

'THE CORE RESOURCE'
***The Role of Informal Caretakers of the
Mentally Ill As Seen in Uganda***

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ABSTRACT: Human experience is constantly mediated by culture. Many new studies have shown the significant role of culture in mental health, mental illness, and mental illness treatment. This project seeks to identify some of the cultural determinants of mental illness treatment in Uganda. Specifically, it has studied the role of family members in a mentally ill patient's healing process.

This study was conducted through semi-structured personal interviews with individuals from three subject groups. Group 1 consisted of mental health professional Group 2 members of organizations offering mental health services, and Group 3 the caretakers of mentally ill persons. All participants consented to an interview and to be included in the results of the study.

The study found that, in Uganda, family members and close friends often assume the role of caretaker for the ill. This is no different for patients with a mental illness. It is often a relative who brings the patient in for treatment in the first place. In many mental health clinics, family members or close friends, known as attendants, stay with the patient for the entire duration of his or her admission. In places where this is not permitted, the doctors urge family members to visit the patient as often as possible. Before a patient is discharged, family members are given explicit instructions about the patient's medication, possible side effects, and how to care for them at home. There are also some new attempts at utilizing family members to fight the stigma of mental illness. Unfortunately this is the ideal, which is not always met. Family members and informal caregivers can sometimes neglect or even aggravate the patient. This often occurs because of stigma, a misunderstanding of mental health, or economic stress. Mental health workers and mental health service providers have made some attempts at assisting caregivers. There are still however, necessary services that are not being provided, and areas of the country that are neglected.

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Finally, I must thank my teacher and mentor Dr. Kearsley Stewart, who helped me find my way, and is still doing so today.

Dedication

This report and study are dedicated to those who are currently fighting mental illness worldwide, and the friends and family members by their side. I am especially grateful and inspired by the members of Schizophrenia Fellowship- Jinja. They are impressive examples of the power of supportive relationships in the face of serious challenges.

Also for Edith and everyone else who deserves more.

Abbreviations

BHCP Basic Health Care Package

BN BasicNeeds

CMD Common Mental Disorder- defined as “disorders which are commonly encountered in the community and whose occurrence signals a break down in the normal functioning¹”

DSH Deliberate self-harm

HAR Hope After Rape

IDP Internally displaced persons

MHU Mental Health Unit

PCO Psychiatric Clinical Officer- (in Uganda) refers to a person formally trained in mental health; not a doctor but higher qualification than a psychiatric nurse

PTSD Post-traumatic stress disorder

SF Schizophrenia Fellowship

TPO Uganda Transcultural Psychosocial Organization Uganda

WHO World Health Organization

Terms

Mulalu Mad person (in the local language, Luganda)

Musawo (pl. basawo) Doctor (in the local language, Luganda)

Mzungu (pl. bazungu) white person (in the local language, Luganda)

Attendant- term used in the Ugandan health system for family members and/or friends that stay in the hospital with patients for the duration of his or her stay

¹ Musisi, Seggane, Elialilia Okello, Fikre Workneh, Stella Neema, Catherine Abbo. “Chapter 69: Complementary and Alternative Medicine in Psychiatry.” The African Textbook of Clinical Psychiatry and Mental Health

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1. Introduction

The purpose of this practicum was to examine the current role of informal caretakers of the mentally ill. In the study period time the researcher conducted forty-four personal interviews from within three subject groups. The first subject group consisted of mental health professionals, specifically psychiatrists, psychologists, psychiatric clinical officers (PCO), and psychiatric nurses. This group was targeted to draw on professional experience and share observations and opinions about informal caretakers. The second subject group was recruited from a number of organizations involved in mental health care services delivery. These organizations included BasicNeeds Uganda, Hope After Rape, the Schizophrenia Fellowship- Uganda, and the Transcultural Psychosocial Organization. From these organizations both administrative and field-based employees were interviewed. This group was similarly asked to make conclusions about the effect that informal caretakers have on mentally ill patients and recovery of mentally ill patients. Finally, the third group was made up of the actual caregivers of the mentally ill. Specifically they were recruited from the attendants² at Mulago National Referral Hospital S.B. Bosa Mental Health Unit (MHU). This group was sought out in order to ascertain what a caretaker would consider his or her responsibilities to a mentally ill patient, and how well they were being supported by the formal health system and organizations.

This paper will first provide a context for the findings, including the mental health environment on a global, African, and local level. The study findings will then be presented in summary, followed by recommendations for the future.

² In the Ugandan setting, “attendant” refers to a person (usually a family member or close friend), who stays at the hospital with an inpatient for the entirety of his or her admittance. Many wards, including the MHU at Mulago, require attendants.

2. Justification

In 2001 the Ministers of the World Health Organization (WHO) published Mental Health: A Call for Action, in which they expressed their commitment “to put mental health right at the core of the global health and development”³. As of 2001, “four of the ten leading causes of disability worldwide [were] neuropsychiatric disorders, accounting for 30.8% of total disability and 12.3% of the total burden of disease,” and these figures were expected to rise⁴. Mental health, however, is inextricably linked with culture and society: culture plays a significant role in how people conceptualize mental health, normality, and healing⁵. For this reason, mental health treatment is most effective when it is informed by knowledge and understanding of the socio-cultural factors influencing the patient. For this reason, WHO’s 2001 World health report calls for further research into the cultural context of mental health, especially in developing countries. In particular, there is an “urgent need” for research on “factors likely to enhance uptake and utilization of effective interventions.”⁶

One important socio-cultural factor in the treatment of the mentally ill is family. It has been shown that social ties, such as the family, can both help and hinder recovery from mental illness. Time consuming and demanding social relationships are correlated with mental illness. This is one explanation for higher rates of mental illness in women. Social support networks, on the other hand, can decrease the likelihood of mental illness and help with a speedy recovery⁷. Although a support network may exist naturally within a family, it has also been found that family resources in the treatment of the mentally ill are often underused. Professional mental health practitioners can overlook the useful information that family members could provide, and take for granted that a family member is a more effective caretaker when well informed⁸.

³ Mental Health: a Call for Action by World Health Ministers. World Health Organization: 54th World Health Assembly. World Health Organization, 2001: 4.

⁴ *ibid* 5.

⁵ Kirmayer, Laurence J. "Cultural Variations in the Response to Psychiatric Disorders and Emotional Distress." Social Science Medicine 29 (1989): 327-331.

⁶ "Chapter 4: Mental Health Policy and Service Provision." WHO: World Health Report. Accessed on 24 Nov. 2007 <<http://www.who.int/whr/2001/chapter4/ed/index.html>>.2001: 1-2.

