Explanatory models for the care of outpatients with mood disorders in Uganda: An exploratory study

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Dissertation presented for the degree of *Doctor of Philosophy in the*
Faculty of Arts and Social Sciences at
Stellenbosch University

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April 2014

Declaration

By submitting this dissertation electronically, I hereby declare that the work contained therein is my own, original work, and that I have not previously submitted it either in part or in its entirety for award of any qualification.

Date: February 2014

Abstract

The growing burden of mental illnesses in low- and middle-income countries, such as Uganda, necessitates effective interventions to promote mental and social well-being among their populations. Mood disorders contribute more substantially to the global burden of mental illnesses than do other forms of mental disorders. The substantial global burden of mental illnesses is projected to grow more rapidly in low- and middle-income countries than in high-income countries in the future. Because experiences of and responses to mood disorders are invariably patterned by social and cultural contexts, as argued in the growing field of cross-cultural psychiatry, health care systems, especially in low- and middle-income countries, need to design and deliver culturally relevant interventions that effectively deal with this problem. However, there is generally a paucity of suitable evidence to guide the planning and delivery of such interventions in countries like Uganda. As a response to the apparent knowledge and research gaps regarding experiences of mood disorders and care in Western Uganda, I conducted a qualitative study involving outpatients and their care providers, that is, outpatients' families, psychiatric health workers, religious healers and traditional healers. Using purposive and snow ball sampling techniques, I selected participants, that is, outpatients as well as psychiatric health workers, outpatients' families, religious healers and traditional healers involved in the care of the outpatients from the Mbarara Regional Referral Hospital (MRRH) and the "Greater Mbarara" region, respectively. The aim of this study is to explore explanatory models that outpatients and care providers in Western Uganda use in responding to mood disorders. I analysed the data collected in the fieldwork using ATLAS.ti 6.2, a computer-software programme designed to support qualitative data analysis. Results from the study indicate that outpatients and their care providers hold complex, diverse and contradictory explanatory models regarding mood disorders and care, which are shaped by their unique social and cultural contexts. Additionally, poor relationships and communication between patients and their care providers, especially between outpatients and psychiatric health workers, are strongly evident; structural barriers significantly hinder the provision and utilisation of care; care is generally inadequate, although it is conceptualised broadly to include biomedical, popular and folk treatments; and outpatients generally exhibit inconsequential (weak) agency in managing distress, which is primarily caused by mood disorders and care-seeking challenges. The results of the current study suggest several implications regarding mental health practice, training, policy and research.

Opsomming

Weens die toenemende geestesiektelas in lae- en middelinkomstelande soos Uganda word intervensies vereis om die geestelike en maatskaplike welsyn van die bevolkings van daardie lande te bevorder. Gemoedsteurings maak ’n groter deel van die wêreldwye geestesiektelas uit as ander vorme van geestesongesteldheid. Die beduidende wêreldwye geestesiektelas sal in die toekoms na verwagting vinniger in lae- en middelinkomstelande as in hoë-inkomstelande toeneem. Aangesien ervarings van én reaksies op gemoedsteurings meestal deur maatskaplike en kulturele kontekste beïnvloed word, soos die groeiende dissipline van transkulturele psigiatrie beweer, moet gesondheidsorgstelsels, veral dié in lae- en middelinkomstelande, kultureel tersaaklike intervensies ontwerp en voorsien wat hierdie probleem doeltreffend hanteer. Tog is daar oor die algemeen ’n skaarste aan geskikte bewyse om die beplanning en voorsiening van sulke intervensies in lande soos Uganda te rig. In antwoord op die klaarblyklike kennis- en navorsingsleemtes met betrekking tot ervarings van gemoedsteurings en sorg in Wes-Uganda het ek ’n kwalitatiewe studie onder buitepasiënte en hul versorgers – met ander woorde hul familie, psigiatriese gesondheidswerkers, geloofsgenesers en tradisionele genesers – onderneem. Die steekproef het bestaan uit pasiënte en hul familielede, psigiatriese gesondheidswerkers sowel as geloofs- en tradisionele genesers wat gemoeid is met die versorging van buitepasiënte by die streeksverwysingshospitaal Mbarara (MRRH) én in die Mbarara-distrik onderskeidelik. Die doel met die studie was om te verken watter verklarende modelle pasiënte en versorgers in Wes-Uganda gebruik om op gemoedsteurings te reageer. Die data wat met die veldwerk ingesamel is, is ontleed met behulp van die rekenaarsagteware ATLAS.ti 6.2, wat ontwerp is om kwalitatiewe dataontleding te ondersteun. Die resultate van die studie toon dat buitepasiënte en hul versorgers oor komplekse, uiteenlopende en teenstellende verklarende modelle met betrekking tot gemoedsteurings en sorg beskik, wat deur hul unieke maatskaplike en kulturele kontekste gevorm word. My navorsing dui daarop dat swak verhoudings en kommunikasie tussen pasiënte en hul versorgers, veral tussen buitepasiënte en psigiatriese gesondheidswerkers, aan die orde van die dag is; dat strukturele versperrings die voorsiening en benutting van sorg beduidend verhinder; dat sorg oor die algemeen onvoldoende is, hoewel dit volgens die algemene begrip biomediese, populêre én volksbehandelings insluit, en dat buitepasiënte meestal ontoereikende (swak) vermoëns toon om nood wat uit gemoedsteurings en uitdagings in die soeke na sorg spruit, te hanteer. Die studie sit uiteindelik ook verskeie belangrike implikasies vir geestesgesondheidspraktyke, -opleiding, -beleid en -navorsing uiteen.

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Acknowledgements

I am grateful to many individuals and institutions for the generous support provided to me during the course of my doctoral studies at Stellenbosch University. Limited space means I cannot list each and every one of them. However, I must mention a few individuals and institutions without whose support it would not have been possible for me to realise my "dream" of attaining a doctoral degree in 2014.

To begin with, I am especially grateful to my supervisor, Professor Ashraf Kagee, for his immeasurable intellectual, moral, financial and material support. As I write this, I recall vividly the intellectual journey Professor Kagee steadfastly made with me, enabling me in every respect to complete the walk I began. I am thus anxious that a mere listing may underestimate his generous support. I am, however, elated by Professor Kagee's sacrifice, patience and care that have made my learning a very enriching experience. For this, I hope that my continued academic advancement and consequent support to students in similar need of supervision and support in my future work in Uganda will be a token of my heartfelt appreciation of Professor Kagee's generous support to me.

I am also grateful to the University of Stellenbosch for the generous scholarship for full-time doctoral studies under the Partnership for Africa's Next Generation of Academics (PANGeA). I am especially indebted to the coordinators, Prof. Johann Groenewald, Ms. Carin De La Querra and Dr. Cindy Lee Steenekamp at the Graduate School, Faculty of Arts and Social Sciences, all who ensured that my stay at Stellenbosch University remains memorable. I thank these individuals for, among other contributions, ensuring that I had a comfortable working office, money to meet basic needs and opportunities to undertake numerous trainings in my area of study and work. I am similarly thankful to the entire staff at the Psychology Department and Centre for Public Mental Health at Stellenbosch University for making me feel at home in South Africa. Among their sustained support, I benefited immensely from regular seminars and colloquia, reading materials, "teas" and "eats" and encouragement that was always timely and abundantly provided. I am especially grateful to Professor Tony Naidoo for visiting me at home to further inspire and support me during the course of conducting my fieldwork in Uganda.

I am grateful to Makerere University for the financial support and study leave that enabled me to undertake full-time doctoral studies at the prestigious Stellenbosch University. I convey my special thanks, particularly, to Dr. Narathius Asingwire, Dr. David Kyaddondo, Dr. Eddy Walakira, Prof. Edward Kirumira and Prof. Charles Bwaana for approving my request for study leave. I hope that the knowledge and skills I have acquired in the course of my doctoral studies will be useful to the Social Work and Social Administration Department, in particular, and Makerere University, in general, to the extent of repaying, at least in part, the generous support provided to me. I am equally grateful to all my colleagues at the Social Work and Social Administration Department who inspired and encouraged me to undertake my doctoral studies and selflessly accepted excessive workloads so that I could take study leave.

Additionally, I am indebted to all participants for taking off their valuable time to participate in my study and for sharing their personal experiences regarding mental illnesses and care. Without their generous support and cooperation I would not have obtained the valuable information needed for writing this dissertation. I humbly pray that the results and implications of the present study will contribute to improved understanding of and response to mood disorders. I am especially grateful to my research assistant, Ms. Lydia Rukundo, for her professionalism and enthusiasm that made my fieldwork a heartening and successful experience.

I would like to thank the following individuals who regularly contacted and motivated me to complete my studies. In no order of importance or otherwise, I am grateful to Mr. Benon Kajuna and family, Dr. Mugumya Levis, Dr. Muhangi Denis, Mr. Edward Mugarura, Prof. Muhwezi and family, Prof. Rwomire, Mr. Julius Bakashaba, Ms. Sharlotte Tusasiirwe, Ms. Everlyn Nakasiita, Mr. James Wasike, Ms. Van Wyk Marleen, Dr. Damian Kajunguri, Mr. Benon Turinawe, Mr. Justus Turamyeomwe, Mr. Godwin Twesigye, Mr. Enock Teye-Kwadjo, Mr. Simon Kizito, Dr. Sekimpi Deo and Dr. Divine Fuh. I am similarly grateful to Ms. Roshila Nair for her editorial support that greatly improved the quality of this dissertation.

Finally, I would like to thank my family for the love, care, sacrifice and prayers they religiously provided me throughout my doctoral studies. I believe they will be proud and inspired by my steadfast pioneering efforts in academia. Once more, as at bachelor’s and master’s levels, I am the pioneer child in our extended family to acquire a doctoral degree. Now that the door is open, I am hopeful that many of my siblings will take a similar route. In a special way, I would like to thank three very special people in my life – my wife, Ms. Hope Nsimenta and children, Alan Twesigye and Blessing Nsimenta – for the tolerance, empathy, sacrifice, love and encouragement they generously exhibited throughout that enabled me to succeed in my doctoral studies. I hope that this academic achievement will bear many fruits for us all.

In spite of the above acknowledged generous support, in the event that any error is found in this dissertation, it is entirely my own.

Dedication

I dedicate this dissertation to the memory of my father, Mr. Gorge Bishobire who passed away in February 2012, leaving us at a time when I needed much inspiration in writing this dissertation. I humbly pray that your soul rests in eternal peace.

Definitions of Key Concepts

Care is the "support and assistance one individual requires of another where the one in need of care is *inevitably dependent*, that is, dependent because they are too young, too ill or too frail, to manage daily self-maintenance alone" (Kittay, Jennings & Wasunna, 2005).

Cultural competence refers to the "attributes or characteristics of service providers and, sometimes, service agencies and organisations that equip them to effectively provide otherwise desirable or warranted health care interventions to an array of culturally diverse patients or clients" (Wendt & Gone, 2011)

Culture refers to "a set of meanings, behavioural norms, values and practices used by members of a particular society as they construct their unique view of the world" (Mezzich, Caracci, Fabrega & Kirmayer, 2009).

Explanatory models refer to the "notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman (1981, p. 105).

A health care system is "a special cultural system that is concerned with the socially organized responses to disease. Moreover, in every culture, illness, the responses to it, individuals experiencing it and treating it, and the social institutions relating to it are all systematically connected" (Kleinman, 1981, p. 24).

Mental disorders are "clinically significant conditions characterised by changes in thinking, mood or behaviour associated with personal distress and impaired functioning" (WHO, 2001).

Mental health is "a state of wellbeing in which the individual realises his or her own abilities, copes with the normal stresses of life, works productively and fruitfully and is able to make a contribution to his or her own community" (WHO, 2001).

Mood disorder is "a mental disorder in which the prominent diagnostic feature is mood disturbance. For example, mood may be unusually elated as in the case of a manic episode of bipolar disorder or mood may be unusually depressed as in the case of a depressive episode of unipolar depression" (American Psychiatric Association, 1994).

Self-care agency is the "complex acquired capacity to meet one's continuing requirements for care of self that regulates life process, maintains or promotes integrity of human structure and functioning and human development, and promotes wellbeing" (Orem 1995 cited in Owens, 2007).

Glossary of Key Terms in the Runyankole-Rukiga Language and their Translated Meanings in English

Eby'ekika means ancestral spirits, which are supernatural attributed causes of mental illnesses.

Ensimbu means epilepsy for members of Banyankole and Bakiga community in Western Uganda, who consider it a kind of madness.

Iraro means madness for members of Banyankole and Bakiga communities in Western Uganda, who use it interchangeably with ***Ebishazi***, depending if a person primarily speaks the Runyankole or Rukiga languages.

Karondozi means intergenerational vulnerability to mental illness for members of Banyankole and Bakiga community in Western Uganda, who use it in reference to a positive family history of mental illness. Members of Banyankole and Bakiga communities in Western Uganda use *Karondozi* interchangeably with ***Eby'akarande***.

Oburwire bw'omutwe is a literal translation for “illness of the head” by members of Banyankole and Bakiga community in Western Uganda, who use it as euphemism for mental illness (madness).

Okusindika orotami is a literal translation of “pushing a person who is resting on his or her heels” by members of Banyankole and Bakiga communities in Western Uganda, who use it to describe the interplay between genetic and psychosocial causes of mental illnesses.

Okutabuka omutwe is a literal translation of “being mixed up in the head” or to “run mad”.

Okweyinamirira is used by members of Banyankole and Bakiga community in Western Uganda as label for unipolar depression; its predominant features include feeling sad, self-pity and being inactive. *Okweyinamirira* closely matches ***Okutundama*** that members of Banyankole and Bakiga communities in Western Uganda also use as a label for unipolar depression; the predominant features of ***Okutundama*** include feeling downcast, being withdrawn and quiet.

Omushazi means a mad person and members for Banyankole and Bakiga communities in Western Uganda, who use this term interchangeably with ***Omugwiraro***, depending if a person primarily speaks either the Rukiga or Runyankole languages.

List of Acronyms and Abbreviations

CTO	Community Treatment Order
DSM	Diagnostic and Statistical Manual of Mental Disorders
HICs	High-Income Countries
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
LAMICs	Low- and Middle-Income Countries
MDGs	Millenium Development Goals
MRRH	Mbarara Regional Referral Hospital
MUST	Mbarara University of Science and Technology
WHO	World Health Organization

Chapter 1
Introduction

1.1. Background to the Study

Culture, the world over, influences the labelling and expression of as well as the response to mental illness (Helman, 2007; Kirmayer, 2005). For example, Kirmayer (2005) states that within moral notions of self and personhood, people organise, experience and express distress in terms of a series of cognitive schemas which comprise knowledge about symptoms, illnesses or other models of affliction. Different social and cultural contexts, such as the workplace, family and health care settings as well as the goals people set and try to achieve, determine the cognitive schema each person employs to explain experiences of illness (Kirmayer, 2005). The pervasive influence of culture thus makes it imperative to assess cultural contexts and configurations to understand illness and well-being as well as to design and deliver appropriate health interventions (Mezzich, Caracci, Fabrega, & Kirmayer, 2009). Similarly, Lewis-Fernández (2009) observes that the inclusion of the cultural formulation in the DSM-IV has been a crucial contribution to the development of the DSM series. The cultural formulation, according to Lewis-Fernández (2009), requires clinicians to systematically assess the following factors with regard to the evaluation of a patient's mental health: (a) the cultural identity of the patient, (b) illness representation, (c) perceived causation, (d) treatment expectations, (e) the cultural context(s) of stressors and supports, and (f) any other cultural-relevant factors.

A well-conducted cultural formulation improves diagnostic validity, helps to align the treatment recommendations of health workers with explanatory models of patients and their families and ultimately serves to prevent dissatisfaction, non-adherence and poor response to treatment on the part of patients (Lewis-Fernández, 2009). A cultural formulation is consistent with cultural competence and is aimed at improving mental health care in contexts of cultural diversity (Anderson et al., 2003; Betancourt, Green, Carrillo, & Par, 2005; Wendt & Gone, 2011). Wendt and Gone (2011) define cultural competence as the "attributes or characteristics of service providers and, sometimes, service agencies and organisations that equip them to effectively provide otherwise desirable or warranted health care interventions to an array of culturally diverse patients or clients". Any form of care is *transcultural* (Kortmann, 2010); effective mental health care, provided by health care providers and organisations, should therefore acknowledge the inherent cultural diversity among service users and care providers.

Despite positive developments such as the above in cross-cultural psychiatry, some scholars are concerned that there is still limited critical attention being paid and consideration given to culture (Kleinman & Benson, 2006; Lewis-Fernández, 2009; Mezzich et al., 2009). For example, Mezzich et al. (2009) note that although introduced in the DSM-IV, the cultural formulation is nonetheless being under-utilised and has received little formal evaluation in psychiatric practice, partly due to the absence of implementation guidelines and illustrative cases. Similarly, Lewis-Fernández (2009) observes that time limitations on the part of clinicians and limited dissemination of the cultural formulation outline constrain the latter's use. While the updated outline for the cultural formulation in the DSM-5 attempts to address some of the above concerns, for example, via the inclusion of the cultural formulation interview guide (American Psychiatric Association, 2013), other concerns, such as lack of time on the part of the clinicians, remain challenges that still need to be addressed urgently.

Furthermore, Kleinman and Benson (2006) argue that popular interventions, such as cultural competence, are often poorly defined and operationalised in psychiatric practice. They also note that incorrect conceptualisations of culture, for example, seeing culture as synonymous with ethnicity, nationality and language, undermine the cultural competence agenda. According to Kleinman and Benson (2006), clinicians often assume that patients of specific ethnic groups, for example, Mexican, share comparable sets of beliefs about illness. Yet, culture, as understood in anthropological terms, is a dynamic and pervasive reality, inseparable from prevailing economic, political, religious and psychological factors. Consistent with this view, Kleinman and Benson (2006) define culture as "a process through which ordinary activities and conditions take on an emotional tone and a moral meaning for individual participants". Mezzich et al. (2009) similarly argue that while culture and ethnicity may be used to categorise people, factors such as age, socio-economic class, geographic location and personal preferences make members of cultural or ethnic groups diverse.

Based on considerations such as these, appropriate mental health care requires the correct and appropriate contextualisation of illness, patients and care providers in social and cultural contexts (Kleinman & Benson, 2006). Careful attention to culture may prevent stereotypical and essentialist attitudes among clinicians towards diverse patients. Using the explanatory model framework, clinicians may, for example, discover "what really matters" for patients, their families and for themselves, which is normally a combination of cultural and personal meanings within specific local worlds (Kleinman & Benson, 2006). For clinicians to reframe culture as "illness meaning" and to enhance effective communication with patients, they need to ask individualised questions, such as, "what do you call this problem?" (Kleinman & Benson, 2006). The use of standardised diagnostic systems, for example, the DSM in cross-cultural psychiatry, however, may constrain effective exploration in this regard for patients and clinicians in LAMICs. This is because the social and cultural contexts in LAMICs differ significantly to that in the West, the latter which has significantly influenced the development of standardised diagnostic systems, such as the DSM itself (Jadhav, Weiss & Littlewood, 2001; Waldram, 2006). It is for the latter reason that the concept of explanatory models, as originally formulated, remains central to the development of effective cross-cultural psychiatry.

1.1.1. The concept of explanatory models. The concept of explanatory models, as used in cross-cultural psychiatry, was initially developed by Kleinman (1980) and further by Helman (2007). Kleinman (1980, p. 105) defines explanatory models as the "notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process". This definition acknowledges that both the patient and his or her care providers possess explanations of the patient's illness that influence decisions regarding treatments sought and provided. According to Kleinman (1980), explanatory models account for the following aspects of an episode of illness: (a) aetiology, (b) time and mode of onset of symptoms, (c) pathophysiology, (d) course of sickness, and (e) treatment. While the explanatory models of the patient and his or her family are often concerned with the most *salient* aspects of the illness, the explanatory models of healers, such as psychiatric health workers, are usually concerned with all the above five aspects of illness (Kleinman, 1980). Kleinman (1980) also observes that the explanatory models are constructed in response to specific episodes of illness and may therefore differ from generally held beliefs regarding illness and health care, the latter which may be influenced by the dominant health ideology in various sectors of a plural health care system. Lay explanatory models, according to Kleinman (1980), are "idiosyncratic and changeable, partly conscious and partly outside of awareness, are characterised by vagueness, multiplicity of meanings, frequent changes, and lack sharp boundaries between ideas and experiences". The explanatory models of health professionals, in contrast, are usually based on "single causal trains of scientific logic" (Kleinman, 1980, p. 107). However, explanatory models of practitioners may be similar to that of the patient's in some respects. For example, explanatory models are largely tacit and a product of circumstances and imprecise assessments to which practitioners are committed. They predispose practitioners to act in particular ways and to rationalise their actions. While clinical explanatory models may closely approximate scientific explanatory models, the two are distinct from each other. Clinical explanatory models, according to Kleinman (1980), may be regarded as a special type of *commonsense* rationality, the latter which is a common feature of popular culture.

Furthermore, Helman (2007) observes that patients and their care providers often hold divergent explanations for the *same* episode of illness because explanatory models are influenced by the varied social and cultural contexts of each. Patients may, for example, express a number of different explanations of their illness episodes for themselves, their families and the health workers attending them at different times and in different health care contexts, such as the home and the doctors' office. Similarly, care providers may understand and respond to patients' health conditions differently. According to Helman (2007), contextual factors such as social and economic organisation and dominant social ideology (for example, religion) influence the explanatory models used by patients and care providers. Helman (2007) also notes that factors such as social class, gender, age and stage in life cycle affect how patients evaluate the seriousness of their illness episodes, based on criteria such as the perceived causes (for example, as having either supernatural or biomedical causes), consequences (for example, being malignant or non-malignant), and treatments (for example, requiring either medication or ritual redress). Social and economic variables, such as poverty and financial affordability, further determine forms of treatment and care accessed for illnesses, including treatment within the various subsectors of a plural health care system, for example, within the popular and professional sectors. Because their social power is derived in part from a higher formal education and social class than that of patients, clinicians may unduly influence the explanatory models of patients to fit a biomedical model of disease (Helman, 2007).

There are always cultural differences between patients and their care providers; all care is therefore transcultural (Kortmann, 2010). While cultural diversity associated with ethnic minority groups may more easily be recognised or acknowledged, this may not be the case with regard to intracultural diversity in relatively *homogenous* populations (Kortmann, 2010). Yet, factors such as gender, age, social class and locality can and often do produce intracultural differences, which, if overlooked, may result in serious problems, such as stereotyping of patients (Mezzich, et al. 1996). Culturally competent health care therefore demands that health workers elicit the explanatory models of patients' illnesses and that they negotiate treatment with them (Kirmayer, 2012). A narrative or story is the main means by which care providers may elicit patients' explanatory models (Helman, 2007). According to Helman (2007), a narrative organises a patient's traumatic experience, thereby giving it a meaning so that the patient and care providers can understand and appropriately manage the illness. A patient's narrative or story may be verbal or nonverbal and telling it contextualises the individual's life history within the wider themes of his or her culture and society. For example, patients usually tell their stories of suffering by drawing on the repertoire of language, idiom, imagery, myths and legends provided by the culture in which the suffering is experienced (Helman, 2007). To facilitate patients telling their stories about their illnesses in their own terms, Kleinman and Benson (2006) suggest using a number of open-ended questions to help clinicians. These questions include: (a) what do you call your problem? (b) what do you think has caused your problem? (c) what are the chief problems your sickness has caused for you? and (d) what kind of treatment do you think you should receive?

While the explanatory model framework was initially formulated by Kleinman (1980) to generate rich narratives from patients, researchers and clinicians have found that qualitative (emic) interviews are far too long and challenging for cross-cultural epidemiological research. As a result, researchers working at the boundary of anthropology and epidemiology have developed semi-structured instruments, such as the Short Explanatory Model Interview (SEMI) by Lloyd et al. (1998) and the Explanatory Model Interview Catalogue (EMIC) by Weiss (1997), to elicit explanatory models of mental illness and to facilitate cross-cultural comparisons. Lloyd et al. (1998) modelled the SEMI on the initial ideas offered by Kleinman (1980). According to Lloyd et al. (1998), the SEMI is a semi-structured instrument that may be used to elicit explanatory models among study subjects. It makes use of simple or plain language that does not include medical jargon and complex terms. Lloyd et al. (1998) recommend that the person administering the SEMI encourages the subjects to talk openly about their attitudes and experiences to elicit concepts held as well as their relationships to the current situation and culture. The interviewer is also encouraged to use probing questions to explore areas of interest about which the interviewee may not volunteer spontaneous responses. The items on the SEMI that occur frequently may be allocated numerical codes and analysed quantitatively. The SEMI comprises the following five sections: (a) personal and cultural background (for example, demographic data, family, work and relationships) information, (b) nature of the problem (for example, reason for consulting and naming the problem), (c) help-seeking (for example, biomedical help-seeking), (d) interaction with physician/traditional healer (for example, role of the healer, expectation and satisfaction), and (e) beliefs related to mental illness (Lloyd et al., 1998). Generally, the explanatory models concept provides a useful framework for clinicians to make effective diagnoses of mental health conditions and to provide culturally relevant care for patients. Such aims are timely, given the high contribution of mental illness to the global burden of disease both in low- and middle-income countries (LAMICs) as well as high-income countries (HICs).

1.1.2. The global burden of mental disorders. Murray et al. (2012) report that mental and behavioural disorders contribute substantially to the global burden of disease, which they estimate at 7.4% of disability-adjusted years (DALYs)[1]. Five different types of mental disorders, according to Murray et al. (2012), caused more than 15 million DALYs for each type by the year 2010, namely, major depressive disorder (2.5%), anxiety disorders (1.1%), drug use disorders (0.8%), alcohol use disorders (0.7%) and schizophrenia (0.6%). Additionally, in terms of overall ranking, major depressive disorder improved from 15th in ranking in 1990 to 11th in 2010 for the 25 leading causes of DALYs, which represented a 37% increase in the relative contribution to

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[1] DALYs refer to "a summary metric of population health. DALYs represent a health gap; they measure the state of a population's health compared to a normative goal. The goal is for individuals to live the standard life expectancy in full health. DALYs are an absolute measure of health lost; they calculate how many years of health life are lost due to death and non-fatal illness or impairments" (Murray et al., 2012, p. 2199).

the global burden of disease. The findings by Murray et al. (2012) hold two other important implications with regard to the global burden of disease. Firstly, they show that there is substantial heterogeneity in the ranking of the leading causes of diseases among different regions. For example, major depressive disorder is ranked 11th globally, 4th in Western Europe, 5th in the High-income United States, 10th in Southern sub-Saharan Africa and 13th in Eastern sub-Saharan Africa. This heterogeneity underscores the role of social and cultural factors in the experience of mental illnesses. Secondly, Murray et al. (2012) state that the absolute share of burden attributable to mental and behavioural disorders, already substantial, is likely to increase in the future. Similar predictions have been made previously (Desjarlais, Eisenberg, Good & Kleinman, 1995; Patel, 2007). It has been particularly predicted that LAMICs could experience a higher burden of mental disorders than HICs for a number of reasons, including a projected increase in the number of young people entering the age of risk for the onset of certain mental disorders, conflicts, disasters, rapid urbanisation and macroeconomic changes (Desjarlais et al., 1995). Desjarlais et al. (1995) further observe that urbanisation, for example, is a risk factor for mental disorders because it is associated with overcrowding, increased homelessness, urban poverty, disruption in family ties and loss of social support. It is thus important to examine the experience of mental illness in countries such as Uganda that are undergoing rapid social, economic and demographic transitions.

1.1.3. The burden of mental disorders in Uganda. As in many other LAMICs, the burden of mental disorders in Uganda is not yet fully understood. For example, epidemiological research on the burden of disease in the country usually relies on mortality data rather than on morbidity data, thus excluding the high contribution of mental disorders (Ministry of Health, Uganda, 2006). There is also a paucity of research on mental health issues in the country (Kigozi, Ssebunnya, Kizza, Cooper & Ndyanabangi, 2010). Furthermore, standardised international diagnostic systems, such as the DSM, when used in social and cultural contexts dissimilar to those in HICs, generate reliable but invalid data (Fabrega, 1996). Summerfield (2012) is critical about the use of quantitative research methods informed by Western ideas in other parts of the world. According to him, “methodologies that lack validity cannot be redeemed by reliability because the very ground they stand on is unsound” (Summerfield, 2012, p. 524). Despite the above concerns, epidemiological research has shown high and varying prevalence rates of psychiatric morbidity in different health settings in Uganda. For example, Abbo, Ekblad, Waako, Okello and Musisi (2009) report the overall prevalence of a current mental illness episode at 60.2% among a sample of patients seeking treatment from traditional healers. Muhwezi, Ågren and Musisi (2007) similarly report the overall prevalence of major depression at 31.6% among a sample of patients attending a primary health care facility. In addition, Kasoro, Sebudde, Kabagambe-Rugamba, Ovuga and Boardman (2002) report the overall prevalence of psychiatric morbidity at 30.7% in a community study sample. High prevalence rates of psychiatric morbidity such as these necessitate a nuanced understanding of the structural factors that undermine the capacity of the health care system to respond effectively to mental illness in Uganda.

1.1.4. Structural barriers to effective care. Limited progress in the mental health sector has been noted since the publication of high profile reports, declarations and conventions. For example, Stein, Stein, Weiss, and Lang (2009) observe that although people with disabilities can live healthy lives, they often do not receive appropriate health care due to a variety of barriers, such as the limited number of health professionals providing care and services to the population and physical inaccessibility of care for affected individuals. This is contrary to principles enshrined in the UN convention on the rights of persons with disabilities (CRPD), the latter which came into force on May 3, 2008 (Stein et al., 2009). The WHO (2011) similarly states that the CRPD aims to "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity". Article 3 of the CRPD outlines laudable principles, such as: (a) respect for inherent dignity, individual autonomy, including the freedom to make one's own choices and independence of persons, (b) non-discrimination, and (c) equality of opportunity. Additionally, The CRPD obligates states endorsing it to, for example, (a) modify or repeal laws, customs or practices that discriminate directly or indirectly, (b) include disability in all relevant policies and programmes, and (c) take all appropriate measures to eliminate discrimination against persons with disabilities by any person, organisation or private enterprise. The provisions of the CRPD, however, remain largely impractical in many LAMICs, including Uganda, because of structural barriers, for example, stigma and discrimination as well as poverty, which undermine the capacity of health care systems to effectively care for people with mental disabilities (Kigozi et al., 2010; Ssebunnya, Kigozi, Kizza, & Okollo, 2009).

Additionally, the publication of two significant reports, namely. “World Mental Health: Problems and Priorities in Low-Income Countries” (Desjarlais et al., 1995) and “The World Health Report 2001, Mental Health: New Understanding, New Hope” (WHO, 2001), have raised expectations and renewed enthusiasm for mitigating the growing burden of mental disorders. Yet, more than a decade since these reports were first published, a wide mental health treatment gap still exists within and across different countries (WHO, 2008). Such a gap implies that there is a scarcity of available resources and failure of related interventions to address the burden of mental disorders. The treatment gap is also believed to be wider in LAMICs where information on service utilisation is less available than in HICs (Kohn, Saxena, Levav, & Saraceno, 2004). The above observations emphasise that mental health care occurs in contexts that uniquely shape experiences of care provision via the care providers and reception of care via the care recipients (Kittay, Jennings & Wasunna, 2005). As in many other LAMICs, mental health care in Uganda is provided by diverse care providers in a plural health care system (Helman, 2007).

1.1.5. Health care pluralism. Responses of patients and their families to mental illness often depend on available therapeutic options that may be utilised in various patterns, for example, simultaneously or sequentially (Helman, 2007). According to Kleinman (1980), the availability of and accessibility to care are central to making decisions regarding care-seeking and care utilisation within the unique social and cultural contexts of mentally ill patients and their families. Particular forms of care are respectively linked to the popular, folk and professional sectors within plural health care systems (Patel, 1998; Swartz, 1998). Because different sectors of the plural health care system are associated with unique beliefs and practices regarding mental illness and care, (Helman, 2007), I set out in this study to triangulate the perspectives of the diverse stakeholders in order to obtain a holistic understanding of mood disorders and care for the outpatients interviewed. The stakeholders interviewed comprise outpatients and members of their respective families, psychiatric health workers, religious healers and traditional healers involved in their care. I also examined the ways in which the outpatients interviewed express self-care agency to cope with their respective mental problems and to harness support from their various care providers.

1.1.6. Expressions of self-care agency among people with mental illnesses. People with mental health conditions often experience significant life adjustments, for which they require various coping strategies (Chamaz, 1991). These strategies reflect their subjective experiences, which are influenced by the social, economic and political circumstances they respectively find themselves in at the time of experiencing illness. Contextual factors, such as perception of citizenship rights, stigma and discrimination, availability of social welfare programmes and social inequality influence expressions of self-care agency[2] among such persons (Saleebey, 2002). The nature and effectiveness of agency manifested by patients often vary due to the unique social and cultural contexts of each patient and care provider (Kartalova-O'Doherty & Doherty, 2010; Speed, 2006). In this regard, very little is known about expressions of agency among people with mental health problems in Uganda. Little, if any, meaning-centred or holistic research has, to my knowledge, to date, been conducted in the plural mental health care system in Western Uganda, the site of the current study, or indeed anywhere else in the country. It is therefore timely and useful to address this knowledge and research gap.

1.2. Statement of the Problem

Mental health care is a transaction that involves the explanatory models of service users and the explanatory models of care providers (Kirmayer, 2012). The explanatory models of service users usually influence the decisions they make about choices and sources of care as well as compliance and satisfaction with care (Kleinman, 1980). Similarly, the explanatory models of care providers usually influence decisions they make about diagnoses and treatment of health problems as well as the care they provide to service users. Discrepancies may occur between the explanatory models of service users and that of care providers (Helman, 2007). Discrepancies may cause significant problems, for example, misdiagnoses of health problems among service users by care providers, inappropriate prescription and/or use of medication by carer providers and service users, non-adherence to treatment by service users and misuse of health facilities by both (Helman, 2007; Kleinman, 1980). Indeed, little is known about the explanatory models employed by service users and care providers regarding mood disorders in the plural mental health care system in Western Uganda or elsewhere in the country. Such lack of awareness is

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[2] In the context of this study, self-care agency refers to the deliberate and purposive actions (behaviours) with which the outpatients studied engage in order to care for themselves. I have used the term "expressions of agency" to refer to both active and passive self-care behaviours among the outpatients studied.

contrary to and impedes the ongoing efforts to improve mental health care in Uganda (Kigozi, 2007; Ministry of health, Uganda, 2006). Hopefully, this study will contribute towards filling this knowledge gap.

1.3. Study Aim and Objectives

The aim of this study is to explore explanatory models that outpatients and care providers in Uganda use in responding to mood disorders. The study triangulates the perspectives of the following: (a) outpatients with mood disorders[3], (b) families of outpatients involved in their care, (c) psychiatric health workers treating outpatients, (d) religious healers, and (e) traditional healers, the latter two also involved in care provision of outpatients. The specific study objectives are:

- to document how outpatients and care providers conceptualise mood disorders,
- to identify challenges outpatients experience in care-seeking,
- to assess the views and attitudes of outpatients and care providers regarding delivery and utilisation of care,
- to explore expressions or manifestations of self-care agency among outpatients.

1.4. Study Rationale

This study is justified on the basis of its research, practice and policy implications.

1.4.1. Knowledge generation. This study addresses the scant information on mood disorders and care in Uganda and seeks to add to the available body of knowledge in this regard. New insights stimulated by the results will hopefully challenge existing theories and assumptions on the conceptualisation of mood disorders and care for people with mental problems in the country as this study generates unique concepts regarding a wide range of issues such as idioms of distress used by stakeholders, attributed aetiology and treatment of mood disorders. It is also hoped that the results will stimulate further research in the field, ultimately contributing to the

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[3] From here on, I use the term "outpatients" to refer to the outpatients with mood disorders studied. I also use the term "families" to refer to the family-based care providers of the outpatients studied.

improvement of mental health literacy and the alleviation of myths and misconceptions associated with mental health problems in Uganda.

1.4.2. Practice of mental health. This study will hopefully contribute to the formulation of evidence-based mental health care in Uganda. The results may particularly contribute to improved understanding of contextual issues associated with mood disorders, for example, how the illness is understood by patients and care providers, and may thus promote more effective care in the Ugandan mental health care system. Improved mental health literacy will enhance service user-care provider communication and interaction as well as collaborative practices between outpatients and care providers. Improved mental health literacy will further enhance accurate diagnosis of mental health conditions, provision of appropriate and effective treatment, satisfaction with and adherence to treatment. In the context of inadequate available resources, improved mental health literacy will also enhance co-ordination of care and referral of outpatients among diverse care providers. It is envisaged and hoped that this study will benefit all of these.

1.4.3. Policy development. Integration of mental health with general health care is viewed favourably by the Government of Uganda (Ministry of health, Uganda, 2006). Kigozi (2007) observes in this regard that a number of health reforms included in the national health policy of 1999 and the Support to the Health Sector Strategic Plan II (2005/06-2009/10) suggest a strong commitment towards collaborative practice and integration of mental health services with general health care. This study, it is hoped, will thus contribute to such a deepening of collaborative practice and integrated health service delivery in Uganda. In particular, it could sensitise policy makers and mental health professionals about the therapeutic opportunities and risks that are possibly engendered by collaboration with stakeholders other than just patients and health workers, that is, families, religious healers and traditional healers involved in care provision. Appropriately informed, policy makers and mental health professionals are likely to commit timely efforts to utilise potential therapeutic opportunities as well as to mitigate potential risks emanating from such collaborative practice.

1.5. Theoretical Framework

In this study, I have adopted the health care system model (Kleinman, 1980) as the theoretical basis. The health care system model acknowledges that health care activities in any society are intricately interrelated. Scholars (for example, Helman, 2007; Patel, 1998) refer to the coexistence of diverse health care systems in local social and cultural contexts as “health care pluralism”. Kleinman (1980) initially conceptualises a health care system as a collective entity comprising elements such as patterns of belief about causes of illness, norms governing choice, evaluation of treatment, socially legitimated statuses, roles, power relationships, interactional settings and institutions. A health care system is thus a social response to disease and is similar to other cultural systems, for example, religion and kinship that serve people’s spiritual and social needs (Kleinman, 1980). Thus, both illness and healing, which are the core elements of any health care system, are the culturally constructed experiences of the patients and activities of the healers (Helman, 2007).

Additionally, the health care system model postulates that patients, healers and the interactions of both can only be fully understood in local contexts because the persons involved (patients and healers) and their actions and interactions are socially and culturally constructed (Kleinman, 1980). This premise suggests that a health care system is both a product and a source of people’s responses to illness. Health care systems shape the ways in which people label and treat illness in terms of the prevailing cultural rules or norms of their contexts. Contextual factors, such as available social institutions (for example, hospitals), social roles (for example, the sick role and the healing role), and interaction settings (for example, the home and a traditional healer’s shrine) influence people’s beliefs and behaviour with regard to instrumental and symbolic activities where illness is concerned (Kleinman, 1980).

Kleinman (1980) initially founded the health care system model based on the theory of the social construction of reality developed by Peter L. Berger and Thomas Luckmann in 1967. The theory of reality construction has since been refined into related theoretical frameworks, for example, social constructivism (Teater, 2010). Social constructivism postulates that there is a dialectical relationship between people and their realities (Teater, 2010). In other words, people create reality, the latter which in turn influences their experiences of the created reality. For example, social institutions such as hospitals are a product of human creative work; subsequently, people experience hospitals differently, for example, as patients and as doctors. Teater (2010) also observes that because people are active participants in the process of reality construction – by interacting with their environments and processing their experiences through their own cognitions – they cannot replicate other people's realities. For example, patients and healers involved in the management of a disease inevitably construct distinctive realities of the disease because of their inherent differences. Social constructivism also acknowledges that historical, social and cultural contexts influence people's reality. In other words, reality evolves from people's social interactions within historical, social and cultural contexts (Fabrega, 1996). In particular, social and cultural contexts influence values and beliefs, which in turn influence individuals' experiences, for example, of illness, and interpretations of those experiences (Helman, 2007).

Furthermore, social constructivism is premised on the notion that objective facts do not exist outside of the subjective meanings people attach to the perceived reality (Teater, 2010). For example, people create ideas, such as healer, patient and medication, as they are subjectively experienced, socially defined and internalised by means of socialisation. Externalisation objectifies people's subjective experiences, the latter which are eventually taken or perceived as the *truth* (Hardcastle, Powers & Wenocur, 2004). Externalisation, as used in this context, refers to the process by which people talk with each other about their experiences, validate their understandings of their experiences and develop habitual behaviours in order to realise their social goals. Language is central to reality construction as it serves as a means by which individuals express and explain their own constructed realities (Teater, 2010). Language also facilitates individuals' attempts to understand other people's realties. Because individuals construct their own realities that can never be fully understood by others, there is no objective reality or one truth (Hardcastle et al., 2004). This means that the views among the outpatients and their care providers studied regarding mood disorders and care, in the context of this study, are equally valid in their unique contexts.

In summary, Kleinman's (1980) initially conceptualised health care system model, in which health care systems are pointed out as cultural systems that are shaped by unique historical, social and cultural contexts, is crucial to the purposes of the current study. Within the health care system model, perspectives and experiences among patients and their healers are conceptualised as forms of social reality. The health care system model suggests that patients and healers create varying social realties because their social and cultural contexts differ markedly. Based on the above theoretical insights, the explanatory models encountered in this study are viewed as socially and culturally constructed realties among the outpatients and care providers studied. The health care system model is an alternative to the biomedical model of disease that is dominant in current psychiatric research and practice. According to Boyle (2013), the biomedical model is reductionist, ethnocentric and prioritises biological processes over other legitimate concerns, for example, social and psychological determinates of health and wellbeing. The health care system model (Kleinman, 1980), in contrast, is integrative and thus more enabling in exploring the personal experiences of mood disorders among the outpatients and their care providers studied as well as the structural forces, such as poverty, that influence delivery and utilisation of care in Uganda.

1.6. Thesis Layout

In the previous sections of this chapter, I provided the background and stated the research problem, aim, objectives and rationale of the study. I also explained the theoretical framework guiding the undertaking of this study. In chapter two, I review the literature in this regard at the global, sub-Saharan and Ugandan levels with regard to culture and mental health. I particularly discuss cultural influences on the conceptualisation of distress, structural barriers to effective care for people with mental illneses, health care provisions in plural health care systems and expressions of self-care agency among people with mental illnesses. In chapter three, I present the methodology that supported the execution of this study. In chapter four, I present and discuss the results concerning the conceptualisation of mood disorders among the participants studied. In chapter five, I present and discuss the results regarding structural barriers to effective care for the outpatients studied. In chapter six, I present and discuss the results regarding the conceptualisation of care, and in chapter seven, I present and discuss the results regarding expressions of self-care agency among the outpatients studied. In chapter eight, I present the conclusion to the thesis.

Chapter 2

Literature Review

2.1. Introduction

In this chapter, I review and discuss literature on the universalist and relativist traditions in cross-cultural psychiatry, notions of mental illness, structural barriers to effective care, care in the context of plural health care systems and expressions of self-care agency among people with mental illnesses. The exploratory nature of this study influenced my decision to organise the reviewed literature according to key themes or constructs (Mouton, 2001). The literature review comprises sources from online data bases at the Stellenbosch University library as well as the internet, utilising Google Scholar as a main search engine in this regard. I also reviewed "grey literature" (Bryman, 2012), obtained from friends and colleagues on relevant topics. The terms used in the literature search, include: explanatory models, culture and mental illness/health, mental illness/health, mood/affective disorders, barriers to care, health care pluralism and self-care agency. In general, I conducted a narrative review of literature, which according to Bryman (2012), is less focussed and more wide-ranging in scope than is a systematic review.

I discuss in detail each of the above sections, beginning with universalist and relativist epistemological traditions and their respective influence on the development of cross-cultural psychiatry.

2.2. Universalist and Relativist Epistemological Traditions in Cross-Cultural Psychiatry

Universalism and relativism are counter epistemological traditions in cross-cultural psychiatric theory and practice (Fabrega, 1989). According to Fabrega (1989), universalism implies application of the Western biomedical psychiatric framework to establish similarities within non-Western cultures. In this regard, universalism is exemplified by the use of standardised diagnostic systems, such as the DSM, to classify and diagnose psychopathology in non-Western cultures (Thakker & Ward, 1998). Thakker and Ward (1998) argue that proponents of universalism believe mental disorders, such as schizophrenia, based on Western psychiatric diagnostic systems, such as the DSM, to be similar in all cultures. Universalism postulates that humans, irrespective of social and cultural contexts, share basic biological processes and that psychopathology is biologically determined (Thakker & Ward, 1998). Helman (2007) refers to this idea (that psychiatric diagnoses based on Western diagnostic categories such as the DSM are applicable to people in other social and cultural contexts) as the "biological approach" when comparing psychological disorders. Helman (2007) also argues that the biological approach emphasises the underlying biological basis of mental disorders, although these may vary in different social and cultural contexts. The presumed underlying biological basis enables universalists to advocate for the use of specific diagnostic systems, as is often the case in medicine (Thakker & Ward, 1998). Universalists also frequently aim to establish universal psychiatric phenomena as well as promote reliability in psychiatric diagnoses when conducting cross-cultural research.

However, universalism as an epistemological tradition has been criticised for giving primacy to Western ideas of psychopathology over indigenous systems of knowledge regarding mental illnesses (Summerfield, 2012). For example, Kleinman (1988) criticises the World Health Cross-Cultural Research Programme, the latter which involved an International Pilot Study of schizophrenia in the 1970s in both pre-modern and modern societies. Kleinman (1988) argues that the diagnosis of schizophrenia in non-Western cultural contexts, based on Western notions of the illness, resulted in a *category fallacy*. A category fallacy, according to Kleinman (1988), implies reification and application of Western nosological categories to people in other cultures for which they are invalid and incongruent. Kleinman (1988) points out that because they used a biased methodology in their study, researchers were inclined to prove that schizophrenia is diagnosable cross-culturally. A biased methodology, according to Kleinman (1988), comprises: (a) the use of the Present State Examination – a standardised diagnostic instrument in differing settings, and (b) stringent inclusion and exclusion criteria – leading to an "artificially homogenous sample". Kleinman (1988) further argues that the researchers emphasised similarities and downplayed a wide-range of variations in aspects such as prevalence, symptomatology, illness behaviour, course and outcome and illness beliefs with regard to schizophrenia. For example, the researchers had found schizophrenia of an acute onset diagnosed among the sample in West Africa and a single genre with indolent onset diagnosed among the sample from Europe and the United States. Schizophrenia with an acute onset has a better prognosis than does schizophrenia with the single genre with indolent onset. A further example in point is that within specific countries and cultures, considerable variations were found, depending on whether lifetime prevalence and point prevalence were considered; some families also had significantly higher prevalence rates of schizophrenia than that of the general population (Kleinman, 1988).

Similarly, Summerfield (2012) argues that structured screening instruments, used to determine prevalence rates of psychiatric morbidity cross-culturally, are inappropriate in assessing complex human experiences. Such instruments, according to Summerfield (2012), usually reify people's subjective consciousnesses through a mechanistic focus on symptoms, thereby generating estimates that are out of synch with people's lived experiences. Because they are unable to effectively assess people, the latter who are influenced by dynamic and complex situations, structured screening instruments often portray ordinary distress as a form of psychopathology. The excessive concern among researchers and clinicians with people's vulnerability to psychopathology, according to Helman (2007), suggests a growing "medicalisation" and "professionalisation" of everyday life. Furthermore, undue dependence on technical interventions, mainly medication and psychotherapy, undermines the capacity of ordinary people to cope with ordinary distress using personal and social resources (Kleinman & Benson, 2006). Summerfield (2012) cautions against the "globalisation" of mental health, that is, characterisation of mental illnesses via application of narrow Western diagnostic categories, such as depression, and biomedical interventions in non-Western cultures.

Relativism, in contrast, postulates mental illness as essentially a social rather than a biological phenomenon, with mental illness often presenting with or without biological aspects (Helman, 2007). Helman (2007) refers to relativism as the "social labelling approach" when comparing psychological disorders. Within this epistemological tradition, mental illness is regarded as culture-bound, as different societies choose specific symptoms and behaviours which they label as deviant as well as forms of deviance labelled as mental illness. Diagnosing mental illness within the relativist tradition necessitates the use of anthropological methods, for example, ethnography, to ensure clear knowledge of the culture of the study's subjects or patients (Thakker & Ward, 1998). Fabrega (1989, p. 415) defines cultural relativism as the "differences in beliefs, feelings, behaviours, traditions, social practices and technological arrangements that are found among diverse peoples of the world". As implied by this definition, relativists believe that cultures differ, with each uniquely influencing the experience, expression and response to mental illness of the members within respective cultural groups (Kirmayer, 2005). The inherent diversity of perspectives within the relativist framework suggests a need to conceptualise mental disorders as social rather than biological phenomena (Thakker & Ward, 1998). In addition, because standard diagnostic systems, such as the DSM, are overly influenced by Western notions of psychopathology, relativists doubt their utility in dissimilar cultures, such as those in LAMICs (Summerfield, 2012). Summerfield (2012) suggests that tools for screening cases and aiding psychiatric diagnoses be developed based on local knowledge, as those developed in the West and adapted for use in other cultures often retain their Western templates. Authentic evidence for guiding public health interventions should rather be based on the "local worlds" of the targeted individuals and communities (Summerfield, 2012).

However, relativism has been criticised for downplaying the biological aspects of mental illness in conditions such as dementia and delirium tremens. In addition, relativism does not acknowledge the universal distribution of severe mental disorders such as schizophrenia and bipolar disorder (Helman, 2007). Because of the respective weaknesses associated with both the universalist and relativist positions, a combined approach integrating elements of universalism and relativism is becoming popular among medical anthropologists (Helman, 2007). A combined approach postulates that while abnormal behaviour comprising, for example, extreme disturbance in conduct, thought or affect occurs universally, there are wide variations in its forms and distribution (Helman, 2007; Kleinman, 1980). Within the combined approach perspective, Western psychiatric categories, for example, depression, are found throughout the world, although they may present and be labelled differently in different social and cultural contexts. Similarly, organic mental disorders can be found in all societies, the difference being that their manifestations are culturally patterned (Helman, 2007). In the current study, because I triangulate the data obtained from psychiatric health workers informed by Western notions of mental illness and lay actors informed by local ideas of mental illness involved in the care of patients, conceptualisation of the study is greatly influenced by a combined approach, as described above.

2.3. An Overview of Culture and Mood Disorders. Mood disorders are among the most prevalent mental illnesses in communities worldwide (Bruce; 1999; Goldberg & Huxley, 1992); and among the leading causes of disability worldwide (Murray et al., 2012). They significantly affect the social functioning of patients and their families. For example, depression causes poor social relationships, increased substance abuse, interference with long-term cognitive functioning and increased use of medical services (Smith, 2011). While bipolar disorder is less prevalent, it is more impairing than depression. Most patients do not function as they did before the onset of bipolar disorder and their social relationships and careers may particularly deteriorate. Bipolar disorder is also associated with risky behaviours, including substance abuse and suicide (Smith, 2011).

The DSM-IV describes mood disorders as comprising major depressive disorder, dysthymic disorder, adjustment disorder with depressed mood, bipolar disorder I and bipolar disorder II (American Psychiatric Association, 1994). In the context of this study, the focus is on major depression (unipolar depression) and bipolar disorder I. The predominant diagnostic feature of mood disorders is disturbance in mood, that is, extreme changes in mood, the latter which significantly impact an individual's functioning, for example, socially or occupationally (Smith, 2011). Mood disorders are episodic in nature, to the extent that major depression is defined by episodes of depression without a history of mania while bipolar disorder is defined by episodes of mania or mixed episodes featuring both mania and depression (Bruce, 1999). A major depressive episode, according to the DSM-IV, manifests a range of symptoms lasting at least two weeks; key among these symptoms is either a depressed mood or anhedonia (loss of interest or pleasure in nearly all activities). A depressed mood among children may feature irritability rather than sadness (American Psychiatric Association, 1994). According to the American Psychiatric Association (APA, 1994), an individual must, in addition to the above symptoms, present with at least four of the following symptoms to meet the full criteria for the diagnosis of major depression: (a) changes in weight or appetite, (b) changes in sleep, (c) changes in psychomotor activity, (d) decreased energy, (e) feelings of worthlessness or feelings of guilt, (f) difficulties in concentrating or making decisions, and (g) recurrent thoughts of death or suicidal ideation, suicidal plans and/or suicidal attempts. These symptoms are applicable to the diagnosis of major depression regarding the following: (a) they do not meet the criteria for a mixed episode, (b) they cause clinically significant distress or impairment in an individual's functioning, for example, socially, (c) they are not due to physiological effects of substance abuse or a general medical condition, for example, hypothyroidism, and (d) they are not better accounted for by bereavement (APA, 1994).

In contrast, a manic episode, according to the DSM-IV, is characterised by an unusually and persistently elevated, expansive or irritable mood lasting at least one week or less, for which hospitalisation is required (APA, 1994). An individual must, in addition to the criteria listed earlier for mood disorders, present with at least three of the following symptoms to meet the full criteria for a diagnosis of bipolar disorder: (a) inflated self-esteem or grandiosity, (b) decreased need for sleep, (c) accelerated speech and thought processes, (d) distractibility (e) increased goal-directed activity or psychomotor agitation, and (f) excessive involvement in pleasurable social activity with a high potential for negative consequences (APA, 1994). In contrast with a manic episode, a mixed episode comprises symptoms that meet the diagnostic criteria for both a manic episode and a depressive episode. During a mixed episode, a patients' mood is labile, that is, it may change quickly from sadness or irritability to euphoria. As with both a manic and a mixed episode, a diagnosis of bipolar I disorder is appropriate in keeping with the following features: (a) the symptoms significantly impair an individual's functioning, for example, socially or occupationally, (b) there is evidence of psychotic symptoms, for example, delusion, and (c) the episode is not primarily due to the physiologic effects of a general medical condition, for example, a brain tumour (APA, 1994).

Although mood disorders are described in standardised diagnostic systems, such as the DSM, experiences and diagnoses of mental illnesses generally vary considerably in different social and cultural contexts (Kirmayer, 2005). Common mental disorders, such as depression, show greater cultural variability than do severe mental illnesses, such as schizophrenia (Helman, 2007). In this regard, Hwang, Myers, Abe-Kim and Ting (2008) argue that culture pervasively influences six domains of health, namely; (a) the prevalence of mental illness, (b) aetiology of disease, (c) phenomenology of distress, (d) diagnostic and assessment issues, (e) coping styles and help-seeking pathways, and (f) treatment and intervention issues. The domains of mental health, according to Hwang et al. (2008), are intricately linked with each other, for example, expression of distress as either a somatic or psychological complaint influences whether a medical or psychiatric diagnosis is made. Similarly, beliefs about causes of distress, such as witchcraft or chemical imbalances, influence the nature of treatment, such as rituals or medication, sought and provided (Helman, 2007). With regard to the prevalence of mental illness, Hwang et al. (2008) indicate that certain populations, such as refugees, experience more stressful experiences, including war, violence and famine that elevate their risk for developing psychiatric disorders, such as depression, than do other members of the public. Acculturative stress, including linguistic difficulties, separation from families and racial discrimination, often aggravates distress experienced by refugees prior to seeking asylum in other countries. Social epidemiologists have similarly found social adversity associated with a refugee status to cause mental illness through the social selection processes involved (Dohrenwend, et al., 1992). I discuss in detail social causation theory on page 39 of this thesis. Similarly, cultural norms and beliefs influence the labelling and socio-cultural meanings of illnesses (Hwang et al., 2008). While some symptoms of depression, for example, lethargy and insomnia, may be found in different cultural contexts (Helman, 2007), patients tend to emphasise different symptom domains, for example, affective, cognitive and somatic complaints (Hwang et al. 2008; Kleinman, 1980). Stigma also determines whether patients disclose having a mental illness, the persons informed about a mental illness and the mode of expression, for example, as a somatic or psychological idiom (Kleinman, 1980). In addition, linguistic differences may hinder effective communication with and assessment of patients as well as diagnoses of mental illness. Moreover, English concepts, such as depression, are often used in the popular culture in ways that are different to their use and understanding in the psychiatric nomenclature (Lehti et al., 2009).

Similarly, Kleinman (1977) advances the view that culture influences the experience of mental illness by distinguishing between the “old transcultural psychiatry” and the “new cross-cultural psychiatry”. In this regard, Kleinman (1977) is seen to be responding to Singer’s (1975) claim (cited in Kleinman, 1977) that “there is insufficient evidence to support a prevalent view that depressive illness in primitive and certain other non-Western cultures has outstanding deviant features”. Kleinman (1977) argues that Singer’s claim is based on the old transcultural psychiatry, a field rife with inherent weaknesses that hinder effective cross-cultural comparisons of psychopathology. These weaknesses, according to Kleinman (1977), include: (a) the use by epidemiologists and clinicians of Western psychiatric categories in other cultures as if the former are not culturally biased, (b) its undue concern with finding cultural universals rather than cultural specifics, (c) its remoteness from anthropological studies of normative behaviour in the same cultural settings, and (d) its inadequate conceptualisation of disease as an entity. As regards the use of Western psychiatric categories in other cultures, Kleinman (1977) argues that while symptoms of depression, such as insomnia and lethargy, seem to be common to many cultures, they represent a limited aspect of a complex depressive phenomenon. Kleinman (1977) also points out that because they aim at establishing cultural universals, epidemiologists and clinicians frequently find what is familiar to them as mental illness and miss what is unfamiliar. Kleinman (1977) terms such biased interests among epidemiologists and clinicians as a kind of "self-fulfilling prophesy".

In contrast, the new cross-cultural psychiatry is a budding interdisciplinary field that integrates anthropological and epidemiological methods in the study of culture and illness (Kleinman, 1977). It aims at overcoming the weaknesses associated with the old transcultural psychiatry by means of, for example, using anthropological data and ethnographic methods and acknowledging indigenous conceptualisations of mental illness. In keeping with the new-cross cultural perspective, Kleinman (1977) reports that culture patterns expression of depression, mainly in somatic idioms (he demonstrates this with the findings in his study among Chinese patients) and not in dysphoric affect, the latter which is the case in the mainstream culture of the West. Kleinman (1977) also claims somatisation to be less prevalent among depressed patients in Western cultural contexts, for example, in the United States, than in non-Western cultural contexts, for example, in China, although somatisation does occur universally. In addition, somatisation, according to Kleinman (1977), is multifaceted; in this regard, in his study of Chinese patients, some were found to conceptualise depression on the basis of indigenous illness categories, such as neurasthenia, while others conceptualised their health problems as depression, but with reference to a somatic affect and a physical disorder rather than as a psychological phenomenon. According to Kleinman (1997), in his study, somatisation in China is mainly due to the excessive stigma and discrimination associated with having a mental illness in Chinese society. Additionally, medical diagnoses, such as neurasthenia for depression, in the Chinese context have a high social efficacy, including a sick role, than does a psychiatric diagnosis, such as depression (Kleinman, 1980).

Furthermore, Karasz (2005) reports that South Asian immigrants and European Americans in New York City in the United States possess diverse representational models for depression. Karasz (2005) informs that whereas South Asian Americans have “single” illness representational models of depression that are mainly social and moral in nature, European Americans have multiple illness representational models of depression that emphasise biological explanations and situational stress. Karasz (2005) also notes that these illness representation models consistently differ with regard to labelling, causes and consequences as well as treatment of depression. For example, European Americans generally regard the health condition described in a case vignette with depression as a mental disorder and mainly as depression; South Asian Americans, on the other hand, label the same health condition in more diverse ways, including, as a “problem”, tension” or “depression”. The labels indicated by the South Asian Americans also emphasise situations such as strained social relationships, for example, relationships with spouses, as causes rather than symptoms of depression. Moreover, South Asian Americans often use English concepts, such as tension and depression, to mean “thinking too much” and having “a life problem”, which are inconsistent with these terms’ conventional use in the psychiatric nomenclature (Karasz, 2005).

As regards treatment for depression, Karasz (2005) reports that while South Asian Americans suggest mainly self-help treatment choices, European Americans suggest mainly professional treatment choices. However, among a professional category in the group studied, South Asian immigrants are more likely than European Americans to suggest seeking medical treatment as they associate depression with physical sequelae. Conversely, European Americans are more likely than South Asian Americans to suggest psychotherapy as treatment for depression. Karasz (2005) argues that the illness representation models demonstrate unique social realities shaped by the social and cultural contexts of the European Americans and South Asian Americans. Karasz (2005) particularly indicates that while narratives among the South Asian Americans focus mainly on family-related problems, for example, strained relationship with a spouse or in-laws, narratives among the European Americans focus mainly on specific life events, for example, death or divorce. These discrepancies in the illness representation models suggest that a depressive syndrome in the context of South Asian Americans does not represent a mental disorder as it is generally conceptualised in the West (APA, 1994).

Similarly, Lehti, Hammarström and Mattsson (2009) identify three themes suggesting a discrepancy in the conceptualisation of depression among general practitioners (GPs) and immigrant patients in Sweden. These themes are: (a) “realising the background”, (b) “struggling for clarity”, and (c) “optimising treatment”. The theme “realising the background” (Lehti et al., 2009) suggests that GPs face challenges while treating immigrant patients about whom they have limited contextual knowledge. Lehti et al. (2005) observe that GPs suspect immigrant patients suffer from depression because of traumatic events experienced in the latter’s native countries, adapting to a new country and experiencing new cultural concepts and cultural clashes. Yet, GPs, in most cases, do not obtain relevant information about past traumatic experiences such as war, sexual violence and torture from these patients. GPs also view living in a foreign country as necessitating significant adjustments, comprising loss of status, familiar people and places in the immigrants’ native countries and feeling alienated in a foreign country. In addition, GPs believe explanations and expressions of depression to be culture-bound. Consequently, they are concerned that depression as a concept is unfamiliar to some immigrant patients, the latter who refer to being “mad”, thus viewing depression as derogatory. GPs are similarly concerned about “essentialising” some cultures on the basis of limited information about cultural norms and religious beliefs accessed via the media (Lehti et al, 2009).

