with the same number of beds as the average non-state facility and that the average length of stay were 25% shorter than in the non-state sector, we would arrive at an estimate of approximately 500 people with substance use disorders being treated per year by public facilities – only 1.3% of the population in need. By this count, the non-state sector would be treating an estimated three times as many people with substance use disorders as the public sector.

These estimates of public sector coverage are purely speculative, however. While the report of Kenya's National Commission on Human Rights suggests that 100% occupancy is a reasonable estimate (Kenya National Commission on Human Rights 2011), no data exist on length of stay from a public mental health facility in Kenya. One might expect that longer-term stays, such as those found at substance use rehabilitation clinics, would be shorter in the public sector, because of financial constraints to the state provider. Inversely, one might

expect that inpatient hospital stays (which tend to be shorter-term than rehabilitation centres) would be somewhat longer in the public sector than those found in Chiromo Lane, because patients are not paying for their own care, and the cost per day is considerably lower (based on WHO unit cost estimates). But it is not possible to put hard numbers to these estimates based on currently available data.

Calculations of treatment coverage are equally, if not more, challenging for other mental disorders. If we assume that the prevalence of schizophrenia-spectrum and bipolar disorders corresponds to the estimate of 0.6% by the first community-based study of psychosis in Kenya (Jenkins et al. 2012) then 228,000 people in Kenya are affected by these illnesses. Using data from Chiromo Lane, we can postulate that people with schizophrenia-spectrum or bipolar disorder represent two-thirds of inpatients at private for-profit facilities, which amounts to 3,332 patients a year. If these numbers are accurate, then only 1.5% of the population with these disorders is receiving inpatient care from a private provider. In the public sector, we know the number of inpatient psychiatric beds (1,114) (Kiima and Jenkins 2010), but there are no data on average length of stay or admissions, so we cannot estimate the treatment coverage. The treatment coverage for depression and anxiety-related disorders (the common mental disorders) is particularly difficult to measure, because these disorders are largely treated on an outpatient basis, including through primary care, and no data exist on the coverage of public outpatient mental health care.

#### 8.3.a.iv Equity of contact

The question of who is in contact with non-state mental health care raises concerns about equity, in particular around illness and gender. In terms of illness, different patients attended different providers. The most striking finding was that people with alcohol and substance use disorders are almost exclusively receiving care through the non-state sector, as discussed in the section on coverage of care above. In addition, common mental disorders were found more commonly in outpatient private practice than in inpatient settings – as might be expected. Over half of patients at private practices were seen for common mental disorders, while they represented only 10-20% of the inpatients at Chiromo Lane.

Variation in illnesses creates a resulting variation in patient gender. Since, across multi-national epidemiological studies women experience common mental disorders with greater frequency than men (Steel et al. 2014), the greater representation of common mental disorders in outpatient private practice means that women are accessing care more through these services. Over half (56%) of mental health patients in private practice were women. Women

were also in the majority at traditional and faith healers, constituting 72% of the sample. Faith healers were significantly more likely to have female patients than traditional healers. This is likely because faith healers themselves were more often women (48% vs. 17%). The diagnoses appeared relatively similar between these two patient groups, though the small sample sizes made comparison challenging.

Though women sought care from outpatient services more commonly than men, data from the economic evaluation of the MHD model suggest that women do not differ from men in their response to treatment. Health outcomes were not statistically different between men and women. That being said, the benefits of the MHD intervention were not only on service users, but also on their carers, who were predominantly (72%) women. The average time spent care-giving was halved from 15 hours at baseline to 8 hours at follow-up, and the number of people who reported being assisted by a carer dropped from 37% to only 8%. The economic and psychological benefits of the intervention to carers thus disproportionately affected women.

### *8.3 - b) Accessibility Coverage (Affordability)*

Limited data were available on income or wealth-levels of the patients studied, however proxy variables provided some insight. Using education level as a proxy for socio-economic status, the patients of the MHD model were among the poorest members of society, as demonstrated by their having attained lower than average levels of primary education (15% vs. 32% in the general population of Central province). By contrast, patients at Chiromo Lane were in the highest socio-economic bracket, as suggested by high levels of formal employment (50.6% as compared to a national average of 9%). We can conclude, predictably, that not-for-profit care targets the lowest socio-economic groups, while for-profit care caters to the wealthier.

That being said, there is considerable grey area around private outpatient services, which appear to serve not only the rich, but also the “middle-class.” It is notable that traditional healers cost approximately the same amount per session as psychiatric nurses in private practice. It would appear mistaken, therefore, to assume that traditional healing is the form of care most financially accessible to the least well-off. Traditional practitioners are, however, more physically accessible in that their numbers are far greater than private practitioners – although the prevalence of non-specialist private practitioners was not examined in this thesis.

### 8.3.b.i Outpatient care

Much as there is variation in capacity between the different cadres of non-state providers, so too is there variation in their costs and charge. Data on outpatient mental health care from private specialist providers suggest that the cost of a visit to a private psychiatric nurse is equivalent to 2.5 days of a farmer's wage, while a visit to a psychiatrist costs two weeks of wages, making the latter unaffordable to most. These costs represent the price rather than the economic cost of care, which was not possible to calculate with the available data.

Data on the economic costs of traditional healing were available from the economic evaluation of the MHD model. Faith healers did not charge for their services, whereas herbalists charged in cash on a fee-for-service basis. Neither faith nor traditional healers in this setting asked for in-kind payments. The mean fee per session with a herbalist was Int \$ 14.7 – equivalent to three days of a farmer's wage. This puts the cost of traditional healing on par with that of seeing a psychiatric nurse in private practice. When taking account of transportation and the opportunity costs of time or lost productivity (and perhaps earnings), the economic cost of seeing a traditional healer came to Int \$ 24.0 per session and Int \$ 53.3 per year – equivalent to three weeks of a farmer's wage.

Findings on the MHD model suggest that it is equitable, favouring poorer segments of the population and shifting the cost burden from them to other payers. Before the intervention, 92% of costs were borne by the service user, whereas after two years, the average user made savings of Int\$ 289. The majority (86% in the first year) of direct costs were born by the NGO. Government costs doubled over the course of the intervention, as care shifted from hospitals to the community; however they remained modest throughout and decreased proportionally, amounting to only 6%-8% of total costs before and in the first year after the intervention. The affordability of this model relies on multi-sectoral participation locally and internationally.

### 8.3.b.ii Inpatient care

Inpatient care at Chiromo Lane was the most costly of the interventions examined. The average cost per inpatient day was Int\$ 266, amounting to a yearly cost of Int\$ 4,262. However, average costs were skewed by a few patients who required longer stays, so the median cost was considerably lower at Int\$ 2,821. This is more than per capita Kenyan GDP (Int\$ 1,015), but on par with the average salary of an employee in the formal sector (Pollin 2009).

One way to offset the financial burden of treatment was through private health insurance. A quarter of patients at Chiromo had their care paid in-full either by an insurance provider or by their employer. Those with a third-party payer were 2.5 times more likely to be readmitted than those paying out-of-pocket, controlling for diagnosis, age, sex, and employment. They also stayed a third longer, and paid 25% more per day than those paying out-of-pocket. The combination of longer stays and higher prices led the overall annual charge to be 71% higher for those with a third-party payer than those paying out-of-pocket. It is impossible to say for sure whether more care reflects the moral hazard of insurance, or increased access to needed services, or both. However, there was no evident over-consumption of care, when benchmarking the findings (on length of stay and ECT use) against other inpatient psychiatric units in Africa. This finding suggests that insurance may be enabling access to needed mental health services.

### *8.3 - c) Acceptability Coverage*

The cultural acceptability of mental health care was addressed exclusively in chapter seven on healers in the informal settlement of Kangemi. One of the assets highlighted by patients about traditional and faith healing is that it offers an explanation and meaning to people's experience of illness – teaching “God's purpose,” or addressing the underlying causes and not just the symptoms to produce a “cure.” This vehicle of meaning appears to be at the heart of what renders healing not only acceptable but desirable to many individuals. Traditional and faith healers alike saw their practice as largely complementary to conventional medicine, either because conventional and traditional medicine are both based in herbs, or because God governs both patients and doctors. By and large, patients were pleased with their experience of traditional and faith healing (albeit more so by faith healing because it was not associated with costly herbs and treatment expenses), and often traditional healing and conventional medicine are used pluralistically in tandem with one another.

### *8.3 - d) Effectiveness coverage*

The question of effectiveness of available mental health care in Kenya is vast and can only partially be addressed by the available data. The data from Chiromo Lane shed some light onto the quality of care in a for-profit inpatient facility, although there are no outcome measures and it is of limited generalizability. The patient-to-staff ratio at the facility was three times higher than that found in the public sector, medicines were available in wide variety and without shortage, electro-convulsive therapy was administered at doses in keeping with NICE



guidelines, and the facilities were clean and hygienic. By contrast, conditions at Mathare Hospital were so poor that 40 male patients escaped in a dramatic episode that took place in May 2012, while this research was being conducted (de Menil 2013). This episode followed on the heels of a report by the Kenya National Commission on Human Rights, which pointed a finger at the “systemic neglect” in effect throughout the public mental health system (Kenya National Commission on Human Rights 2011).

The only true outcome data within the dissertation were found in the evaluation of the model for Mental Health and Development, a product of the NGO BasicNeeds. The MHD model appeared cost-effective from both societal and health systems perspectives, with the most conclusive data for those with schizophrenia spectrum and bipolar disorders over two years. Its cost-effectiveness as estimated by my data in comparison with the literature is in the same order of magnitude as that of anti-retroviral treatments for HIV. The model did not, however, appear cost-effective for common mental disorders in the first year, though the small size of that sample (n=21) makes this finding uncertain. Overall, the data suggest that mental disorders, including schizophrenia spectrum and bipolar disorders, can be effectively treated within the community, using a combination of outpatient mental health visits and social and economic supports in the form of community health workers and self-help groups.

#### **8.4 Limitations**

The findings in this thesis are limited by a number of constraints of the data. Chief among them is the highly fragmented nature of the datasets. As data on mental health care in Kenya are scarce, and more so still on non-state mental health care, the dissertation pulls together information from a diverse range of sources, both primary and secondary. The sources included computer archives, structured interviews, open-ended interviews, a questionnaire, key informants, the internet and the grey literature. The multitude of sources and types of data make the dissertation inevitably uneven from chapter to chapter.

As such, the data in this thesis do not offer a comprehensive map of non-state mental health services, and gaps remain in the evidence. Geographically, the data come largely from Nairobi, Nyeri and Meru counties, which do not represent the country as a whole. This is particularly true of chapter five on for-profit hospital care, which is largely inaccessible to the country’s rural population, as well as to the majority of its urban population for reasons of cost.

In addition, the data do not address mental health care provided by private non-specialist providers, be they lay workers or primary care providers. Collecting non-specialist

data would have been too costly and time-consuming to include in this dissertation. In addition, no quantitative data were analysed on counsellors, a cadre of university-trained specialists who provide psycho-social interventions. Counsellors were only captured in the case study of Chiromo Lane. Indeed, counsellors appear to provide limited treatment for pathological distress – mostly substance use support – tending to focus more on non-pathological distress, such as support for victims of domestic violence and people living with HIV. Closer examination of this cadre of workers would shed light onto not only treatment but also on prevention of mental disorders.

Limitations differed according to the datasets. The data on outpatient care were limited by the small sample size (11). The reason for this, in part, may have been that no financial compensation was offered for participating in research, and the opportunity cost of participating was perceived to be significant for private sector providers. Were I to conduct further research on for-profit providers, I would challenge the prevailing norm among those advising my research in Kenya that views remuneration for participating in research as exploitative.

The data on cost-effectiveness had a relatively large sample (203), but the sample size dropped significantly when looking at individual diagnostic groups, as was necessary when analysing outcomes. The main limitation of that data was the absence of control group – a design choice made for reasons of practicality. The NGO could not afford to identify cases and conduct research on a wait-listed control, as it was funded from intervention money rather than from a research grant. That being said, existence of standardized pre-post outcome measures on an NGO population in Africa is itself a rarity, especially within mental health services, so having any economic data to analyse was exceptional. I addressed the absence of control group by finding data in the literature from neighbouring Ethiopia, which faces similar resource constraints to Kenya, particularly rural Kenya.

Data from Chiromo Lane were limited by the absence of outcome measures, as well as by the dearth of comparison indicators from the public sector. However, it is a rare luxury to have data of this richness, itemizing mental health services and costs, from sub-Saharan Africa, and it is unprecedented to have such data from a private facility. Furthermore, no quantitative data were initially anticipated from the case study of Chiromo. Rather, quantitative data were expected from the Ministry of Health, which – despite many requests – never produced any material. The lesson from that experience is that it would have been more practical to obtain data directly from the major public psychiatric hospital, rather than approaching the Ministry of Health.

The healer dataset was imperfect because of the missing transcripts and the inability to associate patients with specific healers. As a subject of secondary analysis, it also failed to answer some of my research questions, specifically on economic access. Nonetheless, the triangulation of data between providers and patients was a great strength of this dataset. Furthermore, it is challenging to obtain sufficient trust from healers to engage them in research, and as a European researcher, I would have been unlikely to obtain this data were I conducting primary data collection.

## **8.5 Policy Implications**

Private health care in Africa has been the topic of growing interest for several years. One key informant noted, “Governments [in Africa] fall into two categories in their approach to the private sector: either they view it as a necessary evil, or as a reliable partner” (Gitonga 2011, 7 October). Kenya falls clearly into the latter category. A national commitment to working jointly with the private sector has just been reiterated in the new health strategy, reinforcing its prominence in the previous strategy. The current strategy states:

“This Policy recognizes the important role and participation of the private sector in all areas of health delivery... Drawing from past experiences, the private sector can be expected to contribute substantially to the urban primary and tertiary levels. ... The government sees the private sector as a crucial partner, both as a source of financial resources for the health sector and in ensuring program delivery competencies.” (Government of Kenya 2012)

The pro-private tone of Kenya’s health sector finds an echo in the mental health sector. The draft national mental health policy voices equal enthusiasm for private sector involvement. The word “private” is mentioned no fewer than 26 times in the 34 page document, including in the following enthusiastic terms:

“As envisaged in the Kenya Vision 2030 and in this policy, the provision of mental health services will also entail partnership with the private and voluntary sector. The government will encourage and promote the development of the private sector in provision of mental health services. This will enhance the financial and human resource base for provision of mental health services.” (Government of Kenya 2012)

Both of these documents cite comparative advantages of private care. The national health strategy points to the provision of services at primary and tertiary levels in urban settings, while the national mental health strategy points to the private sector as a means of increasing human and financial resources – a “cash cow” of sorts.

What lessons does my research offer to proponents and detractors of private mental health care in Kenya and elsewhere in Africa? Kenya's health strategy was the product of two separate health ministries – the Ministry of Medical Services and the Ministry of Public Health and Sanitation – a division resulting from the coalition government following the election violence in 2007-2008. My findings are more relevant to the former than the latter agency, as they address treatment more than prevention, and they are equally relevant to international donors. Four key policy lessons emerge in line with the sub-themes of my research.

#### *8.5 - a) Availability coverage*

Moving beyond the question of whether non-state care is desirable, from a policy perspective the question at play is how the state should engage with non-state actors. Several models of engagement exist. As outlined by Patouillard, models of engagement include: training, social marketing and vouchers, contracting, franchising, regulation and accreditation (Patouillard et al. 2007). These different forms of engagement work to different ends, some (training, regulation, franchising) to improve quality, others (vouchers) to increase access, and others (contracting) to increase scale, and many forms of engagement address multiple aims simultaneously. The research in this thesis suggests that availability coverage could be increased through more training and possibly contracting out services within certain counties.

Kenya needs to train more nurses in both mental health and general nursing, so as to reduce the internal brain drain of psychiatric nurses to other specialties, and to address the system wide shortfall of nurses. General nurses should also be offered opportunities to increase their training in mental health, since they provide some of these services.

Another way of increasing the scale of services provided would be for the government to contract out services that it is not equipped to provide. The model for Mental Health and Development offers a holistic intervention combining medical, social and economic activities, and appears to be delivered effectively at the community-level through a public-private partnership. It is especially effective for populations with severe mental disorders and epilepsy, while its efficacy in treating common mental disorders remains unproven. Further expanding this model beyond the handful of counties where it is currently implemented could complement existing efforts at integrating mental health into primary care, as well as providing livelihood opportunities to the poorest segments of society.

### 8.5 - b) *Contact coverage*

It is evident that there is a substantial treatment gap across multiple levels of mental health care, which warrants action. The treatment gap for substance use disorders is particularly wide. The for-profit sector is currently providing an estimated three quarters of inpatient services for these disorders. For people with severe mental disorders, there is a great gap in services for supportive residential care, post hospitalization. At present, almost no services exist between the hospital and the home for this population. Finally, for those with common mental disorders, the efforts to address mental health needs through non-specialist primary care providers do not meet the estimated needs, and traditional and faith healers continue to be a first port of call. Making specialist services available in primary care facilities is possible, as demonstrated by the model for Mental Health and Development.