⁷ Kawachi, Ichiro, and Lisa F. Berkman. "Social Ties and Mental Health." Journal of Urban Health 78 (2001): 458-460.

⁸ Friesen, B, and N Koroloff. "Family-Centered Services: Implications for Mental Health Administration and Research." Journal of Mental Health Administration 17 (1990): 13-16.

These studies, however, have all been conducted in Western societies, where the nuclear family is the most common family structure. Ugandan families are much more likely to consist of large, extended networks. There may be grandparents, uncles, aunts, nieces, and nephews, all in one home. Even when not living together, the concept of family includes these relatives, unlike in the US or Europe⁹.

To review, there are three things that have been proven. First of all, that mental illness is a serious health consideration. Secondly, that culture plays an important role when it comes to mental health and especially finding effective mental health treatments. Finally, it has been shown that family structure and behavior affects treatment outcomes of patients in Western countries. What is not known is whether family has a strong influence on treatment outcomes in Uganda. It seems likely that families do play an important role in the healing process, based on the fact that culture is known to be a strong mediator of mental health in Uganda, and that it is common for families to play such a role in other countries.

For this reason, new research needs to be done to determine how families in Uganda are effecting the treatment of mentally ill relatives. Such a study has yet to be conducted. This study is designed to begin to fill this gap in the literature on culture and mental health in Uganda. In so doing it will also be addressing the research areas that the WHO has highlighted as essential in improving and disseminating effective mental health services to all.

⁹ Del Pino, Jerome, and Gordon L. Anderson, eds. "Uganda." Worldwide State of the Family. New York: Paragon House, 1995. 206-207.

3. Objectives

Research Objectives

The main objective of this research project is to explore the current practices of family members in management of the mentally ill in Uganda and to determine the attitude and behaviors of the family members of mentally ill patients.

1. To explore the support and/or care giving practices of the family members.
2. To determine if family members influence the treatment outcomes of the patients.
3. To assess which attitudes, behaviors, and care giving practices are positive, and which are detrimental.
4. This research was undertaken with a view to recommending specific family interventions in the management of the mentally ill in Uganda.

Research Questions

The interviews were conducted for the purpose of gaining the necessary information to meet the study objectives. Specifically, the interviews sought to answer the following questions:

1. Who are the patients that come to the mental health clinic, and what treatment is expected?
2. What are the structures, attitudes, behaviors, expectations, and support activities of the family members to patients at the clinic?
3. How do family members influence the treatment of the patient?

4. Methodology

4.1 Description of Methodology

Study Site

The researcher conducted the Group 3 interviews through Mulago Hospital Department of Psychiatry and the S.B. Bosa Mental Health Unit. Psychiatrists, a medical sociologist, social workers, clinical psychologists, PCOs, nursing officers, medical health assistants and other support staff run the ward. The unit works in close collaboration with the Butabika Mental Hospital and other institutes like the Institute of Psychology and Makerere Institute of Social Research.¹⁰

Study Period

Start Date: October 27th, 2008

End Date: November 30th, 2008

For full project schedule see Appendix I

Research Design

This is a qualitative study, based on intensive semi-structured interviews, analyzed according to established anthropological methods (e.g. *Research Methods in Anthropology; Qualitative and Quantitative Approaches*). The interviews were semi-structured because of time constraints and access to interviewees¹¹. The interviews lasted between thirty minutes and two hours, depending on the subject's availability, and length of responses.

Study Instruments

This study used a standardized set of questions for the interviews, as shown in Appendix II.

Data Analysis

The interview results have been coded for broad themes and analyzed against the standard literature on culture and mental health.

Study Participants

There were three groups of study participants, which were all recruited from urban and rural Uganda.

Group 1: mental health professionals; sample size: 15

Mental health professionals were interviewed in order to gain professional insight. They were able to give direct observations of the informal caregivers in the hospital setting, as well as assess some of the behaviors of informal caregivers in terms of treatment outcomes.

Group 2: members of organizations (NGOs, community based organization, etc) offering

¹⁰ "Department of Psychiatry." Mulago Hospital Complex. Accessed on 10 June 2008
<<http://www.mulago.or.ug/psychiatry.php>>. 2008: 1.

¹¹ Bernard, Russell. *Research Methods in Anthropology: Qualitative and Quantitative Methods*. New York: Rowman Altamira, 2006.

mental health services; sample size: 10

The organizations that participated in the study were able to serve a similar purpose to the Group 1 respondents. They were also able to offer information about the behavior of informal caregivers outside of the hospital, and explain the effect of some community-based factors on treatment outcomes.

Group 3: informal caregivers of mentally ill patients; sample size: 19

Group 3 participants gave information about the activities they were involved in as an informal caregiver of the mentally ill, as well as the effectiveness of mental health workers in supporting them.

Recruitment and Sampling

Group 1: Dr. Seggane Musisi of Makerere University was the researcher's academic advisor. As one of Uganda's leading psychiatrists, he was able to put the researcher in contact with mental health professionals, specifically his colleagues and students, who fall into Group 1.

Group 2: Group 2 participants were identified through research into the organizations currently providing mental health services, as well as referral from Group 1 participants and other Group 2 participants.

Group 3: At Mulago Hospital, all admitted patients are required to have an attendant (an informal caregiver who lives at the hospital with them). Therefore, the researcher was able to go to Mulago and find informal caregivers there, without jeopardizing his or privacy or forcing them to neglect other duties during the interview.

Note: Anthropological studies do not require rigorous sampling design.

Inclusion/Exclusion Criteria

All individuals that fall into one of these three categories and were willing to be interviewed were interviewed. All participants were able to withdraw at any time in the study.

Data Collection

Interviews began with a set of brief demographic questions. Then, if the interview was going to be recorded, the recorder was switched on and the researcher began to ask a set of semi-structured, open-ended questions (see Appendix II).

Confidentiality

During interview: The interviews were conducted in a private setting. Group 1 and 2 participants were mostly interviewed in his or her private office. A private interview room with a door in the Department of Psychiatry was provided for Group 3 participant interviews.

Informant confidentiality: There are only two documents that link an informant's name to the participant number, the consent form and the brief demographic questionnaire. Only the researcher will have access to the consent forms and demographic questionnaires,

which will be stored in a locked drawer. All identifiers were removed from the audio recording, and will appear nowhere in any written materials related to the research.

4.2 Discussion and analysis of methodology

The Group 1 and 2 interviews were conducted with little challenge. This is probably due to the fact that the researcher was seeking professional opinions and observations, not personal information. Furthermore, the subjects are trained and practiced in answering the types of questions asked. The Group 1 interviews were easily conceptualized in the practical context of clinics and hospitals because the researcher spent a significant amount of time in these institutions. One limitation that existed in this subject group was bias. Some of the questions were not completely neutral. Because the subject was at times reporting on his or her professional performance, as well as that of his or her colleagues, it is likely that many of the subjects were predisposed to certain answers.

