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Cultural explanatory models of depression in Uganda

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Cover: Two faces of mental health care services in Uganda. Photo by Solvig Ekblad

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ABSTRACT

Background: Depressive disorders are among the most frequent psychiatric disorders, accounting for up to 30% of primary care service utilisation in developing countries in general, and Uganda in particular. However, delays in seeking treatment, misdiagnosis and non-specific treatments have compromised appropriate care for people with depression.

The general aim of this thesis is to explore and describe how depressive symptoms are conceptualised and communicated by the Baganda and how this conceptualisation may influence their help-seeking behaviour and processes. The research questions that the studies aimed to answer were: i) How do the Baganda understand, talk about and cope with depression? ii) What is perceived as effective treatment and how severe must symptoms be to warrant treatment? iii) Are the sub-types of depression seen as constituting one illness?

Methods: The thesis consists of four exploratory papers employing qualitative methods of individual interviews and Focus Group Discussions. Paper I reports preliminary results of a pilot study on lay explanations of causes, effects and help-seeking behaviour for depression among the Ganda cultural group. Twenty-nine adults participated in four focus group discussions and four individual interviews. Paper II reports results of an interview study among 25 adults receiving treatment for depression, regarding their personal and social meaning of depression, their beliefs on causes and consequences of depression, and what triggered seeking psychiatric help. Paper III reports results of the study that aimed to explore the Baganda's conceptualization of psychotic depression in terms of illness identity, causes and treatment. Members of the general population participated in 31 individual interviews and 12 focus group discussions. Unlabelled case vignettes based on DSM-IV criteria for psychotic depression were used as stimulants for discussion. Paper IV reports results of a study exploring traditional healers' explanatory model of depression without psychotic features. Interviews were conducted with 22 traditional healers.

Results: Depression without psychotic features was regarded as illness of thoughts. Depression with psychotic features was regarded as a "clan illness" (*eByekika*), arising from poor relationships between the living and the dead. Both illnesses were perceived as not requiring Western medication but culturally accepted corrective traditional therapies. Patients' illness behaviours, particularly those defined as socially disruptive, were important determinants of entry to psychiatric care. Non-disruptive symptoms were often ignored, misdiagnosed or treated as physical problems by health-care providers.

Concluding remarks: Conceptualisation of depression among the Baganda differs from the Western biomedical model of depression in terms of cause and treatment. Psychiatric help was sought if patients' behaviour became socially disruptive. There are similarities in the conceptualisation of depression between lay people and traditional healers who are the alternative care providers.

Implications for clinical practice: It may be important to review the way depression is managed in the Western form of psychiatry when the patients reach mental health services in hospitals. The noted similarity between the alternative care providers and the users of their service has clinical implications for therapeutic approaches such as psychotherapy, where the agreement between the care provider and care receiver is key in a therapeutic relationship. These results have policy, research and training implications.

Key Words: Depression, depression subtype, psychotic depression, culture, cultural competence, emic, etic, explanatory models, case vignette, qualitative research, help seeking, pathway to care, indigenous model, traditional healer, health policy.

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LIST OF PUBLICATIONS

This thesis is based on the following papers, which are referred to by their Roman Numerals. These four papers present the results of exploratory studies on Explanatory models of depression among the Baganda.

- I Okello, E., Ekblad, S. Lay concepts of Depression among the Baganda of Uganda: A pilot study. Published in *J Transcultural Psychiatry*, 2006:43(2): 287-313
- II Okello, E., Neema, S. Explanatory models and help seeking behaviour: pathways to psychiatric care among patients admitted for depression in Mulago hospital, Kampala, Uganda. *J Qualitative Health Research*, 2006 (in press)
- III Okello, E., Musisi, S. Depression as a clan illness (eByekika): An Indigenous Model of Psychotic Depression Among the Baganda of Uganda. Published in *J World Cultural Psychiatry Research Review*, 2006:1(2):60-73
- IV Okello, E., Ekblad, S., Neema, S. Beliefs and practices of alternative healers regarding non-psychotic depression: Health policy implications for effective use of scarce health resources in Uganda (Submitted)

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LIST OF ABBREVIATIONS

DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
EMs	Explanatory Models
WHO	World Health Organization
MINI	Mini-International Neuropsychiatric Interview
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
UBOS	Uganda Bureau Of Statistics
UDHS	Uganda Demographic Health Survey
MoH, U	Uganda Ministry of Health
USAID	United States Agency for International Development
THETA	Traditional and modern Health care practitioners Together Against AIDS and other diseases

BACKGROUND

“As one of the most prevalent diseases globally and an important cause of disability, depressive disorder is responsible for as many as one of every five visits to primary care doctors; it occurs everywhere and affects members of all ethnic groups. The rates of depression are increasing, and the disorder is nearly twice as common among the poor as among the wealthy.”

(Arthur Kleinman, 2004 p.951) [1]

Introduction

The general aim of this thesis is to explore and describe how depressive symptoms are conceptualised and communicated by the Baganda and how this conceptualisation may influence their help-seeking behaviour and processes.

My research started out from questions arising from working at the Department of Psychiatry, Makerere University where clinicians offering liaison psychiatry to general services at Mulago hospital frequently discussed difficulties encountered by general practitioners in recognizing and treating depression. In 2002, a study on general medical wards affirmed the complaints made by clinicians [2]. This study indicated that in up to 90% of patients with moderate to severe depression, the attending physicians did not recognise the conditions. At this point I made two reflections: The first one was that perhaps there was a communication problem between the patients and the clinicians. The second was that perhaps the symptoms were not communicated at all. It has been noted that people’s beliefs and attributions about illness are fundamental to the way individuals respond to symptoms; beliefs and attributions inform individuals’ decisions to seek help and the manner in which they present their problems to the services in question [3-5].

The research started with a pilot study (Paper I) and one of the key findings in the pilot study was that depression did not require “modern” or Western medicine. This finding raised the question of what brings depressed patients to psychiatric services since according to the mental health unit’s medical records up to 24.6% were receiving treatment for depression. I decided to address this question by exploring the perceptions of depression among people receiving treatment for depression; the meanings they attached to their symptoms and what triggered them to seek psychiatric help (Paper II). During the second study, the association between psychotic depression and clan illness arose and increased my curiosity to further explore the Baganda’s perceptions about what DSM-IV defines as psychotic depression (Paper III). The fourth article (Paper IV) was the result of a general theme permeating all of the studies regarding the role of traditional healers in the management of depression. This paper was intended to inform policy makers in Uganda about available alternative sources of care for people with depression and identify possible questions for further research.

This thesis will present each study separately. The four articles will be presented at the end. The thesis is presented in the following order: Background information is provided first. This will include a review of literature on the magnitude of depression, and the role of culture in depression. This is followed by a brief presentation of the theoretical framework, methods including a brief summary of the study settings and sites, followed by summary of results of the four papers. A general discussion of theoretical framework, strength and limitations of methods used, results and limitation of the results will be presented. Finally, concluding remarks including implications for further research, clinical work training and policy will be provided.

Time schedule

The schedule for the studies was as follows:

- January 2003 ethical approval was received from the Faculty of Medicine Research and Ethics Committee at Makerere University and the Uganda National Council for Science and Technology. Subsequently, in March 2003 approval was received from the Karolinska Institutet's Regional Ethics Committee (reference number KI Dnr 03-118).
- Data for the four papers were collected between March 2003 and March 2005. Work on the manuscripts for the different papers was carried out between July 2003 and June 2006.
- Thesis writing started April 2006 and was completed in July 2006.

Definition of depression

In this study depression is defined according to the definition of clinical depression found in DSM-IV [6] and ICD-10 [7], where depressed mood and loss of interest in pleasurable activities are regarded as core symptoms. Other symptoms include weight loss, changes in appetite, disturbed sleep patterns, changes in activity levels, loss of confidence and self-esteem, inappropriate guilt, thoughts of death, thoughts of suicide, and diminished concentration.

The distinction between depression with psychotic features and depression without psychotic features [7] was adopted in this study. This distinction was found useful because studies that have made such a comparison have found significant differences in the impairment of attention, response inhibition and verbal declarative memory [8, 9], which may have implications for the management of patients.

Depression and burden of disease in a global context

Depression is among the leading causes of disability in the world and is expected to be the second leading cause of disability worldwide by 2020 [10]. There is evidence that the impact of depression extends far beyond the core symptoms and affects the individual's quality of life including the ability to function socially as well as maintaining and enjoying work, family and other social relationships [11, 12]. Although depression-related health problems are estimated to be huge, a gap in the provision of services has been highlighted by various studies [13, 14]. The problem is said to be even more serious in settings that are already labouring under the burden of inadequate resources and shortage of health care personnel [15].

Despite their frequency and magnitude, depressive disorders are said to show significant cultural variations in clinical presentation [16], making them less likely than many other health problems to be recognised and treated by clinicians [17, 18]. Delays, misdiagnosis and non-specific treatments have been typical pathways to care for people with depression [19, 20].

The World Health Organisation reports that depression is one of the disorders causing increased health care costs due to unnecessary investigations and inappropriate or non-specific treatments [21]. Individuals with depression utilise health care services in the general medical and mental health care sector three times as often as non-depressed individuals, even after controlling for medical comorbidity [22]. Undiagnosed depression places a significant socio-economic burden on individuals, families and communities, in terms of increased service needs, lost employment, reduced productivity, poor parental care with the risk of transgenerational effects and, thus as a whole an increased burden on care givers [21]. It is also associated with more functional disability than chronic medical illness [23, 24].

Depression and burden of disease in the context of Uganda

The few available prevalence studies in Uganda estimate depression at 10-25% in the general population [25-28]. However, the difficulty with depressive illness in Uganda, as in many other parts of the world, is in recognition and many cases therefore remain untreated [2, 29]. There have been a few studies exploring the role of explanatory models of common mental disorders in Africa [30-34]. However, I found no recent published findings on this subject for Uganda. The role played by culture in experience, expression, diagnosis and management of depression has been recognized as an important step in improving care for people with depression.