The theme “struggling for clarity” (Lehti et al., 2009) suggests that GPs are unable to communicate effectively with immigrant patients because of language differences, social norms governing patient-doctor relationships and varying modes of nonverbal communication. GPs also regard experiences of depression among immigrant patients as atypical, the latter which renders irrelevant the use of typical diagnostic criteria, such as those suggested by the DSM. Structured screening instruments are similarly found to be unsuitable in assessing immigrant patients for depression, thereby undermining diagnostic abilities among GPs. Furthermore, the theme “optimising management” (Lehti et al., 2009) suggests that GPs find treating depression using conventional treatments ineffective. While GPs find treating depression with antidepressants to be associated with poor outcomes among immigrant patients, similar treatment is associated with positive outcomes for Swedish patients. However, GPs occasionally prescribe antidepressants for immigrant patients, even if doubtful about their efficacy and compliance. Consequently, GPs experience helplessness and powerlessness in their efforts to alleviate distress among immigrant patients (Lehti et al, 2009).

2.4. Notions of Mental Illnesses in LAMICs. Researchers have found complex concepts of mental illness in many LAMICs (Patel, 1998; Swartz, 1998). Conceptualisation of mental illness in LAMICs is based mainly on etiological and phenomenological criteria (Patel 1995). Supernatural attributions, such as spirit possession, and behavioural symptoms often exemplify mental illness in many LAMICs (Okello & Musisi, 2006; Patel, 1995). Patients, families and other care providers often have multiple and, at times, contradictory explanatory models about mental illnesses. Explanatory models, according to Helman (2007), influence how actors in a plural health care system understand and express symptoms of mental illness and choose and evaluate particular treatments and care. Explanatory models also vary in time, culture and social contexts (Ofori-atta & Linden, 1994; Williams & Healy, 2001). Discrepancy in explanatory models among actors in a plural health care system often results in serious problems, such as misdiagnosis, prescription of inappropriate medication, unnecessary investigations, dissatisfaction with and non adherence to care (Patel, 1998).

2.4.1. Notions of mental illness in sub-Saharan Africa. Researchers have often found diverse conceptions of mental illness in sub-Saharan Africa. For example, in an ethnographic study of the health care system in Zimbabwe, Patel (1998) reports diverse conceptions of mental illness among village health workers, traditional medical practitioners, community psychiatric nurses and relatives of people with mental illnesses. Community psychiatric nurses conceptualise mental illnesses in biomedical terms, such as depression and psychosis, while other care providers, eg families, adopt indigenous conceptualisations, such as *kupenga* (madness). Patel (1998) equates *kupenga* (madness) with the biomedical concept of acute psychosis. Psychosis is frequently reported as exemplifying mental illness in LAMICs (Patel, 1996). Patel (1998) also reports, in the Zimbabwean study mentioned above, that after probing, primary care providers identified other forms of illnesses of the “mind” or “soul”, such as *kufungisisa*, *mahepo* (bad airs often associated with witchcraft) and *pfukwa* or *ngozi* (angry alien spirits of persons who were murdered). Such probing was possible because the researcher adopted a flexible and culturally appropriate research methodology. Additionally, Patel (1998) observes behavioural manifestations to be central to the conceptualisation of mental illness, although patients also often complain of somatic symptoms due to stigma associated with mental illness. Primary care providers, in the Zimbabwean study, were seen to associate mental illness mainly with supernatural attributions, such as spirit possession, witchcraft and sorcery. The latter also believe mental illness to be caused by substance abuse, head trauma and other biomedical causes, such as AIDS and fever. Care providers also attribute mental illness to psychosocial causes, such as thinking too much, bereavement and relationship problems and to socioeconomic factors, such as poverty and unemployment (Patel, 1998).

Similarly, Sorsdhal, Flisher, Wilson and Stein (2010) report traditional healers in South Africa to possess multiple explanatory models for mental illness. According to Sorsdhal et al. (2010), traditional healers perceive psychosis as the exemplar of mental illnesses. In contrast, they do not regard non-psychotic mental disorders, such as depression, as mental illnesses but manifestations of social suffering. In addition, traditional healers identify mental illness with local terms such as *amafufunyana*, which they believe to be mainly caused by witchcraft. Other attributed causes of mental illness identified by traditional healers include poverty and substance abuse. In contrast to *amafufunyana*, traditional healers regard *ukuthwasa* as a positive state of health associated with a “calling” for patients to become traditional healers. Such affected persons could, however, be subsequently diagnosed as suffering from *ukuphambana* (madness) if failing to fulfil the expectations of the calling and/or traditional healer. *Amafufunyana* and *ukuthwasa* have been elsewhere reported as culture-bound syndromes (Swartz, 1998). Furthermore, Sorsdhal et al. (2010) report that traditional healers regard behavioural disturbances, such as picking through garbage, talking randomly, walking for long periods of time and undressing in public, as core symptoms of mental illness. Sorsdhal et al. (2010) also demonstrate beliefs about mental illness among traditional healers to be different from those held by psychiatric health workers in South Africa. For example, Sorsdhal et al. (2010) report that most traditional healers in their study did not identify a case vignette for schizophrenia as a mental illness, associating the presented symptoms with *ukuthwasa* and psychosocial problems. They also did not believe the person with symptoms presented in the case vignette for depression to be at all mentally ill, but rather to be struggling with psychosocial problems, the latter which, according to them, do not require any form of folk-based and/or psychiatric care (Sorsdhal et al., 2010).

Similarly, Aidoo and Hapham (2001) report in their study, urban woman in low-income groups and health care practitioners in Zambia to possess different explanatory models of mental illness. For example, women in low-income groups identify their respective mental health illnesses as “problems of the mind”, while health care practitioners refer to the same health conditions as “stress” and “depression”. Aidoo and Hapham (2001) note that health care practitioners use the terms “stress” and “depression” interchangeably, suggesting low levels of mental health literacy since depression, unlike stress, is listed in the DSM as a specific diagnostic category (APA, 1994). Swartz (1998) suggests that the term “stress” is used loosely because of its multifaceted nature, arguing that in the context of South Africa, the term encompasses broader social and psychological constructs, such as social suffering, oppression and post traumatic stress disorder, all of which may be experienced differently in different social and cultural contexts.

Furthermore, Aidoo and Hapham (2001) report, in their study, that women from low-income groups believe their mental problems to be due to the following factors: (a) psychosocial causes, such as work problems, loss of children and marital dissatisfaction, and (b) spiritual causes, comprising a belief in fate and *mashabe* (spirits). Aidoo and Hapham (2001) observe that while health care practitioners acknowledge spiritual causes, they believe mental problems among this group of women to be caused by psychosocial factors, including lack of social support, work-related problems and the burden of caring for extended families in urban centres. A belief in multiple causes with emphasis on supernatural causes of mental illness has similarly been reported elsewhere (Helman, 2007; Patel, 1998). Additionally, Aidoo and Hapham (2001) report that women from low-income groups associate “problems of the mind” with psychological symptoms such as low self-esteem, unhappiness and suicidal ideation. However, women respondents in Aidoo and Hapham’s (2001) study did not believe these symptoms to be indicative of mental illness. Health care practitioners interviewed by Aidoo and Hapham (2001), in contrast, identified the health conditions among women in low-income groups as “stress and depression” and thus a manifestation of mental illness. Discrepancy in the explanatory models of mental illness among women from low-income groups and health care practitioners is not surprising, as stigma and discrimination associated with mental illness often lead to denial of psychiatric labels and rejection of psychiatric care among patients (Patel, 2001).

2.4.2. Notions of mental illness in Uganda. Ethnographic research on explanatory models of mental illness in Uganda is currently still scarce (Okello & Neema, 2007). For example, none of the available ethnographic studies have explored explanatory models of mental illnesses among the Bakiga and Banyankole peoples of Western Uganda. Moreover, most of the available studies examine explanatory models among individual actors despite the plural nature of the Ugandan health care system (Kigozi et al., 2010). Nevertheless, researchers have frequently reported complex and diverse conceptualisations of mental illness in Uganda. For example, Orley (1970), conducting one of the first detailed ethnographic studies of mental illness among members of the Baganda community in Uganda, admits difficulty in finding conceptual equivalence of the Luganda terms reported by informants in the English language. Nevertheless, Orley (1970), in this same study, reports that members of the Baganda community identified four “diseases of the brain” that are comparable with mental illnesses as known in Europe and the West, namely, *eddalu* (violent madness), *ensimbu* (epilepsy), *obusiru* (foolishness that is either congenital or acquired) and *kantalooze* (dizziness). Orley (1970) reports two additional health conditions among members of the Baganda community that are similar to neurosis, namely, *emmeme etyemuka* (pounding heart with fright) and *emmeme egwa* (characterised by body weakness and loss of appetite). These two health conditions are linked to the heart, which participants in his study believed control emotions. Other health conditions, which Orley (1970) found to be related to mental illness include *amakiro* (affecting women shortly after postpartum), *akawango* (persistent headache) and *enjoka* (stomach aches).

Furthermore, Orley (1970) reports members of the Baganda community to have a three-system criterion for classifying mental illnesses, that is, health conditions that are: (a) *eza kyeyijjira* (came by themselves) or *ez' eddogo* (sent by other people, mainly through witchcraft), (b) *ez' amaanyi* (strong) or *ez' ennafu* (weak), and (c) *Kiganda* (those known by the community from before the period of European colonisation), and *non-Kiganda* (those the community believes to have been brought by European colonialists). Orley (1970) also reports members of the Baganda community to diagnose mental illness on the basis of behavioural disturbances. For example, *eddalu* (violent madness) is characterised by behaviour such as throwing stones, abusing people and engaging in public nudity. According to Orley (1970), refusal to eat food is another reason for suspecting madness and seeking seclusion in the Butabika national referral hospital for affected individual. Members of the Baganda community also identified two milder forms of *eddalu* (madness) as (a) *eddalu ly' akazoole* (mild madness), and (b) *eddalu ly' akalogonjjo* (mild madness) characterised by behaviour such as disorientation and unusual speech. *Eddalu ly' akazoole* (mild madness) is mainly characterised by abusive behaviour while *eddalu ly' akalogonjjo* (another form of mild madness) is mainly characterised by disorientation. Orley (1970) also notes that a person afflicted with *eddalu ly' akalogonjjo* (mild madness) was similarly described as *mutabufu* (being mixed up in the brain or head) and, most importantly, *eddalu ly' akazoole* and *eddalu ly' akalogonjjo* (both conditions referring to mild madness) to have been equated with chronic schizophrenia (Orley, 1970).

Okello and Ekblad (2006) similarly report variations in the conceptualisation of major depression, depression with psychotic features, bipolar disorder and adjustment disorders with depressed mood among members of the Baganda community in Uganda. In particular, Okello and Ekblad (2006) report that lay community members identify the case vignette portraying a patient with major depression as suffering from *okwerarikirira* (too many worrisome thoughts) affecting the person's head but which is neither madness nor a medical illness. This is in keeping with Aidoo and Hapham's (2001) similar finding, reported earlier, that women presenting with psychological symptoms of depression do not identify their health conditions as mental illnesses. Okello and Ekblad (2006) also report that participants believe the *depressed* patient, as described in the case vignette, as not requiring either professional (psychiatric) or traditional treatment. This may be due to the stigma and discrimination associated with mental illness (Corrigan, Kerr & Knudsen, 2005; Rüsch, Angermeyer & Corrigan, 2005). According to Okello and Ekblad (2006), lay community members indicated *okwerarikirira* (too many worrisome thoughts) to be characterised by apathy, the inability to maintain personal hygiene, social withdrawal, suicidal ideation and sleep disturbance. Traditional healers in Okello and Ekblad's (2006) study, in contrast, identified the patient in the same case vignette as suffering from *omutwe omutabuse* (being mixed up head, meaning suffering from madness), which they also stated as mainly caused by witchcraft. This suggests that members of the Baganda community (traditional healers) conceptualise major depression as madness, which Orley (1970) had previously found was identified in the same community as *eddalu ly' akalogonjjo* (a mild form of madness) and which he equated with chronic schizophrenia.

Okello and Ekblad (2006) report that some participants in their study identified a patient in the case vignette depicting an episode of psychotic depression as suffering from HIV/AIDS. However, others described the patient as simply a person who is living an unsuccessful life. Describing mental illness in medical terms such as AIDS has been reported elsewhere. For example, Helman (2007, p. 132) reports that serious or life-threatening medical conditions, such as AIDS, have become "folk illnesses", which accounts for traditional beliefs linked to moral aspects of health, illness and human suffering. According to Helman (2007), diseases that are hard to treat, explain, predict or control, for example, AIDS, often symbolise many of the common *anxieties* experienced by people, such as a fear of the breakdown of ordered society, fear of invasion or fear of divine punishment. In other words, apart from being clinical conditions, diseases such as AIDS are often *metaphors* for a variety of terrors associated with daily life (Helman, 2007). In contrast to psychotic depression, participants in Okello and Ekblaid's (2006) study identified a patient described using the case vignette of bipolar disorder in a manic phase as suffering from *kazoole*. This finding differs from that of Orley (1970), mentioned earlier, that members of the Baganda community believe *akazoole* to be typical madness. Edgerton (1966) similarly reports that lay people in East Africa identify mental illness based on behavioural disturbance with psychosis as the prototype of mental illness. Furthermore, Okello and Ekblad (2006) report that lay women described a patient presented in the case vignette of adjustment disorder with depressed mood as a "display of jealousy" while lay men referred to the same patient as suffering from "too many thoughts" caused by family stress. According to Okello and Ekblad (2006), the case vignette depicting dysthymia also attracted diverse labels such as "family disease", "HIV/AIDS", "problem caused by *eddogo*" (witchcraft) and "worry". In addition, Okello and Ekblad (2006) report that participants stated mental problems to be caused by multiple factors, including: (a) psychosocial causes, for example, unemployment, poverty, marital discord, (b) supernatural causes, for example, witchcraft and spirit possession, and (c) medical causes, for example, hereditary, substance abuse and HIV infection. The belief that multiple factors cause mental health conditions has similarly been reported elsewhere (Helman, 2007; Patel, 1998).

In addition, Okello and Musisi (2006) report that members of the Baganda community identified a patient in a case vignette of depression with psychotic features with mood congruent delusions as suffering from *eByekika* (clan illness). Participants in the study were seen to believe that *eByekika* (clan illness) stems from supernatural causes such as neglecting traditional rituals, breaking taboos and adulterating indigenous religion with Christianity and Islam. An example of conduct involving breaking a taboo is giving a clan name to a child born out of infidelity by the mother (also known as lost kin). Destruction of shrines following conversion to either Christianity or Islam, in contrast to lost kin, is an example of conduct associated with adulteration of indigenous religious beliefs with alien religious beliefs. Participants informed that misconduct attracts punishment for the culprit, which includes spirit possession and subsequent mental illness (Okello & Musisi, 2006). Participants also informed that *eByekika* (clan illness) can be effectively treated using traditional medicines (Okello & Musisi, 2006).

In settings apart from that of the community, Okello and Neema (2007) report that service users of Mulago national referral hospital in Kampala city in Uganda, conceptualised depression mainly in somatic idioms of distress, such as headache and general body weaknesses. In this study, service users identified their mental health problems with biomedical constructs, such as malaria. Somatic symptoms, such as lethargy, have frequently been found to manifest common mental disorders, such as depression (Goldberg & Huxley, 1992; Weiss., Raguram., & Channabasavanna, 1995). Additionally, Okello and Neema (2007) found that service users believe their health problems to emanate from the following multiple causes: (a) psychosocial, for example, loss of opportunity to attend school, and (b) supernatural, for example, witchcraft. Okello and Neema (2007) note that the explanatory models of patients, at times, contradict those held by their families. For example, patients and relatives, at times, disagree on the source of care despite holding seemingly similar beliefs about causes (for example, witchcraft) of mental illnesses (Okello & Neema, 2007). Such disagreement is often due to divergent religious beliefs among patients and their families; consequently, Christians do not seek care from traditional healers even if they believe witchcraft to be the cause of mental illnesses (Okello & Neema, 2007).

Similarly, Johnson, Mayanja, Bangirana and Kizito (2009) report that lay community members, health professionals and traditional healers in Central Uganda conceptualise depression in diverse ways. For example, the participants in their study identified a patient with an episode of unipolar depression presented in a case vignette with concepts that are; (a) psychological, for example, sadness, worry and unhappiness, (b) biomedical, for example, HIV/AIDS, malaria and pregnancy, (c) social, for example, loneliness, (d) socioeconomic, for example, poverty, and (e) cultural, for example, witchcraft. They also identified depression with local concepts such as *bunakuwavu* (sadness), *myike* (excessive sadness or sorrow) and *kiwubalo* (loneliness). However, these lay labels for depression differ from those reported by Orley (1970) and Okello and Ekblad (2006), both discussed earlier, despite these authors having conducted their studies in relatively similar study settings. Johnson et al. (2009) also report that explanatory models among lay community members do not overlap considerably with those of traditional healers when compared with those of other care providers as they had hypothesised. However, there found that there are significant variations in the explanatory models among the three categories of care providers, namely, traditional healers, primary care providers and mental health professionals (Johnson et al., 2009). In contrast, Micklin and Leon (1975) report no significant variations in beliefs regarding mental illness and mental patients among three categories of care providers, namely, graduate nurses, auxiliary nurses and nurse aides in Colombia. Patel (1998) similarly reports community psychiatric nurses, in spite of their biomedical orientation to mental illness, as holding indigenous conceptions of mental illness similar to those of family members and traditional healers involved in patient care.

Furthermore, Abbo, Okello, Ekblad, Waako and Musisi (2008), using case vignettes, report that traditional healers and lay community members in Eastern Uganda distinguished between schizophrenia, mania and psychotic depression. Participants in Abbo et al.’s (2008) study identified schizophrenia as *eddalu* or *ilalu*, mania as *kazoole*, hippomania as *kalogojjo* and depression as an “illness of thoughts”. They were seen to believe *eddalu* to be chronic and severe and *kazoole* (mania) to manifest in mild and intermittent episodes. Moreover, participants in their study indicated *eddalu* (schizophrenia) and illness of thoughts (depression) to be mainly caused by supernatural agents, such as witchcraft, and are thus to be treatable with traditional medicines. However, participants also informed *kazoole* (mania) to be caused by both biomedical and supernatural agents and thus to be treatable by modern and traditional medicines. It is noteworthy that members of the Basoga and Baganda communities use similar lay labels for different psychiatric diagnoses, for example, *kazoole*, for mania and schizophrenia respectively (Abbo et al., 2008; Orley, 1970).

Betancourt and Bass et al. (2009), in an exploratory study in Northern Uganda, report that participants identify psychiatric disorders using local terms. For example, the Acholi people use the local terms "*two tam*", "*par*" and "*kumu*" for anxiety/depression and "*ma lwor*" and "*kwo maraca*" for a syndrome featuring mood, anxiety and conduct disorders. Based on these local constructs, Betancourt and Bass et al. (2009) have developed the Acholi Psychosocial Assessment Instrument (APAI), which they observe to have a high internal reliability for the depression-like symptoms as well as good combined inter-rater and test-retest reliability for most of the scales. However, Kleinman (1996) argues that epidemiological tools, such as the APAI, may generate reliable but invalid findings, as such tools are often not sufficiently culturally nuanced.

In the next sections I discuss the consequences often associated with mental illness.

2.5. Consequences of Mental Illness. Mental illness often has serious consequences for the affected individuals, families and members of the community. These include: (a) stigma and discrimination, (b) aggravated poverty, and (c) somatic complaints. I consider each of these consequences in detail below.

2.5.1. Stigma as a consequence of mental illness. Stigma is perceived as a mark of shame, disgrace or disapproval and results in an individual being rejected, discriminated against and excluded from participating in a number of social activities (WHO, 2001). Stigma is pervasively associated with mental illness, although it may differ in form and intensity according to different psychiatric disorders (Sorsdahl & Stein, 2010). Mental illness has elsewhere been referred to as the "ultimate stigma" (Saxena, Thornicroft, Knapp & Whiteford, 2007). In addition, the burden of stigma significantly aggravates the disabling and distressing symptoms of mental illness (Alonso et al., 2009; Pinto-Foltz & Logsdon, 2009). Stigma is particularly associated with decreased quality of life and with occupational and social impairments in patients with mental illnesses (Alonso et al., 2009; Moroka; 1998). The enactment of stigma is based on the labelling of everyday experiences within people's social and cultural contexts.

2.5.1.1. Labelling and Stigma. Classification is helpful in dealing with complex phenomena in diverse cultural and social contexts (Abbo et al., 2008; Rüsch et al., 2005). For example, without classification of mental illnesses into specific psychiatric disorders, clinical communication is likely to be more difficult (Brown & Harris, 1978). Similarly, labelling enhances comprehension and comparison of particular phenomena. Perception and labelling of phenomena are influenced by people's unique historical, social, political and economic experiences (Fabriga, 1996) and thus, are socially and culturally shaped (Kleinman, 1996). For example, Edgerton (1966) reports that in East Africa, lay people recognise and label mental illnesses based on social rather than psychiatric considerations.

Ironically, labelling is also a basis for stigma and discrimination, as social stereotypes influence the organisation of vast stimuli in social encounters, thereby facilitating the making of impressions and expectations with regard to stigmatised individuals or groups (Corrigan et al., 2005; Rüsch et al., 2005). Labelling people with mental illnesses is thus a cognitive, emotional and behavioural process that results in stereotypes, prejudices and discrimination. It occurs, most particularly, in social and cultural contexts where there is considerable inequality in the social, economic and political power among members of society (Chambers, 1997; Littlewood, 1992; Mills, S., 2003). It is the powerful who usually label and thus stigmatise the weaker in society. Unfortunately, people with mental illnesses are unduly represented in the latter category (Narayan, Chambers, Sha & Petesch, 2000). Hostile social reactions to people with mental illnesses may be due to misconceptions about the nature, causes, consequences and management of mental illness. Such misconceptions include association of mental illness with the following: (a) dangerousness (Sorsdahl & Stein, 2010), (b) spirit possession (Ssebunnya et al., 2009), (c) infectiousness, (d) violence, (e) incompetence, (f) dangerousness, and (g) character weakness (Corrigan et al., 2005). Self-stigma, in contrast, occurs when people with mental illnesses agree with and internalise the negative social stereotypes associated with mental illness (Sayre, 2000). According to Helman (2007), misconceptions about mental illness are illuminating with regard to levels of mental health literacy and the values, beliefs and attitudes that prevail in particular social and cultural contexts. Below, I discuss, in turn, the issues of public and self-stigma associated with mental illness.

2.5.1.2. Public stigma and its consequences. Public stigma manifests in social and personal reactions comprising prejudices, stereotypes and discriminatory behaviours towards persons with mental illnesses (Rüsch et al., 2005). It may also manifest in authoritarian, paternalistic and, in isolated cases, benevolent relationships with such persons (Watson & Eack, 2011). Moroka (1998) reports that in Botswana, exclusionary behaviour manifests in relocation of people with mental illnesses to slums, cattle posts and shrines of traditional healers. Similarly, loss of employment among persons with mental illness is often due to social exclusion rather than loss of essential skills or poor job performance among the latter (Osei-Hwedie, 1989; Ssebunnya et al., 2010). Public stigma is also associated with poor quality housing and homelessness for persons with mental illnesses (Corrigan et al., 2005; Desjarlais, 2010; Sayre, 2000). Although mental illness may undermine patients' capacity to live independently and safely, public stigma associated with mental illness often aggravates the situation. For example, Orley (1970) reports that members of the Baganda community in Uganda often seclude patients in deplorable dwelling places because the former fear violence and contagion associated with mental illness. Consequently, people with mental illnesses lack social contact, stimulation and socialisation. They are also fed a poor diet and severely punished or killed if they wander away from their dwellings. Worse still, Orley (1970) reports people with mental illnesses as well as their families as regarding seclusion (seeking asylum) in Butabika national referral hospital as more comfortable than community-based mental health care. As would otherwise be expected, deplorable housing conditions, such as temporary shelters, for people with mental illnesses have similarly been found in HICs, such as the United States (Desjarlais, 2010).

Furthermore, public stigma is characterised by attribution of blame to people with mental illnesses for the latter's personal suffering, including loss of employment, stagnation at work, financial crisis and family disintegration (Osei-Hweddie, 1989). People with mental illnesses are also often scapegoated for crimes (Orley, 1970). Orley (1970) reports that such persons are often the victims of mob justice if they wander into communities to which they do not belong and/or are mistaken for *kondo* (robbers). However, the great numbers of people with mental illnesses in the criminal justice system (police, courts and prisons), compared with those receiving care from the health and social welfare systems, is due to hostile social reactions and public stigma associated with mental illnesses (Corrigan et al., 2005). Corrigan (2005) argues that the criminalisation of people with mental illnesses, to a great extent, is due to inadequate funding of mental health services, obsolete laws and undue fear of the mentally ill. Okello & Ekblad (2006) additionally report mental illness to cause interpersonal conflicts as well as being a great contributing risk factor to child abuse and antisocial behaviours that increase the propensity for criminalisation of people with mental illnesses. Yet, such unjust criminalisation violates the human rights and undermines the psychological wellbeing and productivity of the latter (Corrigan et al., 2005).

2.5.1.3. Self-stigma and its consequences. Self-stigma refers to the endorsement and internalisation by people with mental illnesses of negative stereotypes and beliefs about mental illness prevalent in specific cultural and social contexts (Rüsch et al., 2005). Self-stigma is associated with the grotesque discrimination of people with mental illnesses in interpersonal interactions, intentional and non-intentional exclusion in both the private and public institutions and negative media images (Alonso et al. 2009). Mental illnesses such as depression, as with stigma, are associated with social withdrawal and loss of employment, social networks and social support (Corrigan & Rao, 2012; Link & Phelan, 1999). Such negative consequences may be due to low self-esteem and self-efficacy precipitated by self-stigma among people with mental illnesses (Sartorius, 2007). However, Rüsch et al. (2005) report that low self-efficacy and low self-esteem caused by stigma associated with mental illness can be distinguished from similar psychological states produced primarily by symptoms of mental illnesses such as depression. In this regard, Rüsch et al. (2005) argue that people with acute episodes of mental illnesses are likely to lack insight and awareness about negative stereotypes, which paradoxically serves as a protective factor against self-stigma.

Corrigan, Watson and Barr (2006) distinguish between self-stigma and perceived stigma. According to Corrigan et al. (2006), while perceived stigma comprises awareness of stigmatising stereotypes, self-stigma comprises stereotype agreement, self-concurrence and self-esteem decrement. Corrigan et al. (2006) also report awareness of stigmatising stereotypes not to be associated with the above three elements of self-stigma; however, stereotype agreement to be significantly associated with self-concurrence and self-esteem decrement. Similarly, self-concurrence and self-esteem decrement are highly associated with measures of self-esteem and self-efficacy. Corrigan et al. (2006) thus argue stereotype agreement to be basically correlated with self-concurrence, to the extent that people apply stereotypes to themselves only when they agree with such stereotypes, consequently, experiencing low self-esteem. According to Corrigan et al. (2006), self-esteem and self-efficacy are not significantly associated with stereotype agreement, because people endorsing stigma associated with mental illness does not automatically suggest that the latter internalise and suffer diminished self-esteem and self-efficacy. Yet, self-esteem and self-efficacy are shown to be significantly associated with stereotype awareness, a finding that Corrigan et al. (2006) report as puzzling since stereotype agreement is not significantly associated with self-esteem or self-efficacy. Corrigan et al. (2006) also note that the significant association of self-concurrence and self-esteem, on the one hand, and lower self-esteem and self-efficacy, on the other, is as expected. Even by controlling for depression (using multiple regression analyses), Corrigan et al. (2006) found self-concurrence and self-esteem to be consistently and significantly associated with lower self-esteem and self-efficacy.

Self-stigma is a barrier to care-seeking and care utilisation (Saxena et al., 2007; Ssebunnya et al., 2010). For example, people with mental illnesses are usually reluctant to disclose their health condition to family members and other care providers (Corrigan & Rao, 2012). Similarly, families are usually unwilling to accept that a family member is suffering from a mental illness and/or to share any suspicions of family members' likely mental illness with potential care providers (Muhwezi, Okello, Neema & Musisi, 2008). Disclosure of mental health status often involves weighing the likely benefits against the possible costs (Rüsch et al, 2005). On the one hand, the benefits of disclosure to family and other care providers may include psychological relief, increased self-esteem and increased social support. On the other, the costs associated with disclosure may include social exclusion and prejudice (Corrigan & Rao, 2012). In addition, disclosure and care-seeking depend on perceptions of trust and the impact of mental illness on identity. The nature and degree of hostility and sympathy received influence whether persons with mental illnesses disclose their conditions to family and other care providers and vary widely in different cultural and social contexts (Kleinman, 1980).

Furthermore, Kranke, Floersch, Townsend and Munson (2009) report adolescents taking psychiatric medication to often experience self-stigma associated with care-seeking and care utilisation. Many adolescents, according to Kranke et al. (2009), internalise stereotypes, such as lack of self-control, associated with mental illness, which make them feel ashamed about having a psychiatric diagnosis and taking medication. They consequently become secretive about taking medication and limit their social interactions with peers. Taking medication, in particular, results in beliefs that they are *different* and thus inferior to other adolescents. Limited interaction with peers, in contrast, comprises behaviours such as: (a) "withdrawal or social distance from peers,

(b) interaction with others of a like condition, (c) interaction with peers who know of their mental illness but are trusted friends, and (d) limited interaction with friends who cannot be trusted with knowledge about their mental illness" (Kranke et al., 2009). Kranke et al. (2009) also report that while 90% (36) of their study participants endorsed themes such as secrecy and shame that suggest internalised stigma, 10% (4) did not endorse such stigma-related themes. According to Kranke et al. (2009), supportive social contexts, including families and peers, and positive evaluation of the effects of medications buffer adolescents against stigma. In addition, adolescents, their friends and families regard taking medication to manifest resumption of "normative" roles, to normalise mental illnesses and to enhance interaction with peers (Kranke et al., 2009).

Contrary to the common view that stigma leads to dire consequences (Corrigan et al., 2005; Sartorius, 2007), Rüsch et al. (2005) report this to not always be the outcome. In this regard, Björkman, Svensson and Lundberg (2007) report that stigma can ironically empower people with mental illnesses. Such empowerment has been associated with "being righteously angry" with stigmatising stereotypes (Rüsch et al., 2005). According to Rüsch et al. (2005), people's perceptions of stereotypes as illegitimate can be protective and empowering. People who agree with stereotypes are therefore likely to experience self-stigma as opposed to those who perceive the same stereotypes as illegitimate and unfair. Jahoda (2010) similarly reports that people with intellectual disabilities and mental illnesses endeavour to establish a positive social identity amidst experiences of stigma. They however, often encounter significant barriers, such as social rejection and over-protection, within their social contexts, for example, from families and peers. Failure to achieve desired goals, such as social acceptance and independence, also precipitate negative emotions such as feelings of embarrassment, shame and anger among people with intellectual disabilities and mental illnesses. Because stigma is rooted in social interactions, social and contextualised interventions, for example, family therapy, are according to Jahoda (2010), more likely to promote positive self-concept and self-perception among patients with intellectual disabilities and mental illnesses than individualised treatments, such as cognitive behavioural therapy.

2.5.2. Poverty as a cause and consequence of mental illness. There is consensus among researchers that mental illness and socioeconomic status are inversely related and that mental illness disproportionately affects people in the lowest social classes (Lund et al., 2010; Patel, Araya, de Lima, Ludermir & Todd, 1999; Perry, 1996; Saxena et al., 2007). What is disputed, however, is whether mental illness causes a low socioeconomic status or whether a low socioeconomic status causes mental illness. Social selection (downward drift) theory and social causation theory are the two leading and contrasting theories that explain the inverse relationship between mental illness and socioeconomic status (Perry, 1996; Yu & Williams, 1999). According to Yu and Williams (1999), social selection theory postulates that low socioeconomic status among people with mental illnesses occurs because of health-related downward mobility. Social selection theory assumes that mental illness prevents individuals from obtaining and/or keeping employment necessary to sustain or improve their socioeconomic status. People with mental illnesses may thus drift into lower socioeconomic groups or fail to climb out of low socioeconomic positions due to the incapacitating effects of their illnesses. Social selection theory also emphasises genetic explanations for variations in the risk of mental illness. In addition, it regards mental illness as a cause of considerable social and occupational impairment, for example, loss of employment, increased care-seeking costs and loss of income that, in turn, account for the low socioeconomic status among people with mental illnesses (Lund et al., 2010; Titov, 2007).

In contrast, social causation theory postulates that mental illness is caused by socioeconomic adversities that people with a low socioeconomic status unduly experience (Yu & Williams (1999). A low socioeconomic status is associated with high levels of pathogenic conditions and few resources for coping with problems of living (Saxena et al., 2007). Psychological distress, characterised by feelings of loss and disappointment, is common among poor people because of undue social adversity associated with severe life events that are also known as long-term threats (Brown & Harris, 1978). Such severe life events include diagnosis of a life-threatening illness in a family member, marital separation or threat, including death, and a major negative revelation about a significant other. Moreover, unrelated life events may produce additive effects among poor people; apart from life events, low socioeconomic status is associated with provoking agents such as social exclusion, malnutrition and increased vulnerability to violence and trauma that cause and perpetuate mental illnesses (Lund et al., 2010). Diverse dimensions of low socioeconomic status in different social and cultural contexts that manifest social disadvantage and are risks for mental illness include gender, age, low levels of income and low levels of formal education (Patel et al., 1999). For example, Patel et al. (1999) report gender to be a risk factor for mental illness because of the multiple roles for women, violence against women and women's lower gender status. Lund et al. (2010) similarly report a low level of formal education to be positively associated with common mental disorders while a high level buffers women against postpartum depression. However, significant disparity in access, retention and educational outcomes are common in LAMICs, such as Uganda, despite official inclusionary policies such as universal primary education (Twikirize, 2012). Additionally, income inequality in liberalised market economies is associated with increased risk for mental illness, such as disparity in access to basic needs, for example, food, education and medical care as well as susceptibility to debt, the latter which causes considerable psychological stress among poor people (Lund et al., 2010; Patel et al., 1999; Saxena et al., 2007). In a similar vein, Boyce et al. (2009) report retention of employment following onset of a mental illness to be a protective factor against relapse; in addition, employment prevents self-stigma and facilitates patients' meeting the costs associated with care-seeking.

To illustrate the inverse relationship between socioeconomic status and mental illness, epidemiologists have examined the underlying causal structure and relative importance of social causation and social selection theories. For example, Hudson (2005) reports a strong inverse relationship between socioeconomic conditions and mental illness due to social causation and not social drift among psychiatric patients in Massachusetts in the middle to late 1990s. Hudson (2005) also notes this inverse relationship to be consistently present when assessing different indicators of socioeconomic status, for example, income, occupation and type of mental illness (such as depression and schizophrenia). Additionally, Hudson (2005) reports the relationship between socioeconomic class and mental illness among low- and middle-income groups as nonlinear to be surprising, arguing that a nonlinear relationship suggests that socioeconomic status impacts on mental health through adverse economic conditions, for example, poverty and unemployment that unduly affect poor people. Hudson (2005) also reports a "residual" or "baseline level" (approximately three sevenths of the maximum) of mental illnesses to be possibly due to biological causes, irrespective of socioeconomic condition. In addition, according to Hudson (2005), among the social causation hypotheses tested, the model that most supported and fitted the data conforms to the idea that socioeconomic stress mediates the impact of socioeconomic status on mental illness. In this regard, alternative models, such as those promoting views that socioeconomic status causes mental illness through economic stress or that lack of family integration causes mental illness, do not sufficiently fit the data (Hudson, 2005).

In keeping with social selection theory, Hudson (2005) reports that several tests conducted to assess patients movement into less favourable community and employment positions subsequent to initial hospitalisation for a mental illness show no or non-significant downward drift, except for schizophrenia (approximately 2%). There is, however, a preponderance of upward mobility with regard to changes in employment. Additionally, tests involving the role of age in mediating downward drift did not support the idea that downward drift occurs prior to rather than subsequent to psychiatric hospitalisation. In view of these findings, Hudson (2005) concludes that social causation theory explains the experience of acute psychiatric hospitalisation of patients in Massachusetts in the middle to late 1990s, and that socioeconomic status causes mental illness through its associated adverse economic conditions, which is stressful, among lower-income groups.

Similarly, Dohrenwend, et al. (1992) have demonstrated the inverse relationship between psychiatric morbidity and socioeconomic status by assessing ethnicity in relation to socioeconomic status among Israeli-born adults of European and North African backgrounds. Dohrenwend et al. (1992) argue that because socioeconomic and ethnic status impact people’s wellbeing, for example, by determining access to employment, goods and services, they can be used to distinguish between social selection and social causation hypotheses. Moreover, an individual’s ethnicity cannot be influenced by psychopathology or personal predispositions to psychopathology. In view of the above theoretical insights, Dohrenwend et al. (1992) report that social selection and social causation processes differ in relative importance by diagnostic type. For example, rates of schizophrenia in the above study were found to be higher among respondents of European background with socioeconomic status controlled, as would be expected, if “sifting” processes function to hold down more healthy persons of disadvantaged North African background while excluding a residue of severely ill persons of advantaged European background (Dohrenwend et al., 1992). This finding, according to Dohrenwend et al. (1992), suggests social selection processes to be more important than social causation processes in the relationship between socioeconomic status and schizophrenia. Similarly, by holding socioeconomic status constant, rates of major depression among women as well as antisocial personality and substance use disorders among men were found to be higher among Israelis of North African background than among Israelis of European background, as would be expected, if an increase in social adversity associated with a disadvantaged ethnic status produces an increment in psychopathology (Dohrenwend et al., 1992). This finding, according to Dohrenwend et al. (1992), suggests social causation processes to be stronger than social selection processes in the respective inverse relationships between socioeconomic status and mental disorders.

2.5.3. Somatic complaints as perceived consequences of mental illness. Patterns and hierarchies of resort among service users are greatly influenced by culturally shaped distress (Kleinman, 1980). Service users and their care providers usually perceive distress in diverse ways. For example, most people with mental illnesses and their primary care providers in LAMICs tend to express and prioritise typical functional complaints and non-disease morbidity (Muhwezi & Okello et al., 2008; Patel, 1996). Such somatisation of distress may simultaneously affect an individual and/or several individuals in a family (Kleinman, 1980). Somatisation associated with common mental disorders, such as depression, often manifests as nonspecific chronic pain, insomnia, weight loss, dry mouth, constipation and loss of energy (Kleinman, 1980). Some patients may also lose their appetite for food (Okello & Ekblad, 2006) and thus suspect that they are suffering from biomedical conditions, such as high blood pressure, pregnancy, ulcers or HIV/AIDS (Johnson et al., 2009). Some patients also experience fever, characterised by joint pains, increased body temperatures and dizziness (Muhwezi & Okello et al., 2008).

Somatisation of distress has been referred to as the cultural patterning of disease, which suggests a similar disease entity as being experienced uniquely in different social and cultural contexts (Kleinman, 1980). Functional complaints and non-disease morbidity are frequently attributed to social and spiritual problems such as poverty, interpersonal conflicts and witchcraft (Patel, 1996). Functional complaints often lead to interventions such as fellowships in church groups, advice from community elders and rituals performed by traditional healers (Okello & Ekblad, 2006). Such beliefs suggest that psychiatric care is usually not perceived as relevant and that when it is, irregularly, sought, somatisation is likely to pose diagnostic and management challenges.

2.5.3.1. Somatisation-related challenges in mental health care. Somatisation poses diagnostic and management challenges to both specialist and general health care providers (Ensink & Roberson, 1999; Swartz, 1998). Symptoms of common mental disorders, such as depression, without a physical basis are often perceived as indicative of social and spiritual imbalances rather than psychiatric morbidity (Patel, 1998). Patients often seek medical attention from primary health care facilities only when somatic complaints become too severe to tolerate (Muhwezi & Okello et al., 2008). In addition, primary health care workers, as with service users, often believe mental illness to be caused by supernatural agents, such as witchcraft (Patel, 1998). Consequently, primary health workers are usually reluctant to assign stigmatising psychiatric labels to service users who complain of non-disease morbidity or to refer them to psychiatric health workers (Muhwezi & Okello et al., 2008).

Additionally, specialist mental health professionals tend to have low levels of mental health literacy regarding the common mental disorders, such as depression, in general, and somatisation, in particular (Goldberg & Huxley, 1992; Patel, 1996). Low levels of mental health literacy may be due to poorly organised psychiatric training, the latter which is mainly based on treating patients with psychosis (WHO, 2007). Based on the above view, psychiatry in LAMICs has, at times, been perceived as a “psychiatry of the psychoses” (Edgerton, 1980). Additionally, guided by the biomedical model, psychiatric health workers habitually assume psychological distress to have a physical basis that can be scientifically verified (Fabrega, 1996). Complaints by patients of a social, psychological and spiritual nature thus remain, in most cases, unassessed, with related management plans not devised (Patel, 1996; Swartz, 1998). Subsequently, service users are coached to present only physical complaints to attract some, but usually, ineffective treatment (Swartz, 1998). Kleinman (1980) reports a similar socialisation in the family context for people with mental illnesses in China. Considering its wide-spread occurrence, Swartz (1998) describes somatisation as “using the body” to speak of and experience distress. According to Swartz (1998), somatisation is a normative and universal phenomenon.

However, exclusive focus on the physical domain of health contradicts perceptions of the mind in sociocentric cultures (Kleinman, 1980; Swartz, 1998) and is inconsistent with the broad definition of health (WHO, 2001; WHO, 2005). In collective cultures, such as in Taiwan, the heart is, for example, perceived as the seat of emotions (Kleinman, 1980). Similarly, among members of the Baganda community in Uganda, the heart is believed to think and to feel (Orley, 1970). Perceptions such as these suggest that clinicians may infer psychological distress from somatic complaints in the same way as they do with physical distress from psychological complaints. Moreover, appropriate focus on patients' somatic complaints is crucial, considering that mental illnesses are usually co-morbid with physical illnesses.

2.5.3.2. Somatisation and the comorbidity of mental illness with physical illness. Mental illness is usually co-morbid with chronic physical illnesses such as diabetes, cancer, cardiovascular disease and obesity (Hall, Degenhardt & Teeson, 2009; Scott, McGee, Schaaf & Baxter, 2008; WHO, 2010). Overlapping symptoms of mental and physical illnesses, consequently, necessitate careful examination of patients (Benjamin, Barnes, Berger, Clarke & Jeacock, 1988; Gili et al., 2010). Swartz (1998), for example, reports that gastroenteritis (inflammation of the gastrointestinal tract), a physical health condition, presents with symptoms such as fatigue, headache, poor appetite and indigestion, disturbed sleep and psychological distress states such as unhappiness, the latter symptoms which are frequently attributed to somatisation of mental illness.

Similarly, emotional problems, such as depression, may present with symptoms such as difficulty breathing, chest tightness, shakiness, headache and dizziness, symptoms normally associated with physical illnesses (WHO, 2010). Furthermore, emotional problems may be due to social and occupational impairments as well as significant role adjustments caused by chronic physical problems, such as cancer and HIV/AIDS. Such emotional problems are estimated to occur in between 25% and 33% of patients with chronic physical health problems (WHO, 2010). However, emotional problems, such as those described above, among patients and primary care providers, usually remain undiagnosed (WHO, 2009a). This inconsistency may be due to biomedical reductionism (Kleinman, 1980). In the few cases where emotional problems are attended to, particularly in the popular sector, it is done so with reference to a presumed physical illness believed to have organic pathophysiology (Kleinman, 1980).

Furthermore, co-morbidity of emotional and physical problems is associated with aggravated social and economic costs for patients, families and governments (Hutter, Scheidt-

Nave & Baumeister, 2009). Depression, for example, usually worsens medical conditions such as cancer and reduces patients' energy, the latter which is essential for coping with such a diagnosis and the demanding treatment schedules entailed (WHO, 2010). Consequently, a vicious cycle of worsening physical and emotional symptoms is frequently experienced by patients. Appropriate balance in managing both physical and psychological illnesses in patients is thus essential in both specialist and general health care (Fenton & Stover, 2006; Scott et al., 2008).

In addition to the challenges associated with somatisation and co-morbidity of mental illnesses with physical illnesses, a number of structural barriers constrain effective care for people with mental illnesses. In the following sections, I discuss in detail such structural barriers to effective care.

2.6. Structural Barriers to Effective Mental Health Care

In the mental health sector limited progress has been made since the publication of high profile reports, declarations and conventions regarding the promotion of mental health as well as treatment and care for people with mental illnesses (Fistein, Holland, Clare, & Gun, 2009; Stein et al., 2009; WHO, 2001) For example, a wide mental health treatment gap still exists within and across different countries worldwide (WHO, 2008), a gap that is wider in LAMICs where information on service utilisation is not available (Kohn et al., 2004). The mental health treatment gap refers to a discrepancy between the apparent mental health care needs of the population and available resources and interventions to alleviate the huge burden of mental disorders (WHO, 2008). While there is considerable evidence regarding effective interventions for mental health services, especially in LAMICs, such evidence is yet to translate into practice (Thornicroft, 2007). Consequently, many people in need of mental health services fail to receive it. Scholars have reported various structural barriers that constrain delivery and utilisation of mental health services (Bird et al., 2011; Isaacs, Pyett, Oakley-Browne, Gruis & Waples-Crowe, 2010; Saxena et al., 2007; WHO, 2007). These barriers can be categorised as follows: (a) low priority of mental health on the public health agenda, (b) poor organisation of mental health services, and (c) social and culture-related barriers, all of which are discussed in detail below.

2.6.1. The low priority of mental health on the public health agenda-related barriers. Individuals, families, governments and donors, especially in LAMICs, usually allocate meagre budgets for mental health (Saxena et al., 2007; Saxena & Maulik, 2003). The resulting scarcity of resources is aggravated by inequity and inefficiency within the mental health care system, resulting in a vicious cycle of barriers to effective care in this sector (Saxena et al, 2007). The allocation of meagre budgets to mental health is due to factors such as inadequate and fragmented advocacy for mental health, stigma of mental illness and competing priorities of governments and donors (WHO, 2007). For example, the lack of consensus on advocacy protocols among interest groups comprising service users, health professionals, academics and NGOs, usually yields minimal pressure on conservative governments and donors. Additionally, in some LAMCs, significantly fewer service-user and family organisations advocate for improved mental health services (Bird et al., 2011).

Furthermore, the lack of up-to-date stewardship instruments (for example, policy and legislation), inadequate funding and well trained human resources as well as poor physical infrastructure are common in many LAMICs (Jacob et al., 2007; Saraceno et al., 2007). While mental health policies and related legislation are vital in informing the provision of mental health services and activities to populations, only approximately a third of the countries worldwide have such official instruments in place (Saxena et al., 2007). The situation is even worse among sub-Saharan African countries. Although some LAMICs, such as Uganda, include mental health in development strategies, for example, the Minimum Health Care Package, such inclusion often fails to translate into funding for mental health (Bird et al., 2011). The lack of an appropriate mental health policy, in general, also constrains the development of mental health programmes and strategies as well as solicitation of funding from the international aid community (Bird et al., 2011).

Additionally, legislation to safeguard against the abuse of basic human and civil rights of people with mental illnesses are usually either missing or outdated in most LAMICs (Saxena et al., 2007). For example, the Ugandan Mental Health Treatment Act was last reviewed in 1964 (Ndyanabangi, Basangwa, Lutakome & Mubiru, 2004), suggesting that the country's government disregards substantial developments regarding treatment and care that have occurred in the last five decades. People with mental illnesses may, consequently, be discriminated against and socially excluded from basic services, such as education and health. Similarly, such persons are often violently treated by their families, communities and institutions such as mental hospitals and prisons (Blitz, Wolff & Shi, 2008; Hunt, 2006; Lucas & Stevenson, 2006). Such forms of abuse may be partly due to the absence of review bodies to monitor observance of service users' rights (Patel, 2007), adoption of international laws not appropriate to local contexts (Jones, 2005) and inadequate resources for mental health (Hunt, 2006).

A critical shortage of well-motivated and qualified mental health professionals, such as psychiatrists and psychologists, is another barrier to mental health care in most LAMICs (Kigozi, 2007; Kigozi et al., 2010; Ovuga, Boardman & Wasserman, 2007; Saraceno et al., 2007). The number of mental health professionals is also over-estimated in LAMICs, as a large number of clinicians are usually engaged in full-time research and administration capacities rather than in actual care of patients (Helman, 2007). Although not a single country worldwide evidences enough human resources to cover all its mental health needs, the human resource gap is experienced more significantly in LAMICs (Swartz & Dick, 2002). The disparity in human resource allocations is also much wider in LAMICs (Saxena et al., 2007). For example, over 60 % of human resources for mental health in Uganda is located in and around Kampala city, where facilities are better and private practice more lucrative than in rural communities (Kigozi et al., 2010). This suggests that people in rural areas rely mainly on popular and folk sectors to meet their mental health needs (Lund, Kleintjes, Kakuma, Flisher, & the MHaPP Research Program Consortium, 2009). Scarcity in human resources in most LAMICs is also steadily being depleted by frequent migrations by professionals to the HICs for better working conditions (Farmer, 2010) and preference for work in the private sector that serves the privileged classes (Swartz, 2007).

Additionally, most LAMICs commit meagre financial resources for mental health care – usually less than 1% of their paltry health budgets (Saxena et al, 2007; Saxena & Maulik, 2003). The government of Uganda, for example, spends about 1% of overall health expenditure on mental health, with about 55% of the latter total expenditure directed to Butabika national referral mental hospital alone (Kigozi et al., 2010). Moreover, ineffective, inequitable and exploitative financing systems, such as out-of-pocket payment methods, are widely used in most LAMICs. The adoption of such ineffective financing strategies for mental health services is mainly attributed to the lack of appropriate infrastructure to support effective financing options, such as tax-based payments and health insurance (WHO, 2007). Out-of-pocket financing mechanisms, apart from being unreliable and ineffective, aggravate poverty and perpetuate poor treatment outcomes among service users (Narayan et al., 2000).

Furthermore, dependence on international donors and aid agencies creates challenges regarding targeting of scarce resources (Ndyanabangi, et al., 2004). This is because major international funding agencies, such as the World Bank, do not prioritise mental health among their sponsored development projects, such as the Millennium Development Goals (MDGs), in LAMICs (Bird et al., 2011; Groce, & Trani, 2009). Such reluctance among development partners is partly due to the lack of convincing evidence regarding cost-effectiveness of related interventions (Chisholm et al., 2000; McDaid, Knapp, & Raja, 2008). Where such evidence is available, it is generally epidemiological and not able to convey the complexity associated with mental health problems and care (Kleinman, 1996). In instances where international aid is secured, funding agencies usually control the mental health agendas of recipient countries (WHO, 2007). Chambers (1997) refers to such forms of reality transfer as “Model-T”, the latter which suggests that the de facto interventions do not address the priorities of recipients.

2.6.2. Poor organisation of mental health services-related barriers. Poor organisation of mental health services is associated with inaccessibility, unacceptability, inefficiency and ineffectiveness of mental health systems in many LAMICs (Jenkins & Strathdee, 2000; Patel, Simon, Chowdhary, Kaaya, & Araya, 2009). In particular, centralisation of mental health services, heterogeneity of the mental health field and inappropriate training of primary health workers usually characterise mental health systems in most LAMICs (WHO, 2007). Because of substantial investment in large asylums, most LAMICs are reluctant to invest in community-based health services (Saxena & Maulik, 2003). Most beds are, as a result, available in specialist mental hospitals (Kigozi et al., 2010; Ndyanabangi et al., 2004; Saxena & Maulik, 2003). In Uganda, for instance, over 60 % of psychiatric beds are located in Butabika national referral hospital and other health facilities in and around Kampala city (Kigozi et al., 2010; Ndyanabangi et al., 2004). Specialist hospitals also usually consume more than half of the budgets for mental health in most LAMICs (Saxena et al., 2007). Community-based mental health services, in contrast with institution-based care, are constrained by a number of factors. These include: (a) the need for double-funding, particularly in the short-term, and (b) the vested interests, such as job security, of senior mental health professionals and administrators of large mental hospitals (WHO, 2007). However, centralised mental health services are often equally characterised by a number of limitations, such as: (a) custodial care, (b) human rights violations, (c) poor treatment outcomes, and (d) poor quality of life among service users (Jacob et al., 2007; Lucas & Stevenson, 2006).

Inadequate leadership in public mental health is another organisational-related barrier to effective mental health care in most LAMICs, as most of the senior administration staff of large mental hospitals and other influential leaders in ministries of health are often clinicians by training (WHO, 2007). The WHO has noted that such administrators possess sophisticated skills for lobbying politicians and policy makers to maintain the status quo, thereby promoting a culture of paternalism and dependency among people with mental illnesses. Furthermore, most LAMICs lack sufficient numbers of qualified mental health professionals to support the shift from institutional to community-based care (Kigozi, et al., 2010; Saxena et al., 2007). In addition, primary health workers tend to be already overwhelmed by a range of problems, including infectious diseases, such as malaria and HIV/AIDS, as well as chronic medical problems, such as diabetes (Kleinman, 2003). In this regard, Kleinman (2003) reports time constraints, lack of drugs such as antidepressants and anxiolytics and the large numbers of patients presenting complaints in the local idioms of distress as key barriers to effective community-based mental health care.

Similarly, heterogeneity in the mental health field creates ambiguity in planning and budgeting for mental health (WHO, 2007). For example, mental health problems can be categorised as follows: (a) behavioural problems, for example, substance abuse, violence and suicide, (b) severe and long-term mental disorders, for example, schizophrenia, (c) common mental disorders, for example, depression and anxiety, and (c) crisis situations, for example, wars and natural disasters. This fragmentation, coupled with competing priorities, such as HIV/AIDS, compels policy makers to overlook the high contribution of mental health problems to the global burden of disease (Bird et al., 2011; McDaid et al., 2008). Yet, such infectious diseases usually increase the global burden of mental disorders (Saxena & Maulik, 2003). The difficulty in developing specific clinical guidelines for treatment of mental illnesses is due to fragmentation of the mental health field (WHO, 2007). The diversity of mental health problems creates challenges with regard to making intervention priorities, such as those focusing on treatment rather than prevention (Ferri, Chisholm, van Ommeren, & Prince, 2004). Most LAMICs spend most of their budgets for mental health on treatment of severe mental disorders, as the latter are easier to diagnose than are the common mental disorders (Saxena & Maulik, 2003). In most cases, little if any, resources are spent on promotion and prevention of mental illnesses. Moreover, most patients and primary care providers usually fail to perceive common mental disorders as forms of mental illness (Swartz, 1998). The inability to detect common mental disorders in primary health care settings is partly due to stigma and the lack of diagnostic skills among health professionals (Ghebrehiwet & Barret, 2007; Muhwezi et al., 2007). Yet, common mental disorders, such as depression, account for a higher contribution towards the global burden of disease compared to severe mental disorders (WHO, 2001).

Additionally, community resources, such as families, NGOs and indigenous healing systems, contribute minimally towards mental health care in most LAMICs (WHO, 2008). On the one hand, the family is, for example, overwhelmed by the burden of care for family members with mental illnesses (Muhwezi & Okello et al., 2008). On the other, NGOs linked to mental health care usually cover very limited areas and populations, compete rather than collaborate with each other, and are frequently focused on meeting donor rather than beneficiary objectives (WHO, 2007). In addition, ministries of health in LAMICs are usually not able to harness community resources, perceiving these role-players as substitutes rather than partners (Hartley, Finkenflugel, Kuipers & Thoma, 2009; Matthews, 2008). Mistrust and suspicion among stakeholders also hinder coordination and cooperation, consequently rendering mental health care systems inefficient and ineffective (Matthews, 2008).

Uncoordinated planning and budgeting with other social service sectors aggravate coordination-related challenges in mental health care systems in most LAMICs (WHO, 2007). While mental health forms part of other health sectors, such as reproductive health, HIV/AIDS, education and social welfare, policy makers and leaders in the mental health sector usually adopt a “silo” (non-integrated or compartmentalised) approach to budgeting (Leutz, 1999; Saxena et al, 2007) in favour of donor demands for explicit budgets and intervention plans. Donor dependency, however, overlooks the complexity and interdependence of mental health with other social sectors (Chambers, 1997). The inadequacy of social welfare services, such as housing, and disability benefits in most LAMICs also necessitates additional budgetary allocations, apart from the costs of coordination (Leutz, 1999; WHO, 2007).

2.6.3. Social and culture-related barriers. Two main social and culture-related barriers exist, namely: (a) stigma and discrimination, and (b) poverty, both which greatly constrain the provision and utilisation of mental health services, especially in LAMICs (Kigozi et al., 2010; Saxena et al., 2007). The association of mental illness with stigma and discrimination has led to the perception that the former is a personal matter (WHO, 2007). In particular, stigma and discrimination usually prevent affected individuals and families from disclosing mental illnesses to care providers (Rüsch et al., 2005). The consequences of stigma and discrimination, such as family disruption, divorce and separation, loss of employment and reluctance among health professionals to specialise in mental health fields such as psychiatry, aggravate mental health care-related challenges (Corrigan et al., 2005).

Because people with mental illnesses, unlike other patients, such as those with cancer, are usually hidden away as a result of stigma, they are often not able to attract sympathy from the general public (Bird et al., 2011; Orley, 1970). People with mental illnesses are usually secluded in large mental hospitals (Orley, 1970), cattle posts, shrines of traditional healers and slums in urban centres (Moroka, 1998). Yet, their very visibility and sunbesquent public support is crucial in advocacy for improved mental health services (WHO, 2007). Politicians are also often restrained in advocating for improved mental health services, as they fear endangering their political careers by incurring disfavour among the public and voters (WHO, 2007). Additionally, proposed health interventions based on morbidity are perceived to be unethical in contexts where mortality rates are quite high (Bird et al., 2011). Other stigma-related barriers to effective care manifest in policies and laws (Ssebunnya, et al., 2010), inadequate funding for mental health research and poor employment terms for mental health professionals compared with other health workers (Levinson & Druss, 2000).

In a study of the Aboriginal or indigenous people of Australia, Isaacs et al. (2010) report that mistrust precipitated by structural barriers, such as a history of racism and discrimination, exacerbate stigma-related barriers. Culture and language differences that shape conceptualisations of mental illness also perpetuate misunderstandings between indigenous Australians and mental health professionals. Other structural barriers to effective mental health care among the Aborigines include inaccessibility, due to long distances, to health facilities and lack of transport, unfriendly mental health staff and long waiting times at health facilities (Isaacs et al., 2010). Similarly, Saxena et al. (2007) report an inverse relationship between need and access to mental health services. The needy and poor usually have inadequate access to mental health services compared to their wealthy and less needy counterparts. The poor comprise mainly women, the least formally educated, rural dwellers, refugees and the homeless (Narayan et al., 2000). Indigenous peoples, such as the Aborigines, are similarly likely to experience limited access to mental health services even if located in high income countries as a result of historical and structural barriers (Isaacs et al., 2010).

Below, I discuss health care pluralism, commonly found in plural health care systems in many LAMICs.

2.7. Mental Health Care Pluralism

Responses of patients and care providers to mental illnesses often depend on possible therapeutic options that can be utilised in a variety of patterns, for example, simultaneously and sequentially (Kleinman, 1980; Swartz, 1998). The coexistence of various care providers offering diverse forms of care has been referred to as “health care pluralism” (Helman, 2007; Patel, 1988). The availability and accessibility of care are central to decision making regarding care-seeking and care-utilisation in different social and cultural contexts (Helman, 2007). Some forms of care are linked to popular, folk and professional sectors in health care systems (Kleinman, 1980; Swartz, 1998), as discussed below.

2.7.1. The popular sector as a function of a plural health care system. The popular sector is considered the most basic and the lay domain of a plural health care system (Helman, 2007; Kleinman, 1980). Helman (2007) estimates over 70% of care to be based in the popular sector. In particular, distress is often first recognised and initial care initiated in the popular sector. The hierarchy of resort[4] in the popular sector ranges from self-help to help-seeking from family

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[4] Kleinman (1980, p. 187) refers to the hierarchy of resort as patterns of health seeking behaviour and the logic engendering family-based health care choices and practices. He identifies, in his study, three major patterns of health seeking behaviour among Taiwanese patients, namely: (a) simultaneous resort, (b) hierarchical resort, exclusive type, and (c) hierarchical resort, mixed type.

members and, finally, from other members of the public (Kleinman, 1980). People with distress may utilise free therapeutic options such as self-treatment, advice and treatment from family, friends and acquaintances (Kermode, Bowen, Arole, Joag & Jorm, 2009). Healing and mutual care activities in settings such as the church may also be utilised in the popular sector (Swartz, 1998). Other therapeutic options available in the popular sector include self-help groups and consultation with persons known to have had special life experiences and overcome life challenges (Helman, 2007). Self-help groups, such as those with parents of children with, for example, a conduct disorder, may be mobilised by professional health workers as support groups for patients (Swartz, 1998). Such groups may serve several functions, such as sharing advice on lifestyle and coping strategies and acting as a socialisation forum for individuals with stigmatised health problems such as mental illnesses (Helman, 2007). Self-help groups have been described as the "community of suffering" and protest movements, the latter focusing on broader social justice concerns, such as inequality and oppression (Helman, 2007).

Care in the popular sector may serve different purposes, that is, curative, health maintenance and preventive (Kleinman, 1980). Examples of curative care may include special diets, tonics, appetite stimulants and sleeping pills (Kermode et al., 2009). Health maintenance, health promotion and distress prevention, in contrast, may involve adjustments with regard to work, sleep, dress and eating patterns (Helman, 2007). Affected persons may also use items such as amulets, for example, for protection against misfortune and to attract good luck. Because health care in the popular sector is provided and utilised within the ambit of close social bonds, such as kinship, friendship and neighbourliness, clients and healers usually share beliefs about illnesses and treatment (Helman, 2007). Consequently, misunderstanding in client-care provider communication is usually minimal in the popular sector. There is also flexibility with regard to people involved in care and in care contexts (Kleinman, 1980). For example, a person can serve as both client and care provider at different times and in different social contexts, such as in the home and at the workplace. In addition, because care in the popular sector is normally provided by individuals with firsthand experience of specific health problems (Swartz, 1998), healers' credentials are based mainly on their own experiences rather than on, for example, education and social status. Thus, attributes such as trust, empathy and satisfaction among clients may be relatively higher in this sector than in others.

As with the folk and professional sectors of a plural health care system, the popular sector is often characterised by some weaknesses. For example, the popular sector is frequently associated with delays in care-seeking for degenerative physical problems (Helman, 2007) and the use of physical restraints to contain patients (Sorsdahl et al., 2010). In the context of poverty, the family, in providing basic care, increasingly experiences difficulty in meeting the needs of all its members (Muhwezi & Okello et al., 2008). Progressive mental disorders, such as dementia, and the associated burden of long-term care often lead to family stress and aggravated poverty (Browne & Hemsley, 2010; WHO 2001).