Psychiatric nurses cannot, however, work simultaneously in hospitals and community facilities, so there may be a trade-off in these two forms of care so as to reach larger numbers of people and intervene earlier in the course of illness. For acute care, there is scope for government or other payers to make more use of private hospitals, which are currently running at low levels of occupancy.

In order to reach more women with mental health needs, it is advisable to increase the amount of outpatient services. This can be done in part by explicitly allowing nurses to work in both public and private sectors, a practice that is implicitly prohibited, though often undertaken. Making cross-sectoral work explicitly legal would clarify roles for nurses and might encourage the participation of some nurses otherwise hesitant to engage in this work.

### 8.5 - c) *Access coverage*

In relation to socio-economic inequities, private mental health care appears to reach the poorer segments of society predominantly through traditional and faith healing. Private outpatient clinics run by psychiatric nurses cost the same as a visit to a traditional healer, however they are less prevalent. Private hospital care is priced far outside of what is affordable to most Kenyans. The primary means by which care can be made more accessible is by lowering costs (through use of generics and less reliance on psychiatrists in the first instance) and by increasing insurance coverage. This lesson applies not only to mental health, but to any chronic, non-communicable disease. Similarly efforts at improving access to public mental health care facilities could help reduce the disparity between the two sectors.

Quality mental health care is not cheap, but it can be cost-effective at ratios equivalent to a comparatively much better funded area, namely HIV. For mental health to be affordable

at scale, plans must be made for its adequate financing. Ultimately more money is needed, given the size of the gap. From the demand side, one way to offer financial protection is by including mental health within insurance schemes and expanding insurance coverage.

From the supply side, a means of potentially increasing funds to mental health would be to include it within budgets and service plans for non-communicable diseases. In addition, mental health interventions should be jointly assessed for their economic benefits in returning people to productive work. Development funders might therefore take interest in opportunities for investing in mental health interventions that promote economic empowerment.

## **8.6 Research Implications**

Reaching beyond policy to research, this dissertation offers a few key insights on how to improve the state of knowledge about non-state mental health care.

1. The private sector is providing a significant amount of mental health care and needs to be tracked by newly developing health information systems.
2. Basic data are needed across all sectors of the health system (public, private, informal) on mental health service use and outcomes – for example, length of stay, number of admissions and readmissions, as well as (ideally) health outcomes.
3. Data on costs need to be more tailored to mental health services.
4. The quality of non-state mental health provision needs to be monitored, particularly that of mushrooming rehabilitation centres.
5. Future research should give a voice to service users with which they can co-produced research.

The WHO's new Mental Health Action Plan underscores the first point about improving health information systems. The Plan defines four key objectives: 1) to strengthen effective leadership and governance for mental health; 2) to provide comprehensive, integrated and responsive mental health and social care services in community-based settings; 3) to implement strategies for promotion and prevention in mental health; and 4) to strengthen information systems, evidence and research for mental health (Organization 2013). The fourth objective is followed by a target of 80% of countries "routinely collecting and reporting at least a core set of mental health indicators every two years through their national health and social information systems by the year 2020." No information is collected by the health ministries on mental health from the private sector, other than a license to operate. If this continues, then Kenyan authorities will be missing a large part of the picture of mental health

services on offer in their country. Their health information systems need to catch up with their policy rhetoric to integrate private health care within the data they track.

The absence of any published data on mental health service use in the public sector is more surprising and constitutes an ostensible gap in the knowledge about the national health system. The scientific literature has published statistics on the numbers of public providers (Kiima and Jenkins 2010) and the diagnostic profiles of patients (Ndetei, Khasakhala, Maru, et al. 2008), but no information is available on length of stay or readmission rates in public hospitals. Nor is there systematic tracking of the number of outpatient mental health visits at the primary care level.

Outcomes of care from both conventional medicine and traditional and faith healers are necessary to evaluate their effectiveness. There is a particular need for greater ease of cross-over between measures of preference-based health-related quality of life and disease-specific outcome measures for the purpose of cost-effectiveness analysis within mental health. This would enable more often use of the QALY as an alternative to the DALY, which is designed to account for disease burden rather than an intervention effect. Research into this area is well underway (Mihalopoulos et al. 2014) and promises to create more options for measuring outcomes relevant to mental health in the future.

Research into traditional and faith healing needs to take account of differing understandings of disease causality, and diagnosis, so as to measure efficacy in a way that is meaningful to the patients and providers of these services. Appropriate research in this area might succeed in differentiating between practices that are helpful and harmful within this treatment class, and furthermore whether there are patient-specific factors that influence the benefits of treatment.

Better measuring the costs of mental health care also presents an area of potential improvement for further research. The WHO unit costs for public outpatient services are likely to under-estimate the amount of time needed for a mental health consultation. Furthermore, when costing mental health services, as with any service for chronic disease, the choice of how to measure unpaid care is fundamental to the evaluations of cost-effectiveness. The concept alone of unpaid care raises questions in a cultural context where a family member may consider it part of their natural role to care for a disabled relative.

With regards to quality of care, this thesis can only comment on the facilities for which data were obtainable and which may not be representative of the norm. The National Authority on drug and alcohol abuse (NACADA) have developed a new instrument for measuring the standards of rehabilitation centres, called the “National Standards for

Treatment and Rehabilitation of Persons with Substance Use Disorders” (Government of Kenya 2010). This very thorough set of standards covers four levels of care, starting from prevention to follow-up: community outreach, non-residential treatment, residential treatment, and continuing care. In addition, it takes into account family supports, levels of documentation, treatments for special populations, the therapeutic environment, and management procedures. A potential concern is that the standards are in fact so thorough (with 97 separate standards) that they may be challenging to implement within the resource constraints. Nonetheless, they form a promising basis on which to begin benchmarking service quality.

Last but certainly not least, to the point about service user involvement, the research on mental health care in Kenya hardly ever involves users other than as research subjects. They are all but absent from research design or implementation. Service users and ex-users could be particularly well-placed to explore questions of quality within mental health treatment settings.

## **8.7 Conclusion**

In conclusion, the treatment gap for mental disorders in Kenya is large, although it is slightly less large than it appears when looking only at public provision. Kenya’s private health sector is quite developed relative to its East African neighbours, and is responsible for approximately half of all general health care visits. Mental health care provision – both for-profit and not-for-profit – is an active component of private health care, although apparently less so than in other areas of health care, such as reproductive health. While private for-profit (or self-financing) care is more costly than public care, it appears also to be of higher quality in some instances. Moreover, it provides access to services to a different population, including people with substance use disorders and women. Finally, it is possible that private provision cross-subsidizes public care by providers working in both sectors. It is important that future policy efforts build on private sector strengths (quality of care) and work on its weaknesses (cost of care). In future service expansion efforts, policy planners should be conscious of the possible flow-on effects of reforms from the public sector to the private sector and vice-versa. The two sectors, public and private, need not be viewed antagonistically, but rather as partners in a joint battle to fill a gaping hole in much-needed mental health services.



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## **10. Appendices**

## 10.1 Data sharing agreement with BasicNeeds and the UCT



THE LONDON SCHOOL  
OF ECONOMICS AND  
POLITICAL SCIENCE ■



**BasicNeeds**  
*BasicRights*

### Memorandum of Understanding

Between **BasicNeeds, the University of Cape Town**  
And  
**Victoria de Menil, London School of Economics**

This Memorandum of Understanding establishes the conditions under which the BasicNeeds-University of Cape Town collaborative Impact Study **data**, collected from BasicNeeds' programme site in Kenya, will be shared with Victoria de Menil. This MOU is in response to her request to use the data in her PhD research at the London School of Economics, under the supervision of Martin Knapp. Victoria will utilize the Impact Study data within the context of examining access to and the economic impact of BasicNeeds' mental health and development interventions in Kenya.

This Memorandum of Understanding will remain in effect until July 1, 2012.

In specific, we agree that:

#### 1. Access

Upon signing of this agreement, Victoria will be granted access to raw data from the BasicNeeds-UCT Impact study in STATA format. She will analyse data at baseline, one year and two years follow-up from the following tools:

- The Economic Status Instrument, adapted from India and translated specifically for the BN-UCT study
- The General Health Questionnaire
- The WHOQOL Bref

In addition, Victoria will access data from BasicNeeds Kenya on their intervention costs in Nyeri and Meru during the time-period of the research.

## **2. Analysis**

Victoria will use the BN-UCT Study data for analysis in the following ways:

### **Analysis of Access to Services**

Victoria will compare data from the Economic Assessment Tool in the Impact Study with data she plans to collect separately on service users in other clinical settings. In particular, she will compare the characteristics of patients attending non-state facilities with those of patients attending state-facilities, and will also compare non-state patients between themselves, looking at the difference between those attending for-profit and those attending not-for-profit facilities, and urban vs rural patients. In all cases, simple statistical tests of association will be used (eg. t-tests and chi-squared). The independent variables of analysis will be as follows:

- Diagnosis
- Age
- Sex
- Household income
- Employment status

### **Economic Analysis**

Victoria plans to undertake three types of economic evaluation for her thesis, which will involve the BasicNeeds-UCT impact data to varying degrees:

*Cost of illness:* This will estimate the lost productivity from illness and the treatment costs of those in treatment for those with common and severe mental disorders and epilepsy. Prevalence data will come from a soon-to-be released study by Rachel Jenkins and colleagues which is the first community-based sampling of mental disorders to be done in Kenya. Cost of illness studies rely on the whole population in an area – in this case Kenya – so the BasicNeeds-UCT Impact data is not sufficient to run this analysis. She will therefore repeat the Economic Status Tool with 155 patients from rural and urban clinics in the public and private sectors.

*Cost-offset:* This analysis calculates the costs of MHD treatment in Nyeri and Meru and the direct savings that offset those costs as a result of the intervention. Savings will be calculated based on gains in productivity of users and carers, and reduction in health care costs.

*Cost-effectiveness:* Using two of the Impact Study's outcome measures (General Health Questionnaire and the WHO-QOL), this analysis will examine the cost of the MHD intervention in relation to its effectiveness. Cost-effectiveness will be modelled using decision analysis, and the choice of comparison will be made based on responses to the question about prior treatment in the Patient Questionnaire. Her working assumption, which is in keeping with WHO CHOICE methodology, is that the best comparison group may be no treatment. Data on the outcomes of a no-treatment control can be imputed from the literature on the natural course of common and severe mental disorders and from interviews with experts.

Victoria will take a social perspective on the economic evaluation. In essence, this means she is looking not only at health costs, but also at productivity effects. Victoria will run the

analysis looking at the effectiveness at both 12 months and 24 months of intervention as compared to baseline.

Variables of interest will come from the Economic Assessment Tool, including: household income level, cost of conventional health care before and after the intervention, cost of traditional healing before and after the intervention, and opportunity cost of lost productive days. Victoria will supplement these variables with additional data that she is obtaining separately on hidden costs, namely: costs of the BasicNeeds intervention in Kenya, costs of government clinics, costs of caring.

### **3. Authorship**

Victoria will use the analyzed data for producing a peer-reviewed journal article on the theme of economic evaluation of BasicNeeds' Mental Health and Development model.

The Co-Authors for this paper will be:

BasicNeeds: Joyce Kingori, Milka Waruguru, Sarah Kippen Wood, Saju Mannarath, Shoba Raja

UCT: Crick Lund

The estimated timeline for this paper is six months from access to data until first submission. Victoria will show drafts of the papers to the co-authors and to her supervisors at the LSE. If further advice is needed, then Victoria will request agreement of the co-authors before sharing any drafts.

Any additional publications generated with this data will recognize the original study researchers according to their level of participation in making the publication. Decisions on authorship will be made with reference to the International Committee of Medical Journal Editors guidelines, *Ethical Consideration in the Conduct and Reporting of Research: Authorship and Contributorship*.<sup>14</sup>

### **4. Dissemination**

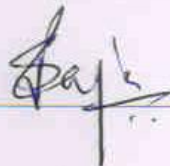
Victoria will disseminate her findings within Kenya jointly with BasicNeeds Kenya, as far as possible, selecting platforms that would be of strategic significance to BasicNeeds Kenya. In the event she has opportunities to present the findings outside Kenya she will do this after getting a written agreement from the head of BasicNeeds Kenya.

### **5. Confidentiality**

At all times Victoria will ensure safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it. At no time will the raw data be shared with a third party other than Victoria, unless agreed separately in writing by the Principle Investigators.

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<sup>14</sup> [http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)



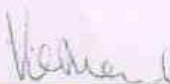
19/12/11

Shoba Raja  
Date  
Director, Policy and Practice and Co-PI BN-UCT Impact Study  
BasicNeeds



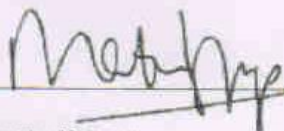
18/11/2011

Joyce Kingori  
Date  
Programme Manager  
BasicNeeds Kenya



18/11/11

Victoria de Menil  
Date  
PhD Candidate, Dept of Social Policy  
London School of Economics



8/12/11

Martin Knapp  
Date  
Professor of Social Policy and Director, Personal Social Services Research Unit  
London School of Economics



22/11/11

Crick Lund  
Date  
Associate Professor of Psychiatry and PI BN-UCT Impact Study  
University of Cape Town



JULIANNE NADLER-VISSER  
Contracts Manager  
Contracts & Intellectual Property Services  
Dept of Research & Innovation  
University of Cape Town

Piet Barnard  
Date  
Director Research and Innovation  
University of Cape Town

20 November 2011

## 10.2 MOU with the Africa Mental Health Foundation



THE LONDON SCHOOL  
OF ECONOMICS AND  
POLITICAL SCIENCE ■

### Memorandum of Understanding (MOU) between the Africa Mental Health Foundation and Victoria de Menil

#### Stakeholders

The Africa Mental Health Foundation (AMHF) is an organization dedicated to the research and practice of community mental health in Kenya and the surrounding region. It was registered in 2004 by Professor David Ndetei, an eminent psychiatrist, and is staffed by three clinical psychologists, two administrators, and a wide network of research assistants. In addition, AMHF hosts visiting overseas researchers studying mental health in Kenya.

Victoria de Menil is a PhD student in the Department of Social Policy at the London School of Economics. She enrolled in 2010 under the supervision of Martin Knapp and David McDaid researching the question: *What is the capacity and economic impact of non-state actors to address Kenya's mental health treatment gap?*

Victoria first encountered the AMHF in 2007 while working at BasicNeeds, an NGO that has partnered with AMHF on past research. In July 2011, at the invitation of Prof. Ndetei, Victoria attended the Alderman Foundation Conference, where she met the AMHF team and the idea for the present collaboration emerged.

#### Background

In 2008, the Africa Mental Health Foundation (AMHF) and BasicNeeds Kenya (BNK) jointly completed data collection on the study *Traditional and faith healers' practices in Kangemi informal settlement, Nairobi Kenya*. The study collected qualitative and quantitative data on the socio-demographic characteristics, practices and experiences of 54 traditional and faith healers, 79 mental health service users and 44 carers. The study was analysed in a 72 page report published in hard-copy jointly by AMHF and BNK, under supervision of David Ndetei, Director of the Africa Mental Health Foundation. The two research officers were Lincoln Khasakhala of AMHF and Allan Oginga of BNK.

The report highlighted several important distinctions between faith and traditional healers, however it did not test these distinctions using statistical tests of association. Moreover, the report has a limited readership, as it is not published online, nor by a peer-reviewed journal, and is not indexed by any academic database (eg. PubMed, PsycInfo, Google Scholar). Further analysis of this data could therefore generate more rigorous knowledge and better dissemination of the study findings.

In October 2010, Victoria de Menil began work on a PhD at the London School of Economics researching the question: *What is the capacity and economic impact of non-state actors to address Kenya's mental health treatment gap?* Traditional healers form one important category of non-state actor within the purview of her thesis. Two sub-questions that the thesis seeks to answer in relation to traditional healers are:

- What is their capacity to provide mental health care?
- Who is accessing their care?

The AMHF-BNK study could provide evidence with which to answer these questions. In addition, the expertise of the AMHF on research practices in Kenya could benefit Victoria's work.

### **Purpose**

The purpose of the present MOU is to mutually benefit the AMHF and Victoria de Menil in the following ways:

1. By hosting Victoria's PhD research under the aegis of the AMHF
2. By engaging in a secondary analysis of the AMHF-BNK data with the aim of publishing these findings in a peer-review journal and in Victoria's PhD thesis.

### **Procedures**

*The AMHF agrees to the following:*

Re purpose 1:

- To provide expertise and guidance on the logistics of Victoria's research implementation.
- Where needed, to provide access to their network of research assistants, at Victoria's expense.

Re purpose 2:

- To enter into a data sharing agreement regarding the data from the 2008 Kangemi healer study, with the option of other datasets in the future.
- To allow Victoria to use the data within her PhD dissertation.
- To discuss this and other relevant data – including a second study of healers undertaken more recently by Anne Mbayo – so as to give depth to the analysis and ensure consensus.