Culture and depression

Tseng and Streltzer [35] define *culture* as “the unique behaviour patterns and lifestyle shared by a group of people that distinguish it from other groups. A culture is characterized by a set of views, beliefs, values, and attitudes.” (p.1). The shared meanings and behaviours are dynamic and subject to continuous change and modification in response to changing internal and external circumstances. Culture is the lens or template used in constructing, defining, and interpreting reality. Thus people from different cultural contexts and traditions define and experience reality in very different ways including their views about mental disorders since these cannot be separated from cultural experiences [36].

In studying the relationship between culture and conception of mental distress, anthropologists have shown how people from different cultures explain mental distress and how these models of distress influence causal attribution and presentation of disorder as well as determining patterns of help seeking [37-39]. Draguns [40] asserts that mental disorder such as depression is shaped by cultural factors and that the symptoms of this disorder are more likely to vary across cultures. Because the diagnosis of patients is directly related to the behavioural signs and reporting of symptoms by patients, rather than by laboratory tests, the clinical judgment and cultural sensitivity of the clinician play an enormous role in the accuracy of the diagnosis of depression. When clinicians and patients interact, their own respective cultures can influence their assumptions and perceptions.

The past cross-cultural studies of depression [41, 42], have drawn the following conclusions:

- i. There is no universal conceptualization of depressive disorders;
- ii. The experience, meaning, and expression of depressive experience vary as a function of culture; and
- iii. Standard personality correlates of depression in Western societies (e.g. low self-esteem) may not be universal across cultures.

Thus, it is now clear that cultural variations exist in all of the following areas of depression: meaning, perceived causes, onset patterns, epidemiology, symptom expression, course and outcome. These variations have important implications for understanding clinical activities including conceptualisation, assessment, and therapy [30, 34, 43]. A more fundamental issue deserving empirical investigation, especially in a non-Western culture, is that of matching problem conceptualisation between the service providers and the prospect service users.

THEORETICAL FRAMEWORK

The studies in this thesis explore lay conceptualisations of depression and the implications of these conceptualisations for help-seeking behaviour for depression. The thesis is anchored in Kleinman's Explanatory Model of illness framework [44]. However, additional sensitising concepts and ideas are derived from other frameworks such as Symbolic interaction theory (discussed in details in paper II), Ecological model (discussed in details in paper IV), cultural competence and emic-etic distinction. This section will give a brief discussion of frameworks from which this thesis derives general ideas and concepts. These include: etic-emic distinction, cultural competence and Explanatory model of illness framework.

Etic-emic distinction

The concepts emic and etic were coined by the linguistic anthropologist Kenneth Pike [45]. Pike defines the emic perspective as one that focuses on the intrinsic cultural distinctions that are meaningful to the members of a given society.

The etic perspective, according to Pike, relies upon the extrinsic concepts and categories that have meaning for the scientific community. The terms "emic" and "etic" should be seen as adjectives modifying the implicit noun "knowledge". Accordingly, the distinction between emic and etic has everything to do with the nature of knowledge and not its source.

Emic constructs are accounts, descriptions, and analyses expressed in terms of the conceptual schemes and categories regarded as meaningful and appropriate by the members of the culture under study. An emic construct is correctly termed "emic" if, and only if, it is in accord with the perceptions and understandings deemed appropriate by the insider's culture. The validation of emic knowledge thus becomes a matter of consensus, namely, the consensus of native informants, who must agree that the construct matches the shared perceptions characteristic of their culture.

Etic constructs are accounts, descriptions, and analyses expressed in terms of the conceptual schemes and categories that are regarded as meaningful and appropriate by the community of scientific observers. An etic construct is correctly termed "etic" if, and only if, it is in accord with the epistemological principles deemed appropriate by science (i.e. etic constructs must be precise, logical, comprehensive, replicable, falsifiable, and observer independent).

In the past decades, the debate in cross-cultural psychiatric research has been between those who advocate the universality of mental illness symptoms irrespective of culture (etic) and those who argue that Western psychiatric categories can not be applied across cultures (emic) [46]. The etic approach assumes that mental illness is similar throughout the world and that psychiatric taxonomy; measuring instruments and models of health care are globally applicable. This triggered the debate about category fallacy [47]. On the other hand the emic approach evaluates phenomena from within a

culture and its context, aiming to understand its significance and relationship with other intra-cultural elements. However, none of these approaches seemed to provide fruitful results when considered independently [31, 46]. Today it is increasingly accepted that the integration of these approaches is essential. The current study was an attempt to integrate these approaches by giving equal value to both emic and etic approaches. Emic knowledge is essential for an intuitive and empathic understanding of a culture. It is often a valuable source of inspiration for etic hypotheses. Etic knowledge, on the other hand, is essential for cross-cultural comparison, because such comparison necessarily demands standard units and categories.

Cultural competence

Demand for cultural competence arose out of the failure of the service delivery system to be responsive to segments of the population. The focus has been mainly on the needs of the minority groups of immigrants and refugees [48-54]. Cultural competence is a skill-focused paradigm. Cultural competence is defined as a “set of cultural behaviours and attitudes integrated into practice methods of professionals to enable them work effectively in a cross cultural situation” (p.3) [55]. Cultural competence is achieved by translating knowledge about individuals or groups of people into specific practices and policies that apply in a cultural setting [56, 57]. It is important to note that cultural dimensions extend far beyond ethnic boundaries. This thesis takes a broad view of culture as a concept to incorporate all dimensions of cultures in patients’ care.

Tseng and Streltzer [35] provide an elaborate description of the role of various dimensions of culture in medical practice. They point out that in the medical setting three types of culture are present: the culture of the patient, the culture of the physician, and the medical culture in which the clinical work is carried out. These different cultural dimensions exact strong influence during the clinical encounter. The culture of the patient, for example, will contribute to his/her understanding of illness, perception and presentation of symptoms and problems, reaction and adjustment to illness. The patient’s expectations of the physician, motivation for treatment, and compliance with treatment recommendations are also influenced by culture. The culture of the physician will shape the pattern of interaction and communication with the patient. The culture of the physician explicitly or implicitly affects his or her attitude towards the patient, understanding of the patient’s problems, and approach to caring for the patient. Medical culture includes traditions, regulations, customs, and attitudes that have developed within the medical service setting beyond medical knowledge and theory. The medical practice in general and psychiatry in particular is strongly embedded in the medical culture that has developed within the medical system. Most physicians and medical staff members have become accustomed to living within this invisible cultural system and may be unaware of its influence on their practice. It often requires outsiders to recognize the existence of medical cultures.

The major issue in the classification of depression is that the diagnostic label is derived from Western language where the term depression in medicine is seen as being closely linked to mood change. However, while the experience of dysphoric mood may be a universal human phenomenon, the concept of depressive disorder which focuses on the mood change as a primary or core feature has evolved within a Western culture and may not be universally applicable [4, 58]. Furthermore, the training of psychiatrists

and health care providers in general in developing countries is based on Western models and categories. This may indeed compound the cultural diversities that may exist between the care providers and their recipients. It has therefore been argued that a more acceptable alternative may develop through the identification of local concepts, which bear some similarity to the construct of depression [59]. These culturally appropriate terminologies for depression, if identified and used, will improve the cultural skills of Western trained mental health workers. This in turn will improve levels of recognition, treatment and compliance.

Explanatory model of illness framework

The explanatory model framework is based on a social construction of reality [60]. An influential definition of explanatory models is that given by Kleinman [44], who defines explanatory models as understanding or explanations of episodes of illness and treatment; framed within the context of the cultural beliefs and norms of the given society, and employed by all engaged in the clinical process as well as in the interaction between healer and patient that is central to the health care system.

Behind the concept of explanatory model is the recognition that individual patients and their families often have their own concepts and categories of illness, which may differ from those of clinicians. How ill health is perceived, how experiences are interpreted and how choices are made about treatment may all form the total picture that needs to be taken into account.

There is evidence that dissonance between patients' and professionals' explanatory models may affect help-seeking behaviour, treatment compliance, satisfaction, and cultural sensitive clinical practice [50, 61, 62]. Through exploration of patients' explanatory models of illness, (why me, why now, what is wrong and who can intervene?) the clinician can achieve a better understanding of the subjective experience of illness and so promote collaboration and improve clinical outcome and patients satisfaction [62].

AIMS OF THE STUDY

General Aim

The general aim of this thesis is to explore and describe how depressive symptoms are conceptualised and communicated by the Baganda of Uganda and how this conceptualisation may influence their help-seeking behaviour and processes.

Research questions

The studies on which this thesis is based set out to answer the following questions:

1. How do the Baganda understand, talk about, and cope with depression?
2. How severe must the symptoms be to warrant treatment, and what is perceived as effective treatment?
3. Are the various sub-types and dimensions of depression seen as the same illness?

Specific aims for the four papers

Paper I: This pilot study was conducted in order to pre-test the instruments and techniques to be used in the main study whose general objective was the exploration of the lay explanations of causes, effects and help-seeking behaviour for depression among the Ganda cultural group.

Paper II: The objective of this part of the study was to examine the perception of depression as defined by the DSM-IV [6], among people receiving treatment for depression, with the aim of describing patients' personal and social meaning of the illness, their beliefs on causes and consequences of depression, and what triggered seeking psychiatric help.

Paper III: The objective of this study was to explore the Baganda's conceptualisation of psychotic depression in terms of illness identity, causes and treatment

Paper IV: The study aims to describe alternative healers' perceptions about causes and treatment for non-psychotic depression.

