Profiles and Outcome of Traditional Healing Practices for Severe Mental Illnesses in two districts of Eastern Uganda

Catherine Abbo

Makerere University

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Karolinska Institutet
SE-171 77 Stockholm • Sweden

Makerere University
P.O. Box 7062 • Kampala • Uganda

DEPARTMENT OF CLINICAL NEUROSCIENCE
Karolinska Institutet, Stockholm, Sweden

DEPARTMENT OF PSYCHIATRY
Makerere University, Kampala, Uganda

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To my dear family: Geoffrey my husband, who stood by me throughout, and our children: Percy, who came into the world during the first degree, Nelly Susan during the second degree and Stacy Georgina during this project.

ABSTRACT

Background: The WHO estimates that more than 80% of African populations attend traditional healers for health reasons. However, little is known about the profiles and outcome of this traditional approach to treatment of mental illnesses.

Main Objective: The purpose of this study was to describe the profiles and outcome of traditional healing practices for severe mental illnesses in Jinja and Iganga districts in the Busoga region of Eastern Uganda. **Methods:** Four studies were conducted (I-IV). Study I used Focus Group Discussions with Case Vignettes with local community members and traditional healers to explore the lay concepts of psychosis. Studies II and III concerned a cross-sectional survey of patients above 18 years at the traditional healer's shrines and study IV was made on a prospective cohort of patients diagnosed with psychosis in study III. Manual content analysis was used in study I; quantitative data in studies II, III and IV were analyzed at Univariate, Bivariate and Multivariate levels to determine the association between psychological distress and sociodemographic factors; for study IV, factors associated with outcome were analyzed. One-way ANOVA for independent samples was the analysis used in Study IV. **Results:** The participants differentiated schizophrenia *(eddalu, ilalu)* from mania *(kazoole)* and psychotic depression (described as illness from too much thinking), describing the symptomatology and natural course. Clan/family/cultural issues were mentioned as causing schizophrenia and psychotic depression, while physical causes and a failed relationship with God were mentioned for mania. Other causes were witchcraft, genetics and substance misuse. Choice of care depended on what was believed to be the cause of the psychotic symptoms (I). The prevalence of psychological distress was 65.1%. Significant associated factors were having a co-wife, more than four children, debts and lack of food. The distressed group was more likely to need explanations for ill health. Those who visited both the healer and a health unit were less likely to be distressed (II). Of the 387 respondents, 60.2% had diagnosable current mental illness and 16.3% had had one disorder in their lifetime. Of those with diagnosable current mental illnesses, 29.7% had psychosis; 5.4% a major depressive episode; 5.6% anxiety disorders; 3.6% mixed anxiety-depression; and 3.9% suicidality. Symptoms were severe in 37.7%, moderate in 35.1%, and mild in 13.2%. Patients with moderate to severe symptoms were more likely to use both biomedical services and traditional healers (III). All the symptom scales showed a percentage reduction of more than 20% at the three- and six-month follow-ups. The differences between the mean scores of the scales were all significant (P<0.0001). The Turkey HSD test was also consistently significant at P<0.01 except for psychotic depression. Over 80% of the participants used biomedical services for the same symptoms in the study period. Patients who combined treatment were less likely to be cases at the three-month follow-up (P=0.002; OR 0.26[0.15-0.58]), but more likely at the six-month follow-up (P=0.020; OR 2.05 [1.10-3.18]). Being in debt was associated with caseness at both three and six months. **Conclusion:** The community gave indigenous names to psychoses (Mania, Schizophrenia and Psychotic depression) and had multiple explanatory models for them. Thus multiple solutions for these problems are sought (I). Tradtional healers shoulder a large burden of care of patients with mental health problems (II and III). An overwhelming majority of Ugandans with psychosis in this study use both biomedical and traditional healing systems. The combined use of these two systems seems to confer some benefits (IV). **Implications:** For policy makers, for mental health professionals, for traditional healers, for researchers – indeed for all those who share the goal of improving the mental health of individuals – there can be no alternative to engaging with traditional healers.

Key words: Mental illness, traditional healers, outcome, Western Medicine

LIST OF PUBLICATIONS

I. **Abbo C**, Okello ES, Ekblad S, Waako P, Musisi S: Lay concepts of psychosis in Busoga, Eastern Uganda: A pilot study. J World Cultural Psychiatry Research Reviews 2008; 3(3):132-145

II. **Abbo C**, Ekblad S, Waako P, Okello ES, Muhwezi W, Musisi S: Psychological distress and associated factors among the attendees of traditional healing practices in Jinja and Iganga districts, Eastern Uganda: a cross-sectional study. International Journal of Mental Health Systems 2008; 2:16

III. **Abbo C**, Ekblad S, Waako P, Okello ES, Musisi S: The prevalence and severity of mental illnesses handled by traditional healers in two districts in Uganda. African Health Sciences 2009; 9(S2): S16-S22

IV. **Catherine Abbo**, Seggane Musisi, Paul Waako, Elialilia S Okello, Solvig Ekblad: Naturalistic outcome of psychosis treatment of by traditional healers in Jinja and Iganga districts, Eastern Uganda – a 3- and 6-month follow-up. (Submitted)

The papers will be referred by their Roman numerals I-IV.

CONTENTS

LIST OF ABBREVIATIONS

CAM: Complementary and Alternative Medicine
DSM-IV: Diagnostic and Statistical Manual, 4th edition
ICD-10:   International Classification of Disease, 10th Edition
NACOTHA: National Council of Traditional Healers Association
PROMETRA: Promotion of Traditional Medicine – Uganda
THETA: Traditional Healers and Modern Medicine Together Against AIDS
WHO: World Health Organization
T/H: Traditional Healer
SRQ: Self Reporting Questionnaire
MINIPlus: Mini International Neuropsychiatric Interview
PANSS: Positive and Negative Symptom Scale for Schizophrenia
YMRS: Young Mania Rating Scale
MÅDRS: Montgomery and Åsberg Depression Rating Scale
MHI: Mental Health Index
GAF: Global Assessment of Functioning
CGI: Clinical Global Impression
EBM: Evidence Based Medicine

LIST OF TABLES AND FIGURES

OPERATIONAL DEFINITIONS

Traditional Medicine: WHO defines Traditional Medicine as including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to diagnose, treat or prevent illness (1).

Traditional Healer: The WHO defines a 'traditional healer' as a person who is recognized by the community in which he/she lives as competent to provide health care by using vegetable, animal, mineral substances or other methods based on social, cultural and religious background as well as on the knowledge, attitudes and beliefs that are prevalent to the community regarding physical, mental and social well-being and causation of disease and disability (2).

Complementary and Alternative Medicine (CAM): The terms 'Complementary' and 'Alternative' Medicine are used to refer to a broad set of health care practices that are not part of a country's own tradition or not integrated into its dominant health care system. WHO draws a distinction between 'traditional medicines' and CAM (1).

Severe Mental Illness (SMI): Three criteria define severe mental illness: Diagnosis, Duration and Disability. Any diagnosis in the family of schizophrenic disorders, any bipolar disorders or any other psychotic disorders falls under the definition of severe mental illness. For other diagnoses, duration and disability criteria have to be met (3).

Effectiveness: The determination – in naturalistic settings – that a treatment has beneficial effects (4).

Efficacy: The determination, usually through clinical trials, that a treatment has beneficial effects (4).

Outcome: Outputs of post-treatment effects (5).

PREFACE

This study originated from my observation as a volunteer medical doctor in Butabika National Mental Referral Hospital in the year 2000. During that time, I noticed the following:

1) That relatives or caretakers of admitted patients would often request to take their patients away, however mentally ill the patient happened to be. The majority would not give reasons for removing their patients. A few would say *'ebizibu byoono sibyaawano'* meaning, 'His/her problems can't be solved here.'

2) Relatives brought patients after they had been to traditional healers.

3) Some patients had herbs on the wards.

4) Sometimes healers visited the patients inside hospitals and administered treatment.

5) Lastly, in my clinical practice, I have experienced something of a dilemma in practicing western psychiatry in a non-western culture. I will give an example: During one ward round, I was confronted with a 30-year-old married woman, a peasant, with five children. She presented with a one-day history of abnormal behavior characterized by episodes of getting into 'spirit possession states'. During these states, she would hurl insults in the third person at another woman whom she believed was her husband's second wife. Between the episodes, she was normal. Members present on the ward round observed the spirit attacks twice. Further psychiatric evaluation revealed that her husband had been away for three days and she subsequently discovered that he was at another woman's home. This was the first time she behaved like this and her first time in a psychiatric hospital but she had been to the traditional healers several times over similar issues. Clinically, there were no other obvious psychiatric symptoms. Seizure states were clinically ruled out. In the process of writing clinical notes and trying to select a DSM-IV diagnosis (the closest was conversion disorder), some questions came to my mind: Can I make a diagnosis of 'spirit possession' in this patient and record it in her file? If so, can I recommend that this patient goes to see a traditional healer? Of course, the answer was obvious. Fortunately, as I was struggling with this, the patient's husband walked in, totally convinced that his wife had been sent spirits and that he therefore needed to take her to where they can get help. All the other relatives agreed with him and who was I to prevent them from going? I didn't even have a DSM-IV diagnosis, let alone treatment for the spirits!

I also noticed that despite the connections our patients had with traditional healers, we who were taking care of them in hospital were not concerned about the traditional healers. I realized that it is not in the patient's interest and benefit that those who care for a patient are ignorant of each other's contributions. I therefore set out to study mental health and traditional healing.

In writing this thesis, it has been my hope that it would be read by clinically active mental health workers, policy makers, and researchers in mental health and those in the global mental health movement, but also traditional healers themselves.

The outline of this thesis is as follows: the background will give an introduction to traditional healing and the provision of mental health services in Uganda and end with the theoretical framework. This is followed by the rationale for the study, its objectives, the methods used, results, discussion, conclusion, implications, acknowledgements and references and finally the four papers.