*Victoria agrees to the following:*

Re purpose 1:

- To credit the AMHF as technical advisors in her research
- To consult with the AMHF regarding methodological issues and to share findings with AMHF staff.
- Where needed, to pay for research assistance from AMHF's network

Re purpose 2:

- To treat the data confidentially and not to share it with third parties, other than for the explicit purpose of assistance with data analysis.
- To discuss all findings – quantitative and qualitative – with Lincoln Khasakhala and Prof. Ndeti to arrive at consensus on their analysis.
- To write up the findings for submission to a peer-review journal, such as *Transcultural Psychiatry* or the *African Journal of Psychiatry*. Victoria will write a first draft, which she will submit to the co-authors for comment and revision.

- To write up the findings as part of her PhD dissertation at the LSE, citing the source of the data.

There will be no financial exchange as part of this memorandum.

### **Oversight**

Compliance with this MOU will be the responsibility of each signatory. Any complaints should first be discussed with the other signatories. If any grievance is found in the conduct of Victoria de Menil, it can be taken up with her supervisors:

- Martin Knapp: [m.knapp@lse.ac.uk](mailto:m.knapp@lse.ac.uk)
- David McDaid: [d.mcdaid@lse.ac.uk](mailto:d.mcdaid@lse.ac.uk)

### **Timeline and Renewal**

The agreement is valid from the date of signature through the completion of Victoria de Menil's thesis, or the publication of findings relating to the AMHF-BNK data, whichever comes later. The estimated dates of application are October 2011 – October 2013. The MOU may be updated at any point during this time to reflect a change in the procedures, on condition of agreement by both parties.



## Data Sharing Agreement 1



<b>Today's Date</b>	23 November 2011
<b>Working Title of Proposed Research</b>	<i>Non state actors in Kenya's mental health care: capacity, access and economic impact</i>
<b>Name of related AMHF study</b>	Traditional and faith healers' practices in Kangemi informal settlement, Nairobi Kenya
<b>Date of AMHF data collection</b>	2007
<b>Authors for publication (First and Last Names and Institution)</b>	de Menil, Victoria – London School of Economics Khasakhala, Lincoln – Africa Mental Health Foundation Kingori, Joyce – BasicNeeds Kenya Oginga, Allan – BasicNeeds Kenya Ndetei, David – Africa Mental Health Foundation
<b>Estimated date of paper submission</b>	31 May 2012
<b>Paper 1</b>	
<b>Research question(s)/hypotheses(s)</b>	<p>Research Question: What are the similarities and differences between traditional and faith healers with regards to socio-demographics and treatment practices?</p> <p>Hypotheses: Re treatment practices: I hypothesize that traditional healers perform fewer home-visits, and are use herbs and cutting with greater frequency than faith healers. I also hypothesize that traditional healers refer patients less frequently to conventional medical systems than faith healers.</p> <p>Re demographics: I hypothesize that faith healers are statistically younger than traditional healers and that their income level and educational attainment are higher. I further hypothesize that the sex distribution and geographic origins are the same between the two groups.</p>
<b>Name of requested data set</b>	Traditional Data.sav

<b>Outcome Variable (Dependent Variable)</b>	Healer type (traditional or faith)
<b>Predictor Variables (Independent Variables)</b>	Demographics: Healer age; sex; education; religion; employment; income; place of origin  Treatment: type of treatment provided; home-visits; referral; follow-up

### **Requested Variables**

***(We do not send full datasets. Please list only those variables you will need for your analyses from the requested dataset.)***

province	Province of birth of healer
other	Other province of birth: country
age	Age
gender	Gender
educatio	Level of education
religion	Religion
r.others	Other religion
type	Faith healer/ traditional healer
employm	Employment
why	If none, why?
sacked	sacked due to...
retired	retired due to...
w.others	Other cause of unemployment (specify)
time	If no employment, for how long?
hseowner	Who owns the house that you live in?
income	Estimated income per month
i.other	Other estimated income per month
tfh2i	If yes, what are the mental disorders that you see or get involved in?
tfh3i	What treatment/care do you provide for the mental disorders mentioned above?
tfh4a	Do you go to the homes of mentally affected persons?
tfh4i	If yes, what treatments do you offer as you visit them?
tfhiq9	Do you carry out any procedures before starting the care? If yes, what procedures do they carry out?
tfhiq10	How do you carry these procedures you have mentioned above?
tf11a	The treatments you have mentioned in 3 above; how do you carry them out? (elaborate each treatment procedure)
tfhiq11a	What drugs (herbal) do you use for conditions named above? (name the condition matching it with drug used)
tfhiq12b	Do you coordinate these services with other people? (health workers, traditional healers or faith healers)? If yes which organizations/persons do coordinate with?
tfhiq13a	The organizations/persons you coordinate with mentioned in 12 above, When do you refer the patients to them?

- tfhiq14 The organizations/persons you coordinate with mentioned in 12 above, do they refer the patients back to you? If yes, when/under what circumstances?
- tfhiq16 The persons you see with mental disorders, how do you follow them up; for them to get further treatment/to complete treatment?
- tfhiq17 How do you view the conventional medical treatment as compared to your mode of treatment(s)



**Africa Mental Health Foundation**

**Data Sharing Agreement 2**

<b>Today's Date</b>	23 November 2011
<b>Working Title of Proposed Research</b>	<i>Non state actors in Kenya's mental health care: capacity, access and economic impact</i>
<b>Name of related AMHF study</b>	Traditional and faith healers' practices in Kangemi informal settlement, Nairobi Kenya
<b>Date of AMHF data collection</b>	2007
<b>Authors for publication (First and Last Names and Institution)</b>	de Menil, Victoria – London School of Economics Khasakhala, Lincoln – Africa Mental Health Foundation Kingori, Joyce – BasicNeeds Kenya Oginga, Allan – BasicNeeds Kenya Ndetei, David – Africa Mental Health Foundation
<b>Estimated date of completion</b>	31 June 2012
<b>Paper 2</b>	
<b>Research question(s)/hypothese(s)</b>	<p>Research Question: Is there a statistical difference between patients of traditional healers and those of faith healers with regards to diagnosis, and demographics?</p> <p>Hypothesis : I hypothesize that patients of faith healers are more likely to have a diagnosis of common mental disorder than patients of traditional healers, as well as being on average younger. I also hypothesize that the socio-economic status and gender distribution of both types of patients are comparable in this sample.</p>
<b>Name of requested data set</b>	Adults data - Kangemi working file August.sav
<b>Outcome Variable (Dependent Variable) for Research Question 2</b>	Attending a traditional or faith healer – I will impute this variable from variables secb2i – secb4vii
<b>Predictor Variables (Independent Variables) for Research Question 2</b>	Diagnosis of mental disorders from the MINI, patient age; sex; education; religion; employment; income

### **Requested Variables**

*(We do not send full datasets. Please list only those variables you will need for your analyses from the requested dataset.)*

serino	serial number
age1	age of patient
age2	age of caregiver
gender1	gender of patient
gender2	gender of caregiver
edu1	education of patient
relig1	religion of patient
emplo1	employment of patient
emplo2	employment of caregiver
inw1	if none, why? (patient)
inwo1	Other
inw2	if none, why? (caregiver)
inwo2	Other
infhl1	if none for how long?(patient)
infhl2	if none for how long? (caregiver)
wothyl1	who owns the house that you live in? (patient)
wothyl2	who owns the house that you live in? (caregiver)
eipm1	estimated patient income per month
eothe1	Other
eipm2	estimated caregiver income per month
eothe2	Other
rbtpatc1	Relationship between the patient and the caregivers ( patient)
rothe1	Other
secb2i	If yes, what treatment do you receive?
secb3	What treatment/care do they provide for the mental disorders mentioned above?
secb8i	What procedures?
secb9	How they you carry out these procedures you have mentioned above?
secb10i	Procedure
secb11	What drugs (herbal) do they use for conditions named above? (Name the condition matching it with drug used)
secb15	Do you feel/ think there is need to form a linkage with the persons/organization mentioned in 12 above?
secb15i	If yes what kind of linkages?
secb17	How do you view the conventional medical treatment as compared to the traditional/faith healers treatment?
a8	Current major depressive episode
a9	Current mood disorder due to general medical condition
a10	Current substance induced mood disorder
b5b	Current dysthymia
csumm	Suicidality
d6	Hypomanic episode
d7	Manic episode
e8	Current panic disorder
e9	Current anxiety disorder with panic attacks due to general medical condition
e10	Substance induced anxiety disorder with panic attacks
f3	Current agoraphobia

g4	Current social phobia
i10	How old were you when you first began having symptoms of OCD?
j6	Current PTSD
k1	In the past 12 months, have you had 3 or more alcoholic drinks within a 3 hour period on 3 or more occasions?
k2summ	Alcohol dependence
k3summ	Alcohol abuse
m11b	Current psychotic disorder NOS
m11c	Current schizophrenia
m13a	Current psychotic disorder due to a general medical condition
m13b	Current substance induced psychotic disorder
p5sum	Current generalized anxiety disorder
p6	Current generalized anxiety due to a medical condition
p7	Current substance induced generalized anxiety

### 10.3 Data sharing agreement with Chiromo Lane Medical Center

Victoria de Menil, MSc  
PhD Candidate, Social Policy  
London School of Economics  
[v.p.de-menil@lse.ac.uk](mailto:v.p.de-menil@lse.ac.uk)  
+254 (0)70 541 8080



THE LONDON SCHOOL  
OF ECONOMICS AND  
POLITICAL SCIENCE ■

#### Non-Disclosure Agreement

18 May 2012

#### Parties

**Victoria de Menil** of the London School of Economics, a university registered in England as a company limited by guarantee (Reg no. 70527), whose registered address is at Houghton Street, London WC2A 2AE +44 (0)207 405 7686 (**the Recipient**);

and

**Chiromo Lane Medical Centre**, a registered medical institution in Kenya whose office is at Chiromo Lane/ Muthithi Road, Westlands, PO Box 1501 00606 Nairobi (**the Discloser**);

#### Agreement

1. The Discloser intends to disclose the confidential information to the Recipient for the purpose of scientific research in completion of a doctoral degree (**the Purpose**).
2. The Recipient undertakes not to use the confidential information for any purpose except the stated Purpose without first obtaining the written agreement of the Discloser.
3. The Recipient undertakes to keep the confidential information secure and not to disclose it to any third party, especially to any local third party in Kenya. The exception is supervisors in health economics, who need to know the same for the Purpose, and who know they owe a duty of confidence to the Discloser, and who are bound by obligations equivalent to those in clause 2 above and this clause 3.
4. The undertakings in clauses 2 and 3 above apply to all of the information disclosed by the Discloser to the Recipient, regardless of the way or form in which it is disclosed or recorded, but they do not apply to:
  - a. Any information which is or in future comes to the public domain (unless as a result of the breach of this Agreement); or
  - b. Any information which is already known to the Recipient and which was not subject to any obligation of confidence before it was disclosed to the Recipient by the Discloser.

5. Nothing in this Agreement will prevent the Recipient from making any disclosure of the confidential information required by law or by any competent authority.
6. The Recipient will, if requested by the Discloser, return all copies and records of the confidential information to the Discloser and will not retain any copies or records of the confidential information.
7. Neither this Agreement nor the supply of any information grants the Recipient any licence, interest or right in respect of any intellectual property rights of the Discloser, except the right to copy the confidential information solely for the Purpose.
8. The undertakings in clauses 2 and 3 will continue in force indefinitely from the date of this Agreement.
9. This Agreement is governed by, and is to be construed in accordance with Kenyan law. The Kenyan Courts will have non-exclusive jurisdiction to deal with any dispute which has arisen or may arise out of, or in connection with this Agreement.

Signed and Delivered as a Deed by

.....

Victoria de Menil  
PhD Candidate, LSE

As witnessed by:

.....

Dr. Frank Njenga  
Upper Hill Medical Center  
Nairobi



## 10.4 Research Permit

REPUBLIC OF KENYA



### NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telegrams: "SCIENCETECH", Nairobi  
Telephone: 254-020-241349, 2213102  
254-020-310571, 2213123  
Fax: 254-020-2213215, 318245, 318249  
When replying please quote

P.O. Box 30623-00100  
NAIROBI-KENYA  
Website: www.ncst.go.ke

Our Ref:

NCST/RRI/12/1/MED-011/198/4

Date:

21<sup>st</sup> December, 2011

Victoria de Menil  
The London School of Economics & Political Science  
25 Alexander Street, London W2 5NT  
LONDON, UK

#### RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on "*Non-state actors in Kenya's mental healthcare: Capacity, access & economic impact*" I am pleased to inform you that you have been authorized to undertake research in Nairobi, Meru & Nyeri for a period ending *31<sup>st</sup> January 2013*.

You are advised to report to the District Commissioners, the District Education Officers & the District Medical Officers of Health in selected districts in Nairobi, Meru & Nyeri before embarking on the research project.

On completion of the research, you are expected to submit **two hard copies and two soft copies** of the research report/thesis to our office.

  
SAID HUSSEIN  
FOR: SECRETARY/CEO

Copy to:  
The District Commissioners  
Selected Districts in Nairobi, Meru & Nyeri

The District Medical Officers of Health  
Selected Districts in Nairobi, Meru & Nyeri

THIS IS TO CERTIFY THAT:

Prof./Dr./Mr./Mrs./Miss VICTORIA DE MENIL

of (Address) THE LONDON SCHOOL OF ECONOMICS & POLITICAL SCIENCE, LONDON has been permitted to conduct research in

Location, NAIROBI, MERU AND NYERI Districts NAIROBI, EASTERN AND CENTRAL Provinces on the topic NON-STATE ACTORS IN KENYA'S MENTAL HEALTHCARE: CAPACITY ACCESS AND ECONOMIC IMPACT

for a period ending 31ST JANUARY 2013

NCST/RRI/12/1/MED-011/198 Research Permit No. 21/12/2011 Date of issue SHS 38,000 Fee received



Applicant's Signature

Signature of Secretary, National Council for Science and Technology

## 10.5 Ethical Clearance for Primary Data Collection



UNIVERSITY OF NAIROBI  
COLLEGE OF HEALTH SCIENCES  
P O BOX 19676 Code 00202  
Telegrams: varsity  
(254-020) 2726300 Ext 44355  
Ref: KNH-ERC/A/280

KNH/UON-ERC  
Email: uonknh\_erc@unobi.ac.ke  
Website: www.unobi.ac.ke



KENYATTA NATIONAL HOSPITAL  
P O BOX 20723 Code 00202  
Tel: 726300-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi  
14<sup>th</sup> November 2011

Victoria de Menil  
London School of Economics,  
Department of Social Policy  
25 Alexander St. London W2 5NT UK  
Email [v.p.de-menil@lse.ac.uk](mailto:v.p.de-menil@lse.ac.uk)

Dear Victoria

**Research Proposal: "Non-state actors in Kenya's mental healthcare: Capacity, access and Economic impact"**  
(P450/10/2011)


This is to inform you that the KNH/UON-Ethics & Research Committee has reviewed and **approved** your above cited research proposal. The approval periods are 14<sup>th</sup> November 2011 to 13<sup>th</sup> November 2012.

You will be required to request for a renewal of the approval if you intend to continue with the study beyond the deadline given. Clearance for export of biological specimens must also be obtained from KNH/UON-Ethics & Research Committee for each batch.

On behalf of the Committee, I wish you a fruitful research and look forward to receiving a summary of the research findings upon completion of the study.

This information will form part of the data base that will be consulted in future when processing related research study so as to minimize chances of study duplication.

Yours sincerely

  
**PROF A N GUANTAI**  
**SECRETARY, KNH/UON-ERC**

c.c. The Deputy Director CS, KNH  
The Principal, College of Health Science, UON  
The HOD, Medical Records, KNH  
Co-investigators: Prof. D.M.Ndetei, Dept. of Psychiatry, UON  
Prof. Martin Knapp, London School of Economics, UK  
Milka Waruguru, BasicNeeds Kenya



**UNIVERSITY OF NAIROBI**  
**COLLEGE OF HEALTH SCIENCES**  
 P O BOX 19676 Code 00202  
 Telegrams: varsity  
 (254-020) 2726300 Ext 44355

**KNH/UON-ERC**  
 Email: nonknh\_erc@uonbi.ac.ke  
 Website: www.uonbi.ac.ke  
 Link: www.uonbi.ac.ke/activities/KNHUoN



**KENYATTA NATIONAL HOSPITAL**  
 P O BOX 20723 Code 00202  
 Tel: 726300-9  
 Fax: 725272  
 Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/ MOD/125

18<sup>th</sup> May 2012

Victoria de Menil  
 London School of Economics  
 Department of Social Policy  
 25 Alexander St. London W2 5NT UK  
 Email. v.p.de-menil@lse.ac.uk

Dear Victoria

**Re: Approval of modifications study titled 'Non-State Actors in Kenya's Mental Healthcare: Capacity, Access and Economic Impact' (P450/10/2011)**

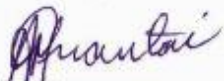
Your communication of 26 April 2012 refers.

The KNH/UON-Ethics and Research committee has reviewed and approved the following modifications:

1. Replacement of the "Hospital Questionnaire" with the "Psychiatric Private practice(PPP) Questionnaire".
2. Replacement of the "Mental Health Professionals Questionnaire" with the "Mental Health Nursing Questionnaire".
3. Omission of "Economic Status Tool".