METHODS

Methodological framework

The four studies included in this thesis used qualitative research methods. Qualitative research is a generic term for investigative methodologies described as ethnographic, naturalistic, anthropological, field, or participant observer research. It emphasizes the importance of looking at study participants in the natural setting in which they are found. Detailed data are gathered through open-ended questions that provide direct quotations. The interviewer is an integral part of the investigation [63]. This differs from quantitative research, which attempts to remove the investigator from the investigation [64]. Qualitative research questions tend to explore "what," "how," and "why" to identify potentially important variables or concepts, to recognize patterns and relationships, and to generate coherent theories and hypotheses.

Qualitative methods of individual interviews and focus group discussions were chosen for the following reasons:

- i. The study area is new, requiring an exploratory design for which qualitative methods are best suited [65].
- ii. Qualitative research seeks to maximize the use of context as a means of locating lay knowledge, understanding and subjective meaning [66]. Qualitative methods make contextualized research and knowledge production possible.
- iii. Qualitative methods allow culturally sensitive interpretations of data [67, 68].
- iv. Qualitative methods especially focus group discussions allow researchers to gain access to communication that people use in day-to-day interaction when talking about issues related to health and illness.

The most essential and challenging features of qualitative methodology are: First that data are analysed in all their wealth of detail while adhering as close as possible to the form in which they are recorded or transcribed [69]. The second is the fact that the qualitative researcher is concerned with process rather than simply outcome and product [70]. Meanings are of essential concern to the qualitative approach. They are concerned with the participants' perspective about how different people make sense out of events in their lives. Qualitative research is particularly useful when describing a phenomenon from the participants' perspective, but requires the researcher to constantly distinguish between the other's world and his/her own (self reflection). By learning the perspective of the participants, qualitative research illuminates the inner dynamics of a situation that are often invisible to the outsider [48].

The people

Uganda is constituted of three main ethnic groups: The Bantu, Nilotic and Nilo-Hamitic ethnic groups. The Bantu are the most numerous and include the Baganda, who constitute more than 17% of the population [71], making it the largest single ethnic group in Uganda. Other Bantu ethnic groups include the Banyankole, Basoga, Bagisu, Bagwere, Bakiga, Banyarwanda, the Banyoro and the Batoro. The residents of the northern parts of the country are largely Nilotic, including the Langi, the Acholi, Lugbara, Alur and Madi. The Itesot occupy the eastern part and the Karamajong occupy the largely pastoral territory in the northeast. These latter two are mainly Nilo-Hamitic. There are many smaller “borders” separating the three major ethnic divisions who mainly represent cross-marriages.

Uganda has an area of 241,039 square kilometres, about half the size of Sweden (450,000 square kilometres). The total population, according to 2002 Uganda population and housing census was 24.2 million people [71]. It is currently estimated to be 26.7 million people with annual growth rate of 3.2% [72]. The country has high fertility and teenage pregnancy rates of 6.9% and 31% respectively [71]. The literacy rate is still low in Uganda. Only 61.4% of the populations have completed primary school education [71]. The United States Agency for International Development (USAID) 2005 report, quoting 2002/3 Uganda National Household Survey indicates that about 38% of Uganda population live on less than 1 dollar a day [73].

HIV/AIDS and Tuberculosis remain significant challenges to Uganda’s health care resources. Although rates of HIV infection in Uganda have declined; changing the proportion of adults living with HIV from around 15% in the early 1990s to around 6.7% in 2005 [74], the severity of the epidemic has left a considerable economic and social impact. Nearly 80% of those infected with HIV are between the ages of 15-45 years, the most economically productive age group. Households supporting AIDS patients are poorer as they spend a lot of their resources and time in caring for the sick. The huge number of clinically ill patients has increased the workload of an already over-stretched health care system, further weakening it [74].

Human resources situation in Uganda

Uganda is categorised under resource-constrained countries in terms of both infrastructure and personnel. World Health Organisation [75] identifies Uganda as one of the countries with critical shortage of health care providers. Uganda like many other developing countries has as yet a poorly developed health infrastructure. In rural Uganda where more than 80% of the population live, only 49% of the population has access to a health care facility within a 5 km radius [76]. There is far less access to mental health care services at all levels of the health care system in Uganda.

In terms of personnel, there are far more traditional healers than modern/Western trained health workers of all cadres especially in rural areas of Uganda. It is estimated that there are up 150,000 active traditional healers in Uganda. This number translates the ratio of traditional healer to patient to 1:200, which is in contrast to that of

conventional/Western medicine, where the practitioner to patient is estimated to be 1:25,000 [77]. Moreover the distribution of Western trained health care personnel is very uneven, with most being found in cities or other urban areas and therefore inaccessible to rural populations. Uganda has about 25 psychiatrists, 18 of them are based in two teaching hospitals in Kampala. The remaining 6 psychiatrists are working in the regional hospitals in the northern, eastern and western parts of the country. Other mental health workers such as psychiatric nurses, psychologists and social workers are also still few.

Buganda

The studies for this thesis were conducted in Buganda. Buganda occupies the largest part of south central Uganda covering fifteen administrative districts of Kampala, Masaka, Mpigi, Mukono, Kayunga, Kalangala, Mubende, Mityana, Luwero, Nakaseke, Nakasongola, Sembabule, Kiboga, Wakiso and Rakai.

Ethnographic reports indicate that the people of Buganda have lived as a kingdom since the 16th century [78]. They are said to have been the largest ethnic grouping in British Protectorate. They were also the most populous and organized kingdom in the Interlacustrine Region [79]. Administratively the Buganda kingdom is divided into counties (Masaza), sub-counties (Magombolola), parishes (miruka) and villages (byaalo) [78, 79].

The people of *Buganda* are referred to as *Baganda* (the singular form is *Muganda*), their language is called *Luganda*, a Bantu dialect that uses prefixes, infixes and suffixes in classifying both living and non-living things. Human beings are classified under the “Mu-ba” class hence the people are called “*Muganda and Baganda*” for singular and plural forms respectively [80]. They refer to their customs as *Kiganda* customs. Sometimes the generic term *Ganda* is used for all of the above.

Spirits are regarded as an important aspect in health and illness. There are two main categories of spirits including family and community ancestors, alien and evil spirits. The Baganda like many other ethnic groups in Africa [30, 81], believe that the body dies and decomposes but the soul still exists as omuzimu (singular of Mizimu). Family and community ancestors are usually involved in the maintenance of good health, although, if they are upset they may cause illness and misfortune. It is the alien and evil spirits that are more likely to cause illness maliciously [38].

The Baganda believe in superhuman spirits in the form of mizimu, Misambwa, and Balubaale (sing. Lubaale). These beliefs were referred to as traditional religion [82]. However, with the coming of missionaries in the 19th century and advent of Christianity the beliefs became more ambiguous following the Christian teaching that considered African belief systems as Satanic or Pagan. In the last generation, however, the new order represented by imported religions and political systems has been found to be wanting, not only in the poor cohesiveness and function of the community but even in the personal conduct of religious and community leaders. Thus, the traditional ways are once again treated with respect, even to the extent that the traditional terms for such things as a shrine (ekiggwa) or a prayer (okusamira) are now being used to describe Christian churches and services. This combination has given rise to its own dilemmas,

with many people indicating that the combination of two systems may be responsible for ill health in the society [83].

The Baganda, like many other cultural groupings have concepts of body functioning that influence concepts of health and illness [25, 84]. Orley and Wing, point out that the Baganda think of their illnesses in terms of the part of the body affected, thus cough may be referred to as 'ekifuba' (chest). It is also indicated that they have two groups of illnesses, the "kiganda illness" and the "non-kiganda illness" [25]. Kiganda illness is an illness that has its origin in the collective group customs and relationships of the Baganda people in their clans. The kiganda-non-kiganda distinction of illnesses has implications for help-seeking behaviour.

Sites

Paper I

The pilot study was conducted in Bajjo, a small village in Mukono, one of the Buganda administrative districts. Bajjo is located about 23 kilometres from Kampala, the capital city of Uganda, and about three kilometres off the Kampala-Jinja highway.

Bajjo village was selected for the pilot study because of its population characteristics and geographical location. Its population is not typically rural but semi-rural, which was thought to be an appropriate setting for pre-testing the instruments that is to be used for both urban and rural population groups. Economic activities in Bajjo include small-scale agriculture mainly worked by women, and brick making carried out by men. Some members of the village are teachers in the nearby primary and secondary schools.

Paper II

Study two was conducted in a clinical setting at Mulago hospital in the mental health department, which is one of the 15 clinical service departments in Mulago hospital. Mulago hospital has other departments including: Medicine, Surgery, Paediatrics, Obstetrics and Gynaecology, Dentistry, Anaesthesia, Radiology, Clinical Laboratory, Orthopaedics, ENT, Ophthalmology, Pathology, Rehabilitation and Family Medicine [85].

Mulago hospital, located in Kampala, serves as both the national referral hospital and regional hospital for the central region in the hierarchical structure of health care service organisation in Uganda. As a regional hospital, Mulago serves the people of Kampala and other surrounding districts, the majority of whom belong to the Ganda cultural group. As a national referral hospital, Mulago receives referred cases from all regions of Uganda for all kind of illnesses including mental illness.

Paper III-IV

The study sites were Rubaga division in Kampala district and Kimenyede and Buikwe sub-counties in Mukono district. Mukono and Kampala districts are part of Buganda located in south central Uganda.