1. BACKGROUND

1.1 TRADITIONAL HEALING

The use of traditional healing[i,ii,iii] and Complementary and Alternative Medicine (CAM) is widely acknowledged and growing in both low- and high-income countries. In North America, Western Europe and other developed regions, an increasing number of patients are seeking out CAM practitioners for mental health care (1, 6). Studies done in this region report that the use of CAM approaches among individuals who meet DSM-IV criteria for some psychiatric disorder is significantly greater than in the general population (6, 7). In Africa, traditional healing is deeply embedded in African traditional beliefs (8-10). People there have close relationships with traditional healers, who often share the same community and culture. A number of centers have assessed the role of traditional healers in mental health interventions. A common finding was that traditional healers could recognize symptoms of severe illness, but that they expressed strong belief in supernatural factors as ultimate causes of mental illness and this influenced the treatments they gave (10, 11).

Several studies have indicated that traditional healers are effective in the milieu in which they operate (12-14). In Taiwan, Kleinman and Sung reported that ten of the twelve cases treated by traditional healers rated themselves as cured. They suggested that similar belief systems about health and illness and the healers' holistic approach explained the subjective improvement (15). However, a number of arguments have been put forward against traditional healing. Some authors have dismissed traditional healing as unhealthy and dangerous (16). It is also argued that traditional healing belongs to pre-civilisation and is open to a wide range of magical or mystical explanations (17). For most western-trained practitioners, explanations of illness that fall outside the laws of natural science are pseudoscientific, primitive and simply wrong (17-19). Claims such as these have created a decidedly negative impression of traditional healing. Indeed, it is often claimed that some of the practices can actually be detrimental to the patients. Reports of prescriptions of mysterious herbal concoctions and unethical and unsavoury behaviour relating to treatment of patients frequently appear in Ugandan newspapers (20, 21). While some unscrupulous people calling themselves traditional healers have thoroughly deserved the negative publicity generated by their disreputable conduct, these stories may have contributed to a negative feeling about all traditional healers and all their healing practices. The church has also maligned traditional healers and often relegates traditional healing to Satanism, only fit to be condemned.

In Uganda, there is no law governing the operation of traditional healers.

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[i] 'Healing' is preferred to 'medicine' because it has more to do with 'wholeness' than the word 'medicine', which in this context may mean herbs.

[ii] Traditional healing is not synonymous with witchcraft. Witchcraft is defined as causing illness or other misfortune to somebody, supposedly by using mystical forces, sorcery or magic powers, especially evil ones (charm).

[iii] A traditional healer is not a witchdoctor. A witchdoctor is a person who practices witchcraft.

The only law, which is outdated, is the Witchcraft Act of 1964, which only stipulates penalties against intended acts of harm (22). The recent wave of ritual murders, including child sacrifice, has prompted Ugandan Parliamentarians to debate and plead with the Government to enact a law regulating the activities and practices of traditional healers and herbalists. In this debate, they noted that there is no institutionalized framework for governing traditional healers (23).

A number of organizations register and represent traditional healers, though some traditional healers prefer not to be registered for various reasons, such as fear of taxation. The traditional healers' several associations include the following; NACOTHA (National Council of Traditional Healers Association), PROMETRA (Promotion of Traditional Medicine-Uganda), UGANDA NE DDAGALA LYAYO (Uganda and Her Native Medicine), UGANDA HERBALISTS ASSOCIATION, THETA (Traditional Healers and Modern Practitioners Together Against AIDS). Recently, the Inspector General of Police of Uganda directed all traditional healers in the country to surrender their licenses for fresh registration, advising them to have one president of their association as opposed to the many at present (24). The exact number of traditional healers in Uganda and their utilization are difficult to assess, as some healers are not registered and some of their clients visit them at night or clandestinely. However, it was recently estimated that there is at least one traditional healer for every village and four out of five Ugandans visit traditional healers, particularly in rural areas (25). The WHO estimates that 60-80% of the population go to traditional healers for their health care need (1). This suggests a massive consumer base. Many of these consultations are carried out at the same time as the patient may be receiving care from the modern health care system (11).

A number of studies have investigated traditional healing as practiced in various indigenous African communities (26-28). They emphasise the psychological relevance of traditional healers in African communities (9, 14, 26, & 29). A few studies have provided useful insights into the psychological relevance of traditional healers in African communities but hardly any comparable studies have focused on the effectiveness of traditional healing of serious mental illnesses. It is against this background that the aims and objectives of the present study have evolved.

Research in traditional healing has covered topics such as social, religious, and political roles, doctor–healer collaborations and the characteristics of those who seek their services (13). However, research methods in outcome studies of traditional healing and CAM have generated controversies. The next subsection will discuss some of these controversies and state the stand of this thesis.

1.2 OUTCOME RESEARCH IN TRADITIONAL HEALING

Methods in outcome research in traditional healing and CAM have been debated for many years in the scientific world (30, 31). The key issue seems to be whether or not traditional healing practices and CAM should be subjected to the same standards of evaluation, given that traditional healing therapies are said to be so complex because their common basis is a holistic approach to life, equilibrium between the mind, body and environment, and an emphasis on health rather than disease. It is argued that this complexity makes evaluation extremely difficult, since so many factors have to be taken into account (32). Some advocates of traditional healing argue that many of these therapies cannot be subjected to the standard scientific methods and thus must rely instead on ethnographic evidence of 'what works', anecdotes, beliefs, social equity,

theories, testimonials and opinions to support effectiveness and continued use (33, 34). Thus, questions that are often asked include:

1) How does one study interventions whose particular component parts or treatment effects necessarily might vary across individual patients, and

2) How does one study efficacy or effectiveness or mechanisms when the constructs, independent variables, outcome measures and/or proposed pathways represent phenomena that violate current scientific consensus and thus are not believed by mainstream biomedicine even to exist?

On the other hand there are those who argue that regardless of the origin or type of therapy, the theoretical underpinnings of its mechanism of action, or the practitioner who delivers it, the critical questions are the same: What is the therapy? What is the disease or condition that is being treated? What is the purported benefit to the patient? What are the risks? How much does it cost? And perhaps most important, does it work? (33). Moreover, for virtually all interventions, the determination of effectiveness and recommendations for clinical applications should be based on the strength of scientific evidence, using explicit criteria for grading the quality of evidence (35). Researchers who argue for the convergence of these two worlds state that addressing both mechanisms and outcome in the same study complicates issues (31). The issue of complex individualized interventions could be resolved by evaluating the effectiveness of the whole system as opposed to individual components (36). Questions should be conceptualized in a way that can be answered clearly, using approaches that can be operationalised and understood by those who do not share the worldview of the investigator, with clear identification of measurable and desirable outcomes (36). These researchers believe that existing biomedical research strategies are robust and appropriate even when the therapeutics of intervention are said to be based on unknown, mysterious, or novel mechanisms of action (31). Researchers can do outcome studies regardless of how multifactorial the intervention is or how unusual the proposed mechanisms of healing are, provided there is agreement to utilize an outcome measure that is accepted and uncontroversial in the mainstream biomedical research world (31).

Another related argument is that traditional outcomes focus on biomedical endpoints; in particular, outcome measurements in psychiatry research are dominated by the measurement of psychiatric symptoms, with little reference to the patient's base measures (37, 38). However, there is an increasing interest in patient-based outcomes, for example, well-being and satisfaction, which measure the impact of illness or interventions on the individual (39).

The assessment of subjective well-being as a measure of treatment outcome has thus become popular in medicine because the concept of well-being concisely captures the notion that the ultimate goal of medical intervention is to improve the well-being of the patient (38). By reflecting on the sense of well-being and satisfaction experienced by people under their current life circumstances, the assessment of this well-being aims to provide a comprehensive evaluation of the individual's overall functionality in regard to a given ailment and its treatment.

In this thesis, we subscribe to the convergence side and in the outcome study we have followed the guiding principles put forward by this side, thus contributing to the evidence that outcome studies in a complex intervention are possible.

The next subsection is about the burden of mental illness and the treatment gap, pointing out that traditional healing has been disregarded as a resource for narrowing or closing the treatment gap.

1.3 GLOBAL BURDEN OF MENTAL ILLNESS, TREATMENT GAP AND GLOBAL MENTAL HEALTH

Mental disorders contribute about 14% of the global burden of disease (40). Neuro-psychiatric conditions are the number one contributor to the worldwide burden of non-communicable disease. Including disorders such as schizophrenia, mood disorders, substance abuse and dementia, these conditions contribute more to the global disease burden than cancer or cardiovascular disease (41). In sub-Saharan Africa, mental disorders account for nearly 10% of the total burden of disease (42).

The WHO has projected that by the year 2030, unipolar depressive disorders will be the number one cause of the disease burden in high-income countries and that depressive disorders will be the third highest cause of the disease burden in middle- and low-income countries, after HIV/AIDS and perinatal death (43).

In Uganda, the bulk of epidemiological research has focused on primary care settings, where most psychiatric disorders are non-psychotic (44). The reported prevalence rates vary widely, from 10% to nearly half of all primary care attendees with a psychiatric problem, with or without a co-existing physical problem. The commonest diagnoses are depression and anxiety (44, 45). In most community-based studies, up to a third of randomly selected persons have been found to suffer from mental illness (46). One of the most influential studies was in a rural community in Uganda by Orley & Wing. They reported that about a quarter of the sample had mental illness. The prevalence of individual psychiatric disorders was as follows: depression 9.3%, anxiety 8.5%, bipolar disorder 4.9% and schizophrenia 1.5 % (47). Petrushkin, Boardman & Ovuga found that as much as 82.6% of their sample patients with HIV had a psychiatric disorder according to DSM-IV diagnoses (48). They observed that the provision of mental health care in Uganda was hampered for various reasons, including cultural concepts of etiology and treatment, myths surrounding mental illness, stigmatization, fear and denial (48). In a study of households in the Kabarole district in Uganda, Kasoro and co-workers found 30.7% of adults had psychiatric disorders (49). None of these Ugandan studies specifically addressed traditional healers' practices, neither did they emphasize severe psychiatric illnesses (psychosis); they concentrated on common mental disorders. There is thus a paucity of literature on prevalence studies in mental health done in traditional healer centers/shrines.

Despite the staggering burden of mental illness, the treatment gap is wide (50). A large proportion of people with mental health problems do not receive treatment and care from a western health facility. A multicenter survey by WHO showed that 76-85% of people with serious mental health problems had received no treatment in the previous 12 months and that for those who did receive treatment; this was most often inadequate (51).

This gap in care is more pronounced in low- and middle-income countries, where fundamental resources are less accessible or unavailable (52). It is also increased by the inefficient appropriation of resources (52). Much of the research linking allocation of resources to outcomes of care has taken place in high-income countries. In developing countries, including Uganda, where 60-80% of the population goes to traditional healers, hardly any resources are allocated to alternative providers of mental health care and there are yet no outcome studies.