The approved instruments have been endorsed for use.

Yours sincerely

  
**PROF.A.N. GUANTAI**  
**SECRETARY, KNH/UON-ERC**

c.c. The Deputy Director CS, KNH  
 The Principal, College of Health Sciences, UoN

## 10.6 Consent Form for BasicNeeds-UCT Impact Study

### PART A CONSENT EXPLANATION

#### **An evaluation of the Mental Health and Development Model in Rural Kenya: collaboration between the Mental Health and Poverty Project (MHaPP)**

##### **Name and institutional affiliations of Investigators**

Principal Investigators: Dr Crick Lund, University of Cape Town; Shoba Raja, BasicNeeds

Co-investigators: Joyce Kingori, Milka Waruguru, Sarah Kippen-Wood Policy and, Saju Mannrath, BasicNeeds; Prof Alan J. Flisher, University of Cape Town.

##### **Information to volunteers**

This is a joint evaluation research project being conducted by the University of Cape Town and BasicNeeds UK in Kenya. The study aims to evaluate how successful the Mental Health and Development Programme is in Meru South and Nyeri North. Participating in the research will benefit you because you will be able to see how your mental health improves as you participate in the programme. It will also help us to improve the programme and benefit others in society, by improving the programme in other areas.

##### **Procedure to be followed**

It will include a minimum number of 180 mentally ill persons and the eligibility criteria includes; those who have been diagnosed by a certified psychiatrist or psychiatric nurse to have mental illness, are above 18 years of age and will give informed consent and sign the consent form. In this evaluation the participants will be required to answer various questions in the five study tools.

##### **Benefits of study**

The precise interventions to be applied are based on the mental health and development model. Such include; Provision of the community mental health programme which is mainstreamed in the government health facilities to continue providing the mental health services in the absence of the programme. The capacity building of the public health sector in order to ensure that the trained psychiatric personnel are available to continuously offer treatment, as well as mainstreaming of livelihoods through self help groups for the mentally ill persons who have stabilized.

There is no potential risk/harm of participation in this study since the study is not intrusive and the persons who refuse to participate in the study will continue to benefit from the programme.

##### **Confidentiality of your identity**

Confidential research data and records will be stored securely in lockable metal filing cabinets already provided in all the clinics at the project areas and will only be accessible to the mental health coordinator (in the two sites a Psychiatric Nurse). Electronic data will be stored in both flash and compact disks and a password installed to limit access. During the course of data analysis, all identifying information will be removed from the data, and no identifying information will be provided in the writing up and dissemination of research results.

##### **Obtaining additional information**

In case of any questions or concerns about your participation in the study please contact any of the following members;

1. Joyce Kingori, Programme Manager, BasicNeeds UK in Kenya, Mai Mahiu, South C, P.O.Box 14590-00100, Nairobi, Kenya.  
Email: [joyce.kingori@basicneeds.org](mailto:joyce.kingori@basicneeds.org)

2. The Secretary, Kenya Medical Research Institute, National Ethics Review Committee, PO Box 54840-00200 Nairobi. Tel #: 020 272 2541; 0722205901; 0733400003.

### PART B CONSENT SEEKING FORM

**Key information to be communicated to each participant, BEFORE the interview. Please TICK appropriately.**

Information	Understood?	
<p>I would like to ask you some questions about your health and how you have been feeling over the last while.</p> <p>This interview will take about 1 hour of your time today.</p> <p>We would then like to come back to interview you in 9 months time and then again in 18 months time. This means that we will interview you 3 times in the next one and a half years.</p> <p>Everything that you say to me will be confidential.</p> <p>You do not have to be interviewed. You may leave when you choose. If you choose to leave, it will not affect your relationship with us or the care you receive from the health services or BasicNeeds. If you would like to, you may discuss any problems you have with me or with a care worker in the programme.</p>		
Will you participate?	<b>YES</b>	<b>NO</b>

**If the participant is literate:**

Participant's name: .....Signature: ..... Date: .....

Witness' name: .....Signature: ..... Date: .....

**If the participant is not literate:**

I have communicated the above information to ..... and he/she has agreed to be involved in the interviews.

Carer's name: .....Signature.....Date: .....

Witness' name: .....Signature:.....Date:.....

Interviewer's name:.....Signature:.....Date: .....

Before we begin, do you have any questions you would like to ask?

.....

## 10.7 LSE Research Checklist and Questionnaire

This checklist should be completed for every research project that involves human participants, personal, medical or otherwise sensitive data or methodologically controversial approaches. It is used to identify whether a full application for ethics approval needs to be submitted. The research ethics review process is not designed to assess the merits of the research in question, but is merely a device to ensure that external risks have been fully considered and that an acceptable research methodology has been applied. This checklist applies to research undertaken by *both* staff and students, but it should be noted that the way the checklist is processed differs between these two groups.

**For staff:** if a full application is required please ensure that you complete the Ethics Review Questionnaire for Researchers and send the completed form to Michael Nelson in the Research Division (RD).

Please accompany the questionnaire with a copy of this checklist and a copy of the research proposal.

**For MSc/PhD students:** if a full application is required please ensure that you complete the Ethics Review Questionnaire for Researchers and discuss the issues raised with your student supervisor in the first instance. You should ensure that the completed forms are accompanied with a copy of the research proposal to ensure that your supervisor can make a fully informed decision on the ethical implications of the research. Where the supervisor is satisfied that all ethical concerns have been addressed s/he must sign the checklist and ensure that a copy is retained within the department as a record of the decision reached. It is appreciated that in certain cases the student supervisor may not be able to reach a decision on the ethical concerns raised. In such instances the matter should be referred to the Research Ethics Committee (please send all relevant forms and a copy of the proposal to Michael Nelson in RD. *Only where an informed decision cannot be reached by the supervisor should paperwork be submitted to the Research Ethics Committee.*

**For undergraduate students:** After completing the checklist, undergraduate students should discuss any issues raised with their supervisor in the first instance. If fully satisfied with the research proposal, the supervisor can sign the checklist on behalf of the department. A copy of the signed form should be retained by the department as a record of the decision reached. It is appreciated that in certain instances the student supervisor may not be able to reach a decision on the ethical concerns raised. In such instances the application for ethics approval should be referred to the Research Ethics Committee (please send all relevant forms and a copy of the proposal to Michael Nelson in RD. *Only where an informed decision cannot be reached by the supervisor should paperwork be submitted to the Research Ethics Committee.*

**Before completing this form, please refer to the LSE Research Ethics Policy.** The principal investigator or, where the principal investigator is a student, the supervisor, is responsible for exercising appropriate professional judgement in this review. For students, your supervisor should be able to provide you with guidance on the ethical implications of the research project. If members of staff have any queries regarding the completion of the checklist they should address these to Michael Nelson (RD in the first instance.

This checklist must be completed before potential participants are approached to take part in any research.

**Section I: Applicant Details**

Name of researcher:	<b>Victoria de Menil</b>
Status(delete as appropriate):	Undergraduate Student/MSc Student/PhD Student/Staff
Email address:	<a href="mailto:v.p.de-menil@lse.ac.uk">v.p.de-menil@lse.ac.uk</a>
Contact address:	25 Alexander Street, London W2 5NT
Telephone number:	07772 844 607

**Section II: Project Details**

<p>Title of the proposal and brief abstract: <b>The Role and Economic Impact of Non-State Actors in Kenya’s Mental Health Care</b></p> <p>This study is examining the role of four types of non-state actor in Kenya’s mental health care provision: formal for-profit; formal not-for-profit; informal for-profit; and informal not-for-profit. The study will use mixed methods including secondary analysis of quantitative data, and primary collection of data from several hundred mental health professionals and an estimated 12 key informants.</p>
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**Section III: Student Details:**

Details of study:	
Supervisor’s name:	Martin Knapp
Email address:	m.knapp@lse.ac.uk
Contact address:	Cowdray House, 4 <sup>th</sup> Floor, Portugal Street, London WC2

**Section IV: Research Checklist**



## Consent

	Yes	No	Not certain
<p>Does the study involve participants who are in any way vulnerable or may have any difficulty giving consent? <i>If you have answered yes or are not certain about this please complete Section 1 of the Research Questionnaire.</i></p> <p><i>As general guidance, the Research Ethics Committee feels that research participants under the age of 18 may be vulnerable.</i></p>	x		
<p>Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g. covert observation of people in public places <i>If you have answered yes or are not certain about this please complete Section 1 of the Research Questionnaire.</i></p>		x	

## Research Design/Methodology

<p>Does the research methodology use deception? <i>If you have answered yes or are not certain about this please complete Section 2 of the Research Questionnaire.</i></p>		x	
<p>Are there any significant concerns regarding the design of the research project?</p> <p>If the proposed research relates to the provision of social or human services is it feasible and/or appropriate that service users or service user representatives should be in some way involved in or consulted upon the development of the project?</p> <p>Does the project involve the handling of any sensitive information?</p> <p><i>If you have answered yes or not certain to these questions please complete Section 3 of the Research Questionnaire.</i></p>		NA	
		x	

## Financial Incentives/Sponsorship

Will the independence of the research be affected by the			
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source of the funding? <i>If you have answered yes or not certain about this please complete Section 4 of the Research Questionnaire.</i>		X	
Are there payments to researchers/participants that may have an impact on the objectivity of the research? <i>If you have answered yes or not certain about this please complete Section 4 of the Research Questionnaire.</i>		X	
Will financial inducements (other than reasonable expenses and compensation for time be offered to participants? <i>If you have answered yes or not certain about this please complete Section 4 of the Research Questionnaire.</i>		X	

### Research Subjects

Is pain or more than mild discomfort likely to result from the study? <i>If you have answered yes or not certain about this please complete Section 5 of the Research Questionnaire.</i>		X	
Could the study induce unacceptable psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life? Will the study involve prolonged or repetitive testing? <i>If you have answered yes or not certain about this please complete Section 5 of the Research Questionnaire.</i>		X	
Are drugs, placebos or other substances to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind? <i>If you have answered yes or not certain about this please complete Section 5 of the Research Questionnaire.</i>		X	

### Risk to Researchers

Do you have any doubts or concerns regarding your (or your colleagues physical or psychological wellbeing during the research period? <i>If you have answered yes or not certain about this please complete Section 6 of the Research Questionnaire.</i>		X	
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### Confidentiality

Do you or your supervisor have any concerns regarding confidentiality, privacy or data protection? <i>If you have answered yes or not certain about this please complete Section 7 of the Research Questionnaire.</i>		<b>x</b>	
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### Dissemination

Are there any particular groups who are likely to be harmed by dissemination of the results of this project? <i>If you have answered yes or not certain about this please complete Section 8 of the Research Questionnaire.</i>		<b>x</b>	
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If you have answered **no** to all the questions, staff members should file the completed form for their records. Students should retain a copy of the form and submit it with their research report or dissertation.

If you have answered **yes** or **not certain** to any of the questions you will need to describe more fully how you plan to deal with the ethical issues raised by your research. You will need to answer the **relevant** questions in the Ethics Review Questionnaire for Researchers form addressing the ethical issues raised by your proposal. Staff should ensure that the completed questionnaire is sent to Michael Nelson in RD. Students should submit their completed questionnaire to their supervisor in the first instance. It will be at the discretion of the supervisor whether they feel that the research should be considered by the Research Ethics Committee.

Please note that it is your responsibility to follow the School's Research Ethics Policy and any relevant academic or professional guidelines in the conduct of your study. This includes providing details of your proposal and completed questionnaire, and ensuring confidentiality in the storage and use of data.

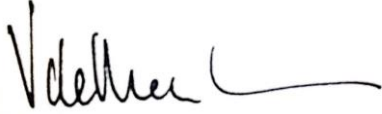
Any significant change in the question, design or conduct over the course of the research should be notified to Michael Nelson in RD.

I have read and understood the LSE Research Ethics Policy and the questions contained in the Research Checklist above.

### Academic Research Staff

Principal Investigator Signature:
Date:

**Undergraduate/MSc Student/PhD Student**

Student Signature: 
Student Name (Please print): Victoria de Menil
Department: Social Policy
Date: 24 August 2011
Date of Research Ethics Seminar attended: 11/11/2010

Summary of any ethical issues identified:
Supervisor Signature*:
Supervisor Name (Please print): Martin Knapp
Department: Social Policy
Date:

\* By signing this document the student supervisor attests to the fact that any ethical issues raised have been dealt with adequately.

# ETHICS REVIEW QUESTIONNAIRE FOR RESEARCHERS

Researchers should consider the following questions when devising research proposals involving human participants, personal, medical or otherwise sensitive data or methodologically controversial approaches. N.B. not all of these questions will be relevant to every study. These questions provide pointers to direct researchers' thinking about the ethical dimensions of their research. It is expected that researchers will already have addressed the academic justification for the project in their proposal; the guidance questions set out below aim to help researchers address specific ethical issues in so far as they relate to participants or data.

In particular, consideration of risks to the research participants versus benefits need to be weighed up by researchers. It is important to think through carefully the likely impact on participants or vulnerable groups of any data collection methods. Certain groups are particularly vulnerable, or will be placed in a vulnerable position in relation to research, and may succumb to pressure; for example children or people with learning disability, or students when they are participating in research as students. Some participants will have diminished capacity to give consent and are therefore less able to protect themselves and require specific consideration (see further guidance given on the RPDD web pages regarding informed consent). The Research Ethics Committee (REC) recognizes that it is not only research with human participants that raises relevant ethical concerns. Researchers may be assessing sensitive information, the publication or analysis of which may have direct impact on agencies, communities or individuals. For example, collection and use of archive, historical, legal, online or visual materials may raise ethical issues (e.g for families and friends of people deceased), and research on provision of social or human services may impact user provision. Similarly, use of other people's primary data may need clearance or raise concerns about its interpretation. The Research Ethics Committee will assess whether the relevant questions have been adequately addressed when it scrutinises proposals. Please ensure that each answer provides the Committee with enough information to make an informed decision on the ethical dimensions of the proposal.

The LSE Research Ethics Policy and guidance will be reviewed annually and may be subject to further development.

**The completed questionnaire should only be returned to Michael Nelson in the Research Division where specific issues have been identified and the supervisor/researcher would like the Research Ethics Committee to consider the application. Where you have considered questions to be irrelevant please indicate this on the form.**

### I. Project Details

**Project Title: Non-State Actors in Kenya's Mental Health Care: Capacity, Access and Costs**

### II. Applicant Details

<b>Name:</b>	Victoria de Menil
<b>Status (delete as applicable)</b>	PhD
<b>Email address:</b>	v.p.de-menil@lse.ac.uk
<b>Room number/contact address:</b>	OLD 1.20

### III. Research Aims

Please provide *brief* details of the research aims and the scientific background of the research. A full copy of the proposal should be attached to this document.

See attached for an executive summary of the thesis proposal.

**ONLY COMPLETE THE RELEVANT PARTS OF THIS DOCUMENT. THESE WILL HAVE BEEN IDENTIFIED AFTER COMPLETION OF THE RESEARCH ETHICS CHECKLIST.**

#### 1. Informed consent.

**1.1** Will potential participants be asked to give informed consent in writing and will they be asked to confirm that they have received and read the information about the study? If not, why not?

All participants will be asked for informed consent in writing. In addition the form will be explained verbally. However, if participants are illiterate, as may be the case for some mental health service users, they will be asked to mark an x in the signature box and a named witness will be requested to similarly sign the form. Thumb prints are not preferred, because of their association with voting.

**1.2.** How has the study been discussed or are there plans to discuss the study with those likely to be involved, including potential participants or those who may represent their views?

The study findings will be presented to selected user group representatives.

**1.3.** Has information (written and oral) about the study been prepared in an appropriate form and language for potential participants? (see Informed Consent guidance which lists questions to be considered). At what point in the study will this information be offered?

Informed consent has been written in basic English and will be translated into local language on site. Informed consent will be delivered prior to interviewing any key informants.

**1.4** How will potential participants be informed of whether there will be adverse consequences of a decision not to participate? Or of a decision to withdraw during the course of the study?

No adverse consequences are foreseen from the questions relating to this study. Participants will be informed prior to the interview of their right to withdraw.

**1.5** What provision has been made to respond to queries and problems raised by participants during the course of the study?

The study is being conducted with the help of a few key contacts, including the director of a mental health NGO. Problems raised by participants can be drawn to the attention of Joyce Kingori, Director of BasicNeeds Kenya, or of my supervisor, Martin Knapp. The contact information of both people will be provided.

## **2. Research methodology.**

**2.1.** How does the research methodology justify the use deception?

**2.2.** If the proposed research involves the deception of persons in vulnerable groups, can the information sought be obtained by other means?

**2.3.** How will data be collected during the project? Please provide details of data analysis.

**2.4.** How have ethical concerns arising from data collection been addressed?

## **3. Research design.**

**3.1** What concerns have been taken into account with regard to the design of the research project? If agencies, communities or individuals are directly affected by the research (e.g. participants, service users, vulnerable communities or relations), what means have you devised to ensure that any harm or distress is minimized and/or that the research is sensitive to the particular needs and perspectives of those so affected?