This limitation also applies to Group 2 interviews. Additionally, the researcher would have benefited from more time to observe the organizations in the field. Furthermore, race played a strong role in the way that Group 2 interviewees perceived the researcher. Being *muzungu*, or a white person, has several connotations in Uganda. Money is one of them. Many of the Group 2 respondents expected the researcher to be equipped and/or prepared to offer financial assistance to the organization he or she was associated with. The perception is likely to have influenced the answers and information given. The problem also existed with Group 3 interviewees, but to a much lesser degree.

There were several limitations to this study when it came to the Group 3 interviews. This includes role of culture, language, translation, and the relationship between the researcher and the interviewee. The first cultural consideration is the expectations of caregivers in Ugandan society. Some of the questions deal with the caregiver's ability to cope with the patient. Some of the respondents seemed reluctant to share the challenges they face in the caretaking role, possibly because it is not socially acceptable to complain about looking after family members or close friends. The one respondent who was not a close relative or friend seemed to be more willing to share with the patient the fact that she found it trying to be an attendant.¹²

¹² Participant 307. Personal interview. 7 November 2008.

Secondly, as an outsider to the culture, the researcher is likely to have missed certain cues in the behavior and words chosen by respondents. This problem existed to an even greater degree in the interviews where translation was necessary. Another challenge associated with translation is detail. Many of the translations were paraphrased accounts of the responses due to time constraints. The language used in translation also reflected the fact that the interpreter had received extensive education in psychology. For example, one participant was recorded as describing the ill family member as “presenting with paranoid behavior”.¹³ This terminology is distinctly clinical. Lastly, the need for translation made the recorder very inefficient, and so it was not used in these cases.

The researcher was an outsider on another level besides racial and cultural. *Musawo* is the Luganda word for “doctor.” It may be more comprehensively defined as the word for “health worker” because it used in reference to doctors, nurses, clinical psychologists, PCOs, etc. many of the Group 3 respondents originally perceived the researcher to be a *musawo*, and the interpreter was, in fact, a *musawo* (specifically a clinical psychologist). Therefore, the respondents may have been afraid to answer the questions regarding the quality of care at the MHU with complete honesty. In order to overcome this barrier, the researcher conducted some of the English Group 3 interviews without the presence of the research assistant, and before asking questions about quality of care, the respondent was remind that none of the staff at the hospital would be informed of the responses given.

The researcher also found it necessary to constantly adapt the questionnaire being used. In the Group 1 interviews, this mostly involved finding ways to probe deeper. For example, the questionnaire did not originally look deeply into what the subject observed in terms of the family members’ perceptions of mental illness, and the family members’ ability and/or willingness to accept the medical explanations for mental illness. This information proved very useful. For the most part, Group 2 interviews diverged greatly from the questionnaire. This is because certain questions did not apply to some organizations or positions within that organization. Quite often, most of the questions in these interviews were generated during the interview to respond to the information being provided.

¹³ Participant 305. Personal interview. 7 November 2008.

It was also necessary for the researcher to make several changes to the Group 3 questions. The original set of questions asked if the MHU staff “did a good job” of caring for the patient and providing the caretaker with information. Possibly because of the aforementioned reasons, the answer was always “yes.” The researcher modified this section of the questionnaire so that it read, “what does the doctor tell you about...” the cause of the illness, the patient, the patient’s treatment, etc. The most common response to these questions was “nothing” or “nothing yet.” This shows that the original set of questions was not worded correctly to get accurate information.

In summary, the interviews were for the most part successful. Group 3 was the most challenging subject group to obtain accurate or complete information from. The steps taken to improve the quality and usefulness of information were a) minimize cultural disruptions b) adapt questionnaire based on which questions were effective and which weren’t.

5. Background

5.1 Global Trends in Mental Health

Mental health has recently been recognized as a priority for global and public health intervention. The WHO has stated, “Nearly 450 million people suffer from mental and behavioral disorders,” and that “mental health problems represent five of the ten leading causes of disability.¹⁴” Depression is projected to be the second leading cause of disability by 2020.¹⁵ It is also clear that in many areas of the world, this challenge is not being met. A recent WHO study has revealed that:

- “Over 40% of countries do not have a mental health policy.
- Over 30% of countries do not have a mental health programme.
- More than 25% of countries do not have access to basic psychiatric medication at the primary care level.
- 70% of the world’s population has access to less than one psychiatrist per 100,000 people.¹⁶”

In addition to few resources, many countries are also failing to effectively use the resources they have for mental health service provision¹⁷. For this reason the WHO has seen fit to urgently call for research regarding effectiveness of mental health interventions and policies in low-resource settings, and research into “factors likely to enhance uptake and utilization of effective interventions.¹⁸ One such factor may be family members and informal caretakers.

One way that the world has confronted mental health in resource poor settings is through community mental health programs. These programs seek to utilize existing infrastructure and human resources to deliver mental health care cheaply and at a grass-roots level. One new strategy for this is to train non-medical workers to diagnose and treat common mental disorders. The largest current project implementing this strategy is in Goa, India. Designed by Dr. Vikram Patel, it had treated over 2,000 patients as of March 2008. As Dr. Patel explains, in caring for the mentally ill “the core resource is

¹⁴ Mental Health Policy Project; Policy and Service Guidance Package. World Health Organization, 2001: 8.

¹⁵ Okello, Elialilia. “Cultural explanatory models of depression in Uganda.” Thesis for doctoral degree (PhD.). Kampala: Makerere University and Karolinska Intitutet, 2006: 3.

¹⁶ *ibid*, 8.

¹⁷ *ibid*, 8.

¹⁸ “Chapter 4: Mental Health Policy and Service Provision.” 2001: 1-2

humans.¹⁹ So far the project has gotten positive feedback from users, but there is an ongoing randomized clinical trial to determine how effective the project is.²⁰ This project is an example of one way that local resources are being utilized. One local resource that has not been seriously studied is the people living with and caring for mentally ill patients.

The methods used in the Goa project are promising for another reason. They use culturally relevant models and treatments of mental illness. It has been shown that cultural models play a significant part in the definition and interpretation of illness. This can happen a number of ways, including socially learned symptomatology, and culturally mediated somatization.²¹ The convergence of anthropology and psychiatry to study how exactly culture influences mental health and illness is being termed “the new cross-cultural psychiatry.”²²

This type of research would be useful in understanding one of cross-cultural psychiatry’s biggest surprises. In 1976 the WHO conducted a study on schizophrenia treatment outcomes in developed and developing countries. Despite significant advantages in terms of resources and training for the developed countries, treatment outcomes in developing countries were much better. There was so much skepticism about these results that another study followed, which confirmed the original results. It has been posited because the extended family network is more present in developing countries, mentally ill individuals are getting more social support.²³ This theory, however, has never been definitively proven, and must be studied country-by-country or cultural setting-by-cultural setting.