Both psychological and pharmacological approaches to the treatment of mental illnesses such as depression and schizophrenia have been shown to be cost-effective, even in developing nations (51). The cost-effectiveness is in fact comparable to that of anti-

retroviral treatment for HIV/AIDS (51). However, despite a better understanding of the burden and effective treatment of mental illnesses, the provision of mental health care in low- and middle-income countries has improved very little in previous decades (53).

Recommendations to strengthen mental health systems around the world were first mentioned in the World Health Report 2001, which focused on mental health. These recommendations were: to provide treatment in primary care; make psychotropic drugs available; give care in the community; educate the public; involve communities, families and consumers; establish national policies, programs and legislation; develop human resources; link with other sectors; monitor community mental health; and support more research (54).

The current global mental health movement puts emphasis on evidence about cost-effective interventions to provide better mental health care in order to narrow or close the treatment gap (51, 52). Among the barriers cited are lack of resources, both financial and human (52).

The term Global Mental Health denotes the international perspective on aspects of mental health. Taking into account cultural differences and country-specific conditions, it deals with the epidemiology of mental disorders in different countries, their treatment options, mental health education, political and financial aspects, the structure of mental health care systems, human resources in mental health and human rights issues, among others. The overall aim of the field of Global Mental Health is to strengthen mental health all over the world by providing information about the mental health situation in all countries and identifying mental health needs in order to develop cost-effective interventions to meet those specific needs. The current global mental health documents make hardly any mention of traditional healing as a resource to close the treatment gap. This could have to do with the emphasis on evidence for interventions; such evidence is scarce for traditional healing.

The next subsection defines psychosis and discusses healers in the context of treating psychosis as this thesis is mainly about severe mental illnesses.

1.4 PSYCHOSIS AND TRADITIONAL HEALERS

The term psychosis has been variously defined in the past and no definition has been universally accepted. The narrowest definition restricts psychosis to delusions or prominent hallucinations, with the hallucinations occurring in the absence of insight into their pathological nature. A slightly less restrictive definition would also include prominent hallucinations that the individual realizes are hallucinatory experiences. Broader still is a definition that includes other positive symptoms of schizophrenia, i.e. disorganized speech, and grossly disorganized behavior or catatonic behavior (55). Unlike these symptom-based definitions, the definition used in DSM III and ICD-9 was probably far too inclusive and focused on the severity of functional impairment. In that context, a mental disorder was termed 'psychotic' if it resulted in "impairment that grossly interfered with the capacity to meet ordinary demands of life." (56)

The term has also previously been defined as a "loss of ego boundaries" or a "gross impairment in reality testing." The American Heritage Stedman's Medical Dictionary defines psychosis as "A severe mental disorder, with or without organic damage, characterized by derangement of personality and loss of contact with reality and causing deterioration of normal social functioning." (57)

Mainstream psychiatry considers psychosis to be a symptom of severe mental illness but not a diagnosis in itself. Psychosis is particularly associated with schizophrenia, bipolar disorder and severe depression.

This study took schizophrenia, mania and psychotic depression as primary psychotic illnesses and defined psychosis in terms of delusions, hallucinations and disorganized behavior (55).

A few studies have shown that some traditional healers in Africa, for example the Yoruba native healers, use both etiological and symptom logical concepts, mostly interchangeably, to describe psychotic illness. Their most common diagnostic label is *"were",* which refers to one who is chronically psychotic, careless in dressing, vagrant in behavior, talks irrationally and suffers auditory and visual hallucinations. Most chronic cases, and perhaps individuals with symptoms of acute schizophrenia, would fall into this category (58, 59). While *"were"* denotes chronic psychosis in Yoruba, in Buganda the equivalent seems to be *"akazoole"* and *"eddalu"* violent madness (60). Okello and Musisi have demonstrated that psychotic depression is recognized and labeled as clan illness, translated as "*ebyekika"* illness by the Baganda and their traditional healers (9). The implication here is that Africans and their traditional healers can identify specific mental illnesses and ascribe treatment to them. This is not dissimilar to western medicine.

The traditional healers treat psychosis with various methods, which include herbs, appeasing the spirits and divination, depending on the perceived cause. Prince identified Rauwolfia vomitoria as one of the psychoactive drugs used by Nigerian native healers in the treatment of psychosis (61).

The next section discusses the current mental health service provision in Uganda.

2. PROVISION OF MENTAL HEALTH SERVICES IN UGANDA

2.1 FORMAL AND INFORMAL SECTORS

Mental health services in Uganda are provided by formal and informal sectors. The informal sector is largely dominated by traditional healing, used by 60-80% of Ugandans (1). Faith healing is also included in the informal sector. Western medical private psychiatric practice is often absent or negligibly minimal. The formal sector is the Government of Uganda through the Ministry of Health, which oversees delivery of health services operating with national health policy documents where the guiding principles of primary health care are the basic philosophy (62).

Uganda's health policy of 1999 decentralized the provision of health services to the districts and health sub-districts (62, 63). Figure 1 presents interactions between the formal and informal sectors and the barriers to the provision of mental health services in Uganda. Mental health is a component of the minimum health care package. The policy also emphasizes a strong collaborative and partnership approach between the public and private sectors, non-governmental organizations and traditional healers, while safeguarding the identity of each partner (64, 65). Thus, there are presumed to be orderly referrals from Health Centre I (village level) through Health Centre II (parish), Health Centre III (Sub-county) and Health Centre IV (County) to district hospitals, regional referral hospitals up to the national referral and teaching hospitals in the capital city (64). Accordingly, mental health units are currently under construction within regional hospitals to provide referral needs for lower hospitals. However, the challenges faced in the delivery of health care services are similar to those enumerated by WHO and the global mental health movement (53, 54). They include too few mental health workers, lack of general health worker skills for managing mental health problems, poor prioritization of mental health problems, resistance to change and lack of research data to guide policy development, planning and implementation (64). Meanwhile, traditional healers continue to be consulted, even when clients are under medical treatment (11, 17). Many consider that traditional healers provide more holistic care than medical practitioners, are more accessible and have an approach that is more appropriate and therefore more acceptable to the community (66). Despite the above, there is no policy or legal framework for the operation of traditional healers in Uganda. Efforts to regulate their practices and support their role in healing have been sluggish, perhaps because of a lack of research evidence of their benefit.

The WHO first recognized the importance of collaborating with traditional healers in 1978 (67). Such collaboration now takes place in a few WHO member countries, e.g. South Africa. In Uganda, a few NGOs working with HIV/AIDS are doing so together with traditional healers (25). As regards mental health, some collaboration in the form of a project has taken place between Mbarara Regional Hospital's Department of Psychiatry and traditional healers in the region, sponsored by the Tropical Health and Education Trust (THET) in the UK (68). There is still no formal collaboration at government level.

The reality of mental health care in Uganda is that service providers offer parallel and sometimes antagonistic services. This requires an understanding of the incentives and disincentives that operate at and across care system boundaries. The difficulties that can

occur include disputing and blurring of boundaries as well as barriers to information-sharing and joint decision-making. The boundaries may also shift with organizational changes or changes in circumstances on one side of the boundary, causing resources and people to cross the boundary, to the detriment of some stakeholders (69).

Table 1: The Structure of Uganda's National Health Care System

Health unit	Physical structure	Location	Population
Health Centre I	None	Village	1,000
Health Centre II	Outpatient services only	Parish	5,000
Health Centre III	Outpatients, maternity, general ward and laboratory	Sub-county	20,000
Health Centre IV	Outpatients, wards, theatre, laboratory, blood transfusion	County	100,000
General Hospital	Hospital, laboratory and X-ray	District	100,000-1,000,000
Regional Referral Hospital	Specialist services	Region (3-5 districts)	1,000,000-2,000,000
National Referral Hospital	Advanced tertiary care	National	Over 20,000,000

Source: Thesis for Doctoral degree by Rutebemberwa page 8 (63). (Adapted from Government of Uganda, Health Sector Strategic Plan, 2000/01-2004/05)

Figure 1: Interactions between the formal and informal sectors and barriers to the provision of mental health services in Uganda
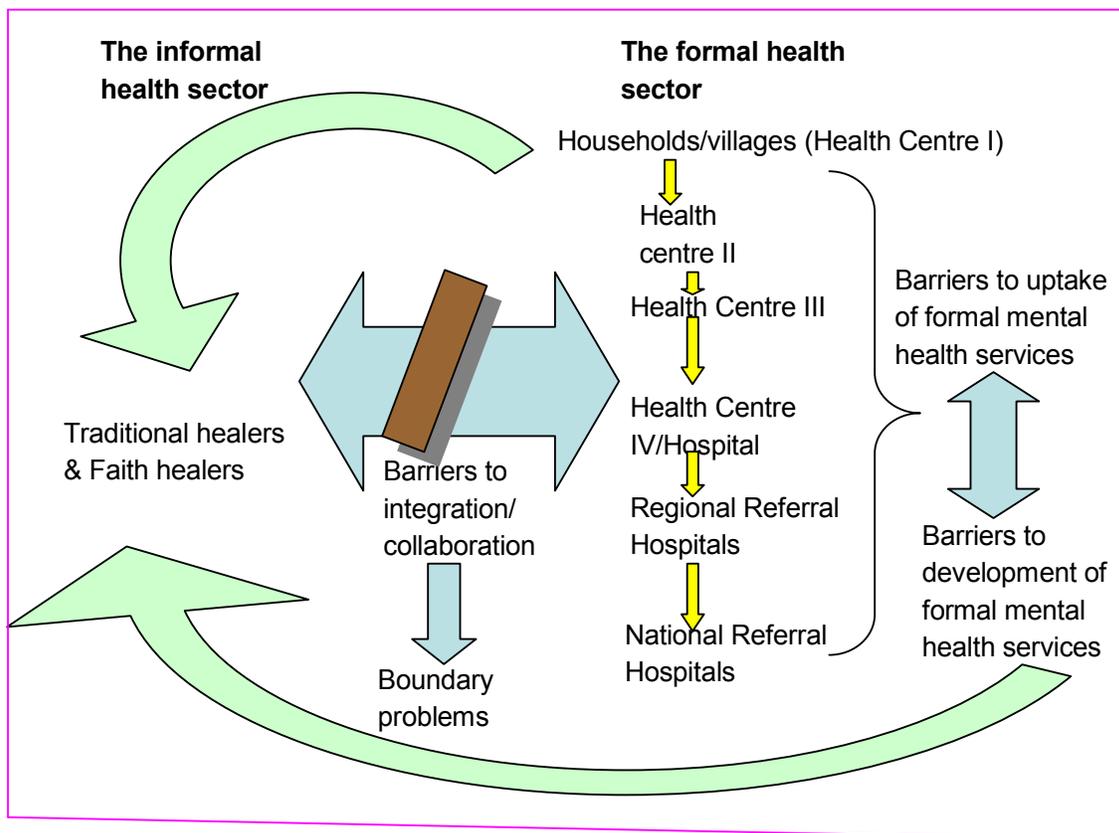
3. THEORETICAL FRAMEWORKS