The project has been designed in such a way as to include service users as well as non-state actors. The questions asked will not be of a sensitive nature. However, if participants find the research distressing, they will be advised in the informed consent of their right to withdraw.

**3.2.** How has the methodology addressed how sensitive information, data or sources will be handled?

The most sensitive information that could be anticipated is diagnostic information. All data will be confidential, and key informants will be de-identified. Codes will be kept in a



password protected document.

**3.3.** Have you been able to devise a timetable of research?

Please see attached for the preliminary research timetable.

**4. Ethical questions arising from financial support/the provision of incentives**

**4.1** Are there any real or perceived conflicts of interest which could compromise the integrity and/or independence of the research due to the nature of the funding body?

**4.2** Have any incentives to the investigator been declared?

**4.3** Are there any restrictions on the freedom of the investigator(s) to publish the results of the research?

**4.4** Are any incentives being offered to participants?

**5. Research Subjects**

**5.1** Who do you identify as the participants in the project? Are other people who are not participants likely to be directly impacted by the project?

**5.2** What arrangements have been made to preserve confidentiality for the participants or those potentially affected?

**5.3.** What are the specific risks to research participants or third parties?

**5.4.** If the research involves pain, stress, physical or emotional risk, please detail the steps taken to minimize such effects? Explain why this is reasonable within the context of the project?

**6. Risk to researchers.**

6.1 Are there any risks to the researcher(s)? Please provide details if risk identified.

**7. Confidentiality**

7.1 Explain the mechanisms in place to ensure confidentiality, privacy and data protection.

**8. Dissemination**

8.1 Will the results of the study be offered to those participants or other affected parties who wish to receive them? If so, what steps have been taken to minimize any discomfort or misrepresentation that may result at the dissemination level.

## 10.8 Informed Consent for Psychiatric Private Practice Interview

Victoria de Menil, MSc  
PhD Candidate, Social Policy  
London School of Economics  
v.p.de-menil@lse.ac.uk



THE LONDON SCHOOL  
OF ECONOMICS AND  
POLITICAL SCIENCE ■

### Research Project:

Non-State Actors in Kenya's Mental Healthcare: Capacity, Access and Economic Impact

**Principle Investigator:** Victoria de Menil, MSc ; Co-Investigators Professor David Ndeti (University of Nairobi) ; Martin Knapp (LSE) ; Milka Waruguru (BasicNeeds)

### Information Sheet

#### **Aim**

You are being invited to participate in research led by Victoria de Menil, a postgraduate student at the London School of Economics. The goal of the research is to find out what role and economic impact non-state actors have in mental health care in Kenya. A non-state actor is a person or agency that provides services but is not employed by the government. You are being invited to participate because you represent a non-state actor providing mental health services.

The main question this research seeks to answer is: What is the capacity and economic impact of non-state actors to address Kenya's mental health treatment gap? The sub-questions are:

1. What is the capacity of non-state actors to deliver mental health care in Kenya?
2. Who is accessing non-state mental health care in Kenya?
3. What are the costs and outcomes of mental health care provided by non-state actors in Kenya?

The findings from this research will be written up in a thesis reviewed by a group of professors from the London School of Economics. In addition, some of the results will be written into papers submitted to scientific journals. The ultimate aim of this research is to find ways of increasing quality mental health care for people who need it in Kenya.

#### **Participation**

I am asking to interview you to find out your experiences of mental health care provision and your knowledge about available resources. This interview should take about half an hour and not longer than an hour. If, for any reason, you do not want to continue the interview, you are welcome to stop at any point. Your participation is entirely voluntary and there is no compensation for participating.

#### **Risks and Benefits**

There is no expected risk to you in participating in this interview. All the information you tell me will remain confidential and will not be associated with your name or identity. The benefit of this research is in helping inform decision makers about the capacity of the non-state sector to deliver mental health care, so as to design more inclusive policies and improve understanding of the mental health system as a whole.

## **Certificate of Consent**

Full Name (please print) : \_\_\_\_\_

Please circle your answer choice:

1. Do you understand the purpose of the research?  
Yes    No
  
2. Do you understand what you are being asked to do?  
Yes    No
  
3. Do you want to participate in the interview?  
Yes    No

### **Participant**

*I have read the previous information or it has been read to me. I have had the opportunity to ask questions about it. I consent voluntarily to participate in this study.*

Signature: \_\_\_\_\_

Date: \_\_\_\_\_  
(day/month/year)

### **Researcher**

*I have read the information sheet to the potential participant and made sure that the participant understands what will be done. The participant was given an opportunity to ask questions. The individual has not been coerced and consent has been given freely and voluntarily. A copy of this consent form has been given to the participant.*

Name of researcher: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## 10.9 Case Study Question Guide

*Note: These questions are a guide to you, the researcher, as you enter the environment you are studying. Not all of them will be relevant, and many of them should not be formulated as questions when talking to a person. Some of them, however, may be useful in discussion with key individuals.*

### **Domain 1: Environment**

- What are local sociocultural attitudes about and behaviors toward persons with mental illness?
- Is there overt evidence of stigma and discrimination?
- Are practices such as chaining, caging, and other forms of abuse common?
- Which conditions are considered to be mental illnesses? Are intellectual disability and substance abuse considered mental illness? What about epilepsy?
- Are any mental illnesses thought to be curable?

### **Domain 2: Health System**

1. General Health Services
  - Is there a functioning public primary care system?
  - Are there secondary and tertiary facilities?
  - Do poor people have access to care, especially maternal and child health services?
2. Mental Health Services
  - What other psychiatric facilities exist in or near the program catchment area? If yes, what are the conditions in those facilities?
  - How many mental health professionals are in the area? How many work in the public sector? In the private sector?
  - Are psychotropic medications readily available and being used in primary care clinics?
3. Alternative medicine
  - Do families frequently bring members who are ill with epilepsy or psychosis to healers before seeking the services of the program?
  - Do families and/or clients discontinue program services in favor of alternative sources of care? If so, what consequences do these actions have for those who are ill?
  - Does the program have a policy about working with alternative healers?

### **Domain 3: Program History**

- When (what year) was the program established?
- What mental health services were available at the time? Biomedical, psychosocial, or both?

- Did the country have national mental health legislation, policy, or plan at the time? When were these established?
- Did people with mental disorders have full rights as citizens? Were people with mental disorders subject to human rights violations?
- Where did the program first operate?
- Why was the program started? What was the key stimulus or defining moment for establishing it?
- Did the program fill a gap in the existing health system?
- Was the program added to or embedded within an existing program or was it established as an independent entity?
- Who founded the program? Has there been a succession of leadership? If so, was it successful?
- What was necessary to get the program up and running? What resources were necessary? From where and how were those resources obtained?
- How long did it take to start up the program?

#### **Domain 4: Program Framework**

- What services does the program offer? Biomedical treatments or psychosocial interventions, or both?
- Does the program follow an explicit model?
- Are services geared toward individuals or families or both?
- Does the program undertake activities to address the need for social inclusion or economic development of its clients?
- Have there been changes over time in the program's orientation to treatment and prevention?
- Do the program administration and staff consider such issues as access, acceptability and equity? If so, how?
- Does the program use evidence-based practice? Does it have a means for keeping up with new evidence?
- Is the program open to having its services evaluated by assessing the clinical, social, and functional outcomes of clients?

#### **Domain 5: Engagement with Broader Systems**

- What relations does the program have with the public mental health system, e.g., local health centres; local schools; local hospitals; other service providers? List any activities and describe them. What brought about these activities?
- Has the program influenced policy or clinical practices at district, national or international levels?
- To what extent has the program been a catalyst for change beyond the program? What brought about this engagement?

#### **Domain 6: Program Resources**

- **HR:** How many staff work in the program and what are their professional and

educational qualifications (include support staff)?

Are there specific challenges to recruiting and retaining staff? For example, is staffing constrained by the program's ability to pay, or by the availability of qualified people? Is employee turn-over high?

- **Volunteers:** Are any unsalaried community supporters or low-pay staff involved in the program? For example, does the program provide lay mental health workers? If so, what sort of supervision is offered? And what are the positive and negative experiences with these workers?
- **Salaries:** How do staff salaries compare to what staff might make if they were working elsewhere? Are staff paid for over-time? Are staff accomplishments recognized? How are staff treated by their superiors and administrators?
- **Training:** Does the program offer on-going training to its staff in clinical and psychosocial interventions?
- **Transportation:** Do staff have access to the means of transportation that are required to deliver services to large catchment areas or remote locations? 1) Must staff share access to the vehicles and, if yes, to what extent does this inhibit their ability to carry out work in the community? 2) When staff do not have access to vehicles, it is possible for them to carry out other essential duties? 3) Are vehicles generally in working order when needed? 4) Are the vehicles safe to drive (functional seat-belts, tires with reasonable amount of treads, spare-tire, unbroken windows, helmets for motorbikes)? Must staff use their own vehicles for work? If yes, does the program reimburse them? How much time do staff spend in transit commuting to the program and delivering services in the community?
- **Funding:** What are the sources of program funding? Does it receive public funds? Or funds from faith-based groups? Is there in-kind support (eg, workers seconded to the program, or government-provided transportation)? How much material support is given by each source? What is the duration of the funding and what are the chances that it will be renewed?
- **Assets:** Does the program own buildings or other property? Does the program have computers, printers, and access to the internet? Does the program give staff mobile phones or must staff use their own? Does the program reimburse staff for phone expenses?

### **Domain 7: Program Management**

- Who manages day-to-day operations? Is there an organigram, or can one be drawn? Include support staff.
- Is there an executive body that has ultimate authority for decision-making processes?
- Have there been any significant changes in the organizational structure of the program since its inception?
- What is the rate of staff turn-over?
- How does the program manage its finances? 1) How does a program budget for its expenses? What are the main budget allocations? 2) What accounting procedures are in place to ensure that the funds are being used as intended? Are staff salaries always paid fully and on time, or are there periods when the program has insufficient funds to meet this obligation? Who is responsible for fundraising and how much of their time is spent raising funds?
- Is staff safety adequately informed about safety policy and practices? Are there rules

about when staff should not travel alone? Does the program employ security guards for its offices?

- Are staff provided with health insurance or other benefits?
- Is there a set of program goals and expected results? Is there a strategy/long-term plan to achieve those goals? Has the project undergone a process of critically reviewing its services and strategically planning for the future? How has that come about? What methods have been/are employed in planning and assessment? Does the program have a Monitoring & Evaluation system in place?

### **Domain 8: Client Populations**

- What are the diagnoses of program participants? How many have psychosis, common mental disorders, epilepsy, substance abuse or intellectual disability? Among clients with psychosis, are there more men than women? Among clients with CMDs, are there more women than men?
- What are the sociodemographic characteristics of the population? What is their age, sex, social class, educational level, ethnicity? Does the program provide services to any specific populations such as homeless people, destitutes, asylum seekers, refugees, orphans?
- Have there been any changes in the diagnoses or sociodemographics of clients since the program began?
- What is the extent of program coverage? What percentage of the total number of potential clients are receiving services from the program?

### **Domain 9: Pathways to Care**

- Where and with whom do clients or families seek care first?
- What is the average duration of illness prior to seeking care?
- What prompts care-seeking?
- What alternative types of care are available to people in the catchment area? Biomedical (specialist and non-specialist; public and private), traditional and spiritual healers, other sources of care (e.g., pharmacists)?
- How do clients come to receive services from the program? Do clients present themselves to services or are they identified elsewhere and referred? Or both? If so, how?
- To what extent do the program's services interact or compete with alternative sources of care? Can individuals and families "shop" for care? Do clients typically see other care providers while enrolled in the program?
- What happens when a client is in need of a service that cannot be provided by the program? Does the program refer clients for other services they might need? Do clients take advantage of the referrals? How quickly are clients seen by those other organizations? Does the program make a point of maintaining its referral network or is contact only in the event of a referral?
- Do other organizations, such as hospitals or healers, refer people to the program?



### **Domain 10: Clinical Interventions**

- Who determines diagnosis? How is diagnosis made? According to ICD or DSM criteria? Or, broader categories?
- What is the range of available treatments?
- Who provides the treatments?
- Where are treatments given?
- Does the program have the capacity to provide emergency treatments, e.g., to those in the midst of an acute episode? Is ECT offered? And if so, is a muscle relaxant used?
- What is the intake process, ie how new clients are enrolled once they have been identified as in need of an intervention?
- How are clients are followed over time? For example, do field workers keep track of clients in the community? Are clients only seen during routine clinics?
- Is there attention to the side-effects of interventions?
- Does the program attempt to find and re-engage clients who have not returned for services? If yes, how?
- Does the program have criteria for discharging or discontinuing services to a client? If yes, what? Does the program have a policy about following-up clients who have been discharged or who are no longer receiving services?
- Does the program have protocols and guidelines for its clinical interventions? If yes, have these been borrowed or have they been developed specifically for the program?
- What is the ratio of clinical staff to patients?

### **Domain 11: Medications**

- Is there a list of the medications used?
- What criteria are used to determine which medications will be purchased?
- Are other medications available locally that are not used by program? Why?
- What are the costs of each medication?
- What is the adequacy, consistency, and quality of the supply? Have there been any recent shortfalls in supplies?
- Does the program provide the medications it prescribes?
- If the program does not provide medications, where do clients go to fill their medications?
- If the program provides medications, how does it plan its purchases? Are purchases based on anticipated needs for the next month, three months, six months?
- From what sources are the medications purchased? Local manufacturers? Foreign manufacturers? Local pharmacies? What, if any, criteria are used to choose a source? Cost?
- Does the program has implemented methods of inventory control?
- How are medications stored? Are they in a cool dry place? Are they locked?
- Is there a dedicated budget line for the purchase of medications? Are funds for purchasing medications consistently available when needed? How are these funds managed?

## **Domain 12: Psychosocial Interventions**

- What types of psychosocial intervention are provided by the program? For example, are any of the following offered, and if so, describe in detail:
  - Individual support
  - Family/carer support
  - Self-help groups
  - Livelihood programs
- Who provides each of these interventions?
- Do any of the interventions target a specific group of clients?
- What sort of support, if any, is provided to caregivers?
- Does the program support and/or operate prevention and promotion activities?
- Does the program have protocols and guidelines for its psychosocial interventions?
- If yes, were these borrowed or were they developed specifically for the program?
- Is the program regularly assessing and documenting the clinical, functional, and social statuses of clients?
- Has the program established a process for evaluating the effectiveness of psychosocial interventions?

### **Self-help**

How many members do the groups have?

What are the criteria for membership?

Does the SHG collect dues? How are the SHG finances managed? How are the funds used?

What are the benefits of membership?

How often do groups meet? What is done at meetings?

Do the groups undertake collective activities? Describe

Having established SHGs, does the program provide them with support? If yes, document the following: What does the CMHP do to remain engaged with the SHGs? Does the CMHP initiate activities in which the SHGs participate? Does the CMHP help the SHGs manage their funds?

### **Livelihoods**

- Does the program operate a livelihood program?
- Does the program provide loans? How much are the loans? What is the interest rate? What are the criteria for applying for loans? What is the procedure for approving loans? How are the loans used? Are the loans being repaid? What are rates of loan repayment? Does the program keep careful records of loans, repayments, and subsequent loans?
- Does the program provide tools to clients so that they can begin a small business, e.g., dress-making, wood-working? How does the program decide who will be given tools?
- Does the program provide opportunities for apprenticeships or occupational training? What are the nature of occupational training and apprenticeships? Does the program have oversight of the apprenticeships? Does the program make regular visits to the work sites to assess clients' progress?

### **Domain 13: Accessibility**

- Where is the clinic located?
- How far away to clients live on average?
- At what times and on what days are services offered?
- Is transportation paid for by the program?
- How much are the program fees?
- Are in-home services available to clients who cannot travel?
- What is the rate of follow-up of clients?

### **Domain 14: Information Systems**

- What information is being collected? Record all fields that are gathered. For example, age, sex, marital status, occupation, diagnoses, date enrolled, functional status, treatment prescribed, other physical problems, referral.
- Who is collecting the data?
- In what format is it being recorded? Is it paper, electronic, both?
- How is it being stored, e.g., paper files, on computers, in databases?
- Are there procedures for generating reports from the data?
- To whom is the information sent, e.g., funding agency, board? Do they have specific reporting requirements?
- Can the program easily generate descriptive statistics about clients and their use of services?
- Is a unique client ID assigned to individuals?
- Is there a record of clients who dropped out of treatment, or left before being discharged?

## **10.10 Agenda for Site-Visit to Meru and Nyeri**

**19-20 July 2011**

### **Goals**

- Understand the MHD model as it was delivered in Meru and Nyeri
- Understand the challenges that have arisen in implementing the MHD model and in conducting the research
- Meet those who collected the data to enable future communication Understand the other work done by the partners and who funds them
- Understand the economic circumstances in the community

### **July 19, 2011 (Meru)**

Meetings with:

1. Milka Waruguru, Research Officer BasicNeeds
2. Visit of Kajuli Dispensary, Chuka
  - a. Rosemary Kabete, Community Health Worker
  - b. John Mueti, Psychiatric Nurse
3. Harriet Kamundi, MHD Coordinator, *Maendeleo ya Wanawake*

Focus Group Discussion with 7 adults with mental disorders (5 men, 2 women) – translated from Kitharaka by Rosemary Kabete

Focus Group Questions:

- What has changed in your life since you started the programme – for better or for worse?
- Are you members of a self-help group, and if so, what is your group doing?
- What are your goals in life? What do you want for yourself?