There is yet another reason to consider culture. As science delves further and further into the mechanics of the human brain, psychiatry and psychology are increasingly equated to neurological processes and therefore treated with biomedical interventions. To this day however, “social, psychotherapeutic, and educational

¹⁹ Kohn, David. "Psychotherapy for All: an Experiment." New York Times 11 Mar. 2008: 2.

²⁰ *ibid.* 1-3.

²¹ Kirmayer 1989: 327-331

²² Kleinman, Arthur M. "Depression, Somatization and the 'New Cross-Cultural Psychiatry.'" Social Science and Medicine 11 (1977): 3., Patel 1995: 1292.

²³ Good, Byron J. "Studying Mental Illness in Context: Local, Global, or Universal?" Ethos 25 (1997): 234.

interventions are still the only known forms of prevention.²⁴” There is no immunization for mental illness, so it is society we must turn to in order to protect individuals from mental illness.

5.2 The African Context

In 2001 the WHO conducted a self-reporting study on countries’ resources to address mental health. Of the African countries that responded, less than half have a mental health policy.^{25 26} In most African countries the psychiatrist to patient ratio is 1: 2 million. Most of the psychiatrists and even lower-level mental health workers are concentrated around the wealth and infrastructure of urban centers. Common mental disorders (CMD)²⁷ are, however, among the most frequent disorders of persons seeking primary health care in Africa.²⁸

It has also been shown that there are certain commonalities in explanatory models of mental illness within in sub-Saharan Africa. Namely, the mind is believed to be distinct from the body and to be housed in the head as well as the heart or elsewhere in the torso. Often mental illness is explained as a due to spiritual disruptions or dysfunctions. Finally, “madness” or psychotic disorders are often defined by the presenting behavioral and sometimes somatic symptoms.²⁹ This information points out that fact that Western measurements of mental illness are invalid in Africa because they do not focus on the symptoms that would be reported. Instead, studies should be done to determine what different populations consider to be mental illness, so that the correct symptomatology can be incorporated into usable measurements and diagnostic tools.

5.3 Mental Health in Uganda

Uganda’s mental health care system is somewhat developed relative to other African countries. It still suffers from serious resource shortages however. In 2006 the WHO categorized Uganda as “research constrained” when it came to mental health,

²⁴ *ibid* 230-231.

²⁵ It is predicted that the actual number of countries with a mental health policy in Africa is lower.

²⁶ “Chapter 4: Mental Health Policy and Service Provision.” 2001: 1-2.

²⁷ Defined as “disorders which are commonly encountered in the community and whose occurrence signals a break down in the normal functioning,”

²⁸ Musisi “Complementary and Alternative Medicine in Psychiatry”

²⁹ Patel, Vikram. “Explanatory Models of Mental Illness in Sub-Saharan Africa.” *Social Science Medicine* 40 (1995): 1291-1298.

because the country lacks infrastructure and personnel.³⁰ As of 2006, Uganda had only about 25 trained psychiatrists, 18 of which were working in Kampala.³¹ Due to the lack of knowledge about mental illnesses, individuals with depression are three times more likely to seek formal healthcare because the mental illness is not being recognized so their symptoms are not relieved.³² If depression was recognized earlier and the correct treatment given, it would lower healthcare costs.³³

The WHO specifies four major challenges to the mental health of populations: poverty, urbanization, disasters, and war and conflict.³⁴ Unfortunately Uganda is currently experiencing three of these four challenges. Poverty and urbanization exist on a wide scale. Finally, violence and war has long been a part of life in Uganda, creating traumatized populations. As a result of these wars and the ongoing wars in surrounding East African countries, refugees and IDPs are another large issue.

It has been estimated that 26% of the population of Uganda lives in chronic poverty. Chronic poverty means that the family or individual is trapped in “severe” and multidimensional poverty” for a long period of time, often being transmitted across generations.³⁵ Mental illness and poverty create a cycle. Just as poverty can cause mental illness, mental illness can impoverish an individual because it may cause disability or discrimination that prevents him or her from working. Similarly, being poor means that treatment is less available.³⁶ Rural poverty, in turn, forces people into urban centers to find work. Between 2000 and 2005 the urban population growth rate was 4.2%, and in 2007 13% of the population was living in an urban area.³⁷ “The population of Kampala has steadily grown in the last three decades faster than the pace at which urban services and housing are provided.”³⁸

³⁰ Working Together for Health: The 2006 World Health Report. World Health Organization: Geneva. 2006.

³¹ Okello 2006: 11-12.

³² Figure determined after controlling for medical co-morbidity.

³³ Okello 2006: 3.

³⁴ Mental Health: a Call for Action by World Health Ministers 2001: 4.

³⁵ “Does Chronic Poverty Matter in Uganda.” Chronic Poverty Research Center, Policy Brief 1. Kampala: Development Research and Training (2006): 1-2.

³⁶ “Management of Mental Disorders in the community; An In-service Training Manual for Health Workers.” Kampala: BasicNeeds and Ministry of Health, 2008: 122-123.

³⁷ “Country Profile- Uganda.” UNData. 2007. United Nations. Accessed on 15 May 2008 <<http://data.un.org/CountryProfile.aspx?crName=Uganda>>.

³⁸ Lwasa, Shuaib. “Urban Expansion Processes of Kampala in Uganda: Perspectives on contrasts with cities

It has been posited that urbanization has had deleterious effects on the close-knit extended family that is common in Africa and Uganda. The theory is that it has a) removed the social pressure to maintain family bonds, and b) put new economic strain on families. This is in comparison to the formerly strong bonds between extended family members, which created a psychosocial support network.³⁹ Recently this assumption has been called into question based on evidence that large families can also cause psychological stress.⁴⁰ What remains clear, however, is that urbanization has disrupted family dynamics in Africa. Furthermore, functional families (of any size or shape) are known to help minimize the effects and/or risk factors of mental illness. Although a recent study found that family *structure* was not a risk factor for depression in Uganda, family-related negative life events were. The depressed study participants were much less likely to have regular incomes and more likely to be separated from his or her spouse, a condition that is more common in the urban setting.⁴¹

One community in particular is at risk to the social and psychological dangers of urban centers. Street children, or children that do not have homes and are living in slum areas, are numerous in Kampala. A recent study has examined the lives of street children in Kampala. The most common reason that children in this study left home was abuse or neglect from parents or the other caregivers in the home. Looking for work, the break-up of the family due to separation or divorce, and parental death were also common reasons.⁴² As mentioned above, these types of events are risk factors for mental illness.