This study explored lay concepts of psychosis among people in the study area and investigated the profiles and treatment outcomes of traditional healing practices for severe mental illnesses as measured by standard instruments. The study therefore drew ideas from various models of health care. Some of the models are explained below:

1) Kleinman's explanatory model of illness framework
Explanatory model (EM) is a term coined by Kleinman to denote the "notions about the episode of sickness and its treatment that are employed by all those engaged in the clinical processes. The notion is framed from a variable cluster of cultural symbols, experiences and expectations associated with a particular category of illnesses and reveals sickness labeling and cultural idioms of experiencing of illness" (70). Explanatory models of illness influence health seeking behavior and health service utilization (71). Kleinman asserts that healing cannot be talked about in the abstract; it must be anchored in particular social and cultural contexts. In each society, there are beliefs about illness, choices of treatment alternatives, sick roles and practitioner roles and health care-related institutions organized as a cultural system. In a clinical context, Kleinman's original approach involved asking questions through an exploratory process of qualitative enquiry. This leads to complex and multi-layered responses which carry with them information about social rituals, symbols in communication, forms of knowledge and illness narratives (72). However, despite the appeal, for various reasons this has not been influential on routine psychiatric practice (73). Some anthropologists argue that given the incomplete understanding of mental illnesses by the scientific community, it is not clear whether the explanatory models alone are able to capture the complex mental health needs of patients across cultures (73).

2) Biopsychosocial model
The biopsychosocial model is a general model or approach that posits that biological, psychological (entailing thoughts, emotions, and behaviors) and social factors all play a significant role in human functioning in the context of disease or illness (74). Asserting that health is best understood in terms of a combination of biological, psychological, and social factors rather than purely in biological terms (74). This model is in contrast to the traditional, reductionist biomedical model of medicine, which suggests that every disease process can be explained in terms of an underlying deviation from normal function, such as a pathogen, a genetic or developmental abnormality, or injury (74). According to the biopsychosocial model, factors that potentially influence any health outcome exist at many levels of organization, and scientific scrutiny is required at all those levels to detect which factors indeed play a significant role. In some cases, so many factors will all play equally important roles that only broadly based biological, psychological, and social interventions will be efficacious in altering the outcome. In other cases, however, scientific scrutiny will reveal that one or a few factors, at one or a few levels, dominate; and the alteration of those few factors is sufficient to produce the desired result. The biopsychosocial model as described by Engel has been criticized by Richter (75). He argued that this model cannot depict the system of psychiatric care and its related problems faithfully. Although it is generally acknowledged that psychiatry should orientate towards the biopsychosocial paradigm, in practice, real changes towards this model cannot be found because the biological approach in etiology and treatment has become more and more important in recent decades (75).

3) Holistic Model
This model combines many health modalities and models of health care with the goal of helping the patient or client achieve optimal physical, mental, emotional, social and spiritual health (76, 77). The ultimate goal of holistic medicine is to use all the available diagnostic and treatment modalities to optimize the health of the person on all levels of well-being, without doing harm to the person. The premise of holistic medicine is to attempt to treat the patient as opposed to the illness. This model presupposes that we exist in five different dimensions simultaneously (76). The five levels are as follows. The lowest or densest is the physical body (level 1), which is the foundation upon which everything else rests. It is the connection to the earth and the source of physical energy. It is what is perceived with the five senses. Level 2 is the energy body, which is the summation of all electric and magnetic events caused by the neuronal activity of the entire nervous system. Most somatic and autonomic nerves in the body travel along the body's longitudinal axis and the nerve currents spread as electric fields along these nerves. The energy body modulates neural transmission, neurotransmitter releases, detoxification and many other body functions. Beliefs, attitudes and thoughts form and organize level 3, the mental body, which encompasses every idea or thought. Every emotion is preceded by a perception and a thought or chain of thoughts; thoughts trigger emotions and other changes in the energy body, which in turn trigger changes in the physical body. Level 4, the intuitive body, is a level beyond the mind and beyond language; it is the home of near-death experiences, past lives, archetypes, spirit possession, ecstatic states and expression of unresolved trans-generational family issues. Level 5, the spirit body, is the plane of self healing (76).

Traditional healing and CAM use the holistic approach or model to health care. However, some critiques of this model argue that not all components of traditional healing and CAM are holistic (77, 78). In this regard, no single model of health care is capable of meeting the entire range of human needs at the time of illness and disease (79). In addition, there is limited information in this area being investigated. Hence the need for this thesis to be based on all the three models in order to achieve a comprehensive view.

4. RATIONALE FOR THE STUDIES

Despite the prevalent use of traditional healing systems by communities in Africa, little information is available about the types of mental health problems that traditional healers manage. Furthermore, there is almost no documented information about the outcome of their treatment; yet 60 - 80% of the population in Africa, including Uganda, go to traditional healers for various health reasons (1) and about 40-60% of these have mental health problems/illness (80, 81).

Although evidence shows that many countries of the world, including Uganda, use both modern and traditional healing systems, the service providers in the two systems have little knowledge about each other's potentials and therefore rarely appreciate each other's contributions. This is more pronounced in the care of mental health problems (25).

The present move towards primary mental health care and community psychiatry confronts professionals more than ever before with the reality that they need to engage with and understand the traditional healing practices in order to forge a meaningful collaboration with them. Having more than one perspective about the diagnosis of mental illness and, in many instances, being conscious of the local models of illness may help in recognizing and treating mental illness appropriately (72).

Whatever forces are driving the use of traditional healing in mental health, the actual benefits of this approach to treatment are not clear. There is limited basic and clinical research data regarding traditional healing practices in Uganda, especially as they relate to mental health/illness, psychosis in particular. For example, little guidance from systemic studies exists regarding optimal doses of herbal medicines, contraindications, drug-to-drug interactions and potential toxicities. The non-herbal treatments are even less studied and there are no outcome data (1). The Uganda Ministry of Health has conducted studies on plants with pharmacotherapeutic effects but little has been done in the field of mental health. There is no legal framework for the practice and use of traditional medicine in the country. However, the National Health Policy does recognize the general role played by traditional healers.

The results of this study may be used to promote an understanding of mental health and mental illnesses from both traditional healers' and mental health workers' perspectives, particularly in regard to psychosis. This interaction could be incorporated in the medical training of students in Uganda and may be useful in policy formation and planning for mental health services delivery at primary health care level.

5. STUDY OBJECTIVES

5.1. GENERAL OBJECTIVE

The general objective of this thesis was to study the profiles of mental disorders as seen in traditional healing practices and evaluate the outcome of traditional healers' treatment for severe mental disorders in two districts in Eastern Uganda.

5.2. SPECIFIC OBJECTIVES

The specific objectives of each of the studies were formulated as below:

The Pilot study
I. To document the lay concepts of psychosis among the Basoga in Eastern Uganda.

Study I generated information for the local adaptation of the instruments used in studies II-IV.

The Profile studies
II. To describe the psychological distress and associated factors of the attendees of traditional healing practices in the Jinja and Iganga districts of Eastern Uganda.
III. To describe the prevalence and severity of mental disorders treated by traditional healers in two districts in Eastern Uganda.

The Outcome study
IV. To evaluate the naturalistic outcome of treatment of psychotic disorders by traditional healers in the Jinja and Iganga districts.

6. METHODS USED IN THE STUDIES

This thesis is based on four studies. This section will detail the methods used in these studies. Area of study and context, data management, data analysis and ethical issues will also be included in this section.

6.1 AREA OF STUDY AND CONTEXT

These studies were carried out in two districts of Uganda, namely Jinja and Iganga. These districts are in the Busoga region, which is situated in the south-eastern part of Uganda with a population of 3 million and an area of 7100 sq. miles (82). The Basoga are the eastern neighbours of the Baganda. They occupy a region covering the administrative districts of Kamuli, Jinja, Iganga, Kaliro, Namutumba, Bugiri and Mayuge. Each is headed by democratically elected chairpersons or a Local Council Five Chairman (L.C.5). Figure 2 shows a map of Uganda and the location of the Busoga region and specifically the Jinja and Iganga districts. Busoga comprises the 11 principalities of the Basoga people and is one of the largest of the five traditional kingdoms in present-day Uganda. The kingdom's capital is located in Bugembe, which is near Jinja. Jinja is the second largest city in Uganda and is Busoga's industrial/economic hub. Busoga is bounded on the north by the swampy Lake Kyoga, which separates it from Lango, on the west by the Victoria Nile, which separates it from Buganda, on the south by Lake Victoria, which separates it from Tanzania and Kenya, and on the east by the Mpologoma River, which separates it from various smaller tribal groups (Padhola, Bugwere, Bugisu, etc). Busoga also includes some islands in Lake Victoria, such as Buvuma Island.

The majority of the Basoga are Christian, the rest practice Islam or African traditional religion; many Christians and Moslems practice a combination of their religion and African traditional religion.

The language is *Lu-Soga*, which is very similar to Luganda, spoken by the Baganda. There exist many Lusoga dialects.