### **July 20, 2011 (Nyeri)**

Meetings with:

1. Dishon Mutiso, Clinical Officer for Health, Nyeri
2. Father Boniface, Director, Caritas Nyeri
3. Helen Wangui, MHD Coordinator, Caritas Nyeri

Self-Help Group Meeting: Mugunda Group (22 participants: 14 women, 8 men) – translated from Kikuyu by the group Treasurer

**10.11 General Health Questionnaire (GHQ-12)**

	<b>much less than usual</b>	<b>same as usual</b>	<b>more than usual</b>	<b>much more than usual</b>
1. Been able to concentrate on whatever you are doing?				
2. Lost much sleep over worry?				
3. Felt that you were playing a useful part in things?				
4. Felt capable of making decisions about things?				
5. Felt constantly under strain?				
6. Felt that you couldn't overcome your difficulties?				
7. Been able to enjoy your normal day-to-day activities?				
8. Been able to face up to your problems?				
9. Been feeling unhappy and depressed?				
10. Been losing self-confidence in yourself?				
11. Been thinking of yourself as a worthless person?				
12. Been feeling reasonably happy, all things considered?				
<b>Total</b>				

## 10.12 WHOQOL Bref

*Questions are set out here by domain.*

*Each question is scored on a Likert scale of 1-5*

### General

Qx 1. How would you rate your quality of life?

Qx 2. How satisfied are you with your health?

### Health

Qx 3. To what extent do you feel that physical **pain** prevents you from doing what you need to do?

Qx 4. How much do you need any **medical treatment** to function in your daily life?

Qx 10. Do you have enough **energy** for everyday life?

Qx 15 (**mobility**) How well are you able to get around?

Qx 16. How satisfied are you with your **sleep**?

Qx 17. How satisfied are you with your ability to perform your **daily living activities**?

Qx 18. How satisfied are you with your **capacity for work**?

### Psychology

Qx 5. How much do you **enjoy life**?

Qx 6. To what extent do you feel your life to be **meaningful**?

Qx 7. How well are you able to **concentrate**?

Qx 11. Are you able to accept your **bodily appearance**?

Qx 19. How satisfied are you with yourself?

### Social

Qx 20 How satisfied are you with your personal **relationships**?

Qx21 How satisfied are you with your **sex** life?

Qx 22 How satisfied are you with the support you get from your **friends**?

### Environmental

Qx 9. How healthy is your **physical environment**?

Qx 12. Have you enough **money** to meet your needs?

Qx 13. How available to you is the **information that you need** in your day-to-day life?

Qx 14. To what extent do you have the **opportunity for leisure** activities?

Qx 23. How satisfied are you with the **conditions of your living** place?

Qx 24. How satisfied are you with your **access to health services**?

Qx 25. How satisfied are you with your **transport**?

### 10.13 Economic Status Tool

Subject ID:

Place (Village, Sub-location, Location).....

#### 1. Family Statistics

1. Number of members in the family (homestead)? .....
2. Main source of income of family?  
**1 Casual Labour      2 Family farming      3 Salaried Job      4 Business (non-farming)      5 Other**
3. Average monthly income of family in the last 6 months (Kenyan Shillings).....

#### 2. Demographics regarding the person with mental illness:

1. Date of Birth ..... b.  
Age.....
- c. Sex **1. Female      2. Male**

#### 3. Educational Qualification

- 1 Never been to school      2 Some primary school      3 Completed primary school**
- 4 Completed secondary school      5 College and Above**

#### 4. Marital Status

- 1 Unmarried      2 Married      3 Divorced      4 Widow / Widower**

#### 5. With whom do you stay?

- 1 Alone      2 With Husband / Wife      3 With Husband / Wife and children**
- 4 With father / mother / relatives      5 Other.....**

#### 6. Have you ever worked?      **0 No      1 Yes**

#### 7. What is your current occupation? (State the option on which you spend most time).

- Occupation: .....
- 1 Unemployed (Don't have capacity / ability to work)      2 Unemployed (Have capacity / ability to work)**
  - 3 Household work (Part time)      4 Household work (Full time)**
  - 5 Working but without monetary benefit      6 Service / Job / Business (Full time)**
  - 7 Service / Job / Business (Part time)      8 Studying**

8. If you are involved in any income generation activity (If not then go straight to Question no. 9):
- What is the work you are involved in?  
.....
  - How much do you earn from that? .....
  - Earn the above amount in                    **1 Daily**                    **2 Weekly**                    **3 Monthly**                    **4 In one season**
  - Did you have to stop your work due to illness?                    **0 No**                    **1 Yes**
  - if yes, then for how many days in last one month?.....

9. a) In the **last 9 months**, have you been admitted to a hospital / institution?  
**0 No**                    **1 Yes**

If yes, then:

- Name of the Hospital / Institution / Organization.....
- Place.....
- How many times did you go there? .....
- What was the distance of that place from your house (Km) .....
- How much money did you spend in traveling (on each occasion)?  
.....
- How much did you pay in hospital fees for each admission?  
.....
- For how many days were you admitted (on each occasion)?  
.....
- How much did you spend on medicines each month? .....
- How much did you pay the doctor as consultation fee?  
.....

10. a) In the **last 9 months** have you had contact with services such as traditional healing, faith based healing, etc?                    **0 No**                    **1 Yes**

If yes:

- What was the type of treatment? .....
- Where did you receive it? .....
- How many times did you meet? .....
- If you paid in kind, what did you pay? .....
- If you paid in cash, how much money did you spend each time on the treatment?  
.....
- How much money did you spend to travel to that place?  
.....
- How do you normally get there? .....
- How much time (hours) does it take you to reach that place?  
.....

11. a) In the **last 9 months** did your family have to sell any item / property or took loan to meet your treatment costs?

**0 No**                    **1 Yes**

- b) If yes, then what was the cost of sold item / property or loan amount (Kenyan shillings)

.....



12. a) In **last 9 months**, did you receive help from any carers in performing any activity

b) What type of activity did you receive help with?	Which carer (or carers) helped you?		How many hours in a week (approx) did they help?	
	c) Carer 1	d) Carer 2	e) Carer 1	f) Carer 2

13. a) In **last 9 months**, did any of the above carers have to leave their job / work and stay at home to take care of you?

**0 No                      1 Yes**

If yes, then...

b) Carer1            No of days.....            c) Type of Work / job he / she had to stop  
 ..... (Fill in code from below. Note: enter the work/job which he/she had to stop most).

d) Carer2            No of days.....            e) Type of Work / job he / she had to stop .....  
 (Fill in code from below. Note: enter the work/job which he/she had to stop most).

**[CODE:      1 Casual Labour                      2 Family Farming  
 3 Salaried job            4 Business (non-farming)    5 Household work    6 Other]**

**FOR TIME 2 AND TIME 3 ONLY:**

14. If your job status has changed since you began the programme, how much do you attribute this change to your involvement in the programme?

**1 No change/ not at all      2 A little                      3 Some                      4 Most                      5 All**

**FOR TIME 2 AND TIME 3 ONLY:**

15. If your income has changed since you began the programme, how much do you attribute this change to your involvement in the programme?

**1 No change/ not at all      2 A little                      3 Some                      4 Most                      5 All**

**FOR TIME 2 AND TIME 3 ONLY:**

16. Since entering the programme, how much do you/your family spend on travel to the clinic in the last month (in Ks.)?.....

**FOR TIME 2 AND TIME 3 ONLY:**

17. a) How do you get to the clinic? .....  
 b) How long does it take you to get to there (in minutes)? .....

**TO BE COMPLETED FROM CLINICAL FILE:**

18. Details of medicines taken in **last two months**

a) Have you taken any medicine in the last two months? **0 No**      **1 Yes**

b) Name of medicine	c) Dosage (mg)	d) How many tablets a day?	e) How many days in last 2 months?	f) Where did you get the medication?	g) How much did it cost?
<i>Example:</i> <i>Valox</i>	<i>200 mg</i>	<i>3 times</i>	<i>60 days</i>	<i>Clinic</i>	<i>Ks30</i>
1.					
2.					
3.					
4.					
5.					

19. Diagnosis (from file) (tick one):

- Epilepsy
- Schizophrenia
- Bipolar Disorder (Manic Depression)
- Depression
- Anxiety

### 10.14 Projected deaths at 12 and 24 months by diagnosis in MHD sample

Month	CMD			SMD			Epilepsy		
	N start	Deaths	N end	N start	Deaths	N end	N start	Deaths	N end
1	24	0.1	23.9	117	0.1	116.9	56	-	56
2	23.9	0.1	23.8	116.9	0.1	116.8	56	-	56
3	23.8	0.1	23.7	116.8	0.1	116.7	56	-	56
4	23.7	0.1	23.6	116.7	0.1	116.6	56	-	56
5	23.6	0.1	23.5	116.6	0.1	116.5	56	-	56
6	23.5	0.1	23.4	116.5	0.1	116.4	56	-	56
7	23.4	0.1	23.3	116.4	0.1	116.3	56	-	56
8	23.3	0.1	23.2	116.3	0.1	116.2	56	-	56
9	23.2	0.1	23.1	116.2	0.1	116.1	56	-	56
10	23.1	0.1	23	116.1	0.1	116	56	-	56
11	23	-	23	116	0.5	115.5	56	0.1	55.9
<b>12</b>	<b>23</b>	<b>-</b>	<b>23</b>	<b>115.5</b>	<b>0.5</b>	<b>115</b>	<b>55.9</b>	<b>0.1</b>	<b>55.8</b>
13	23	-	23	115	0.5	114.5	55.8	0.1	55.7
14	23	-	23	114.5	0.5	114	55.7	0.1	55.6
15	23	-	23	114	0.5	113.5	55.6	0.1	55.5
16	23	-	23	113.5	0.5	113	55.5	0.1	55.4
17	23	-	23	113	0.5	112.5	55.4	0.1	55.3
18	23	-	23	112.5	0.5	112	55.3	0.1	55.2
19	23	-	23	112	0.5	111.5	55.2	0.1	55.1
20	23	-	23	111.5	0.5	111	55.1	0.1	55
21	23	-	23	111	0.5	110.5	55	0.1	54.9
22	23	-	23	110.5	0.5	110	54.9	0.1	54.8
23	23	-	23	110	0.5	109.5	54.8	0.1	54.7
<b>24</b>	<b>23</b>	<b>-</b>	<b>23</b>	<b>109.5</b>	<b>0.5</b>	<b>109</b>	<b>54.7</b>	<b>0.1</b>	<b>54.6</b>
<b>deaths</b>	<b>1</b>			<b>8</b>			<b>1.4</b>		

	CMD	SMD	Epilepsy
Death rate 0-12m	0.04	0.02	0.00
Death rate 12-24m	-	0.05	0.20

### 10.15 Costs before and after the MHD Model by diagnosis

a) Severe mental disorders

	Before						After 1 Year						After 2 Years					
	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)
<b>Government</b>	117	0	45000	712	4515	<b>20</b>	113	1010	3635	1034	247	<b>24</b>	104	2021	58271	2839	6176	<b>67</b>
<b>NGO</b>	117	0	0	0	0	<b>0</b>	117	22941	22941	22941	0	<b>540</b>	117	46649	46649	46649	0	<b>1098</b>
<b>Direct user:</b>	117	0	95382	2700	12735	<b>64</b>	113	549	52593	1569	4879	<b>37</b>	104	924	105417	2972	11572	<b>70</b>
medicines	117	0	42815	1295	6665	30	117	0	3211	579	620	14	117	0	6300	1136	1216	27
traditional healing	117	0	10466	192	1111	5	113	0	0	0	0	0	113	0	0	0	0	0
outpatient clinic	117	0	0	0	0	0	113	549	549	549	0	13	113	1078	1078	1078	0	25
hospital	117	0	52567	1213	6801	29	113	0	49475	438	4654	10	104	0	118966	1741	13106	41
<b>Indirect user:</b>	117	0	77112	5948	11430	<b>140</b>	112	-58271	52021	-337	23731	<b>-8</b>	103	-64924	62229	-15268	35130	<b>-359</b>
change in productivity	117	0	0	0	0	0	112	-58271	52021	-1135	23327	<b>-27</b>	104	-69581	62229	-16917	33605	<b>-398</b>
time sick	117	0	43416	1670	6274	39	113	0	50544	678	5297	16	104	0	50544	1607	8004	38
informal care	117	0	51840	4278	8184	101	113	0	8424	114	842	3	104	0	676	6	66	0
<b>Total user</b>	117	0	119341	8648	19736	<b>0</b>	113	-57008	53855	1242	23605	<b>29</b>	104	-62458	96017	-12276	36517	<b>-289</b>
<b>Total cost</b>	<b>193</b>	<b>0</b>	<b>77806</b>	<b>25676</b>	<b>22021</b>	<b>220</b>	<b>113</b>	<b>-33057</b>	<b>77806</b>	<b>25217</b>	<b>23622</b>	<b>594</b>	<b>104</b>	<b>-13788</b>	<b>200937</b>	<b>37220</b>	<b>39039</b>	<b>876</b>

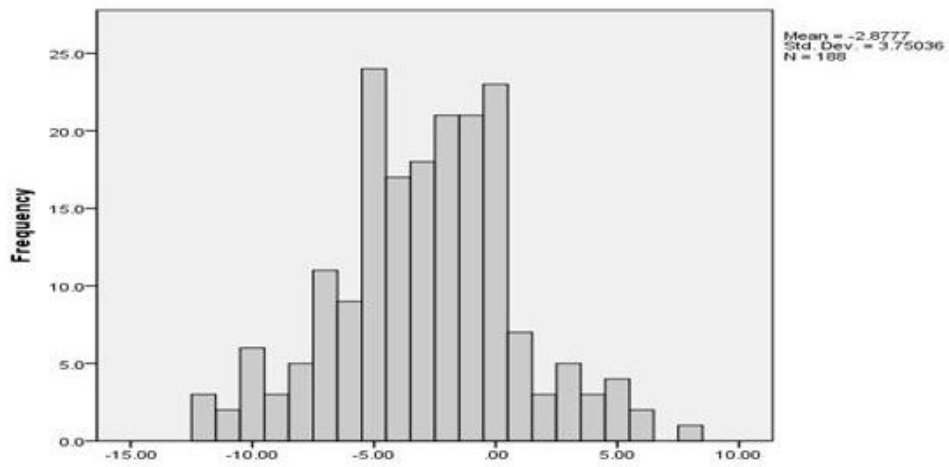
b) Common mental disorders

	Before						After 1 Year						After 2 Years					
	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)
<b>Government</b>	0	0	15750	656	3215	15	22	1010	1010	1010	0	24	19	2021	2021	2021	0	48
<b>NGO</b>	24	0	0	0	0	0	24	22941	22941	22941	0	540	24	46649	46649	46649	0	1098
<b>Direct user:</b>	24	0	54311	2607	11078	61	22	549	2440	989	512	23	19	924	2514	1289	403	30
medicines	24	0	42815	1784	8740	42	24	0	1891	456	528	11	24	0	3710	895	1035	21
traditional healing	24	0	5074	344	1197	8	22	0	0	0	0	0	22	0	0	0	0	0
outpatient clinic	24	0	0	0	0	0	22	549	549	549	0	13	22	1078	1078	1078	0	25
hospital	24	0	11497	479	2347	11	22	0	0	0	0	0	19	0	0	0	0	0
<b>Indirect user:</b>	24	0	56194	11022	15067	259	22	-27402	27625	3247	15019	76	19	-56572	52940	-9902	31177	-233
change in productivity	24	0	0	0	0	0	22	-27402	27625	2938	15062	69	19	-56572	52940	-10260	31331	-242
time sick	24	0	9072	378	1852	9	22	0	6804	309	1451	7	19	0	6804	358	1561	8
informal care	24	0	47122	10644	13957	251	22	0	0	0	0	0	19	0	0	0	0	0
<b>Total user</b>	24	0	0	0	0	0	22	-26723	28353	4236	15007	100	19	-55648	54014	-8613	31091	-203
<b>Total cost</b>	24	0	139874	16495	29655	388	22	-2771	52304	28188	15007	664	19	-6978	102683	40057	31091	943