Street kids are also subject to a wide range of traumatic events once they are on the streets. Among the participants of the aforementioned study, 80% reported physical harassment from the police and general public, 50% reported not having shelter, and 28% reported going hungry. Although the girls were the only ones to report sexual harassment, the figures are staggering. 84% of the girls reported being sexually abused, and 43% reported being raped. 11% of them turned to prostitution for survival. Another common

of developed countries.” PERN Cyberseminar on Urban Spatial Expansion. Accessed on 15 May 2008 <http://www.populationenvironmentresearch.org/papers/Lwasa_contribution.pdf>. 2.

³⁹ Muhwezi, Wilson, Hans Agren, Stella Neema, Seggane Musisi, Albert Maganda. “Life events and depression in the context of the changing African family; the case of Uganda.” *World Cultural Psychiatry Research Review* 10 (2007): 10-15.

⁴⁰ Good 1997:236.

⁴¹ Muhwezi, et al. 2007: 12-18.

⁴² Musisi 1992: 197.

survival tactic is stealing (100% reported stealing), and substance abuse (27%). The most common reasons given for abusing substances like alcohol, marijuana, and fuel, were to numb feelings or go to sleep.⁴³ Due to the many negative life events street children are exposed to, they often experience some degree of psychological and emotional damage, especially relating to abandonment and insecurity.⁴⁴ It has been shown that, in Uganda, successful rehabilitation and reintegration of street children involves an extremely supportive social environment, most importantly in the home and family unit.⁴⁵

Trauma also exists in Uganda as a result of war and torture. It is widely accepted that torture results in a variety of mental health complications; in fact this is often the goal of perpetrators of torture. A study of patient records at the Kampala-based African Centre for Treatment and Rehabilitation of Torture Victims showed that the most common forms of torture were kicking and beating, witnessing the torture of family members or other victims, and rape. The prevalence of mental illness in these patients was significantly higher than is expected in a general population. 75.4% were diagnosed with Post-Traumatic Stress Disorder (PTSD)⁴⁶, 32% with somatoform disorders, 28% with depression, and 17% with anxiety disorders.⁴⁷

There are also a number of conflicts, both resolved and ongoing, that have been disrupting mental health in Uganda. It is estimated that, in populations affected by armed conflict, at least 10% will develop mental health problems and an additional 10% will have trouble functioning as a result of trauma.⁴⁸ Mental health problems due to trauma are most prevalent immediately following the incident. Different studies of populations

⁴³ Musisi 1992: 198.

⁴⁴ Young, Lorraine. "The place of street children in Kampala, Uganda: marginalization, resistance and acceptance in the urban environment." *Environment and Planning D: Society and Space* 21:5 (2002): 607-612.

⁴⁵ Wakiraza, Christopher. "Chapter Twelve: Reintegration of Street Children: A Critical Look at Sustainable Success." 223-233. *Poverty, AIDS, and Street Children in East Africa* ed. Joe Lugalla and Colleta Kibassa. Lewiston, New York: The Edwin Mellen Press, 1992: 223-233.

⁴⁶ The most common forms of PTSD were chronic (67% of patients in the study) and complex (9% of patients on the study).

⁴⁷ Musisi, Seggane, Eugene Kinyanda, Helen Liebling, R. Mayengo-Kiziri. "Post-traumatic torture disorders in Uganda: A three-year retrospective study of patient records at a specialized torture treatment centre in Kampala, Uganda." *Torture* 10 (2000): 81-87

⁴⁸ Murthy, R. Srinvasa, Rashmi Lakshminarayana. "Mental health consequences of war; a brief review of research findings." *World Psychiatry* 5 (2006): 25.

that had recently experienced trauma showed depression rates of 40-80%.⁴⁹ The war experienced in Uganda can be characterized as “low intensity warfare” or conflicts that target civilian populations. The goal in these wars is often to destroy, terrorize and demoralize a population to stop or prevent resistance.⁵⁰ It’s working. In war-affected Ugandans in the North, prevalence rates were as follows: 39.9% PTSD, 52% depression, anxiety disorders 60%, somatization disorders 72.2%, suicidal behavior 22.7%, and alcohol abuse 18.2%. The study that yielded these results also found that the number of traumatic events in a person’s lifetime is highly correlated to developing PTSD. Prevalence rates were 23% in those reporting three or more trauma experiences, and 100% in those reporting twenty-eight or more trauma experiences.⁵¹

Another result of the past and current conflicts in Uganda and East Africa is a large number of refugees and internally displaced persons (IDPs). These populations are not only exposed to trauma because of the conflict, but face additional trauma as a result of being displaced.⁵² In the process, many societal constructs and bonds are destroyed. This type of “cultural discontinuity” is often correlated with depression, alcoholism, suicide, and violence.⁵³ These psychological stressors exist in Uganda refugee and IDP camps. Among refugees at a camp in the West Nile region⁵⁴ 31.6% of the males and 40.1% of the females had PTSD.⁵⁵ Another study found that over 25% of refugee children was severely psychologically disturbed.⁵⁶ Among these children, a supportive family was found to be the most effective protective factor from mental illness.⁵⁷ At an IDP camp in Pader, 62% of women surveyed admitted to contemplating suicide.⁵⁸ At a camp in Gulu District there were similarly high rates of mental illness, and 6% of respondents reported

⁴⁹ Njenga, Frank, et al. “Post-traumatic stress after terrorist attack: psychological reactions following the US embassy bombing in Nairobi.” British Journal of Psychiatry 185 (2004):328.

⁵⁰ Musisi, Seggane. “Mass trauma and mental health in Africa.” African Health Sciences 4 (2004): 80.

⁵¹ Njenga, Frank, Anna Nguithi, Rachel Kang’ethe. “War and mental disorders in Africa.” World Psychiatry 5 (2006): 38-39.

⁵² Fazel, Mina and Alan Stein. “The mental health of refugee children.” Arch Dis Child 87 (2002): 366.

⁵³ Kirmayer, Laurence J., G.M. Brass, and C.L. Tait. “The mental health of Aboriginal people: transformations of identity and community.” Canadian Journal of Psychiatry 45 (2000): 607-608.

⁵⁴ The majority of the refugees were from Sudan.

⁵⁵ Njenga, et al. 2006:38.

⁵⁶ Fazel, Mina and Alan Stein. “Mental health of refugee children: comparative study.” British Medical Journal 327 (2003): 134.

⁵⁷ Fazel and Stein 2002: 367-368.