Figure 2: Map of Uganda showing the location of Busoga region and specifically Jinja and Iganga Districts
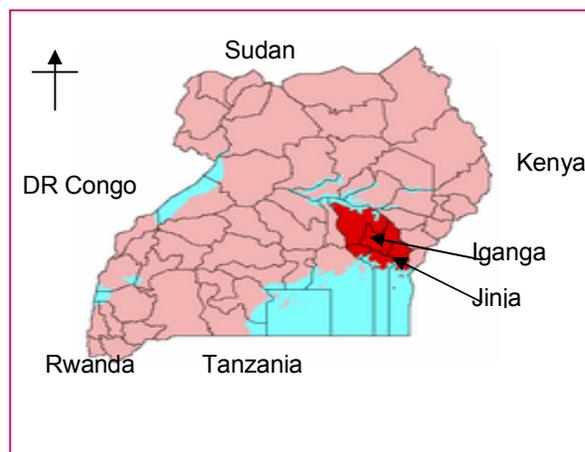
The Basoga are classified as one of the Bantu ethnic groups. However, they are located between the two major linguistic ethnic and cultural groupings: the Lou Nilotics to the north and east and the Bantu peoples to the south and west, thus having an interesting cultural mix.

These studies were carried out in two districts in Busoga. Below is a brief description of the health care service situation in the two districts.

Health care services in the Jinja and Iganga districts

Jinja district: Borders the districts of Iganga and Kamuli to the north, Mukono to the southwest, Kayunga to the west, Mayuge to the east and Lake Victoria to the south. It is the western portion of the former Busoga district. The district has a total population of 413,996, of whom 206,709 female and 207,287 male (82).

Health services: The district has 36 government dispensaries (Health Centre II), 13 Health Centres III at county level, 4 Health Centres IV at sub-district level and 1 hospital. In addition, there are 9 private/NGO dispensaries, 26 clinics and 3 Health Centres III and 1 private hospital. Jinja Hospital has 443 beds and Kakira Hospital has 100 beds. In terms of mental health services, there is one psychiatrist and 9 psychiatric clinical officers.

Iganga district: Borders the districts of Bugiri and Tororo to the east, Jinja and Mayuge to the west and northwest and Pallisa to the northeast. The district has a total population of 716,311, of whom 371,891 are female and 344,420 male (82).

Health services: The district has 43 government dispensaries (Health Centres II), 20 Health Centres III at county level, 4 Health Centres IV at sub-district level and 1 hospital. In addition, there are 26 private/NGO dispensaries, 31 clinics and 1 Health Centre III. The Government District Hospital has 117 beds and the Uganda Catholic Medical Bureau-St Francis, Buluba, has 164 beds. In terms of mental health services, there is one psychiatric clinical officer.

6.1.1 The setting: The shrine

Traditional healers (T/H) have their place of practice within the community. It is usually separate from their place of abode but nearby or within the compound. This place of practice or shrine is often a grass-thatched hut (illustrated on the cover). It is in such huts that clients who are admitted are hospitalized. Inside the shrine, the floor is usually covered with mats *(mikeeka)*. In one corner there may be containers of medicines in the form of dried leaves, roots, and bark of trees of varying texture, animal skins, dried animal meat or bark cloth or animal or mineral matter such as certain clays or natural salts.

The healers usually sit on bark cloth or skin. In front of them are the 'diagnostic' tools, which included cowrie shells, beads or sticks wrapped in bark cloth and put in a basket. Some shrines may have a curtain of bark cloth that separates the sleeping or resting area from the working area.

6.2 DATA COLLECTION METHODS

Both qualitative and quantitative methods were used. To elicit lay concepts of psychosis in the local community (Study I), focus group discussions using case vignettes were employed. For Studies II and III, cross-sectional surveys were carried out to determine the magnitude of and factors associated with psychological distress and other mental illnesses. To determine the outcome of treatment of psychosis by traditional healers, a prospective cohort study was carried out (Study IV). Details of the methods follow below with a summary in figure 3:

6.2.1 Focus Group Discussion

Focus Group Discussion was chosen as a useful tool for exploring topics connected with group norms and the group meanings that underlie those norms (83). Focus groups generate alternative views on an issue and the intention is not to reach consensus. Focus Group Discussion does not require formal training of moderators and observers but the literature does recommend interpersonal skills (83). An advantage of using Focus Group Discussion to collect original data is the connection with oral traditions, which makes it preferable when participants have little or no educational background. Further, Focus Group Discussion is relatively easy to arrange, inexpensive and flexible in terms of format, types of question and desired outcomes but it takes time to analyse.

6.2.2. Case vignettes

The vignette technique is a method that can elicit perceptions, opinions, beliefs and attitudes from responses or comments to stories depicting scenarios and situations (84). Vignettes are employed in different ways and for different purposes (84). Some of the major differences are: whether they are used as a self-contained method or an adjunct to other research techniques; how the story is presented; at what stage in the data collection process they are introduced; and how responses are structured. Nevertheless, vignettes generally fulfill three main purposes (85). These are:

1. Interpretation of actions and occurrences that allows situational context to be explored and influential variables to be elucidated.
2. Clarification of individual judgments, often in relation to moral dilemmas.
3. Discussion of sensitive experiences in comparison with the 'normality' of the vignette.

Vignettes can be used with participants individually or within a 'focus' group, a method that is becoming increasingly popular with social researchers (86). However, little has been written about the use of vignettes in groups, although it is often used as a warm-up exercise to get participants to start talking to each other (87). In this thesis, case vignettes were used as an adjunct to guide the focus group discussions.

6.2.3. Surveys

Surveys are either cross sectional or longitudinal; specific timing of measurements is ideally well-matched to the research questions and the phenomena that are being studied (88). In cross-sectional surveys (Studies II and III), information is obtained at a single point in time, while in longitudinal surveys (study IV), information is obtained repeatedly, on two or more occasions. The main emphasis in surveys is on their descriptive information-gathering capacity rather than on the goal of testing causal relationships (89).

In Studies II and III, cross-sectional surveys were conducted in patients aged 18 years and above attending traditional healing practices.

In these studies, patients who attended traditional healing practices in the Jinja and Iganga districts between January and March 2008 were consecutively recruited and screened using the Self-Reporting Questionnaire (SRQ-25). This was estimated with the Kish Leslie formula for single proportions for descriptive study (90). The sample size was determined assuming a prevalence of 48% for psychological distress at the traditional healer's facility (80). On the basis of this assumption, at a 95% confidence interval with a 5% level of precision, a total of 400 clients were consecutively recruited. The level of significance was set at $p < 0.05$.

Those who had a cut-off point of 6 and above for the first 20 questions and/or any 'yes' answer to any of the four questions that screen for psychosis were administered the diagnostic instrument, the Mini International Neuropsychiatric Interview (MINI plus) to make specific diagnosis.

In Study IV, patients who had been screened using SRQ-25 and had been diagnosed using MINI as having Psychosis (schizophrenia, mania or psychotic depression) in Study III were subjected to the respective instrument to measure severity (clinical outcome), i.e. the Positive and Negative Syndrome Scale (PANSS) for schizophrenia, the Young Mania Rating Scale (YMRS) for mania and the Montgomery-Åsberg Depression Rating Scale (MÅDRS) for depression. In addition, the Global Assessment of Functioning (GAF) was used to measure general severity (functional outcome).

Subjective well–being was also measured, using COMPASS Mental Health Index (5). Objective improvement was assessed using the Clinical Global Impression (CGI). Only patients diagnosed with psychosis were to be followed up and previous studies had estimated that about 60% of patients who go to traditional healers have psychosis (91). Thus it was estimated that 132 patients, including loss to follow-up, would be followed up. All the instruments were translated in the local language of Lusoga and back translated, modified accordingly and adapted.

6.3 SAMPLING OF TRADITIONAL HEALERS

All traditional healers who could be reached in the two districts were included in the study. The number of patients per traditional healer per district was worked out proportionately. According to the register, at the time of the study there were 180 traditional healers in Jinja district and 60 in Iganga district. This gave the following calculation:

Total number of traditional healers: 180+60=240.

Total number of patients recruited in Jinja district: 180/240x400=300 patients.

Total number of patients recruited in Iganga district: 60/240x400=100 patients.

Number of patients per traditional healer:
> Jinja district: 300/240=1.25; rounded off to 2 patients per traditional healer.
>
> Iganga district: 100/60=1.67; rounded off to 2 patients per traditional healer.

Therefore at least two patients per traditional healer in each district were assessed.

6.4 DATA COLLECTION PROCEDURE

The four research assistants were psychiatric clinical officers who work in Jinja and Iganga district health units and the hospitals. They are clinical officers with sufficient knowledge and training to make a psychiatric diagnosis using the MINI Plus. The research assistants had training by the author of this thesis in the use of the instruments (one day for each instument). At the start of data collection, it was evident that the MINI plus was the most difficult to fill appropiately. Thus the author of this thesis carried out consistent and regular checks of all the questionaires twice a week and during this process retraining would take place. In addition, where the diagnosis was not clear, a clinical psychiatric evaluation was done. This was done particularly for the patients to be followed up.

After making a diagnosis of psychosis, they administered the severity questionnaire, depending on the type of psychosis and detailed contact with the patient, including telephone contact, and the L.C.I chairperson in the area. Appointments for follow-ups were then made for visits in the patient's home at three months and at six months.

Figure 3: Summary of methods used in the studies I-IV

Studies II &III

Profile study
Aim: To describe the profiles of mental disorders treated by traditional healers.
Subjects: Patients at T/H's shrine
Design: Cross-sectional descriptive
Sample Size: 400
Tools: SRQ-25, MINI plus

Study I

Pilot Study
Aim: To describe lay concepts of psychosis among the Basoga.
Subjects: Local people and T/Hs
Design: Qualitative
Tools: FGDs and Case Vignettes

Study IV

The psychosis study
Aim: To determine symptom outcome and subjective well-being.
Subjects: Patients at their homes
Design: Prospective cohort
Tools: PANSS, YMRS, MADRS, MHI, GAF, CGI

Patients with psychosis from study III

6.5 DATA MANAGEMENT

6.5.1 Qualitative data for Study I

Data were tape recorded and supplemented with field notes. Tape-recording allowed us to get details and accuracy that would not be available from either field notes or memory (92). Tape-recording also allowed more eye contact between the moderator and the respondent. Although tape-recording was important for us, it did not prevent us from getting the non-verbal communication that could not be tape-recorded (92).

Interviews were transcribed in accordance with guidelines for handling qualitative data (86). The whole interview was translated literally from Lusoga into English from the cassette recorder and then written down verbatim by a bilingual speaker. These transcriptions were checked, evaluated and edited by another bilingual speaker. After transcription, the author read through the transcript several times and grouped the content by themes with the help of an experienced medical anthropologist and senior scientist with PhD. The original version was kept even after the transcription.