c) Epilepsy

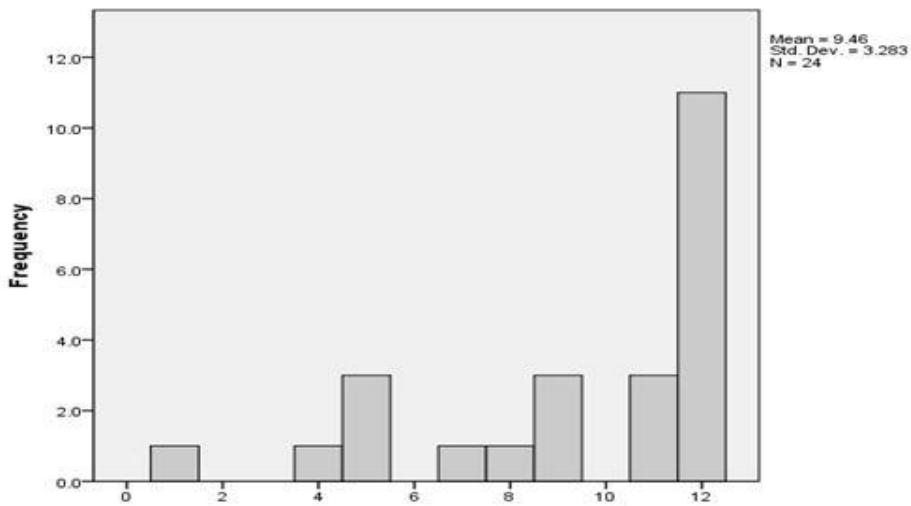
	Before						After 1 Year						After 2 Years					
	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)	N	min	max	mean (Ksh)	sd	mean (Int\$)
<b>Government</b>	56	0	11250	228	1513	5	53	1010	10010	1180	1236	28	46	2021	11021	2216	1327	52
<b>NGO</b>	56	0	0	0	0	0	56	22941	22941	22941	0	540	56	46649	46649	46649	0	1098
<b>Direct user:</b>	56	0	22517	562	3153	13	53	549	11348	1433	1562	34	46	924	10004	1719	1400	40
medicines	56	0	11417	280	1620	7	56	0	8135	836	1223	20	56	0	15961	1640	2400	39
traditional healing	56	0	2537	72	381	2	53	0	0	0	0	0	53	0	0	0	0	0
outpatient clinic	56	0	0	0	0	0	53	549	549	549	0	13	53	1078	1078	1078	0	25
hospital	56	0	8563	210	1213	5	53	0	2664	50	366	1	46	0	2664	58	393	1
<b>Indirect user:</b>	56	0	59583	9523	14159	224	53	-35660	45180	-402	21409	-9	46	-60405	62229	-8313	38353	-196
change in productivity	56	0	0	0	0	0	53	-35660	45180	-850	21319	-20	46	-60405	62229	-8830	38201	-208
time sick	56	0	27216	1261	4926	30	53	0	0	0	0	0	46	0	0	0	0	0
informal care	56	0	52650	8261	12214	194	53	0	8424	448	1816	11	46	0	599	13	88	0
<b>Total user</b>	56	0	0	0	0	0	53	-34397	47870	1031	21636	24	46	-59421	63333	-6594	38234	-155
<b>Total cost</b>	<b>56</b>	<b>0</b>	<b>106759</b>	<b>12158</b>	<b>19804</b>	<b>286</b>	<b>53</b>	<b>-10446</b>	<b>71822</b>	<b>25152</b>	<b>21685</b>	<b>592</b>	<b>46</b>	<b>-10752</b>	<b>112003</b>	<b>42271</b>	<b>38053</b>	<b>995</b>

**10.16 Mean change in GHQ score, whole sample, from baseline to 10 months**

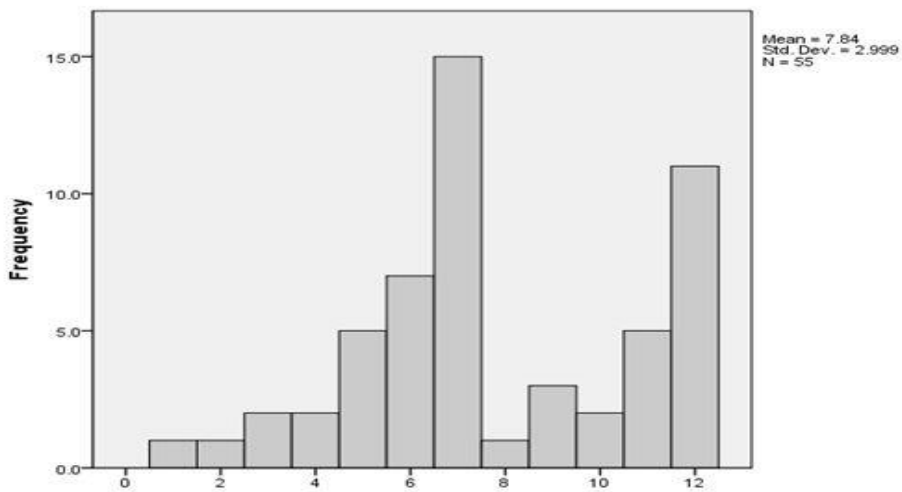


**10.17 Distribution of baseline GHQ-12 for common mental disorders and epilepsy**

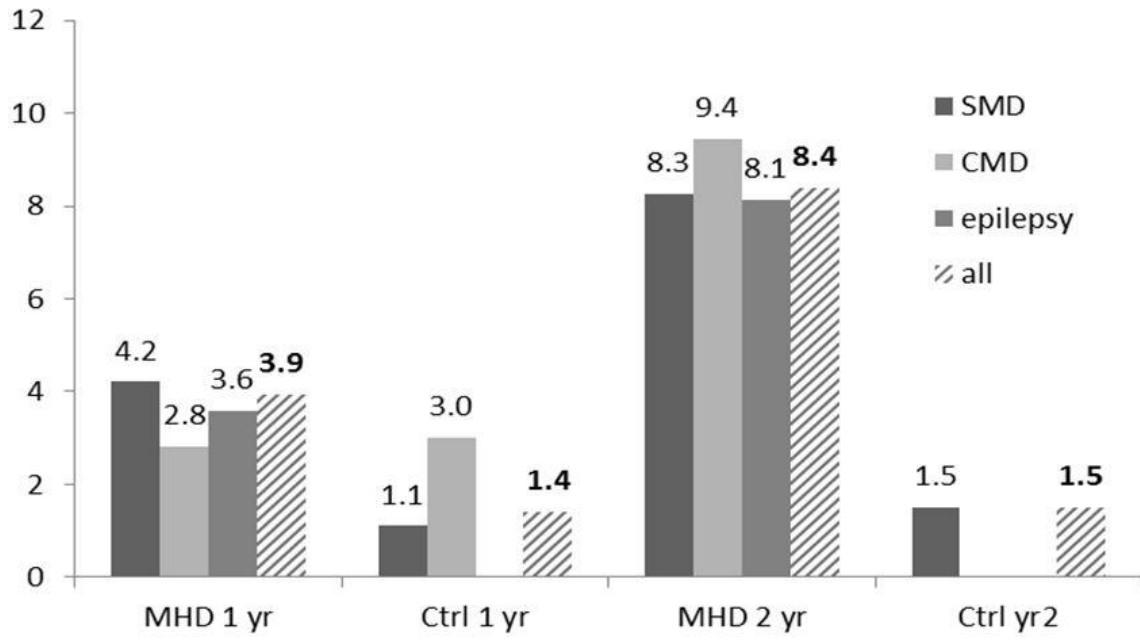
a) Common mental disorders



b) Epilepsy

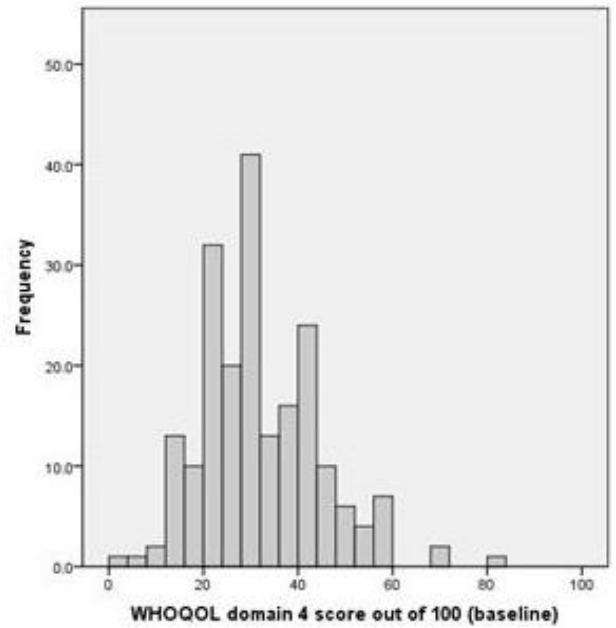
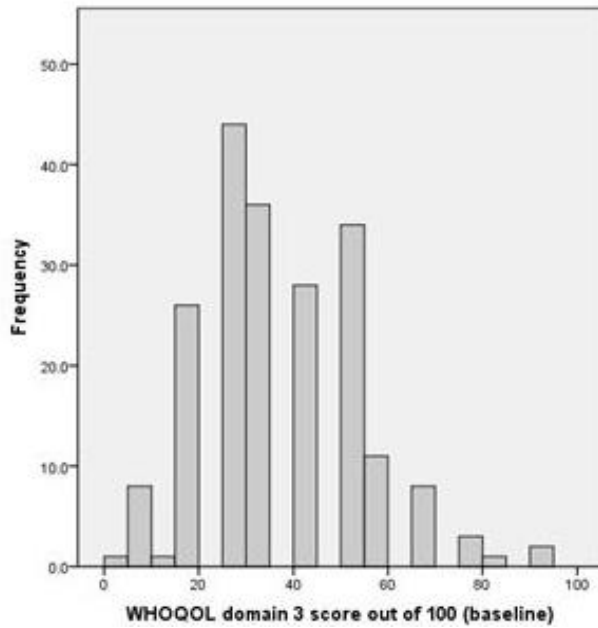
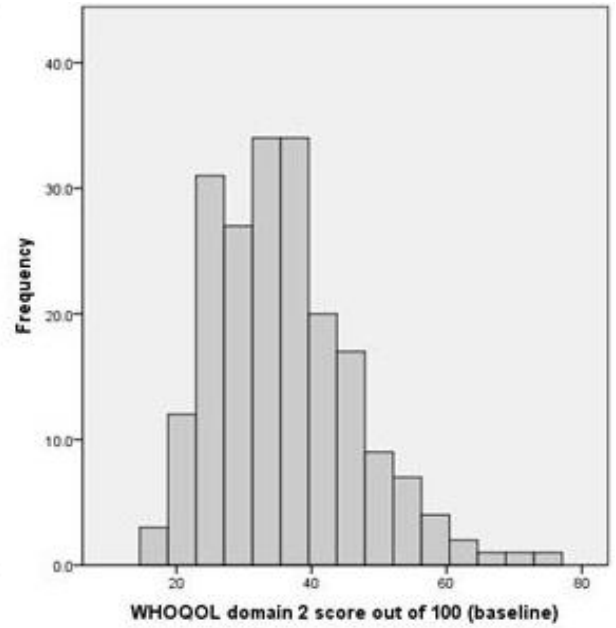
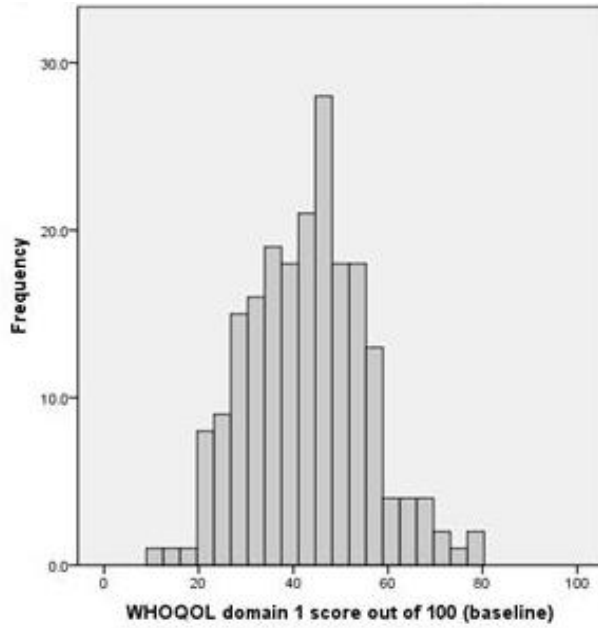


**10.18 Mean annualized change in GHQ score, by diagnosis**



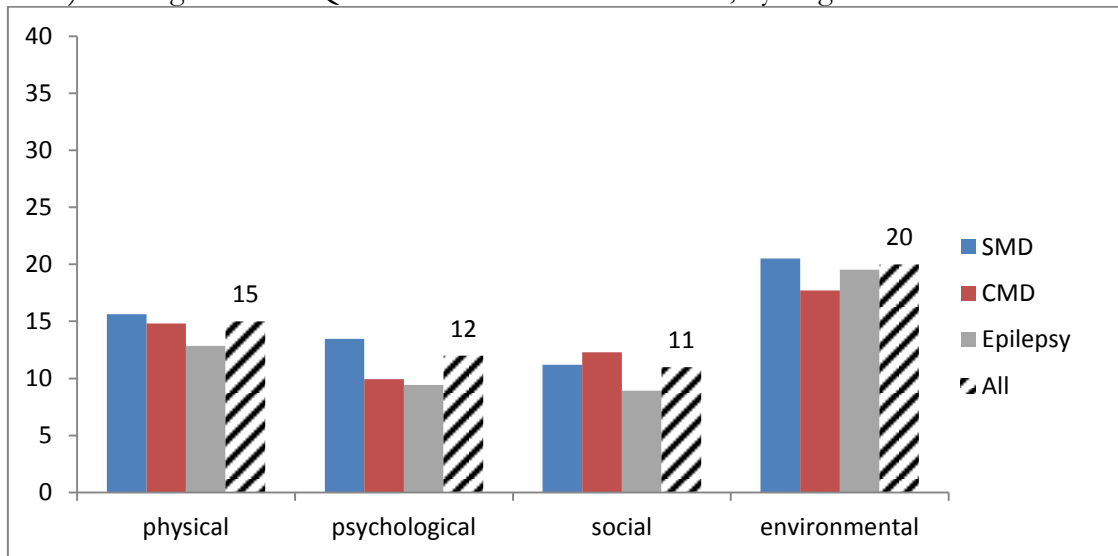


### 10.19 Distribution of WHOQOL domain scores at baseline

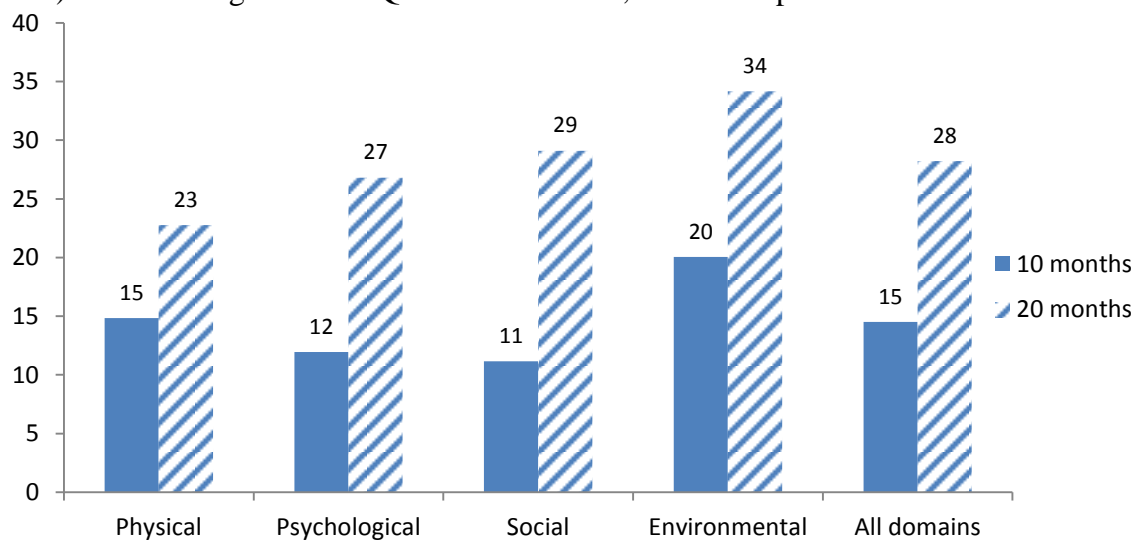


## 10.20 Mean change in WHOQOL scores

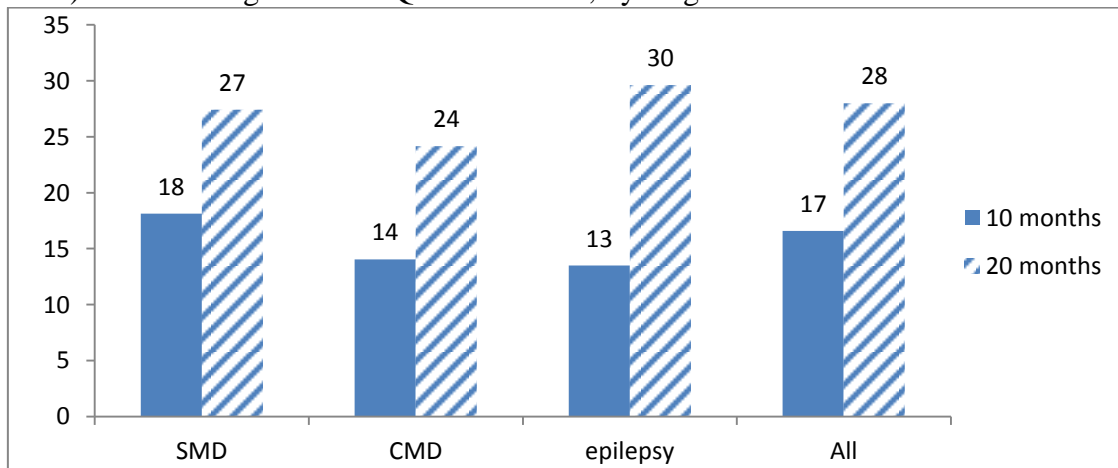
a) Change in WHOQOL domain score at 10 months, by diagnosis



b) Mean change in WHOQOL domain score, whole sample



c) Mean change in WHOQOL raw score, by diagnosis



### **10.21 Cleaning Procedures for Impact Study Data**

Data collection was overseen by Milka Waruguru, a master's level research officer at BasicNeeds Kenya and entered into Excel by Kenyan research assistants. The datasets were sent to India and initial data cleaning was overseen Saju Mannarath, a BasicNeeds Research Officer. The Excel data were sent in string format to South Africa, for preliminary analysis by Crick Lund and his research team. Eric Breuer, a member of the UCT team, relabelled the subject IDs to become unique identifiers and recoded most of the string data into numerical form. Together, we transferred the data into long-format in SPSS 19. I renamed and labelled the 595 variables in the original dataset and undertook the rest of the editing, coding and management of missing variables under the supervision of Crick Lund.