2.7.2. The folk sector as a function of a plural health care system. The popular sector is an intermediate sector between the popular and professional sectors of a plural health care system (Helman, 2007). The folk sector comprises mainly healers who specialise in sacred healing, secular healing or a combination of the two (Swartz, 1998). Secular healing, on the one hand, may include treatments by, for example, bone-setters, tooth extractors and herbalists. Sacred healing, on the other, may include rituals performed by spiritual healers. Sacred healing, especially in the Protestant and Pentecostal churches, is usually conducted in the form of group rituals, with “laying of hands” on patients and prayer performed for them. Okello and Neema (2007) similarly report the concept of being “born again” to be central to sacred healing.

Furthermore, Crawford and Lipsedge (2004) report the basic values and worldviews of most folk healers to be closely related to those held by their clients. Folk healers and their clients thus often share beliefs regarding origins, significance and treatments of clients’ health problems. Social attributions, such as sorcery, and supernatural attributions, such as spirit possession, are associated with health problems that require consultation with folk healers (Patel, 1998). To arrive at a diagnosis, folk healers normally conduct an assessment of the client’s conduct both prior to and at the onset of the problem (Helman, 2007). Methods such as observation, interviews and gossip may be used in carrying out assessments (Kleinman, 1980). Similarly, rituals, including divination using tools, such as cards, bones, straws, shells and special stones, may also be used to diagnose and treat clients’ problems (Helman, 2007). Folk healers also often employ diagnostic techniques such as interpretation of dreams and visions and direct consultation with supernatural beings via trance (Helman, 2007).

Folk healing is associated with a number of strengths over other sectors of the plural health care system (Helman, 2007). For example, folk healers are good at actively involving clients and their families in diagnoses and management of health problems (Kleinman, 1980). Kleinman (1980) reports that the focus of folk healing is often simultaneously on clients, their families and other close associates, unlike in biomedicine where treatment is highly individualised. Moreover, there are usually other helpers working alongside the folk healer to augment the quality and quantity of care provided to clients. Such helpers may, for example, answer clients' questions, give further explanations regarding diagnoses and management of illnesses and reassure clients by encouraging them to expect a positive prognosis (Kleinman, 1980). The closely-related world view on the presenting health problems and management between the client and the folk healer enhances client-care provider interaction in the folk sector (Helman, 2007). In addition, the use of everyday language and the informal interactional nature between folk healers and clients enhance empathy, closeness and warmth during consultations (Kleinman, 1980).

Additionally, folk healing is associated with holistic care (Crawford & Lipsedge, 2004). For example, Kleinman (1980) reports folk healers to be usually in practice for the good of clients, families and the community at large as well as the gods. Folk healers thus often influence interactions in the community by modifying patients' social relationships and behaviours (Helman, 2007). Similarly, Kleinman (1980) reports that folk healers manage all the clients' complaints concurrently, rather than focusing on specific aspects of health problems, as is usually the case with professional health workers. Clients' complaints may include physical, social and psychological distress as well as various combinations of these categories. Folk healers tend to manage various complaints of clients simultaneously for pragmatic purposes, as they believe such problems to often have similar underlying causes, such as witchcraft and sorcery (Okello & Musisi, 2006; Okello & Neema, 2007).

Additionally, Feng, Chiam, Kua and Ng (2010) report patients to seek folk healing, at times, in order to complement biomedical treatments being received. While patients often consider professional health workers to be good at managing symptoms of distress, they perceive folk healers as effective in treating the underlying causes (Alem, Jacobsson, Araya, Kebede & Kullgren, 1999). In this regard, Alem et al. (1999) suggest that mental health professionals work closely with traditional healers if they are to gain the acceptance and confidence of service users.

Collaboration between mental health professionals and traditional healers is also likely to help in addressing harmful practices, such as the use of physical restraints on patients seeking care in the folk sector (Alem et al., 1999).

However, folk healing is also associated with some weaknesses. For example, Helman (2007) reports that folk healers may ignore, misdiagnose and ineffectively treat signs of serious physical illness and mental disorders, resulting in serious consequences, such as death of clients. For example, folk healers may mistake health conditions such as psychosis, epilepsy and brain tumours for spirit possession. In their study, Appiah-Poku, Laugharne, Mensah, Osei and Burns (2004) report that service users who consulted traditional healers informed experiencing considerable delays in seeking psychiatric care. Additionally, Sorsdhal et al. (2010) report that traditional healers often physically restrain patients to keep them at shrines for long periods of time in order to ensure the latter's adherence to traditional treatments. Yet, the use of physical restraint by folk healers to contain patients violate the latter's right to care in the least restrictive care environments (Patel, 2007). Worse still, Sorsdhal et al. (2010) report that traditional healers often administer treatments such as exorcisms, strong herbal concoctions, special diets and extreme forms of prayer and/or fasting, all of which can cause considerable physical and psychological trauma and other health complications among service users. According to Helman (2007), some folk healers take advantage of clients' vulnerability, exploiting them financially and sexually.

2.7.3. The professional sector as a function of a plural health care system. The professional sector consists of the formally organised and legally sanctioned healing practice of, mainly, biomedicine (Kleinman, 1980). This sector includes medical professionals of various specialisations and paramedical professionals, such as nurses, midwives and physiotherapists. Like other sectors of the health care system, the professional sector is shaped by unique social and cultural contexts (Swartz, 1998). However, the practice of biomedicine in most LAMICs traces its origins to the industrialised countries of the United States and Europe (Fabrega, 1996). As a result, biomedicine, to a large extent, manifests more cultural nuances of the industrialised West than those of LAMICs, in which it is also practiced (Helman, 2007).

Although some traditional medical systems, such as Ayurveda in India, are fairly professionalised, biomedicine is by far dominant in the professional sector worldwide

(Kleinman, 1980). In many countries, biomedicine is the prototype of the professional health sector. Different biomedical treatment options may be provided, depending on the type and severity of a mental disorder, the skills of care providers and the associated benefits and costs (Roos, Joubert & Stein, 2001). Such treatment options include medication, electroconvulsive therapy (ECT) and psychological interventions. Medical treatment for mental illness, for example, is believed to work by controlling the level of chemical activity in the brain. Psychotropic drugs used in medical treatment include prozac for depression, chlorpramazine and respiridone for schizophrenia and mood stabilisers, such as lithium carbonate, for bipolar disorder. Psychological interventions, in contrast, include cognitive behavioural therapy and counselling, the latter which may include psycho-education and family therapy (Malcom & Barard, 2001). In their study, Kazdin and Blasé (2011) report that psychological interventions are likely to have limited impact in addressing the burden of mental disorders as they mostly take the form of individualised treatment. Kazdin and Blasé (2011) suggest that psychological interventions instead focus on the contextual issues associated with mental illnesses as well as potential challenges for care providers to enhance collaborative care.

The professional sector, like the other sectors of a plural health care system, is associated with a number of other weaknesses. For example, compared with the popular sector, the professional sector serves a relatively smaller proportion of the population (Kleinman, 1980). The minimal utilisation of biomedicine may be due to inefficient and inequitable distribution of medical resources (Saxena et al., 2007). In a few instances, cultural beliefs are incorrectly blamed for under-utilisation of biomedicine (Ndyanabangi et al., 2004). Biomedicine is also associated with prescription of strong, and sometimes dangerous, treatments for patients (Roos et al., 2001). For example, some older generation psychotropic medication causes amenorrhea, preventing women from reproducing in the long-term (Helman, 2007). Antidepressants, if administered in large doses, can cause severe side effects such as seizures, decreased libido and weight gain, which, in turn, hinder adherence to medical treatment (Roos et al., 2001).

Biomedicine is also associated with abuse of psychiatric power via hospitalisation of patients diagnosed as psychotic (Foucault, 2006). Hospitalisation deprives patients of their freedom and right to living in the community. Hospitals are also usually under-resourced to provide effective psychiatric care (Ensink & Robertson, 1999). Moreover, clinicians frequently control patients' diets, behaviour and sleeping patterns and can subject them to a variety of tests, such as biopsies and X-rays (Helman, 2007). Clinicians can also assign labels to patients, labelling the latter as infectious, incurable or fully recovered, for example (Kleinman, 1980). Such labels are sometimes incongruent with the perspectives held by service users and their families, which may have far-reaching effects for the latter two (Corrigan et al., 2005). For example, labelling can confirm patients' sick roles, influence their health insurance and pension payments and lead to stigma and discrimination.

In summary, each of the three sectors of the plural health care system is associated with both strengths and weaknesses. In this regard, Swartz (1998) argues that because distressed people are usually desperate, they tend to be more concerned with recovery than with the source of treatment. Consequently, they often seek and utilise care from diverse care providers in plural health care systems, based on the dynamic explanatory models they hold, the latter which are shaped by their unique social and cultural contexts. Care-seeking, among other coping strategies, manifests agency among people with mental illnesses, as is discussed below.

2.8. Expressions of Agency among People with Mental Illnesses

People with mental illnesses often experience significant life adjustments for which they require strategies for coping with the diagnosis, symptoms and care-seeking challenges (Charmaz, 1991). Such coping strategies reflect patients' subjective experiences, influenced by their social, economic and political circumstances (Akyol, Çetinkaya, Bakan, Yarali & Akkus, 2007). Diverse factors such as perceptions of citizenship rights, stigma and discrimination, availability of social welfare programmes and social inequality particularly influence patients' expressions of agency. Scholars have reported on the varying nature and effectiveness of agency that people with chronic health problems, such as mental illnesses, express (Speed, 2006; Sayre, 2000). Conceptualisation of agency comprises the assessment of and attributions of health conditions (Sayre, 2000), analysis of discourses (Speed, 2006) and analysis of health seeking behaviours among service users (Kartalova-O'Doherty & Doherty, 2010).

2.8.1. Attributions of mental illnesses and expressions of agency. Sayre (2000) reports service users with psychotic illnesses to often adopt attribution strategies that preserve their sense of self-worth against hospitalisation, the latter which they regard as threatening and stigmatising. Service users identify six attributions with regard to hospitalisation, namely: (a) having a problem, (b) having a disease, (c) having a crisis, (d) punishment, (e) ordination, and (f) violation. These attributions fall on a passive-active continuum, in the sense that service users attributing their hospitalisation to a problem are indicated as more passive than those who consider hospitalisation as a violation of their rights (Sayre, 2000). In this regard, Garner (1968) reports hospitalisation to be associated with a "self-fulfilling prophecy", to the extent that the former often encourages patients to present with a sense of hopelessness, apathy, bizarre actions and passive obedience in keeping with the sick role expectations of care providers. Additionally, Sayre (2000) notes passive service users adopt a "psychologising" frame of reference, unlike active service users who perceive hospitalisation as a form of social injustice. Tomm (1989) similarly reports self-labelling and "pathologising" of health problems to often deprive service users of confidence and motivation for self-care.

Lilja and Hellzén (2008) similarly report service users' descriptions of hospitalisation-related experiences to express varying degrees of agency. Lilja and Hellzén (2008) particularly note that some service users associate hospitalisation with being identified: (a) with diseased, (b) as struggling for a sense of control in alienating and frightening care contexts, (c) as submitting to suppressive care, (d) to being dominated by health care providers, and (e) to being optimistic despite the above challenges. In instances where service users believe they are being identified as cases of disease rather than as individual people, they perceive hospitalisation as a form of coercion. Worse still, service users in Lilja and Hellzén's (2008) study describe the ward environment as cold, lonely and dull. Being seen as a case of disease also signifies the dominance of pharmacological treatment, which service users associate with overdose and lack of warm and caring relationships with care providers. Skorpen, Anderssen, Øye and Bjelland (2009) have reported similar findings elsewhere.

In contrast, service users' who experienced a "struggle for a sense of control" (Lilja & Hellzén, 2008) manifest active behaviours, such as rejecting psychiatric care, participating in recreational exercises (for example, playing cards) and being aggressive to fellow service users and care providers. However, social withdrawal behaviours, such as sleeping for extended time periods, manifest passivity among service users. Lilja and Hellzén (2008) sum up hospitalisation experiences of service users as a "struggle" for dignity in an uncomfortable care environment, the latter which is characterised by discrimination and rejection.

2.8.2. Service user discourse and expressions of agency. Speed (2006) categorises the identity of service users into three groups, namely, patients, consumers and survivors, depending on the degree of agency expressed.

2.8.2.1. Service users as patients. Service users who identify themselves as patients frame their views within the biomedical model and thus prioritise pathology over personal strengths (Saleebey, 2002). Patients with psychiatric disorders such as schizophrenia may identify themselves as schizophrenic, the latter label which objectifies them as a kind of "pathology" (Tomm, 1989). Such patients also become highly dependent on psychiatric health workers for expert care. Additionally, patients are often assigned psychiatric diagnoses that are stigmatising, from which they are, however, protected from self-blame for their mental illnesses and easily granted a sick role (Kleinman, 1980).

Ironically, a sick role for patients often necessitates compliance and passive acceptance of expectations of and dependency on care providers (Garner, 1968). Psychiatric health workers also usually disregard principles emphasising patient-centred care (Skorpen, et al., 2009). In particular, Skorpen et al. (2009) report that psychiatric health workers overlook the legal rights of service users to participate in making decisions regarding psychiatric care, even though patient-centred care is premised on user participation. Passivity associated with persistent poor quality of health care may also hinder partnerships between service users and care providers (Swartz & Dick, 2002). Swartz and Dick (2002) indicate service users to often perceive participation in long-term care as likely to aggravate poverty and social alienation as they may, for example, be required to pay for services. Similarly, Rourke (1991) refers to service users' passivity in their own care as "environmental-docility". Such passivity, according to Rourke (1991) may be due to social and intellectual disadvantages accruing from social and cultural inequalities and injustices often experienced by service users. In addition, Skorpen et al. (2009) report psychiatric health workers to be usually reluctant to explore service users' experiences of and perspectives on mental health care. Consequently, service users do not influence the planning and delivery of their own care.

2.8.2.2. Service users as consumers. In a study of mental health service user discourse, Speed (2006) reports service users who identify themselves as consumers to assume more active roles than those who identify themselves as patients. “Consumers” also consider themselves as less objectified by the health care system than do “patients”. The consumer identity has been associated with the growing number of consumer organisations as well as the growing belief in recovery among people with mental illnesses (Kartalova-O’Doherty & Doherty, 2010). Consequently, collaboration and consultation between health workers and service users and families is regarded as best practice (WHO, 2001). In some countries, such as Australia, the role of the consumer has been introduced in academic institutions to influence education and training of mental health professionals (Happell & Roper, 2009). Happell and Roper (2009) argue the success of the consumer role to depend greatly on factors such as genuine partnership, commitment, support and autonomy. However, such conditions are often untenable in most LAMICs, where consumer organisations are highly uncoordinated, weak, poorly financed and taken advantage of by politicians (Lang & Murangira, 2009).

2.8.2.3. Service users as survivors. The survivor discourse of anti-psychiatry stands in opposition to the identity discourses of service users as patients and consumers (Speed, 2006). Survivor discourse thus delegitimises biomedicine and suggests alternative ways of conceptualising mental illness. In this regard, Speed (2006) observes service users adopting a survivor identity to perceive their mental health problems as emotional distress rather than as psychiatric disorders. The latter also believe in the psychosocial causes of mental illness, such as social exclusion, rather than biological causes, for example, chemical imbalances in the brain (Speed, 2006).

2.8.3. Health seeking behaviours and expressions of agency. Nurjannah, FitzGerald and Foster (2009) report that service users’ account for absconding from psychiatric hospitals in ways that manifest the latter’s agency. They categorise the reasons for absconding into three themes, namely: (a) “the call to home”, (b) “hopes and realities”, and (c) “us and them”. The call to home (Nurjannah et al., 2009) signifies service users’ resolve to reunite with their families and to obtain safety from the threatening hospital environment. In particular, service users abscond from hospitals because of delays in being discharged, lack of visits from family members and a need to reunite with families and friends. Orley (1970) similarly reports that families often seclude service users in Butabika mental hospital in Uganda, believing mental illness to lead to permanent head damage and that it is dangerous to live with mental patients in the community.

Furthermore, “hopes and realities” (Nurjannah et al., 2009) suggest service users’ desire for happiness and for living meaningful lives as do other community members. Yet, service users perceive these goals as constrained by family and hospital care contexts. Control by both the family and hospital thus prevents service users from realising social needs, such as intimacy. Closely related to the above, is the theme “us and them” (Nurjannah et al., 2009), which implies service users perceive their own interests to be in conflict with those of their families and psychiatric health workers. In particular, service users believe their opinions about psychiatric diagnoses, recovery and hospitalisation to be overlooked by families and psychiatric health workers. It also signifies the existing power imbalances between service users and care providers (Kelly, 2006).

Furthermore, in their study of service users’ recovery, Kartalova-O’Doherty and Doherty (2010) report that service users were seen to adopt two broad strategies for coping with mental health problems, namely, (a) “giving up”, and (b) “fighting to get better”. “Giving up”, according to the authors, suggests that service users accept the passive identity of being a mental patient with a chronic mental problem. Passivity is associated with perceptions that service users need medication for the rest of their lives and reassurance of ongoing professional support. Passivity also suggests that service users lack intrinsic motivation for improved mental wellbeing. According to Phares (1976), passivity is often due to patients having an external locus of control. In addition, Rourke (1991) attributes passivity among service users to learned helplessness, the latter which results from persistent failure in overcoming obstacles to self-care. In contrast, “fighting to get better” (Kartalova-O’Doherty & Doherty, 2010) manifests aspects of “fighting for” and “fighting against”. “Fighting”, as used in this context, conveys behaviour aimed at managing the symptoms and consequences of mental illness, such as taking medication, talking to peers and health workers and participating in recreational and relaxation exercises. Service users, on the one hand, fight for personal and social reasons, such as love and safety, as well as for children and spouses. On the other hand, they fight against personal and social aspects, such as relapse, feelings of hopelessness, stigma and hospitalisation. Fighting also implies service users to have both internal and external motivations as well as balance between internal and external loci of control (Phares, 1976). According to Kartalova-O’Doherty and Doherty (2010), “fighting to get better” poses both risky and rewarding consequences for service users. The risks include victim-blaming, particularly if other people perceive self-care endeavours among service users as expressions of self-abuse (Rourke, 1991). The rewards, in contrast, include enhanced self-confidence, independence and membership rights, for example, dignity, respect and responsibility (Saleebey, 2002).

In summary, it is clear that scholars employ diverse approaches to explore expressions of agency among people with mental illnesses. Moreover, people with mental illnesses often express both active and passive coping strategies to deal with distress caused by mental illnesses and care-seeking challenges. Such coping strategies are greatly shaped by their subjective experiences in unique social, cultural, economic and political contexts.

In conclusion, this literature review has revealed that people with mental illnesses and care providers, especially in LAMICs, conceptualise mental illnesses in complex ways. Service users and care providers associate mental illness with diverse idioms of distress, attribute mental illness to multiple causal factors and attribute severe consequences to mental illnesses. The literature has also shown care for people with mental illnesses to be greatly constrained by structural barriers, such as stigma and discrimination. In addition, care providers offer various forms of care to service users, which may be both complementary and contradictory in plural health care systems because of the diverse explanatory models held by the various role-players involved in care as well as by patients. Finally, conceptualisation of agency among people with mental illnesses is similarly complex and contextually determined. While many patients employ active coping strategies to manage distress caused by their mental illnesses, others employ passive coping strategies in this regard.

In the next chapter, I discuss the methodology guiding the current study.

Chapter 3

Methodology

3.1. Introduction

In this chapter, I restate my study aim and objectives, describe the research design, study sites and contexts as well as the techniques and procedures adopted for selecting the participants involved in the study. In addition, I describe the methods used for data collection and analysis. Finally, I discuss ethical considerations informing the study.

3.2. Study Aim and Objectives

The aim of this study is to explore the explanatory models that outpatients and their care providers in Uganda employ in responding to mood disorders. The objective of this study is to triangulate the perspectives offered by the participants, that is: (a) outpatients, (b) their families, (c) psychiatric health workers, (d) religious healers, and (e) traditional healers, the persons in the latter four categories, all of whom are involved in the care of the former. In this regard, the specific objectives of this study are:

- to document how outpatients and their care providers conceptualise mood disorders,
- to identify challenges experienced by outpatients in care-seeking,
- to assess the views and attitudes of outpatients and care providers regarding delivery and utilisation of care, and
- to explore expressions or manifestations of self-care agency among outpatients.

3.3. Research Design

In this study, I have adopted a qualitative research design involving multiple cases. The design choice is guided by the belief that data from multiple cases provides for more enriching opportunities and scope for theorising because such a design importantly facilitates cross-case analysis, which is not possible with use of a single case (Yin, 2011). A qualitative research design enables the researcher to investigate a variety of important factors pertaining to the research study, namely, (a) how and/or why questions are being asked, (b) the possible limitations with regard to the control the researcher has over events, and (c) to focus on contemporary phenomena within the real-life context(s) (Yin, 2011). Because I am interested in describing holistically how mood disorders are currently being understood and responded to in Uganda, I enrolled the use of multiple sources of evidence to enable the convergence of the data in a triangulated manner (Henning, van Rensburg & Smit, 2009). A qualitative research design such as this allows for the use of flexible methods, such as in-depth interviews, the latter which are generally more effective in studying people's lived experiences (Hancock & Algozzine, 2006; Holliday, 2010). Additionally, it encourages, at the very outset of the research process, the selection of information-rich cases, facilitates both the learning about mental health care from an "emic perspective[5]" and the making of adjustments in the interview process, such as the use of additional probing questions to elicit more precise information and views, the latter which may arise during the data collection process (Babbie, 2010). Qualitative research methods, such as the in-depth interviews I conducted, enable collection of data that is not otherwise accessible through quantitative research methods, such as structured interviews (Babbie & Mouton, 2002).

3.4. Study Sites and Contexts

The study undertaken was conducted among outpatients[6] and psychiatric health workers from the Psychiatric Unit at the Mbarara Regional Referral Hospital (MRRH), the families[7], and religious healers and traditional healers of the outpatients involved in the study, from the Greater Mbarara region in Western Uganda. The MRRH is located in the Mbarara district in the Greater

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[5] An emic point of view underscores notions and labels derived from the experiences within a culture (Draguns & Tanaka-Matsumi, 2003, p. 757).

[6] I chose to conduct my study among the outpatients rather than inpatients for the following reasons: (a) the latter tend to be in a more dependent relationship with their care providers and are likely to perform less capably in the interview process than the former, and (b) the high possibility of acute episodes of mood disorders among inpatients hindering the conducting of effective interviews with them, a possibility less likely to occur among the outpatients who by their status as outpatients have already been "pre-sorted" into a more mentally stable group not requiring 24-hour supervision by care providers.

[7] Families in the context of this study refer to the individuals that the outpatients interviewed identified as their primary family-based carers. For each outpatient interviewed, only one family-based carer was enrolled into the study.

Mbarara region and is a referral hospital for other districts, including Ibanda, Isingiro, Kiruhura, Kazo, Bushenyi and Ntungamo. Participants were selected from each of the above districts, except Bushenyi and Ntungamo, because the latter two, unlike the other stated districts, are not part of the Greater Mbarara region. The districts in Greater Mbarara, as it is popularly known among the locals, gained their status from Mbarara district around 2005. As a public hospital funded by the Ugandan Ministry of Health, the majority of its service users are expected to receive free general health care. The MRRH also serves as a teaching hospital for medical students attending the Mbarara University of Science and Technology (MUST). It is important to note that the clinical staff members at the MRRH is comprised largely of medical students and medical residents of MUST.

The selection of the MRRH and the Greater Mbarara region for this study was, to a great extent, influenced by the fact that I am particularly fluent in the Rukiga-Runyankole language, commonly spoken in Western Uganda and am familiar with the local culture of the region. Rukiga and Runyankole are indigenous Bantu dialects spoken by the Bakiga and Banyankole groups, respectively. My familiarity with the local culture enhanced effective data collection and analysis (Swartz, 1998). Additionally, I limited my focus to the MRRH and the Greater Mbarara region to ensure the feasibility of the study in terms of access to participants and overall financial costs.

Below is a map of the Republic of Uganda, showing the Greater Mbarara represented in this map by Mbarara and Ibanda.

A map showing the regions and districts of the Republic of Uganda

Source: http://www.nationsonline.org/maps/uganda-administrative-map.

3.5. Selection of Participants

The primary participants involved in the study comprised: (a) outpatients, (b) families, (c) psychiatric health workers, (d) religious healers, and (e) traditional healers, the latter four who are all involved in the care of the outpatients. I adopted purposive and snow-ball sampling techniques in enrolling the participants into this study. These techniques allow the researcher to target "information rich" sources to gain a deeper understanding of the relevant issues (Green & Thorogood, 2004). As well, the use of purposive and snowball sampling is justified because it was possible to identify for study only a subset, that is, some members only and not a large section of the population, in particular, "deviant cases", the latter which refer to study subjects who "do not fit into fairly regular patterns and behaviours" (Babbie, 2010, p. 193). Mental illness, it should be remembered, is a stigmatised health condition and the outpatients in the context of this study may thus be seen as a *unique* population in comparison to patients with non-stigmatised health conditions, for example, malaria. Furthermore, purposive and snowball sampling procedures enable "theoretical sampling" (Babbie, 2010, p 193) and I was thus able to enrol the care providers successively, based on the initial insights, information and consent given by the outpatients. For the purpose of comparing their respective perspectives, I enrolled participants with lived experiences of a psychiatric diagnosis of a mood disorder either as outpatients or as care providers. In particular, all the outpatients I enrolled had been diagnosed by psychiatric health workers as suffering from a mood disorder in accordance with the DSM-IV TR criteria. Because the study is focused on outpatients with a psychiatric diagnosis of a mood disorder and their care providers, I recruited the outpatients and psychiatric health workers from the MRRH and the outpatients' families, religious healers and traditional healers from communities in the Greater Mbarara region. Selection of the MRRH and the Greater Mbarara region as the base for enrolling the participants also adhere to the principles of a qualitative research design, which necessitate contextualisation of results within a specific setting (Babbie & Mouton, 2002).

3.5.1. Enrolment procedures for participants. To maximise variations of the results, I enrolled diverse participants with regard to basic socio-demographic attributes, such as gender, age, occupation and presenting mood disorder (that is, unipolar depression and bipolar disorder). In keeping with the principles of exploratory qualitative study design (Babbie, 2010), I enrolled and interviewed a relatively small number of participants as follows: (a) 7 outpatients, (b) 7 families, (c) 7 psychiatric health workers, (d) 3 religious healers, and (e) 3 traditional healers. For information on the participants and their socio-demographic characteristics, see Appendix A for the outpatients, Appendix B for the families, Appendix C for the psychiatric health workers, Appendix D for the religious healers and Appendix E for the traditional healers. It is important to note the use of pseudonyms as opposed to the real names of participants throughout this thesis, including in the above-mentioned appendices to ensure anonymity of the participants. Furthermore, I enrolled and interviewed the participants until a "saturation point" was reached. A saturation point, in the context of qualitative interviews, refers to the moment in an interview process when no new information emerges from a successive interview (Babbie & Mouton, 2002).

To ensure effective execution of my study, I recruited as a research assistant, a senior medical social worker employed by the MRRH at that time. I trained her in the dynamics of fieldwork, including interview skills, observation skills and ethical obligations. During the course of this study, my research assistant helped me to review and revise the interview guides, recruitment scripts and informed consent forms used, especially those translated into the Runyankole-Rukiga language. She also publicised my study at staff meetings at the psychiatric unit's outpatients' clinic at the MRRH and community outreach venues in the Greater Mbarara region. My research assistant also fielded telephone calls from outpatients expressing interest in the advertised study and provided them with the relevant information in this regard. She also made telephone calls to introduce me to potential participants and to schedule interviews with them. After obtaining informed consent from each outpatient participating in the study, my research assistant verified their respective psychiatric diagnoses of mood disorders from hospital files, obtained confirmation from their respective attending psychiatrists that episodes of a mood disorder were in remission and that the respective outpatients were mentally stable for enrolment into this study. As well, my research assistant made backup notes during all the interview sessions I conducted with participants. Finally, she undertook the verbal transcription of ten of the twenty seven interviews I conducted and translated into English five of the twenty interviews I conducted in the Runyankole-Rukiga language.

3.5.1.1. Enrolment of outpatients. I adopted the following criteria for enrolling the outpatients into this study: (a) a psychiatric diagnosis of either unipolar depression or bipolar disorder, (b) being an outpatient for at least 6 months, (c) willingness to participate in the study, and (d) residency in the Greater Mbarara region. Enrolment of the outpatients into the study involved two major processes, namely, publicity and screening. With the support of the Head of the Psychiatric Unit at the MRRH, I publicised my envisaged study on notice boards at the unit.

Such publicity enabled me to: (a) explain preliminary key issues regarding the study, such as what the study is all about and who would be eligible to participate, and (b) to appeal to eligible and interested outpatients to communicate their willingness to participate in the study. For the study advert, see Appendix F. I provided two options to establish and facilitate effective communication from outpatients interested in participating in the study. Individuals could either call me at any time on my mobile telephone or they could call my research assistant at her office at the MRRH during official hours. With the help of my research assistant, I also publicised the envisaged study at review sessions of outpatients at the Psychiatric Unit at the MRRH and at follow-up community visits.

I also screened all outpatients who expressed interest in participating in the study so as to select eligible and accessible candidates. During this screening phase, I undertook the following: (a) provided more information about the study to the interested outpatients, (b) obtained their informed consent, (c) obtained contact information, such as telephone numbers of those selected and (d) reviewed for further information the medical records of the selected outpatients with mood disorders. The recruitment script, and the information leaflet and informed consent forms used are attached as appendices G and H, including the translated English versions, which follow immediately the original versions in the Runyankole-Rukiga language.

3.5.1.2. Enrolment of families. I adopted the following criteria in enrolling the families of the selected outpatients into this study: (a) willingness to participate in the study, (b) status enjoyed as a trusted confidant of the selected outpatient as indicated by the latter, and (c) close involvement in the care of the selected outpatient for at least 6 months. All the outpatients selected provided me with verbal consent to approach their families to request their participation in the study. I also requested beforehand that each selected outpatient inform his or her family about the study and provide me with feedback on the responses of the latter. Most of the families approached thus arranged to communicate with me by telephone their responses regarding willingness to participate in the study. I also made direct telephone calls to some families to introduce myself and to explain the key issues involved in the study. In this process, I ensured that each individual clearly understood the critical issues, such as: (a) what the study is all about, (b) who would be eligible to participate in the study, and (c) the possible benefits and costs associated with participation in the study. The few families for which the selected outpatients had provided only a physical address and for which initial contact via telephone was not therefore possible, I conducted home visits to meet with and inform them about the study. I also obtained informed consent from all the families enrolled for this study. The recruitment script, the information leaflet and informed consent forms are attached as appendices I and H, including the English versions of the original Runyankole-Rukiga versions.

3.5.1.3. Enrolment of psychiatric health workers. I adopted the following criteria as the basis for inclusion of the psychiatric health workers involved in the study: (a) position as a team member in the Psychiatric Unit at the MRRH, (b) provision of psychiatric services to outpatients for at least 6 months, and (c) willingness to participate in the study. To enrol the psychiatric health workers, I publicised the study on notice boards at the Psychiatric Unit at the MRRH. The study advertisement is attached as Appendix J. In addition, the Head of the Psychiatric Unit at the MRRH undertook to introduce me to members of his staff at their respective offices. I used the opportunity of my orientation week at the MRRH to explain the key issues of the study, such as, what the study is all about, who would be eligible to participate and the study outputs, benefits and costs. I also appealed to the health workers to consider participating in the study. I requested those interested in participating in the study to provide me with their telephone numbers so that I could follow up with them at a later time at their convenience. I screened all the psychiatric health workers expressing such interest in order to ensure effective enrolment. The recruitment script, information leaflet and informed consent form in this regard are attached as appendices K and L.

3.5.1.4. Enrolment of the religious healers. I adopted the following criteria to enrol religious healers into the study: (a) willingness to participate in the study (b) involvement in the care of persons with mental health illnesses for at least 6 months, (c) identification by at least one of the selected outpatients, and (d) residency in the Greater Mbarara region. The selected outpatients suggested the religious healers[8] to be enrolled into this study, providing me with the names and physical addresses of those religious healers who had provided or were currently providing them with care. I obtained the telephone numbers of these healers from their assistants and colleagues at their respective church offices. By means of telephone calls, I introduced

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[8] In the context of this study, I define religious healers as individuals who engage in pastoral care for people with mental health problems and who are also leaders in their respective churches. I enrolled into the study only pastors from Pentecostal Churches as they met my selection criteria.

myself to each one, explained the relevant details about the study, such as: (a) how they had been identified, (b) what the study is all about, (c) who would be eligible to participate in the study, and (d) the possible benefits and costs associated with their participation in the study. I made appointments to meet each of them at their respective church offices to provide them with additional information, to conduct eligibility screening and to obtain consent to conduct future interviews with them. The recruitment script, the information leaflet and informed consent forms in this regard are attached as appendices I and H, including the English versions of the original in the Runyankole-Rukiga language.

3.5.1.5. Enrolment of traditional healers. I enrolled traditional healers into this study based on the following criteria: (a) their involvement in care of people with mental health illnesses for at least 6 months, (b) their willingness to participate in the study, (e) identification of them as a source of care by the selected outpatients and their families, and (d) residency in the Greater Mbarara region. My research assistant had previously participated in the mobilisation of traditional healers in the Greater Mbarara region for training by the Health Education Trust-UK (THET) and, having their telephone numbers and physical addresses, was well placed to make contact with them. At my request, she also introduced me to traditional healers she knew to be involved in caring for people with mental health illnesses and who the selected outpatients had identified as their care providers. In this regard, she made introductory telephone calls to some of them and advised them to expect follow-up telephone calls from me. In contacting them, I explained the key concerns of the study, such as: (a) how they had been identified, (b) what the study is all about, (c) who was eligible to participate in the study, and (d) the possible benefits and costs associated with their participation in the study. I later made appointments to meet each of the selected traditional healers at their respective homes to provide them with additional information about the study, to conduct eligibility screening and to obtain consent to conduct future interviews with them. In this regard, the recruitment script, the information leaflet and informed consent forms used are attached as appendices I and H, including the English versions of the original Runyankole-Rukiga versions.

3.6. Data Collection Methods and Instruments

Below, I describe how I developed the interview guides used for data collection and conducted in-depth personal interviews with participants.

3.6.1. Development of instruments. I developed interview guides for the outpatients, their families, religious healers and traditional healers, first in English, after which my research assistant and I translated them into Runyankole-Rukiga, which is the commonly spoken in the Greater Mbarara region. A lecturer of indigenous languages at Makerere University, bilingual in both English and Runyankole-Rukiga, blind back-translated the interview guides from Runyankole-Rukiga into English to ensure their conceptual consistency and accuracy (Swartz, 1998). I pilot–tested the interview guides at the Butabika mental hospital in Kampala during the month of February 2011, reviewing and revising them for commencement of the fieldwork for this study in March 2011. For the interviews with the outpatients, families, religious healers and traditional healers, I used the Runyankole-Rukiga language versions. The interview guides for the outpatients are attached as Appendix M and for the families, religious healers and traditional healers as Appendix N, including the English versions of both these tools. I used only the English version of the interview guide for the psychiatric health workers as they are fluent in English. This is attached as Appendix O. It is worth noting that in the course of fieldwork, I added and/or dropped some of the content in the interview guides when necessary. Although in most instances I had preset questions in the interview guides, based on the literature I had reviewed before doing the fieldwork, I remained flexible in this regard during the interviews, allowing each interview session to flow naturally as with a conversation (Yin, 2011). I interrupted only to introduce new content into the discussion and/or to probe for more detail.

3.6.2. In-depth interviews with participants. I used individual in-depth interviews as the main method of data collection and triangulated the sources of the data to enhance validity of the results (Henning et al., 2009; Yin, 2011). Triangulation of data sources prevents personal bias being introduced into a study, a difficulty encountered by researchers using the single study approach (Henning et al., 2009).The different sources of data in this study comprised the outpatients and the family members, psychiatric health workers, religious healers and traditional healers involved in their care. In-depth individual interviews enabled me to explore participants' perceptions and the local idioms they used to express mood disorders, attitudes and opinions about delivery and utilisation of care for outpatients, care-seeking challenges experienced by the latter as well as opinions about outpatients' expressions of self-care agency. To enhance validity of the data, I conducted interviews with the selected participants at either their homes or offices in the participants' commonly spoken languages. I agreed on the venue with each participant beforehand in order to ensure the participant's privacy, familiarity, convenience, accessibility and comfort during the interviews (Newman, 2004). I conducted personal interviews because the flexibility entailed in the personal interview method enabled me to explore in detail participants' lived experiences regarding mood disorders and care (Babbie & Mouton, 2002). My prior knowledge of stigma surrounding mental health conditions influenced my choice of the individual interview method, enabling and ensuring privacy of individual participants as well as confidentiality of the information they shared with me.

During the interviews, my research assistant took notes and I made audio-recordings after obtaining approval from each participant, backing up the collected data immediately after each interview session (Newman, 2004). My research assistant and I transcribed verbatim the collected data, ordered the interviews chronologically with dates, time and place clearly recorded for each in computer files. The duration of each interview is as follows: approximately 53 minutes with outpatients, approximately 55 minutes with families, approximately 56 minutes with traditional healers, approximately 75 minutes with religious healers and approximately 100 minutes with psychiatric health workers. I held meetings with my research assistant in the evening to review interviews conducted during the day, to resolve inconsistencies, if any, to share experiences and to develop future action plans together for the remaining fieldwork.

3.7. Data Analysis

I analysed the data for patterns and themes using the thematic analysis method (Braun & Clarke, 2006). According to Braun and Clarke (2006), thematic analysis is a flexible method of analysing qualitative data that can be carried out within both essentialist and constructionist paradigms. As an essentialist or realist method, on the one hand, thematic analysis facilitates understanding of the experiences, meanings and realities of participants. As a constructionist method, on the other, thematic analysis aids understanding of the specific ways by which social and cultural contexts influence the realities, meanings and experiences of participants (Braun & Clarke, 2006). In the context of this study, I conducted thematic analysis within the social constructivism perspective, as presented in Chapter 1 on page 13. I identified latent themes across all the individual data sets, the latter comprising interview transcripts of the outpatients, their families, psychiatric health workers, religious healers and traditional healers. In this regard, I examined the ideas, assumptions and conceptualisations underlying the semantic content of the data while identifying emerging themes.

After familiarising myself with the verbal transcripts of the data by reading several times the verbal transcripts and listening to the audio interviews for overall understanding (Yin, 2011), I coded the data to identify themes using a computer software programme known as Atlasti 6.2, the latter which has been developed to support qualitative analysis of research data (Friese, 2012). The coding process involved open coding, in vivo coding, axial coding and selective coding (Saldana, 2009) based on a codebook attached as Appendix P. Data analysis involved inductive, deductive and iterative processes. Iterative process means that I undertook back and forth engagement with data collection and analysis (Bradley, Curry & Devers 2007). To accurately identify themes, I read through the verbal transcripts for evidence suggesting processes, actions, assumptions and consequences (Straus & Corbin, 2008). I also identified metaphors, repetitions across the interviews and shifts in content that suggested relevant themes (Agar & Hobbs, 1985). I present an analytic narrative with data extracts, that is, quotations from participants' reports for each of the themes I identified and discussed in detail in the results'chapters 4–7 in respect of my research question and the extant literature.

3.8. Ethical Clearance

I sought ethical clearance from the Health Research Ethics Committee of the Faculty of Health Sciences at Stellenbosch University (see Appendix Q) and from the Uganda National Council for Science and Technology (see Appendix R). I also presented the study proposal to the Doctoral Admissions Committee of the Psychology Department in the Faculty of Arts and Social

Sciences at Stellenbosch University as a complementary quality assurance measure (see Appendix S).

3.9. Ethical Considerations

Below, I present the ethical principles I adhered to in order to ensure ethical conduct during the entire research process.

3.9.1. Gaining access and informed consent. I sought approval from the relevant authorities before enrolling individual participants into this study (Baker, 1999; Newman, 2004). These included: (a) the President's Office, Republic of Uganda (see Appendix T), (b) the District Health Officer, Mbarara district, (c) the Executive Director of the MRRH (see Appendix U), and (d) the Head of the Psychiatric Unit at the MRRH. I also sought study approval from the heads of the families of each selected outpatient participating in the study. When I made initial contact with the potential participants by means of personal visits or telephone calls, I provided them with clear information about the study. The information about the study which I shared honestly with them during the screening phase and before each interview include: (a) my identity as a student, (b) the title of the research study, (c) the objectives of the study, (c) the selection criteria for participants, and (d) the expected outputs from the raw data and results. I sought written consent of the potential participants before engaging them in interviews.

3.9.2. Anonymity and confidentiality. I treated all information collected during fieldwork with the utmost confidentiality (Babbie & Mouton, 2001; Baker, 1999). I ensured nondisclosure of information to any person other than my academic supervisor and my research assistant, both of whom worked directly with me on this research project and are equally bound by the ethics of nondisclosure. I removed and, where necessary, altered personal identifying information, such as names to anonymise participants. I have also used pseudonyms in this thesis when directly quoting participants from their interviews. I have further ensured that all data collected is to be securely stored and will destroy this after five years following successful publication of the results (APA, 2010).

3.9.3. Safety and wellbeing of participants. None of the participants experienced physical or psychological injury while participating in this study. In the fieldwork stage, I felt concerned that some participants might experience discomfort sharing information about their private experiences, particularly because mental illness often leads to prejudice against patients and their care providers from friends, relatives, colleagues and members of the community (Newman, 2004). I therefore informed participants that they were under no pressure to respond to all the questions asked. To enhance their sense of security and control over the interview process and to prevent unnecessary costs on their behalf, for example, for transport, I conducted all the interviews at the venues considered personally convenient by each participant. Additionally, I decided beforehand and was prepared to terminate an interview if I thought the safety or wellbeing of a participant was being compromised. In that happenstance, I would have immediately referred the affected participant to a clinical psychologist at the MRRH, having beforehand elicited the support of one such psychologist who had agreed to provide emotional care to participants if required.

In conclusion, I have in this chapter described and justified all the elements of the methodology adopted in carrying out this study. In particular, I adopted a qualitative research design because its flexibility enabled me to explore the complex experiences of people with mood disorders and their care providers. I triangulated the perspectives of various stakeholders, namely, outpatients, their families, psychiatric health workers, religious healers and traditional healers, all selected from the MRRH and the Greater Mbarara region in order to ascertain a holistic understanding of mood disorders, care provision and utilisation in Uganda. Because the subject of my study is highly sensitive, I adhered strictly to the relevant ethical requirements to protect the rights and wellbeing of participants and to ensure the high quality of results.

In the following four chapters, I present and discuss the results that emerged from the data collected, after which I present the conclusion to this study.

Chapter 4

Conceptualisation of Mood Disorders

4.1. Introduction

Three subthemes regarding the conceptualisation of mood disorders emerged from the data. These are: (a) manifestations and lay labelling of mood disorders, (b) perceived causes of mood disorders, and (c) perceived consequences of mood disorders. Below, I consider each of these subthemes in detail.

4.2. Manifestations and Lay Labelling of Mood Disorders

Outpatients and families, religious healers and traditional healers involved in their care reported that they understand both bipolar disorder and unipolar depression, diagnosed by the attending psychiatrists according to DSM criteria, mainly as *iraro* and *ebishazi* (each term referring to madness) and *oburwire bw'omutwe* (illness of the head) in the Runyankole-Rukiga language. Other lay labels, reported less frequently, are *okweyinamirira* (feelings of sadness and self-pity and being inactive) and *okutundama* (feeling downcast, being withdrawn and quiet) for unipolar depression.

4.3. The Notion of *Ebishazi/Iraro* (madness). Outpatients and families, religious healers and traditional healers involved in their care use the lay labels *ebishazi* (madness) and *iraro* (madness) interchangeably to identify both bipolar disorder and unipolar depression. For example, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder explained in this regard: *Ebishazi* (madness) and *iraro* (madness) refer to a similar mental health condition. The word *omushazi* (mad person) is commonly used in Rukiga language and *omugwiraro* (mad person) in Runyankole language". Mulefu, a 50 year old male traditional healer similarly stated: "*Ebishazi* (madness) and *iraro* (madness) mean one thing, which in English is mental disorder. When a person's head does not function well, he is either *omushazi* (mad person) or *omugwiraro* (mad person)". These reports suggest that participants believe it is appropriate for lay people to identify mood disorders as either *ebishazi* or *iraro* (both terms which mean madness) if using the Rukiga or Runyankole languages. Because of the cross-cutting or comparable nature of the Runyankole and Rukiga languages, the terms *ebishazi* and *iraro* (both meaning madness) are, however, commonly used among the different Bakiga-Banyankole groups. By associating madness with deficits in the patient's head, participants distinguished between the body and mind concepts as used in the psychiatric nomenclature.

While holding similar views to that of the families, religious healers and traditional healers involved in their care, that is, that mood disorders can be labelled as *ebishazi and iraro*, (each term meaning madness), outpatients reported that madness manifests in a variety of ways. For example, Nkole, a 48 year old male outpatient with bipolar disorder explained:

> From my experience with mental patients, I have observed that *iraro* (madness) is of a diverse nature. There is *iraro* (madness) that is associated with violence, *iraro* (madness) that is associated with *okutundama* (social withdrawal, being quiet and feeling downcast) and there is *ensimbu* (epilepsy).

This report suggests that Nkole associates mood disorders with diverse symptoms, such as violence and social withdrawal. He also believes that epilepsy is a form of mental illness, although in the psychiatric context, epilepsy is diagnosed as a neurological condition.

The finding that participants in the present study conceptualise both unipolar depression and bipolar disorder as elements of a single disease category, namely, madness is consistent with that of Abbo et al. (2008) who report that members of the Basoga community in Eastern Uganda believe that schizophrenia, bipolar disorder (mania) and psychotic depression are types of generic psychosis. While members of the Basoga community regard schizophrenia as severe and chronic, they regard mania as episodic and less severe than schizophrenia. Members of the Basoga community also regard depression with psychotic features as characterised by "too much thinking" (Abbo et al., 2008). Orley (1970), in a previous study, also reports that members of the Baganda community in Central Uganda distinguish between three types of madness, depending on levels of severity, namely, *eddalu* (severe madness) and *eddalu ly'akazoole* and *eddalu ly'akalogonjjo,* (each regarded as a distinct type of mild madness). According to Orley (1970), members of the Baganda community describe a patient who presents with *eddalu ly'akalogonjjo* (mild madness) as *mutabufu*, which means having a "mixed up" brain or head. Additionally, they identify violence as the core symptom of *eddalu* (severe madness), disorientation, strange speech and abusive behaviour as core symptoms of *eddalu ly'akazoole* (one type of mild madness) and disorientation as the core symptom of *eddalu ly'akalogonjjo* (the other type of mild madness). In view of these symptoms, Orley (1970) suggests that the two types of mild madness approximate chronic schizophrenia.

The finding that participants categorise epilepsy, a neurological condition, alongside mood disorders as aspects of generic psychosis is in keeping with that of previous researchers (Alem et al., 1999; Kleinman, 1995). For example, Alem et al. (1999) in their study of awareness, attitudes and help-seeking in Ethiopia report that participants believe epilepsy to be the most prevalent mental disorder, while depression the least prevalent. Alem et al. (1999) also observe that participants, in contrast, perceive schizophrenia as the most severe of all the mental disorders. Similarly, Orley (1970) reports that members of the Baganda community in Central Uganda conceptualise epilepsy as a mental disorder that affects patients in a way similar to madness and that the two conditions possibly have a similar aetiology. They also believe that mental illness alters the patients' personality in a way similar to the loss of control over actions during an epileptic fit (Orley, 1970). Participants in Orley's study attributed the strange behaviour exhibited by patients with epilepsy and mental illness to spirit possession and believe that spirit possession is mainly caused by witchcraft. Furthermore, because of the misconception that epilepsy and mental illness are contagious, both conditions are highly stigmatised (McQueen & Swartz, 1995). McQueen and Swartz (1995) report that stigma associated with epilepsy causes negative consequences for both patients and their families, the latter which include reduced marriage prospects and associated high costs of arranging marriage for children with epilepsy and an aggravated burden of care. Kleinman (1995) similarly reports that epilepsy leads to moral "delegitimation" of patients and their families. Moral delegitimation, as used in this context, means that members of the public perceive persons suffering from epilepsy and their families as morally bankrupt and capable of bankrupting others. The *loss of face*, accompanying moral delegitimation results in *social death* via the blocking of vital social interactions for patients and their families.

4.3.1. Behavioural manifestations of mood disorders as* iraro *(madness). Participants conceptualised both unipolar depression and bipolar disorder as *ebishazi/iraro* (madness), mainly based on their observation of behavioural disturbances among outpatients. For example, Bwengye, the 46 year old brother of Nkole, the 48 year old male patient with bipolar disorder, stated in this regard:

> We think Nkole is *omugwiraro* (a mad person) because whatever he does portray him as *omugwiraro* (a mad person). If you lock him in a house and he destroys two ventilators and escapes, don't you see that he is *omugwiraro* (a mad person)?

Nabasa, the 40 year old daughter of Murungi, a 60 year old female patient with unipolar depression similarly stated: "My mother suffers from *iraro* (madness) because what she talks sometimes differs from what a person with a stable brain communicates. She spends nights talking to herself". As these reports evidence, participants respectively conceptualise the illnesses based on observing outpatients exhibiting severe symptoms of mood disorders, such as speech impairments, auditory hallucinations and destructive behaviour. These reports also suggest that families physically restrain outpatients who display manic symptoms, thus aggravating manic episodes and stigmatisation of mental illness.

The finding that most participants in the present study identify both bipolar disorder and unipolar depression as types of psychosis, based on their observing outpatients presenting with unusual behaviours, is in keeping with the findings of researchers in the past. For example, Patel (1996) notes that patients with mood disorders often present with acute symptoms because the patients and their primary care providers often attribute symptoms of common mental disorders, such as depression, to social problems, such as poverty, and spiritual problems, such as the failure to observe customary rituals. As a result psychiatric care is initially considered by patients and their families as irrelevant, to be sought only as a last resort. Initial care-seeking instead includes fellowships in church groups, advice from community elders and performing traditional rituals (Okello & Ekblad, 2006) that often lack an evidentiary base. Service users seek psychiatric care only when symptoms of mood disorders become severe (Patel, 1996). Furthermore, Sorsdhal et al. (2010) report that because psychosis is associated with behavioural manifestations, traditional healers regard it as the prototype of mental illness. In contrast, traditional healers believe that patients with non-psychotic mental disorders, such as depression, are experiencing social suffering (Sorsdhal et al., 2010). Similarly, Orley (1970) reports that members of the Baganda community in Central Uganda often associate both severe and mild madness with behavioural disturbances, manifestations of which include stone throwing, abusing people and engaging in public nudity in the case of severe madness and disorientation and strange speech with regard to mild madness.

4.3.2. Use of euphemisms in identifying mood disorders. Participants identified bipolar disorder and unipolar depression as *oburwire bw'omutwe* (illness of the head), a euphemism for madness. For example, Mutungi, a 35 year old male patient with bipolar disorder, informed:

> I have never known the type of my mental illness but I know that I suffer from *oburwire bw' omutwe* (illness of the head). By the way, few people know that I have this health condition because whenever it starts, my wife quickly takes me to the hospital before outsiders notice. But in my opinion, my health condition is not *iraro* (madness).

Mukiga, a 41 year old male patient with unipolar depression, similarly stated: “My health condition is *oburwire bw' omutwe* (illness of the head); it does not have a specific name which I can call it. Even many people don’t know that I seek treatment for a mental illness”. These reports suggest that both Mutungi and Mukiga respectively present with mild episodes of a mood disorder and are stabilised after receiving psychiatric care. These outpatients, however, are seen to deny suffering from a mental illness because they see their respective health conditions as more generic than *iraro* (madness), the latter which they believe typifies mental illness. The reports also suggest that these participants associate *oburwire bw' omutwe* (illness of the head) with stigma due to their respective concerns with being identified by members of the public as having a mental illness.

Additionally, participants reported that *oburwire bw'omutwe* (illness of the head) and *iraro* (madness) can be distinguished on the basis of symptom severity and duration. For example, Sonia, a 41 year old female religious healer, revealed in this regard:

> *Omurwire w' omutwe* (a person with an illness of the head) is one who has experienced life problems and he becomes mentally disturbed without becoming mad. Such a patient may feel tortured, confused and may benefit

> exclusively from counselling. *Omugwiraro* (a mad person), in contrast, is a person with frank madness. Such a patient will have experienced a relatively long period of mental disturbance.

This report suggests that Sonia believes that life challenges are risk factors for psychological distress and the latter does not manifest mental illness. According to her, prolonged exposure to life challenges and psychological distress, however, contributes to or causes mental illness. Sonia perceives *iraro* (madness) as a typical example of mental illness and that, unlike psychological distress, madness cannot be treated by psychological treatments.

The finding that participants identify both bipolar disorder and unipolar depression with euphemisms such as *oburwire bw'omutwe* (illness of the head) has similarly been reported by researchers previously. For example, Orley, (1970) reports that members of the Baganda community in Central Uganda use euphemisms for mild forms of mental illness. Similarly, Kleinman (1980) notes that patients and their families often use euphemisms to cope with the stigma and *anxiety* often caused by a psychiatric diagnosis. Additionally, Rüsch et al. (2005) indicate that refusal to accept psychiatric labels for a mental illness is associated with the issue of empowerment among patients, arguing that patients who perceive stereotypes associated with mental illness as illegitimate tend to become *righteously angry* while those who agree with such stereotypes are likely to experience self-stigma.

4.3.3. Other lay labels for mood disorders. Compared with *ebishazi/iraro* (madness) and *oburwire bw'omutwe* (illness of the head), outpatients and religious and traditional healers involved in their care identified unipolar disorder, less frequently, by the following lay labels: (a) *okweyinamirira* (feelings of sadness and self-pity and being inactive), and (b) *okutundama* (feeling downcast, being withdrawn and quiet). These lay labels for unipolar depression closely match each other in meaning as the following reports illustrate. Kusiima, a 42 year old female patient with unipolar depression described her health condition as *okweyinamirira* (feelings of sadness and self-pity and being inactive) thus: “Whenever the pain (headache) came, I would lose peace and I suffer from *okweyinamirira* (feelings of sadness and self-pity and being inactive) for a long time”. Similarly, Martha, a 37 year old female religious healer, described *okutundama* (feeling downcast, being withdrawn and quiet) in the following terms:

> We have a patient suffering from *okutundama* (feeling downcast, being withdrawn and quiet). She is so withdrawn even though she receives psychiatric care. She may sit, stay there and if she is looking at that window, she might keep her eyes fixed there. She also becomes non-communicative.

It is evident from these reports that participants believe headache and loss of peace to be antecedents to *okweyinamirira* (feelings of sadness and self-pity and being inactive), a mental problem that lasts for a relatively long period of time. They also perceive *okutundama* (feeling downcast, being withdrawn and quiet) as non-responsive to psychiatric care, their inability to benefit from such care thus suggesting their mental health conditions to be misdiagnosed and ineffectively treated.

The finding that participants identified mood disorders with diverse labels such as *iraro* (madness), *oburwire bw'omutwe* (illness of the head) and *okutundama* (feeling downcast, withdrawn and being quiet) has similarly been reported elsewhere. For example, Patel (1998) reports that village health workers, traditional medical practitioners, community psychiatric nurses and families of service users in Zimbabwe possess various concepts for mental illness. For example, psychiatric nurses, on the one hand, conceptualise mental illness mainly in biomedical terms, such as psychosis. On the other hand, lay care providers, such as traditional medical practitioners, conceptualise mental illness mainly in indigenous terms such as *kupenga* (madness). Similarly, Patel (1996) notes that whereas patients and their primary care providers perceive the local idioms for distress as culturally valid, clinicians often prefer psychiatric diagnostic labels, for example, depression, for the same health conditions. Patients and their families, however, perceive psychiatric diagnoses of depression, for example, as both culturally invalid and stigmatising. This mismatch between local idioms for distress and standardised psychiatric diagnoses has been cause for concern among researchers and clinicians interested in cross-cultural psychiatry over the years (Kleinman & Benson, 2006; Summerfield, 2012). For example, Fabrega (1996) points out that historical, social and cultural contexts influence psychiatric diagnoses the world over. The use of standardised international diagnostic systems, such as the DSM, cannot therefore assess with validity local idioms for distress *vis a vis* other cultural contexts because they unduly represent the dominant experience of people in the industrialised West (Summerfield, 2012). As a result, clinicians using standardised psychiatric diagnoses, for example, depression cannot effectively understand and treat the culturally nuanced complaints of their service users, especially in LAMICs. Moreover, the marginal inclusion of some local idioms for distress, for example, *Kufungisisa* (thinking too much, among the Shona of Zimbabwe) and exclusion of similar local idioms for distress, for example, *Mamali* (disturbed mind, in South Sudan), *Amutwe alluhire* (tired head, in Democratic Republic of Congo) (Ventevogel, Jodrdans, Reis and de Jong, 2013) in the DSM-5 (American Psychiatric Association, 2013) points to imbalances in social and political power governing cross-cultural psychiatry (Fabrega, 1996; Littlewood, 1992).

4.3.4. Translations of bipolar disorder and unipolar depression. In the current study, psychiatric health workers reported that they translate psychiatric diagnoses of bipolar disorder and unipolar depression into the Runyankole-Rukiga language to effect better communication with outpatients. They, however, also stated that because of the lack of precise terms for translating the psychiatric diagnoses of bipolar disorder and unipolar depression, they use core symptoms as improvised lay labels for mood disorders. For example, Agaba, a 50 year old male clinical officer, stated in this regard:

> We call bipolar disorder *endwara eyi obumwe noba oshemereirwe munonga kandi obumwe oyine enaku nyingi* (an illness with which the patient at one time is very happy and at another time is very sad). But again, there is no single word which cuts across the board that we can say this is bipolar in Runyankole-Rukiga language.

Milly, a 35 year old female psychiatrist, similarly reported: “At least for depression we can identify it as *endwara y’okutuntuzibwa* (an illness that is associated with feeling worried), *obutashemererwa* (feeling unhappy), *okujumagirirwa* (feeling downcast), *okunakuhara* (sorrowfulness). So we need to use a description rather than one word”.

Njuna, a 40 year old female counsellor, was similarly concerned about the difficulty in translating mood disorders into local idioms of distress, stating that:

> You know trying to explain those chemical imbalances – that is the tricky part of my job. *Nimbagambira ngu omutwe gwawe gurimu* those things (I tell them

> that there are those things in your head). I say that our brains are made up of such and in such a way; *emitwe yeitu ekozirwe eti. Obumwe nihazamu obutabalansinga* (this is how our heads are composed and sometimes there are imbalances).

As these reports indicate, some psychiatric health workers perceive excessive happiness alternating with profound sadness as the core symptoms and thus the improvised local label for bipolar disorder. Other psychiatric health workers perceive feeling unhappy, downcast and sorrow as core symptoms of depression, which then also serves as the improvised local label for unipolar depression. Psychiatric health workers are therefore seen to lack consensus over the core symptoms and local labels for bipolar disorder and unipolar depression. Moreover, some of them attempt to translate English terms, for example, chemical imbalances in the brain, into the Runyankole-Rukiga language. Because they lack knowledge of the local terms to exactly match the English terms, their translations of these mood disorders are unclear to colleagues and outpatients.

Researchers have similarly found in the past that language diversity and translation are some of the leading barriers to cultural competence in cross-cultural psychiatry. For example, Swartz (1998) notes in this regard that appropriate communication is essential for effective assessment, diagnosis, intervention and evaluation in the mental health care of patients. Yet, language diversity often calls for translation in mental health care. Swartz (1998) frames his analysis of problems encountered in translation in relation to two theories of language, namely, the empiricist approach and the constructionist approach to language. The empiricist approach suggests that language refers to objects and/or ideas and is helpful solely in labelling existent reality. Within this framework, different languages imply different sets of labels for phenomena that are prevalent worldwide. Translation therefore involves identification of labels in two languages referring to the same things. The constructionist perspective, in contrast, suggests that language is central to the construction of meaning. The pervasive influence of language in the construction and experience of reality makes the translation of words in the constructionist perspective complicated. Because mental illness is a lived experienced and thus culturally and socially constructed (Kleinman, 1995; Patel, 1998), Swartz (1998) argues with regard to this point that the constructionist approach to translation is more effective in cross-cultural psychiatry. Translation that focuses exclusively on words fails to capture the central influence of language on emotions and generally on the experience of mental illness. Because experiences of mental disorders, such as unipolar depression, are complex, dynamic and emotionally loaded, they are difficult to translate and transmit in what is often considered conceptually equivalent labels in the translation process (Swartz, 1998).

In summary, most outpatients and families, religious and traditional healers involved in their care reported that they understand both bipolar disorder and unipolar depression mainly as *ebishazi/iraro* (madness) and as *oburwire bw'omutwe* (illness of the head). These participants also reported, infrequently, that they understand unipolar depression as *okweyinamirira* (feelings of sadness and self-pity and being inactive) and *okutundama* (feeling downcast, being withdrawn and quiet). In general, outpatients, families, religious healers and traditional healers reported closely matched lay labels for mood disorders. The translations of mood disorders made by psychiatric health workers do not match lay labels of the same health conditions made by outpatients, families, religious healers and traditional healers.

4.4. Perceived causes of mood disorders

Three subthemes regarding the perceived causes of mood disorders among participants emerged from the data. These are: (a) perceived supernatural causes, (b) perceived biomedical causes, and (c) perceived psychosocial causes. The finding that participants believe mood disorders are due to multiple factors including supernatural causes, biomedical causes, and psychosocial causes has similarly been found by researchers in the past (Helman, 2007; Kleinman, 1980; Patel, 1998). For example, Helman (2007) reports that multi-causal attributions of illness usually fall within the supernatural, social, natural and individual domains. Within the supernatural domain for instance, illnesses are caused by supernatural agents such as gods and spirits while in the natural domain illnesses are caused by natural conditions such as weather changes (e.g. excessive heat and coldness (Helman, 2007). Because of the dynamic nature of explanatory models, it is common for patients and their families to hold varying and at times contradictory attributed causes of illnesses (Kleinman, 1980).

Below, I consider each of the above categories of perceived causes of mood disorders in detail.

4.4.1. Perceived supernatural causes of mood disorders. All participants, with the exception of psychiatric health workers, reported that they believe supernatural forces, such as demonic attacks and witchcraft, cause bipolar disorder and unipolar depression. Below, I present the participants' descriptions of each of these perceived supernatural causes of mood disorders in turn.