6.5.2 Quantitative data

Completed forms were checked for completeness, consistency and accuracy on a daily basis and before data entry into a computer. Epidata was used for data entry and the data analysis was performed using SPSS version 15.0 for Windows.

6.6 DATA ANALYSIS

6.6.1 Manual content analysis

Analysis of data from Focus Group Discussions followed steps described by Warden and Wong (93). The basic steps are shown in the figure 4 below.

Figure 4: Basic steps taken in qualitative data analysis

18
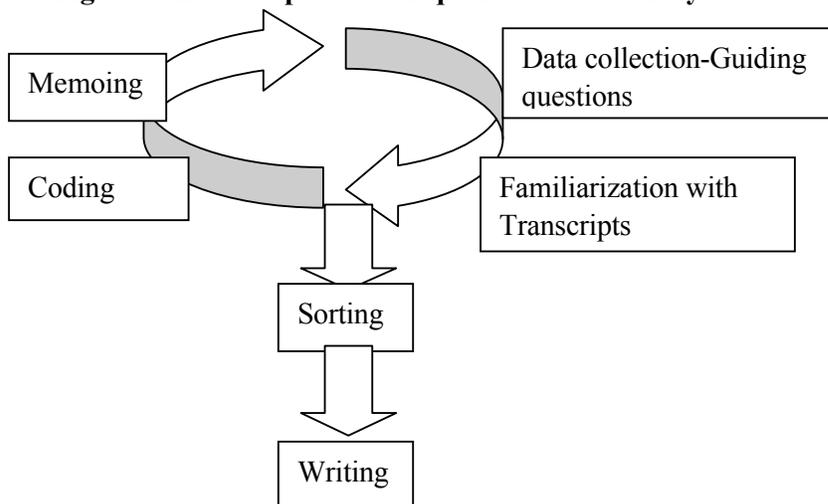
The case vignettes had guiding questions to produce transcripts. A bilingual clinician transcribed the recorded discussions verbatim. The researcher then read through the transcripts several times to become familiar with the data. Coding (highlighting ideas, categories or themes) of the data according to the questions discussed took place as the researcher read through the transcripts. This was done by placing expressions, lines or paragraphs (sorting) that described similar codes on the left-hand side. Common themes or patterns that emerged were then placed together and interpreted.

6.6.2 Logistic regression

For Study II, associations between socio-demographic factors and psychological distress were evaluated using an SRQ cut-off point of at least 6 of the first 20 items of SRQ. This level was based on reports from validation studies conducted in Kampala and elsewhere in Africa (94-97). Multivariate logistic regression was applied to produce odds ratios (OR) of associations between independent demographic variables and outcomes of cut-off points of SRQ, and adjusted to address the influence of other significant variables. Based upon the cut-off levels, the outcome of psychological distress was dichotomized into respondents exhibiting psychological distress (≥ 6 'yes' answers) and those not exhibiting psychological distress (≤ 5 'yes' answers).

Continuous independent variables were categorized for the analysis. All demographic data which were statistically significant (P<0.05) following a univariate analysis to test for the strength of association were included for the multivariate analysis.

For Study III, the relationship between severity and the combined use of biomedical services and traditional healers was explored using Pearson's chi–square tests and odds ratios. For Study IV, bivariate and multivariate analyses were used to determine factors associated with outcome.

The level of statistical significance was set at 5% (i.e. P<0.05).

6.6.3 One-way ANOVA for independent samples

In Study IV, outcome was determined by the mean scores of the scales at the three levels of follow-up (i.e. point of first contact as baseline and three and six months later). The mean scores were calculated using one-way ANOVA for independent samples. The Turkey HSD test was used for post-ANOVA comparisons.

6.7 ETHICAL CLEARANCES AND CONSIDERATIONS

The study was approved by the local research ethics committee at Makerere University, the National Council of Science and Technology (HS 323) and the Research Committee (Forskningsutskottet), Ethical Council, at the Karolinska Institutet (Dnr 05/07). The Office of the Resident District Commissioner, Jinja and Iganga districts, and leaders of traditional healers also approved the study. Every participant gave informed verbal and written consent.

For Study I, ethical issues in qualitative research differ somewhat from other data collection methods in terms of consent, confidentiality, anonymity, privacy and voluntary participation (98-100). What was important was the responsibility of the individual focus group's code of conduct regarding the above. The moderators accordingly had another set of ground rules to which everyone had to adhere. Focus group data were collective data and had to be treated as such. The ground rules and reciprocal trust were negotiated upfront for the shared protection of all participants (98). This was particularly crucial because the topic under investigation was sensitive. The other ethical issue in Study I concerned dealing with perceptions of mental illnesses from the biomedical point of view. During the collection of these data, it was clear that the perceptions of some participants differed from the biomedical view of the causation of mental illness and therefore its treatment. In addition, there was a demand from the participants for information about biomedical aspects of the cases under investigation. This could not be dealt with during data collection because that would have biased the whole process. The solution was to organise an open discussion after the FGDs to answer some of the questions. However, we did not attempt to impose the biomedical view of mental illness on the participants.

Studies II-IV were conducted at the traditional healers' shrines; this raised special ethical concerns regarding traditional healer's clients who needed life-saving interventions. We dealt with this by discussing with the traditional healer the possibility of referring the patient to a health center. We did not collect any data from these patients.

6.8 TIMELINE FOR THE FOUR STUDIES

Table 2. Timeline for the four studies

Time/year	Activities
June 2005	➢ Writing of concept paper begins
2006	➢ Concept paper approval by ethical committee
	➢ Provisional registration at Makerere University
	➢ Writing of full proposal
2007	➢ Pilot study carried out (Study I)
	➢ Approval of full proposal
	➢ Full registration at Makerere University
	➢ Registration at Karolinska Institutet
	➢ Ethical approval from Karolinska Institutet
	➢ Data collection for Studies II, III and IV starts
2008	➢ Data analysis and writing Studies II, III and IV
	➢ Half time seminar control
2009	➢ Writing of thesis and defense

7. RESULTS

7.1 LAY CONCEPTS OF PSYCHOSIS (I)

This was a pilot study to explore the lay concepts of psychosis among the local people in the study area. The themes that emerged were categorized as follows:

I)   Identification/classifying/naming of the illnesses
II)   Perception of causation of the illnesses
III)   Suggested treatment of the illnesses

All the participants agreed that they had seen or dealt with individuals like those in the three case vignettes. They differentiated the severe mental illnesses by giving them different names. Schizophrenia was called *eddalu* or *ilalu* (madness), which they regarded as more serious than mania. They called Mania *kazoole,* describing it as an illness with intervals of normality, and Psychotic depression as an illness of "thinking too much," relating it to social adversity. *Kalogojjo* was the name given to Minor forms of mania. The traditional healers were reluctant to give the illnesses names, emphasizing that their interest is not in the naming of the illness but in making the patient better.

This seems to tally with Hippocrates' dictum:

"It is more important to know what sort of person has the disease than to know what sort of disease a person has" (101).

Regarding causation and treatment, schizophrenia and psychotic depression were generally said to be caused by family/clan issues, including ancestral spirits and witchcraft, which called for the performance of rituals. Physical complaints, e.g. HIV and malaria, were mentioned as the cause of mania; referral to hospital was then mentioned as part of the treatment, in addition to the traditional healer's herbal treatment.

A few participants thought that the patient with mania was not ill but was exhibiting God's power or backsliding; faith healing was therefore mentioned as the appropriate treatment. Substance misuse came up as causes of the above illnesses, with a tone of condemnation. The figure below illustrates the relationship between perceived causation, help-seeking and a holistic model.

Figure 5: Emic illness concepts from Focus Group Discussions, their interrelationships, perceived causation, severity and choice of treatment

The five levels of healing: P=Physical, E=Energy, M=Mental, I=Intuitive, S=Spiritual.
B=Body: Adapted from Rutebemberwa (63) and Klinghardt (76)
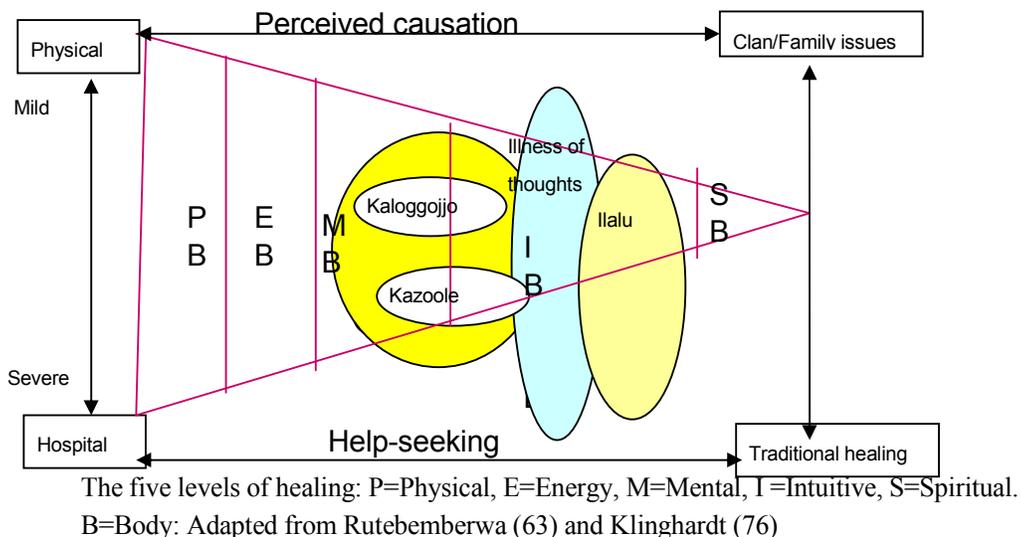
7.2 PREVALENCE AND ASSOCIATED FACTORS OF PSYCHOLOGICAL DISTRESS (II) AND MENTAL ILLNESS (III)

Study II aimed to determine the magnitude and associated factors of psychological distress among persons who attend traditional healing. Of those attending traditional healing practices, 252 (65.1%) scored 6 or more on SRQ 20. They were therefore classified as having psychological distress. In terms of gender, 70.4% of the males were distressed compared to 61.2% of the females but the difference was not statistically significant. The multivariate logistic regression analysis of the associations between demographic variables and the outcomes of psychological distress revealed that married females with co-wives were over three times more likely to be distressed than those who were the only wife (P =0.012; OR 3.62 [95%CI 1.38-10.98]). In contrast, married men with more than one wife seemed to be protected for psychological distress (P= 0.001; OR 0.20 [95%CI 0.06- 0.63]), suggesting that polygamy is psychologically protecting for men but psychologically distressing to women.