#### **1.2.b.i Editing**

Data on age varied by more than a year from one time to the next with age sometimes dropping over time. The most accurate measure of age was thought to be the year of birth, so I calculated the difference between the current year of study and the year of birth to determine a consistent measurement of age. The same inconsistency was found over time with sex in five cases, so I reconciled the subject's name with their sex.

Interview dates were used to estimate the number of days spent in good health, so the accuracy of this information was paramount. Dates were entered in three different forms in the raw data: day/month/year; month/day/year; and year/month/day. Since ID numbers were allocated sequentially by interview date at baseline, it was possible to correct all the baseline dates by sorting the data by ID. Corrections were made to 74 cases (35% of the sample) in this way. At time 2, interviews were delivered between the months of May and August of 2010, so corrections were made to all dates with months other than 5-8: 45 cases (23% of the sample) were corrected. At time 3, interviews were delivered between March and May 2011, and using the same logic as for time 2, 44 cases (24%) were corrected.

#### **1.2.b.ii Coding**

The study recorded primary diagnosis, rather than comorbidities, and in 18 cases (9%), the participant's diagnosis shifted at least once between baseline, time 2 and time 3. I contacted the lead research assistant in Kenya, who communicated with two of the psychiatric nurses making those diagnoses to ask which diagnosis they deemed most accurate. After their amendments, there remained five cases with dual diagnosis of epilepsy and a mental disorder.

The following options were considered jointly with Crick Lund: 1) exclude the five dual diagnosis cases from analysis; 2) only include them in the epilepsy cohort; 3) include them in both diagnostic cohorts; 4) only include them in the other diagnostic group. The PI chose to code the five cases as epilepsy (option 2). He ruled out coding them in both diagnostic groups, because he argued that would be inconsistent with the other cases, for whom comorbidities had not been recorded. Furthermore, from a clinical perspective, he argued that the organic components of epilepsy could drive other symptoms of mental illness.

An additional challenge emerged with ten cases (5%) receiving a diagnosis of acute organic brain syndrome (AOBS), which does not figure in the current International Classification of Diseases (World Health Organization 1994). This diagnosis was made exclusively by one psychiatric nurse. Kaplan and Sadock's psychiatric textbook notes that with the advent of the DSM IV in 1994, the term "organic" was dropped in favour of "due to a general medical condition" (Benjamin James Sadock and Sadock 2008). AOBS is any disorder with a physiological rather than a functional etiology, for example caused by injury or infection. Thus AOBS could become anxiety due to a general medical condition, psychosis due to a general medical condition and so forth. As a result, whenever AOBS presented as a diagnosis, we used an alternate diagnosis recorded at a different time.

Finally, I collapsed diagnoses into three main categories: 1) severe mental disorders (including schizophrenia, bipolar, schizo-affective and psychotic disorders); 2) common mental disorders (primarily anxiety & depression); and 3) epilepsy. This grouping aligns with three priority conditions in the WHO's flagship mental health programme, mhGAP (World Health Organization 2008) and provided larger samples than the full range of recorded diagnoses. Six cases with other diagnoses, such as dementia or sleep disorder, were excluded from analysis of outcomes.

#### 1.2.b.iii Missing and excluded data

A few subjects failed to complete all of the research tools at follow-up. The number of completed GHQ forms at baseline, year 1 and year 2 were 203, 189 and 173 respectively. In one instance, only 11 of 12 questions on the GHQ had been completed, but, in keeping with scoring guidelines I took the sum of the questions. If more than one item was missing, the case was dropped.

## 10.22 Raw and Computed Variables from Chiromo Lane Medical Center

Raw variable	Type
1. ID	Nominal
2. Patient name	String
3. Age	Nominal
4. Sex	Nominal
5. City address	String
6. Religion	String
7. Marital status	String
8. Diagnosis	String
9. Occupation	String
10. Date of admission	Date
11. Date of discharge	Date
12. Attending doctor	Nominal
13. Payer	Nominal
14. Notes on invoice	String
15. Number of detailed invoices	Nominal
16. Invoice for individual counseling (Ksh)	Nominal
17. Number of counselling sessions	Nominal
18. Invoice for group therapy (Ksh)	Nominal
19. Number of sessions of group therapy	Nominal
20. Invoice for medication (Ksh)	Scale
21. Syringe used for medicines (yes/no)	Nominal
22. Invoice for bed charges (Ksh)	Scale
23. Unit cost for bed night	Scale
24. Cost of bed per night (Ksh)	Scale
25. Invoice for labs (Ksh)	Scale
26. Invoice for scans (x-ray, CT, ultrasound) (Ksh)	Scale
27. Invoice for ECT (Ksh)	Scale
28. Number of ECT sessions	Nominal
29. National Health Insurance Fund (NHIF) claim amount	Scale
30. Invoice for prescription (take-home meds)	Scale
31. Invoice for doctor's fees (Ksh)	Scale
32. Invoice for other service or product (Ksh)	Nominal
33. Specify other service or product	String

<b>Computed variable</b>	<b>Type</b>
Length of stay (per discharge)	Scale
Total length of stay (in 12 months)	Scale
Readmission (yes/no)	Nominal
Readmission (number)	Scale
Total charge (in 12 months)	Scale
Mean charge per day	Scale
Received counselling (yes/no)	Nominal
Received group therapy (yes/no)	Nominal
Received lab tests (yes/no)	Nominal
Received a scan (yes/no)	Nominal
Received ECT (yes/no)	Nominal
Reimbursed by NHIF (yes/no)	Nominal

## 10.23 Mental Health Nursing Questionnaire

The following questionnaire is for nurses who treat psychiatric patients. All information provided will remain confidential and not associated with you personally. If you do not treat psychiatric patients or are not a nurse, please do not fill in this questionnaire.

### PART 1

Please provide a little information about yourself

1. Age: \_\_\_\_\_ 2. Sex (*circle*): Male Female
  
3. Which province do you work in?
  - Central
  - Coast
  - Eastern
  - Nairobi
  - North Eastern
  - Nyanza
  - Rift Valley
  - Western
  
4. What nursing degree(s) do you have? (*circle all that apply*)
  1. General nursing
  2. Psychiatric nursing, diploma
  3. Psychiatric nursing, certificate
  4. Other: (*describe*) \_\_\_\_\_
  
5. Have you treated patients in the last month? (*circle*) Yes No
  
6. *If you are not treating patients:* What sort of work do you do? (*circle*)
  1. Teaching
  2. Administration
  3. Studying
  4. Other: (*describe*) \_\_\_\_\_
  
7. Have you ever run your own outpatient health clinic? (*circle*) Yes No  
*If yes, continue, otherwise skip to Part 2.*
8. How many patients would you see in a typical week in your private practice?
  - a. Mental health patients \_\_\_\_\_
  - b. Other patients \_\_\_\_\_
  
9. How many hours did you run your own clinic in a typical week? \_\_\_\_\_
  
10. Did you run this clinic last month? (*circle*) YesNo





## 10.24 Private Psychiatric Practice Questionnaire

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THE LONDON SCHOOL  
OF ECONOMICS AND  
POLITICAL SCIENCE ■

Interview ID: \_\_\_\_\_ Date: \_\_\_\_\_ Location (county): \_\_\_\_\_

Profession (*circle*): Psychiatrist    Psychiatric Nurse    Age: \_\_\_\_\_ Sex (*circle*): M    F

### **INPATIENT CARE**

I will start by asking some questions about inpatient care for mental disorders, and then I will ask you about your outpatient practice. (*Mark in the list on the final page*)

#### **Facilities**

1. What are the names of the private or faith-based hospitals where you have admitting rights or have admitted a psychiatric patient in the past?
2. Do any of these facilities have a specialized psychiatric ward, or are psychiatric patients integrated in general wards?
3. Do any of these facilities offer ECT?
4. Do you know of any other private hospitals or nursing homes that offer specialized mental health services in Nairobi? (*substitute with Meru and Nyeri counties, when interviewing from there*)
5. Do you know of any privately-run places that offer long-term (ie longer than a year) residential care for people with mental disorders? This could be nursing homes, rehabilitation centres, old people's homes, where people can live with support other than their family, but outside of a hospital. If so, please name them.

#### **Patients**

Do you often refer people to go inpatient? (*Don't code*)

6. In the last month, how many people have you referred to inpatient services?
7. What diagnoses did they have? By diagnosis, I mean their *primary* diagnosis in the case of patients with comorbidities.
8. How many days on average were the patients hospitalized? (*If the respondent gives precise numbers of days, code all the numbers given and write in the margins*)
  - a. Serious mental disorder                      No of inpatients: \_\_\_\_\_ Days: \_\_\_\_\_
  - b. Common mental disorder                      No of inpatients: \_\_\_\_\_ Days: \_\_\_\_\_
  - c. Substance abuse                                      No of inpatients: \_\_\_\_\_ Days: \_\_\_\_\_



### Costs

18. What is the average length of time you spend with a patient (*code in minutes*) on a first consultation? \_\_\_\_\_ on a follow-up consultation? \_\_\_\_\_
19. What is the average waiting time for a patient to see you? (*code in minutes*) \_\_\_\_\_
20. What is the range of costs of a consultation to patients? If this varies, please explain the criteria. Do you vary your costs at all based on a person's ability to pay? (*Examples of criteria include diagnosis, illness severity, ability to pay*)
- a. First consultation: \_\_\_\_\_
- b. Follow-up visit: \_\_\_\_\_
- c. Criteria: \_\_\_\_\_
- \_\_\_\_\_

### Treatments

21. One of the goals of this research is to determine the costs of treating mental illness and compare them to the costs of *not* treating mental illness. One of the treatment costs is medicines. I know that prescription depends a lot on the individual, but I'd like to ask you in a general way about the medicines you prescribe. What drugs would you typically prescribe for the following conditions (*code name, dose and frequency*):
- a) psychosis
- b) bipolar disorder
- c) depression
- d) anxiety
- e) alcohol or drug abuse
- f) epilepsy
22. Do you sell drugs at your clinic? (*circle*) Yes    No
23. If no, what is the name of the pharmacy you would recommend? *Note: After the interview, try to get a price list for the drugs named from the pharmacy.*

### Public vs. Private

- g) How long have you been working in the private sector?
- h) Do you only work in the private sector, or do you also work in the public sector?
- a) (*Circle*)    Only private                      Both public & private
- b) When do you run your private clinic? (*Eg weekends, afternoons, Mon, Weds, Fri*)
- c) (*If both*) Does the treatment differ in your public and private clinics? If so, how?

**Thank you for your contributions, the interview ends here.**

## Inpatient Facilities Offering Psychiatric Services in Nairobi, Meru and Nyeri

1. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

2. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

3. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

4. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

5. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

6. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

7. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

8. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

9. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

10. Name: \_\_\_\_\_

(circle) **Admitting rights:** Yes No    **Wards:** Integrated Specialized    **ECT:** Yes  
No

## 10.25 In Depth Interview on Healing

### *Provider Version*

1. Are you involved with persons with mental disability (mental disorder)? YES |\_\_| NO
2. If yes, what are the mental disorders that you see or get involved in?
3. What treatment or care do you provide for the mental disorders mentioned above?
4. Do you go to the homes of mentally affected persons (provide home services-mobile)? YES |\_\_| NO |\_\_| If yes; what treatments do you offer when you visit them?
5. Do you address disabilities as well as symptoms? YES |\_\_| NO |\_\_|
6. What symptoms do you observe to indicate your client has a mental disorder? (describe the symptoms matching them with a particular mental disorders)
7. Do you provide treatment and care that is specific to diagnosis of each individual?
8. The mental disorders you have mentioned in 2 above; how do you arrive at the diagnosis? (elaborate on each disorder how a diagnosis is made)
9. Do you carry out any procedures *before starting* the care? If yes what procedures?
10. How do you carry out these procedures you have mentioned above?
11. The treatments you have mentioned in 3 above, please elaborate each procedure.
12. What (if any) herbal remedies do you use for conditions named above? (Name the condition matching it with remedies used.)
13. Do you coordinate these services with other people? (Health workers, traditional healers or faith healers)? If yes which organizations or persons do coordinate with?
14. The organizations or persons you coordinate with (mentioned in 12 above), when do you refer the patients to them?
15. The organizations or persons you coordinate with (mentioned in 12 above), do they refer the patients back or to you? If yes, when and under what circumstances?
16. Do think there is need to form a linkage with the persons or organization (mentioned in 12 above)? If yes what kind of linkages?
17. The persons you see with mental disorders, how do you follow them up for them to get further treatment or to complete treatment?
18. How do you view conventional medical treatment as compared to your mode of treatment?
19. Do you have any other views on how persons with mental illness can be treated or cured?

***In Depth Interview on Healing  
Patient Version***

1. Do you visit traditional or faith healers for management of the mental illness?  
YES |\_\_| NO |\_\_|
2. If yes, what are the mental disorders that you see them for?
3. What treatment or care do they provide for the mental disorders mentioned above? (Brief answers)
4. Do they come to your home (provide home services-mobile)? YES |\_\_| NO |\_\_|
5. Do they address disabilities as well as symptoms? YES |\_\_| NO |\_\_|
6. What symptoms indicate that one has a mental disorder? (describe the symptoms matching them with a particular mental disorders)
7. Do the healers provide treatment and care that is specific to the diagnosis and needs of each individual? YES |\_\_| NO |\_\_|
8. Do they carry out any procedures before starting the care? If yes what procedures?
9. The treatments you have mentioned (in 3 above), how do they carry them out? Elaborate each treatment procedure.
10. What herbal remedies do they use?
11. Do they coordinate their services with other persons (health workers, traditional or faith healers)? If yes which organizations or persons do they coordinate with?
12. If yes, when do they refer the patient to the organizations or persons they coordinate with?
13. Do those organizations or persons refer the patients to the faith and traditional healers? If yes, when and under what circumstance?
14. Do you think there is need to form a linkage with the persons or organization mentioned above? If yes what kind of linkages?
15. How do you follow up the treatment they prescribe for you so that you get further treatment or to complete treatment?
16. How do you view conventional medical treatment as compared to the traditional and faith healers' treatment?
17. Do you have any other views on how persons with mental illness can be treated or cured?

## Patient and Healer Socio-demographic Questionnaire

<b>Study Number</b>	
1. Name	
2. Province of birth	
1. Nairobi	
2. Central	
3. Eastern	
4. North Eastern	
5. Coast	
6. Western	
7. Nyanza.	
8. Rift Valley	
3. Age (in years)	
4. Gender	
5. Marital status	
a Single	
b Married (No. of wives)	
c Widowed	
d Divorced/separated	
e Cohabiting	
f Other (specify)	
6. Education	
1. None	
2. Primary level	
3. "O" level	
4. "A" level	
5. College	
6. University level	
7. Religion	
1. Muslim	
2. Catholic	
3. Protestant	
4. Hindu	
5 Buddhist	
6. None (atheist)	
7. Other (specify)	
8. Employment	
1. None	
2. Part-time	
3. Full-time	
9. If not employed, why?	
1. Never been employed	

2. Sacked	
3. Retired	
4. Other (specify)	
10. If not employed, for how long?	
1. Less than one year	
2. Over 1 but less than 2 years	
3. Over two years	
11. Who owns the house you live in?	
1. Rented house	
2. Own house	
3. Family house	
4. Other (specify)	
12. With whom do you stay?	
1. Parent	
2. Spouse	
3. Sibling	
4. Cousin	
5. Uncle	
6. Aunt	
7. Friend	
8. Other (specify)	
13. Estimated income per month	
1. Less than 1000	
2. 1000-4,999	
3. 5000-9,999	
4. Over 10000	
5. Do not know	
6. Other (specify)	