⁵⁸ “Pader: A Community in Crisis- A Preliminary Analysis of MSF-Holland’s Baseline Mental health Assessment in Pader.” Medicine Sans Frontieres- Holland: 2004.

homicidal thoughts.⁵⁹ This points to the cyclic nature of violence and psychological trauma. It has been found that in Uganda, mass trauma can create a tendency to solve all conflicts militarily, even interpersonal ones.⁶⁰

There was a time when Western researchers claimed that PTSD and other trauma-related mental disorders did not exist in Africa. It was soon uncovered by researchers native to African countries that the former studies had yielded inaccurate results because the studies were designed for Western societies. More comprehensive and culturally sensitive research has shown that in traumatized populations there is a core set of mental health symptoms that manifest themselves differently in varying cultural situations.⁶¹ These are now referred to as “post-traumatic culture bound syndromes.”⁶² In Africa these syndromes most commonly consist of dissociation and possession syndromes.⁶³ In Northern Uganda, group interpersonal psychotherapy was an effective intervention for depressed adolescents, partially because the measurements and treatment took locally described syndromes into account.⁶⁴ When interventions do not provide for cultural considerations treatment and diagnosis are less effective. In fact, it may even cause additional stress to the patient. For example, Western models of treatment that are based on the postmodern concept of science and the individual over tradition, religion, and community can put unwanted pressure on the individual to accept Western conceptual models.⁶⁵ Additionally, in Uganda, it is clear that mentally ill individuals respond better to treatment when the caregiver is somebody who understands the cultural meaning behind his or her illness.⁶⁶ This has been proven through studying the work of traditional healers, but it is possible that family members could also be utilized in the capacity of providing socially and culturally meaningful treatment.

⁵⁹ Kinyanda, Eugene and Seggane Musisi. “War traumatization and its psychological consequences on women of Gulu District.” Review of Women’s Studies 102-122.

⁶⁰ Musisi 2004:81.

⁶¹ *ibid* 80-82.

⁶² Musisi, Seggane and Pratiwi Sudarmono. “Traditional Healing in Conflict/Post-Conflict Societies.” 94.

⁶³ *ibid* 94.

⁶⁴ Bolton, Paul, et al. “Interventions for Depressive Symptoms Among Adolescent Survivors of War and Displacement in Northern Uganda; A Randomized Controlled Study.” Journal of the American Medical Association 298 (2007): 519-521.

⁶⁵ Bracken, Patrick, Joan E. Giller, and Derek Summerfield. “Rethinking Mental Health Work with Survivors of Wartime Violence and Refugees.” Journal of Refugee Studies 10 (1997): 431-442.

⁶⁶ Musisi and Sudarmono 107. , Okello, Elialilia, Solvig Ekblad, and Stella Neema. “Beliefs and practices of traditional healers regarding non-psychotic depression: Implications for the health policy in Uganda.” (Submitted 2006): 15.

6. Findings and Discussion

6.1 *The mental health service users in Uganda*

The first step in this study was to find out who in Uganda is coming to the study sites, namely Mulago National Referral Hospital's S.B. Bosa Mental Health Unit, and Butabika National Referral Hospital. Both institutions see more male patients, with the ratio of men to women at around 2:1 or 3:1 at different times.⁶⁷ This is due to the fact that men are more likely than women to become violent, which is the most common reason for hospitalization of the mentally ill in Uganda. As one participant put it, "quietly depressed women are ignored."⁶⁸ Most patients are roughly between the ages of twenty and forty. This is because most of the illnesses seen present at around that age.⁶⁹ The most common diagnoses are bi-polar disorder, schizophrenia, depression, and epilepsy⁷⁰. Mulago and Butabika often see very severely ill individuals because they are both national referral hospitals, and because mental health services are not usually sought out except in extreme cases.⁷¹

Because only the severe cases are being brought to Mulago and Butabika, treatment almost always involves psychopharmacological interventions. Few patients are able to see psychologists because there are not many available, and the severe psychosis disorders do not necessarily lend themselves to psychotherapy. Hospitalizations are briefer, relative to common practice in the West. A patient presenting with depression or an affective disorder usually stays at Butabika 2-3 weeks, a patient with a substance abuse problem about 1 month, and a patient with schizophrenia or other psychosis 1-2 months. These figures are similar at Mulago, although the stays are a bit shorter. There are several reasons for short admission periods. First of all, as mentioned, many patients brought to these clinics are severely ill, so they respond quickly to drug therapy. Second of all, hospitalization at Mulago can be a burden to family members because an attendant is required. Thus, a member of the family is removed from economic activity for the

⁶⁷ Participant 110. Personal interview. 6 November 2008., Participant 115. Personal interview. 27 November 2008.

⁶⁸ Participant 115. 27 November 2008.

⁶⁹ *ibid.*

⁷⁰ Although not considered a mental illness in the West, epilepsy is dealt with in mental health units because of the frequency of behavioral symptoms and the neurological basis.

⁷¹ Participant 106. Personal interview. 3 November 2008.

hospitalization period. Additionally, there is some evidence to show that hospitalizations for mental health should be as short as possible to avoid “social breakdown syndrome.” This occurs when a mentally ill individual is removed from his or her social environment and social role for an extended period of time, and can be just as detrimental as the original illness.⁷²

Outpatients can be seen for a period of anywhere from a few months to several years, depending on the severity of the illness. The frequency of visits also depends on the disorder, but follow-ups generally take place weekly, biweekly, monthly, or bimonthly.⁷³

6.2 Informal caretakers for the mentally ill in the Ugandan setting

A number of factors make family members and friends of the mentally ill an important group to study. First of all, there is the aforementioned problem of human capacity. There are simply not enough mental health professionals to deal with the average burden of mental health, let alone the additional challenges in Uganda resulting from poverty, urbanization, torture, war, and displacement. Therefore, it is necessary to look for support from outside the professional sphere. Furthermore, the beliefs and attitudes of a society toward mental illness have a considerable effect on the way the community interacts with and responds to mentally ill individuals. These interactions both directly and indirectly influence the illness and treatment outcome.⁷⁴ It is possible that this influence is even stronger among family members, but has not been studied. Finally, it has been shown that caregivers who are familiar to the patient are more effective.⁷⁵ It was reported that there is a large gap between patients and doctors, who often come from a higher socioeconomic class and are viewed as “bosses.”⁷⁶ For example, one attendant at Mulago reported that the patient would not accept food, medication, or assistance from *basawo* (Luganda word for doctors), because they were frightening.⁷⁷ Despite knowing that patients benefit more from care given by someone he or she feels comfortable with, it has not been determined to what degree family members

⁷² Good 1997: 236.

⁷³ Participant 105, 108, 110, 116. 31 October- 28 November 2008.