Instruments and Measurements

- i) Explanatory model interview guide. This is an open-ended interview guide based on Kleinman's original concepts [44] examining health and sickness from an anthropological point of view. The language was simple and did not include medical terms or technical phrases. The instrument encouraged the participants to talk openly about their attitudes and experiences with the aim of eliciting held concepts and their relationship to their current situation and culture. Probes were employed to confirm the mentioned concepts. The interview was divided into three sections to cover the participants' personal background information such as age, gender, marital status, religion, education, income, and any other relevant background factors; perceptions about causes of depression; and help-seeking behaviour.
- ii) Case vignettes describing diagnostically unlabelled cases of depression. These case vignettes were comprised of different sub-types of depression, different ages and gender. These subtypes were based on the DSM-IV [6] and ICD-10 [7] depression categories.
- iii) The Mini-International Neuropsychiatric Interview (MINI) [86] was used as a screening instrument to confirm and identify the sub-type of depression.
- iv) The Montgomery-Åsberg Depression Rating Scale MADRS [87] was used with participants with a confirmed diagnosis of depression to measure the severity of depressive symptoms.

The standard instruments (MINI and MADRS) were used for the purpose of defining depression with reference to the Western biomedical model.

Design, methods of data collection, study participants and procedure

Paper I

The study adopted an exploratory design, using qualitative methods of data collection including four focus group discussions involving 25 participants, and four individual interviews. The total number of participants in the study was 29. Thirteen out of the 29 participants were women and sixteen men. Each of the four groups consisted of

individuals with a similar range of socio-demographic characteristics, such as level of education, gender, and age.

A senior consultant psychiatrist reviewed all the vignettes with the aim of ensuring that they met the DSM-IV diagnostic criteria [6]. To ensure conceptual equivalence [88, 89] the vignettes as well as the interview and focus group discussion guides were translated into Luganda, the local language spoken in Buganda, blindly back-translated into English, and reviewed by two independent bilingual speakers. Institutional ethical clearance was obtained and permission was sought from all the participants.

The traditional healers who participated in the interviews were contacted individually through the help of the District Cultural Officer and asked to participate in the interview after being given information about the general purpose of the study. Focus group participants were mobilized with the help of the village authority for the village participants and the school authority for secondary school students and primary school teachers.

The coverage in the pilot study was ambitious, with five discussion themes addressing five sub-types of mood disorder according to DSM-IV; i.e. depression without psychotic features, depression with psychotic features, manic illness, adjustment disorder with depressed mood and Dysthymia. The discussion of each of the themes started with the presentation of a case vignette.

During the discussion the moderator read each vignette slowly for everyone to hear clearly and understand, and clarified anything that was unclear before starting the discussion. This was done in order to ensure the uniformity and clarity of the symptoms presented in the vignette and also to allow the participants who could not read the material to participate in the study.

Paper II

This is a qualitative interview study involving 25 patients receiving treatment for depression. The study was conducted with the aim of developing an understanding of depression from the patients' point of view. This was done by exploring how people diagnosed with depression conceptualised their illness and how their conceptualisation shaped courses of action in the search for help. The intention was to capture the complexity of the decision to seek help for depression. A qualitative research design was chosen because it facilitated the obtaining of in-depth knowledge of human realities and meanings [90].

Permission was sought from the head of the mental health unit and the attending psychiatrists were requested to refer patients being treated for depression. The referred patients were given detailed information about the study and asked to participate. Consenting participants included 19 women and 6 men ranging from 18 to 75 years with a median age of 45 years. I, together with the help of trained research assistants, a clinical psychologist and a psychiatric nurse conducted diagnostic interviews using MINI [86] for Axis I diagnoses in order to confirm the psychiatric assessment of the clinician. We administered the MADRS [87] to gauge the severity of the symptoms. The above standard instruments were only used to ascertain the biomedical explanation of the symptoms. After this was ascertained we requested the respondents to participate

in the explanatory interview. Two participants left the hospital before participating in explanatory interview. These two were therefore excluded from the analysis.

Paper III

A descriptive qualitative study design based on the Explanatory Model Framework [44] was used. Qualitative methods of focus group discussions and individual interviews were employed in order to gain a richer and more complete description of how depressive symptoms were conceptualised and expressed from the emic viewpoint using hypothetical case vignettes for psychotic depression to stimulate discussion.

The study was conducted among members of a general population belonging to the Ganda cultural group aged 18-75 years, using the following methods: 31 individual interviews and 12 focus group discussions. A total of 52 women and 60 men participated in interviews and focus group discussions. Respondents were asked to conceptualise the problem described and answer questions regarding its causes, effects and sources of help. The participants were recruited according to generation, and the groups were stratified by age within the focus groups. This approach was utilized to reveal potential differences regarding health issues between the generations.

Paper IV

A descriptive qualitative study design, based on the Explanatory Model of illness framework was used. Individual interviews were conducted with 22 traditional healers, the alternative providers of health care in Uganda. Out of these, 8 participants were women and 14 were men. An unlabelled case vignette was used as a stimulant for discussion. The traditional healers were contacted through district and village administrative authorities. The research team visited the villages in the study area. The village leaders provided guides to the research team. These guides introduced us to various healers in the village.

For practical reasons, individual interviews were conducted in the participants' homes or 'offices' according to convenience. The interviewer used the interview guide but was flexible enough to follow important leads brought up by the participants.

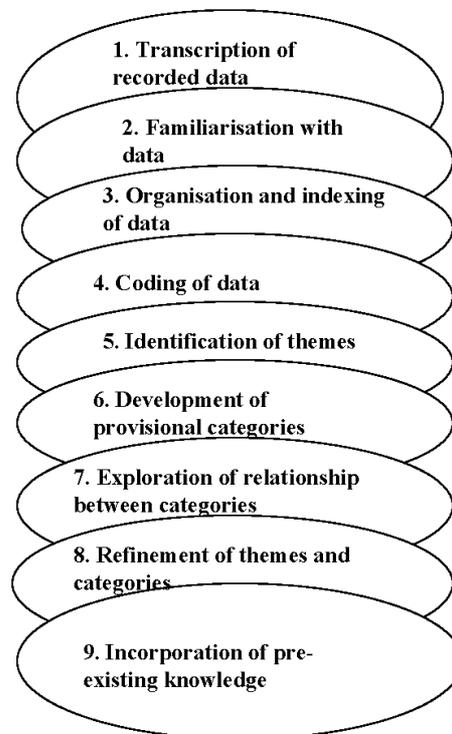
Data analysis

A modified grounded theory approach was used in analysing the data. According to Glaser and other proponents of grounded theory [91-95], a researcher using grounded theory should enter the area of study without a clearly defined research question since the key issues are expected to emerge during the study. The researcher ought to use theoretical sampling during data collection. The current study used a modified grounded theory because the above prescriptions were not adhered to. The research had clearly defined research questions from the onset and therefore clear preconceived

ideas of what the key issues were [96]. Purposive sampling was used instead of theoretical sampling.

The studies used focus group and individual interview methods, which utilized semi-structured guides to produce transcripts [97]. A bilingual speaker transcribed the recorded interviews verbatim. A sample of focus group discussions and interview transcripts were checked and verified prior to formatting and entry into the qualitative software analysis program, NVivo [98]. Figure 2 below show the steps followed during analysis process.

Figure 2. Analysis steps



Okello, E 2006

These steps are presented in a spiral form because the process was not linear. After transcription of the recorded data the next step was to gain familiarity with the data by reading the transcripts several times. Organising and indexing data followed. The next step was coding of data. The coding stage started with open coding. The open coding involved initial fracture of the data into expressions, lines or paragraphs [99]. At this stage meaningful units or segments were identified in terms of categories or codes in order to construct and interpret common themes or patterns [100]. These independent meaningful units or segments of text were labelled and organized. After initial coding was completed, the data were reviewed, reinterpreted and reorganized into categories. This was done in order to explore all possible aspect of the ideas. The second level of analysis entailed moving from codes to interpretation and reconstruction. This process allowed making links and connections between different codes and patterns and

between categories. This involved putting data together to achieve a new understanding. However, this was only possible with reference to the raw data [65]. The NVivo program [98] facilitated the process of re-thinking with the data, re-coding, re-organizing, testing and checking the interpretation. The final level of analysis focused on the integration with the literature and construction of theoretical understanding. All the data except for Paper I, which used both manual and computer-assisted analysis, were entered retrieved and analysed using the software.

Reliability and validity issues Paper I-IV

Reliability and validity are conceptualized as trustworthiness, rigour and quality in qualitative paradigm. Trustworthiness, quality and rigor are meant differentiating a 'good' from 'bad' research. The basic question addressed by the notion of trustworthiness, according to Lincoln and Guba [101], is: "How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?" (p.290)

Lincoln and Guba [101] have identified four general criteria for rigour in qualitative research. These are credibility, transferability, dependability and confirmability. Several strategies have been identified to ensure trustworthiness in qualitative studies. These include triangulation, peer examination or debriefing, inclusion of thick description in the analysis to reflect the complexity of the data and audit trail among others. In the current study we used several strategies to ensure trustworthiness and rigour. These were triangulation, inclusion of thick description in the analysis reflecting the complexity of data and peer examination and debriefing.

Creswell and Miller [102] defines triangulation as "a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study" (p.126). Two types of triangulations were used. These were methodological and data triangulation [103]. Methodological triangulation involved use of multiple qualitative methods including interviews and focus group discussions. Data triangulation involved the use of different sources of data/information [104]. These were patients, members of general population of various age groups and gender. This strategy was meant to corroborate the findings. However, it should be noted that in qualitative research, the purpose of corroboration is not to confirm whether people's perceptions are accurate or true reflections of a situation but rather to ensure that the research findings accurately reflect people's perceptions, whatever they may be [105].

During the analysis the criteria for rigour advocated by Leininger [106] and Muhlbauer [107] of credibility, confirmability, recurrent patterning and saturation was used. Credibility refers to truth, accuracy and believability of findings. The accuracy was supported by the similarity of the findings with data from varied sources, and credibility was supported by the repetition of similar perceptions and experiences of the participants. Confirmability refers to the existence of repeated, direct and documented evidence with repeated explanations from informants about the phenomena. Confirmation was evidenced by the frequency of cited conceptualization of causes and

treatment of depression. Recurrent patterning refers to repeated instances, sequences that occur over time in designated ways and contexts. Saturation means that the researcher has conducted an exhaustive study and that no further information or insights are forthcoming.