Among other socio-economic indicators, persons who had lacked food at least once in the past month or who were in debt were twice as likely to be distressed; (P= 0.001; OR 2.52 [95%CI.1.25-4.72]) and (P= 0.002; OR 2.52 [95%CI 1.40-4.53]), respectively. Respondents who were attending the traditional healer's place both for treatment and for explanations for their illness were twice as more likely to be distressed (P =0.02; OR 2.17 [95%CI 1.33-3.34]) as those who wanted treatment only. On the other hand, those who stated they had visited a health centre as well as the traditional healer for the same problems were less likely to be distressed (P<0.001; OR 0.28 [95%CI 0.18-0.44]).

In Study III with 387 respondents, 233 (60.2%) had at least one current diagnosed disorder. There were 63 (16.3%) who had experienced at least one disorder in their lifetime, while 170 (44%) had had two or more episodes. Psychosis was most frequent, occurring in 115 (29.7 %) of the sample, 5.4% major depressive episode; 5.6% anxiety disorders; 3.6% mixed anxiety-depression; and 3.9% suicidality. In terms of severity, 37.7% of the current mental illnesses were severe, 35.1% moderate and 13.2% mild.

The exploration of the relationship between GAF scores, number of episodes, combined use of traditional healing practices, and a positive family history revealed that patients with GAF scores in the moderate and severe range were more likely to have a family history of mental illness (P<0.0001), to have had two or more episodes previously (P= 0.06 and 0.03 respectively) and to have sought help from traditional healers and biomedical services for the same problems (P<0.0001).

7.3 OUTCOME OF TREATMENT (IV)

This study was a follow-up of a cohort of patients with severe mental illness attending traditional healers. There was a general trend for symptom scales to show a reduction at the 3- and 6-month follow-ups. The percentage reduction was greatest for PANSS (30%, 40%), followed by YMRS (21%, 28%) and MÅDRS (29%, 20%). However, in terms of patients' cut-off points for diagnosis, the general improvement at 3 months was greatest in patients with mania (54.0%), less so with psychotic depression (42.0%) and least with schizophrenia (14.8%). At 6 months, the percentage of patients who showed an improvement was as follows: mania (58.3%); psychotic depression (46.4%) and schizophrenia (30.7%). One-way ANOVA for independent samples analysis showed that the differences between the mean scores of the scales were all significant (P<0.0001). The Turkey HSD tests were also all significant at P <0.01 except for MÅDRS, where severity of depression did not differ significantly between 3 and 6 months.

Traditional healing and biomedical services were used concurrently by over 80% of the subjects, of whom the majority were patients with mania. Concurrent use was greatest in the first three months of follow-up. At bivariate level of analysis, poor economic status, early age of onset, longer duration of symptoms, previous episodes, positive family history, current illness severity, and co-morbidity were factors significantly associated with poor outcome. In multivariate analysis, only two variables – combined use of biomedical services and traditional healing, and socioeconomic status (represented here by being in worrisome debt) – remained significant at both the three- and the six-month follow-up. Those who combined treatment were less likely to be cases at the three-month follow-up (P =0.002; OR 0.26 [0.15-0.58]) but more likely at the six-month follow-up (P= 0.020; OR 2.05 [1.10-3.19]). Being in worrisome debt was associated with caseness at both three and six months, P <0.001; OR 11.21 [6.58-17.26]) and P=0.01; OR 2.23[1.41-3.53], respectively.

8. DISCUSSION

8.1 MAIN FINDINGS

This thesis highlights the local concepts of psychosis among the Basoga, the burden of care of mental health problems born by traditional healers and the outcome of treatment of psychosis by traditional healers. More than half of the attendees of traditional healing practices have psychological distress. Associated factors include poverty, number of children, polygamy, reason for visiting the healer and use of both traditional healing and biomedical services. In addition, a considerable number have DSM-IV diagnosable mental disorders, the majority with moderate to severe symptoms. The follow-up study of patients with psychosis suggests that combining biomedical services and traditional healing may have some positive effects for patients.

8.1.1 Universality of psychosis and influence of culture

Psychosis is a characteristic of human populations, not of the circumstances or manner in which the populations live. It is an affliction of humanity and its origins are closely related to those of the species (102).

However, experience and understanding of symptoms of psychosis are embedded in a network of local meanings that vary from nation to nation, within different subcultural groups in a single nation and over time as communities undergo social changes (103). Culture influences individuals' perception of the world, the content of their thoughts and therefore the form and quality of symptoms (104). It helps to determine the interpretation of symptoms and their subsequent social impact and guides both help-seeking and the response to treatment. At group level, culture can be considered important not only in defining and creating specific modes of coping with distress but also in providing specific modes of coping with distress and social responses to distress and disability (104).

In order to conduct culturally sensitive assessments of mental illness with western research instruments, we employed both emic and etic approaches.

8.1.2 Burden of care of mental illness on traditional healers

The care of people with mental and brain disorders is a growing public health concern. These disorders are highly prevalent and exact a high emotional toll on individuals, families, and society. Worldwide, community-based epidemiological studies have estimated rates of lifetime prevalence of mental disorders among adults, ranging from 12.2% to 48.6%, and 12-month prevalence rates ranging from 8.4% to 29.1% (105, 106). These rates do not include neurological conditions affecting the brain. The WHO has estimated that in their lifetime, approximately 450 million individuals worldwide suffer from neuropsychiatric disorders (54).

The WHO has reported that the treatment gap for serious disorders is 76 to 85 percent for low- and middle-income countries (50,106) and also states that shortages of healthcare professionals have been shown to be the main factor that limits the delivery of mental healthcare in most of these countries. Our studies suggest that when people need help, they look for it wherever it can be found. Thus, in this study, a traditional healer, present in every village, bears the burden of the community's mental illnesses. Further research is necessary on the effectiveness of treatment by traditional healers to help us understand their role in reducing the burden of mental illnesses (107).

8.1.3 Use of biomedical health care and traditional healing: A holistic approach

Holistic medicine is a system of health care which fosters a cooperative relationship among all those involved, leading towards optimal attainment of the physical, mental emotional, social and spiritual aspects of health (76). It emphasizes the need to look at the whole person, including analysis of physical, nutritional, environmental, emotional, social, spiritual and lifestyle values. Health cannot be achieved without achieving a balance in life with others and with the environment. Beliefs, values and attitudes affect health and must be part of the cure (76).

The current health system tends to place overt emphasis on a commitment to the biomedical model; too much is invested in this model, yet it tends to avoid the personal dimension (74). According to the holistic integrated model of health and healing, we exist in five different dimensions simultaneously and our patients need care on every level of existence (76). Although the design of this study did not allow for comparisons with patients who use biomedical services only, results of studies II and IV suggests that patients who use both biomedical services and traditional healing may fair better than those who do not combine these forms of care.

The current mental health care system can be characterized as fragmented and disintegrated. Fragmentation is to be found within psychiatric services. The hospitals have a small range of mental health professions. Professional competence is bound by tradition. Medical core competence is still seen as somatic diagnosis and therapy, particularly in psychopharmacology (75). Efforts at professional integration face many barriers (64). Another form of fragmentation may be far more serious for patients. It is the fragmentation of the professional health care providers. Contacts between hospital professionals and health workers are virtually non-existent at community level. The patients' daily world and its related problems are scarcely present inside the hospital. The very few mental health professionals are unable to know their patients' homes. Basic skills for coping with daily life and basic social and communicative techniques that could make life easier for the mentally ill remain a distant prospect.

The current mental health care system and its fragmentation would not cause concern if there were a recognized facilitated integrating body that could adequately unite all forces for the patient's comprehensive needs. But, at least in Uganda, this does not exist; mental health professionals and traditional healers operate separately.

It became clear to the WHO thirty years ago and it should be clearer now to the global health movement that timely joint efforts are the main component of an optimized mental health care system. A range of options has been suggested (17). They range from banning traditional healers and hunting them down so that their practices are stopped, through options such as the retention of the status quo (with western health care in the formal sector and traditional healing in the informal sector) with pockets of co-operation, to alternatives in which the state actively intervenes to achieve collaborative, incorporative or integrative programs (17). Within the fragmented and disintegrated system of today's psychiatric care in Uganda, it may be impossible to meet patients' needs, at least in the near future.

The next section discusses methodological considerations, focusing on validity issues in transcultural psychiatry and levels of the quality of evidence. Although this thesis is about outcome and not healing mechanisms, we feel that some discussion of those mechanisms is relevant. This is also included in the next section.

8.2 METHODOLOGICAL CONSIDERATIONS

8.2.1 Validity issues in transcultural epidemiology

Problems of validity are more likely to occur in transcultural epidemiology – defined here as when the views, concepts or measures of the investigator extend beyond the scope of one cultural unit to another (108). The context of research affects research validity. Realistic and effective methods for reducing uncertainty in findings of transcultrual studies are available and were used in this thesis. We achieved diagnostic validity by first exploring the lay understanding of psychosis (Study I), which gave us ideas about local concepts and phrases used to describe symptoms, syndromes, course and clinical features of psychosis. This gave us evidence that psychosis exists in this community in forms similar to those cultures from which the standardized instruments came.

Literal translation can reduce content validity (109), which is the extent to which a measure's content represents the concept to be assessed. To maintain content validity, locally meaningful equivalent terms were substituted (109).

Regarding criterion-related validity, which is the strength of the relationship between the measure and the measurable external criterion (the ideal external criterion is considered to be diagnosis by independent clinicians who are trained in using semi-structured diagnostic instruments that have evidence for measurement validity and reliability), we used clinicians who are trained to make psychiatric diagnosis and trained them in the use of a semi-structured diagnostic instrument, the MINI-Plus.