⁷⁴ Good1997: 233.

⁷⁵ Musisi and Sudarmono: 99-100.

⁷⁶ Participant 108. 3 November 2008.

⁷⁷ Participant 313. Personal interview. 19 November 2008.

and friends are filling this role in Uganda, or if there is any way to improve the utilization of informal caregivers.

This study found that the people close to mentally ill individuals fill the role of caregiver in several ways. It is most often somebody living with or near a mentally ill person who recognizes the illness. With the exception of cases that require police involvement, relatives almost always bring the patient to the hospital or clinic.⁷⁸ All except for two of the nineteen Group 3 participants that were interviewed were family members. Female relatives come more frequently than male. Only one of the attendants at Mulago of the fourteen interviewed was male, and none of the five family members that were interviewed from Schizophrenia Fellowship (SF) were male. Men only become involved if the patient is extremely violent or physically unmanageable. There are several explanations for why women are more involved in taking care of the mentally ill. First of all, there is a strong cultural expectation that women fill the care-giving role, while men financially support the family. Since, in reality, men more likely to be supporting the family, there is also an economic component to charging the women with the time-consuming caretaker role.⁷⁹

After the patient has gone to the hospital, informal caretakers are essential for providing three types of support. First of all, they are often the ones ensuring that the patient's basic needs are met. While at Mulago Hospital, attendants help with everything from feeding, to washing clothes, to bathing and hygiene. Many attendants make sure that the patients are eating properly, or if they request special food items they bring them. After discharge, it is usually a family member who takes over responsibility for ensuring the physical well being of the patient. This includes protecting them from harm and harassment, either self-inflicted, or at the hands of others. In Uganda, it is also common for mentally ill persons to wander, so it is the caregiver's job to ensure that they don't become lost.⁸⁰

Doctors and nurses also utilize caregivers to assist in treatment. Even when patients are still at Mulago, the attendants monitor and give medication. Occasionally it is necessary for family members to find and purchase medications that are not available at

⁷⁸ Participant 106. 3 November 2008., Participant 107. Personal interview. 4 November 2008.

⁷⁹ Participant 106, 107 109, 115, 202. Personal interview. 3-27 November 2008.

⁸⁰ Participant 202, 209, 301-319. 29 October-22 November 2008.

the hospital. After discharge, mental health workers absolutely depend on the informal caregivers. They are the ones who remind and encourage the patient to continue taking medication properly, and are considered responsible for making certain that the patient go to his or her follow-up appointments.⁸¹

Finally, informal caregivers can provide crucial emotional and social support. This report has so far mentioned several cases in which and reasons that this type of support is needed. In Uganda, this type of assistance takes two forms. The first, and possibly most effective, is listening. Many Group 3 participants reported that they help the patient by listening to them. Several also said that the “counsel” the patient, or offer them advice on how to face certain challenges, including stress. Secondly, sometimes the caretakers are helping the patient psychologically without even being aware of it. One psychiatrist reported that his patients’ treatment outcomes were better when the family was treating the patient like a “normal” human being, or similarly to the way they were treated before the illness. For example, families that were able to keep that patient involved in the work at home were very successful. It is also important that, over time, the family or caretakers encourage the individual to become as independent as possible by encouraging them to take care of themselves and find work.⁸²

Children in particular are in need of informal caregivers, and it is best if the family is the source. It has been proven that in Uganda, children respond strongly to negative life events associated with family members, particularly parents. In fact, it is the most significant risk factor for deliberate self-harm (DSH), which is not only possibly fatal, but itself a risk factor for suicide.⁸³ Children are also more likely to be psychologically traumatized if the parents are also.⁸⁴ Although negative experiences related to family are the most damaging in children, family is also the saving grace. A strong, functional family is cited in a Ugandan training manual for health workers as the number one protective factor against psychological trauma. For this reason, family members and caregivers of mentally ill children are given special attention. The

⁸¹ Participant 109, 209. 5-22 November 2008.

⁸² Participant 109, 114, 209, 310. Personal interview. 5-22 November 2008.

⁸³ Kinyanda, Eugene, H. Hjelmeland, and Seggane Musisi. “Negative Life Events Associated With Deliberate Self-Harm in an African Population in Uganda.” *Crisis* 26 (2005): 506.

⁸⁴ Kinyanda, Eugene, Sheila Ndyabangi, Ruth Ochieng, and Juliet Were Oguttu (Eds). Management of Medical and Psychological Effects of War Trauma; Training Manual for Operational Level Health Workers. Kampala: Isis WICCE, 2006: 88.

aforementioned manual mentions in several places the importance of counseling and psycho-educating parents. In particular, it is important for the parents to recognize that the child is ill, despite the fact that this realization may be upsetting.⁸⁵ For this reason, Butabika children's ward holds group sessions for family members. These group sessions involve some psychoeducation and then plenty of time for the family members to ask questions and discuss among themselves. In this way it also functions as an informal support group or group therapy. The family members also undergo their own form of counseling, to help them deal with having a mentally ill child and prepare them to care for the child.⁸⁶

Unfortunately, the effect that family members and friends have on the mentally ill is not always positive. First of all, they do not always exhibit ideal help seeking behavior on the behalf of the patient. As previously discussed, it is only patients displaying severe behavioral symptoms that are recognized as ill. In the absence of recognizably "mad" or disturbing behavior, an individual is not considered ill, and therefore not brought to the hospital.

Even when patients are brought to the hospital or clinic, it is often as a last resort. First the mentally ill person will be taken to traditional healers, spiritual healers, churches, priests, or all of the above. Traditional healers and churches are preferred for a variety of reasons. When a community or family recognizes a mental illness, or as it is commonly referred to, "madness," the consensus is usually that it is caused by something other than psychological or psychiatric factors. There are a variety of cultural explanations, from a curse from a neighbor to a neglected ancestor. In this case, a traditional or spiritual healer is sought out. Some also believe that it stems from a spiritual deficiency or problem from within a Christian religion, in which case the family turns to the church for healing. One Group 3 participant was still convinced that the patient's problem was a result of being bewitched by a female neighbor, and that God was the only answer to the problem. Furthermore, traditional healers and churches are more available. As mentioned before, mental health workers are few and far between. If the family or community is far from a well-known mental health center like Butabika,

⁸⁵ Kinyanda, et al. 84.