4.4.1.1. Demonic possession as a perceived supernatural cause of mood disorders. Most participants reported that demonic possession cause mood disorders among outpatients. For example, Murungi, a 60 year old female patient with unipolar disorder, stated in this regard:

> My mental illness was caused by those dead mad persons (demons) who entered my body. I don't know where they came from. There are 2 dead persons in my body, a man and a woman. I am a person and I was created as one person. But now I hear voices of other persons in my body. Where did those other persons come from?

Similarly, Nsheme, a 28 year old female patient with bipolar disorder, informed:

> I think that my biological father, wherever he is complains about me. He complains that he needs his child and my mother fails to unite me with him. I think that he sometimes sends those things (demons) which come and disturb my head.

Additionally, Martha, a 37 year old female religious healer, reported that possession by multiple demons causes mood disorders among outpatients as follows:

> As it is well-known that *concerted efforts lead to success*, when demons are united in attack, they overstay in the person, they affect him so badly and they are reluctant to leave him. One demon may be cowardly and says; "let us leave and the others say, you are becoming stupid". When we are praying for the patients, we hear the demons also deliberating with each other.

These reports indicate that participants believe that alien and ancestral demons cause mood disorders among outpatients. Some outpatients indicated that they are terrified because of the uncertainty over the origins of the alien demons, which they believe possess them. According to participants, demonic attacks alter the biological constitutions of outpatients, thereby enabling the latter to acquire the capacity to host the demons. Some participants stated that family members deliberately sent demonic forces to cause mental illness among outpatients due to family disputes. For example, Nsheme (mentioned above) reported that ancestral demons are the cause of her mental illness because her mother refuses to unite her with her father. Yet, Nsheme could possibly be suffering considerable psychological distress as a result of unmet attachment needs to her father. In addition, the above examples show that outpatients seeking care from religious healers (for example, Martha) experience prolonged episodes of a mood disorder, which they regard as possession by several demons. Participants are also seen to believe that unusual speech patterns associated with severe mental illness manifest demonic attacks among outpatients.

Some participants believe that demonic possession, and subsequently mental illness, signals a positive experience among outpatients. For example, Mulefu, a 50 year male traditional healer, reported in this regard:

> We notice that some people become mentally ill because they are gifted to take up the responsibility of healing other patients.... Out of 10 patients whom we care for in this place, about two mental patients usually get trained to continue with the mission of this place, which is caring for sick people.

Similarly, Nsheme, a 28 year old female patient with bipolar disorder, reported in this regard:

> Supernatural forces needed *orurembo* (shrine) where I would treat young children. However, my mother told them that she was not able to build *orurembo* (shrine) for me because her husband is not my father. That my powers could not fit in the ancestral heritage of my present family. When they failed to build *orurembo* (shrine) for me supernatural powers caused my head to get disturbed.

These reports suggest that Nsheme and Mulefu perceive mental illness as a positive experience for outpatients if it involves a divine call for them to be healers. Mental illness is thus seen to redefine the identity of the outpatient and signifies important and improved social and economic status. However, it is to be noted that for a number of uniquely personal reasons participants could erroneously perceive psychotic symptoms, such as delusions – usually associated with severe mental illness – as signs of a divine calling for outpatients to become healers. It may be seen that Nsheme is particularly concerned that the blended nature of her family prevents her mother from supporting her divine call to become a healer. It is possible that her mother has rationalised a possibly painful and negative attitude towards Nsheme for not being a biological child of her current husband by indicating the present family setting as not allowing Nsheme the space to become a divine healer.

In the next section, I present participants' descriptions of witchcraft as another perceived cause of mood disorders among outpatients.

4.4.1.2. Witchcraft as a perceived supernatural cause of mood disorders. While most participants reported witchcraft as a cause of mood disorders, a few, especially psychiatric health workers, reported witchcraft as simply a *scapegoat* for misfortunes experienced by outpatients. Mukaira, a 64 year old female patient with unipolar depression, offered an example evidencing the perception among outpatients that witchcraft causes mood disorders, stating in this regard:

> I do not know whether I can elaborate the whole story because there are many things. The wife to my brother in-law is not happy with my children's health. She has been targeting me and my daughter (also a patient with mental illness) whom I have told you about, with witchcraft. We thought it was only this woman but nowadays she has teamed up with her son and they have become very serious in witchcraft.

Bernard, a 65 year old male traditional healer, similarly reported that:

> A person may give you medicines for bewitching another one. When you send the medicines, for example, to me and they find that I smeared myself with stronger medicines, the medicines rebound and cause you the sender to run mad.

These reports indicate that participants hold similar but differing perspectives about witchcraft as a cause of mood disorders among outpatients. Mukaira, on the one hand, is seen to perceive witchcraft as a complex phenomenon as it affects her family at large and is carried out by a group of witches that includes members of her extended family. She is also seen to believe that witchcraft can be hereditary, with a parent being capable of teaming up with children in the practice of witchcraft. On the other hand, Bernard is seen to believe that the outpatients are agents of witches who intend to hurt other people by means of witchcraft. He is therefore not likely to empathise with outpatients he believes to be possibly malicious to other people via witchcraft. Bernard is also seen to believe that people who succeed in bewitching others cannot suffer from mental illness.

A few participants showed scepticism that witchcraft causes mood disorders among outpatients. For example, Milly, a 35 year female psychiatrist, observed: “In Africa, at least from my experience, people do not believe you can naturally get a mental problem. People believe that a mental problem comes as a result of witchcraft, a curse, and possession by the evil spirits but in actual sense, these are simply myths”.

Mulefu, a 50 year old male traditional healer, similarly reported: “When a person dies, people will always find something to fault. When a person suffers from madness, other people will suspect that maybe he stole some money and was bewitched as a result”.

These reports suggest that Milly and Mulefu are dismissive of the practice of witchcraft or that witchcraft causes mental illness among outpatients. By dismissing outpatients’ explanations of witchcraft as a perceived cause of their health conditions, care providers, such as Milly, are not likely to empathise with such outpatients. It is likely that outpatients do not easily disclose any relevant information to aid their respective diagnoses and treatments if they believe care providers, like Mulefu, doubt supernatural causes of mood disorders.

Below, I present participants’ descriptions of curses as another perceived cause of mood disorders.

4.4.1.3. Curses as a perceived supernatural cause of mood disorders. Participants reported that some outpatients develop mood disorders because they are cursed by their significant others. For example, Janet, a 62 year old female traditional healer, reported in this regard:

> Mental illness is due to children beating up their fathers. When a parent dies disgruntled and lamenting children suffer from mental illness. If you do not provide sugar and a new shirt to your father, if he says haah (laments), you become mad. This tongue can cause a family to suffer from madness.

John, a 50 year old male religious healer, similarly informed: “It is possible to curse a child even before he is born. When you curse a pregnant woman, the growing child in her womb may also get affected by the curse”. These reports indicate that participants perceive elderly people as vulnerable to violence and neglect by their families, as the former use the threat of curses for self-protection by instilling fear among their children. The use of threats (for example, curses) to meet their basic needs (for example, food) suggests that elderly people experience destitution. In addition, participants believe that children with a congenital psychiatric disability are suffering from curses. Worse still, the belief that children are born with a congenital psychiatric disability because their mothers are cursed is likely to exacerbate family distress, stigma and hinder timely care seeking.

The finding that participants believe supernatural factors cause mood disorders is consistent with findings by researchers in the past, who report supernatural forces as the perceived leading attributed cause of mental illness (Jacobosson, 2002; Patel, 1995). For example, in a review of research on explanatory models of mental illness in 11 sub-Saharan African countries, Patel (1995) reports that mental illness is frequently attributed to supernatural causes such as spirit possession and witchcraft. Patel (1995) argues that the view that *external* causes such as spirits and witchcraft cause both mental and physical illness is common in many African cultures. According to Patel (1995), spirits associated with mental illness include family spirits, community ancestors and evil and alien spirits. Family spirits and community ancestors are believed to be benevolent, although they can also cause illness and misfortune. Benevolent spirits can be upset in various ways, for example, when people break social taboos; evil and alien spirits, on the other hand, are basically malevolent and can cause illness in and other misfortunes to people randomly (Patel, 1995).

Similarly, Okello and Musisi (2006) report that members of the Baganda community in Central Uganda regard supernatural forces as the *ultimate* cause of psychotic depression, the latter which is locally identified as *eByekika* (clan illness). The ultimate cause, in the context of Okello and Musisi's (2006) study, accounts for *why* an illness is contracted. According to these authors, members of the Baganda community believe that behaviour, such as neglect of traditional rituals, lost kin, breaking of taboos and mixing of indigenous religious beliefs with foreign ones, comprise the ultimate causes of psychotic depression. For example, neglect of traditional rituals includes neglect and intermittent performance of worship rituals for ancestral spirits and failure to attend to the family ancestral shrine. Misfortunes such as mental illness are therefore perceived as reminders to family members of their unfulfilled duties regarding ancestral worship. Okello and Musisi (2006) also report that members of the Baganda community believe that lost kin can cause mental illness in two ways. The first instance involves erroneously giving a clan name to a child conceived by a woman outside clan circles. Angry family demons can cause the child to be affected by a mental illness as a means of expressing their displeasure for the lost kin. The second instance involves burial of a clan member in a foreign land. The spirit of a deceased clan member is thought to possess a living relative as a means of compelling the affected family to search for the corpse in order to give it a decent burial in the family's ancestral burial grounds (Okello & Musisi, 2006).

The finding that participants believe mood disorders signify a divine call to become healers and is thus regarded as a positive life experience has been similarly reported by researchers in the past. For example, Swartz (1998) reports that some care providers, such as families and religious healers, often conceptualise severe mental disorders, such as bipolar disorder, as spiritual illnesses and that *ukthwasa* (a divine call to be a traditional healer) in South Africa is believed to run in some families. Similarly, Sorsdhal et al. (2010), in a study involving traditional healers in South Africa, report that participants were seen to believe that *ukuthwasa* (a divine call to be a traditional healer) is not a mental illness but a positive state of health. They are also were seen to believe that it is necessary for the families of individuals called to serve as divine healers to organise initiation ceremonies, such ceremonies being characterised by performing rituals, offering sacrifices, administering traditional medicines and communicating with family ancestors (Sorsdhal et al., 2010). Orley (1970) similarly reports that among members of the Baganda community in Central Uganda, being called to be a traditional healer necessitates the *initiate* constructing a shrine on his or her own homestead, collecting various small articles to be placed in the shrine and wearing small ornaments on his or her body. Subsequently, the initiate is required to organise a ceremony during which traditional doctors are invited to offer various articles and animals to the *balubaale* (spirits). According to Swartz (1998), failure to accept a divine call to be a healer is believed to lead to negative consequences, including *ukuphambana* (insanity).

In summary, participants reported that they believe supernatural forces cause mood disorders among outpatients. Such perceived supernatural causes are thought to include demonic possession, witchcraft, curses and a divine call to be healers.

4.4.2. Perceived biomedical causes of mood disorders. All participants reported that biomedical factors cause mood disorders among outpatients. These causes include genetic predisposition and other health conditions, such as HIV/AIDS, malaria and substance abuse. Below, I consider each of these biomedical attributions of mood disorders in turn.

4.4.2.1. Genetic predisposition as a perceived biomedical cause of mood disorder. Many participants reported that they believe mood disorders to be hereditary. For example, Mukaira, a 64 year old female patient with unipolar disorder, stated in this regard:

> My father used to suffer from a mental illness but whenever he bathed in cold water he would recover. But eventually, by that time I was already married, he got a headache in the evening and he said, "I am exhausted" and he died shortly after. So, I believe that is where my mental illness originated.

Agaba, a 50 year old male clinical officer, similarly reported:

> Depression runs in some families and you have no control over it whether you want it or not. Your aunt, your father or grandfather had depression in the past, so you are prone to having it. You inherit genes as they run in your family. And you cannot pinpoint on chromosomes ABC that they are the source of the mental problem.

These reports suggest that participants believe mood disorders of a genetic origin to be unavoidable because psychiatric health workers are unable to identify the specific chromosomes that cause the disorder. Because persistent life challenges, for example, poverty, can cause psychological distress in some families over generations, it is likely that psychiatric health workers may erroneously attribute mood disorders among some outpatients to genetic predisposition.

Furthermore, religious and traditional healers describe what they believe is a genetic predisposition to a mood disorder as *karondizi* and *eby' akarande* (each term meaning intergenerational vulnerability). For example, John, a 50 year old male religious healer, reported in this regard:

> At times we find mental illness is caused by *karondozi* (intergenerational vulnerability to mental illness). This is when mental illness is passed from one generation to another, from the one mental patient in the past to the present mental patient and possibly to another person in the future in the same family.

Janet, a 55 year old female traditional healer, similarly informed: "[T]he Banyankole know *ebishazi* (madness) as *eby'akarande* (intergenerational vulnerability to mental illness). You find that among the patient's dead relatives there was one who also suffered from mental illness". These reports suggest a perception on the part of the participants that *karondozi* and *eby' akarande* (both terms which refer to intergenerational vulnerability to mental illness) is just one of several causes of mental illness. Because some families experience mental illness across generations, participants are seen to believe that mental illness of a genetic origin is incurable.

Researchers have in the past similarly found that genetic factors elevate the risk of developing mental disorders in some families. A basic premise offered regarding genetic explanation is that relatives of patients show a greater prevalence of mental illness compared to relatives of non-patients (Faraone, Glatt & Tsuang, 2003). Family studies, twin studies and adoption studies are the commonly used methods in genetic epidemiology to assess genetic causes of mental illness. For example, Tsuang and Faraone (1990) report that family studies suggest that relatives of ill individuals are likely to be at higher risk than relatives of well individuals if genes are etiologically important to a particular mental disorder. Such susceptibility of relatives of ill individuals should correlate with the number of genes they have in common with the ill individual. According to Tsuang and Faraone (1990), first-degree relatives share 50% of their genes with the pro band while second-degree relatives share 25% of their genes with the pro band. They further state that parents, children, and siblings of pro bands are more susceptible than second-degree relatives (for example, grandparents, aunts, nephews and nieces) if genes are etiologically important to a particular mental illness. Mondimore (1990) similarly reports that people with a first-degree relative (for example, parents, siblings and children) with major depression are between 1½ and 3 times more at risk to develop a mood disorder than is the general population. Additionally, up to 25% of people with major depression are likely to have a relative with some sort of mood disorder. The risk of developing a mental illness is higher among first-degree relatives of people with bipolar than among the relatives of patients with major depression. In other words, according to Mondimore (1990), up to 50% of those with bipolar disorder also have a first-degree relative with a mood disorder. Such susceptibility risk among relatives of people with major depression is between 10 and 20 times higher than for the general population (Mondimore, 1990). In contrast, Wesner and Winokur (1990) report that twin studies compare concordance rates among pairs of monozygotic and dizygotic twins. They also note that while monozygotic twins possess identical sets of genes, dizygotic twins share only 50% of the genes inherited from parents. In other words, dizygotic twins are similar in genetic endowment to their non-twin siblings. Environmental and cultural influences notwithstanding, twin studies suggest higher concordance rates of affective disorders among monozagotic twins than among dizygotic twins (Tsuang & Faraone, 1990).

However, Goldberg and Huxley (1992) argue that psychiatric research has generally produced weak evidence regarding the role of genetic causation in mental illness. According to them, the most common mental disorders, such as anxiety and depressive illnesses, obsessive-compulsive disorder and agoraphobia, usually run in particular families because of indeterminate cultural and environmental influences. Similarly, Tsuang and Faraone (1990) point out that culture and shared familial environments can confound genetic predisposition to mental illness. For example, mental disorders such as substance abuse may be due to socialisation of children instead of genetic predisposition in particular families. Additionally, pathogens (bacteria and viruses), learned helplessness and emotional deficits may be linked to the cultural and environmental contexts of some families (Tsuang & Faraone, 1990). It is therefore likely that the role of genetic predisposition in mood disturbance may be unduly stated.

4.4.2.2. Other medical conditions as perceived biomedical causes of mood disorders. Many participants reported that health conditions such as HIV/AIDS, malaria and substance abuse cause mood disorders among outpatients. Below, I consider each of these medical conditions as perceived causes of mood disorders.

4.4.2.2.1. HIV/AIDS as perceived causes of mood disorders. Many participants attributed mood disorders to a diagnosis of HIV infection and AIDS. For example, Meya, a 36 year old male occupational therapist, reported in this regard:

> Mental illness is caused by diagnosis of some of these deadly diseases. Health workers may tell you that you have got HIV and then you cannot accept it. For some time, you attempt to adjust and then you get depressed.

Similarly, Mulefu, a 50 year old male traditional healer, informed: “Diseases like this common AIDS epidemic; when a person discovers he is HIV positive, he may experience a lot of thoughts and ends up becoming mad”. As these reports evidence, participants associate the onset of mood disorders with an HIV/AIDS diagnosis among some outpatients, suggesting that the latter suffer from mood disorders as a result of receiving inadequate emotional support when informed about a positive HIV/AIDS diagnosis. However, HIV infection can indeed directly cause organic mood disorders among outpatients.

Some participants reported that having a mood disorder suggests that outpatients are HIV infected. For example, Mugore, the 43 year old mother of Nsheme, a 28 year old female patient with bipolar, informed in this regard:

> I suspected that my daughter’s mental illness was due to AIDS. When I took her for the HIV test I found she was HIV negative. She has now tested seven times without finding the HIV. I ask her that is it not a lie and she replies no, I don’t have HIV/AIDS.

Madamu, a 36 year old wife of Mutungi, a 35 year old male patient with bipolar disorder, similarly stated:

> We were told that if a person suffers from HIV/AIDS he develops a mental illness. Even today some people are saying that his mental problem is due to

> HIV infection. When a mental patient quarrels or says something, people say "you see; the HIV has now matured".

As these reports indicate, the belief that mood disorders are caused by HIV/AIDs leads to outpatients seeking frequent medical examinations, such as HIV testing, to establish the root cause of their respective mental health conditions. According to participants, the belief that HIV/AIDS causes mental illness is highly prevalent in the community and can precipitate stigma among outpatients.

4.4.2.2.2. Malaria as a perceived cause of mood disorders. Some participants attributed mood disorders among outpatients to malaria. For example, Nkole, a 48 year old male patient with bipolar disorder, reported in this regard:

> All these mental illnesses have a genesis in life challenges such as malaria. That is why when a patient is treated for cerebral malaria the violence associated with madness also goes; they all get cured and the person becomes well once and for good.

Janet, a 55 year old female traditional healer, similarly stated: "There is a category of madness that is associated with medical conditions such as malaria. When you treat malaria this kind of mental illness also gets cured". These reports suggest that participants perceive malaria as a common life challenge, one amongst many, experienced by outpatients. Participants are also seen to believe mental illness caused by life challenges such as malaria to be associated with violence and that effective treatment for it (and with any other such life challenges) simultaneously cures the associated mental illness.

Researchers have in the past similarly found that patients and health workers commonly attribute mental health problems to biomedical conditions such as HIV and AIDS. For example, Helman (2007) points out that it is relatively easy for clinicians and researchers to assess health problems using biological markers such as HIV because of improved technological advancements in the dominant biological psychiatry to diagnose mental illnesses. Furthermore, Swartz (1998) observes that perceptions of a "neatly-divided" world are pervasive among some researchers and clinicians. For example, some researchers and clinicians, according to Swartz

(1998), believe they can separate the biological attributions from the psychosocial attributions of mental illnesses. Yet, disentangling the biological and psychosocial factors at the etiological and clinical levels is complicated because of the complex interactions between the two in mental illness causation (Swartz, 1998). For example, Suni (1967) in Swartz (1998) demonstrates that the relationship between transient psychosis and malaria is a complex interplay of both biological and psychosocial factors in illness and disease-causation. For instance, malaria parasites can affect the brain and thus cause organic psychosis and/or a person may contract both malaria and a psychotic condition such as schizophrenia concurrently. Similarly, Weiss (1985) reports that the effects of malaria may constitute biological, psychological and social stressors operating in a cultural context, precipitating and shaping features of psychiatric symptomatology.

Additionally, while writing about the Chinese context, Kleinman (1980) notes that people in the popular (lay) sector usually hold biomedical attributions of health problems that are popularisations of ideas and beliefs prevalent in the folk and professional sectors of the health care system. Kleinman (1980) states in this regard that neurasthenia, for example, is the single most commonly-used label for sanctioning a medical sick role for minor psychiatric and interpersonal problems among the Taiwanese of China. While Western-style doctors in his study often described neurasthenia in psychological terms such as depression when communicating with colleagues, they used this diagnosis to refer to a physical disorder when communicating the illness with patients. In addition, both the Chinese-style and Western-style doctors were seen to often treat somatic rather than psychological problems among such patients (Kleinman, 1980). The undue concern with somatic complaints subsequently socialises patients with psychological problems to present only the somatic complaints as they attract some treatment from care providers. However, as these somatic complaints often have a psychological cause, purely somatic treatments are likely to be ineffective (Swartz, 1998).

Furthermore, Teuton, Bentall and Dowrick (2007) report that indigenous and religious healers in Uganda frequently use biomedical attributions such as HIV/AIDS and malaria in their conceptualisations of mental illness. Teuton et al. (2007) observe that increased use of biomedical attributions is due to improved awareness among communities about diagnoses of biomedical conditions such as AIDS. They argue that because of their high prevalence rates, the government of Uganda has made significant investment in the health education and management of HIV/AIDS and malaria. The belief that malaria and HIV/AIDS cause mental illness may therefore be regarded as an unintended consequence of government intervention, for example, health education, regarding these infectious diseases. Researchers have in the past (for example, Johnson et al., 2009; Muhwezi & Okello et al., 2008) advanced similar explanations about the relationship between mental illnesses and biomedical attributions, for example, HIV/AIDS and malaria. For example, Johnson et al. (2009) in their study of concepts of depression in Uganda report that biomedical attributions such as HIV/AIDS and malaria constitute 28% of all the overall attributions reported by participants.

4.4.2.2.3. The role of substance abuse in mood disturbance. Many participants attributed mood disorders to substance abuse among outpatients. For example, Mutungi, a 35 year old male patient with bipolar disorder, informed in this regard:

> There are people who indulge themselves in drinking alcohol and casual sexual relationships, which drain their finances. Of course, to get alcohol and women in town you have to spend much on buying them. As a result, your family gets dissatisfied with you and they neglect you.

Madamu, a 36 year old wife of Mutungi, above, stated similarly:

> My husband drank too much alcohol and also smoked cigarettes. Some people told me that he even smoked marijuana. I think those are the things which caused his mental health condition. He used to drink any kind of alcohol that he came across and he would also drink too much of it.

Milly, a 35 year old male psychiatrist, similarly informed:

> We observe manic symptoms occurring to people who have used substances ranging from alcohol to cannabis to cocaine to whatever. We believe that alcohol and other substances of abuse cause intoxication in brain tissues leading to symptoms of mental illness.

These reports indicate that participants believe families lose concern for patients who abuse alcohol, which in turn results in such patients becoming psychologically distressed. Moreover, risky behaviour, such as casual sexual relationships, and associated excessive financial costs can cause considerable psychological distress among those who abuse substances. Poly-substance abuse suggests that some outpatients possess a dual diagnosis of a mood disorder with a substance abuse disorder. Furthermore, participants believe that organic mental disorders, such as substance abuse, mimic symptoms of mood disorders such as bipolar disorder.

The finding that people who develop mental illness abuse a variety of substances, such as alcohol, marijuana and cocaine, is in keeping with the findings of previous researchers that substance abuse is a major public health problem in many LAMICs (Desjarlais et al., 1995). Swartz (1998), for example, reports that although alcohol may be the most abused substance, drugs, such as cocaine, heroin, cannabis (dagga) and tobacco, are also abused in many sub-Saharan countries. Kinyanda (2009) similarly points out that alcohol is by far the most abused substance in Uganda. While participants in the present study indicated that substance abuse results in the loss of family support, which in turn aggravates the problem of substance abuse among outpatients, researchers have in the past also found that loss of family support causes substance abuse. For example, Mager (2004) reports that because migrant black mine workers in South Africa experience long periods of separation and subsequent alienation from their families, they often resort to ineffective coping strategies, for example, binge drinking, as an alternate means of mitigating their psychologically distressing situation as well as that of the hard manual labour they perform, with grain (or traditional home brewed) beer often being used as a reward for manual labour. There is additionally a distinctive lack of alternatives for spending leisure time in their living environments, such as going to the cinema and other arts and entertainment venues. Moreover, cheap grain beer is more readily available in the compound bars for the hostel dwellers than the alternate forms of entertainment mentioned (Mager, 2004). Desjarlais et al. (1995) similarly report that under strenuous and exploitative work conditions, people, at times, use or even abuse substances to cope with severe psychological distress.

In the present study, participants informed that outpatients who abuse substances present with symptoms similar to that of mental conditions such as depression. In this regard, researchers have in the past also found that the symptoms of substance abuse and mood disorders overlap considerably. For example, Mondimore (1990) reports that substance abuse causes symptoms such as disturbed sleep patterns, weight loss, feelings of shame and guilt and impairment in work performance, symptoms that are also caused by mood disorders, such as depression. Regehlr and Glancy (2010) similarly argue that because of their overlapping symptoms, it is usually difficult to determine whether a mood disorder, such as depression, or that of substance abuse is the primary disorder for appropriate treatment to be administered to patients.

In the current study, some participants stated that they observe outpatients abusing substances, such as marijuana. For example, Bernard, a 67 year old male traditional healer, informed in this regard:

> When you observe carefully, you notice that a bigger percentage of mental patients take marijuana. Marijuana can actually cause madness to even a person who is mentally stable. There are also people who drink alcohol when their (physical) health cannot tolerate it and it results in madness.

This report suggests that people with mental illnesses use substances as a form of self-medication. Yet, substance abuse aggravates episodes of mood disorders. It also suggests that participants believe that substance abuse causes mental illness in individuals with weak genetic constitutions but not in those with strong physical constitutions.

The finding that participants believe that people with mental illness use or abuse substances has been similarly reported elsewhere. For example, Mondimore (1990) describes the use and abuse of substances, such as alcohol, by people with mental illness as a form of *self-medication*. Regehlr and Glancy (2010) similarly point to the “tension-reduction hypothesis” to account for substance abuse among people with mental illness, that is, that people use substances in order to obtain relief from the distressing symptoms of mental illnesses.

While participants in this study believe physical weakness to be associated with symptoms of substance abuse among outpatients, researchers have in the past instead found that biomedical factors, such as malnutrition, cause physical weakness among persons using substances. For example, Mager (2004) reports that alcohol often undermines physical health among migrant black mine workers in South Africa because it often contains iron poisoning (from the iron pots used in beer brewing) and also leads to malnutrition among its users. The physical effects of iron poisoning include cirrhosis of the liver, damage to the pancreas and bone thinning. Malnutrition results from the substitution of maize grits, which has less vitamin and nutritious contents, with sorghum, as maize is cheaper and easier to brew.

In summary, participants in this study reported that health conditions such as HIV/AIDS, malaria and substance abuse cause mental illness among outpatients. According to them, a positive HIV diagnosis causes considerable distress, with mental illness signalling HIV infection among outpatients. They were also seen to believe that malaria is a common life challenge that also causes mental illness. Lastly, participants were seen to believe that substance abuse leads to loss of family support, which in turn aggravates distress among affected individuals and that substance abuse can cause mental illness to persons already physically weak.

4.4.3. Perceived psychosocial causes of mood disorders. All participants reported that psychosocial factors, namely, family conflicts and work-related problems, cause mood disorders among outpatients. Below, I consider each of these subthemes.

4.4.3.1. Family conflicts as perceived psychosocial causes of mood disorders. Many participants stated that family conflicts cause mood disorders. For example, Nsheme, a 28 year old female patient with bipolar, stated in this regard:

> My former husband with whom I produced a child was from Eastern Uganda. When I rejected him for marriage, he kidnapped my child. That is the time when I started thinking poorly. He opted to kidnap my child so that in case I felt concerned about the child, I would go and marry him.

Evidently, Nsheme believes separation from her child to be the cause of her mood disorder. Her casual sexual relationship could have been due to increased libido, often a symptom of bipolar disorder. The causal sexual relationship also suggests that Nsheme is vulnerable to contracting sexually transmitted infections, such as HIV. Separation from the mother places her child at a risk of suffering intergenerational vulnerability to mental illness if inadequate parental care is experienced.

Researchers have in the past similarly found that life events involving significant loss, for instance, of loved ones, to be associated with mental illnesses (Brown & Harris, 1978; Smith, 2011). For example, Brown and Harris (1978) report that any significant loss involving, for example, children, relationships with partners and family members and valued assets, causes depression among working women. In particular, the loss of significant social relationships that may follow separation of mothers from children may precipitate negative beliefs and feelings such as a sense of incompetence and resentment (Smith, 2011). Psychiatric symptoms, such as feelings of hopelessness, loss of motivation and self-criticism, associated with mood disorders such as depression may manifest distortions in patients' perceptions caused by life events involving significant loss (Smith, 2011). Furthermore, (Goldberg & Huxley, 1992) observes that inadequate parenting is a risk factor for intergenerational susceptibility to mental illness in some families. Child neglect that may follow separation of children from parents, especially mothers, is associated with mental illness in adulthood through structural vulnerability (for example, unemployment) and emotional vulnerability (for example, low self-esteem). According to Goldberg and Huxley (1992), child neglect is often associated with a sense of hopelessness experienced by affected children, the latter who tend to generalise unpleasant childhood experiences with later life experiences. In addition, because childhood neglect is associated with low self-confidence, survivors are less likely to establish supportive social relationships in adulthood.

In contrast, Mariya, a 34 year old female social worker, attributes mood disorders to marital discord, which causes divorce and separation among outpatients. She stated in this regard:

> Infidelity in marriage has now increased because there are challenges of urbanisation such as poverty. People sell sexual services for money and there are cases of couples citing instances of seductive short messages (SMs) on mobile phones), which trigger fights and consequently divorce among couples.

This statement suggests that Mariya believes urbanisation to be a risk factor for mental illness because it precipitates marital infidelity, especially among poor women. It also suggests that poor women engage in commercial sex work because they lack alternative employment to support personal and family welfare. Moreover, marital infidelity is associated with family conflict, which in turn leads to separation and divorce among affected couples.

The finding that divorce and separation causes mood disorders among outpatients has similarly been reported by researchers in the past (Bloom, Asher & White, 1978; Smith, 2011). For example, Bloom et al. (1978) describe divorce as a complex experience that involves several dimensions, such as emotional divorce, (for example, loss of a love object), economic divorce, (for example, sharing family property), co-parental divorce, (for example, handling child custody concerns) and community divorce, (for example, dealing with the attitudes of and relationships with friends and relatives). Such dimensions of marital destabilisation and disintegration usually necessitate significant adjustments by all the affected individuals (Bloom et al., 1978). In addition, Bloom et al. (1978) report that child care and household responsibilities can, for example, make it difficult for women to work full-time following divorce or separation. Furthermore, separation and divorce can result in other serious consequences, such as sexual problems (loss of intimacy), feelings of failure, unattractiveness and shame, and loss of identity as either a mother or a father (Bloom et al., 1978). Such difficulties affect unduly individuals who are older at the time of divorce, who have been married for a longer period of time, who suffer from low self-esteem and consequently have high levels of anxiety, who have experienced divorce at the suggestion of their spouses, who have families that were opposed to their marriage to begin with, and who have inadequate economic status (Bloom et al., 1978).

Furthermore, some participants attribute mood disorders to discrimination and mistreatment of outpatients by families. For example, Nsheme, a 28 year old female patient with bipolar disorder, stated in this regard:

> My step father used to call me *ekinyandaro* (bastard). Whenever he would be drunk, he would tell my mother that; "take away your *ekinyandaro* (bastard). I picked it in a plastic bag so take it to its father". I would also complain to my mother. You see I lack my father; I am insulted and mistreated as a result.

Similarly, John, a 50 year old male religious healer, informed: "Some people in the villages are discriminated against and rejected, which leads them to become mad. You will find a child growing up in a family, for instance, being called a bastard. This treatment leads him to develop a low self-opinion". These reports suggest that participants perceive the blended family as a risk factor for mental illness because children may be emotionally abused by step parents. Emotional abuse can, at times, be directed at the mothers of children born from previous marriages or relationships. Participants were also seen to associate emotional abuse with low self-confidence, which they believe manifests as mental illness.

Researchers have in the past similarly found emotional abuse in the family to be a risk factor for mental illness in adulthood. For example, Goldberg and Huxley (1992) report that inadequate parental care, characterised by adverse conditions, such as emotional abuse and inability to meet a child's attachment needs, can predispose the child to depression in adulthood. According to Goldberg and Huxley (1992), adverse childhood experiences are associated with increased risk of psychological distress. In addition, adverse childhood experiences, such as emotional and physical abuse, are likely to compel women to marry for negative reasons, such as the desire to escape misery in their families. Such women are also likely to marry men from similarly deprived family backgrounds and therefore also likely to experience multiple problems, such as poor housing and unemployment. Goldberg and Huxley (1992) also report that people with adverse childhood experiences are likely to develop cognitive orientations with an inclination to appraise many external stimuli, such as work, as frustrating. Because they tend to exhibit external locus of control, they are less likely to adopt proactive measures to deal with stressful events. Such passivity may be attributed to the learned helplessness associated with a persistent failure to overcome psychological distress caused by adverse childhood experiences (Bandura, 1989).

Additionally, some participants attribute mood disorders to property-related wrangles in the families. For example, Agaba, a 50 year old male clinical officer, reported in this regard:

> These days, the bigger the family, the more are the stresses that are experienced because one has to cater for many dependants. Yet there are no means to help you to do it … The husband will be accusing his wife for collaborating with their children in order to kill him so as to take control of his property.

This report suggests that Agaba perceives parenting in large families as highly distressing in the context of poverty. Enmeshed family relationships, where parents become more closely attached to their children than to their spouses, suggest loss of intimacy and emotional support among couples. Agaba is also seen to believe that enmeshed family relationships are often associated with family conflicts. Additionally, he is seen to associate mental illness with patriarchal organisation, in which men primarily own family property and are thus at risk of suffering from mental illness if they lose such privileged family position or status.

Muhwezi et al. (2007) similarly report the extended family system to be associated with considerable psychological distress, particularly for the head of the household. They further report that the high costs associated with health care, education and housing needs of the family cause considerable psychological distress, again, particularly for the head of the household. The latter's inability to provide for the basic needs of dependents, such as education, nutrition and health care, is associated with feelings of inadequacy, anxiety, helplessness, shame and betrayal (Muhwezi et al., 2007).

4.4.3.2. Work-related problems as perceived psychosocial causes of mood disorders. Many participants reported that work-related problems, such as work overload and loss of employment, cause mood disorders among outpatients. For example, Murungi, a 60 year old female patient with unipolar depression, stated in this regard:

> My health problem was caused by the excessive work which I was doing. I was doing a lot of demanding work including crop farming and looking after cows. I over-worked because as a widow, I was solely responsible for all my family and personal needs.

This report suggests that, in the context of poverty, widowhood challenges traditional concepts of work, with outpatients having to perform both masculine and feminine work, both which are physically and psychologically strenuous. It also suggests the lack of welfare-oriented community support to assist Murungi with meeting the basic needs of her family.

Milly, a 35 year old female psychiatrist, similarly stated: “For some people, such as the teachers, mental illness may be due to work overload, which causes them to break down with depression”. Her report suggests the lack of effective legislation to regulate formal employment and to prevent psychological distress among formal employees. It also suggests a lack of stress management programmes at the workplace to prevent burnout among formal employees, such as teachers, for instance.

The finding that participants attribute mood disorders to work overload is in keeping with finding by researchers in the past that certain work characteristics are associated with increased psychological distress among workers. For example, Kandel, Davis and Raveis (1985) report that performance of multiple roles clustered around marital, occupational and housework domains are associated with increased psychological distress. The strain experienced in a particular role set, for example, marital roles, can aggravate strain experienced in other role domains, for example, in occupational roles (Kandel et al., 1985). Psychological distress is thus a consequence of the additive strains associated with the multiple roles that individuals perform (Brown & Harris, 1978). Similarly, Stanfeld, Fuhrer and Marmot (1999) report that poor social support at work, low status with regard to decision-making and authority, high job demands and effort-reward imbalance in the workplace are associated with increased risk of psychiatric disorders, such as depression.

In contrast to the above view, Gadi, a 34 year old male nurse, attributes mood disorders among outpatients to the loss of employment. He stated in this regard: “When you lose your job that has been a source of income and you have to take care of your family needs it hits you hard and you get depressed. Loss of employment is common among our patients”. This report suggests that participants believe the loss of employment to significantly affect people’s lives and to cause considerable psychological distress to affected individuals. It also suggests that, in the context of poverty, outpatients lack savings and alternative means to safeguard against unemployment with regard to meeting the most basic needs, such as food.

The attribution of mental illness to hardships associated with loss of employment is in keeping with the findings of researchers in the past, who have also found mental illness to be associated with work-related problems. For example, Liem and Liem (1978) describe unemployment as a protracted process involving numerous incidents, such as anticipation of job loss, actual job loss and failure to find new work or re-employment. Unemployment, according to Liem and Liem (1978), is associated with aggravated poverty, financial insecurity and the inability to meet personal and family needs. Such consequences in turn cause negative psychological states, characterised by feelings of low self-esteem, estrangement from family and friends, deterioration in interpersonal relationships and self-blame (Liem & Liem, 1978). Muhwezi et al. (2007) similarly note that unemployment causes psychological distress among affected individuals, especially in terms of the high cost of living in Uganda. They also report that psychological distress associated with unemployment mainly affects people in extended family settings in urban areas. In contrast, Myers, Lindenthal and Pepper (1974) observe employment and job security to be associated with better mental health outcomes. For example, they note that employment enhances an individual’s self-confidence, positive self-concept, self-identity and sense of security. Employment is also associated with the availability of resources, for example, money, essential for coping with life events, including episodes of illness in the family (Myers et al., 1974).

A few participants reported that unemployment, and subsequent psychological distress, among outpatients stems from a poor attitude towards work. For example, Bernard, a 67 year old male traditional healer, stated in this regard:

> Employment is available but some unemployed people are simply stupid. If, for instance, I give you a job to weed in my banana garden and after three steps you say the job is done and you go home, whose fault is it? If you are employed as a clerical officer and you sell the papers, you come to work when intoxicated and you embezzle the organization’s money, you will be fired and you won’t find another job.

This report suggests that Bernard believes that some outpatients suffer unemployment and subsequently mental illness because they engage in vices at the workplace, such as embezzlement and misappropriation of resources. Stressful work conditions, for example, exploitation of workers, can, however, lead to negative behaviour at the workplace, such as embezzlement of resources. The belief that unemployed people are responsible for their loss of employment and mental illness may be seen as blaming the victims of negative circumstances, such as poor wages, for example.

Blaming employees for work-related problems and associated psychological distress is also reported elsewhere. For example, Cartwright (1851) in Fernando, Trivedi, and Ferns (2013) observes that in the time of slavery in the southern states of the United States, black slaves, working under exploitative work conditions, often exhibited negative behaviour, for example, the irresistible tendency to run away from the plantations on which they worked; this behaviour was during that era given the psychiatric diagnostic label of *drapetomania*. Narayan et al. (2000) similarly report mental health problems, such as depression, to be common in situations of exploitative work conditions characterised by poor pay, low emotional support, low job satisfaction and lack of opportunities for carrier advancement.

In summary, participants reported that they believe psychosocial factors, such as family conflicts and work-related problems, cause mood disorders among outpatients. A few reported that poor work etiquette, such as laziness, causes work-related problems and subsequently mood disorders among outpatients.

4.5. Perceived consequences of mood disorders

Three subcategories of the perceived consequences of mood disorders among outpatients emerged from the data. These are: (a) stigma and discrimination, (b) aggravated poverty, and (c) somatic complaints. In the sections that follow, I consider each of them.

4.5.1. Stigma and discrimination as perceived consequences of mood disorders. All participants reported that members of the public stigmatise and discriminate against outpatients. Stigmatisation and discrimination, according to the participants, manifest as the following: (a) exclusionary behaviours, (b) stereotyping behaviours, and (c) endorsement behaviours, as described below.

4.5.1.1 Social exclusion of outpatients as a function of stigma and discrimination. All participants reported that members of the public socially exclude outpatients from participating in public life because of the latter's mental illness. For example, Nsheme, a 28 year old female patient with bipolar disorder, stated in this regard: "When I was sick, all my friends abandoned me. They were asking themselves 'of what use is befriending this *Mugwiraro* (mad person)?' They were ashamed of me".

Mulefu, a 50 year old male traditional healer, similarly informed:

> People on earth like to associate with those who are well-off. When you become mad, the relationships end there, people start avoiding you. People like other people who have something to offer, for instance, whom they can converse with and they get constructive advice.

These reports suggest participants believe associates of outpatients to be unreliable as they abandon them at critical times of need. They are also seen to believe that social relationships can only flourish if associates perceive outpatients as being of some benefit to the former.

Additionally, participants are seen to believe people engage in social relationships basically for selfish reasons. Thus, members of the public detest social relationships with outpatients, believing the latter is incapable of offering benefits, such as advice.

Furthermore, participants reported that family stigma exacerbates social exclusion among outpatients. For example, Madamu, the 36 year old wife of Mutungi, a 35 year old male patient with bipolar disorder, informed in this regard: “Most people do not know that he suffers from mental illness. One reason as to why I took him to the village was to ensure that people in Mbarara town did not know he was suffering from mental illness”. This report suggests that this outpatient lost social support from his associates in Mbarara town because his wife relocated him to the village to prevent members of the public learning about his mental illness. Relocation also suggests that the family incurred increased expenses, for example, transport costs. Such costs, in fact, are seen to have constrained this outpatient from seeking psychiatric care, which was available in Mbarara town.

Participants also reported that mood disorders leads to disinheritance among outpatients. For example, John, a 50 year old male religious healer, informed in this regard:

> A mad person may be considered as dead. Some people will wish to see him die so that they can inherit whatever belongs to him. If a person can cheat a normal person’s property, including their relatives, how about cheating a mad person?

This report suggests that John believes that members of the public are less concerned with outpatients’ recovery than with material gain from them. The former can cut off support to create conditions of neglect to accelerate the death of outpatients to realise material benefits. Wealthy outpatients are therefore at risk of being neglected by families and community members to cause the death and disinheritance of the latter.

Additionally, participants reported that families and communities exclude outpatients from decision-making in personal matters such as care-seeking. For example, Agaba, a 50 year old male clinical officer, informed in this regard: “Because of mental illness, partners are overlooked in decision-making. Their spouses think that the mental patients can no longer make good decisions regarding family matters. They are overlooked by the family and the community members".

Frida, the 30 year old daughter-in-law of Mukaira, a 64 year old female patient with depression, similarly stated:

> In fact it's a big problem because when she is in a meeting and in church deliberating, other people overlook her suggestions on the grounds that she is a mad person. Even if what she is saying is right, usually it is rejected on the ground that she is mad and that she does not know what she says.

As these reports indicate, members of families and the public overlook the abilities and contributions of outpatients regarding decision-making in personal, family and community matters. The undemocratic decision-making processes in the family and community contexts imply that the interests of outpatients are either ignored or misrepresented.

Researchers have in the past similarly found the social exclusion of people with mental illness to be prevalent in LAMICs. For example, Orley (1970) reports that members of the Baganda community in Central Uganda frequently seclude relatives suspected of suffering from mental illnesses at the Butabika mental hospital. He additionally reports that families show extreme reluctance at receiving them back home, even when clinicians at the hospital succeed in managing the patients' symptoms reasonably well. According to Orley (1970), seclusion of such patients is, however, an improvement in care as many Baganda have been reported to keep relatives with mental illnesses in stocks until the latter are cured naturally or die from neglect. Orley (1970) further notes that because members of the Baganda community seclude relatives with mental illness in isolated makeshift houses, such patients suffer from social contact, stimulation and socialisation, as well as being exclusively fed a poor diet and given severe punishment (even being killed) if they leave their dwellings. Similarly, Moroka (1998) reports that people with mental illnesses in Botswana are often relocated to slums, cattle posts and shrines of traditional healers. Contrary to what one would expect, deplorable housing conditions for patients, characterised by temporary shelters and homelessness, attributed to the stigma of mental illness have similarly been found in HICs such as the United States (Desjarlais, 2010).

Social exclusion experienced by outpatients, as described above, is viewed among the poor as akin to "ill-being" (Narayan et al., 2000, p. 31), the latter term which Chambers (1997) defines as the experience of a bad quality of life. Narayan et al. (2000) similarly describe ill-being as the experience and feeling of being isolated, excluded, looked down upon, alienated, pushed aside and ignored by mainstream socio-cultural and political processes. Ill-being is thus seen to be linked to structural barriers to social and economic inclusion and participation, including lack of access to productive resources, information, opportunities and power (Narayan et al., 2000). Furthermore, Narayan et al. (2000) observe that poverty is often associated with behaviour such as begging, stealing and eating from trash bins, which privileged members of the community regard as antisocial and criminal behaviour. As a result, the latter look down on or view with suspicion poor people, including those with mental illnesses, who engage in such behaviour. Poverty is also associated with other clusters of disadvantage, for example, powerlessness, inaccessibility and ill-health, which aggravates the experience of alienation among the poor (Chambers, 1997).

4.5.1.2. Stereotyping outpatients as a function of stigma and discrimination. Outpatients, their families and religious healers involved in their care reported that members of families and the public stereotype outpatients due to the mental health condition of the latter. For example, Mugore, the 45 year old mother of Nsheme, a 28 year old female patient with bipolar disorder, informed in this regard:

> She has her young sisters who are fond of teasing her. You hear them saying eeh, eeh, (mocking laughter) her things (madness) have come back mummy; they (madness) are back. They say mummy that eeh, eeh, she has again become *Omugwiraro* (a mad person) now that she is conducting herself like that. Then she stays there, accusing her siblings of disturbance and things like that.

Nsheme herself similarly stated in this regard: "When I became mentally ill my young siblings started addressing me as *omugwiraro* (a mad person). Calling me by this tag makes me angry for a long time". These reports indicate that families can and do identify the tell-tale signs associated with relapse among outpatients. However, instead of communicating their concerns, some family members ridicule the presenting symptoms of mood disorders. They also blame outpatients for reacting angrily to such mistreatment. Labelling outpatients with a derogatory term, for example, *omugwiraro* (mad person), such family members show undue concern with outpatient's psychiatric disability rather than with their strengths. The distress caused by such stereotyping behaviour can aggravate episodes of mood disorders, such as those experienced by Nsheme.

Researchers have in the past similarly found mental illness to be associated with various stereotypes and misconceptions (Corrigan et al., 2005; Rüsch et al., 2005). For example, Watson and Eack (2011) report that because it is associated with various negative stereotypes, mental illness is one of the most discrediting of labels that can be attached to a person. Mental illness is elsewhere also referred to as the "ultimate stigma" (Saxena et al., 2007). Additionally, Watson and Eack (2011) report that members of the public often believe people with mental illnesses to be dangerous, unpredictable, incompetent, irresponsible, at fault for their illness and unlikely to recover. Sartorius (2007) similarly reports that hostile societal reactions, such as shackling persons suffering from mental illnesses, are due to misconceptions about the nature, causes, consequences and management of mental illness. Such misconceptions include the belief that people with mental illnesses are dangerous (Sorsdahl & Stein, 2010), are possessed by malevolent spirits (Ssebunnya et al., 2009), and that mental illness is infectiousness, leading to violence, incompetence and character weakness (Corrigan et al., 2005). Furthermore, Watson and Eack (2011) report that because mental illness is associated with the patient having a *child-like* mind, care providers often get over involved in caring for mental patients. The belief that as a result of being child like, a patient is incapable of self-care results in benevolence stigma, which in turn perpetuates the perception that mental patients differ significantly from those not suffering from mental illness, are incompetent, are unable to recover and thus are unable to participate in social life.

In addition, participants associated stigma with the use of mechanical metaphors (for example, *wires* in their heads) to refer to outpatients. For example, Madamu, the 36 year old wife of Mutungi, a 35 year old male patient with bipolar disorder, informed in this regard: "There are times when he (outpatient) comes home after his *wires* have gone off. I am now aware of his mental status; he usually comes when he is irritable".

Martha, a 37 year old female religious healer, similarly informed:

> When you know this person is always introverted and then you notice that the same person is becoming talkative and doing this and that; is actually out of his usual moods; that is how you come to know that there is a *wire* in his head, which has loosened.

As these reports indicate, participants view outpatients in mechanical terms, regarding the latter as having poor physical constitutions akin to a low quality or malfunctioning machine, such as a radio, loose wires associated in this regard with poor functioning. Osherson and AmaraSingham (1981) explain mechanical metaphors in terms of unique events, such as increased technological sophistication, which flourished in the West at the time of the Enlightenment (1700s) as well as the Flexner report of 1910, the latter which greatly shaped the institutionalisation of medicine as a profession. Osherson and AmaraSingham (1981) argue that because clinicians are able to identify objective markers of disease, for example, neuron transmitters in the brain, as a result of technological advancements, mental illness is conceptualised as a specific and localised entity. The concern with objective markers, dominant in biological psychiatry, also marks a shift in the doctor-patient relationship, that is, from doctors being dependent on the patient for information to using machines to find the objective signs of illness (Helman, 2007). The unintended consequences of such technological advancements in medicine include stigmatisation of the patient's body, perceived in this framework as a mere machine. However, such narrow conceptualisation of mental illness also suggests that patients, rather than their social contexts, are often blamed for the psychological distress they experience.

4.5.1.3. Endorsement of stereotypes as a function of stigma and discrimination. Outpatients, families and traditional healers involved in their care reported that outpatients often enact the stereotypes of the mental illness they are experiencing. For example, Nkole, a 48 year old male patient with bipolar disorder, informed in this regard:

> My own family believes that because of my health condition, I cannot do anything developmental and indeed, you have heard the years I have spent renting my business premises. When I work (workshop business) and get to somewhere everything collapses because of relapse and I have to start all over again.

Mugurusi, the 60 year old father of Bwerere, a 20 year male old patient with bipolar disorder, similarly informed: “He (the outpatient) believes that he is not like other people because he did not go to school, does not have his own house and generally he is different from his age mates, which makes him feel unhappy”.

Mulefu, a 50 year old female traditional healer, similarly stated:

> Mental patients are usually not aware of the wrong things such as raping women that they do. When the patient is informed that “you did wrong when you were mentally ill”, he develops self-hatred. The patient will ask you; “how did I do that?”

Apparently, participants believe outpatients to be generally unsuccessful in their lives because they do not realise basic milestones, such as running a business or having a house. In addition, emotional reactions of family members and other care providers worsen self-stigma among outpatients. For example, outpatients lose self-confidence if they percieve their families doubt their abilities for social and economic advancement because of their mental illness. Outpatients are also often accused of criminal misconduct, such as rape, which they are not aware of having committed.

Researchers have in the past similarly found mental illness to be associated with self-stigma. For example, Rüsch et al. (2005) describe self-stigma as the enactment of negative societal stereotypes and beliefs about mental illness that may be prevalent in specific cultural and social contexts. Alonso et al. (2009), in contrast, argue that self-stigmatisation is due to the discrimination experienced by persons with a mental illness in interpersonal interactions as well as intentional and non-intentional social exclusion in private and public institutions and negative images abounding in the media. Additionally, Okello and Ekblad (2006) report mental illness to be possibly associated with social withdrawal and, consequently, the loss of employment, social networks and support. Such negative consequences may, in turn, lead to feelings of low self-esteem and experience of low self-efficacy, often associated with self-stigma (Watson & Eack, 2011). Because people with acute episodes of mental illness usually lack insight into societal stereotypes that are likely to precipitate stigma, psychological states such as loss of self-esteem caused by mental illness can be distinguished from those caused by self-stigma (Rüsch et al., 2005). The lack of insight into subtle stigmatising stereotypes, on the one hand, may be a protective factor against self-stigma during acute episodes of mental illness. On the other, insight into one's mental illness and awareness of associated stereotypes may actually lead to self-stigma in patients (Rüsch et al., 2005). Additionally, Narayan et al. (2000) report self-stigma among the poor, including those with mental illnesses, to be often due to social adversity. Adverse social and economic conditions, such as homelessness and unemployment, lead to poor people becoming more introspective and introverted, which, in turn, leads to self-exclusion from community interaction. The risk of self-exclusion also includes linguistic disadvantages and lower literacy skills among such persons. The humiliation associated with poverty and neglect from members of the community exacerbate feelings of inferiority and alienation among the poor (Narayan et al., 2000).

In summary, participants reported that they believe members of families and the public stigmatise and discriminate against outpatients, which, according to them, manifest in exclusionary, stereotyping and endorsement behaviours that members of the public and outpatients enact.

4.5.2. Aggravated poverty as a perceived consequence of mood disorders. All participants reported that mood disorders aggravate poverty among outpatients and their families. They reported, in this regard, aggravated poverty to be associated with the following: (a) increased financial expenses, (b) loss of livelihood assets, and (c) exploitation of the outpatients, each of which is discussed below.

4.5.2.1. Increased expenses for care-seeking as a function of aggravated poverty. Many participants reported that episodes of mood disorders increase financial expenses for outpatients and their families, in the form of consultation and compensation fees. For example, Mutungi, a 35 year old male patient with bipolar disorder, stated in this regard:

> Traditional healers took a lot of my money and they did not heal me; I felt so sad. A traditional healer would say, I want 50, 000/= (R 156)[9], then they would give it to him; I want 180, 000/= (R 562), they would give it to him; I want

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[9] At the time of conducting the fieldwork for this study, the exchange rate of the Ugandan shilling to the South African Rand was 320: 1.

> 100, 000/= (R 312), they give it to him. Whatever amount of money he wants, that is exactly what you give him.

Sonia, a 41 year old female religious healer, similarly informed:

> Many times, when a person develops a mental illness, if the family is not religious and aware of psychiatric services in MRRH; and actually very few are aware, they first consult traditional healers. They extort much money from the patients for exorcising the demons until the little money the patients have is all spent.

Evidently, participants believe that outpatients pay excessive consultation fees to traditional healers in search of a *cure* for mood disorders. Outpatients are, however, dissatisfied with the care provided by traditional healers because such care fails to ameliorate symptoms of their respective mental health conditions. Participants are also seen to believe that the MRRH does not disseminate effective information about psychiatric care available for outpatients. In contrast, persons with mental health conditions readily access information about therapeutic services provided by traditional healers. Furthermore, participants, for example, Sonia, mentioned above, believe that religiosity is a protective factor for outpatients and their families against financial and material exploitation by traditional healers. However, mental patients are also susceptible to exploitation by the church, as it is possible for religious healers to encourage them to donate their wealth in anticipation of the latter’s divine salvation.

Researchers have in the past similarly found care-seeking from traditional healers to be associated with excessive financial and material costs. For example, Stekelenburg et al. (2005) report that most service users of traditional healers pay excessive fees. According to Stekelenburg et al. (2005), most service users pay consultation fees to traditional healers mainly in kind, for example, in the form of a cow to the value of between US $ 67 and US $ 133, and that such high fees is due to three main reasons. Firstly, traditional healers believe the treatment of mental illness, which they attribute to witchcraft, to be highly risky, treatment of which places the traditional healers themselves at risk of becoming bewitched. There is a similar misconception among members of the community that mental illness is infectious (Corrigan et al., 2005). Secondly, most traditional healers adopt a "no cure no pay" system (Stekelenburg et al., 2005), reported elsewhere as well. For example, Edgerton (1980) reports that West Africans consider each period of respite from florid illness, for example, schizophrenia, as a cure. Service users and their families thus regard relapse or recurrence of the symptoms of mental illness as a completely new disease. Edgerton (1980) also states, in this regard, some Yoruba traditional healers to have disclosed often inducing cure by administering a poison to their service users to worsen symptoms in the latter so that patients thus appear to visibly "cure" when administration of the poison to such patients is stopped. In addition, Edgerton (1980) reports that traditional healers signify cure for mental illness with elaborate discharge and cleansing ceremonies, which involve payment for a successful healing. Thirdly, traditional healers accept payment in instalments spread over a period of time (Stekelenburg et al., 2005). Traditional healers interviewed in the present study also reported adopting part-payment methods for their services, such method of payment, however, also suggesting that outpatients have to mortgage future personal earnings, thus making it highly unlikely that they will ever pay off the debt (Narayan et al., 2000).

Some participants also attributed aggravated poverty to compensation fees made by outpatients for destruction caused to other people's property while ill. For example, Bwengye, the 46 year old brother of Nkole, a 48 year old male patient with bipolar disorder, revealed in this regard:

> After he has recovered from his mental illness and you tell him how he destroyed your property, he goes and buys a replacement for you or gives you money to buy the replacement. He says "you know I destroyed your property when I was not aware because of the illness".

This report suggests that Nkole's family view him as destructive and lacking insight during acute episodes of his mood disorder. However, it may also be seen that outpatients such as Nkole are at risk of being scapegoated for property destruction of and recompensation to others because their families believe they lack insight into their conduct when ill. It is, however, also possible that Nkole may have pretended to be unaware of his actions to avoid accountability for his destructive behaviour exhibited during manic episodes.

Researchers have in the past similarly found people with mental illness to be frequently scapegoated for various crimes. For example, Orley (1970) reports that members of the public in Uganda often unfairly treat people with mental illness as thieves, often resulting in the latter being subjected to mob-justice when, for example, wandering into villages in which they are not known. Additionally, lay assessors who assist judges in Ugandan courts by means of advice regarding customary law are usually reluctant to accept the plea of “guilty but insane” (Orley, 1970). Judges therefore tend to hand down maximum sentences for crimes such as destruction of property allegedly committed by mental patients. Orley (1970) notes additionally with regard to perceptions held by members of the public, especially on the issue of accountability, for theft crimes committed by mental patients that theft committed by patients with symptoms including a state of extreme confusion and verbal ambiguity is held to be excusable only if the stolen goods are recovered. In instances where property is destroyed or if violence is involved, however, a patient is likely to be killed by members of the public if caught. Corrigan et al. (2005) similarly attribute the high numbers of people with mental illnesses in the criminal justice system (police, courts and prisons) to hostile reactions precipitated by public stigma of mental illness. They also note that the undue criminalisation of people with mental illnesses may be due to inadequate funding of mental health services, the existence of obsolete laws and unjustified fears associated with mental illness.

4.5.2.2. Loss of family assets as function of aggravated poverty. Many participants stated that the need to raise money to support outpatients leads to loss of family assets, thus aggravating the poverty experienced by such families. For example, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder, revealed in this regard:

> I sell cows and I keep on selling and selling. I ask myself if the cows get finished what will happen. It makes me sad when I think about other parents of children with a mental illness. If there are other people experiencing the same situation as I do and without anything to sell and those people are actually there, how do they survive? Of course they do the little they can and they fail as I am about to fail.

Madamu, the 36 year old wife of Mutungi, a 35 year old male patient with bipolar disorder, similarly reported:

> If I am not sure that today I have earned 10,000/= (R 31) and 3000/= (R 9) is the profit so that when we spend 2,000 (R 6) we can save 1,000/= (R 3) so that the savings help us when we experience emergencies, it means we are living a precarious life. At the moment, we cannot save anything because when my husband says he needs to drink some alcohol, eat meat and whatever, he wants it there and then.

Bernard, a 67 year old male traditional healer, similarly commented on aggravated poverty among outpatients:

> At times the patient sells his land and he becomes landless but at least he regains his health. The Banyankole say *"amagara nigakira amagana*" (health is more important than wealth). When patients are leaving for home after treatment, however, I see that they go lamenting about the loss of their properties.

These reports suggest participants to be concerned with financial and material insecurity associated with care of outpatients. Families experience a burden of care that can and often does lead to neglect of outpatients. The burden of care is aggravated by the belief that poor families are helpless and neglect relatives with mental problems because of over reliance on self-help. The phrase *"amagara nigakira amagana"* (health is more important than wealth), as used in this context, suggests that participants believe outpatients value being healthy over being wealthy. Outpatients are therefore inclined to sell their property to support care-seeking in order to regain and secure mental health, even though they are aware that such transactions aggravate poverty. In the event of a poor prognosis, as is common with mental health conditions such as schizophrenia, outpatients and their families experience aggravated distress and loss of livelihood assets.

Researchers have in the past similarly found episodes of illness to be associated with loss of assets, such as domestic animals and houses, thus aggravating poverty among the poor (Narayan et al., 2000). Narayan et al. (2000), however, attribute loss of such assets to structural factors, such as lack of affordable and effective health services, rather than to episodes of illness as suggested by the social drift hypothesis (Titov, 2007). The cost of health care could, for example, rise because of government policies requiring patients to pay for health and social services. Another reason could be the widespread embezzlement of resources for health care by state officials (Saxena et al., 2007). Additionally, Narayan et al. (2000) report that because poor people seldom have savings, episodes of illness compel them to sell their basic assets, such as houses, to meet the costs associated with care-seeking. Poor people also borrow money from money lenders, often resulting in increased debt in the form of new loans taken to pay off earlier loans. Furthermore, illness that inflicts a breadwinner, may lead to immediate loss of family income, withdrawal of children from school to save money or to earn money for the family and reduction in nutrition calorie intake among the whole family. Chronic illness and disability among the poor are also associated with loss of hope with regard to financial recovery (Narayan et al., 2000).

4.5.2.3. Vulnerability to exploitation as function of aggravated poverty. Many participants reported that exploitation by members of the public aggravate poverty among outpatients. For example, Nkole, a 48 year old male patient with bipolar disorder, informed in this regard: “Previously, I used my money recklessly by buying alcohol, food, etc. for people. Sometimes people would con me by asking for money, which I would give to them freely”.

Similarly, Bwengye, Nkole’s 46 year old brother, stated in this regard:

> He sold off and gave away all the cows and closed the kraal. He used to give out his cows to strangers and casual friends. Later, after recovery, he would feel much distressed because of the loss of his wealth.

Milly, a 35 year old female psychiatrist, similarly observed in this regard:

> The patients with bipolar disorder can be so extravagant. As mental patient I can decide to sell off everything of mine to show people that I am rich. I may go to a supermarket and I buy everything there and I have no use for them. I sell everything and I waste everything and I end up on the streets as a destitute.

The above reports indicate that participants believe loss of personal assets and aggravated poverty experienced by outpatients to be due to personal weakness, for example, undue generosity shown by mental patients to members of the public. Yet, members of the public take advantage of patients' lack of insight into their mental health conditions and defraud them of their money and material goods. Participants also believe that outpatients lack the financial means and other resources to support care-seeking because of the aggravated poverty they experience.