Users of epidemiological data, such as policy-makers, need to know to what extent findings have external validity, i.e. generalizability to the target population, or other populations and across time and place. Generalizability to the target population depends on the ability to randomly draw a representative sample from the entire population of relevant persons (109). The ability to do so requires the availability of reliable registers with contact information for the entire target population. In our studies, we used the registers of traditional healers in the two districts. However, for various reasons, not all traditional healers are registered. Generalizability to the target population also depends on the study's participation rate, i.e. the percentage of sampled people who are willing to participate in the study. In our study, no participant refused to take part, which enhanced out external validity.

The extent to which findings from one cultural unit can be generalized to other populations is still a matter for debate. Not much is known about the generalizabiltiy of epidemiological findings across populations (109).

In a qualitative study, one potential bias is researcher bias (i.e. searching for and finding or confirming only what you want or expect to find). Two strategies that were used to reduce researcher bias were reflexivity, i.e. constantly thinking about our potential biases and how we can minimize their effects, and negative case sampling (attempting to locate and examine cases that disconfirm your expectations). We used the following strategies to promote the qualitative aspect of the study:

Verbatims (i.e. direct quotations) as low-inference descriptors; focus groups consisting of men and women of varying ages; local people and traditional healers served for data triangulation; and multi-disciplinary researchers for collecting, analysis and interpretation of data (investigator triangulation). In addition, we had a feedback and discussion of our interpretations and conclusions with the actual participants and other members of the participant community for verification and insight. Discussion of our findings with other

peers included one senior researcher and clinician who is not engaged in our research; peers who are familiar with the research helped to provide useful challenges and insights.

8.2.2 Outcome measures in psychiatry and levels of evidence

Mental health care increasingly faces a challenge to be 'evidence-based'. Mental health professionals are encouraged to practice only evidence-based care. Researchers are supposed to provide the evidence on which mental health care is to be based. However, this raises the questions of what constitutes evidence and to what extend we agree on what is regarded as evidence. There are large variations in the quality of scientific evidence that may exist in support of medical diagnoses and treatment (110). Lawrence and Mickalide has stratified the quality of evidence from best to worst (35). Table 3 below illustrates levels of evidence.

Table 3: Quality of evidence of effectiveness of intervention

Rank	Methodology	Description
1	Systematic reviews	A statistical analysis that combines or integrates the results of several independent clinical trials considered by the analyst to be 'combinable' usually to the level of reanalyzing the original data, also sometimes called: pooling, quantitative synthesis.
	Meta-analysis	Review of a body of data that uses explicit methods to locate primary studies, and explicit criteria to assess their quality.
	Prospective, masked randomized controlled clinical trials	Individuals are randomly allocated to a control group and a group who receive intervention. Otherwise the two groups are identical for any significant variables. They are followed up for specific end points.
2	Cohort studies	Groups of people are selected on the basis of their exposure to a particular agent and followed up for specific outcomes.
3	Case control studies	'Cases' with the condition are matched with 'controls' and retrospective analysis is used to look for differences between the two groups.
4	Cross-sectional surveys	Survey or interview of a sample of the population of interest at a point in time.
	Case reports or case series	A report based on a single patient or subject; sometimes collected together into a short series.
5	Expert opinion	A consensus of experience from the good and the great.
6	Anecdote, Clinical experience	A conversation.

The third phase of the study was basically at the level of an uncontrolled cohort study, where patients were enrolled who were receiving traditional healing treatment from the shrines, but there was no control group. A study protocol specified the characteristics of subjects, treatment and outcome measures. Because there was no control group, the

results of this particular study should be interpreted with caution as a number factors could have biased (defined as a systematic overestimation or underestimation of the effects of treatment) the results (111). Some of these factors are discussed below:

The Hawthorne effect: the tendency of subjects to do better solely because they are being studied (112, 113). This may involve subjects' expectations but can also be a result of nonspecific effects of the study situation, such as increased attention.

The Pygmalion effect and co interventions, also called the experimenter expectancy effect: experimenters' expectations of effects of treatment may result in differential attention to or interaction with some subjects and thereby lead to a change in subjects' behaviour towards the experimenter's hypothesis (114). A related effect is that of a clinician involved in the study providing additional care (e.g. time, support) to patients in the study group. This effect is known as performance bias (112).

The third nonspecific effect is the placebo effect (115, 116). In this effect, it is the subject's expectation of an improvement, combined with other nonspecific psychotherapeutic effects, that leads to improvement (116). The magnitude of the placebo response varies between disorders. It is greater in depression and anxiety than in schizophrenia and mania (117).

The final important source of bias is observer, detection or ascertainment bias (118). If an interviewer or rater knows which treatment a patient is receiving, he or she may differentially inquire about certain systems or see an improvement where none exists. In our study, this was minimized because the raters did not know what the traditional healers were giving the patient.

Despite the above sources of bias, we nevertheless believe that the results of the outcome study may provide a stepping-stone for future research in this area. Although methods vary in the strength of the evidence they produce, every method, when used appropriately, can lead to valuable conclusions (119). All these study designs have merits and all can produce useful findings (119). In fact, new medical knowledge is most often obtained through observational means, whether through a complex prospective cohort study or through a simple case series. This is typically an important first step in understanding an effect on the particular outcome of a previously unconsidered factor (120).

8.2.3 Proposed mechanism of action of traditional healing

The positive effects of traditional healing and CAM have been attributed to a placebo, defined as 'any therapy prescribed knowingly or unknowingly by a healer, or used by laymen, for its therapeutic effect on a symptom or disease, but which actually is ineffective or not specifically effective for the symptom or disorder being treated' (121). Placebo effects are also defined as the nonspecific, psychological, or psycho-physiological therapeutic effect produced by placebo, or the effect of spontaneous improvement attributed to placebo (122). Explanations for the placebo effect have been debated in the medical literature for decades. Various mechanisms have been hypothesised: anxiety relief, expectation, transference, meaning effects and conditioning (122, 123). In controlled clinical trials, high response rates in a placebo arm are not uncommon (124). For centuries, it has been known that sick people frequently get better when administered an 'inert' intervention by a healer or medicine man. Despite this, the term "placebo effect" has increasingly had a dismissive tone, used to justify a response that is not properly understood.

At the same time, medical anthropologists are challenging the notion of "placebo", asking how a placebo, by definition an inert substance, can have any effect at all. If it does

something, it is not inert. Something else must be at play (70). Daniel Moerman suggests a very different approach to the problem and uses the term "meaning response", defined as "the psychological and physiological effects of meaning in the treatment of illness". Meaning response is applicable to most of the results traditionally attributed to placebo effect. As a definition it brings the non-physiological elements into treatment success, aiming at a better understanding of this phenomenon (125).

In this thesis, we take the view that treatment 'meaning' plays a substantial role in outcome. There is considerable evidence that placebo effects have strong biological underpinnings (126). Recent research from neuroimaging has revealed that the effect is associated with biological correlates in the brain. The demonstrable therapeutic successes of placebos mean that the question today is not so much whether or how placebos work but rather how we can understand the intrinsic roles of culture, meaning and belief and how they are linked to brain functioning. Placebos place belief and meaning at the centre of the therapeutic encounter. Something more than a neurobiological system is therefore needed to explain how traditional healing works. Morris suggests a biocultural model (124). We know, for instance, that the experience of psychosis is universal but that the expression of symptoms may be culturally specific (101). For example, the experience of delusion by a patient with schizophrenia might depend on the patient's cultural background. But we do not know whether such differences are reflected in structural and functional differences in the brain. In the same line, what happens to the structure and function of the brain when the patient goes to the traditional healer for treatment? This may call for further studies.

9. CONCLUSION

The main conclusions from this thesis:

1. The local people in this study had indigenous names for different types of psychoses and multiple explanatory models for them. Thus, multiple solutions are sought.

2. Traditional healers bear a high burden of care of patients with mental health problems.

3. An overwhelming majority of Ugandans with severe mental illness in the Jinja and Iganga districts use both biomedical services and traditional healing systems.

4. For patients with psychosis, the use of both biomedical services and traditional healing practices seems to confer some benefits.

10. IMPLICATIONS

10.1 POLICY

The enormous existing and planned investment in biomedical services alone strongly favors approaches to the care of patients which emphasize the biomedical model of care. Planning for systems of medical care and their financing is excessively influenced by the availability of evidence of effectiveness, which is often used as the criterion on which policy decisions are based. Clearly, the gap to be closed is between biomedical health workers ready to carry out research in traditional healing and policy-makers eager to change policies for the benefit of the patient.

10.2 MEDICAL EDUCATION AND CLINICAL PRACTICE

Since growing numbers of Ugandan patients use traditional healing, biomedical doctors need to know about potential dangers, including toxicity and drug interaction with herbs. Secondly, knowledge of the patient's use of traditional healing may build a stronger patient-doctor relationship by allowing the patient to speak out and ask questions about traditional healing. This also gives a window into the patient's approach to health and healing. Thirdly, some traditional healing practices, though not adequately studied in well controlled trials, might plausibly improve health outcomes, and patients should not be denied the option of these possibly helpful therapies when dealing with health concerns in the here and now.

Clinical decision-making requires the ability to deal with uncertainty, and the same skills are needed to assess all therapies, whether identified as biomedical or as traditional. Practitioners of biomedicine and traditional healing must both draw on diverse knowledge bases with varying levels of certainty and different ways of knowing. It would be a good development if both practitioners had open, respectful discussions of their different ways of doing things. Exploring this in the context of the medical school curriculum would enrich the dialogue between current practitioners and help develop an open-minded generation of physicians better able to assess the therapies that might help individual patients.

Thus, a growing interest in diversity and training in traditional healing may increase cultural competence. As the boundaries of health care systems become blurred, exploring therapies currently identified as traditional healing may help direct productive biomedical, psychological and socio-medical research agendas.

10.3 RESEARCH

Research identifying effective and ineffective traditional healing practices in mental health contributes to evidence-based medicine and can improve medical care. It can help mental health professionals in deciding whether to support, encourage or counsel against traditional healing practices used by their patients. Perhaps more importantly, given the widespread use of traditional healing, sound research findings will help consumers make more informed personal health care choices. In addition, only through research will the mechanisms of action of effective traditional healing therapies be revealed, with the potential to enhance understanding and treatment of mental illnesses.

Finally, research on traditional healing practices may lead to the discovery of new ways of dealing with the prevalent mental health problems; for example, perhaps the combination of traditional healing practices and modern medicine could be an answer.

11. ACKNOWLEDGEMENTS

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