The use of computer software has also been documented as improving rigour for qualitative analysis [108, 109], due to its ability to keep and link together for easy access many kinds of documents. I was able to quickly trace the progression of an idea from its earliest stages using NVivo.

ETHICAL CONSIDERATIONS PAPER I-IV

The following bodies approved the protocol for the studies:

- i) Faculty of Medicine Research and Ethics Committee at Makerere University
- ii) The Uganda National Council for Science and Technology
- iii) The Karolinska Institutet's Regional Ethics Committee (Karolinska Institutets regionala forskningsetikkommitté) reference number KI Dnr 03-118
- iv) District and Local Administrations
- v) Head of Mental health unit, Mulago hospital

Informed consent was also sought from every participant and, with the participants' consent, the discussions and the interviews were tape-recorded.

SUMMARY OF RESULTS

Paper I

This paper presents the findings of a pilot study conducted with the aim of testing the use of case vignettes in exploring the explanatory models of various sub-types of depression. The results showed the depressive spectrum symptoms to be categorised as follows:

- i) Illness of thoughts, this included what would be considered to be Major Depression without psychotic features and Adjustment Disorder with depressed mood according to DSM-IV criteria. This category was considered to involve pain that is not physical and therefore hard to explain to a stranger, a non-chronic condition caused by worrisome thoughts about psychosocial problems. The condition was perceived to require no medication. Lay help from significant relatives, elders and friends was deemed adequate.
- ii) Clan/ancestral illness (eByekika illness): according to the participants this was caused by angry ancestral spirits (Misambwa/mizimu). The symptoms were put in this category if they were recurrent and characterized by loss of touch with reality. It was equivalent to the DSM-IV category diagnosis of major depressive episode with psychotic features. This category was seen to require the attention of a traditional healer, who would identify the cause while patient and his/her relatives would perform the necessary ameliorative rituals.
- iii) Undefined chronic illness. This constituted what would be considered to be chronic but mild depressive symptoms equivalent to a diagnosis of Dysthymia according to DSM-IV. The cause was either witchcraft or chronic physical disease such as HIV/AIDS or syphilis. Both traditional and modern care providers were identified as sources of help depending on what was considered to be the cause.

Depressive symptoms presented in these vignettes seem to be conceptualized as a problem related to thoughts (thinking too much) rather than emotion (sadness) or behaviour and the resulting condition is referred to as "*illness of thoughts*". Worrisome thoughts resulting from various socio-economic problems were seen as important aetiological factors for the *illness of thoughts* and deemed not to require medication, as it was believed that there was no medication for thoughts. There are culturally accepted ways of dealing with and healing the condition. Once the illness becomes recurrent or chronic, other explanations about causes and a different course of action were considered.

Paper II

The focus of the study was to explore how depression, as defined in DSM-IV [6], is conceptualized by people diagnosed with it and how their conceptualization may have shaped their pathways to care.

Twenty-two of 25 participants met the criteria for Major Depression current episode. Thirteen of these had recurrent depression, three had chronic symptoms and seven were admitted for their first episode. Two participants met the criteria for Dysthymia and one fulfilled the criteria for Adjustment Disorder with Depressed Mood [6]. The three participants who did not meet the criteria for Major Depression were referred from the outpatient clinic.

Montgomery and Åsberg's Depression Rating Scale [87] was used to assess the severity of the symptoms. The severity of the symptoms was determined using Mueller and others' [110] score of 31 as a cut-off point between severe and moderate symptoms. A score of 31 or less was interpreted as moderate while greater than 31 regarded as severe. Fifteen participants had severe symptoms ranging from 32 to 51 points. Ten participants were moderately depressed with scores ranging from 19 to 31 at the time of the interview.

Participants defined their depressive symptoms first in somatic form. Somatic symptoms were spontaneously reported, on further enquiry however, patients began talking about the condition that brings about the somatic distress. With probing it became apparent that the pains in their bodies were anchored in the contexts of their everyday lives as participants expanded the explanations of physical pains to include social circumstances relating to their distress. Some of the social circumstances included conflicts in the family, difficulties in marriage, and perceived neglect of the elderly. Though the pains were located inside the individual body they reflected the events and constraints of the social space of which the person was a part. Participants evaluated the consequences in social relations, particularly the stigma of psychiatric labelling and admission to an inpatient facility.

Somatisation of emotional problems, variations in causal attribution between patients and their significant others, the nature of the available health care system and burden of infectious disease; where attending clinicians have insufficient time with individual patients complicated access to psychiatric care.

The behaviour defined by others as socially disruptive, such as suicide attempts, bizarre behaviour, extreme isolation, refusal to talk or psychotic symptoms triggered the need for psychiatric attention. These findings suggest the need to raise awareness of the primary care providers about how to recognise and appropriately help people with depression in this setting.

Paper III

This paper describes the findings of a qualitative study aimed at understanding how depression with psychotic features as a subtype of depression is culturally

conceptualised amongst the Baganda and how such conceptualisation may influence help seeking.

The key findings are that the totality of symptoms categorized in the DSM-IV [6] as psychotic depression with mood congruent delusions is recognized and labelled as a clan illness and translated as *eByekika* illness by the Baganda. The condition is recognized and conceptualized as a result of wrongs (omissions or commissions) by the living against their clan/family dead. These may be in form of failure or inconsistency in the performance of culturally demanded rituals, incorporating alien beliefs into Ganda belief systems or breaking taboos. The traditional healers and the participation of other members of the clan into the healing process were seen as central to correcting what was perceived as a collective (clan/family) wrong. Western medicine was seen as inappropriate for such a condition especially as it emphasized individual brain problem and treatments. Thus, although the symptoms of depression were seen as constituting an illness, its conceptualization, name, causation and treatment were not deemed to fit in conventional Western biomedical psychiatry. The illness was believed to have its origins in a faulty relationship between the living and the dead. Its management therefore required dealing with this relationship problem. The illness belonged to what the Baganda refer to as a Kiganda illness (an illness that has its origin in the collective group customs and relationships of the Baganda people in their clans). The help-seeking behaviour was therefore social and collective and was intended to address both proximate and ultimate causes of the illness. The nearest similarity of this to Western psychiatry is group therapy, the group being composed of the clan members. The implication of this for modern mental health service providers is to incorporate culturally sensitive tools and methods in the assessment and treatment of depression with psychotic features.

In terms of socio-demographic characteristics, the data were drawn from a sample, which varied by gender, age, education and religious affiliations. Younger participants were on average more educated than the rest of the sample, while men were on average more educated than women in the older age groups. Given such a demographically varied sample, one would expect variations in terms of perceptions about causes and treatment of psychotic depression. However, the findings seem to indicate a high degree of consensus among the study participants across the socio-demographic variables. The slight difference is found regarding the sources of help, where Born Again Christians believed prayer was the appropriate source of help for people with *eByekika* illness, otherwise called depression with psychotic features according to DSM-IV. However, this difference is obscured by the fact that all the respondents in general agreed that the ultimate cause of illness should be the target in any treatment programme. Modern medicine was seen to fall short of the ability to deal with this ultimate cause of clan illness.

Paper IV

This paper describes the findings of a qualitative study aimed at exploring the beliefs and practices of traditional healers regarding non-psychotic depression. In terms of socio-demographic characteristics, the data are drawn from a sample of an adult

population involving both faith and traditional healers. There were no significant differences between these groups in terms of level of education, level of income or age.

Depression without psychotic features was described as an *illness of thoughts* characterized by thinking too much. Individual, interpersonal, community and societal factors were seen as aetiological factors. Participants adopted a situational causal model described psychological distress in the context of social and interpersonal adversity as opposed to the biological psychiatry model of depression, which emphasizes brain, anatomy, heredity and neurochemistry. Western medicine was seen as inappropriate for the symptoms attributed to thoughts/thinking. Contextual treatment approaches of one-on-one or group sessions where many received treatment and support were identified as helpful approaches. This could be equated with contextual approaches such as bereavement therapy, interpersonal, family or group therapy in modern Western psychology/psychiatry.

These findings are consistent with findings of research conducted elsewhere regarding lay beliefs about depression [5, 18, 19, 33, 111, 112]. Although depression has complex causes involving interplay of biological, psychological and social factors, the lay public's beliefs about causes have been reported as generally less sophisticated. The fact that there is similarity between the traditional healers and the users of their service has clinical implications for therapeutic approaches such as psychotherapy, where agreement between the care provider and care receiver is the key element in a therapeutic relationship and treatment outcome.

DISCUSSION

The discussion of the four papers will start with some comments on the theoretical framework. This will be followed by a discussion of strengths and limitations of the methods used. A discussion of salient findings focusing on answers to the questions posed at the beginning of the study is then presented. Finally, concluding remarks about implications for practice, policy, training and future research will be presented.

On theoretical framework

Explanatory models

“The explanatory models’ framework provides the clinician with an expeditious practical method to assess the more accessible meanings that hold clear-cut importance for care. The picture so constructed is doubtless crude, incomplete, biased. But it is usually ‘good enough’ for the purpose at hand: namely, to alert the clinician to the psychosocial setting of the sickness and to make available to him an appreciation of at least some of the dominant meanings expressed and reproduced by the illness experience.”