The belief held by participants that mental illness leads to recklessness among outpatients may be attributed to the tendency to blame the victim for social injustices, for example, exploitation of the poor by members of the public (Chambers, 1997). Narayan et al. (2000), for example, report that poor people regularly depend for survival on shopkeepers, pawnbrokers and moneylenders, from whom they borrow money and buy goods on credit and to whom they sell personal property because they are not able to access formal credit services, the poor needing credit to deal with both crisis situations and daily living expenditure for themselves and their families. Although participants in Narayan et al.'s (2000) study often refer to such shopkeepers, pawnbrokers and moneylenders as *bloodsuckers* due to the high interest rates and penalties associated with non-payment charged by the latter, they acknowledge that they are swift, flexible and non-bureaucratic in giving them credit. Narayan et al. (2000) further note that exploitation of the poor is due to the relative powerlessness of the latter in relation to moneylenders. Poor people are also aware of being cheated by middlemen, who offer low prices on goods bought on credit and kept on layby, but often resell these same goods, even if full-payment is received from the original debtor. They are also aware of being exploited by employers, who offer low wages and frequently penalise them for "poor job performance" (Narayan et al., 2000). Kigozi et al. (2010) similarly report that exploitation of mental patients appears to be inevitable in Uganda because of out-dated mental legislation in that country, the Mental Health Treatment Act having last been reviewed in 1964.

In summary, participants reported that mood disorders aggravate poverty experienced by outpatients and their families. According to them, mood disorders experienced by outpatients lead to excessive financial expenses, loss of personal and family assets and increased vulnerability to exploitation by members of the public.

4.5.3. Somatic complaints as perceived consequences of mood disorders. All participants, with the exception of traditional healers, reported that mood disorders cause somatic complaints among outpatients, including physical weakness, persistent headache, physical injury and side effects from medication. Below, I consider each of these somatic complaints.

4.5.3.1. Physical weakness as a somatic complaint among outpatients. Participants stated that mood disorders results in weakness among outpatients. For example, Mukaira, a 64 year old female patient with unipolar depression, stated in this regard:

> I usually sleep by 12: 00 am and I am awake by 3: 00 am. When I feel physically weak I just realize it is a usual experience as patients generally live. When I feel energetic, I go and work and when I feel weak, I stay home having the looks of *enyamurimi* (an anti-bear).

Bosi, a 30 year old male nurse, informed similarly: “In my experience, most depressed persons become like maybe I should use the word “useless” at some point. First of all, they do not have energy to wake up in the morning and to be productive”.

These reports show clearly that participants believe that physical weakness undermines work performance, daily routines and self-care among outpatients. Because they view physical weakness as a usual attribute of patients, family members are willing to grant the former a sick role. The phrase “the looks of *enyamurimi* (anti-bear)”, as used in the context of the report above, suggests that this particular outpatient believes herself to be appallingly dirty, lethargy having resulted in neglect of her personal hygiene. The above reports also suggest that participants perceive outpatients as hopeless because of the long periods of time the latter spend being bedridden. Because most or many outpatients are unable to work, they struggle to meet basic needs, such as food, for themselves, becoming highly dependent on family members for such basic needs.

Some participants, in contrast, attribute physical weakness among outpatients to acute manic episodes experienced by the latter. For example, Bwengye, the 46 year old brother of Nkole, a 48 year old male patient with bipolar disorder, informed in this regard: “He becomes physically weak because he does not eat as he engages exclusively in crazy behaviour such as talking endlessly and restlessness. Even if it were you spending a month without eating you would become emaciated".

Similarly, Milly, a 35 year old female psychiatrist, stated in this regard:

> Patients presenting with manic symptoms usually become physically weak because they use too much energy to do things such as talking, walking and digging. The patients become hyperactive and cannot rest. They are doing one activity after another although they tend not to complete any.

These reports suggest that participants believe outpatients experience acute and disruptive manic symptoms that last for a relatively long time. The prolonged acute symptoms of mania suggest that outpatients delay seeking psychiatric care. Participants are also seen to believe that outpatients waste personal resources, such as time, energy and other inputs, by engaging in ineffective actions during acute episodes of mood disorders. In addition, outpatients are viewed as vulnerable to accidents and physical injury at the workplace because of their perceived carelessess.

Researchers have in the past similarly found mental illness, such as depression, to be associated with somatic symptoms, for example, lethargy, among patients. For example, Helman (2007) reports that depressed people frequently complain of a variety of physical ailments causing them distress, such as headache, palpitations and dizziness. Swartz (1998) similarly refers to somatic symptoms in such patients as "using the body" to speak and to experience distress. Somatisation of distress generally occurs both in HICs and LAMICs (Patel, 1998). Psychological symptoms of mental illness, however, may be solicited in patients presenting with somatic complaints, particularly in LAMICs, only with careful further probing of patients (Patel, 1998). However, patients presenting with somatic and psychological symptoms in LAMICs usually deny having psychiatric disorders such as depression and, instead, often talk about their concern with social and spiritual issues such as poverty and family conflicts (Okello & Ekblad, 2006). Denial of psychological distress among mental patients has been attributed to factors such as the unique social and cultural contexts patterning socialisation, perceptions and idioms of distress and stigma associated with mental illness (Swartz, 1998). For example, writing about the Taiwanese context, Kleinman (1980) reports that physical complaints are the basis for granting a sick role and related exemptions, such as failure in school and absence from work, among the Taiwanese. Psychological complaints, in contrast, do not suggest social efficacy for patients as does physical complaints. Members of the Taiwanese community are also reported in the study to believe that excessive expression of emotions such as anger cause physical distress, as a result, preferring to use Hokkien and Chinese language terms indicating richer bodily states for their dysfunctions than the poorer psychological terms in the Taiwanese language. Taiwanese patients were also often seen to express emotions with reference to particular body organs. For example, they used the term *mên* for depression or “troubled in the heart” because, according to popular belief in Taiwan, the heart is believed to be the seat of emotions (Kleinman, 1980).

4.5.3.2. Persistent headache as a somatic complaint among outpatients. Many participants reported that mood disorders cause persistent headache among outpatients. For example, Mukaira, a 64 year old female outpatient with unipolar depression, stated in this regard:

> There is no single day that I have ever spent without having headache. Even as I take medicines, I still experience headache. There is one time when my head got swollen and my eyes disappeared because of too much headache; some people told me it was allergy.

Similarly, Nsheme, a 28 year old female patient with bipolar disorder, stated in this regard:

> When I don’t get medicines from MRRH; when the health workers write the prescriptions for me to buy, I spend the whole day having headache, the headache is so much that I am unable to do my usual chores such as digging in my gardens.

Bwengye, the 46 year old a brother of Nkole, a 48 year old patient with bipolar disorder, similarly revealed: “He failed to study because of experiencing too much headache. He used to have severe headache that would force him to go home for about a week before returning to school”. The above reports suggest participants perceive psychiatric care as ineffective because it had not *cured* headache, which some outpatients consider to be their main complaint. Some outpatients are therefore discouraged from seeking psychiatric care, which they perceive as ineffective in treating headache. The reports also suggest that participants believe outpatients suffer from persistent headache due to non-adherence to medical treatment. The psychological distress associated with the inability to buy prescribed medicines also aggravates the headaches they experience. Participants are also seen to believe that persistent headache undermines occupational and academic performance among outpatients.

Researchers in the past have similarly found persistent headache to be a common complaint among mentally ill patients (Helman, 2007; Mondimore, 1990). Writing about the Taiwanese context, Kleinman (1980) reports in his study that perceptions of headache among Taiwanese patients differed significantly from perceptions held by Western-style doctors treating them. The patients perceived headache as involving three unique manifestations, namely; *t'ou-yün* (the sensation of a film before the patients' eyes, hazy images, moving objects and a feeling of falling down)*, t'ou-chung* (the sensation of fullness or heaviness in the head) and *t'ou-t'ung* (literally meaning "head pain", the term most commonly used to communicate a headache). Western-style doctors in Taiwan, in contrast, translated *t'ou-yün* (the sensation of a film before the patients' eyes, hazy images, moving objects and a feeling of falling down) to mean dizziness. According to Kleinman (1980), *t'ou-yün*, as described by patients, incorporates both dizziness and vertigo, which Western-style doctors in Taiwan perceive as distinct aspects of illness. Additionally, the patients were reported to perceive the above three types of headache as problems affecting their brains but not as psychological disorders such as depression. However, neurological examinations of patients complaining of brain damage failed to reveal nerve damage. Psychiatric assessment, in contrast, suggests that such patients suffered from psychiatric disorders such as depression (Kleinman, 1980). Similarly, Orley (1970) reports that members of the Baganda community in Central Uganda reported suffering from a kind of headache they label *akawango* (chronic and persistent headache on the top part of the head). Because the illness is at times described as *ekiwanga* (skull), the label *akawango* (chronic and persistent headache on top of the head) is derived from the term, "skull". Orley (1970) also observes that among most patients, *akawango* (chronic and persistent headache on the top part of the head) was seen to be caused by stress and anxiety, a health condition referred to as tension headaches. Because members of the Baganda community believe that *akawango* (chronic and persistent headache on top of the head) is likely to spoil the brain, they were seen to often experience additional anxiety, often becoming even more depressed as a result of distress about the headache (Orley, 1970).

4.5.3.3. Physical injury as a somatic complaint among outpatients. Many participants reported that mood disorders result in physical injury among outpatients. For example, Meya, a 36 year male occupational therapist, stated in this regard:

> When a mental patient has mania, he is going to fight, hurt himself, sustain physical injuries and perhaps injure other people. You may have seen some patients who come here when they are tied up and they have got wounds. For depression, some patients may be bedridden for long periods of time and suffer from bed sores.

In contrast, Mutungi, a 35 year old male patient with bipolar disorder stated: “I would not mind about people restraining the mental patients. However, I see that some mental patients are restrained with ropes and chains to the extent of wounding their hands and legs”. These reports suggest that participants believe outpatients with mania to be automatically violent towards members of the public, the latter who are likely to assault and restrain outpatients as a form of self-defence. However, such members of the public were regarded as applying a disproportionate amount of force to restrain outpatients, resulting in physical injuries to the latter. Mutungi, mentioned above, believes it is possible for members of the public to restrain outpatients using safer and more effective measures. Participants are seen to believe, in contrast, that outpatients with depression develop bedsores because they lack adequate nursing and care with regard to personal hygiene.

Researchers have in the past similarly found physical injuries and accidents to be common among mental patients, due, however, mainly to victimisation rather than perpetration among them (Corrigan et al., 2005; Orley, 1970). For example, Orley (1970) reports that members of the Baganda community in Uganda believe *omulalu* (a madman) to possess superhuman powers, the latter then justifying the belief that a person with mental illness, even if showing no violent behaviour, will ultimately become violent, again further justifying actions such as physically seizing and restraing with ropes such a person. This kind of violent response to mental patients is therefore seen as quite inevitable (Orley, 1970).

4.5.3.4. Side effects of medications as somatic complaints among outpatients. Many participants reported that side effects of medications cause somatic complaints among outpatients, including disturbed sleep patterns and appetite. For example, Mutungi, a 35 year old male patient with bipolar disorder, stated in this regard:

> There are medicines which I used to take and I would sleep the whole day. I would wake up around 4: 00 pm to have food, take more medicines and I would wake up at the same time the following day.

Similarly, Nabasa, the 41 year old daughter of Murungi, a 60 year old female patient with unipolar depression stated:

> When she started taking medicines, she sleeps at 9:00 pm and does not open up her eyes until 3:00 pm. We get worried and monitor her regularly to find out whether she is still breathing. Despite our worries, she is expected to continue taking medicines. When she wakes up she takes more medicines.

Gadi, a 34 year old male nurse, also observed:

> Some mental patients sleep for long hours because of medications. By 10 pm, the patient is still struggling in bed and the body is very weak. The patient returns the sachet of medication to the hospital and tells us; I cannot manage living such a life; don't even provide me with more medication if there is no alternative.

These reports indicate participants believe that outpatients become occupationally and socially impaired as a result of the side effects, such as disturbed sleep patterns, of medication. The reports also suggest that outpatients become highly dependent on their families for meeting basic needs, such as food and personal hygiene, and feel unable to adhere to psychiatric care because of the side effects of medication.

Additionally, in this regard, Frida, the 30 year old daughter-in-law of Mukaira, a 64 year old female patient with unipolar disorder, reported disturbance in appetite as a perceived consequence of medical treatment for a mood disorder, stating:

> The medicines which she takes cause her to loss appetite for food and drinks. You also find she is very thirsty but does not drink porridge (from maize and

> millet grains). What she likes is some milk. Yet, she also has a problem of high blood pressure, which prohibits from taking milk.

This report suggests that Frida perceives loss of appetite in Mukaira to be due to the medical treatment received by the latter. Yet, loss of appetite is likely to be a symptom of the depression for which Mukaira receives psychiatric care. It is possible that Mukaira could, in the future, terminate medical treatment to prevent starvation, thus aggravating her depressive episodes. Furthermore, it may be seen that multiple medical complaints hinder Mukaira from adhering to psychiatric care.

Researchers have in the past similarly found psychotropic medication to cause severe side effects among users (Roos et al., 2001). For example, Gadit (2003) reports that psychotropic medication may cause side effects, such as hypotension, lack of coordination, headache and epileptic seizures. Roos et al., (2001) similarly report that large doses of antidepressant medication may cause seizures, decreased libido and weight gain. I discuss in detail the use of low quality psychotropic medications as a barrier to effective care for outpatients on page 139.

In summary, participants reported they believe that mental illness causes somatic complaints among outpatients, including physical weakness, persistent headache, physical injury and side effects of medication used.

In conclusion, this chapter has shown that participants in the study conceptualise mood disorders in complex and varied ways. For example, outpatients and families, religious healers and traditional healers involved in their care conceptualise the mental health conditions of the former as psychosis, which is significantly different from the conceptualisation of psychiatric health workers in this regard. Similarly, participants hold diverse perspectives regarding the aetiology and consequences of mood disorders. While complex notions of mental disorders have similarly been reported elsewhere, the results in the present study show rich and unique cultural nuances pertaining to the conceptualisation of mood disorders in Uganda.

In the next chapter, I present and discuss the results with regard to structural barriers that prevent effective care of the outpatients studied.

Chapter 5

Structural Barriers to Effective Care

5.1. Introduction

Three subthemes regarding structural barriers preventing effective care for the outpatients in this study emerged from the data. These are: (a) the low priority status of mental health on the public health agenda, (b) poor organisation of mental health services, and (c) social and culture-related barriers. Below, I consider each of these subthemes in detail.

5.2. Low Priority Status of Mental Health on the Public Health Agenda Related Barriers

Participants in this study reported the following barriers to be indicative of the low priority status of mental health on the public health agenda in Uganda: (a) inadequate staffing at the MRRH, (b) consequences of irregular medical supplies to the MRRH, and (c) the use of inferior medication to treat mental disorders. Below, I consider each of these further barriers to effective mental health care for the outpatients considered in this study.

5.2.1. Inadequate staffing at the MRRH as a function of the low priority status of mental health on the public health agenda. All participants, except the religious and traditional healers, reported inadequate staffing at the MRRH to be a barrier to effective care for outpatients. For example, Bosi, a 30 year old male nurse, informed in this regard:

> You sometimes find there are only two health workers in the ward who are supposed to treat patients, handle cleric work, make orders for the drugs, and to collect sundries from the stores. As a result, they cannot easily serve every patient. So, they use the attendants (families) to do some part of care and they report to the health workers when they need assistance.

As the above report illustrates, Bosi believes understaffing at the MRRH to be associated with role strain among psychiatric health workers due to the latter being overburdened with multiple responsibilities. The inclusion of families as backup staff suggests that patients do not receive professional care. Additionally, families are unable to receive respite care when outpatients relapse and are readmitted due to understaffing at the MRRH.

Similarly, Mukiga, a 41 year old male patient with unipolar depression, reported:

> At times, you reach at MRRH and you find the few available health workers are already tired and preoccupied with their problems; then they tell you to go back home. You have come to the hospital in pain and you have to go back home with your pain.

This report indicates that Mukiga believes psychiatric health workers neglect outpatients due to work-related stress. The belief that the latter displace psychological distress to outpatients suggests Mukiga perceives outpatients to be powerless.

Furthermore, some participants reported understaffing to mean that the MRRH relies unduly on part-time staff to care for outpatients. For example, Njuna, a 40 year old female counsellor, stated in this regard:

> There is one counsellor for the whole of MRRH. I am here in the hospital; well but not here because I am employed by Mbarara University of Science and Technology. When I come for one day and I see one, two or three patients, maybe I am done for the week. There is a big need but I cannot meet it and that is the bottom line. If I say let me be here full-time, I would end up getting a mental break down.

Njuna is seen to believe that the mental health needs of both outpatients and psychiatric health workers remain unmet, as there are too many patients to be cared for by a single part-time counsellor. Attempting to meet the overwhelming psychological needs of outpatients and care providers on a full-time basis, according to Njuna, would also be a considerable burden that is also likely to lead to excessive psychological distress for a single counsellor.

In addition, families are especially concerned that the Ugandan government does not prioritise staffing at the MRRH to enhance its human resource capacity for the care of outpatients. For example, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder, observed in this regard:

> It surprises me to see that up till today, the government has not yet trained and employed enough health workers to treat mental patients. If doctors were many as the patients are consulting, some doctors would have time to greet the patients and their relatives, to counsel and educate us on mental illness. They would also appreciate our work and encourage us to continue caring for the patients.

Importantly, Mugurusi believes the unmet mental health needs of outpatients and their families to be clearly apparent to government leaders and can easily be met by training and employing more psychiatric health workers. The inability to meet mental health care needs implies neglect by government of mental patients and their families. He is seen to believe that inadequate staffing at the MRRH constrains provision of psychosocial care, especially to outpatients and their families.

Researchers have in the past similarly found low levels of human resources to be a barrier to effective mental health care, especially in LAMICs. For example, Saxena et al. (2007) report a critical shortage of mental health professionals, for example, psychiatrists, to be common in LAMICs, as each of the following sub-Saharan African countries: (a) Chad (domestic population of 9 million), (b) Eretria (domestic population of 4 million), and (c) Liberia (domestic population of 2 million) has only one psychiatrist. Moreover, there is an average of 0.5 psychiatrists and 0.16 psychiatric nurses per 100, 000 of each of the respective populations in LAMICs. The ratio of psychiatric health workers to the population, in contrast, is about 200 times higher in HICs (Saxena et al., 2007). Other researchers (for example, Kigozi et al., 2010; Ovuga et al., 2007; Saraceno et al., 2007; Saxena & Maulik, 2003) similarly report human resources for mental health to be too low to meet the mental health care needs of populations in LAMICs. In fact, because a large number of clinicians are full-time researchers and administrators, the number of mental health professionals in clinical practice may be overestimated (WHO, 2007). Yet, effective mental health care relies heavily on committed and skilled care providers, more so than on advanced technology or equipment (Saxena et al., 2007). The paucity of human resources for mental health care in LAMICs may be due to factors such as the large-scale migration of mental health professionals to HICs (Farmer, 2010; Saxena et al., 2007), the low status of mental health professions, for example, psychiatry in comparison to medical specialties such as surgery, better working conditions in the private sector than in the public sector, the former which serves a small and more privileged middle class and the latter which serves the majority poorer people (Saraceno et al., 2007). There is also a lack of incentives to attract mental health professionals to work in rural areas where the majority of needy people reside. A wide disparity in access to human resources for mental health is thus prevalent in many LAMICs. For example, Kigozi et al. (2010) report that over 60% of mental health professionals in Uganda work in and around Kampala city.

The burden of care among psychiatric health workers, which participants in the current study believe is due to the soaring numbers of service users, has similarly been reported elsewhere. For example, Coetzee, Kagee and Vermeulen (2011) report that limited numbers of health workers for very large numbers of service users hinder adherence to antiretroviral therapy among the latter in South Africa. For instance, because health workers often experience burnout, they engage in abusive behaviour towards service users. Coetzee et al. (2011) also report that many service users often wait for long periods of time before consulting with health workers to receive treatments prescribed for them. To reduce the waiting time for health services, service users also travel to hospital in the dangerous morning hours, usually at around 4 am (Kagee & Delport, 2010). Many of them thus feel discouraged to keep review appointments at the hospital (Coetzee et al., 2011). Moreover, because of such transport problems, some service users decrease their treatment doses to make medication last longer so as to reduce the number of clinic visits (Kagee et al., 2011). Severe staff shortages in public health units, according to Kagee et al. (2011), also lead to inadequate interaction between health workers and service users, thus preventing effective assessment and treatment of complex health conditions. Additionally, Narayan et al. (2000) report the lengthy time period involved for service users to travel to health units, receive treatment, acquire medicines and return home to often be a disincentive to care-seeking among poor people. Loss of such time experienced by service users is worsened by discriminatory behaviours shown them by health workers, who are reported to favour service users who dress well, are able to pay bribes and who enjoy higher social status than poorer service users. Many poor service users also experience hunger while awaiting treatment at health facilities because they are unable to afford buying lunch away from home (Narayan et al., 2000).

The resort to families of outpatients and lecturers from MUST as backup and part-time health care staff at the MRRH appears to be a familiar coping strategy in under-resourced health care systems in LAMICs. For example, Kagee et al. (2011) report that to lessen the excessive burden among professional health workers, lay counsellors are recruited to provide pre- and post-test HIV counselling in South Africa. However, insufficient human and financial resources, means that lay counsellors do not receive adequate training, regular supervision and support. Consequently, they merely disseminate basic information about HIV/AIDS as they are not able to deal with service users' emotional distress, facilitate cognitive restructuring and modify maladjusted behavioural patterns, for example, non-adherence to treatment (Kagee et al., 2011).

5.2.2. Consequences of irregular medical supplies as a function of the low priority of mental health on the public health agenda. All participants, except traditional healers, reported consequences of irregular medical supplies (for example, adhering to only partial and not full medical treatments among patients) to be barriers to effective care for outpatients. For example, Nkore, a 48 year old male patient with bipolar disorder, informed in this regard:

> I have been getting free medicines in MRRH except in the last 2 months. Health workers have been advising us to buy our medicines in pharmacies in Mbarara town. Each tablet costs 200/= (R 0.625) and in one month I am supposed to buy medicines worth 15, 000/= (R 47) but I always do not have the money to buy my dose.

Similarly, Martha, a 34 year old female religious healer who cares for a relative with a mental health condition, reported: "Presently, when you go to MRRH, the health workers tell you to go and buy the medicines in the pharmacy. At times you find that you don't have money to buy the prescribed medicines". These reports reveal that participants believe out-of-pocket payments hinder access and adherence to medical treatment as many outpatients are poor. Unable to buy medication, they thus fail to adhere to their medical treatment. In addition, because they access care providers in an un-coordinated manner, for example, at the MRRH and pharmacies in Mbarara town, outpatients incur undue time and transport costs, which in turn aggravate their poverty.

Furthermore, psychiatric health workers reported being concerned about the lack of explanation by administrators regarding irregular medical supplies to the MRRH. For example, Milly, a 35 year old female psychiatrist, reported in this regard:

> There are no medications in MRRH, especially of recent, and even inpatients buy their own medications. There is no clear explanation from the hospital administrators as to why we don't have those medications … Of course our hands are tied because some patients actually cannot afford the medicines that we prescribe for them.

Milly is seen to believe that a communication breakdown between psychiatric health workers and hospital administrators precipitates uncertainty regarding provision of psychiatric care for outpatients. The lack of medical supplies is also seen to lead to ethical dilemmas for psychiatric health workers, who have to advise patients to buy their own medication, even though the latter cannot not afford to.

Additionally, participants reported being concerned that outpatients often take partial medical treatments because of irregular medical supplies to the MRRH. For example, Agaba, a 50 year old male clinical officer, reported in this regard:

> Sometimes, for a patient who needs to take carbamazepine and haloperidol, we find there is only one drug and the other drug is not available in MRRH. When we ask patients to buy a dose for one month until their next date of review, they swallow one drug which we may have given to them because they cannot afford a full dose.

Agaba is seen to believe that irregular medical supplies to the MRRH and poverty contribute to non-adherence to medical treatment among outpatients. Non-adherence means that outpatients are at increased risk of suffering negative treatment outcomes, for example, prolonged episodes of a mood disorder and severe side effects of medication.

A few outpatients reported being considerate to psychiatric health workers who inform them about the unavailability of medication at the MRRH. For example, Murungi, a 60 year old female patient with unipolar disorder, informed in this regard:

> Health workers don't refuse to give us the medicines, but patients are too many to be sufficiently supplied with the medicines. In fact, I have never felt that the health workers deny me medicines. When I don't find medicines in MRRH, I get satisfied and I believe they are not there. If the medicines were available would the health workers eat them like food?

Murungi is seen to believe that psychiatric health workers display honesty in caring for outpatients. She does not, for example, suspect them of embezzling medication for personal financial benefit. The belief that medical supplies to the MRRH are irregular due to large numbers of outpatients suggests that Murungi has internalised oppression and powerlessness and is thus not able to assertively claim her citizenship rights and entitlements, for example, health care.

Researchers have in the past similarly found the lack of essential medical supplies to be a critical barrier to effective mental health care in LAMICs. For example, Saxena et al. (2007) report that about a quarter of LAMICs do not provide basic antidepressant medicines at primary health care facilities. In some LAMICs, the supply of essential medicines either fails to cover all regions or is irregular. Yet, effective pharmacological treatments for many disorders require uninterrupted use by service users over a long period of time (Saxena et al., 2007). Saraceno (2002) similarly reports that while approximately 85% of countries worldwide have essential drug lists, which they use as a basis for procurement of therapeutic medication in primary health care settings, about 20% do not include at least one anti-epileptic drug on their lists. The inability of many LAMICs to translate declarations and policies into services in the mental health sector has been reported elsewhere (Fistein et al., 2009; Stein et al., 2009). Furthermore, the use of out-of-pocket payment as a financing method for psychiatric care has also been reported elsewhere (Saxena et al., 2007; WHO, 2007). Because people with mental illnesses are often poor (Lund et al., 2010; Perry, 1996), the out-of-pocket financing method can aggravate poverty and hinder adherence to psychiatric care. Besides, Saxena et al. (2007) report essential psychotropic medication to be relatively expensive for service users in LAMICs. In particular, a year's supply of the cheapest antidepressant could cost patients in LAMICs twice as much as what patients in HICs would pay. Yet, the gross national product (GNP) for HICs is 12.5 times higher than in LAMICs (Saxena et al., 2007).

Similarly, the WHO (2007) reports the out-of-pocket payment method, widely used in LAMICs, to be an ineffective, inequitable and exploitative financing method for mental health care. The out-of-pocket payment method aggravates poverty and results in poor treatment outcomes, such as relapse, among service users (Narayan et al., 2000). In particular, the out-of-pocket payment method for health mental care often leads to disposal of livelihood assets and acquisition of debt among service users and their families (Van Damme, Van Leemput, Por, Harderman & Meessen, 2004). I discuss in detail the issue of aggravated poverty as an attributed consequence of mood disorders on page 118. The use of the out-of-pocket payment method for mental health care may be due to the lack of appropriate infrastructure for more effective financing options, such as tax-based payments and health insurance (WHO, 2007). Okuonzi (2004), in contrast, attributes the introduction of the out-of-pocket payment method in the Ugandan health care system in the early 1990s mainly to conditions set by donors and vested business interests.

5.2.3. The use of inferior medication as a function of the low priority of mental health on the public health-related agenda. All participants, except traditional healers, reported the use of inferior medication to be a barrier to effective care for outpatients. According to them, outpatients experience various challenges mainly associated with side effects of inferior medication. For example, Mutungi, a 35 year old male patient with bipolar disorder, informed in this regard:

> There is a medicine that I took that made me feel very bad. Whenever I would take it, for example, I would see the world turning yellow and I would feel dizzy. I would realize that the medicine is very strong for my body.

It is clear that Mutungi believes side effects of medication, such as visual hallucinations, to indicate the medication overwhelming his body due to its high potency. Such side effects often stem from use of older generation psychotropic medication, such as imipramine, which can hinder adherence to medical treatment.

Similarly, Agaba, a 50 year old male clinical officer, reported in this regard:

> If a patient is using imipramine or amtriptyline, he may suffer from postural hypotension, dry mouth, which is very common among our patients, skin rashes and sexual potency is reduced. Compared with some of the new drugs, like fluoxetine, the medicines that we prescribe for the patients have severe side effects.

It is clear that Agaba views the use of older psychotropic drugs as a leading cause of severe side effects of medication experienced by outpatients. By calling attention to the potential side effects of medication, Agaba is seen to be pessimistic about adherence to medical treatment among outpatients. Agaba is also seen to be concerned that outpatients are not able to access better (new) medication, the latter which is not being dispensed at the MRRH.

Some participants reported they view the side effects of medication to be major illnesses, second to the mood disorders of outpatients. For example, Frida, the 30 year old daughter-in-law of Mukaira, a 64 year old female patient with depression, stated in this regard:

> Her other problem is the medicines which she takes because they cause her to lose appetite and to become physically weak. You find she is very thirsty but does not like porridge and also she cannot drink milk because of high blood pressure.

Similarly, Martha, a 37 year old female religious healer, informed:

> Medicines which patients receive from MRRH make them physically weak. I mean, medicines are very strong, to the extent that they appear to cause another illness. Because of the side-effects of the medicines, patients tend to terminate medications whenever they feel better.

These reports indicate participants believe medical treatment causes somatic complaints, such as physical weakness, among outpatients. Yet, such somatic complaints can be basic symptoms of mood disorders, such as depression. Outpatients are likely to terminate their respective medical treatments as a result of such beliefs.

Some participants reported that outpatients experience dilemmas about adhering to medical treatment because they associate severe side effects with the use of inferior medication. For example, Nkore, the 48 year old male patient with bipolar disorder, stated in this regard:

> I realise that if you insist on taking the medicines as prescribed by the doctors you are going to be weak full-time and unable to work. When the medicines cause me to be physically weak, sometimes I explain to the health workers to reduce on the prescribed dose. Yet, I think that reducing on the dose triggers my frequent relapse.

This report suggests that Nkole believes determining an appropriate dose of medication for him to experience effective treatment to be complicated by the inevitability of the severe side effects of such medication, on the one hand, and relapse, on the other. Nkole is seen to have to choose either adherence to a high dose of medication, and thus to suffer from occupational impairment, or a reduced dosage, and thus to experience relapse. Because both these choices are undesirable, Nkole experiences considerable psychological distress and discouragement in seeking psychiatric care.

Additionally, participants reported that families misunderstand the side effects of medication among outpatients, for example, seeing lethargy as laziness. Mariya, a 34 year old female social worker, reported in this regard:

> Some patients take drugs and become very weak and if they were initially active in weeding the banana gardens and they can no longer do their part, the families will accuse them of many things. They say that "because you are mentally ill you are lazy, you have so many excuses. You tell us that you can only eat food and you cannot do the rest of work".

According to Mariya, families unduly blame outpatients for being "lazy" because the former have low levels of mental health literacy regarding the side effects of medication. Such accusations of laziness by families convey an attitude of "blaming the victims" of circumstances that are beyond the control of patients. In addition, family neglect is likely to precipitate psychological distress and aggravate episodes of mood disorders among outpatients.

Researchers have in the past similarly found the use of older generation drugs to cause severe side effects, hindering medical compliance among people with mental illnesses. For example, the WHO (2001) reported that although older generation drugs, for example, amtriptyline, are as effective as newer drugs, for example, fluoextine, the former often causes more severe side effects than the latter. New drugs thus find more favour among patients. However, newer drugs are less accessible, particularly in LAMICs, because of their prohibitive costs. Similarly, other researchers (for example, Gadit, 2003; Roos et al., 2001) report that high doses of psychotropic medication cause severe side effects among service users, such as hypotension, dry mouth, blurred vision, headaches, epileptic seizures, decreased libido and weight gain. In addition, the side effect of amenorrhea in women prevents them from reproducing in the long-term (Helman, 2007).

Furthermore, Kleinman (1980) reports the logic engendered in the explanatory models of service users and their families to influence perceptions of side effects of medications. Writing about the Taiwanese context, Kleinman (1980) reports that because popular ideology in Taiwan suggests use of Chinese medicines to have no side effects, patients were seen to not be alarmed even when they experienced what medical health workers identify as side effects. In contrast, such patients were seen to consider even a bad taste as a side effect of Western medication, believing such side effects to be inevitable of this type of medication. Additionally, in contexts where the private sector is unregulated and business owners more concerned with profits over patients’ health, dispensing of drugs that have expired and wrong prescriptions are inevitable, increasing the possibility for side effects among outpatients (Okuonzi & Macrae, 1995).

In summary, participants reported the low priority status of mental health on the public health agenda to be a barrier to effective care for outpatients. The low priority status of mental health on the public-health agenda, according to them, manifests in the following ways: (a) inadequate staffing at the MRRH, (b) negative consequences of irregular medical supplies to the MRRH, and (c) the provision of inferior medication to patients.

Below, I consider participants’ descriptions of poor organisation related-barriers to effective care for outpatients.

5.3. Poor Organisation of Mental Health Services as a Barrier to Effective Care

Two subthemes regarding poor organisation of mental health services as a barrier to effective care for outpatients emerged from the data. These are: (a) centralised delivery of psychiatric care at the MRRH, and (b) ineffective communication between psychiatric health workers and outpatients. Below, I consider each of these in detail.

5.3.1. Centralised delivery of psychiatric care at the MRRH as a function of poor organisation of mental health services. Outpatients and psychiatric health workers reported centralised delivery of psychiatric care at the MRRH to be a barrier to effective care to outpatients. For example, Agaba, a 50 year old male clinical officer, informed in this regard:

> Patients should not be coming to MRRR unless they have passed through the lower levels of the health care system. But the referral system is so poor that if you are to go through those levels, you will be humiliated, disappointed, frustrated and you can get another illness in the process. That is why a person now needs to travel a long distance to come here.

This report shows that Agaba believes outpatients seek psychiatric care directly from the MRRH because they are not able to receive treatment or referrals from lower level health units in the Greater Mbarara region. The long distances they have to travel from rural areas to seek psychiatric care at the MRRH results in excessive costs being incurred by them, for example, for transport. As a result, poor outpatients, not able to meet the costs associated with travelling to the MRRH, fail to access psychiatric care.

Similarly, participants reported the absence of qualified health workers in lower health units to hinder provision of psychiatric care in the community. For example, Njuna, a 40 year old female counsellor, reported in this regard:

> If there is only one nurse or a midwife at the health centre IV and III, what are her priorities? Midwives are for delivering mothers. If a mother comes in labour, she will take my attention more than a psychiatric patient. I think it would be expecting too much from these lower level health centres that are managed by one health worker that they should provide psychiatric care.

According to Njuna, lower level health facilities lack capacity in providing psychiatric care, as they are manned by too few health workers. Njuna is also seen to believe the few available health workers in lower health facilities to be trained in other specialties, such as maternity, which in practice, they prioritise over psychiatric care.

Similarly, Mukiga, a 41 year old male patient with unipolar depression, stated in this regard:

> MRRH is the only health facility in the region where mental health services are provided. This is why there is too much congestion in the psychiatric ward. The excessive number of patients causes the medicines to run out of stock. We also waste a lot of time waiting to consult a doctor.

Mukiga is thus seen to believe centralised delivery of psychiatric care at the MRRH causes many care-seeking challenges for outpatients, including congestion in the psychiatric ward, irregular medical supplies and loss of time for patients associated with care-seeking. The multiple challenges associated with centralised delivery of psychiatric care are discouraging to outpatients such as Mukiga seeking psychiatric care.

Researchers have in the past similarly found poor organisation of mental health services to be associated with inequitable, inefficient and ineffective utilisation of mental health care systems in LAMICs (Jenkins & Strathdee, 2000; Patel et al., 2009). For example, Saraceno et al. (2007) report most of the resources for mental health to be centrally located in large hospitals and asylums located in or around large cities in many LAMICs. Kigozi et al. (2010) similarly report over 60 % of psychiatric beds to be located in Butabika mental hospital and other health facilities located in and around Kampala city in Uganda. Kigozi et al. (2010) also report about 55% of the total budget for mental health in Uganda to be directed to Butabika mental hospital alone. Saraceno et al. (2007) additionally report the provision of care in centralised mental health institutions to be associated with high operational costs as well as isolation of service users from their families and communities. Centralised mental health institutions are also characterised by undignified living conditions, human rights violations and stigma (Lucas & Stevenson, 2006). Moreover, while common mental disorders, highly prevalent in the community, contribute majorly to the global burden of disease, mental health institutions often provide specialist psychiatric care to only a small group of people with severe mental disorders (Goldberg & Huxley, 1992).

Additionally, the lack of an effective referral system in the Greater Mbarara region hinders integration of mental health care into general health care, because the latter necessitates a functional and mutually supportive referral system in the country's health care system (Saraceno et al., 2007), which is lacking in Uganda. Participants have reported frequent absenteeism among health workers and unavailability of psychotropic drugs, both which make it difficult to integrate mental and general health care at primary health care facilities. Other obstacles to effective care for people with mental illnesses in primary care settings include lack of relevant training and supervision of primary health workers in detecting and managing mental disorders as well as referral of patients (Saraceno et al., 2007). Primary health workers are also possibly already overwhelmed by a range of problems, including infectious diseases, such as HIV/AIDS, and chronic medical problems, such as diabetes (Kleinman, 2003).

The finding that participants perceive lack of alternative health units, especially in the community, to be a barrier to effective care has similarly been reported elsewhere. For example, Narayan et al. (2000) report a total lack of health facilities in the rural areas of many African countries, for example, Malawi and Zambia, and patients having to walk discouraging distances (over 10 kilometres) in search of health care. Narayan et al. (2000) also report being informed of patients having died and babies being born in the process of patients travelling to the vastly distant health care facilities. The prohibitive costs of hiring private means of transport, for example, cars, and impassable roads, especially during rainy seasons, also prevent patients from seeking care (Narayan et al., 2000).

In the following section, I present and discuss results regarding ineffective communication between psychiatric health workers and outpatients as a further barrier to effective care, the latter which is associated with poor organisation of mental health services.

5.3.2. Ineffective communication between psychiatric health workers and outpatients as a function of poor organisation of mental health services. All participants, except religious and traditional healers, reported ineffective communication between psychiatric health workers and outpatients to be a barrier to effective care. For example, Agaba, the 50 year old male clinical officer, stated in this regard:

> Telling patients their diagnoses in Runyankole-Rukiga language is our big challenge because we lack precise translations for bipolar disorder and unipolar depression. We are, though, aware that it is the patients' right to know their diagnoses. Indeed, a few patients ask, "Doctor, what am I suffering from?" Others don't ask but I think, again, it has been a weakness on our part as health workers because we don't give them the time and the opportunity to ask.

This report suggests that Agaba believes the inability of psychiatric health workers to translate bipolar disorder and unipolar depression in the outpatients' commonly spoken language to be a violation of the right of patients to knowledge and effective psychiatric care. Inadequate translations of terms for mood disorders into the local language means psychiatric health workers deny outpatients the opportunity to inquire about their diagnoses. The resulting lack of informational support from psychiatric health workers is likely to precipitate uncertainty among outpatients regarding the prognosis of their mental health conditions.

In this regard, Nkole, a 48 year old male patient with bipolar disorder, informed:

> It is unnecessary to ask about mental problems because they are diagnoses that health workers learn in their medical language. Most of their names are in English and also in their medical language. Even if health workers tell you your diagnosis, you cannot understand it.

This report reveals Nkole's belief that psychiatric health workers exclusively own knowledge regarding psychiatric diagnoses of mood disorders. Psychiatric health workers' monopoly over such knowledge translates into outpatients being unduly dependent for care on these specialists. Nkole is also seen to believe it hopeless to ask psychiatric health workers about his psychiatric diagnosis, as any communication of such knowledge would be conducted in English, which he does not understand. Due to the minimal level of communication between outpatients and psychiatric health workers, it is highly possible for negative consequences, such as misdiagnosis and mistreatment, to occur.

Participants also reported a lack of open communication channels to promote communication between psychiatric health workers and outpatients. For example, Mukiga, a 41 year old male patient with unipolar depression, informed in this regard:

> Nowadays, you go to MRRH and you fail to get medicines and there is no committee member whom you know. So there is nowhere to communicate such concerns. You just feel helpless and hanging in space. You don't even know the person who supervises the health workers in the ward.

It is apparent that Mukiga believes care-related concerns among outpatients to remain unaddressed because of the lack of open communication channels to the relevant offices. This lack means that psychiatric health workers fail to receive and address outpatient feedback on care, an unfortunate missed opportunity that could greatly influence priority setting in planning and delivering psychiatric health care.

Some participants attributed ineffective communication between psychiatric health workers and service users to power imbalances between the two groups. For example, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder, reported in this regard:

> At times you reach at MRRH and you hold back what you thought you would tell the health workers. If this is the only health worker you are expecting to assist you, how do tell him without offending him that he is behaving rudely to the patients?

According to Mugurusi, outpatients fail to provide feedback about service and care for fear of upsetting psychiatric health workers, the latter who could, in turn, victimise them. This undue dependency on psychiatric care, the latter which is available only at the MRRH, renders outpatients and their families overly cautious in their interactions with psychiatric health workers for fear of annoying the latter and to prevent possible victimisation. As a result, outpatients and their families are forced to ignore their feelings and needs with regard to care, experiencing considerable distress in the course of accessing psychiatric care at the MRRH.

In addition, Meya, a 36 year old male occupational therapist, informed:

> Because of time constraints and partly arrogance, doctors did not usually talk so much with the patients. Traditionally, doctors used to be small gods I think and, therefore, their word was final. It seems they knew all about the patients' health problems and the patients knew little.

This report implies Meya's belief that psychiatric health workers disregard the views of outpatients regarding mood disorders and care because of contextual factors, such as time constraints and personality traits, for example, superiority complexes among health care workers. Psychiatric health workers thus collect insufficient information about patients, which result in serious consequences such as poor diagnosis of mood disorders and inappropriate treatment for outpatients, which in turn can negatively affect psychiatric care.

Researchers have in the past similarly found poor communication to be a barrier to effective care for service users. For example, writing about the Taiwanese context, Kleinman (1980) reports having observed a minimal level of communication, averaging two to three minutes, often occurring between Western-style doctors and their Taiwanese patients. Service users are reported to have often been dissatisfied with these doctors' communication style for a number of reasons, including the doctors' use of technical terms that service users could not understand and inability to explain patients' health conditions as well as dealing with their concerns such as costs of treatment. Kleinman (1980) also reports having observed Western-style doctors to be often more concerned with disease than illness, thus preferring technical interventions rather than communication with service users. Moreover, Taiwanese patients were also seen to feel intimidated to ask for explanations about their illnesses or to challenge doctors' views because patients are socialised to display politeness and subservience in the presence of high status individuals. Service users were also seen to believe that these doctors would ignore them if asked for explanations about their illnesses (Kleinman, 1980).

Additionally, Good (1994) reports poor communication between health workers and service users to be due to the formers' socialisation as medical students with regard to constructing and presenting patients as numbers and lab values for appropriate treatment. According to Good (1994), writing and speaking are two of the crucial formative practices of medicine that account for the minimal communication that occurs between health workers and service users. Writing up cases is seen to necessitate the adoption of a standard structure for medical interviews with patients. Standardised medical interviews, consequently, become official documents on the basis of which various clinicians decide patient care and assess the writer's performance. A medical interview necessitates a health worker (writer) interpreting phenomenological descriptions of a patient's behaviour into pathophysiologic processes, thus only "the important stuff" is captured (Good, 1994). Intimate details of patients, the latter which usually require health workers to listen extensively to patients' stories, are therefore discouraged in medical training and in actual practice. Good (1994) also reports that health workers present the constructed cases in various contexts, such as morning rounds, work rounds and visit rounds and that presentation of stereotyped cases in a persuasive way, in this context, is particularly rewarding, especially to junior health workers (Good, 1994).

The finding that participants believe the difficulty in translating psychiatric diagnoses, such as bipolar disorder, into local idioms of distress engenders poor communication between health workers and outpatients has similarly been reported elsewhere. For example, Orley (1970) reports that members of the Baganda community in Central Uganda use words such as "disease" loosely, with such words thus not fitting well into the rigid psychiatric diagnostic categories of mental disorders. Members of the Baganda community also use the word *ensimbu* to imply grand mal seizures, but not for all forms of epilepsy. Translation often focuses mainly on words, thus failing to capture the influence of language on emotions and, in general, the experience of mental illnesses (Kleinman, 1995). I discuss in detail the issue of translation of mood disorders on page 86. Additionally, the finding that participants believe there is a lack of open communication channels, and therefore limited participation in the management of mental health services among outpatients, may be attributed to the absence of active groups of service users and their families advocating for improvements in mental health care (Kigozi et al., 2010). For example, Rüsch et al. (2005) report greater social inclusion and participation of people with mental illnesses in countries such as the United States and Germany, where groups of families and service users are active regarding the rights of patients with mental illnesses. Such groups use various strategies, such as protest and public education, to reduce stigma associated with mental illness and to enhance involvement and participation of people with mental illnesses in social and economic development endeavours. In contrast, Lang and Murangira (2009) report such consumer organisations in Uganda to be highly uncoordinated, weak, poorly financed and, often manipulated by politicians.

In summary, participants reported centralised delivery of psychiatric care at the MRRH as well as ineffective communication between psychiatric health workers and outpatients to be barriers adversely affecting care of the latter. On the one hand, centralised delivery of psychiatric care manifests an ineffective referral system in the Greater Mbarara region and lack of human resource capacity to provide psychiatric care in lower level health units. On the other hand, ineffective communication between psychiatric health workers and outpatients comprises: (a) inability of psychiatric health workers to communicate psychiatric diagnoses of mood disorders in the local language, and (b) lack of open communication channels for outpatients to report their concerns to the relevant offices.

Below, I discuss the social and culture-related barriers participants reported hindering effective care for outpatients.

5.4. Social and Culture-Related Barriers to Effective care

Two subthemes regarding social and culture-related barriers to effective care for outpatients emerged from the data. These are: (a) stigma and discrimination-related barriers, and (b) poverty-related barriers. Below, I consider each of these barriers to effective care in turn.

5.4.1. Stigma and discrimination as a function of social and culture-related barriers to effective care. All participants reported stigma and discrimination by members of the public to be barriers to effective care for outpatients. For example, Nsheme, a 28 year old female patient with bipolar disorder, informed in this regard: “When I was sick, all my friends abandoned me. They were asking themselves ‘of what use is befriending this *Mugwiraro* (mad person)?’ They were ashamed of me”. This report suggests that Nsheme believes friends to be unreliable because they abandon her at critical times of need. Nsheme is also seen to believe that social relationships are maintained only if close associates perceive her as being of some benefit to them.

Participants reported that families similarly stigmatise and discriminate against outpatients. For example, Mariya, a 34 year old female social worker, reported in this regard:

> There is a patient who, on discharge, her children ran away because of her previous bizarre behaviours. The children expected that their mother would be aggressive to them again. She cooked and the children refused to eat. They locked themselves in the bedroom. Within two days, the patient returned to the hospital in a relapsed state.

According to Mariya, convalescing outpatients often relapse as a result of undue fears and reactions expressed toward them by their families. The above report also indicates that psychiatric health workers fail to effectively make and implement discharge and reintegration plans to ensure that families accept convalescing outpatients returning home from the MRRH.

Martha, a 37 year old female religious healer, similarly stated:

> When a person develops a mental illness, his family gets shocked and they ask themselves; "what has befallen us? Where can we hide this person?" Someone who should have been taken to MRRH may be locked in a house at home and some are often brought and abandoned in the church.

Martha is seen to believe that families are embarrassed to care for outpatients, the former viewing mental illnesses as strange health conditions. Many families are also seen to lack knowledge that mental illnesses can be effectively treated at the MRRH. As a result, families violate the rights of outpatients by secluding them at home or abandoning them to the church.

The finding that participants believe outpatients to be socially excluded because of the latter's mental illnesses has similarly been reported elsewhere (for example, see Corrigan et al., 2005; Moroka, 1998). I discuss in detail the issue of social exclusion as a perceived consequence of mood disorders on page 111.

Additionally, participants reported that families stigmatise outpatients by assigning the latter derogatory labels. For example, Milly, a 35 year old female psychiatrist, informed in this regard:

> Attendants call a mental patient "*omugwiraro wangye*" (my mad patient). I try to tell them that they are patients, not mad people, but it is not being practiced in MRRH. Even when patients return home, it is still the same thing. You hear them say; "I have not yet administered drugs to my mad person".

This report suggests that Milly believes families impose derogatory labels on outpatients both at the MRRH and within the community. Stereotyping of outpatients is seen to be pervasive in spite of health education provided by Milly to families, suggesting that family beliefs about mental illness to be deeply ingrained. The above report also suggests that psychiatric health workers at the MRRH discharge outpatients even if the latter are acutely ill, thus making such patients highly dependent on families for care. The prevalence of stigma associated with mental illness in the home context means that families neglect and stereotype outpatients, worsening the formers' episodes of mood disorders.

Similarly, participants reported health care settings, in which outpatients receive care, to be equally stereotyped and stigmatised. For example, Bosi, a 30 year old male nurse, informed in this regard: "If a person is suspected to be mentally sick, the general health workers in MRRH tell that person that 'you go down to *ekiraru* (mad house, referring to the Psychiatric Unit at the MRRH) and some patients feel embarrassed because of our address".

It is implied in this report that Bosi believes stereotypes relating to the Psychiatric Unit and poor communication skills among general health workers at the MRRH and members of the public discourages people with mental illnesses from seeking psychiatric care. The derogatory label of "*ekiraru"* (mad house) suggests that people with mental illnesses perceive the Psychiatric Unit as uncomfortable and unhelpful to them. The report also suggests the derogatory term, *"ekiraru"* (mad house), used in reference to the Psychiatric Unit at the MRRH, to be well-known and frequently used by members of the public.

Furthermore, John, a 50 year old male religious healer, provided information that shows Pentecostal churches providing care to outpatients to be similarly stigmatised. He stated in this regard:

> People who bring patients to church are those who are exceptionally concerned about the patients' well-being because traditional churches are generally biased against Pentecostal Church. People fear being accused of crossing from traditional churches to the Pentecostal Church. By the time a family brings a patient to the Pentecostal Church, they will have decided that come what may.

John is seen to believe that, unlike the Pentecostal Church, established religious denominations in Uganda, such as the Anglican Church, are unable to effectively care for people with mental illnesses, resulting in outpatients from established churches converting to the Pentecostal Church in order to receive care for their mental illnesses. However, because both mental illness and the Pentecostal Church are both stigmatised, outpatients seeking spiritual healing (care) at the Pentecostal Church are, in fact, likely to experience aggravated stigma.

The finding that participants believe derogatory labels for outpatients by members of the public and care providers to be barriers to effective care has similarly been reported by researchers previously. For example, Saleebey (2002) reports mental illnesses to be often conceptualised within the biomedical model framework, which emphasises pathology over patients’ strengths. A person with a psychiatric diagnosis, for example, schizophrenia, could therefore be identified as a “schizophrenic”. Labelling subsequently leads to objectification of people with mental illnesses, the patient being viewed as a “kind of pathology” (Tomm, 1989). Additionally, Garner (1968) reports labelling to be associated with negative treatment outcomes, such as hopelessness and apathy, among service users by means of self-fulfilling prophesy. Labelling and stigma also precipitate non-adherence to medical treatment as service users experience anxiety over being identified as pathological, for example, by entering a psychiatric ward in a general hospital, buying psychiatric medication at pharmacies or receiving psychiatric labels, such as depression in diagnoses (Angela, 2000). The pervasive influence of stigma runs counter to the rationality espoused by the Health Belief Model, the latter which suggests people with mental illnesses to be more likely to seek treatment to promote recovery and psychological wellbeing if medically diagnosed (Janz & Becker, 1984).

Furthermore, participants reported taking psychiatric medication to precipitate stigma among outpatients. For example, Mukaira, a 64 year old female patient with unipolar depression, stated in this regard:

> People do not treat me as a mad person, but I know it myself that I am one because I take medicines of mad people. If you are taking Chloroquine (medication for malaria) and you observe other people also taking it, won’t you know that you all have malaria?

This report suggests that Mukaira believes receiving psychiatric care to signify that she is a mad person. Mukaira, it is seen, has observed people whom she herself believes are mad receiving psychiatric care as she herself does. The report also suggests that Mukaira is anxious about adopting a sick role, which her family may dispute, as the latter do not treat her like a mad person.

The finding that participants believe taking psychotropic medication precipitates stigma among outpatients has similarly been found to be a barrier to adherence to antiretroviral therapy in South Africa. For example, Kagee and Delport (2010) report that because service users often fail to disclose their HIV-positive status to their families for of fear of being ostracised, they usually avoid taking medication for the illness in the presence of their families. This stigma-induced secrecy affects dosage and schedule adherence among service users. In contrast, service users who take their ARVs openly often experience negative feelings, such as shame and guilt, despite having disclosed their HIV-positive status to their families. Coetzee et al. (2011) similarly report stigma-induced secrecy in both care-seeking patterns and taking medication to be a barrier to adherence in antiretroviral therapy in South Africa. This barrier occurs because optimal adherence to antiretroviral therapy necessitates service users taking their medication daily, in the right dosage and at the right time, which is not possible when secrecy-related constraints, such as lack of privacy and time-off from work, are experienced. Tomm (1989) similarly reports that taking medication usually precipitates self-labelling and “pathologising” of health problems, which deprive service users of confidence and motivation for self-care.

In summary, participants reported stigma and discrimination by families and members of the public to be barriers to effective care for outpatients. Stigma and discrimination leads to outpatients being socially excluded and stereotyped as well as being discouraged from taking medication.

5.4.2. Poverty as a function of social and culture-related barriers to effective care. All participants reported poverty to be a barrier to effective care for outpatients. For example, Bosi, the 30 year old male nurse, informed in this regard:

> There are families who bring patients to MRRH with about 15, 000/= (R 46) and they know that going back home requires 10, 000/= (R 31) as transport costs. When the attendant sees that 5000/= (R 15) is already spent, she comes

> here and says, "I have no way out. I better take my patient home sick as he is but I make sure that I deliver him home. It will put him on chains with treatment and when he settles down, I will remove the chains".

This report suggests that Bosi believes that families violate the rights of outpatients to humane care in the least restrictive care environments because such families are unable to afford the costs associated with hospitalisation. Physical restraints used by families, together with medication, undermine the utility of psychiatric care as they precipitate psychological distress, stigma and relapse among outpatients.

Researchers have in the past similarly found poor people, who are usually most in need, to often lack access to mental health services in liberalised health care contexts. For example, Okuonzi (2004) describes the Ugandan health care system as deprived and thus incapable of meeting the basic health care needs of service users. Okuonzi (2004) argues the poor state of health services in Uganda to be due to vested business interests and conditions stipulated by donors and international funding agencies, such as the World Bank. According to Okuonzi (2004), the World Bank demands that the Ugandan government liberalises its health sector if it is to obtain funding for rebuilding the Ugandan economy, the latter which was destroyed by civil and military conflicts in the 1970s and 1980s. Liberalisation of the health sector and adoption of market principles mandate individuals, charities and private organisations to be the main providers of health services. It also restricts public funding to health promotion and prevention of disease, limits the role of the central government to policy formulation and technical guidance and devolves delivery of health services to the private sector and local authorities. Limited funds distributed to districts in Uganda are specifically earmarked for interventions prioritised by donors (Okuonzi, 2004). Similarly, Farmer (2003) reports that principles of demand and supply engendered in liberalised market economies fail to serve the interests of the poor. Consequently, the poor struggle to access basic human rights, such as health care.

Unaffordable transport costs to keep regular hospital appointments is another poverty-related barrier participants reported as hindering effective care for outpatients. For example, Nsheme, a 28 year old female patient with bipolar disorder, stated in this regard:

> I struggle to get transport to and from MRRH because I stay very far. I pay 3, 000/= (R 9) for a *boda boda* (motorcycle used for public transport) for a one way trip to MRRH. When I am lucky to get transport to go to MRRH, I stay there and I go home on foot and hungry.

This report indicates that Nsheme's hospital appointments are characterised by unpunctuality and intermittency because of the financial constraints she experiences. In addition, side effects of the psychotropic medication she takes and hunger she experiences possibly also make it difficult for Nsheme to make the long return journey from home to hospital by foot. As a result of the above challenges, Nsheme is likely to be discouraged from seeking psychiatric care.

In contrast, Mugore, the 43 year old mother of Nsheme, reported:

> MRRH is not very far from her home. Nsheme can walk there to collect the medicines. She wakes up very early and walks to MRRH and she comes back. The distance is about 4 miles to MRRH but she knows how to walk fast.

This report suggests that Mugore believes Nsheme to be capable of walking the return distance of approximately 8 miles with relative ease in order to receive psychiatric care. However, Mugore likely underestimates the ardour linked to the distance of 8 miles, considering that Nsheme experiences hunger and possibly sedative effects caused by the medication she takes.

Researchers have in the past similarly found excessive transport costs to be a barrier to effective care for poor service users. For example, Kagee and Delport (2010) report that people with HIV/AIDS fail to attend clinics regularly because of prohibitive transport costs and poorly developed transport networks in peri-urban areas in South Africa. According to them, people with HIV/AIDS have to walk long distances because public transport operates only along major routes, which are often too far from the ART clinics (Kagee & Delport, 2010). Physical fatigue from walking long distances, at times with young children, also discourages many service users from fulfilling their review appointments at the ART clinics (Kagee & Delport, 2010). Additionally, Narayan et al. (2000) report excessive transport costs that poor service users incur to be due to inequitable distribution of health facilities in many sub-Saharan African countries.

According to Narayan et al. (2000), many rural areas in countries, such as Malawi, lack even the most basic health care facilities. Service users are thus forced to walk discouraging distances (over 10 kilometres) to seek health services. The prohibitive costs involved in hiring private means of transport, such as cars, and impassable roads, particularly during rainy seasons, discourage poor people from seeking timely care. I discuss in detail the issue of centralised delivery of psychiatric care as a barrier to effective care on page 143.

Additionally, participants reported discouragement among outpatients in seeking hospital admission because the latter lack effective social networks. For example, Miriya, a 34 year old female social worker, stated in this regard:

> For poor patients, there is no one who comes to visit them in MRRH. Their social networks are very weak and cannot sustain their stay here. At times, inpatients worry about the goats which they left behind because there is no one to tether them and nobody is there to care for their children.

Apparently, Mariya believes hospitalisation at the MRRH to lead to social isolation of outpatients, because the latter’s social support networks are poor and thus unsupportive. The lack of social support (for example, emotional support such as empathy and instrumental support such as material and financial resources) is likely due to stigma associated with mental illness and the excessive cost of transport for visitors travelling to hospitals to see patients from rural communities. Yet social support, such as emotional encouragement and stimulation, are essential for coping with psychological distress, the latter which mental illness and hospitalisation often cause. Psychological distress associated with insecurity of children and livelihoods also exacerbate episodes of mood disorders, hindering recovery and prompting premature hospital discharge among outpatients.

In addition, Njuna, a 40 year old female counsellor, stated: “Initially, everybody in the family, that is mother, sister, brother, children and grand children, come with the patients to MRRH. As time goes on, you find maybe only two people may stay with this admitted patient because of financial problems”. This report suggests that Njuna believes an episode of a mood disorder to significantly alter family dynamics, including work and expenditure, as many family members are simultaneously involved in care-seeking. Because several relatives are admitted with the outpatients to provide for the latter's care, care-related challenges, such as overcrowding in wards and increased risk of acquiring infections (such as cholera), are inevitable and can likely negatively impact psychiatric care.

Researchers have in the past similarly found mental illness to be associated with diminished social support among patients. For example, Edgerton (1980) reports that although family ties among the Yoruba of Nigeria are considerably strong, mental illnesses, especially psychosis, quicly disrupt family relationships, leading to loss of social support for service users. Edgerton (1980) also reports a tendancy in spouses to quickly lose interest in partners with mental illnesses. While siblings and fathers display persistent neglect towards family members with chronic mental illnesses, mothers remain concerned and supportive. Edgerton (1980) attributes the loss of family support to the excessive costs associated with care-seeking. I discuss in detail the issue of excessive financial expenses as a barrier to effective care on page 118. Furthermore, Narayan et al. (2000) report financial hardships experienced by poor families to often lead to decline in community social ties, since poor people become more individualistic to cope with associated financial and material stress. Narayan et al. (2000), report for example, that because of decline in food availability, poor people in Malawi hide food to avoid sharing it with more needy relatives. In contrast, Rüsch et al. (2005) attribute loss of social support among patients to stigma associated with mental illness. Social exclusion, in turn, aggravates social withdrawal and is primarily caused by mental illnesses such as depression. A vicious cycle of stigma, loss of social support and social withdrawal thus occurs among people with mental illnesses. I discuss in detail the issue of social exclusion as a barrier to effective care for outpatients on page 111.

The finding that participants believe outpatients to be preoccupied with the insecurity of their livelihoods and families has similarly been reported elsewhere. For example, Narayan et al. (2000) report poor people to be constantly anxious about survival, hunger and the search for food and shelter because of diminished assets. In contexts of severe land shortage and dependence on unpredictable weather, precarious livelihoods engender a tension-filled life among poor people. Narayan et al. (2000) also report insecurity of livelihood to have a rural-urban dimension. For example, poor people in rural areas tend to be more concerned about insecurities involving, for example, unreliable rainfall and pests, both which affect subsistence agriculture, while poor people in urban areas tend to be concerned about insecurities involving unemployment, mainly casual labour and exploitation. With regard to concerns about child care, which participants reported as a barrier to effective care among outpatients, Kagee et al. (2011) similarly report the lack of child-care services to hinder adherence to antiretroviral therapy in South Africa. In particular, high levels of poverty is likely to prevent service users from attending regular mental health clinics or seeking admission at hospitals because they are unable to hire a child attendant or to pay for day-care services to ensure their children's safety.

It is noteworthy that participants described the different care providers, that is, psychiatric health workers, religious healers and traditional healers, as perpetrators of aggravated poverty among outpatients. For example, Milly, a 35 year old female psychiatrist, informed in this regard: "Patients go everywhere – they go to the witches, the traditional healers and herbalists while searching for a *cure*. By the time they come to the psychiatric ward, they will have almost sold everything". This report suggests that Milly believes outpatients seek psychiatric care from the MRRH only after they have explored alternative sources of care. Factors such as poor dissemination of information about mental health care options and stigma could account for outpatients' delay in seeking psychiatric care. The above report also suggests outpatients to be too poor to meet basic needs, for example, food, when they eventually do seek psychiatric care at the MRRH.

Similarly, Mulefu, a 50 year old male traditional healer, stated in this regard:

> By the time patients come here (traditional healer's shrine), they will have already wasted much money and become too poor to provide their basic needs, such as food. People with money usually don't believe that a shrine like this can be of help to them through only prayers.

This report suggests that Mulefu perceives other forms of care, for example, psychiatric care, as ineffective in treating mental illnesses among outpatients. Mulefu is also seen to believe that outpatients become poor because they waste money in seeking ineffective care and only seek supernatural intervention when too poor to continue the search for a cure. Mulefu is further seen to perceive supernatural intervention as more accessible to outpatients than, for example, psychiatric care.

Sonia, a 41 year old female religious healer, similarly stated: “Most of the patients whom we pray for in this church come here as their last resort. Patients believe that since they have already done everything, wasted much money and have failed to recover it is only God who can cure them”. This report suggests similar implications to those stated above by Mulefu. Because Sonia believes supernatural intervention to be more effective than other forms of care, for example, psychiatric care, she does not refer outpatients to other care providers, such as psychiatrists.

Researchers have in the past similarly found care-seeking, for instance, from traditional healers and other care providers, to be associated with excessive financial and material costs, thus aggravating poverty among people with mental illnesses. I discuss in detail the issue of excessive consultation fees as a function of aggravated poverty on page 118.

Hunger is another poverty-related barrier participants reported as hindering effective care for outpatients. For example, Gadi, a 34 year old male nurse, informed in this regard:

> There are patients who we admit and if the social worker does not provide a meal, they stay hungry; they get the treatment only. If I admit ten patients, I can say eight, if not nine, might also be incapable of buying their medications.

According to Gadi, poor outpatients prioritise buying medication over food when admitted to the MRRH. However, starvation worsens illness episodes and is likely to precipitate other complaints, such as physical weakness, leading to premature hospital discharge among outpatients.

Mulefu, a 50 year old male traditional healer, similarly stated:

> One basic indicator that the patient is recovering is when he is able to eat. When the patient comes here, the first prayer is for gaining appetite. However, because of feeding many patients, we have debts associated with buying food.

As indicated, Mulefu believes he is unable to provide effective care due to the high costs of providing food to outpatients. However, it is likely that because of limited food supply, increased appetite is more indicative of desperation caused by hunger rather than signs of recovery among patients.

Researchers have in the past similarly found hunger to be a barrier to effective care among poor service users. For example, Farmer (2003) reports having observed that poor people with tuberculosis in Haiti often fail to adhere to chemotherapy because they lack food to take alongside their biomedical treatment. Appropriate nutrition is necessary for the restoration of physical strength and weight among service users, who argue that to “give them medicines without food was tantamount to washing one’s hands and then wiping them dry in the dirt” (Farmer, 2003, p. 149). Similarly, Narayan et al. (2000) report food insecurity in many sub-Saharan countries, such as Malawi and Ethiopia, to be a pervasive preoccupation among poor people both in rural and urban areas. As a result, many poor people have only one meal per day, usually lunch and, at times, spend several days without eating at all. As such, poor people regard access to at least three meals a day as a prime indicator of well-being and wealth (Narayan et al., 2000).

Overdependence by outpatients on their families is another poverty-related barrier that participants reported as hindering effective care. For example, Martha, a 37 year old female religious healer, stated in this regard: “Patients are so dependent on relatives for care. If other people don’t take them to the hospital, they don’t go there. If other people don’t facilitate patients with the needed money, they cannot go to the hospital as well”. This report suggests that Martha believes outpatients lack personal resources, autonomy and insight to support their own care. Because of being highly dependent on their families, their needs are likely to be accorded less priority than those of other family members.

Similarly, Nkole, a 48 year old male patient with bipolar disorder, stated:

> My family believes it is their responsibility to care for me, but as a person, I notice that I am burdening them. If a person helps you today, tomorrow and the need for help becomes endless, sometimes you feel that you have overburdened this person.

Evidently, Nkole believes his family experiences a considerable burden of care because of his ongoing need for support. It also suggests that Nkole experiences recurrent mood disorder episodes, which necessitate regular family support, for example, financial.

Researchers have in the past similarly found care-seeking to be associated with increased dependency by service users on care providers. For example, Speed (2006) reports service users accepting the identity of a “patient” to be more likely to be granted a sick role by their families and other care providers. However, fulfilment of the sick role expectations leads to increased dependency by service users on their care providers, such dependency often manifesting in behaviours such as adherence to medical treatment and passivity among service users. In addition, Strandberg, Norberg and Jansson (2003) report increased dependency on care providers to often overwhelm service users. According to Strandberg et al. (2003) dependency is inversely related to productivity and autonomy – values that many patients cherish highly. Coping mechanisms service users employ to manage feelings of powerlessness and hopelessness associated with dependency are also psychologically demanding. Strandberg et al. (2003) particularly report service users as enduring a great deal of suffering before asking for help from care providers to avoid being labelled burdensome. They also contain strong emotional feelings they suspect might result in disapproval and withholding of care by care providers. Furthermore, service users often experience “double helplessness” (Strandberg et al., 2003). Double helplessness, according to Strandberg et al. (2003), refers to primary vulnerability associated with being dependent on care and secondary vulnerability associated with being denied care requested by a dependent patient. In addition, service users endeavour to learn skills, such as appropriate timing, to ensure they receive the needed care. They, however, lack the choice between good and bad care and also grieve the loss of personal abilities for independent living (Strandberg et al., 2003).

Participants also reported that poverty means outpatients have to balance providing manual labour on other people’s farms to raise funds to support care-seeking and working on personal farms to ensure food security. For example, Nsheme, a 28 year old female patient with bipolar disorder, stated in this regard:

> I do not get time to provide manual labour to raise money for buying my drugs because I have to do my own subsistence farming. When I stay without taking medicines, I get a headache for the whole day.

Mugore, her 43 year old mother, similarly stated: “Her husband advised Nsheme to provide manual labour in other people’s gardens in order to get money for buying the medicines. Now don’t you see that surely they impoverished?” These reports suggest that participants attribute outpatients’ non-adherence to medical treatment to dependence on manual labour for income to facilitate care-seeking. However, symptoms of mood disorders and side effects associated with use of inferior medication are likely to lead to occupational impairment and aggravated poverty, thus hindering care-seeking. Moreover, it is possible that Nsheme is underpaid or exploited for manual labour because of her desperation to raise funds for her psychiatric care.

Researchers have in the past similarly found manual labour to be the main source of income among poor people. For example, Narayan et al. (2000) report the body to be the main or only asset for many poor people. Because most poor people are usually less formally educated and skilled, they tend to earn their living by performing manual work, for example, farming and other physical jobs. However, food shortage and sickness often lead to somatic and psychological distress and weakens, which devalue the body (Narayan et al., 2000). Sickness among the poor thus often results in a vicious cycle of somatic and psychological distress, reduced returns from manual labour, for example, food and income and increased costs associated with care-seeking. I discuss in detail the issue of somatic complaints as perceived consequences of mood disorders on page 125. According to Narayan et al. (2000) poor women, in particular, experience *time poverty*. Time poverty, as used in this context, means poor women lack the time to rest, reflect, enjoy a social life and participate in community events because of their increased need to earn income in addition to the burden of caring for their families. Narayan et al. (2000) also report women to be at increased risk of acquiring sexually transmitted infections, for example, HIV, because they often engage in commercial sex to generate income to meet personal and family needs. Muhwezi and Okello et al. (2008) similarly report that poor families engage in manual labour to care for relatives with physical and mental illnesses. Because manual labour does not yield much return in terms of money and food and also leads to significant psychological distress, many such families are unable to provide effective care.

In summary, participants reported poverty to be a barrier to effective care for outpatients. Poverty-related barriers, according to participants, comprise barriers such as premature hospital discharge, prohibitive transport costs, poor and unsupportive social networks and increased dependency among outpatients.

In this chapter, I have presented and discussed results on participants' perspectives regarding structural barriers to effective care. As these discussions have shown, structural barriers to effective care for outpatients are categorised as follows: (a) the low priority status of mental health care on the public-health agenda, (b) poor organisation of mental health services, and (c) social and culture-related barriers. In conclusion to this section, there was consensus among all participants that structural barriers significantly constrain care for outpatients. Structural barriers to effective care, such as poverty, stigma and discrimination, exacerbate the distress associated with mental illness and care-seeking. They also constrain both the supply of and demand for psychiatric care. However, participants emphasised different categories and dimensions of structural barriers to effective care, consistent with their unique experiences and care contexts.

In the following chapter, I present and discuss results regarding participants' conceptualisations of care.

Chapter 6

Conceptualisation of Care

6.1. Introduction

Five subthemes regarding conceptualisation of care emerged from the data. These are: (a) provision of family social welfare support, (b) provision of psychotropic and traditional medication, (c) provision of health education, (d) provision of counselling, and (e) belief in spiritual healing. In the following sections, I consider each of these subthemes in detail.

6.2. Provision of Family Social Welfare Support

All participants reported provision of family social welfare support to comprise care for outpatients. For example, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder, stated in this regard:

> I used to buy tablets from the pharmacies in Mbarara town for him and he used to take one tablet per day, each costing 1,000/= (R 3). So, for a month his tablets would cost 30,000/= (R 94). After sometime health workers changed his prescription to an injection and now he requires 100mls, which I buy at 50,000/= (R 156) per month.

As this report shows, Mugurusi believes it a familial duty to buy medication for outpatients from private pharmacies when psychiatric health workers at the MRRH do not dispense such medication. Mugurusi's altruistic attitude is thus seen to enhance his son's adherence to medical treatment. Mugurusi is, however, seen to be concerned about the out-of-pocket payments incurred for psychiatric care, which is highly likely to aggravate poverty among outpatients and their families.

Similarly, participants reported provision of food and drinks to comprise family social welfare support to outpatients. For example, Nsheme, a 28 year old female patient with bipolar disorder, informed: "My mother tried her level best to ensure that I had food and drinks because the medicines would make me physically weak. She used to prepare good food for me because I used to get hungry all the time". It is obvious Nsheme considers food to be a necessary treatment for physical weakness. Self-medication with food means Nsheme's mental health condition is likely to be ineffectively managed. In addition, the cost of providing food regularly to Nsheme is likely to aggravate family poverty and the burden of care.

Similarly, Kabale, the 38 year old wife of Mukiga, a 41 year old male patient with unipolar disorder, stated:

> He tells me that he would rather not get food but gets drinking water. I make sure that I have his drinking water available for 24 hours. When he wakes up in the morning, it is a must for him to drink 2 mugs of water in order to neutralize his sedating medicines.

This report implies that Kabale believes her husband drinks water as a form of treatment to counter side effects of the medication he takes. Kabale is seen to be supportive of her husband's high regard for self-medication with water. The report also shows that this outpatient is uncomfortable with and unlikely adhere to psychiatric care because of the side effects of medication he takes. Self-medication also indicates that he does not receive timely medical support from psychiatric health workers regarding management of the side effects of the medication he takes.

Furthermore, participants reported provision of clothes to comprise family welfare support to outpatients. For example, Mutungi, a 35 year old male patient with bipolar disorder, stated: "When I was ill, my wife used to buy for me nice things; she would bring me something like a pair of trousers, shoes, or a shirt and I would appreciate that she cares about me".

Similarly, John, a 50 year old male religious healer, commented on the provision of clothes as a form of social welfare support to outpatients as follows:

> After praying for mental patients, we change their clothes. The patients bathe and they receive new clothes to signify that they are new persons. We ask the congregation, who wants to bless this person? Some people provide clothes for mental patients.

As the above reports show, Mutungi and John consider the provision of basic needs, for example, clothes, to outpatients as reassurance of the latter's continued care by the family and community. The provision of clothes, for example, prevents outpatients from walking around naked in public, which members of the public often associate with severe mental illness. John is seen to view the wearing of new clothes in the church context as symbolic of recovery among outpatients. Because having new clothes symbolises recovery from a mental illness, John is unlikely to refer outpatients for evidence-based psychiatric care.

Additionally, participants reported maintaining the personal hygiene of outpatients to comprise family social welfare support. For example, Nabasa, the 40 year old daughter of Murungi, a 60 year old female patient with depression, reported:

> I stay very close with my mother to ensure that she has clean clothes to wear. I also ensure that she sleeps in a hygienically good bed; so generally I am always available for her care because she is very sick.

This report reveals Nabasa believes her mother to be too ill to take care of herself and to be responsible for her personal hygiene. Because she is bedridden most of the time, Murungi is at risk of developing pressure sores, is occupationally impaired and thus dependent on her family for basic needs, such as nutrition. Moreover, the family is seen to experience a considerable burden of caring for such a severely ill patient within the community, because they are not able to access inpatient care.

Worse still, participants reported nursing of outpatients by their families to similarly occur in the hospital context. For example, Agaba, a 50 year old male clinical officer, reported:

> Family-based carers come and look after their patients when they are admitted in MRRH. When it comes to bathing the patients, the family attendants help. They also help in terms of feeding the patients and physically restraining them because when patients lack concentration, they may end up destroying other people's belongings.

It is apparent Agaba believes the provision of nursing care for patients admitted to the MRRH to be a duty of their families. Because they are nursed by lay care providers (their families) when admitted to the MRRH, patients are not likely to receive quality (professional) nursing care. It may be inferred, that families also experience an aggravated burden of care while caring for hospitalised relatives as they are unable to access respite care from psychiatric health workers. In addition, the use of violent measures, for example, seclusion at the MRRH, suggests that the poor care provided by their families aggravates episodes of mood disorders among inpatients.

The finding that families shoulder much of the care responsibility for outpatients is in keeping with findings by researchers elsewhere, who report approximately 70% of total health care to be usually provided within the patients’ close bonds, such as kinship, friendship and neighbourliness (Helman, 2007). For example, in his study involving 115 Taiwanese families, Kleinman (1980) reports 411 sickness episodes among 724 family members, of which 93% had been initially treated in patients’ families, with 73% receiving the only available treatment within patients’ families. According to Kleinman (1980), socioeconomic factors, such as age and social class, influence the nature of patients’ sick roles and care-seeking patterns. For example, while 42% of sickness episodes among children in his study were observed to have received treatment from either professional or folk practitioners, only 14% of sickness episodes among the elderly and 9% of sickness among other adults were seen to have been similarly treated. Furthermore, while all the elderly patients (100%) and 98% of the adult patients were seen to have initially been treated at home, only 88% of the children were seen to have been similarly treated. With regard to socioeconomic class, Kleinman (1980) observes that poor patients experience the largest number of sickness episodes and treat all sickness episodes within their family boundaries.

The centrality of food in treatment of persons with mental illness has similarly been reported elsewhere. For example, Mavundla, Toth, and Mphelane (2009) report families as regarding provision of physiological needs, for example, food, as a basic aspect of care for persons with mental illnesses in South Africa. Mavundla, et al. (2009), however, additionally note that patients often demand special diets, which families struggle to provide because of financial constraints. Similarly, McLeod and Bywaters (1999) report over-reliance on home remedies in managing sickness episodes to be due to factors such as perceived stigma and inefficacy of Western medication as well as internalised assumptions, for example, self-reliance, among poor people. I discuss in detail the issue of hunger as a poverty-related barrier to effective care for outpatients on page 160.

The increased involvement of families in nursing people with severe illness has similarly been reported by other researchers. For example, McLeod and Bywaters (1999) report family-based care to be rife due to various factors, for example, underfunding of health and social care and *commodification* of health by the UK government. McLeod and Bywaters (1999) describe increased transfer of costs and responsibility for health care from the National Health Services (NHS) to individuals and their families as the *domestication* of health care. Domestication of health care is associated with reduction in the number of available hospital beds, rapid reduction in patients' length of stay at hospital and increased numbers of outpatients. It also signifies greater involvement of private health care providers, for example, nursing and residential homes, paid domiciliary care and health insurance companies. Okuonzi (2004) similarly reports increased family responsibility for patient care in Uganda to be due to liberalisation and adoption of market principles in provision of health services. According to Okuonzi (2004), the latter stems from conditional funding provided by international donors, for example, the World Bank. Donors require limitation of public expenditure in Uganda, which is aimed mainly at health promotion and prevention of disease. Donors also advise reorientation of the role of the central government from that of main provider of health services to policy formulation and provision of technical guidance to private health care providers (Okuonzi, 2004).

Below, I present and discuss participants' descriptions of medical treatment, which they reported as another form of care for outpatients.

6.3. Provision of Medical Treatment

All participants, except religious healers, reported the provision of medical treatment by psychiatric health workers, families, and traditional healers to comprise care for outpatients. For example, Milly, a 35 year old female psychiatrist, informed in this regard:

> We treat patients with bipolar disorder with chlorpromazene, haldolperidol; those are the common drugs that we have here. We also provide the patients

> with mood stabilizers mainly carbemazepine. We give patients with depression antidepressants mainly amitriptyline, imipramine and diazepam.

It is clear from this report that Milly is concerned about the limited available prescription kit, which constrains effective psychiatric care for outpatients. In addition, it is seen that psychiatric health workers prescribe for outpatients relatively older psychotropic drugs, often associated with severe side effects.

Additionally, Mutungi, a 35 year old male patient with bipolar disorder, commented on medical treatment by psychiatric health workers as follows: "Health workers in MRRH treated me well and gave me my medicines, which I used to take in the morning and evening. When we came back home, my mother also took me to church for prayers". As indicated in this report, Mutungi and his mother believe it is necessary to complement medical treatment with spiritual healing, which implies that they are either dissatisfied with psychiatric care or believe it to be a complementary treatment to medical treatment.

The finding that participants regarded the provision of medical treatment to be a major form of care for outpatients is in keeping with findings of researchers elsewhere, who report biomedical interventions to be dominant in biological psychiatry (Helman, 2007). Biomedical interventions comprise a range of therapeutic options, such as medication and electroconvulsive therapy (ECT) (Patel et al., 2009; Roos et al., 2001). In addition, Patel (2003) reports the use of medication such as serotonin boosters to treat mental illness by regulating the level of chemical activity in a patient's brain. Prescription by psychiatric health workers of antipsychotic drugs, antidepressants and mood stabilisers for outpatients is thus in keeping with modern treatment practices for bipolar disorder and unipolar depression (WHO, 2009b). For example, Patel (2003) observes antidepressant medication, used to treat common mental disorders, for example, depression, as comprising mainly of three types, namely: (a) tricyclic antidepressants, for example, amitriptyline, (b) serotonin boosters, for example, fluoxetine, and (c) other new drugs, for example, paraxetine. In contrast, antipsychotic medication, used to treat severe mental disorders, such as bipolar disorder, comprises two types, namely; (a) older antipsychotic drugs, for example, haloperidol, and (b) newer antipsychotic drugs, for example, resperidone. According to Patel (2003), mood stabilisers such as lithium carbonate, sodium valpoate and carbamazepine can be used to prevent relapse among service users with a manic-depressive disorder. However, because of their prohibitive costs, new generation drugs, such as fluoxtine for depression and resperidone for bipolar disorder, are largely inaccessible to service users in most LAMICs (WHO, 2001; WHO, 2009b). Most service users in LAMICs are therefore given older generation drugs, such as amtriptyline for depression and chlorpromazine for bipolar disorder. According to Patel (2003), older generation drugs, such as amtriptyline, are as effective as new generation drugs, such as resperidone, but have more side effects. I discuss in detail the use of low quality psychotropic medication as a barrier to effective care on page 139.

Apart from psychotropic medication administered by psychiatric health workers, participants reported that families and traditional healers administer traditional medication to outpatients. For example, Mutungi, a 35 year old male patient with bipolar disorder, informed in this regard:

> My mother gave me herbs, which I used to take and feel somehow better. She used to squeeze, boil and give me *enderema* (botanical name is *Basela alba*) and *omubirizi* (botanical name is *Vernonia amygdalina*) to drink. She gave me herbs to prevent me from becoming mad. She also wanted to prevent my head from getting damaged because she thought that I was bewitched.

Madamu, the 36 year old wife of Mutungi, corroborates his views as follows: “His relatives asked me to take him to the village so that they could care for him. They gave him traditional medicines and I did not object to their assistance but his mental problem worsened”. It is apparent from these reports that Mutungi believes traditional medicines to be a treatment for severe mental illness caused by witchcraft and that the severity of such illness can lead to head damage. However, initial use of traditional medication accounts for Mutungi’s delay in seeking psychiatric care. In addition, while Madamu is seen to doubt the efficacy of traditional medicine in treating mental illness, she is also seen to cooperate with her husband in seeking care from a traditional healer.

Furthermore, participants reported outpatients to simultaneously seek traditional medication and psychiatric care. For example, Agaba, a 50 year old male clinical officer, stated in this regard: “When we are administering psychotropic medications, patients also seek help from traditional healers. I have seen this one happening here in the ward. As we are giving the patients medicines, their families are also giving them herbal medicines". This report indicates that Agaba believes that outpatients seek psychiatric care and traditional treatment as either a matter of trial and error or as complementary treatment. It also implies that psychiatric health workers encourage patients to utilise traditional medication alongside psychotropic medication when admitted to the MRRH. Taking traditional medication while admitted to the MRRH, however, implies that patients fail to adhere to medical treatment. Moreover, patients are at high risk of suffering from medical complications such as intoxication as a result of the simultaneous use of psychotropic and traditional medication.

Janet, a 55 year old female traditional healer, describes the mode of administration of traditional medication to outpatients as follows:

> Firstly, I put medicines in his nose and I also give him medicines to take and to bathe. I also give the patient a medicine for burning on a piece of broken clay pot. This medicine produces much smoke which covers and enters the patient to help him to sleep and to recover gradually.

This report suggests that Janet administers overdoses of traditional medicines that cause physical effects, such as suffocation, among outpatients. Janet is seen to perceive physical effects such as physical exhaustion as signs of recovery among outpatients. The report also shows that Janet violates the rights of outpatients to evidentiary-based and humane care by administering overdoses of medication.

Researchers have in the past similarly found families and traditional healers to often treat people with mental illness with traditional medication. For example, Sorsdahl et al. (2010) report that traditional healers in South Africa treat psychotic illness with *muti* (traditional medicine), administration of which includes drinking, bathing and sniffing. Treatment by traditional healers usually requires service users and their families to live at the traditional healers' shrine for a relatively long period of time, ranging from two weeks to over a year. In addition, Sorsdahl et al. (2010) report that traditional healers, at times, physically restrain service users with chains and ropes to administer traditional medication and to ensure adherence to treatment. Treatment provided by some traditional healers, according to Sorsdhal et al. (2010) is highly structured, for instance, involving taking a teaspoon of *muti* (traditional medicine) with food three times a day.

These researchers also particularly note that traditional healers treat *amafufunyana* (madness) with a mixture consisting of the following ingredients: (a) one teaspoon of methylated spirit, (b) one half of a teaspoon of Benzine (a colourless, flammable liquid used as a cleaning agent, (c) a few pieces of *indonya* (a traditional herb), and (d) one half of a teaspoon of *umdlebe* (a traditional herb) (Sorsdhal et al., 2010). Subsequent to administration of such medicine, traditional healers perform rituals to enhance and signify recovery among service users (Sorsdhal et al., 2010). The simultaneous use of traditional medicines and psychotropic medication is not a phenomenon unique to this study context as it has been reported elsewhere. For example, writing about the Taiwanese context, Kleinman (1980) reports that Taiwanese patients were seen to believe Western medicine to be effective in treating physical effects, such as loss of appetite and fatigue, and, in contrast, Chinese (traditional) medicine to be effective in addressing the root cause of physical symptoms, such as fatigue. As a result, Taiwanese patients were seen to use both Western and Chinese medicines simultaneously for different but complementary ends. Kleinman (1980) also reports that Taiwanese patients were also seen to sometimes use traditional medication to mitigate the side effects of Western medication. Swartz (1998) similarly reports that because distressed persons are often desperate, they are more concerned with *cure* than with the source of such a *cure*. For this reason, they often take different treatments to improve their recovery prospects (Swartz, 1998).

In the following section, I present and discuss participants' descriptions of health education, which they reported as another form of care for outpatients.

6.4. Provision of Health Education

All participants reported the provision of health education by the families, psychiatric health workers, religious and traditional healers involved in the care of outpatients to be another major form care for the latter. For example, Madamu, the 36 year old wife of Mutungi, a 35 year old patient with bipolar disorder, informed in this regard:

> I remind my husband that doctors told him that "if you need your life you must leave drinking alcohol and smoking cigarettes". He tells me that when he does

> not drink alcohol and smoke cigarettes he feels bad. I tell him that when you are taking something, you consider its costs and benefits.

In contrast, Mutungi himself described the provision of health education by psychiatric health workers as follows:

> There is a doctor who educates me on how to remain healthy. He tells me that if I am drinking alcohol, I should stop and if I am smoking cigarettes I should stop. I follow those instructions and that is the peace which I have nowadays.

These reports indicate that Madamu believes that Mutungi can live positively with his mental illness, provided he stops engaging in risky behaviour, such as drinking alcohol. As a result, Madamu is seen to emphasise the health education messages Mutungi receives from psychiatric health workers to encourage him from abstaining from such risky behaviour. The continued use and abuse of substances indicated in the above reports, however, suggest that Mutungi lacks insight into his mental health condition and is at risk of experiencing negative treatment outcomes, such as frequent relapse. Mutungi himself, in contrast, reports that he benefits from health education and is living positively with his mental health condition.

Additionally, Milly, a 35 year old female psychiatrist, commented on the provision of health education to outpatients as follows: “We give the outpatients medications and advice on how to take them and what to expect from these medications; the tell-tale signs for relapse, what can happen so that they can pay attention to it before it gets worse”. It is notable that Milly believes it essential for outpatients to comprehend the complexity of their respective mental conditions and management thereof. Milly is also seen to believe that improved mental health literacy and insight foster adherence to medical treatment and prevent risky behaviour, such as substance abuse, among outpatients.

Researchers have elsewhere similarly found provision of health education to be central to care for persons with mental illnesses. For example, Prichard (2006) reports that psycho-education helps patients and their families to understand mental health conditions and boosts their morale for care-seeking and care provision. Health education particularly mitigates the likelihood of a vicious cycle of highly expressed family emotion (critical and hostile remarks made by family members) and increased vulnerability of the patient to relapse. According to Prichard (2006), sharing modern knowledge, for example, on risk factors for relapse and early intervention, with persons with mental health illnesses and their families, assists mental health professionals in demystifying and destigmatising mental illness. Similarly, Gonzalez-Pinto et al., (2004) report psycho-education combined with pharmacological treatment to enhance adherence to medical treatment among service users. They also report training patients and their families in timely identification of manic symptoms to be central to improvement of treatment outcomes and prevention of relapse among patients with bipolar disorder (Gonzalez-Pinto et al., 2004). Additionally, Pinto-Foltz and Logsdon (2009) report that in the United States, mental health professionals in collaboration with service users, implement health educational initiatives, such as "Depression is Real", to counter stigmatisation of affected individuals and families. Health education in this regard aims to challenge and clarify misconceptions associated with mental disorders (Pinto-Foltz and Logsdon, 2009).

Despite the above positive reports, most participants, especially outpatients and families, reported that psychiatric health workers fail to provide adequate health education to outpatients. For example, Mukaira, a 64 year old woman with unipolar depression, informed in this regard:

> Health workers had started providing health education but it stopped. There was a white lady who was facilitating a health education session and Doctor Denis asked me if I understood English. I told him that "I don't understand even a single word in English".

This report illustrates that Mukaira believes health education provided by psychiatric health workers to have been of no benefit to her as it was delivered in English, a language which many outpatients do not understand.

Similarly, Nabasa, the 40 year old daughter of Murungi, a 60 year old female patient with depression reported: "I have not seen health education being provided in MRRH. I have also not yet asked health workers to explain to me my mother's health condition. I would be happy to know the root cause of her mental condition". It can be seen that Nabasa lacks the confidence to request basic information regarding her mother's mental illness. However, it is likely that Nabasa does not request such explanations because she believes health workers would be unwilling to provide them to her.

The finding that most participants believe psychiatric health workers do not provide health education to outpatients and their families has similarly been reported elsewhere. For example, Rolfe, Sheehan and Davidson (2008) report significant gaps in information provided by clinicians to service users on community treatment orders (CTO). A community treatment order is a legal instrument compelling involuntary patients to utilise mental health services (Rolfe et al., 2008). According to Rolfe et al. (2008), persons with mental disorders on CTO are entitled to information regarding access to a mental health review board, an advocate from the Council of Official Visitors and the opportunity for a second opinion from another psychiatrist regarding their psychiatric diagnoses as stipulated in the Western Australian Mental Health Act. However, Rolfe et al. (2008) report that psychiatric health workers fail to adhere to such provisions and note that 33% of service users studied had not been informed about the reasons for their placement on a CTO and the implications of being on a CTO. Additionally, 55.5% of service users had not been informed of their right to a second opinion from another psychiatrist if they were not satisfied with their current psychiatric diagnosis, while 38.7% had not been informed of their right to access an advocate from the Council of Official Visitors if they required one. According to Rolfe et al. (2008), it is likely that clinicians consider raising awareness among service users about their rights and entitlements a non priority in psychiatric care. However, such lack of awareness and its associated responsibilities suggest that service users unintentionally breach the law with regard to CTO. Because of the lack of a mental health policy, an amended mental treatment act and a mental health review board to safeguard service users in Uganda, the rights of outpatients in a study were similarly noted as being violated (Kigozi et al., 2010). Furthermore, writing about the Taiwanese context, Kleinman (1980) reports that Western-style health workers were seen to often spend minimal consultation time with service users, failing to solicit sufficient information, for example, to ensure effective diagnoses of conditions presented by service users. Western-style doctors were also seen to fail to provide sufficient information regarding their diagnoses of and medical treatment for service users. Mavundla et al. (2009) similarly report families of persons with mental illnesses in South Africa to be often frustrated by the lack of health education by mental health professionals. They also report that although families show interest in knowing more about their relatives' mental conditions and treatment, the former are uncertain about alternative sources to access relevant information (Mavundla et al., 2009). Mavundla et al. (2009) report that such families believe this failure to be linked to the stigma associated with mental illness. I discuss in detail the issue of ineffective communication between psychiatric health workers and outpatients as a barrier to effective care on page 145.

Furthermore, participants reported that religious and traditional healers provide health education to outpatients. For example, John, a 50 year old male religious healer, informed in this regard:

> The Bible says that we renew our mind on the word of God. We therefore tell the patients what God thinks about them and what he wants them to be. For instance, the outpatients are supposed to seek the word of God and live according to the scriptures.

This report indicates that John believes health education to signify spiritual growth among outpatients. In addition, John is seen to encourage outpatients to perceive their respective mental illnesses as God-given and therefore treatable by divine intervention.

In contrast, Bernard, a 67 year old male traditional healer, reported:

> I educate patients against stealing other people's property and beating elderly persons. I also educate patients how to treat madness. In fact, most mental patients after recovery come here to receive medicines which they plant and use in treating madness.

This report indicates Bernard believes behavioural change to be crucial in promoting mental wellbeing and serves as a protective factor against relapse since, in his view, antisocial behaviour causes mental illness among outpatients. Consequently, it is seen that some outpatients self-medicate on the basis of training received from Bernard.

The finding that participants believe religious and traditional healers provide health education to outpatients is surprising in this study as researchers have in the past reported sacred and secular healers to be very secretive about their knowledge regarding care for clients (Sorsdahl et al., 2010). For example, writing about the Taiwanese context, Kleinman (1980) reports that shamans were often observed to not obtain histories of their clients' complaints, as popular Taiwanese ideology suggests that a healer must be able to divine clients' symptoms. Shamans were therefore seen to be often less informed about their clients' problems, especially if lacking casual contact with them. In addition, because shamans often do not conduct follow-up consultations with clients, they were seen to be generally uninformed about aspects of the care provided, in particular, regarding its effectiveness. Moreover, because most clients expect supernatural interventions, shamans were observed as being careful not to undermine clients' commitment to sacred explanatory models regarding their mental illnesses. Shamans were also seen to be reluctant to employ other explanatory models, even if they believed sacred explanatory models to be inadequate in accounting for their clients' mental illnesses (Kleinman, 1980).

Furthermore, Kleinman (1980) reports that although Chinese-style doctors were seen to maintain a narrow social distance from their patients, there still exists a wide knowledge gap between both these actors. For example, unlike their patients, Chinese-style doctors were seen to possess ancient medical classics, books that have been passed down over several generations in the family and believed to contain "secret prescriptions" (Kleinman, 1980, p.261). Kleinman (1980) also notes having often observed minimal verbal communication between Chinese-style doctors and their patients. For example, Chinese-style doctors made diagnoses mainly by taking a patients pulse, which they complemented with making observations of the patient's features, for example, eyes, hair type, and, at times, the tongue. According to Kleinman (1980), most Chinese-style doctors in his study rarely stated their diagnosis or provided explanations to patients regarding causes, pathophysiology or course of their health problems.

Below, I present and discuss participants' descriptions of counselling, which they reported as another form of care for outpatients.

6.5. Provision of Counselling

All participants reported the provision of counselling by psychiatric health workers, families, religious healers and traditional healers to be another form of care for outpatients. For example, Milly, a 35 year old female psychiatrist, informed in this regard:

> We give the patients assurance that mental illness is a condition that they can have and still live a normal life as long as they keep on medication. We cite other examples; “think about people who have got hypertension, diabetes or HIV, they also take medications. If they can do it, then you can also do it”.

It is notable that Milly fosters hope among outpatients for a positive prognosis as she believes mood disorders to be non life-threatening. According to Milly, adherence to the prescribed medical treatment can enable outpatients to live well-adjusted lives.

Similarly, Mugore, the 43 year old mother of Nsheme, a 28 year old female patient with bipolar disorder, stated: “Health workers used to sit with us and to converse with Nsheme to make her comfortable in the hospital. She used to love talking with the health workers about her mental problems”. This report indicates that Mugore believes psychiatric health workers to be empathetic and friendly. Mugore is also seen to regard counselling to have been beneficial to her daughter when the latter was hospitalised at the MRRH.

The finding that participants believe provision of counselling by psychiatric health workers to be a core aspect of care for outpatients has similarly been reported elsewhere. For example, Carrillo, Green and Betancourt (1999) report that patients often exhibit deeply ingrained beliefs regarding attributions for their distress and do not accept the medical model of illness and its associated technical interventions. Because clinicians are usually experts on disease and service users experts on illness, negotiation regarding both explanatory models becomes essential to harmonise clinicians and service users’ concerns, agendas, meanings and values. Kleinman (1980, p. 72) defines disease as a “malfunction of biological and/or psychological processes” and illness as the “psychosocial experience and meaning of perceived disease”. Thus, by acknowledging their belief systems, talking therapies enhance service users’ acceptance and adherence to biomedical interventions, for example, use of medication (Gonzalez-Pinto et al., 2004). Similarly, Gould (2010) reports symptoms of mental disorders, for example sexual disinhibition and violence in bipolar disorder, to precipitate feelings of distress such as shame, regret and guilt among persons with mental illnesses. Consequently, supportive counselling is essential to care received by service users and their families. Additionally, Gould (2010) reports care-seeking to often aggravate distress and manifest in feelings of failure, low self-efficacy and low self-esteem among service users and their families. Psychosocial interventions, such as cognitive behavioural therapy (CBT), are thus essential to facilitate cognitive restructuring and to decrease symptoms of mental illness among service users (Gonzalez-Pinto et al., 2004). Cognitive restructuring, according to Smith (2011), involves tackling self-defeating habitual thoughts about the self, the world and the future, with the aim of substituting them with more optimistic cognitions. Techniques such as self-monitoring, problem-solving, affect regulation and relaxation, which CBT espouses, are invaluable in fostering mastery and competence among service users to manage their mental conditions (Smith, 2011).

Despite the above positive reports, most participants, especially outpatients and families, indicated that psychiatric health workers at the MRRH fail to provide adequate counselling to outpatients. For example, Kusiima, a 42 year old female patient with unipolar depression, stated in this regard: “There is no health worker in MRRH who has ever provided to me any form of counselling. Not even for once; it is not there”. It is obvious that Kusiima believes psychiatric health workers to be unconcerned with meeting the psychosocial needs of outpatients. The neglect of her psychosocial needs implies that Kusiima either does not express a need for counselling to psychiatric health workers or that the latter do not perceive any psychosocial issues necessitating provision of counselling to her.

In contrast, Njuna, a 40 year old female counsellor, informs that psychiatric health workers believe that outpatients fail to benefit from counselling:

> When I see patients, I talk to them and when they come again and they are reporting no any improvement in their psychological wellbeing then I know these patients are drug-persons; they only want medicines. Even if you try harder, such patients will not benefit because they do not believe in counselling.

This report indicates that Njuna believes many outpatients to prefer medical treatment over counselling. Consequently, Njuna is seen to be impatient with outpatients if the latter do not realise the quick benefits of the counselling she initially provides them with. It is also possible that poor quality of initial counselling discourages outpatients from seeking follow-up counselling.

The finding that participants believe psychiatric health workers do not provide counselling to outpatients has similarly been reported by other researchers. For example, Patel (2003) reports health workers often believe that mere counselling does not constitute mental health care for persons with mental illnesses. Writing about the Taiwanese context, Kleinman (1980) similarly reports that both patients and health professionals were often seen to perceive physical treatments, such as injections, medication, and ECT, as more effective than psychotherapy. Participants' perceived lack of psychosocial interventions in the current study thus suggests that physical treatments, for example, medication, to be associated with biological psychiatry and to be dominant in the care of outpatients. Additionally, Patel (2003) reports that mental health professionals fail to provide counselling, at times, downplaying the significance of complaints among service users. According to Patel (2003), mental health professionals view some patients as mere neurotics, undeserving of care, dismissing the latter as not having a severe enough mental condition to warrant care. Similarly, Johnson et al. (2009) report that while many lay people perceive counselling as effective in treating depression, very few service users are provided with counselling when seeking psychiatric care. Yet, undue disregard of service users' complaints often aggravates their distress (Patel, 2003).

Additionally, participants reported that families provide counselling to outpatients. For example, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder, informed in this regard:

> We also try to counsel him so that he does not get mentally disturbed, especially when there is something that he wants, such as visiting our other home. As of now we know how we treat him; we explain to him that we may not be able to provide what he wants immediately but we assure him that we would provide it as soon as it is possible.

It is obvious from this report that Mugurusi believes psychological measures, such as empathic communication, to be effective in preventing his son from experiencing relapse. Mugurusi is also seen to believe relapse of his son to be predictable and caused by the latter's unmet needs, such as the desire to have a day out for leisure. The implication is that meeting this outpatient's basic needs, will promote his mental wellbeing and prevent relapse.

Furthermore, some outpatients reported receiving supportive counselling from their families. For example, Mutungi, a 35 year male patient with bipolar disorder, stated in this regard: “My wife counselled me to prevent a deterioration of my mental state. She used to counsel and encourage me that I would recover. She tells me to be firm because I will recover from the mental illness”. This report indicates that Mutungi associates emotional support received from his wife with positive treatment outcomes, such as recovery, which in turn foster a positive self-concept, adherence to psychiatric treatment and a better prognosis.

Participants also reported religious and traditional healers to provide counselling to outpatients. For example, John, a 50 year old male religious healer, informed in this regard:

> After demons have left, patients still behave abnormally. This is usually because patients’ minds had been taken by the devil and they have not been reasoning normally for a long time. So, I work on the patients’ minds by speaking words of encouragement, like “Jesus loves you”.

This report shows that John complements prayers with counselling to enhance recovery prospects among outpatients. In particular, John is seen to prioritise spiritual counselling, based on his belief that outpatients’ mental health conditions are caused by demonic forces.

Similarly, Janet, a 50 year old female traditional healer, stated:

> When I am counselling a mental patient, I tell him or her that it is okay to be mentally ill because all people become ill; we are all potentially mad. I reassure the patient to be calm because the medicines I give will only cure the mental condition if the patient believes so.

As this report illustrates, Jane normalises mental health problems among outpatients as common life experiences, which serves to reduce the stigma associated with mental illness. However, Janet is seen to falsely reassure outpatients that she can *cure* their mental health conditions.

Researchers have in the past similarly found lay care providers such as families, religious healers and traditional healers to be actively involved in provision of counselling to distressed persons. For example, Durlak (1979) and Wills (1982), cited in McLeod (2003), identify a number of qualities that evidence counselling provided by non-professionals to be more effective than that provided by qualified health professionals. Such qualities possessed by lay counsellors include: (a) being less likely to apply a stigmatising label to service users, (b) being able to give more time to service users, (c) being highly motivated to help service users, and (d) clients being able to attribute success and progress to the self rather than to the therapist's expertise. Similarly, Okello and Ekblad (2006) report members of the Baganda community in Central Uganda believe in the provision of counselling by lay care providers, for example, families, close associates, elders and religious healers, to be essential in the treatment of depression. They also believe that lay care providers, such as elderly community members and friends, are good listeners, experienced and therefore inclined to be more empathetic than are strangers. Muhwezi and Okello et al. (2008) similarly report that families provide counselling, which contributes to mitigation of self-pity and boosting of self-esteem among depressed persons. Furthermore, Okello and Ekblad (2006) report that members of the Baganda community believe religious healers to be capable of providing emotional support to depressed persons through promotion of active participation in religious activities, such as patients "getting saved" (that is, attaining spiritual salvation) and feeling a sense of belonging and mental wellbeing. Additionally, Patel (2003) reports that while administration of psychotropic medication is important, health workers are likely to enhance recovery prospects among service users strongly inclined to attributing their mental conditions to spiritual forces by referring them to religious healers. Similarly, Mills (2005) reports some patients to seek care from traditional healers because they are desperate for a willing listener, one who will bear witness to their overwhelming personal distress. Mills (2005) also reports that some patients attribute their mental conditions to traumatic personal experiences, such as rape, which they have not disclosed to their families and close associates. Such patients, however, consider traditional healers a less risky alternative for disclosure of personal secrets and emotional support (Mills, 2005).

In the following section, I present and discuss participants' descriptions of belief in spiritual healing as a form of care for outpatients.

6.6. Belief in Religious Healers- and Traditional Healers-based Spiritual Healing

All participants reported a belief in spiritual healing by religious and traditional healers to comprise care for outpatients. For example, Martha, a 37 year old woman and a religious healer, informed in this regard:

> When I find a patient's case is big and related with demonic forces, I pray for the mental patient and he will recover …. You cannot see the real Satan because it is air but the person will manifest signs indicative of Satan, such as talking in differing voices. If the patient's case necessitates treatment from doctors, I refer him or her to MRRH.

As this report indicates, Martha believes herself to be more capable than psychiatric health workers in treating severe mental illnesses, which are caused by demonic possession. Martha is seen to infer demonic possession from speech impairments among outpatients. Martha is also seen to delay referring outpatients to psychiatric health workers, believing severe mental conditions to be treatable by supernatural interventions, such as prayer, only.

Participants also reported belief in spiritual healing to enhance hope for recovery among outpatients. For example, Murungi, a 60 year old patient with depression, informed in this regard:

> The church prayed and encouraged me to be hopeful about recovery. Whenever they prayed and counselled me in the church, I would go home and find sleep. The born again Christians used to come and they still come here to pray for me. On Sundays, I also go to church to pray and I leave the church feeling peaceful.

Similarly, Nabasa, Murungi's 40 year old daughter, stated:

> My mother is a born again Christian and she attends Sunday services regularly. When she is very sick and she fails to go to church, the religious leader and other born again Christians come here to pray for her. And she regains some physical and emotional strength.

These reports indicate that Murungi and Nabasa believe spiritual interventions improve mental wellbeing among outpatients. For example, the supportive social networks provided by the church encourage Murungi to belong, to socialise and to develop a positive sense of self-regard. Participants also believe participation in religious activities, for example, prayer, to simultaneously improve outpatient's spiritual, social and physical wellbeing.

Additionally, Bernard, a 67 year old male traditional healer, elaborated his views on spiritual healing:

> A patient, who comes here if he or she agrees to become wholly born again, is expected to refrain from witchcraft, murder and theft. Therefore, patients repent all the sins such as witchcraft, killing and theft and we pray for them and they recover from madness. Unlike Christians in churches who pray through Jesus Christ, here we pray through the Angels. Our care involves prayers only.

This report indicates that Bernard perceives antisocial behaviour, such as theft, as the root cause of mental illness among outpatients; consequently he is seen to encourage them to stop engaging in such behaviour in order for them to be forgiven in a spiritual context. He is also seen to believe that outpatients who believe they have repented and been forgiven for antisocial behaviour, experience positive psychological states. However, it is also noted that Bernard treats outpatients solely with supernatural interventions without an evidentiary base, which is highly likely to lead to those patients with degenerative conditions, such as organic mood disorder, being at high risk of poor treatment outcomes, including premature death.

In regard to the above, psychiatric health workers also evidenced scepticism over the utility of supernatural interventions in treating mood disorders. For example, Milly, a 35 year female psychiatrist, stated in this regard:

> Especially in the Pentecostal churches, people believe that miracles happen. So people are going there to pray for recovery. In Africa, in my experience, people do not believe that you can naturally get a mental problem. Mental illness is wrongly believed to be caused by curses, witchcraft and spirit possession and miracles are believed to take away the demons.

As this report indicates, Milly believes outpatients who seek care from religious healers to possess low levels of mental health literacy. Because mood disorders, according to Milly, are caused by non-spiritual causes, supernatural interventions, such as miracles, sought by outpatients are inappropriate. Milly is seen not to acknowledge the legitimacy of a spiritual basis for mental illness and therefore does not refer outpatients for spiritual healing.

Researchers have in the past similarly found spiritual healing to be a vital aspect of care for persons with mental disorders. For example, Ali (2013) points out, historically in the East, religious therapy to have been integral to mental health care when the first hospitals were built in Baghdad in 705 AD and in Cairo in 800 AD. Bartocci and Dein (2007) similarly note in the West that care for people with mental conditions until the early 19th Century focused mainly on service users' subjective experiences and that such care usually occurred in the context of the church. Following decades of neglect of religious healing, however, there has been a recurrence of interest in religion and mental health both in research and practice (Ali, 2013; Bartocci & Dein, 2007). The finding that involvement of clients in religious rites, such as baptism and bible study, improves mental well-being among outpatients has elsewhere been found. For example, Kleinman (2006) reports that significant life events, for example, diagnosis of a mental disorder, often causes a profound sense of inadequacy and spurs existential fears. Subsequently, affected persons often resort to religious rituals and establish significant relationships with co-religionists and religious healers. Kleinman (2006) also reports that while misfortunes such as illness and personal limitations to overcome distress boost religious beliefs, religion empowers distressed persons to prevail over their fears regarding personal failure and to live as best they can in an uncertain world. In addition, by confronting their deepest fears, for example, loss of employment and family, distressed persons experience a kind of quiet liberation, which he describes as "aspiration in defeat" (Kleinman, 2006, p. 219). Aspiration in defeat, according to Kleinman (2006), implies that distressed people acknowledge human limitations when dealing with significant life situations such as illness. Kleinman (2006) also notes that religious belief enables distressed persons to devise appropriate practices in ordinary life to forge new synergies between their values and emotions to ensure individual and collective significance, transcendence and an increased sense of order and control.

Bartocci and Dein (2007) similarly observe that religious belief offers meaningful perspectives regarding people’s adverse experiences. Religious faith often leads to the perception of severe life events, such as illness, as mere learning experiences. Perception of severe life events as ultimately benign and occasionally beneficial defuses the distress associated with such events, including diagnosis of a mental disorder (Bartocci & Dein, 2007). While participants in the present study reported outpatients to have repented sins perpetrated against others, other researchers have, in contrast, found religious service users to often forgive people who afflict distress on them. For example, Loewenthal (2006) reports forgiveness to be an aspect of character strength and virtue, enhancing a sense of well-being among religious people. McCullogh and Worthington (1999) in Loewenthal (2006) particularly note forgiveness as having the effect of modulating people’s negative experiences and encouraging resumption of more pro-social and harmonious interpersonal relations.

In summary, participants reported care of outpatients to comprise the following: (a) provision of family social welfare support, (b) provision of medical treatment, (c) provision of health education, (d) provision of counselling, and (e) belief in spiritual healing.

In conclusion to this chapter, participants’ conceptualisation of care is seen to be broad and transcends the limits of biomedical psychiatric care. Although there was consensus among participants that families primarily provide social welfare support to outpatients in the different care contexts, they nonetheless reported contradictory views regarding other forms of care. On the one hand, some reported psychiatric health workers to provide health education and counselling to outpatients and their families. On the other, most reported psychiatric health workers as failing to provide adequate health education and counselling, even though outpatients and their families need these forms of care. Similarly, while outpatients, families, religious and traditional healers reported a belief in spiritual healing to be essential to care, psychiatric health workers were generally sceptical about the utility of spiritual healing.

In the following chapter, I present and discuss the results regarding participants’ descriptions of self-care agency among outpatients.

Chapter 7

Expressions of Self-Care Agency among Outpatients

7.1. Introduction

Two subthemes regarding expressions of self-care agency among outpatients emerged from the data. These are: (a) manifestations of self-care agency, and (b) manifestations of passivity. Below, I consider each of these subthemes in detail.

7.2. Manifestations of Self-Care Agency among Outpatients

All participants, except religious healers, reported they believe outpatients to be active in managing their mental health conditions and challenges associated with care-seeking. For example, Nkole, a 48 year old male patient with bipolar disorder, stated in this regard:

> First of all, I know that this mental illness is my personal problem. When I am well, I make sure that I personally visit MRRH to consult with the health workers and to collect my medicines. In addition, I take the medicines as they are prescribed for me by health workers.

Apparently, Nkole conceptualises his mental health problem within a biomedical framework, which defines psychiatric disability as a personal tragedy. In addition, Nkole can be seen to be unduly dependent on medication to manage his mental health condition.

In contrast, Mugurusi, the 60 year old father of Bwerere, a 20 year old male patient with bipolar disorder, is concerned that outpatients hold the majority responsibility in managing their respective mental health conditions, informing in this regard:

> I realise that nowadays the patients have became *banyamwegyendaho* (self-helpers) because they have to meet most of their care needs, such as buying medicines, even when they are admitted in the hospital. But when patients become *banyamwegyendaho* (self-helpers) in their homes and hospital, it is extraordinary.

Evidently, Mugurusi expects the MRRH to grant a sick role to outpatients. A sick role can involve psychiatric health workers taking the major share of responsibility in caring for outpatients, including providing them with free medication. This is because outpatients taking major responsibility for their own care likely aggravates poverty, hinders care-seeking and leads to dissatisfaction with psychiatric care among outpatients.

Furthermore, participants were seen to consider taking rationed doses of medication, due to irregular medical supplies at the MRRH, as a manifestation of self-care agency among outpatients. For example, Nsheme, a 28 year old female patient with bipolar disorder, stated in this regard:

> When health workers tell you that medicines are not available in the hospital, you go and buy at least one sachet of your dose to maintain you for a few days. You keep buying a few more tablets until the end of the month and then you go back to the hospital.

This report indicates that Nsheme improvises her medical treatment by buying medicines in small quantities, which she takes intermittently, depending on the availability of money to buy them. However, purchasing medication in this piecemeal fashion implies that Nsheme is unlikely to adhere to medical treatment.

Similarly, Njuna, a 40 year old female counsellor, reported:

> Some patients keep walking back to see if there are free drugs instead of buying them. They don’t have money, so they keep walking here to see if there are free drugs available to be given to them so that they can start swallowing them.

This report reveals that Njuna believes outpatients to be desperate, as they fail to receive psychiatric care despite making regular hospital visits. Consequently, outpatients fail to adhere to medical treatment because they are too poor to afford out-of-pocket payments for psychiatric care in addition to transport and time costs incurred with care-seeking. Moreover, it may be seen that Njuna believes outpatients to be highly dependent on the MRRH for free medical treatment.

Similarly, Agaba, a 50 year old male clinical officer, stated in this regard:

> When patients find themselves in a tight corner, they find ways of overcoming their difficulties. Even someone who is sinking in a lake fights for his life before he eventually drowns. So, that is how some mental patients are trying to cope with the care-seeking challenges. Even when we are talking of long distances to MRRH and the associated transport challenges, every day we receive many patients.

This report indicates that Agaba believes outpatients to be committed to care-seeking despite the massive care-seeking challenges they experience, such as travelling long distances to the MRRH. Moreover, Agaba is seen to be concerned that many outpatients eventually succumb to these challenges because of the unrelenting nature of the latter associated with their respective chronic mental health conditions.

The finding in this study that participants view outpatients to be active in seeking and using psychiatric care is comparable with findings of previous researchers. For example, in his study of service user discourse, Speed (2006) describes service users actively involved in seeking and utilising psychiatric services as “consumers”. According to Speed (2006), service users who accepted the identity of consumers are more active than those identifying themselves as “patients”, but less active than those identifying themselves as “survivors” of mental health services. Consumers are also susceptible to dependency on psychiatric care; for example, they are occasionally hospitalised and treated with high doses of medication (Lilja & Hellzén, 2008). The belief among participants in the current study that outpatients who regard mood disorders as personal problems to be active in their care is surprising as researchers elsewhere have found service users who conceptualise mental conditions as personal problems to be passive. For example, Sayre (2000) reports service users who attribute their hospitalisation for mental health conditions to having “a problem” to be more passive than those attributing their hospitalisation to other factors, for example, violation of their human rights. Similarly, Speed (2006) notes that service users who conceptualise mental health conditions as personal problems tend to accept the identity of patients and are more passive than consumers and survivors of psychiatric health services. In addition, Sayre (2000) reports that patients tend to adopt a *psychlogizing* frame of reference for their health problems, whereas Tomm (1989) reports that patients are predisposed to self-labelling and *pathologizing* their mental health problems. Additionally, the WHO (2009a) reports that mental health and illness are social development indicators that require both individual and social considerations; therefore individualising mental health problems manifests a “disembodied psychology” that isolates what goes on inside people’s heads from their social and cultural contexts. Saleebey (2002) similarly refers to individualised assessments of health problems as “context-stripping”. Disregard for contextual factors is a barrier to patient care because interventions adopted to address individualised health problems unduly focus on changing patients’ thought processes instead of focusing on upstream factors, such as poverty, that cause psychological distress (WHO, 2009a). The finding that outpatients view mood disorders as personal problems implies that the latter frame health problems within the biomedical model of disability. For example, Saleebey (2002) observes in this regard that the biomedical model of psychiatric disability emphasises the service users’ deficits rather than their strengths. Similarly, Gould (2010) reports that the biomedical model of psychiatric disability contradicts the basic tenets of the recovery model, such as the capacity of patients to overcome symptoms that meet diagnostic criteria for psychiatric conditions such as depression, often without any outside intervention such as medical treatment. Recovery is also referred to as a “process of improvement and remission of symptoms as a result of purposeful use of efficacious treatments” (Gould, 2010). Fundamental in the recovery model is the recovery of hope and purpose among persons with mental illnesses. In keeping with this observation, Nurjannah et al. (2009) report that the theme of “hopes and realities” indicate active service users’ desire to live happy and meaningful lives as do other members of community, even though such desires are often undermined by the opposing interests of care providers.

Furthermore, participants in the current study reported mobilisation of resources to support care-seeking to manifest self-care agency among outpatients. For example, Murungi, a 60 year female patient with depression, stated in this regard:

> When I don’t have the money, I borrow transport from friends to enable me to seek treatment from MRRH. I borrow money from micro finance schemes in the village. It is a must that I seek treatment because when I don’t have the medicines, I cannot sleep at all.

This report reveals that Murungi establishes social networks to access loans to meet the costs associated with care-seeking. However, borrowing money to support care-seeking suggests that Murungi is likely to be financially insecure and in debt. Debt is also likely to undermine her intrinsic resources, such as self-confidence, essential for her to cope with her mental illness.

In contrast, Mugore, the 43 year old mother of Nsheme, a 28 year old patient with bipolar disorder, reported:

> Nsheme tills the land and grows some crops to raise income to meet her health care needs. At times, she provides labour in other people's farms so as to generate some income for self-care. Presently, people pay her 3, 000/= (R 9) for a day's labour.

This report illustrates that Mugore is concerned that her daughter is not able to raise sufficient funds through selling her labour to meet the costs of her care-seeking as the daily wage for manual labour is relatively low in comparison to the high costs associated with care-seeking.

Additionally, Gadi, a 34 year old male nurse, commented on mobilisation of resources as a display of self-care agency among outpatients: “Some patients have some wealth, for example, they have goats, cows and food gardens, which they sell. So, the moment they do not get free drugs in MRRH, patients go to pharmacies in Mbarara town and buy them”. As this report indicates, Gadi believes some outpatients to be wealthy and thus able to afford out-of-pocket payments for psychiatric care with relative ease. Disposal of personal and family property to meet care-seeking expenses, however, is highly likely to aggravate poverty among outpatients.

Similarly, Janet, a 55 year old female traditional healer, reported: “Some patients sell their farm produce, like beans, which they hoard for emergencies. The main source of income for the ordinary person is by digging and growing some crops”. This report implies similar financial consequences for outpatients to those presented above. In addition, disposal of food crops is likely to lead to hunger and malnutrition, further hampering care-seeking among outpatients and their families.

Researchers have in the past similarly found mobilisation of resources to be a common strategy for coping with distress. For example, the WHO (2009) reports that service users often mobilise three categories of resources to deal with mental health problems, namely, (a) environmental capital, for example, structural factors and features of the natural and built environment, (b) social capital, for example, social networks, cohesion and cooperation for mutual benefit and emotional support, and (c) cognitive capital, for example, emotional intelligence. However, Patel et al. (1999) report that some resource mobilisation strategies, such as borrowing from money lenders, in liberalised economies often lead to debt, aggravating poverty and mental illness among poor people. Furthermore, Narayan et al. (2000) report that poor people often engage in manual labour, sell their property and sell relatives as slaves in order to pay for health services. In addition, poor women, girls and, to a lesser degree, boys engage in commercial sex work to generate financial and material resources in order to meet personal and family needs. Narayan et al. (2000) argue that poor people engage in such risky behaviour because they lack alternative employment and livelihoods. In the same vein, Desjarlais et al. (1995) report that bondage and forced slavery occur among poor people, including those with mental illnesses, in both LAMICs and HICs. Bondage and slave labour, according to Desjarlais et al. (1995), are often associated with a variety of problems such as hunger and malnutrition, violence and aggravated emotional and behavioural disturbance among poor people.

In summary, participants reported that outpatients express self-care agency to manage the symptoms of their mental health conditions and challenges associated with care-seeking. Self-care agency, according to participants, manifests in taking the major share of the caring responsibility, appropriating medical treatment, conducting regular consultation meetings with psychiatric health workers and mobilising resources to support care-seeking.

In the section following, I present and discuss results regarding manifestations of passivity among outpatients.

7.3. Manifestations of Passivity among Outpatients

All participants, with the exception of traditional healers, reported that outpatients manifest passivity when it comes to managing mental health conditions and care-seeking challenges. For example, Agaba, a 50 year old male clinical officer, stated in this regard:

> Many patients give up toiling because of the overwhelming life challenges, such as poverty, that are caused by mental illness. There is what we call

> learned helplessness and hopelessness. They think "this is my fate and I cannot do anything about it and I will live like that".

Notably, Agaba believes that pervasive life challenges, such as poverty, caused by mental illness undermine outpatients' capacity for self-care and that outpatients consequently give up care-seeking and experience negative outcomes, such as frequent relapse.

Similarly, Nkole, a 48 year old male patient with bipolar disorder, informed in this regard:

> There is generally no success in coping with my mental illness because I still have it and I do not know when it will be cured. I have already realised that because of my illness, I am expected to take medicines for ever.

As this report indicates, Nkole believes his mental health condition to be incurable as it requires him to take medication for a long period of time. He is also dissatisfied with psychiatric care, believing it cannot cure his mental illness.

Nabasa, the 40 year old daughter of Murungi, a 60 year old patient with unipolar depression, similarly stated:

> When my mother feels she is failing to go to MRRH to collect drugs, she accepts defeat. She says that "let come what may because this is the time for me to die. I have already lived my years. Let the Lord do what He pleases to do". She does not fear death.

This report indicates that Nabasa believes Murungi to be overly preoccupied with end-of-life issues, such as bereavement, as she is unable to seek timely and adequate psychiatric care. Nabasa is also seen to believe that Murungi experiences considerable psychological distress due to non-adherence to medical treatment. Nabasa is also seen to view supernatural intervention as likely to influence, for better or worse, Murungi's health, in particular, and life, in general.

Furthermore, participants reported passivity among outpatients to manifest in maladaptive behaviour. For example, Martha, a 37 year old female religious healer, stated in this regard: "When a mental illness is ongoing, many patients fail to deal with their life problems and sometimes, the patients deal with them in inappropriate ways, such as committing suicide and escaping from home". This report indicates that Martha believes mental illness to be associated with pervasive life challenges, such as stigma, among outpatients. As a result, outpatients display maladaptive behaviour, such as escaping from home, feeling too hopeless and powerless to overcome their life challenges.

Similarly, Bosi a 30 year old male nurse, reported in this regard:

> Because relatives give up, then the person relapses; nobody cares to take you to the hospital. So, you wander away from home and you end up on the streets. By the way, about 50% of mental patients give up struggling with their life challenges.

It is apparent that Bosi believes family neglect of outpatients to be associated with the considerable burden of care experienced by the former. Such neglect may be due to factors such as lack of financial resources to facilitate care-seeking and stigma associated with mental illness. Bosi is also seen to be concerned that a considerable number of outpatients are vulnerable to family neglect and show a negative illness trajectory.

Additionally, participants reported passivity among outpatients to manifest in seeking supernatural intervention. For example, Mukaira, a 64 year old female patient with unipolar depression, stated in this regard:

> I cope with my life challenges by getting saved, repenting all my sins and resting in Jesus Christ. People may talk that "you are lazy" but you know your laziness; when you fail in doing something as people may say that my house is incomplete but you know what you are up to.

This report indicates that Mukaira seeks supernatural intervention because she believes her life challenges cannot be solved by personal effort. Additionally, Mukaira is concerned about public opinion regarding the poor state of her shelter as she cannot afford better housing facilities. Surrendering effort on her part, it is highly likely for Mukaira to experience a chronic illness trajectory.

Kusiima, a 42 year old female patient with unipolar depression, similarly informed:

> I don't worry about my health condition because when I got saved, God succeeded in taking all my bad thoughts, sadness caused by widowhood, including my plight in singlehandedly caring for my children. I deal with challenges in Jesus Christ because I don't have the authority to deal with those challenges.

Similarly, Bosi, a 30 year old male nurse, reported in this regard: "Most mental patients are incapable of managing their care-seeking challenges successfully. *Abingi nibakorera aha embabazi ez'omujuni* (the majority live by the grace of God)" As the above reports indicate, participants believe that many outpatients seek supernatural intervention because they lack a sense of self-efficacy to manage their life challenges, including mental illness and poverty. The belief in supernatural intervention to cope with life challenges is likely due to internalised oppression and diminished citizenship rights among outpatients.