(Arthur Kleinman, 1981, p.374) [113]

The design of the studies included in this thesis was based on Kleinman’s [44, 114] explanatory model approach. This approach has been useful in exploring the lay concepts of depression. However, it was limited in making an in-depth exploration of the meaning of illness. For example, the rigid guide would miss the process through which patients gave meaning to the illness, admission and diagnosis. Results of Paper II indicated that even after admission to psychiatric services patients continue to define their illness, evaluate and re-evaluate what was being done about it and re-evaluate theories that had been proposed regarding the illness. Such findings challenge the assumptions that patients make choices about therapeutic options with clearly developed theories about their symptoms. It became necessary to incorporate concepts from symbolic interaction theory regarding illness meaning when exploring patients’ perspective of depression. Bäärnhielm and Ekblad [48] have noted a similar limitation in the exploration of the meaning of somatisation among Swedish and Turkish female patients.

This limitation has prompted other researchers that have used this framework to propose other concepts such as the exploratory map [115], preliminary explanation or prototype [116] instead of explanatory models. These propositions hint to the fluidity of lay explanations of illness.

However, Kleinman [113] argues that explanatory models are not ways of thinking or systems of thought but practical statements about particular illness experiences. They

are expressed guides to help seeking and clinical decision-making. Hence the explanatory model framework is a useful and richly evocative technique by which to teach clinicians about the psychological, social and cultural context and functions of clinical communication. Furthermore, the same technique can be turned on its head, so to speak, and employed by the clinician or health educator to engage patients and families more fully and knowledgeably in a clinical encounter. The explanatory model approach, however inadequate it may seem, brings meaning, the person, family, and feelings into the process of clinical judgment. This openness to the human nature of suffering, is often all that is needed to reaffirm for the physician the critical importance of psychological and social issues in a particular case and thereby make him or her less tolerant of simply delivering a technical 'fix' [113].

On methods

Strengths and limitations

The qualitative methods where the researcher becomes an instrument of data collection were used [117, 118]. The strength of the methodology employed lies in the fact that it had a holistic focus, allowing for flexibility and attainment of deeper understanding. It allowed the respondents to raise issues which the researcher might not have included in the interview guide, thus enhancing the quality of data collected [119]. One may argue that the findings of this study are subject to the limitation due to methods used and verification of scientific data. When a researcher becomes an instrument of data collection, language used during data collection, becomes an important issue [117, 118]. The study was conducted in Luganda, the local language, thus requiring translation into English, which brought with it issues of equivalency. The complexity and challenges involved for conceptual equivalence in this process have been noted [120]. In trying to address this challenge, two independent bilingual translators translated a sample of transcripts. There were some minor differences in the text. I, together with the two translators discussed these differences while listening to original tapes. During the discussion it became apparent that the minor variations were a result of different writing styles. This was an important issue because validity in qualitative research is defined as the quality of craftsmanship during the investigation, where continual checking, questioning and theoretical interpretation are key issues [48, 121]. Validity assessment is a quality control tool that permeates the knowledge production process in qualitative research.

Use of hypothetical case vignettes

Use of DSM-IV-based unlabelled depression case vignettes with the general population is another issue that deserves comment. The intention of the study was to compare lay and biomedical conceptualisation of depression. The DSM-IV criteria-based vignette represented the biomedical explanation of depression.

One could argue that the use of hypothetical case vignettes could compromise the usefulness of the findings. However, it is difficult to access a one hundred per cent culturally representative clinical sample. The question therefore is how well cultural explanatory models of non-patient samples correlate with that of actual (in vivo) clinical samples? This broad question is answered when one compares the explanatory models of non-patient samples with explanatory models of real patient samples. The conceptualisation is the same regarding causes and appropriate source of help. The only aspect that is not obvious in a non-clinical sample is the point at which seeking help outside the culturally prescribed sources becomes necessary.

Investigators have used case vignettes as data collection tools since the 1950s as a method to encourage discussion of unexplored topics [122, 123]. Such vignettes have been defined as a simulation of real events and have been used in the exploration of beliefs and practices about mental illness [31, 122]. The advantage of case vignettes over asking open-ended questions without specific scenarios is that they encourage the participants to think about concrete situations that could apply to them or people they know. This was felt to be particularly pertinent to the aim of the studies in terms of exploring ideas about depression and in eliciting what were considered to be practical ideas and solutions.

Use of interview and focus group discussions

The value of qualitative methodology is well recognised, especially semi-structured interviews allowing the informants a substantial amount of control over the session [117, 124]. However, the approach is not without limitations. An interview study involves the collection of large amounts of complex material, which entails a challenge in the selection and contextualisation of interview statements during analysis. It has been recommended that one possible way to address this limitation is by using multiple interpreters for the interview material in order to ensure control of the analysis [121] which we, the authors of various papers included in the thesis, attempted to do during the analysis.

Sometimes mobilization of focus group members relies heavily on the gatekeepers. Gatekeepers are individuals who are part of or have access to a particular group, but who are also involved in the broader community beyond that group. They are trusted, respected, and are often sought out by community members needing help or advice. The use of gatekeepers may pose two main problems relating to access and recruitment. The first problem relates to access to potential participants. It is possible that a gatekeeper may screen the participants according to his or her vested interest. The second problem is an ethical one, whereby an enthusiastic gatekeeper may facilitate access without passing on all the relevant information. These limitations were recognized during the pilot study. During the subsequent studies, we tried to avoid these problems by identifying and delivering invitations ourselves instead of using gatekeepers. We avoided the problem of insufficient information by providing all the necessary information and asking participants for their consent before starting the discussion.

On results

General comments

The findings reported in Paper I were preliminary and based on a pilot study presenting preliminary local concepts for major depression from the general population, laying the foundation for further exploration of these concepts in Paper II, III and IV. Paper III and IV focused more on further exploration of conceptualisation of depression by members of the general population and the alternative health care providers. There are similarities between lay people and alternative healers regarding definition, cause and treatment or type of help for depression. The general pattern in the results of the four articles is that lay explanations of depression are based on social models of illness rather than a biomedical model.

In terms of socio-demographic characteristics, the data for the four papers were drawn from a sample, which varied by gender, age, education and religious affiliations. Younger participants were on average more educated than the rest of the sample, while men were on average more educated than women in the older age groups. With qualitative studies one cannot draw definitive final empirical generalizations, where data may be assumed to represent a wider population in terms of socio-demographic variables such as gender and age in a probabilistic sense [125].

Across the studies there were agreements among the lay people regarding illness identity of depression. Nevertheless, there was a noticeable difference regarding the causes and effects of depression without psychotic features. Marital problems, although mentioned by both men and women, were singled out as an important factor in causing illness of thoughts and these affected women more than men. The reason given was that men were less restricted by societal norms and therefore able to find ways of coping outside the home. Many participants referred to men's activities outside the home including drinking alcohol that helped men to cope with thoughts. Women on the other hand, were more confined and tied to the family especially with respect to child rearing, which impacted on their ability to find support outside the home. Sir Michael Marmot [126] in his book "Status Syndrome" presents evidence to prove that inequality drives ill health. According to Marmot social inequalities are not a footnote to the real causes of ill health; they are the cause. Therefore the lower the people's position in the hierarchy, the less they have a sense of controlling their own destiny. A low level of control leads to chronic stress. Hence women with less choice, control and participation compared to men are likely to have poorer mental health.

For men, the most important factors that could elicit worrying thoughts were poverty, and being deserted by a wife. This entailed having to take charge of the welfare of children, which was seen as an unfamiliar role for men. A man left with children, particularly young children, was more likely to get illness of thoughts.

The aim of the thesis was to answer the three research questions posed at the beginning of the study. These were: i) How do the Baganda understand, talk about and cope with depression? ii) What is perceived as effective treatment and how severe must the symptoms be to warrant treatment? iii) Are the sub-types of depression seen as same illness? The four papers included in this thesis have presented answers to these

questions. Specific answers to these questions are the focus of the first part of remaining section of the discussion. The final part of section discusses the proximate (how) and ultimate (why) categorisation of causes of depression and its implications for help seeking behaviour.

Research question 1: How do Baganda conceptualise and cope with depression?

The answer to this question is from the response based on the hypothetical case vignettes assessing non-psychotic and psychotic depression.

Lay conceptualisation and coping strategies

Non-depressive symptoms were conceptualized as a problem related to thoughts (thinking too much) rather than emotion (sadness) or behaviour and the resulting condition is referred to as "*illness of thoughts*". The *illness of thoughts* was considered a non-chronic condition caused by worrisome thoughts about psychosocial problems, which was perceived to require no medication, as it was believed that there was no medication for thoughts. Lay help from ones social groups such as religious group, significant relatives, elders, friends and traditional healers were proposed as appropriate sources of help.

Depression with psychotic features with mood congruent delusions was recognised and labelled as a clan illness (*eByekika*). The illness was believed to have its origins in a faulty relationship between the living and the dead. Its management therefore required dealing with this relationship problem. The illness belonged to what the Baganda refer to as a Kiganda illness (an illness that has its origin in the collective group customs and relationships of the Baganda people in their clans). The healing process involved the healer, patient and the clan members.

The conceptualisation indicates that the two constitute two different illnesses. However, sharing the problem either through supportive communication or through sharing a healing ritual with members of ones social group was the main mode of coping with symptoms. Thus, although the symptoms of depression were seen as constituting an illness, its conceptualization, name, causation and treatment differ from conventional Western biomedical psychiatry.

Symptoms presentation and illness recognition

Results from people receiving treatment for depression (Paper II) show that during the contact with health care providers at various levels, somatic complaints were spontaneously volunteered as a reason for seeking help. Somatisation has been variously described as functional, and bio-medically unexplained, somatic symptoms, somatic preoccupation or worry about illness or undue emphasis on the somatic concomitants of psychiatric disorders [127]. It is also regarded as an important reason

for under utilisation of mental health services among non-Western societies [128]. Though somatic symptoms were spontaneously reported, on further inquiry, patients began talking about the condition that brings about the somatic distress. With probing it became apparent that the pains in their bodies were anchored in the contexts of their everyday lives as participants expanded the explanations of physical pains to include social circumstances relating to their distress. Some of the social circumstances included conflicts in the family, difficulties in marriage, and perceived neglect of the elderly. Though the pains were located inside the individual body they reflected the events and constraints of the social space of which the person was a part. The physical experience of the body was always modified by the social categories through which it was known and sustained in a particular view of the society. The body in pain may contain within it an image as well as a message.