Participants also reported passivity to manifest in lowering life ambitions among outpatients. For example, Murungi, a 60 year old female patient with unipolar depression, stated in this regard:

> I used to think that I was going to build a nice house but now I cannot afford to build it; I would think about having 200 cows and I am unable to have them because I don't have them; I would think that I would have a big banana garden to support me and I am unable to have it. Therefore, when I got saved, I disregarded all of them.

This report shows that Murungi believes she is unable to acquire material wealth because she has failed to achieve many of the personal goals she set for herself. This fatalistic attitude towards gaining material wealth is likely to discourage Murungi from committing sufficient efforts to acquire gainful work, thus causing her to drift into aggravated poverty. Murungi is seen to have resigned herself to a life of destitution since her previous endeavours failed to bring her material wealth and to fulfil her desired goals.

Similarly, Nkole, the 48 year old male patient with bipolar disorder, informed in this regard:

> I make sure that I disregard some things which I consider unrealistic. I behave like when you have some money and bargain for a commodity but you fall short of the set price. You decide to leave the commodity because you lack enough money to buy it. For instance, at my age, shouldn't I be having my own workshop premises?

This report reveals that Nkole is concerned about his unmet needs, such as a better workplace for himself and stagnation in his occupational and social status, because of the poverty he experiences. His perceived futility regarding advancement in his career is likely to discourage Nkole from committing sufficient effort to work, thereby further aggravating his poverty.

Furthermore, participants reported passivity among outpatients to manifest in cautious interaction with psychiatric health workers. For example, Mukiga, a 41 year old male patient with unipolar depression, stated in this regard:

> I cannot confront a nurse for communicating poorly to fellow patients because I don't have the authority to advise health workers on how to treat patients. The health worker may refuse to provide me with the medicines. When the health worker barks at you *nofa mamigye* (you die graciously).

Similarly, Mugurusi, the 60 year old father of Bwerere, the 20 year old male patient with bipolar disorder, informed:

> Some people fear telling the health workers that we are not happy with the way they shout at the patients so as not to upset them. We become *bakitandugaho* (risk averse). One of the reasons as to why I cannot confront the health workers is that I am instructed to go the hospital monthly and there is no alternative health facility where I can obtain psychiatric care for my son.

The above reports show that participants believe psychiatric health workers to have considerable power over outpatients, with which they abuse the latter. Consequently, outpatients are unable to either communicate assertively with psychiatric health workers or to provide useful feedback regarding their care for fear of being victimised. Participants also believe that the lack of alternative health facilities providing psychiatric care precipitates a sense of apathy and fear among outpatients.

Researchers have in the past similarly found persons with mental illnesses to manifest passivity in dealing with distress. For example, Kartalova-O'Doherty and Doherty (2010) report that persons with chronic health problems usually exhibit "giving up" attitudes, implying that service users become highly dependent on medication and professional care for the rest of their lives. Passivity is often due to learned helplessness and hopelessness associated with persistent life challenges (Saleebey, 2002). According to Bandura (1989), passivity is probably due to low self-efficacy beliefs, which influence people's actions through cognitive, motivational and affective intervening processes. In particular, people's perceptions of their efficacy influence the form of anticipatory images they construct and reiterate for themselves. For example, people who believe they are ineffective tend to visualise failure scenarios, which, in turn, undermines performance in the tasks they undertake (Bandura, 1989).

Being overwhelmed by mental health conditions, which participants reported the outpatients experience, is comparable to "immersion into illness", a condition which Charmaz (1991) has noted among patients with chronic illnesses. Immersion into illness, according to Charmaz (1991) signifies experiences such as recasting life, facing dependency, slipping into illness routines, and weathering serious illness episodes among patients. For example, recasting life, according to Charmaz (1991), implies that the illness pervades patients' lives, thus trapping them in a state of hopelessness. Patients thus experience a pervading sense of victimisation, ever present and worrisome illness and significantly diminished belief in a positive, progressive and productive life (Charmaz, 1991). Additionally, the finding that outpatients are often preoccupied with end-of-life issues is consistent with that of Charmaz (1991) who refers to this preoccupation among people with chronic health problems as "being on edge". Being on edge describes patient's experience of impending death, diminished control over their lives and increased fear. Persons with chronic health problems who are on edge often display overt behaviour, such as being visibly distracted, withdrawn and moaning noticeably (Charmaz, 1991).

The finding that outpatients often lower their life goals is comparable with that of previous researchers who report chronic health problems to be the cause of significant *tradeoffs* among service users. For example, Charmaz (1991) explains that making tradeoffs involves simplifying life, reordering time, and juggling and pacing activities. Simplifying life also involves elimination of some events, activities and tasks entirely and reducing the steps, obstacles, complexities and necessary time for these as well as the space of others. Such adjustments reduce effort and stress but are associated with considerable costs for the patients, the latter which involve making changes, compromises and sacrifices in the preferences, tastes and demands necessitated by the need to carry on living but in a simplified state. The costs also comprise, for example, hiring help for tasks patients previously used to do themselves, selling off their property, such as houses, downward revising of their standard of living and eliminating visitors (Charmaz, 1991). Similarly, Orley (1970) reports that persons with mental illnesses in Uganda often simplify their lives by giving up personal effort and work for begging.

Furthermore, displays of maladaptive behaviour, such as suicide, which participants in the current study identified as passive coping strategies, underscore the importance of social support for patients coping with mental illness. Mattlin, Wethington and Kessler (1990) observe that passivity as a coping strategy is often contextually determined. Similarly, Mavundla et al. (2009) report poverty and stigma to be some of the family-specific factors that undermined the care and general well-being of persons with mental illnesses as well as that of their relatives. The burden of care for family members with chronic illness also leads to a decline in the caregivers' mental and physical health (Chang, Chiou & Chen, 2010). Yet, family-based caregivers do not receive professional support to address the consequences of care, such as burnout and patient neglect, associated with the considerable burden of care (van der Voort, Goossens, & van der Bijl, 2009).

The finding in this study that outpatients were concerned with being victimised by psychiatric health workers has similarly been reported elsewhere. Victimisation has particularly been associated with power imbalances in service user-care provider relationships (Chambers, 1997; Mills, S., 2003). For example, Chambers (1997) reports that barriers such as personal distance, denial and blaming the victim prevent the *uppers*, for example, care providers from being effective helpers to the *lowers*, for example, the patients. Saleebey (2002) similarly points out that powerlessness often compels service users to identify with their oppressors by assuming, for example, the latter's identification labels, such as psychiatric diagnoses. According to

Saleebey (2002), labelling, often associated with a self-fulfilling prophecy, meets the care providers' expectations of what they anticipate or want service users to become.

In summary, participants reported they believe some outpatients to manifest passivity in dealing with their mental health conditions and care-seeking challenges. Passivity, according to participants, manifests in outpatients being overwhelmed by their mental illnesses, displaying maladaptive behaviours, believing in supernatural intervention, lowering life goals and being cautious in interactions with care providers.

In this chapter, I have presented and discussed results regarding expressions of self-care agency among outpatients under two subthemes, namely, (a) manifestations of self-care agency, and (b) manifestations of passivity. In general, participants reported modest but varied expressions of self-care agency among outpatients. In conclusion, this chapter has shown that participants conceptualised self-care agency among outpatients in diverse ways and perceived the strategies outpatients employ to cope with distress as either active or passive in nature. Participants also reported diverse dimensions of self-care agency among outpatients, depending on different care contexts and experiences.

In the next chapter, I draw conclusions and implications from the results presented and discussed in chapters 4, 5, 6 and 7 as well as highlight the limitations of the current study.

Chapter 8

Conclusion

8.1. Introduction

In this chapter, I draw conclusions from the presented results and suggest implications that may be considered to improve care for outpatients with mood disorders, in particular, and persons with mental illnesses, in general. Finally, I highlight the limitations of the present study in order to contextualise the results, conclusions and implications presented.

8.2. Conclusions

Regarding the results presented and discussed in chapters 4, 5, 6, and 7, I have the conclusions below to make.

Evidently, there is poor patient-care provider relationships and communication in view of the complex, diverse and contrasting conceptualisations of mood disorders among the diverse participants. More specifically, there are considerable discrepancies in participants' conceptualisations in various areas, including manifestations and labelling, perceived causes and consequences of mood disorders. Additionally, conceptualisations of mood disorders among outpatients differ more markedly from those held by psychiatric health workers than those held by other care providers, that is, families, religious healers and traditional healers. In this regard, poor patient-care provider communication and relationships are inevitably more likely to occur between outpatients and psychiatric health workers than between outpatients and other care providers. For example, whereas outpatients, families, religious healers and traditional healers understand mood disorders in lay terms, mainly as *iraro* (madness), local translations of terms for mood disorders used by psychiatric health workers fail totally to match such lay labels. Similarly, although discrepancies in conceptualisations of mood disorders are more apparent between different categories of participants, for example, between outpatients and psychiatric health workers than within other categories of participants, considerable discrepancies are surprising notable within specific categories of participants, for example, among psychiatric health workers. Similarly, individual participants tend to hold multiple and, at times, contradictory views, for example, belief in both supernatural and biomedical causes, regarding mood disorders. The wide-ranging perspectives regarding manifestation and labelling, perceived causes and consequences of mood disorders reported by outpatients and care providers imply, for example, difficulty in assessment and diagnosis of the health conditions presented by outpatients, mistrust and suspicion of care providers by outpatients, uncertainty regarding prognosis and treatment and dissatisfaction with care among outpatients and care providers.

Furthermore, it is evident that structural barriers, such as the low priority status of mental health on the public health agenda and poor organisation of mental health services, significantly hinder effective provision and utilisation of care. While some structural barriers, such as the low priority status of mental health on the public health agenda, are, by and large, context-specific, for example, specific with regard to conditions at the MRRH, other structural barriers, such as stigma and discrimination, are generally encountered across different care contexts, that is, in the homes of outpatients, at the MRRH and in churches. Additionally, structural barriers distinctively constrain outpatient care, for example, poverty affects mainly the demand for care while irregular medical supplies affect mainly its supply. Moreover, structural barriers mutually reinforce each other, for example, poverty leads to stigma and discrimination and vice-versa.

It is also apparent that participants conceptualise care broadly to comprise family-based social welfare support, medical treatment, health education, counselling and spiritual healing. Such broad conceptualisation is in keeping with complex conceptualisations of mood disorders as well as with structural barriers to effective care. More importantly, it is indicative of the fragmented, piecemeal, intermittent and uncoordinated provision and utilisation of care, the latter which is based on dynamic and unique value systems, philosophies, protocols and resources among outpatients and care providers in different care contexts. Although participants, in many instances, are more favourably disposed towards specific forms of care while disregarding others, for example, psychiatric health workers show scepticism toward spiritual healing and religious healers do not believe in the use of traditional medication, they all generally agree that family-based social welfare support is essential to outpatients, irrespective of care contexts, that is, family- or hospital-based. The centrality of family-based social welfare support to outpatients is similarly indicative of the inadequacy of other forms of care, such as medication, to the extent that families are inevitably expected to support outpatients, for example, by providing financial, material, or, indeed, all other forms of care. It also suggests inequitable access to different forms of care, the latter ranging from medication to psychotherapy to medical treatment, mainly due to differing levels of family support (for example, financial and material support) among outpatients.

Similarly, it is clear that outpatients generally exhibit modest (weak) agency in managing distress caused by mood disorders and challenges associated with care-seeking. Participants regard outpatients as employing both active and negative coping strategies, and such strategies are unduly influenced by the biomedical model of disease. The biomedical model of disease emphasises chronicity, deficits and weaknesses associated with disease rather than strengths and recovery prospects among patients. In keeping with the biomedical model perspective, outpatients regarded by participants as active tend to perceive their mental health conditions as chronic and thus persistently seek and utilise care amidst considerable and persistent challenges, including side effects of medication and aggravated poverty. In contrast, patients regarded by participants as passive irregularly seek and use care or terminate care entirely. Passivity, in the context of this study, implies that some patients succumb to their mental illnesses, lose hope for recovery, give up toiling to support their recovery and are neglected by care providers, including families, the latter mainly due to unrelenting care-seeking challenges such as aggravated poverty.

Below, I present the implications of the current study.

8.3. Implications of the Study

This study has a number of important implications for clinical psychiatric practice, mental health policy, training of mental health professionals and mental health research. Regarding clinical psychiatric practice, psychiatric health workers, in particular, need to contextualise health conditions presented by patients in order to make valid psychiatric diagnoses. Effective communication is essential for making effective psychiatric assessment and diagnoses; psychiatric health workers therefore need to take histories of presenting problems from patients and share with them reformulated psychiatric diagnoses in patients' commonly spoken languages. In this regard, psychiatric health workers need to translate Western notions of psychopathology, using local terms to render them explicable to patients. Translation should also be made available to immigrant patients, for example, in the current study context, refugees from neighbouring countries such as the Democratic Republic of Congo (DRC), Rwanda and South Sudan, whose cultures, especially with regard to language, differ markedly from those of their host communities in Western Uganda to ensure effective diagnosis and treatment of mental illnesses. Labelling mental illnesses in patients’ local languages and idioms for distress acknowledges the latter’s unique experiences and expertise regarding their personal and social suffering.

Related to the above, care providers, especially psychiatric health workers, should strive to distinguish ordinary suffering caused by adverse social conditions, such as aggravated poverty, from psychopathology diagnosed via standardised diagnostic systems, for example, the DSM. It is thus imperative for care providers to obtain sufficient contextual information regarding, for example, patients’ occupational status, housing situation and social support networks before hastily labelling the presenting distress with psychiatric labels, for example, depression. Such caution is necessary as psychiatric diagnoses, once made, are enduring, stigmatising and likely to aggravate distress among people with mental illnesses. Appropriate treatment also depends on effective assessment and diagnosis of mental illnesses and should transcend the usually limited biomedical interventions, for example, medication, to include social and psychological interventions, such as income and housing support, nutritional supplements, counselling and ritual performance, especially among poor patients.

Similarly, care providers should contextualise interventions by targeting the latter not only at individual patients, but also at social systems that cause and sustain psychiatric conditions, for example, depression. Such systems include patients’ families, work places and community agencies, the latter including hospitals, which may cause and perpetuate mental illness via mechanisms such as marginalisation, oppression, abuse and exploitation of, especially poor, people. Because individuals are social beings or are socially constructed, suffering may constantly be reinforced by social conditions that are often left untouched by individual-targeted interventions, for example, medication, which lead to loss of resources, such as money, time and, possibly, lives.

In the same vein, care providers should conceptualise care broadly to include aspects such as mental health promotion and prevention of mental disorders alongside curative care. Psychiatric health workers, for example, should devote substantial resources, such as time and money, towards public mental health interventions that include identification of individuals and families at risk for referral and timely support for patients, mental health hygiene programmes, for example, stress management sessions at the workplace, and crisis interventions, for example, trauma counselling. They should prioritise raising awareness about various mental health issues, for example, manifestation, aetiology, consequences and management of care in hospital and community settings. Improved mental health awareness and literacy may subsequently overcome the abounding myths and misconceptions regarding mood disorders, safeguard the rights of patients and promote utilisation and adherence to care.

Care providers, especially psychiatric health workers, should also recognise that patients often seek treatment with the expectation of being completely *cured* of their mental health conditions and consequently get frustrated when advised to take medical treatment indefinitely. Patients may thus seek care from multiple care providers, either simultaneously or consecutively, to enhance their recovery prospects. Care providers must therefore exercise patience, especially with individuals with recent onset of mental illnesses, the latter who often desperately and relentlessly search for such a complete cure from diverse care providers, such as psychiatric health workers, religious healers and traditional healers. Such indiscriminate search for a cure also usually involves high financial and material expenses and aggravates poverty, subsequently hindering the search for evidence-based psychiatric care. Thus, care providers, especially psychiatric health workers, should ensure that patients and families try treatments such as medication for a considerable trial time before switching to alternative modes and forms of treatment, for example, traditional healing.

Furthermore, psychiatric health workers should develop capacity within families to provide efficient social welfare support to patients since the latter play a central role in care. In this regard, interventions, for example, aimed at addressing the burden of care, including family therapy, respite care and informational support on mental illnesses should be prioritised. For example, informational support should address issues such as risk of relapse, side effects of medication and methods for effectively and humanely restraining acute patients. Psychiatric health workers should also conduct regular follow-up checks on outpatients in the latter's family and community settings to intervene in crises, for example, in family conflicts that may precipitate episodes of mood disorders and hinder effective care. Psychiatric health workers should also identify and establish social support networks in cases where patients are totally neglected by their families or where close relatives are lacking, for example, linking such patients with members of their extended families, community volunteers and NGOs that help needy people.

Psychiatric health workers should priorities rehabilitation to foster recovery from episodes of mood disorders and enhance social and occupational functioning among outpatients. Rehabilitation activities, such as sewing, leather work and craft making, commonly used for rehabilitation of people with physical disabilities, could be considered, for example, as income generating activities for psychiatric patients, the latter effort which might consequently assist in supporting care-seeking. Similarly, in instances where fertile land and favourable climatic conditions are available, farming could be promoted as an effective rehabilitation activity since it is highly rewarding, engaging and more aptly suited to rehabilitation in the context of rural and peri-urban settings.

Regarding mental health policy, the current study suggests several implications. In particular, mental health policy makers should encourage collaboration among mental health professionals, including psychiatric health workers and lay care providers, such as families, religious and traditional healers, by formulating policies aligned towards this purpose. Collaboration is necessary as no single role player among these categories of care providers has the "magic bullet" for assisting in the care of patients with mood disorders, in particular, and mental illnesses, in general. Such policies should aim at establishing inventories of the available therapeutic resources, mechanisms for coordination, including referral of patients among diverse care providers, mechanisms for supervision and sanctioning and monitoring of care providers. Effective coordination and mutually respectfully relationships between professional and lay care providers may greatly help in the timely identification and prevention of problems, for example, non-adherence to treatment by and exploitation and abuse of people with mental illnesses.

Similarly, policy makers should raise the priority status of mental health on the public health agenda so that it is allocated the fair share of resources necessary to overcome structural barriers to effective care. Concerted and coordinated advocacy could, for example, increase resources (that is, financial, human and material resources) that the Ugandan government allocates towards hospital- and community-based care commensurate with the large numbers of patients needing mental health care. Improved advocacy efforts, could also, for instance, ensure procurement and regular supply of better quality psychiatric medication with fewer side effects, thus enhancing patient adherence to medical treatment.

Furthermore, there is a need to streamline decentralisation of health services by building capacity in lower level health facilities in the Greater Mbarara region, in particular, and in Uganda, in general, to provide more effective psychiatric care in the community and to more efficiently identify and refer patients in need of specialised treatment to higher lever health facilities. In this regard, policy makers should prioritise construction of smaller, more widely scattered health units, rather than the large, centralised ones often demanded by politicians, the latter who mistakenly believe larger, centralised health facilities to more effective than smaller, localised ones. Moreover, structural barriers such as poverty often hinder patients from accessing psychiatric care from large centralised health facilities because of poorly developed public transport systems and unaffordable private means of transport. Similarly, stigma and discrimination associated with mental illness often hinder patients from using public transport to access psychiatric care. It is thus also vital to integrate mental health services with general health and social services to enhance accessibility of the former, to address the stigma associated with mental illness and to rationalise resource use. For example, probation, social welfare and community development officers already working closely with families and communities should be given more responsibility to indentify people suspected of having a mental illness, to conduct referrals of such individuals to health facilities and to offer crisis intervention services in coordination with mental health professionals and lay care providers. Similarly, because mental illness is usually comorbid with physical health conditions such as diabetes and HIV/AIDS, general health workers should be capacitated to treat mental illness alongside such diseases. Integration of mental health services with general health and social services necessitates provision of basic training, reorientation and supervision of non-psychiatric professionals, such as probation and social welfare officers, in the identification and referral of the mentally ill as well as in basic management of specific mental illnesses, such as bipolar disorder.

Furthermore, mental health policy should encourage and support mobilisation of patients and families to advocate for improved mental health services. The collective voices of organised groups of patients and families may convince policy makers to allocate adequate resources, to formulate appropriate policies and legislation to safeguard the rights of people with mental illnesses, to promote accountability for budgetary resources for mental health and to generally improve the availability and quality of care for people with mental illnesses.

As regards training, institutions training helping professionals in biomedicine, psychology, social work and law should incorporate mental health as a core content area in their respective curricula for both undergraduate and graduate students due to the cross-cutting nature of mental health in society. Introducing helping professionals such as lawyers and psychologists to the basic concepts of mental health will enable them to provide “first aid” mental health support as well as to participate in the identification and referral of individuals suspected of having psychiatric problems to specialist mental health professionals. Similarly, mental health professionals should provide basic training to lay care providers who are frequently involved in caring for people with mental illnesses, for example, religious and traditional healers, in the identification, basic management of mental illness and referral of individuals suspected of having, especially, organic, degenerative and severe mental health conditions so that such persons may be properly managed by specialist mental health professionals.

Similarly, trainers of mental health professionals should expose students to a wide range of mental health problems, including the following: (a) behavioural problems, for example, substance abuse, (b) severe and long-term mental disorders, for example, schizophrenia, (c) common mental disorders, for example, depression, and (d) crisis situations, for example, wars and natural disasters. Because in many LAMICs, such as Uganda, members of the general public often do not regard common mental disorders, such as depression, as mental health problems compared to severe mental disorders, such as schizophrenia, patients presenting with the former, unlike patients presenting with the latter, often fail to seek psychiatric care and thus rarely get admitted to psychiatric institutions. It is worth noting in this regard that clinical training in psychiatry is mainly conducted in psychiatric institutions and thus on patients with severe mental disorders, such as schizophrenia, and not on common mental disorders, such as depression. Clinical psychiatric training should therefore include exposure of students to both severe mental disorders, often prevalent in psychiatric institutions, and to common mental disorders, usually prevalent in the community, to promote effective assessment, diagnoses and management of the different categories of mental disorders.

There is need to promote indigenous concepts of mental illness that may be more contextually valid and understandable to patients and care providers. Much of the formal psychiatric training in many LAMICs, such as Uganda, is based on Western notions of mental illnesses, the latter which may have limited relevancy in LAMICs, thus hindering effective patient-care provider communication and utilisation of psychiatric care. Similarly, standardised diagnostic tools, for example, the DSM, and assessment instruments, for example, the Present State Examination, are culturally nuanced by Western notions of psychopathology, to the extent that these often generate reliable but invalid psychiatric diagnoses when used in LAMICs. Mental health experts in Uganda should therefore validate such standardised diagnostic and assessment tools as well as write local cases and reference materials to generate and promote culturally-relevant scientific idioms for distress and terms regarding mental illnesses.

Furthermore, there is a need to actively involve people with mental illnesses and families in the training of mental health professionals so that the latter benefit from first hand lived experiences regarding mental illnesses in order to mitigate stigma and discrimination and to prioritise the interests and perspectives of psychiatric service users in both the training and practice of mental health professionals. Mental health patients need to be involved in various aspects of training, including curricula development, delivery of courses, for example, as guest lecturers or workshop participants, and as experts on mental health issues, research and evaluation of mental health services, for example, as consultants.

As regards mental health research, there is a need for conducting further research on a number of issues to enhance understanding of mood disorders, in particular, and mental illness and care, in general, both in Uganda and other LAMICs. More specifically, it is imperative to conduct phenomenological studies of mood disorders to establish symptom patterns that may be universally and/or specifically applicable to patients in Uganda and patients from other social and cultural contexts, for example, in Europe and the United States. Such studies should enrol participants mainly from the community, as many people with mood disorders often fail to seek psychiatric care and thus may differ significantly from patients usually enrolled in such studies from psychiatric institutions. Phenomenological studies are similarly important because of the high variability of mood disorders, as patients in collective cultures, especially in LAMICs, tend to present mainly somatic symptoms, for example, headache and nonspecific chronic pain, while patients in individualistic cultures, especially in the West, often present psychological symptoms, such as sadness and guilt.

Further research should also be conducted regarding the validity and reliability of diagnostic and assessment systems and instruments, for example, the DSM and the Present Mental Examination, both which are influenced mainly by Western cultures yet are frequently used in LAMICs, such as Uganda. Because such diagnostic and assessment systems and tools are socially constructed and are thus not culture-neutral, they often assess different phenomena when uncritically applied in non-Western cultural and social contexts, such as Uganda. Similarly, further research should aim at developing indigenous assessment and diagnostic tools in addition to validating diagnostic and assessment tools developed in other social and cultural contexts in order to contribute to effective assessment and diagnosis of mental health problems as well as to effective treatment of patients. Effective assessment and diagnosis are similarly essential in determining with more accuracy the burden posed by mental disorders so that commensurate interventions for redress can be planned and implemented in Uganda.

More research should as well be conducted to establish effectiveness of various interventions such as medical treatment and spiritual healing provided and utilised in highly deprived care contexts, as is the case in Western Uganda. Such research may also highlight the strengths and weaknesses that diverse care providers exhibit and thus aid in rationalising use of the plural health care system. Similarly, it is essential to establish levels of satisfaction that patients derive from various forms of care, the burden of care among various care providers, for example, families, psychiatric health workers and religious healers, for effective mental policy planning and implementation in Uganda.

Finally, further research should be conducted on structural barriers to effective care, for example, to determine the latter’s impact on the morale and motivation as well as the burden of care among care providers, on the one hand, and adherence to care, satisfaction with care and prognosis among service users, on the other. Intervention research targeted at specific barriers such as stigma, discrimination and aggravated poverty should also be conducted, for instance, to promote positive attitudes among members of the public towards people with mental illnesses and to mitigate the effects of poverty on care-seeking and care utilisation.

8.4. Study Limitations

The conclusions that I have drawn above from the results and recommendations presented in this study, and that I have suggested for improving care, should be considered in view of the limitations of the current study presented below.

This study was limited in scope with regard to the subject matter and the population considered. For example, I focused only on mood disorders and thus excluded a wide range of mental disorders such as psychotic and substance abuse disorders. Because of their uniqueness, inclusion of other mental conditions, for example, schizophrenia, could have greatly enriched the results I found. With regard to the population considered in the current study, I enrolled only outpatients with mood disorders and their care providers. I did not explore the experiences and perspectives of probable populations such as inpatients and other community members. The small and limited sample of participants in the current study also implies that my results should be contextualised, rather than generalised, to a wider population. Selection of mood disorders as the focus of the current study, however, took into consideration their relative higher prevalence in the community and higher contribution to the global burden of disease than is the case with other forms of mental conditions. Additionally, because my study is meaning-centred, I enrolled individuals whom I believe had direct experience of mood disorders and mental health care. Inpatients with mood disorders would have indeed met the above criterion. However, I did not enrol inpatients into the current study because I believe that acute episodes of mood disturbance could have constrained the conducting of effective interviews with them. Beatie (1964) informs in this regard that it is only feasible to study complex phenomena by being selective. Because it is impossible to comprehend all aspects of reality simultaneously, it is thus acceptable to choose certain aspects of what researchers wish to study. I therefore selected the study participants and the subject matter based on the above considerations.

Because all participants hail from the Greater Mbarara region and belong to the Bakiga and Banyankole groups, results of the current study are highly nuanced by the Banyankole and

Bakiga cultures. Consequently, the results presented may have limited relevance to other regions and cultures in Uganda. Indeed, Uganda being a multicultural country with over thirty recognised languages (Byakutaaga, 2006), significant variations with regard to constructions of mood disorders and care are highly plausible. However, my results nevertheless provide useful insights into the likely variations in perspectives on mood disorders and associated care because I selected participants from most of the groups defined as stakeholders in mental health in the draft mental health policy of Uganda (Ministry of health, Uganda, 2006). These include service users (outpatients), families of outpatients, psychiatric health workers, religious healers and traditional healers involved in outpatients' care. Moreover, to promote cross-cultural communication in mental health, it is essential to discover cultural specifics alongside universals so that mental health professionals can better contextualise knowledge in practice and in research. Most importantly, the current study is the first of its kind in the Greater Mbarara region and its replication in other regions and cultures of Uganda could significantly contribute to identification of cultural universals and specifics, consequently enhancing cultural competence in mental health care in the country.

I conducted interviews with outpatients, families, religious healers and traditional healers in the Runyankole-Rukiga language, which is the commonly spoken language in the Greater Mbarara region. The use of the Runyankole-Rukiga language was essential in eliciting participant's perspectives in their own terms regarding mood disorders and care. However, I did experience a degree of difficulty in translating verbatim-transcribed interviews as I could not find the exact English equivalents for many culturally nuanced local terms and phrases contained in the data. Although I enlisted the support of a lecturer of indigenous languages at Makerere University and aimed at conceptual equivalence in translation, I believe the quality of the data in this regard to have been undermined, to an extent. However, I did retain some words and phrases in the original Runyankole-Rukiga language in the data analysis and reporting in order to preserve the richness of the data.

My results could have further been enriched by triangulation of data collection methods such as observation, focus group discussions and key informant interviews. For example, key informant interviews with political and senior health official could have explored structural and policy issues that impact conceptualisations of mental health conditions and care. However, financial and time constraints did not allow the use of such multiple data collection methods. To augment the quality of results, however, I triangulated the sources of data by enrolling outpatients, families, psychiatric health workers, religious healers and traditional healers involved in outpatients' care. I also recognised that participants would not appreciate being the object of cursory interaction in data collection and therefore spent considerable time establishing rapport with them individually to ensure effective in-depth interviews with them. For example, when necessary, I allowed breaks during in-depth interviews to enable participants to reflect on and recollect some of the ideas expressed. Consequently, in-depth interviews enabled participants to explore the study subject matter both extensively and intensively.

Another limitation of this study regards the use of a "gate-keeper", that is, employing as my research assistant a person that in the fieldwork phase of the current study was employed at the MRRH in the capacity of a senior social worker. For example, politics at the work place could imply that only colleagues favourably disposed towards her may have opted to participate in the current study because of her active involvement in it. Additionally, some service users may have felt compromised to participate in the present study because my research assistant held a position of authority at the MRRH. In particular, some service users may have felt that non-participation in the study could lead to negative consequences, such as denial of psychiatric care. However, I believe that my research assistant, being a familiar individual at the MRRH, boosted confidence and encouraged colleagues and service users to participate in the current study, taking care to inform them at great length and depth about the scope and purposes of the study as well as to reassure them of the ethics involved in the study at all times, including the prioritising of confidentiality and well being of all participants, especially that of the outpatients. I myself personally screened individuals who expressed interest in participating in the current study and obtained informed consent from each individual after explaining the eligibility criteria for enrolment into the study. In addition, I carefully chose to work with and selected a research assistant who was familiar with the participants and the subject matter based on my belief that such a choice is good practice in participatory research. In addition, my research assistant, apart from helping in data collection, benefitted from the learning opportunity presented in the data collection phase by sitting in on interviews and thus listening first hand to the perspectives and insights of colleagues and service users regarding mood disorders and care at the MRRH and in the Greater Mbarara region. To ensure ethical conduct, I trained my research assistant in research ethics and data collection and effectively supervised her, regularly monitored her work and provided her with the necessary emotional support throughout the fieldwork phase.

Additionally, I encountered a problem with fatigue and apathy regarding participation in the current research study among participants. Most service users, families and psychiatric health workers indicated that they had participated in many research projects without any practical benefits accruing to them, the institution or the community. I am not surprised by this view because as a teaching hospital for the Mbarara University of Science and Technology (MUST), it is inevitable that patients and care providers at the MRRH are unduly studied. Such research fatigue and apathy expressed by participants can be attributed to deception by researchers about unlikely benefits to participants participating in research or to negligence on the researchers' part to promote clear understanding about the scope, goals and purposes of the studies being conducted. To maintain the participants' interest and to build their confidence in participating in my study, I explained objectively and with the highest degree of integrity the purpose, costs and benefits that could accrue from participation in the current study as well as stressing the primary or direct benefits for the research. Because there are no financial and material benefits for participants, I conducted interviews in participants' respective homes, except for those conducted with psychiatric health workers, whom I interviewed at their offices at the MRRH. I provided each participant with a soft drink for refreshment during interviews. I also reimbursed money that is equivalent to a daily wage in the community (at the time of the fieldwork) as compensation for time participants took off their daily routines to participate in the current study.

Despite the above acknowledged limitations, the current study is nonetheless, in my opinion, highly informative about explanatory models that outpatients and care providers in the plural health care system in Western Uganda employ in response to mental illnesses.

In conclusion, this concluding chapter reaffirms the view commonly held in cross-cultural psychiatry that social and cultural contexts influence significantly understanding and responses to distress. It was found that there are significant discrepancies in the understanding of mood disorders and care among the different participants in this study. Although the current study has limitations as has been specified above, it is nonetheless highly informative about complex notions of mood disorders and care in Western Uganda.

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Appendices

Appendix A

Table showing outpatients and their socio-demographiccharacteristics

No. & Name	Gender	Age in years	Marital status	Highest level of formal education	Religious affiliation	Number of dependant	Occupation	Description of housing
1 Bwerere*	Male	20	Single	No formal education	Catholic	No dependent	Subsistence farmer	Stays in parents' house made of bricks & cement, no piped water and no electricity.
2. Kusiima*	Female	42	Widowed	Senior 4	Anglican	4 children	Police officer	Official house, made of bricks & cement, has electricity & piped water
3. Mukaira	Female	64	Widowed	Primary 6	Anglican	5 children	Subsistence farmer	Own house made of mud & wattle, no piped water, no electricity.
4. Mukiga	Male	41	Married	Primary 5	Anglican	4 children	Subsistence farmer	Own house, made of mud & wattle, no electricity and no piped water.
5. Murungi	Female	60	Widowed	No formal education	Pentecostal	11 own & grandchildren	Subsistence farmer	Own house made of bricks & cement, solar panels for mainly lighting, no piped water.
6. Mutungi	Male	35	Married	Senior 3	Anglican	5 Children	Sells groceries	Own house, made of bricks & cement, has electricity & piped water.

7. Nkole	Male	48	Separated	Senior 4	Anglican	5 Children	Carpenter	Rented house made of bricks and cement, has electricity but no piped water.
8. Nsheme	Female	28	Married	Primary 3	Anglican	2 Children	Subsistence farmer	Rented house made of mud & wattle, no piped water, no electricity.

Note:

I did not interview Bwerere because I found he had relapsed during the time I had a scheduled interview with him. However, I interviewed his father (Mugurusi) who is listed as No. 6 on appendix B as a special case because the latter was caring for a relapsed outpatient and was one of the two male family-based care providers who expressed interest in this study.

Kusiima (No. 2) indicated that she did not have a family-based care provider. I interviewed her because of her uniqueness as other outpatients indicated they have family-based care providers.

Appendix B

Table showing families and their socio-demographiccharacteristics

No. & Name	**Gender**	**Age in years & Marital status**	**Relationship with the outpatient**	**Highest level of formal education**	**Religious affiliation**	**Number of dependents**	**Occupation**	**Description of housing**
1 Bwengye	Male	46 & Married (2 wives)	Brother (7)*	Senior 4	Anglican	15 dependents	Subsistence farmer	Own house made of bricks & cement, no electricity & no piped water.
2 Frida	Female	30 & Married	Daughter-in-law (3)*	Grade Three certificate	Anglican	7 dependents	Primary teacher	Own house made of bricks & cement, no electricity and no piped water.
3 Kabale	Female	38 & Married	Wife (4)*	Primary 5	Anglican	5 Dependents	Subsistence farmer	Own house, made of mud & wattle, no electricity & no piped water.
4 Madamu	Female	36 & Married	Wife (6)*	No formal education	Anglican	6 Dependents	Sells groceries	Own house, made of bricks & cement, has electricity & piped water.
5 Mugore	Female	45 & Married	Mother (8)*	Primary 5	Anglican	9 Dependents	Subsistence farmer	Own house made of bricks & cement, has piped water but no electricity.
6 Mugurusi	Male	60 & Married	Father (01)*	Certificate (tertiary level)	Catholic	12 Dependents	Substance farmer	Own house made of brick & cement, no electricity & no piped water.
Nabasa	Female	40 &	Daughter	Primary 7	Pentecostal	10	Subsistence	Own house made of

		Separated	(05)*			Dependents	farmer	bricks and cement, no electricity & no piped water.

Note: The bracketed numbers refer to corresponding outpatients listed in appendix A for whom respective families are responsible.

Appendix C

Table showing psychiatric health workers and their socio-demographiccharacteristics

No. & Name	Gender	Age in years	Marital status	Highest level of formal education	Religious affiliation	Number of dependents	Occupation	Description of housing
1 Agaba	Male	50	Married	Diploma	Anglican	8 Dependents	Clinical Officer	Own house made of bricks & cement, has electricity & piped water.
2 Bosi	Male	30	Married	Certificate (tertiary level)	Anglican	2 Dependents	Nurse	Rented house made of bricks & cement, has electricity but no piped water.
3 Gadi	Male	34	Married	Certificate (tertiary level)	Anglican	3 Dependents	Nurse	Rented house made of bricks & cement, has electricity & piped water.
4 Mariya	Female	34	Single	Master's Degree	Catholic	No Dependent	Social Worker	Rented house made of bricks & cement, has electricity & piped water.
5 Meya	Male	36	Married	Diploma	Muslim	5 Dependents	Occupational therapist	Own house made of bricks & cement, has piped water but no electricity.
6 Milly	Female	35	Married	Master's Degree	Catholic	4 Dependents	Psychiatrist	Own house made of bricks & cement, has electricity & piped water.
7 Njuna	Female	40	Single	Master's	Pentecostal	1 Dependent	Counselor	Rented house made

				Degree				of bricks & cement, has electricity & piped water.

Appendix D

Table showing the religious healers and their socio-demographiccharacteristics

No. & Name	Gender	Age in sears	Marital status	Highest level of formal education	Religious affiliation	Number of dependents	Occupation	Description of housing
1 John	Male	50	Married	Diploma	Pentecostal	7 Dependents	Pastor	Rented house made of bricks & cement, has electricity & piped water.
2 Martha	Female	37	Single	Certificate (tertiary level)	Catholic	2 Dependents	Pastor	Official house made of bricks & cement, has electricity & piped water.
3 Sonia	Female	41	Single	Senior 6	Pentecostal	4 Dependents	Pastor	Rented house made of brick & cement, has electricity & piped water.

Appendix E

Table showing the traditional healers and their socio-demographiccharacteristics

No. & Name	Gender	Age in years	Marital status	Highest level of formal education	Religious affiliation	Number of dependents	Occupation	Description of housing
1 Bernard	Male	65	Married	Primary 3	Catholic	14 Dependents	Traditional healer	Own house made of bricks & cement, no electricity & no piped water.
2 Jane	Female	55	Widowed	Primary 3	Catholic	13 Dependents	Traditional healer	Own house made of bricks & cement, no electricity & no piped water.
Mulefu	Male	50	Married	Senior 2	Anglican	14 Dependents	Traditional healer	Own house made of bricks & cement, no electricity & no piped water.

Appendix F

Study Advert for Outpatients (Runyankole-Rukiga Version)

Okuronda Ab'okwetaba omu Mushomo gwe eby'amagara

Noobaasa kuba ohikire kwetaba omu mushomo gwe eby' okureeberera abarwaire b'omutwe omwi Irwariro rya Mbarara. (Mbarara Hospital). Omushomo ogurikuza kukorwa tigurikubarirwa mu obujanjabi nainga obuheereza obu orikuha nainga obu orikutunga.

Okusharamu kwaawe kwetaba nainga kuteetaba omu mushomo ogu tikwine ekikurayiheho/aha/kakwate n'obujanjabi obw'orikutunga nainga obundi buheereza obu orikuha nainga obu orikutunga).

Waaba nooyenda kumanya ebirikukiraho, buuza/ hikiirira Mr. Twesigye Justus aha simu 0782 422877 nainga Ms. Rukondo Lydia (Social Worker) aha simu 0752 864 744

Omushomo ogu nigukorwa Mr. Twesigye Justus, orikushomera omu Yunivasite ya Stellenbosch omuri South Africa, ori kureebererwa Professor Kagee Ashraf ow'omu Department ya Psychology, Faculty of Arts and Social Sciences omu Yunivasite egyo eyagambwaho.

Appendix F (English Version)

Health Study

You may qualify to participate in a study on mental health care at the Mbarara Hospital in Western Uganda This study is not part of treatment or services you provide or receive. Your decision to participate or not, will therefore, not affect the treatment or other services you provide or receive at the Mbarara Hospital.

For more information, contact: Mr. Twesigye Justus on Telephone No. +256 782 422 877 or Ms. Rukundo Lydia (social Worker) on Telephone No. +256 752 864

This research project is being conducted by Mr. Twesigye Justus from Stellenbosch University, South Africa. Professor Kagee Ashraf at the Psychology Department, Faculty of Arts and Social Sciences in Stellenbosch University, South Africa is supervising this research project.

Appendix G

Recruitment Script for Outpatients (Runyankole-Rukiga Version)

Orupapura rw'okuronderaho abarwaire b'omutwe abatarikuraara mu irwariro ab'okwetaba omu mushomo

Haro. Nibanyeta/Amaziina gangye niinye Twesigye Justus. Ninduga omu kitongore kyirikushomesa eby' emitwarize ne emiteekateekyere y'abantu - *Psychology,* Faculty of Arts and Social Sciences omu Yunivasite ya Stellenbosch ey'omuri South Africa. Yebare okungarukamu/kumpikaho ahabw'omushomo ogu ndangiriire, ogu ndikwenda kukora. Ninteekateeka kukora omushomo aha byamagara, ogushashuriirwe Yunivasite ya Stellenbosch. Omushomo ogu gurimu okuganiira na (okubuuza ebibuuzo) abarwaire b'omutwe abatarikuraara mu irwariro, kandi abarikutungira obujanjabi n'obundi buhwezi omu irwariro rya Mbarara (Mbarara Hospital). Okuganiira (okubuuza ebibuuzo) oku nikwija kutwara edakiika eziri ahagati ya 50-80. Omushomo ogu nabwo gurimu okuganiira na (okubuuza ebibuuzo) abo abarikureeberera abarwaire: abajanjabi abatendekirwe n'abatatendekirwe. Ninza kuba nimbuuza abarwaire oku barikwetegyereza embeera ezi barimu n'emuringo eyibarikujanjaabwamu/ eyibarikureebererwamu. Ebiraaruge omu kushoma oku, niinyenda kubyejunisa/ kubikoresa omu kuhandiika ekitabo ahabw'okushoma kwangye okwa diguri y'obwa dokita. Okwongyerera ahari ekyi, ebiraaruge omu mushomo ogu, nyine amasiko ngu nibyiija kuyamba omu kutunguura/okwongyera aha omutindo gw'okureeberera abarwaire b'omutwe omu Uganda. Torikugyemwa kwetaba omu mushomo ogu; okwetaba omu mushomo ogu n'okweyendera. Nabwo noobaasa kusharamu kuruga omu mushomo ogu eshaaha yoona waahurira nooyenda kugurugamu. Nahabwekyo okwanga kwetaba omu mushomo ogu, nainga okugurugamu waaba waakutandikire tikurikwihaho/ tikwine kakwate n'obujanjabi nainga obuhwezi obu orikutunga. Nooyenda kwetaba omu mushomo ogu?

Waaba OTARIKWIKIRIZA kwetaba omu mushomo ogu, yebare kutuha obwire bwawe.

Waaba NOIKIRIZA kwetaba omu mushomo ogu, nyine ebibuuzo bina ebiraanyambe kumanya yaaba ohikire kwetaba omu mushomo ogu. Ninkushaba orinde byona mbanze naabibuuza reero obone kungarukamu. Noobaasa kugira ngu EEGO eky'okugarukamu ahabwa buri kibuuzo kyaba kiri EEGO. Ahandi noobaasa kugira ngu NGAAHA haaba hariho ekibuuzo omuri ebyo bina eki orikwija kugarukwamu ngu NGAAHA.

Nootuura omu kicweka kya Mbarara eya'ira etakashazirwemu, obwahati erimu disiturikiti ya Isingiro, Ibanda, Kiruhura, na Mbarara?

Otwire nootungira obujanjabi n'obuheereza obundi aha irwariro rya Mbarara (Mbarara Hospital) haakiri kumara emyezi 6?

Noonyikiriza ngu nshwijuma ebihandiiko ebiri omu fairo yaawe ebirikukwata aha magara gaawe kwenda kwongyera kukwetegyereza?

Noonyikiriza kuganiira naabo abarikukuha obujanjabi n'obundi buhwezi/buyambi, kwenda kweyongyera kumanya ebirikukukwataho?

Waagira ngu NGAAHA, nikimanyisa ngu waagarukamu ngu NGAAHA hakiri ekibuuzo kimwe. Waaba noohamya eki waagarukamu, nigira ngu 'tohikire kwetaba omu mushomo ogu' kwonka yebare kutuha obwire bwawe'. Waaba otakahamize eki garukwamu shaba ogarukyemu ebibuuzo by'okukyencura ab'okwetaba omu mushomo ogu ebyaheza kubuuzibwa.

Waagira ngu EEGO, nikimanyisa ngu waagarukamu EEGO ebibuuzo byona. Omurwaire yaaheza kuhamya eki yaagarukamu, gumizamu oronde fairo reero ogyetegyereze kureeba yaaba omurwaire ogwo yaakyebereiwe bakashanga aine oburwaire obwa *unipolar* depression nainga *bipolar disorder*. Gaaruka oyetegyereze fairo ye ahabw'ebigarukwamu by'ebibuuzo 1 na 2. Byaba bitahamiibwe, gira ngu 'tohikire kwetaba omu mushomo ogu kwoka yebare kutuha obwire bwawe.

Omurwaire waashanga baamukyebeire bakashanga aine oburwaire bwa *unipolar* depression nainga bwa *bipolar disorder*, n'eby'okugarukamu ahabw'ebibuuzo 1 na 2 byahamibwa, gumizamu n'orupapura oru.

Omushomo ogu nigwija kutandika n'okushwijuma ebihandiiko ebirikukwata aha kujanjaabwa kwawe hakurateho okugaaniira (omu muringo gw'okubuuza ebibuuzo). Okuganira/ okubuuza ebibuuzo) nikwija kutwara edakiika ziri ahagati ya 50-80. Okuganiira (okubuuza ebibuuzo) nikwija kukorerwa aha mwanya, ekiro n'eshaaha ebi oyesiimiire. Nyine omuhwezi orikuza kuba naanyambaho omukuhandika ebituraganiire, omushomo ogu. Ku oraabe oine ebibuuzo byona, ninza kubigarukamu, ntakakutaahize omu mushomo ogu. Oine obushoboorozi kwanga kwetaba omu mushomo ogu waaba noohuria ngu ebibuuzo byawe byona tibyagarukwamu kurungi (nk'oku waaba nooyenda). Ebi orangambire byona nibiza kubiikwa gye omu kihama kandi tibirikwija kukoresibwa ahabw'ekindi kintu kyona okwihaho omushomo ogu gwonka. Iwe nk'omuntu, tihaine eki oraatuge kuruga omu mumuishomo ogu. Niinyija kukuha ekyokunywa kyonka okugaaniira kwaba nikugyenda omumaisho, hamwe n'okukugarurira esente zaawe za turansipoota ahabw'okwetaba omu mushomo ogu. Oine ekibuuzo ekikwasire aha mushomo ogu? (hunamamu otegyereze abanze akugarukemu).

Noikiriza kwetaba omu mushomo ogu? (hunamamu otegyereze abanze akugarukemu).

Waaba otaikiriza kwetaba omu mushomo ogu, Yebare kutuha obwire bwawe.

Waaba waikiriza kwetaba omu mushomo ogu, nooyenda ngu okuganiira (okubuuza ebibuuzo) kubeho ryari? (ikirizana nawe aha kiro n'obwire kandi omwiheho n'endagiiriro hamwe n'esimu ye).

Ebiro by'okukoreraho okuganiira (okubuuza) ______________________

Omwanya ogu arikutuuramu (arikuraramu) ________________________

Esimu____

Amaziina g'orikuza kwetaba omu mushomo________________________

Appendix G (English Version)

Recruitment Script for Outpatients

Hello. My name is Twesigye Justus. I am a doctoral student at the Psychology Department, Faculty of Arts and Social Sciences, Stellenbosch University in South Africa. Thank you for contacting me about my advertised study. I am planning to conduct a health study, which is sponsored by Stellenbosch University. This study includes personal interviews (approximately between 50 - 80 minutes) with outpatients who are receiving treatment and care for unipolar depression and bipolar disorder from Mbarara Regional Referral Hospital (MRRH). The study also involves interviews with outpatients' care providers (professional and lay care providers). I will be asking outpatients how they understand their health conditions and how care providers are caring for them. I will also be asking care providers how they understand outpatients' health conditions and how they are caring for them. I would like to use information gathered in this study to write a doctoral thesis. In addition, information collected I hope will contribute to improving mental health care in Uganda. Your decision to participate in this study or not, is entirely voluntary. You can withdraw from this study any time you wish to do so, during data collection. Thus, refusal to take part or withdrawal from this study will not in any way affect care or services that you receive. Would you like to participate in this study?

If NO, 'Thank you for your time'.

If YES, 'I have four questions which will help me to find out if you are eligible to participate in this study. Kindly wait until I have asked all four questions before you answer. Give one answer for all the four questions. You may say YES if your answer to each of of the four questions is YES. Otherwise, you may say NO if your answer to any of the four questions is NO.

1. Are you a native of '*Greater Mbarara*' (Isingiro, Ibanda, Kazo, Kiruhura and Mbarara districts)
2. Have you been receiving health care from MRRH for at least 6 months?
3. Would you allow me to review your medical file to know more about you?
4. Would you allow me to talk to your care providers for more information about you?

If NO, it means your answer is NO to at least one of the four questions. 'Please do not tell me which question'. 'If confirmed', say 'You are not eligible for this study but thank you for your time' If not confirmed, ask screening questions again.

If YES, say 'Your answer is yes to all the 4 questions'. 'If confirmed', ask for outpatient's file and cross check whether he or she has diagnosis of either unipolar depression or bipolar disorder. Also cross check for answers for question 1 and 2. If the outpatient does not have a diagnosis of either unipolar depression or bipolar disorder and answers for questions 1 and 2 are not confirmed, say 'You are not eligible for this study but thank you for your time'.

If the outpatient has a diagnosis of either unipolar depression or bipolar disorder and answers for question 1 and 2 are confirmed, then continue with the script.

This study will start with review of your medical records followed by a personal interview with you. The interview may last between 50 – 80 minutes and will be conducted at the venue, date and time of your convenience. I will conduct the interview with help of a well-trained research assistant. Before enrolling you into the study, I will answer your questions. You may refuse to participate in this research if you feel that not all of your questions have been answered satisfactorily. Information I will get from you will be kept confidential and will be used for research purposes only. There are no personal benefits accruing to your participation in this study. I will only give you a soft drink for refreshment during the course of interview and transport refund for participating in this study. Do you have any questions about this study? (Pause for response)

Would you be willing to participate? (Pause for response)

If NO, Thank you for your time.

If YES, When would you like to have the interview done (make an appointment and request for contact details):

Date of interview: ______________________
Physical address _________________
Phone number:_______________________
Participant’s name ___________________________

Appendix H

Information Leaflet and Informed Consent Form for Outpatients, Families, Religious Healers, and Traditional Healers (Runyankole-Rukiga Version)

FOOMU Y'OKWIKIRIZA N'OKWEKUNDIRA KWETABA OMU MUSHOMO HAMWE N'AMAKURU AGU ORIKWETENGA KUMANYA AHA MUSHOMO OGU

ETHICS REFERENCE NUMBER: N10/09/284 (Stellenbosch University and SS2462 (UNCST)

TITTLE OF THE STUDY: Explanatory models for the care of outpatients with mood disorders in Uganda: An explanatory study.

Principal Investigator: Twesigye Justus, PhD candidate in Psychology, Faculty of Arts and Social Sciences, Stellenbosch University, South Africa.

CONTACT NUMBER: +256782422877

CANDIDATE'S SUPERVISOR: Professor Kagee Ashraf, Psychology Department, Faculty of Arts and Social Sciences, Stellenbosch University, South Africa.

CONTACT NUMBER: +27 834433002 (Cell)

Nooyetwa kwetaba omu mushomo ogu. Nooshabwa kutwara obwire okashoma amakuru agari omu foomu egi, agarikuha omu bwijire ebirikukwata aha mushomo ogu. Ninkushaba kumbuuza ebibuuzo byona ebi oine aha mushomo ogu aha bintu ebi otarikwetegyereza kurungi. Ni kikuru kwetegyereza kurungi eki omushomo ogu gurikukwataho n'oku waakubaasa kugwetabamu. Okusharamu kwetaba omu mushomo ogu nainga kutagwetabamu n'okwekundira. Noobaasa na kusharamu kuruga omu mushomo ogu eshaaha yoona waahurira waayenda kugurugamu. Okwanga kwetaba omu mushomo ogu nainga okukurugamu waagutandikire tikiine kabi kwona ahari iwe.

Akakiiko akarikureberera/okukuria ebye mishomo ye by' amagara - *Health Research Ethics Committee omu Faculty of Health Sciences* omu Yunivasite ya Stellenbosch kaikiriize omushomo ogu ku kugyenda omumaisho. Waaba nooyenda kugira eki waabuza ab'akakiiko aka nootera esimu +27 21 9389140, nainga osindike *fax* ahari +27 21 931 3352, nainga osindike ebaruha aha *email* egi: carlis@sun.ac.za. Okucondooza oku nabwo nikukuratira engyenderwaho n'ebiragiro ebirikukwata aha mishomo kushemereire kuba nikugyendamu, ebiri omu *International Declaration* eya Helsinki hamwe n'ebiragiro by'okutwazamu kwemishomo ebyateirweho *Uganda Nationala Council for Science and Technology (UNCST)*. Waaba oine eki orikwenda kubabuuza, noobaasa kubateerera esimu +256 414 250 499/+256 414 705 500, nainga osindike *fax* ahari +256 412 234 579 nainga osindike ebaruha aha *email* egi: uncst@starcom.co.ug.

Omushomo ogu nigukwata ahari ki?

Ekigyendererwa ky'omushomo ogu n'okwenda kutunga okushoboorokerwa aha miringo eyi abarwaire b'omutwe, barikujanjaabwamu/barikureebererwamu omu Uganda. Omushomo ogu niguza kukorwa aha barwaire abarikwija omu irwariro kuraguza kwonka batarikuraarayo, abajanjaabi abatendekirwe na abatatendekirwe abarikubareeberera abarwaire b'omutwe, omu kicweka kya Burengyerwa-izooba ekya Uganda. Omushomo ogu nabwo gurimu okushwijuma ebihandiiko by'abarwaire aba ebiri omu irwariro ebirikukwata aha magara gaabo, okugaaniira (omu muringo gw'okubuuza ebibuuzo) n'abarwaire boonyini hamwe na abajanjaabi abatendekirwe n'abatatendekirwe abarikubareeberera. Okuganiira na (okubuuza ebibuuzo) abarwaire nikuteekateekwa kumara edakiika ziri ahagati ya 50-80. Okuganiiira na nabarikubareeberera nikuteekateekwa kumara edakiika ziri ahagati ya 30-60. Omushomo ogu nigwija kukorerwa aha mwanya, ekiro, n'eshaaha ebi orikubuuzibwa ayesiimiire. Nyine omuhwezi orikuza kuba naanyambaho omu kuhandika ebituraganeireho omu mushomo ogu. Noikirizibwa kumbuuza ebibuuzo ntakakutaahize mu mushomo ogu. Nitwija kukwata aha katambi kandi tugarukye tuhandiike ebi oraatugambire, kureeba ngu amakuru goona ag'omugasho twagatunga. Amakuru goona agu oraatuhe nitwija kugabiika omu kihama kandi twaheza kugakoresa eki tugyendereire, nitwija kugasangura/kugashiisha/kuganaga). Ebiraaruge omu mushomo ogu niinyija kubikoresa omu kuhandiika ekitabo ahabw'okushoma kwangye okwa diguri ey'obwa dokita aha bikwatireine n'okushoma aha emitwarize ne miteekateekyere y'abantu nainga shi *Psychology* hamwe n'okushohoza ebyaruga omu mushomo ogu omu mpapura - *journals* z'ebyobwegyese. Nyine amasiko ngu amakuru agaraaruge omu mushomo ogu nigaija kukoresibwa kutunguura/kwongyera omutindo gw'obuheereza omu kureeberera abarwaire b'omutwe omu Uganda. Omushomo ogu nigwetabwamu obujanjaabi abatendekirwe n'abatatendekirwe kandi gushashurirwa Yunivasite ya Stellenbosch ey'omuri South Africa.

Ahabwenki otoorainwe kwetaba omu mushomo ogu?

Otoorainwe kwetaba omu mushomo ogu ahabwokuba:

Nookora omurimo gw'okujanjaaba n'okureeberera abarwaire b'omutwe/oine oburemeezi bw'okurwara omutwe, (yihamu ekihikire kurugiirira yaaba ari omurwaire, nainga omujanjaabi otendekirwe, nainga otatendekirwe)

Oine obubonero bwona obu tubaire nitwenda ahabw'omuntu ogwo ohikire kwetaba omu kucondooza oku.

Obujunaanizibwa bwawe ni buuha omu omu mushomo ogu?

Ninza kukushaba kugarukamu ebibuuzo ebi ndakubuuze. Noija kungambira ebi orikwetegyereza aha burwaire bw'omutwe n'obujanjabi hamwe n'obuheereza obu abarwaire abo barikutunga kuruga omu irwariro rya Mbarara (Mbarara Hospital).

Haine eki orikwija kutunga waayetaba omu mushomo ogu?

Tihaine eki orikwija kutunga iwe nk'omuntu ahabw'okwetaba omu mushomo ogu. Kwonka omushomo ogu nigubaasa kuyamba omu kwongyera kwetegyereza aha burwaire bw'omutwe, kandi kuyamba omu kutunguura omutindo gw'okujanjaaba/okureeberera abarwaire abo omu Uganda omu bwire bw'omumaisho. Kwonka niinyija kukuha ekyokunywa twaba nituganira/ (okugaaniira kwaba nikugyenda omumaisho), hamwe n'okukugarurira esente zaawe za turansipoota ahabw'okwetaba omu mushomo ogu.

Haine akabi kwona akarikwija kukuhikaho abaw'okwetaba omu kucondooza oku?

Tihariho kabi kwona akarikwija kuba aha magara gaawe waayetaba omu kucondooza oku. Kwonka okucondooza oku nikubaasa kukureetera otaatebenkana na waagira obusaasi omu mutima. Waahurira otaatebenkaine omu mutima, otaatiina ongambire ngyezeho nkurondere obuhwezi bw' okukuhumuriza. Nshabire omukugu omu miteekateekyere (*Psychology*) y'abantu omu irwariro rya Mbarara Hospital otari ha tiimu y'okucondooza oku, kuha obuhwezi abo abaraahurira baagira obusaasi n'okushoberwa omu mutima, n'obuhwezi obundi bwona obweyongyeireyo obu baakwetenga. Nabwo noobaasa kusharamu kuruga omu kucondooza oku eshaaha yoona ahu oraayendere. Torikugyemwa kugarukamu ebibuuzo byona ebi ndikuza kukubuuza.

Waaba otaikiriize kwetaba omu kucondooza oku, ni bintu ki ebindi ebi waakubaasa kukora?

Noobaasa kusharamu kwetaba nainga kuteetaba omu kucondooza oku. Waasharamu kwetaba omu kucondooza oku noobaasa nabwo kukurugamu eshaaha yoona ahu oraayendere kandi hatagira ekintu kibi kyona ekyakubaho. Nabwo torikugyemwa kugarukamu ebibuuzo byona ebiraakubuuzibwe.

Nooha orikwikirizibwa kumanya amakuru agu waatuheereza?

Tiimu erikukora okucondooza oku neija kubiika gye omu kihama amakuru goona agaraatungwe omu kucondooza oku. Ebi oraatugambire titurikwija kubigambira banywani baawe, abanyabuzaare, abu orikukora nabo, nainga ondiijo muntu weena otari ha tiimu erikukora okucondooza oku. Amakuru agu oraatuhe ningaija kutunga enamba erikwija kuba neemanywa abo bonka abaikiriziibwe kugimanya, kandi ebiikwe omu ofiisi etarikugiibwamu abantu baingi. Amakuru agararugye omu kucondooza gaaheza kushohozibwa, torikwija kumanywa nk'owaagatuhaire ahabwokuba eiziina ryawe niriija kuba ritahandiikireho. Amakuru aga nigaija kushiishwa ahanyima y'emyaka 5 gamazire kushohozibwa (okukozesibwa).

Nooza kushashurwa, nainga hariho esente ezi orikwetenga kushashura ahabw'okwetaba omu kucondooza oku?

Ngaaha torikwija kushashurwa ahabw'okwetaba omu kucondooza oku kandi torikwija kushashura sente ahabw'okwetaba omu kucondooza oku, kwonka niinyija kukuha ekyokunywa okugaaniira kwaba nikugyenda omumaisho, hamwe n'okukugarurira esente zaawe za turansipoota ahabw'okwetaba omu kucondooza oku.

Hariho ekindi kintu kyona eki oshemereire kumanya nainga kukora?

Waaba oine ebibuuzo ebindi nainga waatunga obuzibu bwona, noobaasa kuhikiirira Omwami Justus Twesigye aha simu +256 782 422 877.

Haaba hariho ekintu kyona ekindi eki orikwenda kumanya eki ntaabaasa kukugambira nk'oku waaba nooyenda, noobaasa kuhikiirira Profeesa Kagee Ashraf orikureeberera okucondooza oku aha simu + 27834433002.

Noija kutunga kope y'ekipapura eki erimu amakuru hamwe n'okuhamya ku waikiriza kwetaba omu kucondooza ogyebiikire.

Okwikiriza kwetaba omu kucondooza

Naikiriza kuta omukono ahaifo, nikimanyisa ngu nyowe…………………………………naikiriza kwetaba omu kucondooza okurikukwata aha kushoboorokyerwa oku abarwaire b'omutwe omu Uganda barikurebererwa/kujanjabwa barikutwazibwamu. (*Explanatory models for the care of outpatients with mood disorders in Uganda: An explanatory study*)

Niinyikiriza ku:

Naashoma nainga ku naashomerwa ebiri omu foomu y'okwikiriza kwetaba omu kucondooza, kandi ehaandiikire omu rurimi oru ndikwetegyereza kurungi.

Naatunga omugisha kubuuza ebibuuzo kandi ebibuuzo byona ebi naabuuza byagarukwamu nk'oku naaba niinyenda.

Niinyetegyereza ngu okwetaba omu kucondooza oku n'okweyendera; tihaine wangyema kukwetabamu.

Nimbaasa kusharamu kukurugamu eshaaha yoona naahurira naayenda kukurugamu kandi eki tikiine kabi kwona ahariinye omu muringo gwona.

Omwanya……………………………..ebiro……...2011

………………………………………..

Omukono gw'orikuza kwetaba omu kucondooza

Orikuza kukora okucondooza

Nyowe………………………………………. ebiro……….2011:

Naashobororera ………………………………………amakuru agari omu kihandiiko eki.

Naamutamu omuhimbo kubuuza ebibuuzo kandi naatwara obwire kumugarukamu.

Niimanya ngu ebintu byona ebyagambwaho omu kihandiiko eki ebirikukwata aha kucondooza okurikuza kukorwa yaabyetegyereza kurungi.

Omwanya…………………………………..ebiro……….2011

………………………………………………..

Omukono gw'orikukora okucondooza.

Appendix H (English Version)

INFORMATION LEAFLET AND CONSENT FORM FOR OUTPATIENTS, FAMILIES, RELIGIOUS HEALERS, AND TRADITIONAL HEALERS

THICS REFERENCE NUMBER: N10/09/284 (Stellenbosch University and SS 2462 (UNCST)

TITTLE OF THE STUDY: Explanatory models for the care of outpatients with mood disorders in Uganda: An exploratory study.

PRINCIPAL INVESTIGATOR:

Twesigye Justus, PhD candidate at the Psychology Department, Faculty of Arts and Social Sciences, Stellenbosch University.

CONTACT NUMBER: 021-8083459 (Work) or +256 782 422 877 (Cell)

CANDIDATE'S SUPERVISOR:

Kagee Ashraf, Professor at the Psychology Department, Faculty of Arts and Social Sciences, Stellenbosch University.

CONTACT NUMBER: + 27 021- 8083442 (Office): +27 834433002 (Cell).

You are being invited to take part in a research project. Please take some time to read information on this form, which will explain details concerning this research project. Please ask me any questions about this research project, which you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research project entails and how you could be involved. The decision to participate in this research project or not is totally voluntary. You can also withdraw from this research project any time you wish to do so, during data collection. Refusal to take part or withdrawal from this research project will not in any way affect you negatively.

This research project has been approved by the **Health Research Ethics Committee in the Faculty of Health Sciences at Stellenbosch University. Their Contact details: +27 21 9389140, Fax +27 21 931 3352, email: carlis@sun.ac.za.** In addition, this research project will be conducted in accordance with ethical guidelines and principles of the International Declaration of Helsinki as well and ethical guidelines for research of the **Uganda National Council for Science and Technology (UNCST). The contact details for UNCST: +256 414 250 499/+256 414 705 500, Fax +256 412 234 579, email: uncst@starcom.co.ug.**

What this research proeject is all about?

The aim of this research project is to obtain a description of explanatory models for care of outpatients with mood disorders in Uganda. The research project will be conducted among outpatients and their professional and non-professional care providers in Western Uganda. It will involve review of outpatients' medical records followed by personal interviews with outpatients and their professional and non-professional care providers. An interview with an outpatient is estimated to last between 50 – 80 minutes while an interview with a care provider is estimated to last between 30 - 60 minutes. Interviews will be conducted at venues, dates and time of participants' convenience. I will conduct interviews with assistance of a well-trained research assistant. We will audio-record interviews and take notes to ensure that all relevant information is captured. Information will be kept confidential and be destroyed after serving the purpose for which they will be collected. Information will be used in compiling my PhD thesis and published in relevant academic journals. I hope the information I will collecte will contribute to improving mental health care in Uganda. This research project is sponsored by Stellenbosch University.

Why have you been invited to participate?

You have been invited to participate in this reaserch project because:

(i) You are involved in mental health care as (consider appropriate response from outpatient, professional care provider and non-professional care provider).

(ii) You match all recruitment criteria

What will be your responsibility?

I will request you to participate in an interview with me, which will involve asking you questions about your understanding of mood disorders and care of outpatients of Mbarara Regional Referral Hospital (MRRH).

Will you benefit from taking part in this research project?

There are no direct benefits that will come to you for participating in this research project. The study however, may contribute to understanding mental illness and thus improve mental health care in Uganda in the long-run. However, I will provide you with a soft drink for refreshment during the interview and transport refund for your participation in this research project.

Are there risks involved in your taking part in this research proeject?

I don't foresee physical risks that may arise due to your participation in this research project. The interview may however, pose emotional discomfort to you. In case you become emotionally disturbed during the interview, feel free to inform me so that I can refer you for appropriate help. I have requested a clinical psychologist in MH who is not a member of this research team to provide emotional care and further support if required. You may also stop your participation at any time. You are under no pressure to answer all the questions that I am going to ask you.

If you do not agree to take part, what alternatives do you have?

You can choose whether to participate in this research project. If you decide to participate in this research project, you may withdraw at any time without any negative consequences and it is not compulsory to answer all questions I will ask you.

Who will have access to your information?

The research team will keep any information that is gathered in this research project confidential. Responses provided will not be revealed to your friends, relatives, colleagues or anyone else outside the research team. Information you provide will be used only for the stated research purpose. Data will be password–protected and kept in offices with limited access. If data are published, you will not be identified by name. The data will be deleted after 5 years following their publication.

Will you be paid to take part in this research project and are there any costs involved?

No, you will not be paid to take part in this research project. There will be no costs for you if you take part in this research project. However, I will give you a soft drink for refreshment during the interview and a transport refund.

Is there anything else that you should know or do?

You can contact Mr. Justus Twesigye at telephone +256 782 422 8777 if you have further queries or encounter any problems.

You can contact Professor Kagee Ashraf (supervisor) at telephone +27834433002 if you have any concerns or complaints that have not been adequately addressed by me.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I..agree to take part in a research study entitled '*Explanatory models for the care outpatients with mood disorders in Uganda: An exploratory study'*.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this research project is **voluntary** and I have not been pressured to take part.
- I may choose to leave the study at any time and this will not affect me negatively in any way.

Signed at (*place* ....on (*date*)..2011

....

Signature of participant

Declaration by investigator

I (*name*)..declare that:

- I explained information in this document to..
- I encouraged him/her to ask questions and take adequate time to answer them.
- I am satisfied that s/he adequately understands all aspects of this research project as discussed above.

Signed at (*place*)..on (*date*)..2011

....

Signature of investigator

Appendix I

Recruitment Script for Families, Religious Healers, and Traditional Healers (Runyankole-Rukiga Version)

Orupapura rw'okuronderaho abajanjabi ba' abarwaire b'omutwe abahikire kwetaba omu mushomo

Haro. Nibanyeta/amaziina gangye niinye Twesigye Justus. Ninduga omu kitongore ekiri kushomesa eby'emitwarize/emiteekateekyere y'abantu - *Psychology, Faculty of Arts and Social Sciences* omu Yunivasite ya Stellenbosch omuri South Africa. Yebare kungarukamu/kumpikaho ahabw'omushomo ogu ndangiriire ogu ndikwenda kukora. Ninyenda/Ninteekateeka kukora omushomo aha byamagara, ogushashuriirwe Yunivasite ya Stellenbosch omuri South Africa. Omushomo ogu gurimu okubuuza abajanjabi/abantu abarikureeberera (abatendekirwe) abarwaire b'omutwe na' abajajambi abatatendekirwe. Omushomo ogu gurimu n'abarwaire abatarikuraara mu irwariro kwonka abarikutungira obujanjabi omu irwariro erya Mbarara (Mbarara Hospital). Niinyija kuba nimbuuza abajanjabi/abantu abarikureeberera abarwaire aba, oku barikwetegyereza oburemeezi bw'abarwaire baabo hamwe n'emuringo eyi barikubajanjabamu/ barikubareebereramu. Okubuza okwe nikwija kumaraho ahagati y'endakiika 30 na 60. Niinyija no'okubuuza abarwaire boonyini oku barikwetegyereza oburemeezi bwa magara gaabo obu barimu n'oku bari kujanjabwa/barikureebererwa. Ebiraaruge omu mushomo ogu niinyija kubyejunisa/kubikoresa omu kuhandiika ekitabo ahabw'okushoma kwangye okwa diguri ey'obwa dokita. Nyine amasiko ngu ebiraarugye omu mushomo ogu nibyija kukoresibwa kutunguura/kwongyera omutindo gwe bwo'obuheereza omu kujanjaaba/kureeberera abarwaire b'omutwe omu Uganda. Torikugyemwa kwetaba omu mushomo ogu; okusharamu kwawe kwetaba omu mushomo ogu nainga okutagwetabamu n'okweyendera. Noobaasa nabwo kuruga omu mushomo ogu ahu oraayendere. Nahabwekyo okwanga kwetaba omu mushomo ogu nainga okukurugamu waagutandikire tikiine kabi kwona ahari iwe. Nooyenda kwetaba omu mushomo ogu?

Waaba OTARIKWENDA, Yebare kutuha obwire bwawe.

Waaba WAIKIRIZA kwetaba omu mushomo ogu, nyine ebibuuzo bibiri ebi ndikwenda kukubuuza, ngyendereire kumanya yaaba ohikire kwetaba omu mushomo ogu. Ninkushaba kutegyereza nkabanza naakubuuza ebibuuzo byombi reero okabona kungarukamu. Noobaasa kugarukamu EEGO ebigarukwamu by'ebibuuzo byombi byaba biri EEGO. Waaba nooza kugarukamu ngaaha ahabw'ekibuuzo kimwe nainga ahabw'ebibuuzo byombi, nooza kugarukamu NGAAHA.

Omu myezi mukaaga ehwire, obaire ori omwe omu abarikuha obujanjaabi n'okureeberera abarwaire b'omutwe omu irwariro rya Mbarara (Mbarara Hospital)?

Naiwe muntu ou omurwaire (ogu) (arikukirayo)or arikwesiga munonga omubaantu boona abarikumujanjaaba/abarikumureeberera? (nk'omunyabuzaare nainga munywaniwe).

Ekyokugarukamu kyawe ahabw'ekibuuzo 1 kyaba kiri NGAAHA, tohikire kwetaba omu mushomo ogu kwonka yebare kumpa obwire bwawe. Waaba noogira ngu EEGO, nikimanyisa ngu ekyokugarukamu kyawe ni EEGO haakiri ahabw'ekibuuzo 1. Waaba noohamya okugarukwamu, GUMIZAMU n'orupapura oru.

Omu mushomo ogu, ninza kwetegyereza ebihandiiko ebirikukwata aha magara g'abarwaire, ngireho okugaaniira (omu muringo gw'okubuuza ebibuuzo) n'abarwaire, hamwe naimwe abajanjaabi abatendekirwe hamwe n'abajanjaabi abatatendekirwe abarikureeberera abarwaire b'omutwe abatarikuraara mu irwariro. Okuganiira (okubuuza ebibuuzo) nikwija kutwara edakiika ziri ahagati ya 30-60. Okuganiira (okubuuza ebibuuzo) nikwija kuba aha mwanya ogu oyetoraneire, ebiro n'obwire ebi oyesiimiire. Nyine omuhwezi orikuza kuba naanyambaho (omukuhandika ebituraganire) omu mushomo ogu. Noikirizibwa kumbuuza ebibuuzo ntakakutaahize mu mushomo ogu. Noobaasa kwanga kwetaba omu mushomo ogu waaba noohurira ngu ebibuuzo byawe byona tibyagarukwamu kurungi (nk'oku waaba nooyenda). Amakuru goona agu oraatuhe nigaza kubiikwa gye omu kihama, kandi gaije kukoresibwa ahabw'omurimo gw'okushoma gwonka. Tiharimu magoba agu orikwija kutunga iwe nk'omuntu ahabw'okwetaba omu mushomo ogu; kwihaho niinyija kukuha ekyokunywa omushomo gwaba nigugyenda omu maisho, hamwe n'okukugaruria esente za turansipoota waayetaba omu mumushomo ogu. Oine ebibuuzo ebikwasire aha mushomo ogu? (hunamamu otegyereze abanze akugarukemu).

Waikiriza kwetaba omu mushomo ogu? (hunamamu otegyereze abanze akugarukemu).

Waaba otaikiriza kwetaba omu mushomo ogu, yebare kutuha obwire bwawe.

Waaba waikiriza kwetaba omu mushomo ogu, nooyenda ngu okuganira/okubuuza ebibuuzo kubeho ryari? (ikirizana nawe aha kiro n'obwire bw'okubuganiraho kandi omwiheho n'endagiiriro hamwe n'esimu ye).

Ebiro by'okuganira/okukoreraho okubuuza ________________
Omwanya ogu arikutuuramu/okuraraamu ___________________________
Esimu ___________________
Amaziina g'orikuza kwetaba omu mushomo________________

Appendix I (English Version)

Recruitment Script for Families, Religious Healers, and Traditional Healers

Hello. My name is Twesigye Justus. I am a doctoral student at the Psychology department, Faculty of Arts and Social Sciences in Stellenbosch University. Thank you for contacting me about my advertised study. I am planning to conduct a health study, which is sponsored by Stellenbosch University. This study includes personal interviews (approximately between 30–60 minutes) with care providers (professional and non-professional) caring for outpatients with unipolar depression and bipolar disorder. It also involves interviews with the outpatients who are receiving treatment from MH for unipolar depression and bipolar disorder. I will be asking care providers how they understand outpatients' health conditions and how they are caring for them. Additionally, I will be asking outpatients how they understand their health conditions and how they experience care. I would like to use information gathered from this study in writing my doctoral thesis. I hope information collected will also contribute to improving mental health care in Uganda. Your decision to participate in this study or not, is entirely voluntary. You can withdraw from this study any time you wish to do so, during data collection. Thus, refusal to take part or withdrawal from this study will not in any way be used against you. Would you like to participate in this study?

If NO, 'Thank you for your time'.

If YES, I have two questions which will help me to find out if you are eligible to participate. Kindly wait until I have asked all the two questions before you answer. Give one answer for all the two questions. You may say YES if your answer to each of the two questions is YES. Otherwise, you may say NO if your answer to any of the two questions is NO.

For professional care providers

1. Are you a member of the psychiatric team of MH?
2. Have you been closely involved in treatment and care of out-patients of MH in the last 6 months?

For non-professional care providers

1. Have you been closely involved in treatment and care of outpatients in the last 6 months?
2. Are you are a confidant of (specified) outpatient? (e.g. relative or friend of outpatient).

For professional care providers,

If NO, it means your answer is NO to at least one of the two questions. Please do not tell me which question'. If confirmed, say 'You are not eligible for this study but thank you for your time'. If not confirmed, ask the screening questions again. If YES, say 'Your answer is yes to all the two questions'. 'If confirmed', then continue with the script.

For non-professional care providers,

If NO to question number 1, say 'You are not eligible for this study but thank you for your time'. If YES, say 'Your answer is at least yes to question number 1'. 'If confirmed', then continue with the script.

In this study, I will review outpatients' medical records, conduct personal interviews with outpatients and you (professional and non-professional care providers). An interview with you may last between 30 – 60 minutes and will be conducted at the venue, date and time of your convenience. I will be assisted by a well-trained research assistant during the interview. Before enrolling you into this study, I will answer your questions. You may refuse to participate in this study if you feel that not all of your questions have been answered satisfactorily. All the information obtained from you will be kept confidential and will be only used for research purposes. There are no personal benefits accruing to your participation in this study. I will only give you a soft drink for refreshment during the interview and transport refund for participating in this study. Do you have any questions about this study? (Pause for response)

Would you be willing to participate? (Pause for response)

If NO, Thank you for your time.

If YES, When would you like to have the interview done (make an appointment and request for contact details)

Date of interview: ______________________
Physical address __________________________
Phone number: _______________________
Participant’s name ___________________________

Appendix J

Study Advert for Psychiatric Health Workers

Health Study

You may qualify to participate in a study on mental health care at the Mbarara Hospital in Western Uganda This study is not part of the treatment or services you provide or receive. Your decision to participate or not, will therefore, not affect treatment or other services you provide or receive.

For more information, contact: Mr. Twesigye Justus on Telephone No. +256 782 422 877 or Ms. Rukundo Lydia (social Worker) on Telephone No. +256 752 864

This research project is being conducted by Mr. Twesigye Justus from Stellenbosch University, South Africa. Kagee Ashraf, professor at the Psychology Department, Faculty of Arts and Social Sciences in Stellenbosch University is supervising this research project.

Appendix K

Recruitment Script for Psychiatric Health Workers

Hello. My name is Twesigye Justus. I am a doctoral student at the Psychology Department, Faculty of Arts and Social Sciences in Stellenbosch University. Thank you for contacting me about my advertised study. I am planning to conduct a health study, which is sponsored by Stellenbosch University. This study includes personal interviews (between 30 – 60 minutes) with care providers (psychiatric health workers, families, religious healers and traditional healers) for outpatients with unipolar depression and bipolar disorder. It also involves interviews with outpatients who are receiving treatment at the Mbarara hospital (MH) for unipolar depression and bipolar disorder. I will be asking care providers how they understand outpatients' problems and how they are caring for them. Additionally, I will be asking outpatients how they understand their health problems and how care providers are caring for them. I would like to use information gathered from this study in writing my doctoral thesis. I hope the information collected will also contribute to improving mental health care in Uganda. Your decision to participate in this study or not, is entirely voluntary. You can also withdraw from the study any time you wish to do so, during data collection. Thus, refusal to take part or withdrawal from the study will not in any way be used against you. Would you like to participate in this study?

If NO, Thank you for your time.

If YES, I have two questions which will help me to find out if you are eligible to participate. Kindly wait until I have asked all the two questions before you answer. Give one answer for all the two questions. You may say YES if your answer to each of the two questions is YES. Otherwise, you may say NO if your answer to any of the two questions is NO.

1. Are you a member of the psychiatric team of MH?
2. Have you been closely involved in treatment and care of out-patients of MH in the last 6 months?

If NO, it means your answer is NO to at least one of the two questions. Please do not tell me which question. If confirmed, say; you are not eligible for this study but thank you for your time. If not confirmed, ask the screening questions again. If YES, say; your answer is yes to all the two questions. If confirmed, then continue with the script.

In this study, I will review outpatients' medical records, conduct personal interviews with outpatients and you (psychiatric health workers). An interview with you will last between 30 – 60 minutes and will be conducted at the venue, date and time of your convenience. I will be assisted by a well-trained research assistant during the interview. Before enrolling you into this study, I will answer your questions. You may refuse to participate in this research if you feel that not all of your questions have been answered satisfactorily. Information obtained from you will be kept confidential and will be used for research purposes only. There are no personal benefits accruing to your participation in this study. I will only give you a soft drink for refreshment during the interview and transport refund for participating in this study. Do you have any questions about this study? (Pause for response)

Would you be willing to participate? (Pause for response)

If NO, Thank you for your time.

If YES, When would you like to have the interview done (make an appointment and request for contact details)

Participant’s name: _______________________
Phone number ___________________________
Date of interview: ______________________
Physical address __________________________

Appendix L

INFORMATION LEAFLET AND CONSENT FORM FOR PSYCHIATRIC HEALTH WORKERS

ETHICS REFERENCE NUMBER: N10/09/284 (Stellenbosch University and SS 2462 (UNCST)
TITTLE OF THE STUDY: Explanatory models for the care outpatients with mood disorders in Uganda: An exploratory study.
PRINCIPAL INVESTIGATOR: Twesigye Justus, PhD candidate at the Psychology Department, Faculty of Arts and Social Sciences in Stellenbosch University.
CONTACT NUMBER: +256 782 422 877
CANDIDATE'S SUPERVISOR: Kagee Ashraf, Professor at the Psychology Department, Faculty of Arts and Social Sciences, Stellenbosch University.
CONTACT NUMBER: + 27 021- 8083442 (Office): +27 834433002 (Cell).

You are being invited to take part in a research project. Please take some time to read the information on this form, which will explain the details of the project. Please ask me any questions about the research project, which you do not fully understand. It is very important that you are fully satisfied that you clearly understand what the research entails and how you could be involved. The decision to participate in research project or not is totally voluntary. You can also withdraw from research project any time you wish to do so, during data collection. Refusal to take part or withdrawal from research project will not in any way affect you negatively.

This research project has been approved by the Health Research Ethics Committee in the Faculty of Health Sciences at Stellenbosch University. Their Contact details are: +27 21 9389140, Fax +27 21 931 3352 and email: **carlis@sun.ac.za**. In addition, the study will be conducted in accordance with the ethical guidelines and principles of the International Declaration of Helsinki as well and ethical guidelines for research of the Uganda National Council for Science and Technology (UNCST). The contact details for UNCT: +256 414 250 499/+256 414 705 500, Fax +256 412 234 579, email: **uncst@starcom.co.ug**.

What this research project is all about?

The aim of research project is to obtain a description of explanatory models for the care of outpatients with mood disorders in Uganda. This research project will be conducted among outpatients, their families, psychiatric health workers, religious healers and traditional healers in the Greater Mbarara in Western Uganda. It will involve review of outpatients' medical records followed by personal interviews with outpatients and their care providers. An interview with an outpatient is estimated to last between 50 – 80 minutes. An interview with a care provider is estimated to last between 30 - 60 minutes. Interviews will be conducted at the venues, dates and time of the participants' convenience. I will conduct interviews with assistance of a well-trained research assistant. We will audio-record interviews and take notes to ensure that all relevant information is captured. Information will be kept confidential and be destroyed after serving the purpose for which they will be collected. Information will be used in compiling my PhD thesis in Psychology and published in relevant academic journals. I hope information collected will contribute to improving mental health care in Uganda. This study is sponsored by Stellenbosch University.

Why have you been invited to participate?

You have been invited to participate in the study because:

You are involved in mental health care as psychiatric health worker
You match all the recruitment criteria

What will be your responsibility?

I will request you to participate in an interview with me, which will involve asking you questions about your understanding of mood disorders and care of outpatients with mood disorders.

Will you benefit from taking part in this research project?

There are no direct benefits that will come to you for participating in this research project. The research project, however, may contribute to understanding mental illness and thus improve mental health care in Uganda in the long-run. However, I will provide you with a soft drink for refreshment during the interview and transport refund for your participation in this research project.

Are there risks involved in your taking part in this research project?

I don't foresee physical risks that may arise due to your participation in this research project. The interview may however, pose emotional discomfort to you. In case you become emotionally disturbed during the interview, feel free to inform me so that I can refer you for appropriate help. I have requested a clinical psychologist in MH who is not a member of this research team to provide emotional care and further support if required. You may also stop your participation at any time. You are under no pressure to answer all questions that I am going to ask you.

If you do not agree to take part, what alternatives do you have?

You can choose whether to participate in this research project or not. If you decide to participate in this research project, you may withdraw at any time without any negative consequences. It is also not compulsory to answer all questions asked to you.

Who will have access to your information?

The research team will keep any information that is gathered in this research project confidential. Responses provided will not be revealed to your friends, relatives, colleagues or anyone else outside the research team. Information you provide will be used only for the stated research purpose. Data will be password–protected and kept in offices with limited access. If the data are published, you will not be identified by name. The data will be deleted after 5 years following their publication.

Will you be paid to take part in this project and are there any costs involved?

No, you will not be paid to take part in this research project. There will be no costs for you if you take part in this study. However, I will give you a soft drink for refreshment during the interview and a transport refund.

Is there anything else that you should know or do?

You can contact Mr. Justus Twesigye at telephone +256 782 422 8777 if you have further queries or encounter any problems.

You can contact Professor Kagee Ashraf at telephone +27834433002 if you have any concerns or complaints that have not been adequately addressed by me.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I...agree to take part in a research study entitled: Explanatory models for the care of outpatients with mood disorders in Uganda: An exploratory study).

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this resrach project is **voluntary** and I have not been pressured to take part.

I may choose to leave this research project at any time and this will not affect me negatively in any way.

Signed at (*place* ....on (*date*)..2011

....
Signature of participant

Declaration by investigator

I (*name*)..declare that:

I explained the information in this document to..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that s/he adequately understands all aspects of this research project, as discussed above.

Signed at (*place*)..on (*date*)..2011

....
Signature of investigator.

Appendix M

Interview Guide for Outpatients (Runyakole-Rukiga Version)

Ebibuuzo eby'abarwaire

Omutwe gw'omushomo: Explanatory models for the care of outpatients with mood disorders in Uganda. An explanatory study

Orunaku rw'okubuurizaho (mm/dd/yyy)……………………
Eshaaha z'okubuurizaho………………*am* nainga…………*pm*
Enamba ehairwe owaayetaba omu kucondooza ………………

Ebirikukwata aha murwaire owaayetaba omu kucondooza

1. Omushaija/ omukazi
2. Emyaka
3. Oshwire/oshwire nainga oine omukundwa
4. Obuzaare obu oine n'omuntu orikukirayo omu kukureeberera (otatendekirwe omu murimo ogu)
5. Ediini yaawe
6. Omurimo gw'omuntu orikukirayo kukureeberera
7. Omurimo ogu orikukora
8. Oshomire ota? Okagarukira aha idaara rya kangahi?
9. Oine abantu abu orikureeberera? (omukazi/omushaija, abaana abazaire baawe n'abandi)

Okushoboorora aha ku enju ei murikutuuramu erikushusha

1. Yaaba mwine amashanyarazi omu nju eri murikutuuramu
2. Amaizi g'okunywa/ag'okuteekyesa ahu murikugaiha

Okwetegyereza empindahinduka omu mbeera z'abarwaire b'omutwe

1. Oburwaire obu orwaire noobwetegyereza ota? Nibwetwa buta omu rurimi rwawe rw'enzaarwa?
2. Oburwaire obu bukatandika ryari? Okakimanya ryari ku otatebenkaine, kandi okakimanya ota ku otatebenkaine? Ni ki ekyakureeteire waaza kuronda obuhwezi?
3. Nooteekateeka ngu oburwaire obu bukareetwa ki?
4. Ahabwenki nooteekateeka ngu ekyo (eki waagamba) nikyo kyatumire waabo otyo? Ni ki ekyakureeteire waaza kuronda obuhwezi? Ni ki ekyayongyereire obuzibu obwo?
5. Oburwaire obu orwaire bwine kabi ki aha magara gaawe? Nookira kuba noohurira ota?
6. Obuzibu obu orimu n'obw'amaani? Nooteekateeka ngu oburwaire obu nibwija kurahuka kukira?
7. Ni ki eki orikukira kweraarikirira aha burwaire obu?

Enteekateeka n'emitwarize omu kujanjaba n'okuha obuhwezi ahabw'oburwaire bw'omutwe

1. Ni bujanjabi ki kandi ni buhwezi ki obu orikutunga ahabw'oburwaire obu?
2. Obuhwezi obu orikutunga, nooha orikubukuha?
3. Obujanjabi n'obuhwezi obundi noobutunga ota?
4. N'enki eki orikukanda aha muringo ogu orikutungiramu obuhwezi? Ahabwenki?
5. N'enki eki otarikukanda aha muringo ogu orikutungiramu obuhwezi? Ahabwenki?
6. Nooteekateeka ngu obujanjabi n'obuhwezi obu orikutunga noija kuganyurwamu ki?

7. Ni buhwezi ki obundi obu orikuteekateeka kwija kutunga ahanyima y'obu orikutunga hati?

Oburemeezi obu abarwaire b'omutwe barikubugana n'okubwakubaasa kumarwaho

1. Ni buremeezi ki obu orikubugana omu kugyezaho kuronda obujanjabi/obuhwezi?
2. Oburemeezi obwagambwaho (omuri 18) bwongyeire kabi ki aha mbeera y'okurwara ei orimu?
3. Oburemeezi obwagambwaho bureesire kabi ki aha magara gaawe goona okutwarira hamwe?
4. Oburemeezi obwo nookira kubutwaza ota?
5. Ni buryo ki obundi obu waakubaasa kutaho kumaraho oburemeezi obwo?

Abarwaire nk'abajwekyerwa b'obuheereza bw'amagara gaabo

1. Iwe nk'omuntu ogyerizeho ota omu kubaasa oburwaire oburikuteganisa amagara gaawe?
2. Noohurira omazirwe omu buryo obu otaireho omu kugyezaho kubaasa oburwaire oburikuteganisa amagara gaawe?
3. Ni bintu ki ebirikukuhwera omu kugyezaho kureeberera amagara gaawe?
4. Ni bintu ebirikukuteganisa/kukuremesa kugyezaho kureeberera amagara gaawe?
5. Oine ekibuuzo kyona eki orikwenda kumbuuza?

Yebare munonga

Appendix M (English Version)

Interview Guide for Outpatients

Study title: Explanatory models for the care of outpatients with mood disorders in Uganda: An exploratory study.

1. Interview date
2. Time of interview
3. Participant's ID

Socio-demographic data

1. Gender
2. Religious affiliation
3. Marital status
4. Age
5. Occupation/main source of income
6. Highest level of formal education
7. Years of seeking psychiatric care

Conceptualisation of mood disorders

1. What do you call your health condition in Runyankolre/Rukiga?
2. When and how did you notice that you had this health condition?
3. What do you think caused this health condition?
4. Why do you think your health condition started when it did?
5. What does this condition affect your health in particular and life in general?
6. How severe is your health condition?
7. What concerns do have regarding your health condition?

Opinions and attitudes towards treatment and care

8. What forms of treatment/care do you receive for your health condition?
9. Who provides care that you receive and how?
10. To what extent are you satisfied with the way care is provided and why?
11. How do you hope to benefit from treatment/care which you receive?
12. What additional care do you wish to receive for your health condition?
13. Who should provide this care? Why?
14. How else can the care which you receive be improved?

Outpatient's challenges and ways of dealing with them

15. What are the main difficulties, which you encounter in seeking care?
16. How do such difficulties affect your health in particular and life in general?
17. How do you try to overcome these difficulties?
18. How successful have you been in dealing with these difficulties?
19. How else can such the above difficulties be overcome?

Outpatients as agents of their own care

20. How are you involved in managing your health condition?
21. To what extent are you satisfied with involvement in your own care?
22. What factors do facilitate involvement in your own care?
23. What factors do constrain involvement in your own care?
24. Any questions you would like to ask me?

Thank you very much

Appendix N

Interview Guide for Families, Religious Healers, and Traditional Healers (Runyankole-Rukiga Version)

Ebibuuzo eby'abajanjaabi aba buriijo
Omutwe gw'omushomo: Explanatory models for the care of outpatients with mood disorders in Uganda. An exploratory study

Ebiro by'okwezi..
Obwiire/ eshaaha..
Enamba yomujanjaabi..

Ebirikukwata aha bajanjaabi owaburiijo

1. Omushaija nainga omukazi
2. Ediini yaawe
3. Oshwire/oshwire nainga oine omukundwa
4. Emyaka ey'obukuru
5. Omurimo
6. Orurengo orw' obwegyese

Okushoborora aha murwaire

1. Obuzaare bwoyine nomurwaire
2. Emyaka ei omazire orikukora omurimo gw'okujangaba omurwaire w'omutwe (abarwaire b'omutwe)

Okushoboorora aha enju ei murikutuuramu

1. Enju neshwaki (permanent or nanga ney'emiti)
2. Enju neyanyu narishi nimupangisa
3. Yaaba mwine amashanyarazi
4. Amaizi g'okunywa/ag'okuteekyesa ahu murikugataha

Okwetegyereza empindahinduka omu mbeera z'abarwaire b'omutwe

1. Hariho eiziina omu rurimi rwawe rw'enzaarwa eri oburwaire bwo murwaire waawe bwiine?
2. Omurwaire waawe akakwatwa ryari? Okamanya ota ngu yagyiraho empinduka ahamagara ge?
3. Noteekateeka ngu embeera egi ekaretwaki? Ahabwenki nooteekateeka ngu ebyo (ebiwagaamba) nibyo byatumire omurwaire waawe yaabo otyo? Ni ki ekyayongyereire obuzibu obwo?
4. Nogyira ngu ahabwenki embeera egi yatandikire obwiire obuyatandikire?
5. Oburwaire obu bwine kabi ki aha magara g'omurwaire waawe (nibumukosya buta)? Nibumuteganisa buta?
6. Niki ekirikwerarikiriza munonga omurwaire waawe aha b'obwire bwe?

Enteekateeka aha emitwarize yokujanjaba abarwaire bw'omutwe

1. Nibujanjabi hamwe na n'endeeberera ki ebi orikukira kuha omurwaire waawe?
2. Nohurira omazirwe ota ahabw'oburyo obu orikutaho omukujanjaaba n'okurebereera omurwaire waawe? (i) ebi'arikukunda omu kumujanjaaba kwaawe (ii) ebi'atarikukunda omu kumujanjaaba kwaawe?
3. Ni ki eki omurwaire waawe ashemereire kwetekatekyera kutunga omu bujanjaabi n'obuheereza obu orikumuha?

4. Ni bujanjaabi ki obu abantu abandi barikuheereza omurwaire waawe?
5. Ni bujanjaabi ki hamwe n'endeeberera ebi wakwenzire ngu omurwaire waawe oheebwe? Nooha owu wakwenzire ngu amuheereze obujanjabi obwo? Ahabwenki?

Oburemeezi bw'abwirwaire n'oku abarwaire barikuburwanisa

1. Nibizibu ki ebi omurwaire waawe akizire kubuguna aha bw'oburwaire(embeera y'amagara gaawe)?
2. Nibizibu ki ebindi obi omurwaire waawe akizire kubugana omu kuronda obujanjaabi/obuhwezi?
3. Ebizibu obwagambwaho birabanisemu bita (i) amagara gomurwaire waawe? (ii) embeera yomurwaire waawe yona ebariirwe hamwe?
4. Omurwaire waawe naotaho buryo ki iwe nk' omuntu kurwanisa ebizibu ebyo?
5. Nibusinguzi ki obw'omurwaire waawe abasize kutunga omukurwanisa ebizibu ebyo?

Abarwaire kwejumba omu bujanjaabi bwabo

1. Nogyezaho ota kureeba ngu omurwaire wawe yayejumba omu kwejanjaaba n'okutebekanisa amagara ge?
2. Nohuria omazirwe ota omu kwehayo kwo'omurwaire waawe ateiremu mukwejanjaaba n'okurebereera amagara ge?
3. Ni bintu ki ebirikuteganisa omurwaire waawe omukugyezaho akejanjaaba kandi akareberera amagara ge?
4. Oine ekibuuzo kyona eki orikwenda kumbuuza?

Webare munonga

Appendix N (English Version)

Interview Guide for Families, Religious Healers, and Traditional Healers

Study title: Explanatory models for the care of outpatients with mood disorders in Uganda: An exploratory study.

4. Interview date (mm/dd/yyyy)
5. Time of interview …. ……………..................
6. Participant's identification number………..

Socio-demographicdata

8. Gender
9. Age
10. Marital status
11. Religious affiliation
12. Home location (urban or rural)
13. Number of working years in health care
14. Number of working years in psychiatric care
15. Number of people in your household
16. Description of housing
17. Main source of fuel for cooking
18. Electricity in your household
19. Main source of water for drinking/cooking
20. Type of toilet facility used by the household
21. Main means of transport used
22. Occupational category and position
23. Highest level of formal education attained
24. Number of dependants (e.g. partner, children, parents etc)

Conceptualisation of mood disorders

25. What is the name of your patients' health problem?
26. How did you notice that your patient has this specific health problem?
27. Timing for onset of the above health problem and why? Circumstances surrounding patients' seeking your care?
28. What causes the above health problem? Precipitating factors?
29. What does the above health problem do to your patient? (How does it work?)
30. How severe is the above health problem? (Does it have short or long course)
31. What does your patient fear most about the above health problem?

Opinion and attitudes towards treatment and care

32. What forms of care do you provide to your patients? How is the care provided?
33. What are the most important results that the patient should hope to get from your care?
34. Who else contributes to care of your patient and how?
35. How do you assess the ways in which care is being provided by other providers?
36. What additional care do you wish to see your patient getting for his/her health problem?
37. Who should provide this care? Why?

Outpatient's challenges and ways of dealing with them

38. What are the main (illness-specific) problems which the health problem causes to your patient?
39. What other problems does your patient experience in seeking/receiving care?
40. How have such problems affected your patient's health in particular?

41. How have such problems affected your patient's life in general?
42. How does your patient deal with such problems?
43. To what extent does your patient succeed in dealing with such problems?

Outpatients as agents of their own care

44. How do involve your patient in managing his/her health problem?
45. To what extent are you satisfied with your patient's involvement in managing his/her health problem?
46. What factors do facilitate your patient's involvement in his/her health care?
47. What factors do constrain your patient's involvement in his/her health care?
48. Any questions you would like to ask me?

Thank you very much

Appendix O

Interview Guide for Psychiatric Health Workers

Study title: Explanatory models for the care of outpatients with mood disorders in Uganda: An exploratory study.

Interview date
Time of interview
Participant's ID

Socio-demographicdata

1. Gender
2. Marital status
3. Age
4. Religious affiliation
5. Occupation/main source of income
6. Highest level of formal education
7. Description of housing
8. Number of dependents

Conceptualisation of mood disorders

1. Briefly, how do you describe mood disorders?
2. How common are mood disorders (unipolar depression and bipolar disorder) among your patients?
3. How do you diagnose these mood disorders?
4. What is common timing for onset of unipolar depression and bipolar depression and why?
5. How do you communicate these diagnoses in Runyankole/Rukiga with your patients and their significant others?
6. What causes these mood disorders?
7. What effects do these health conditions have on your patients health and lives in general?
8. How severe are these health problems?
9. What concerns do these diagnoses commonly cause to your patients?

Opinions and attitudes on care for outpatients

1. What forms of care do you provide to outpatients with the above health conditions?
2. To what extent are you satisfied with the way care is provided in MRRH?
3. Who else contributes to care of your outpatients with mood disorders and how?
4. To what extent are you satisfied with the ways care is provided by those other providers and why?
5. What additional treatment/care do you wish to see your outpatients receiving because of their health conditions? Who should provide this treatment/care and why?

Care-seeking challenges among outpatients

1. What are the main difficulties which outpatients with mood disorders encounter in seeking care?
2. How do such difficulties affect your patients' health in particular and lives in general?
3. How do your patients deal with such difficulties?

4. To what extent do your patients succeed in dealing with such difficulties?
5. How else can such difficulties be overcome?

Manifestations of agency among outpatients

1. How do you involve patients in managing their health conditions?
2. To what extent are you satisfied with your patients' involvement in their own care?
3. What factors do facilitate your patients' involvement in their own care?
4. What factors do constrain your patients' involvement in their own care?
5. Any questions you would like to ask me?

Thank you very much

Appendix P

Codebook used in data analysis

Labelling mood disorders
MD – bipolar
MD – clinical identity
MD – depression
MD – dynamic nature
MD – examples
MD - vague diagnosis
MD - vague diagnosis
MD - lay identity – bipolar
MD - lay identity – depression
Causes of MD
MD causes – accidents
MD causes – blocked blood flow
MD causes – don’t know
MD causes – genetics
MD causes – other illnesses
MD causes – poverty
MD causes – rebellious to authority
MD causes – stressors
MD causes – substance abuse
MD causes – supernatural powers
MD causes – suspecting accident
MD causes – suspecting demons
MD causes – suspecting witchcraft
MD causes – war
MD causes – weather
MD causes PSS – conflicts
MD causes PSS – losses
MD causes PSS – disappointments
MD causes PSS – family care-related concerns
MD causes PSS – financial difficulties
MD causes PSS – strained social relationships
MD causes PSS - work-related concerns
Triggering factors for MDs
MD precipitators – accident
MD precipitators – chronic stressors
MD precipitators – conflicts
MD precipitators – don’t know
MD precipitators – exciting events
MD precipitators – family care-related stress
MD precipitators – financial difficulties
MD precipitators – lack of social support
MD precipitators – loss of a friend
MD precipitators – loss of animals
MD precipitators – loss of child

MD precipitators – loss of spouse
MD precipitators – nonadherence
MD precipitators – other illnesses
MD precipitators – stigma
MD precipitators – substance abuse

Diagnostic criteria for MDs

Diagnostic criteria – intake interview
Diagnostic criteria – supernatural powers
Diagnostic criteria bipolar – behavioural
Diagnostic criteria bipolar – feelings
Diagnostic criteria bipolar – not aware
Diagnostic criteria bipolar – physical
Diagnostic criteria bipolar – psychosocial functioning
Diagnostic criteria bipolar – psychotic features
Diagnostic criteria bipolar – time duration
Diagnostic criteria depression – atypical
Diagnostic criteria depression – behavioural
Diagnostic criteria depression – physical
Diagnostic criteria depression – psychotic features
Diagnostic criteria depression – time duration
Diagnostic criteria general – intake history
MD diagnosis – feelings
Presenting complaints – physical symptoms

Prevalence of MDs

MD prevalence – comparisons
MD prevalence – estimates

Onset for MDs

MD onset – don’t know
MD onset – early adulthood
MD onset – early childhood
MD onset – insidious

Outpatients’ pathways to care

Motivation for hospital care – treatment outcomes
Pathways to hospital care - churches
Pathways to hospital care – clinics
Pathways to hospital care – herbs
Pathways to hospital care – traditional healers

Care-seeking triggering events

Care-seeking triggering events – concern of significant others
Care-seeking triggering events – functional deterioration
Care-seeking triggering events – referral

Consequences of MDs

MD effects - death
MD effects – family care problems
MD effects – labels
MD effects – loss of money
MD effects – loss of property
MD effects – loss of weight
MD effects – negative feelings
MD effects – negative thinking

MD effects – physical
MD effects – poverty
MD effects – schooling problems
MD effects – stigma
MD effects – strained social relationships
MD effects – trouble with the law
MD effects – work-related problems
Prognosis of MDs
MD prognosis – lack of cure
MD prognosis – death
MD prognosis – episodic
MD prognosis – less severe
MD prognosis – life threatening
MD prognosis – loss of insight
MD prognosis – ongoing medication
MD prognosis – physical symptoms
MD prognosis - recovery
MD prognosis – recurrence
MD prognosis – reduced functional abilities
MD prognosis – severe
MD prognosis - stigma
MD prognosis – trajectory
Outpatients’ concerns due to MDs
MD patients’ concerns – common perceptions
MD patients’ concerns – family care-related
MD patients’ concerns – getting saved
MD patients’ concerns – happy to know diagnosis
MD patients’ concerns – labels
MD patients’ concerns – lack of cure
MD patients’ concerns – no worries
MD patients’ concerns – lack of insight
MD patients’ concerns – medication-related
MD patients’ concerns – nkabone nkarye
MD patients’ concerns – physical effects
MD patients’ concerns – stigma
MD patients’ concerns – strained social relationships
MD patients’ concerns – transport costs
MD patients’ concerns – unacceptable illness
MD patients’ concerns – work-related

Opinions and attitudes about care
Psychiatric care package
Prof care – appraisal
Prof care package – admission
Prof care package – counselling
Prof care package – feeding
Prof care package – health education
Prof care package – liaison psychiatry
Prof care package – medication
Prof care package – OT

Prof care package – referral
Constraints to psychiatric care
Prof care constraints – advocacy
Prof care constraints – institutional weaknesses
Prof care constraints – irregular meetings
Prof care constraints – leadership
Prof care constraints – limited health education
Prof care constraints – limited outreaches
Prof care constraints – logistics
Prof care constraints – low staff morale
Prof care constraints – medical supplies
Prof care constraints – personal weaknesses
Prof care constraints – policy
Prof care constraints – poor OT facilities
Prof care constraints – poor referral system
Prof care constraints – side effects
Prof care constraints – stigma
Prof care constraints – uncomfortable care environments

Lay care providers’ contribution
Partners’ care contribution – appraisal
Partners’ care contribution – buying medicines
Partners’ care contribution – coordination
Partners’ care contribution – counselling
Partners’ care contribution – feedback
Partners’ care contribution – financial
Partners’ care contribution – herbs
Partners’ care contribution – hygiene
Partners’ care contribution – justification
Partners’ care contribution – monitoring patients
Partners’ care contribution – partner examples
Partners’ care contribution – patient’s protection
Partners’ care contribution – performance of rituals
Partners’ care contribution – prayers
Partners’ care contribution – referral of patients
Partners’ care contribution – relief items
Partners’ care contribution – social support
Partners’ care contribution – transport
Partners’ care contribution – welfare
Care-seeking challenges
Barriers to care
Care-seeking challenge – poor memory
Care-seeking challenge – witchcraft
Care-seeking challenges – communication
Care-seeking challenges – demonic forces
Care-seeking challenges - dependency
Care-seeking challenges – financial difficulties
Care-seeking challenges – impact
Care-seeking challenges – lack of awareness
Care-seeking challenges – lack of care coordination

Care-seeking challenges – lack of social support
Care-seeking challenges – limited health staff
Care-seeking challenges – low staff morale
Care-seeking challenges – medical supplies
Care-seeking challenges – mental health illiteracy
Care-seeking challenges – mistrust
Care-seeking challenges – mistrust
Care-seeking challenges – neglect
Care-seeking challenges – neglect
Care-seeking challenges – ongoing medication
Care-seeking challenges – other carers
Care-seeking challenges – physical restraints
Care-seeking challenges – pill burden
Care-seeking challenges – poor adherence
Care-seeking challenges – poor feeding
Care-seeking challenges – rubbing where hands reach
Care-seeking challenges – side effects
Care-seeking challenges – stigma
Care-seeking challenges – time constraints
Care-seeking challenges – transport-related difficulties
Care-seeking challenges – uncomfortable care environments
Care-seeking challenges – work-related

Ways of overcoming care-seeking challenges

Overcoming care-seeking challenges – adherence
Overcoming care-seeking challenges – advice from health staff
Overcoming care-seeking challenges – appealing to leaders
Overcoming care-seeking challenges – borrowing money
Overcoming care-seeking challenges – buying medicines
Overcoming care-seeking challenges – dying graciously
Overcoming care-seeking challenges – fighting
Overcoming care-seeking challenges – getting saved
Overcoming care-seeking challenges – giving up
Overcoming care-seeking challenges – income generation
Overcoming care-seeking challenges – income generation
Overcoming care-seeking challenges – institutionalisation
Overcoming care-seeking challenges – less medication
Overcoming care-seeking challenges – manual labour
Overcoming care-seeking challenges – self carers
Overcoming care-seeking challenges – selling property
Overcoming care-seeking challenges – shock absorbers
Overcoming care-seeking challenges – social support
Overcoming care-seeking challenges – taking a holiday/social support

Manifestations of agency

CA – appraisal
CA activities – consultation meetings
CA activities – distress prevention
CA activities – domestic chores
CA activities – encouraging responsibility
CA activities – financial contribution
CA activities – getting saved

CA activities – health education
CA activities – medical compliance
CA activities – mobilisation
CA activities – prayers
CA activities – review visits
Constraining factors
CA constraining factors – community events
CA constraining factors – dependency
CA constraining factors – gender
CA constraining factors – marketing herbs
CA constraining factors – highly expressed family emotions
CA constraining factors – labels
CA constraining factors – lack of awareness
CA constraining factors – lack of collective voice
CA constraining factors – lack of insight
CA constraining factors – lack of money
CA constraining factors – lack of social support
CA constraining factors – limited health education
CA constraining factors – limited health staff
CA constraining factors – logistics
CA constraining factors – low staff morale
CA constraining factors – nkabone nkarye
CA constraining factors – old age
CA constraining factors – other carers
CA constraining factors – other illnesses
CA constraining factors – personal weaknesses
CA constraining factors – policy
CA constraining factors – political leadership
CA constraining factors – poor communication
CA constraining factors – poor customer service
CA constraining factors – Satan (replace with demonic forces)
CA constraining factors – side effects
CA constraining factors – stigma
Ca constraining factors – supernatural powers
CA constraining factors – time constraints
CA constraining factors – treatment outcomes
CA constraining factors – unclear diagnosis
CA constraining factors – untimely discharge
Enabling factors
CA enabling factors – awareness of services
CA enabling factors – care outcomes (cross-check treatment outcomes)
CA enabling factors – committed health staff
CA enabling factors – customer service
CA enabling factors – effective communication
CA enabling factors – experience with other carers
CA enabling factors – getting saved
CA enabling factors – health better than wealth
CA enabling factors – hospital experience
CA enabling factors – income generation
CA enabling factors – insight

CA enabling factors – keep in contact with health staff
CA enabling factors – level of education
CA enabling factors – marriage
CA enabling factors – ownership of service
CA enabling factors – personality
CA enabling factors – severity of illness
CA enabling factors – social support
CA enabling factors – treatment outcomes
CA enabling factors – treatment outcomes – (consider replacing with care outcomes)

Notes

1. Substitute loss of marital partners with loss of spouse
2. Substitute vague categorisation with vague diagnosis
3. Substitute admission with caretakers with other carers
4. Check if low staff morale can substitute personal weaknesses
5. Consider substituting keep touch with health workers with effective communication or coordination of care
6. Consider substituting work environments with care environments
7. Consider substituting partners' care contribution transport with financial
8. Replace young adulthood with early adulthood
9. Replace MD prognosis – curable with recovery
10. Replace scaling up care-seeking – improved feeding with improve feeding
11. Relate care-seeking challenges - rubbing where hands reach with dependency
12. Harmonise CA activities – medical compliance and CA activities – adherence
13. Merge CA activities – consultation meetings with Ca activities – review visits
14. Merge care-seeking challenges - poor adherence with nonadherence
15. Consider substituting neglect with stigma or financial difficulties or as impact of care-seeking challenges

Appendix-Q Clearance Letter from Health Research Ethics Committe, Stellenbosch University

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

25 October 2010 **MAILED**

Mr J Twesigye
Department of Psychology
Academia, Block 23
Hammanshand Road
Stellenbosch
7600

Dear Mr Twesigye

"Explanatory Models of Mental Illness and Health Care of Patients in Uganda."

ETHICS REFERENCE NO: N10/09/284

RE : APPROVED WITH STIPULATIONS

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project with STIPULATIONS on 25 October 2010, including the ethical aspects involved, for a period of one year from this date.

1. Please include the international dialling codes for the contact numbers of the Principal Investigator and supervisor in the informed consent form.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be

25 October 2010 14:40 Page 1 of 2

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

a

conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval Date: 20 October 2010

Expiry Date: 20 October 2011

Yours faithfully

MS CARLI SAGER
RESEARCH DEVELOPMENT AND SUPPORT
Tel: +27 21 938 9140 / E-mail: carlis@sun.ac.za
Fax: +27 21 931 3352

Appendix R: Clearance Letter from Uganda National Council for Science and Technology

Uganda National Council For Science and Technology
(Established by Act of Parliament of the Republic of Uganda)
UNCST

Your ref: ....
Our ref: ....SS 2462..

Date : ....
06/01/2011

Mr. Justus Twesigye
C/O Social Work and Social Administration Department
Faculty of Social Sciences
Makerere University
P.O Box 7062
Kampala

Dear Mr. Twesigye,

RE: RESEARCH PROJECT, "EXPLANATORY MODELS OF CARE AMONG UGANDAN OUTPATIENTS WITH MOOD DISORDERS: AN EXPLORATORY STUDY"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **November 30, 2010.** The approval will expire on **November 30, 2011.** If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION / CORRESPONDENCE
Plot 3/5/7, Nasser Road
P.O. Box 6884
Kampala, Uganda

COMMUNICATION
TEL: (256) 414-250 499, (256) 414 705 500
FAX: (256)414-234 579
EMAIL: uncst@starcom.co.ug
WEBSITE: http://www.uncst.go.ug

Appendix S: Clearance Letter from Psychology Department, Stellenbosch University

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

2 November 2010

TO WHOM IT MAY CONCERN

Mr Justus Twesigye is enrolled in the Psychology Department of Stellenbosch University, South Africa.

Mr Twesigye is the recipient of the prestigious African Doctoral Academy scholarship of the University for completion of his doctoral degree. His doctoral proposal has been approved and his ethics clearance has also been approved by the university's Ethics Committee.

As a doctoral candidate, he has been cleared to engage with the relevant authorities in his home country to obtain the necessary permission to conduct his field research.

Please contact me should you need further information to facilitate permission for him to collect his data for his research.

Sincerely

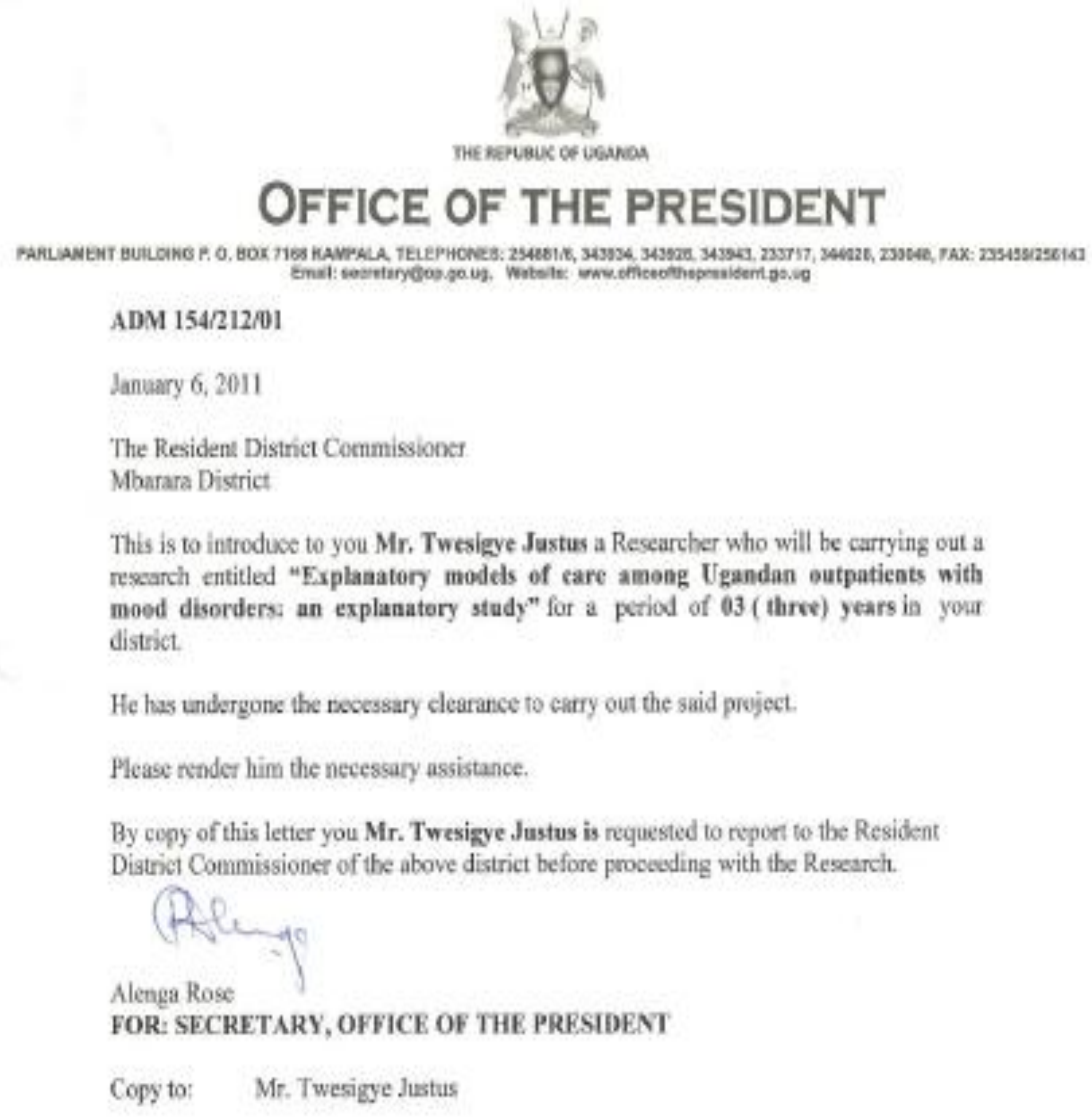
Prof. Anthony Naidoo
Departmental Chairman
Psychology Department
Stellenbosch University

Fakulteit Lettere & Wysbegeerte
•
Faculty of Arts

Departement Sielkunde • Department of Psychology

Universiteitskantoor / University Office
Privaatsak/Private Bag X1 • Matieland, 7602 • Suid-Afrika/South Africa, Tel: +27 (0) 21 8083466, Faks/Fax +27 (0) 21 808 3584

Appendix T Clearance Letter from Office of the President, Republic of Uganda



THE REPUBLIC OF UGANDA

OFFICE OF THE PRESIDENT

PARLIAMENT BUILDING P. O. BOX 7168 KAMPALA, TELEPHONES: 254881/6, 343934, 343926, 343943, 233717, 344026, 230048, FAX: 235459/256143
Email: secretary@op.go.ug, Website: www.officeofthepresident.go.ug

ADM 154/212/01

January 6, 2011

The Resident District Commissioner
Mbarara District

This is to introduce to you **Mr. Twesigye Justus** a Researcher who will be carrying out a research entitled **"Explanatory models of care among Ugandan outpatients with mood disorders: an explanatory study"** for a period of **03 (three) years** in your district.

He has undergone the necessary clearance to carry out the said project.

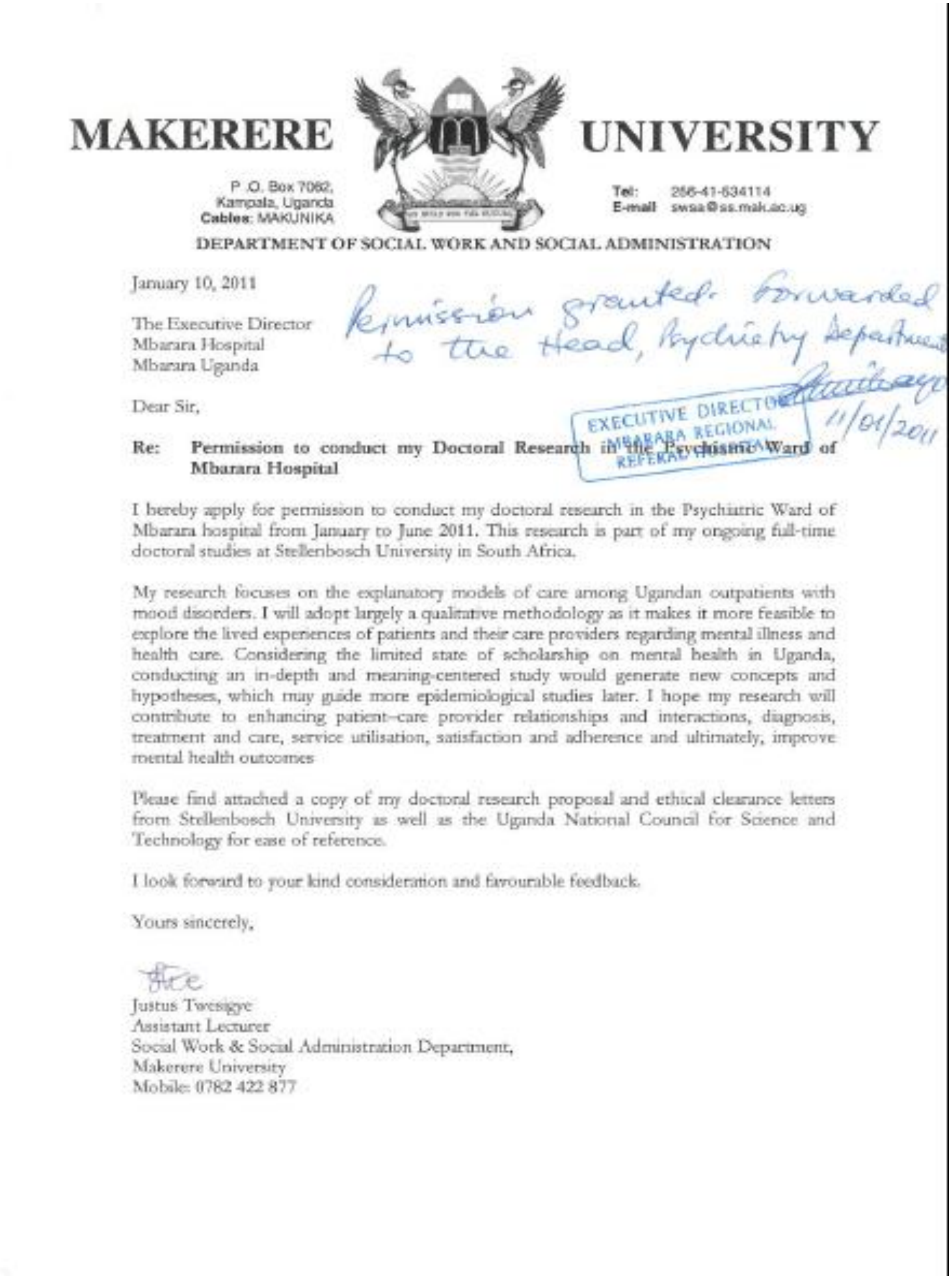
Please render him the necessary assistance.

By copy of this letter you **Mr. Twesigye Justus is** requested to report to the Resident District Commissioner of the above district before proceeding with the Research.

Alenga Rose
FOR: SECRETARY, OFFICE OF THE PRESIDENT

Copy to: Mr. Twesigye Justus

Appendix U: Clearance from Executive Director, Mbarar Regional Referral Hospital



MAKERERE UNIVERSITY

P. O. Box 7062,
Kampala, Uganda
Cables: MAKUNIKA

Tel: 256-41-534114
E-mail swsa@ss.mak.ac.ug

DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION

January 10, 2011

The Executive Director
Mbarara Hospital
Mbarara Uganda

Permission granted. Forwarded to the Head, Psychiatry Department

11/01/2011

EXECUTIVE DIRECTOR
MBARARA REGIONAL
REFERAL HOSPITAL

Dear Sir,

Re: Permission to conduct my Doctoral Research in the Psychiatric Ward of Mbarara Hospital

I hereby apply for permission to conduct my doctoral research in the Psychiatric Ward of Mbarara hospital from January to June 2011. This research is part of my ongoing full-time doctoral studies at Stellenbosch University in South Africa.

My research focuses on the explanatory models of care among Ugandan outpatients with mood disorders. I will adopt largely a qualitative methodology as it makes it more feasible to explore the lived experiences of patients and their care providers regarding mental illness and health care. Considering the limited state of scholarship on mental health in Uganda, conducting an in-depth and meaning-centered study would generate new concepts and hypotheses, which may guide more epidemiological studies later. I hope my research will contribute to enhancing patient–care provider relationships and interactions, diagnosis, treatment and care, service utilisation, satisfaction and adherence and ultimately, improve mental health outcomes

Please find attached a copy of my doctoral research proposal and ethical clearance letters from Stellenbosch University as well as the Uganda National Council for Science and Technology for ease of reference.

I look forward to your kind consideration and favourable feedback.

Yours sincerely,

Justus Twesigye
Assistant Lecturer
Social Work & Social Administration Department,
Makerere University
Mobile: 0782 422 877