Apparently, a patient's narrative of his/her illness included statements linking his/her physical distress to social predicaments, moral sentiments and otherwise unexpressed emotions. Hence, complaints that seem (to the medical practitioner) to be evidence of a syndrome of somatic symptoms may, in reality, encode an ethno medical theory. This may in part explain the fact that the treatment focus in the earlier consultations was on the somatic complaints making entry to psychiatry only possible when there was emotional breakdown. An elderly female patient who had had several contacts with psychiatric services presented her reason for seeking help as follows:

“I have a problem with my stomach here. Something attacks from within and hurts so much... and my legs are also hurting a lot.”

In the course of the interview however, she expounded on the cause of her illness as follows:

“I have the pain, I am unhappy; I do not feel I am what I should be. I pray to God to save me from this misery... My people leave me home alone without any one to help me. I used to have a servant, she used to help me but she went. My son used to help me unfortunately he died recently.” (75 years old woman with recurring depression)

A young man admitted with depression with psychotic features, describes his illness as follows:

“I do not think I have a name for the condition...how it started; I got headache and my body was paining. I went to the clinic in the village and they gave me some tablets for pain. But you see in the village I am active. I have been involving myself in a number of activities. Even the local leader in our area had promised to take me for a course in modern agriculture. People may not be very happy about my progress. They become jealous because I am successful; I think they are bewitching me. I think they are doing certain things to hinder my progress.” (Young man aged 20 years)

The above extracts indicate that given time patients may provide information regarding their perceptions of their symptoms and their expectations from the intervention. This information may be important in helping health care providers to provide appropriate intervention.

Psychiatric admission and stigma

Stigma has been found to be widespread among depressed patients. Stigma concerns were found to be more common in depression than in medical conditions [129, 130].

Most evident in relation to psychiatric admission was the patients' efforts to answer the question: "How did I get here?" Participants contacting psychiatric services for the first time spent a substantial amount of time trying to evaluate the meaning of psychiatric admission. Participants needed to evaluate the consequences of illness for their identity and future life. These efforts can be viewed in relation to the stigma attached to psychiatric diagnosis and treatment.

A psychiatric label is said to activate negative images about mental illness that are applied to the individual by others or him/herself. The resulting internalisation of stigma is said to interfere with several areas of life including general well-being and self-esteem [129].

Contact with psychiatric experts forced patients to reformulate their identity, go through a reconstruction of the past in terms of current experiences; look for causes of their situation; construct theories about the nature of illness, and establish modes of coping. This finding is similar to what David Karp [131] referred to as social construction of illness identity.

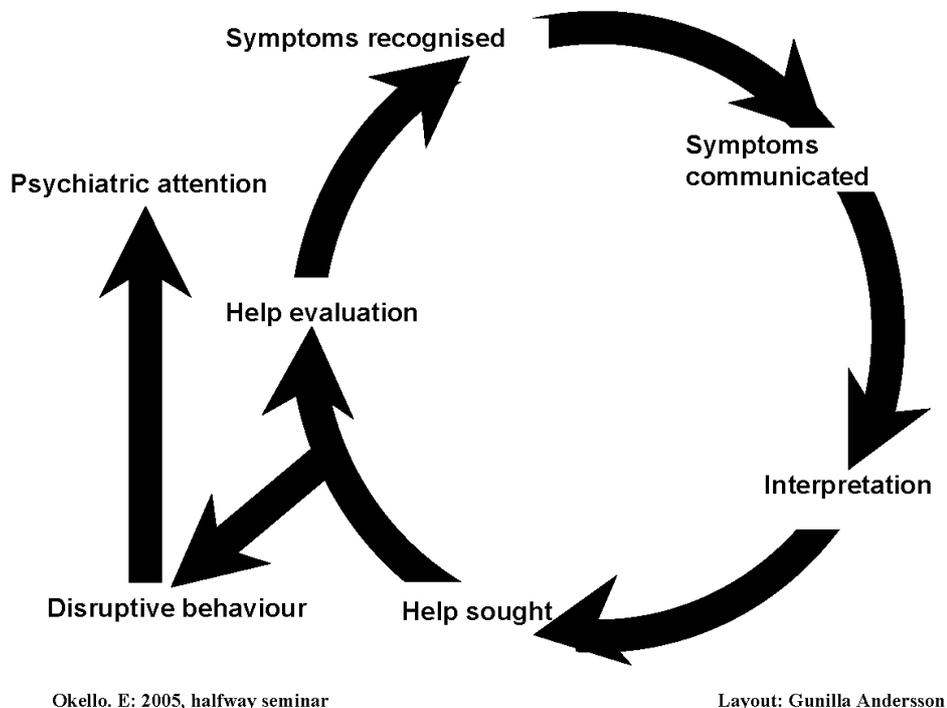
Research question 2: How severe must symptoms be to warrant psychiatric help?

Participants' stories indicated that symptoms, which were considered by others as socially disruptive, were important triggers that led to psychiatric attention. Disruptive behaviour included attempting suicide, bizarre behaviour such as hearing voices, talking to oneself, refusing to talk/being mute, and extreme social withdrawal.

Socially disruptive behaviour as a trigger for seeking psychiatric help

In the results presented in Paper II, psychiatric admission was described as the end of a long journey in search of help that took patients and their significant others a substantial amount of time and resources to accomplish. In the process of help seeking, for many respondents, this journey started from an individual feeling unwell. The feelings were expressed to significant others and the individual and significant others interpreted the illness using a combination of both lay and biomedical theories. Depending on the interpretation, help was sought. When no improvement was registered, new explanations were developed, and new help was sought. The process involved multiple visits to health care facilities at various levels in the health care system. Figure 3, below, represents a rough model of help-seeking circles:

Figure 3. Simple model of help seeking process among people with depression



It was not until others did define the patient's behaviour as socially disruptive that the attention of a psychiatrist was sought. About 35 years ago, Orley [132] hinted at the same issue regarding depression among the Baganda. What such findings may mean is that psychological pain caused by the illness and impaired social functioning must result in what others define as socially disruptive behaviour, for example, actual suicide attempt or complete failure to function socially on the part of the patient, if psychiatric help is to be sought.

Research question 3: Are the symptoms of major depression seen as constituting one illness?

According to the lay models of depression a clear distinction was made between depression with psychotic features and depression without psychotic features. These were seen as separate illnesses demanding different approaches to treatment.

Depression with psychotic features

Depression with psychotic features was conceptualised as *eByekika (Clan) illness* that was caused by actions or behaviour of the living toward the dead. The condition is

recognised and conceptualised as a result of wrongs (omissions or commissions) by the living against their clan/family dead. These may take the form of failure or inconsistency in performance of culturally demanded rituals, incorporating alien beliefs into Ganda belief systems or breaking taboos. These seem to relate to what is referred to in the DSM-IV as “mood congruent delusions” of deserved punishment. The mood congruent delusions, the most common symptom in psychotic depression, fit in well with the idea of deserved punishment for individual or group transgressions against the ancestors and placating shame. Under the circumstances even suicidal ideation is tolerated, though suicide attempts and actually committing suicide are highly condemned and stigmatised behaviours among the Baganda.

These results suggest that illness representation is not only part of culture in terms of shaping experience but also mirrors and reflects cultural realities. Illness-related knowledge is a complex cultural domain that entails risk and causal factors, complications and treatment strategies. Causal explanations provide meaning to human suffering and have an important role in shaping illness behaviour.

It has been noted that the idea of prevention among African societies fulfils functions far beyond offering reasons for or curing ill health. At a societal level, the belief that violation of social, religious, or sexual codes of conduct would bring about disease (either by actions of others or through ancestral intervention) comprises a powerful mechanism for ensuring social cohesion and stability [133]. If supernatural forces dominate human experience, then believing that these are rational forces would bring a sense of order to unfortunate events or fate. Thus, good behaviour, patience and doing communal good provided an opportunity to control these forces and reduce the likelihood of potential catastrophe [134, 135].

Depression with psychotic features belonged to what the Baganda refer to as a Kiganda illness (an illness that has its origin in the collective group customs and relationships of the Baganda people in their clans). The help-seeking behaviour was therefore social and collective and was intended to address both proximate and ultimate causes of the illness. The nearest similarity with Western psychiatry is group therapy, the group being composed of the clan/family members.

For the Baganda both proximate and ultimate causes require effective treatment if the illness is to be cured. To treat proximate (how) causes and physical symptoms people may consult medical personnel and/or traditional healers for appropriate remedies. However, for a total cure, the ultimate (why) causes must also be dealt with. These were believed to lie within supernatural domains; thus, cure must be sought from healers believed to have access to such domains. The Baganda believe that only traditional healers and diviners are capable of useful insights and therapies for these supernatural ultimate causes. The traditional healers and the participation of other members of the clan in the healing process are central to correcting what is perceived as a collective (clan/family) wrong. Western medicine was seen as inappropriate for such a condition especially as it emphasised individual brain problem and treatments.

There are clear differences between lay and biomedical explanations of what DSM-IV and ICD-10 define as psychotic depression. These differences impact not only on help-seeking patterns and behaviour but also on how the symptoms are communicated when the patient comes into contact with health care services.

Depression without psychotic features

This was labelled an illness of thoughts; this label was spontaneously followed by explanations of what could have caused these many thoughts. The condition was regarded as a life situation and as a relatively normal reaction to severe social and personal threats and losses.

Individual, interpersonal, community and societal factors were identified as the perceived causes of thinking too much, thus causing the “*illness of thoughts*”. This situational model described psychological distress in the context of social and interpersonal situations and has also been described elsewhere [5, 34, 136-138]. It is an explanatory strategy that stresses interpersonal situations as opposed to the biological model of depression as a disease. The identified individual factors included individual characteristics that made one vulnerable such as age, gender, economic status and role in the family. Interpersonal factors included mainly relationship problems such as marital problems, child-parent relationships and peer relationships. Although the symptoms were seen as serious, requiring attention and help, the appropriate care for the problem was believed to lie outside the realm of modern medicine and the hospital.

The literature points out the importance of perceived helpfulness of the service providers and treatment offered by them in influencing help-seeking behaviour [139]. According to these results, mental health professionals and the services they offer were perceived as unhelpful for depression with and without psychotic features. This has implication for training, research and clinical care in Uganda.

Proximate and ultimate categorisation of causes and its implication for understanding the Baganda’s approach to depression with psychotic features

There is a general consensus in the literature that cultures across Africa define two types of causes of illness [135, 140-144]. These are proximate (how) and ultimate (why). A proximate cause accounts for how a disease is contracted. Contagion from pollutants is an example of a proximate cause while an ultimate cause accounts for why a particular person contracted a particular disease [141, 143, 144]. Among the main types of ultimate cause invoked in explaining illness are: contact with pollutants such as death and ancestral vengeance or punishment [142, 144]. Since contact with pollutants cannot always be avoided, people fortify themselves against contamination by maintaining strict moral codes and observing protective rituals [141].

In the description of causes, of depression with psychotic features the above categorisation featured prominently. These attributed causes could be grouped under the following categories:

- (i) Neglect of or abandoning traditional rituals
- (ii) Lost kin
- (iii) Mixing belief systems (traditional and foreign)
- (iv) Breaking taboos

Neglect of or abandoning traditional ritual

People in Buganda (the Baganda), like people in many other parts of Africa believe that the survival of ancestors in the spirit world depends on ancestors being accorded regular attention by the living. This attention is manifest in rituals, sacrifices, observance of taboos and high standards of social behaviour. Where these requirements are not met, ancestral spirits may send an illness as a warning or punishment. The following is an extract from one elderly Muganda man:

“Dead great grandparents (Bajjajja) may want one of you the family members to work on clan things. If this is not done, they make him get spoilt in the head. But if he works on them and after settling them, he becomes a very calm man who is sane again. So, when Lubaale is up on him, his brains are changed a bit. You see that?” (Elderly man)

Lost kin

Lost kin (lost blood) was another reason that was believed to cause the Lubaale spirits to appear. Loss of kin could arise in two instances: i) if a child was born and for some (social) reason the mother did not disclose the real biological father of the child then the child could be given a wrong name and assigned to a wrong clan or (ii) if a dead member of a clan did not receive a descent burial perhaps because he died in an alien place, the ancestors may make one of the living ill until the situation is redressed. These two instances could both be regarded as lost blood as demonstrated by the following extracts:

“At times it comes about when that child was given to a clan where he/she doesn’t belong. So the clan things of where he/she belongs may be struggling to get him/her back home. It could be that the father or aunt died. Now he is using the force he has to see that he gets this lost son/daughter back home.” (FGD Adults female)

“And maybe I will tell you this. We were one time in a shrine and some thing was disturbing the child. It had got him out of school. We brought the boy to the shrine in front of the spirits (Lubaale), the spirit was talking to us through him “it is me so and so...they buried me at those ends of Kasawo but I want you to come for me”. We asked ‘but we don’t know the particular place. Can you get in the child’s head as we come for you and you direct us? The sprit used the child to direct us and we found the place. So you can see.” (Elderly man)

Mixing belief systems

Participants believed that the tendency to mix Christian, Islamic and traditional religious practices had a role in the aetiology of clan illness. Actions like destroying shrines and burning the Lubaale things had had serious repercussions in the lives of people who had done so particularly as far as mental illness was concerned. Consequently they saw a relationship between frequencies in symptoms similar to the one described in the vignette among the people in the community and the increase in the number of foreign religions in Buganda region.

Breaking taboos

Other causes that were mentioned that could trigger vengeance in the ancestors included killing someone, especially one's own child, building in forbidden areas or eating foods unacceptable to the Lubaale or life style behaviour such as drinking alcohol and smoking especially if one is appointed to maintaining the shrine.

The above descriptions of deserved punishment fit well with what is referred to in the American Diagnostic and Statistical Manual DSM-IV as "mood congruent delusions", the most common symptom in psychotic depression. The difference, however, is that the deserved punishment is divorced from individual action and one individual takes the punishment on behalf of the clan or family especially regarding the omission of necessary rituals. Due to this difference, the feeling of shame is more profound than guilt with regard to depressive illness.

Both proximate and ultimate causes require treatment if the illness is to be cured. However, for a total cure the ultimate (why) causes of illness were believed to lie within supernatural domains; thus cure must be sought from healers that have access to such domains. The Baganda believe that only traditional healers and diviners are capable of useful insights and therapies for these supernatural ultimate causes. The traditional healer was therefore to play more the role of a diviner than a healer. As a diviner, a traditional healer was seen as having a special vision that enabled him/her to witness the connection between the hidden and the manifest; his/her transformative powers enabled him/her to manipulate it. The traditional healer was to advise the family and if necessary take them through kusamira rituals (ancestral spirit worship). During the ritual, therapy was not necessarily directed toward the patient's physical person, but toward the social relations in which, he/she exists. The restoration of order in social relations that had been disrupted and the realization in social life of meaning that previously have been obscured within it are both processes, essential to the patient's recovery.

Failure by the biomedical approach to address the "why" question may explain why participants believed that hospital medicine had no role in "eByekika illness" since the symptoms of an individual are seen as a reflection of a problem in the social relationships, and not as the individual's problem as such. Hence the approaches of Western psychology/psychiatry of treating symptoms of depression as an individual problem were seen as insufficient in addressing problem that has social significance

where individual suffering is interpreted as an indication of a communal problem in the social order.

Limitations of the results

These are findings from exploratory studies; one cannot draw definitive final empirical generalisations, where data may be assumed to represent a wider population in probabilistic sense [125] due to methods used. However, a theoretical generalisation is possible, since the data from the current studies provide theoretical insights, which are sufficiently generalisable or universal to allow their projection to other contexts, or situations, comparable to the context in the current studies.

These studies are also limited to a single cultural group, the Baganda. Further research combining qualitative and quantitative methods may need to include other cultural groups to enhance comparison across large cultural groups within Uganda and Africa.

CONCLUDING REMARKS AND IMPLICATIONS

Concluding remarks

- i) Conceptualisations of depression among the Baganda differ from the biomedical models of depression. The causal models incorporated both proximate (how) and ultimate (why) questions. Western medicine was seen as inappropriate for what was conceived as an illness of thoughts or a clan illness.
- ii) Socially disruptive behaviour triggered seeking of psychiatric help. Patients who did not exhibit behaviour that was considered socially disruptive were not brought to the attention of modern psychiatry.
- iii) The two subtypes of depression (psychotic and non-psychotic) were seen as different illnesses. Psychotic features, specifically the mood congruent delusions were the key in the definition of illness.
- iv) There are similarities in the conceptualisation of depression between lay people and traditional healers who are the alternative care providers in Uganda.

Implications for clinical practice

The results of this thesis suggest several important implications for management of depression among the studied cultural group. First is to appreciate the importance of the lay understanding of the ultimate cause of illness as this lay model of causality impacts on help seeking. Thus it is very important to review the way depression is managed in the Western form of psychiatry when the patients reach mental health services in hospitals. Secondly, the emphasis was on the role of the social support group (the family or clan) in the management of this eByekika illness (Depression). This implied that the individual patient approach employed by Western-trained psychiatrists and other cadres of mental health workers may fall short of what the patient and significant others expect from the intervention. It may therefore negatively impact on their follow-up attendance and suggested psychotherapeutic management. The recent report of successful “Interactive Group Psychotherapy” techniques in the treatment of depression in Uganda [27] may therefore be in line with a cultural approach to treatment of depression.

The noted similarity in the perception of depression between the traditional healers and the users of their service has clinical implications for therapeutic approaches such as psychotherapy, where the agreement between the care provider and care receiver is key in a therapeutic relationship.

Policy Implications

The findings of Study IV play a useful role in helping to bring to light needs and resources for developing locally relevant community mental health programmes to meet health needs of the population. There is evidence that people use other sources of care such as traditional healers to cope with depressive symptoms. With the current resource situation and help-seeking behaviour in Uganda, it is highly desirable to reduce the polarization between traditional healers and modern medicine by exploring more opportunities for integration of the two. The provision of care for psychosocial problems may be one of those areas that may lend itself to this shared interest.

Research implications

There is a need to conduct a larger study that would combine both qualitative and quantitative methods to assess the validity of the local concepts that have been presented in this thesis. Such a study will facilitate inclusion of local concepts used to describe depression in the assessment of patients, particularly in primary care settings where they first come into contact with a modern health care system.

The second research area should focus on the effectiveness of the treatment approaches recommended by the alternative healers. This should preferably be a clinical trial. The recommended studies will provide evidence that may inform policy makers on how to incorporate traditional healers' services into the existing mental health services to enable people to gain access to care services according to their needs.

Implications for training

The training of psychiatrists and health care providers in general in developing countries should incorporate culturally relevant concepts aimed at enabling health care providers to provide culturally sensitive care. Both curricular and in-service courses exploring the facets of cultural awareness, cultural knowledge, cultural understanding, cultural sensitivity and cultural skills could be an effective approach in training health care providers and medical students in Uganda.

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