⁸⁶ Participant 104. Personal interview. 29 October 2008.

they may decide that it would be too expensive to travel the far distance to the health center. Traditional healers and churches, on the other hand are plentiful. Families also face social pressure from the community to seek out cultural or spiritual assistance first, even if they are questioning the effectiveness of these measures.⁸⁷

Another reason to avoid the mental health unit or hospital is stigma. Community members who do not understand mental illness have been observed doing any of the following to mentally ill persons: taunting, beating, ignoring in order to dehumanize, demoralizing, and name calling. When faced with stigmatizing behavior, patients often internalize the stigma, which translates into self-hatred and low self-esteem, both of which have very detrimental effects on recovery and improvement. Also, in order to avoid such abuses, mentally ill persons may withdraw from social situations, perpetuating the poor social functioning that often accompanies mental illness. “The tendency is for [mentally ill persons] to sit around, once everybody knows they are sick.” To protect himself or herself from community abuse, a mentally ill person may try to hide his or her illness for as long as possible, in anticipation of stigmatization.⁸⁸

Mental illness is not only stigmatizing for the individual, but also for the whole family. To avoid judgment, families might try to hide the patient instead of seeking treatment.⁸⁹ Butabika in particular, is well known as a mental health hospital, and therefore does not appeal to families who are uncomfortable with public knowledge of the illness. Unfortunately, fewer people know about the mental health services offered at other institutions, such as Mulago or other health centers. Most attendants and family members that I spoke to were referred from another ward of the hospital, usually the emergency ward. In Jinja, the Schizophrenia Fellowship is working to spread the word. Most of the members are relatives to and caretakers of mentally ill persons. Of the ones interviewed, they had all heard about mental health services offered at Bugembe Health Center IV from somebody who was already a member of the organization. This kind of grass roots information dissemination was found to be very effective in this setting. Finally, families or caretakers may simply be in denial about the illness. It can be upsetting to acknowledge that somebody is seriously ill, especially if the family or

⁸⁷ Participant 108, 112, 204, 209, 210, 308. 3-26 November 2008.

⁸⁸ Participant 114. Personal interview. 18 November 2008

⁸⁹ Participant 109. 5 November 2008

caretakers is blaming themselves or the ill individual. As a result of lack of knowledge, fear of stigma, and denial, most mentally ill persons are not brought to formal services until he or she has been ill for some time, and the illness has become severe.⁹⁰

The ways in which family members can negatively impact treatment outcomes go beyond missing out on formal services. They can actually reverse some of the progress made by treatment. Stigma does not only come from the community. Caretakers are often observed using the term *mulalu* or “mad person” when addressing or referring to the patient. Even more common, and less obvious, is the tendency for the family or other people living with the patient to marginalize him or her. They quietly remove the patient from daily activities, refuse to eat with them, discount what he or she says, expect little or no productive activity from the person, etc. Some parents go so far as to remove children from school unnecessarily. If the patient becomes upset at any point, it will be attributed to the illness, despite the fact that anger and sadness are common emotions. While it is true that mental illness can cause disability, most people in treatment can function quite well in his or her previous role. When they are denied the chance to, the result is withdrawal and self-stigmatization.⁹¹

Sometimes families or caretakers give up on the patient and recovery. Instead of taking them for help, they will bring them to hospitals to get rid of them. Some even go so far as to beg psychiatrists to admit them, when the chosen course of intervention was outpatient treatment. One doctor had observed families that bring a patient over and over hoping that a different doctor will admit the patient. If they are unsuccessful at “dumping” the patient at the hospital, the family may force the person out of the home, or pretend not to know the patient. In other cases, the patient is tied up, tied to a tree, or locked in a room to remove them from the family and society. Frustration on the part of the caretakers can also lead to what is called “high expressed emotions”, which is essentially a lack of patience or understanding leading to visible anger with the patient. Even physical abuse is fairly common, especially in patients who are aggressive as a result of his or her illness.⁹²

All of this behavior has negative impacts on treatment and recovery. It essentially

⁹⁰ Participant 113, 203. 17-18 November 2008.

⁹¹ Participant 113-115. 17-27 November 2008., Participant 204. 21 November 2008.

⁹² Participant 113-116, 202, 204. 17-28 November 2008.

consists of mild to severe forms of psychological torture, and is known to aggravate mental illnesses in most patients. At the very least, it inhibits recovery. If a patient is being told or shown through marginalization that they are not able to function in society, it is unlikely that they will. Several mental health professionals had observed that the above actions consistently cause relapses or “episodes.” One member of Schizophrenia Fellowship, herself a former patient, explained that when community members stigmatize or harass her, her natural response is to get upset or angry. Stress caused by hurtful and abusive behavior made it more difficult for her to overcome her illness.⁹³

At this point, the prescribed intervention for damaging family or caretakers is family therapy or counseling. It would also be useful to counsel communities in which mentally ill persons are living. The community mental health program based at Butabika has attempted to do some of this, but faces resource restraints that prevent them from doing the necessary follow-up. Another protective factor is the patient’s ability to care for himself or herself. Those that are able to provide for their own basic needs are better at overcoming community stigma and familial abuse. Because women are more often involved in activities like cooking, cleaning, etc., a female patient is more likely to function well in the absence of a supportive network of friends and/or family. Additionally, psychoeducation and sensitization is an extremely effective method for preventing harmful practices in the care of the mentally ill.⁹⁴

6.3 Challenges to informal caretakers

The most common difficulty in caring for a mentally ill person mentioned by the caretakers interviewed was financial challenges. It is expensive to transport the individual and caretaker or caretakers (who often accompany patients to the hospital the first time and for follow-ups) to the hospital. The best solution is decentralization of mental health services, which the government is currently working on. There is also a community mental health program being run through Butabika. The program, which is “rather amorphous” according to one psychiatrist, runs four outreach clinics and handles some cases that require special attention to the discharge and reintegration process. Although it is only reaching communities in about a ten-kilometer radius of Butabika, it is doing

⁹³ Participant 106, 107, 113, 115, 207. 3-27 November 2008.

⁹⁴ Participant 112-114, 202. 12-18 November 2008.

some good. For example, women are more plentiful at the outreach clinics, which means that in some areas, it is not only the violent male patients that are getting treatment. The outreach workers are also more likely to examine the family and social environment of the patient. Even when the patient is going to an outreach clinic, however, it may require a considerable amount of time and money to reach. The program itself also lacks the funds and resources to do the home visits and follow-up on reintegration that is necessary in many cases. For patients whose home is far away, “reintegration” may involve putting them on public transport home, by themselves, because there are not enough funds to send a counselor or nurse with them.⁹⁵

The next financial hurdle is medication. The majority of the Group 3 respondents specifically requested or suggested that drug availability be improved, and prices lowered. Mental health treatment is now part of the Basic Health Care Package (BHCP), which means that it should be free at government health centers, including psychopharmacological treatments. While most necessary drugs can be found at Mulago and Butabika, the supply is inconsistent. A patient may come in for follow-up and the drug they were taking successfully is not in stock. At that point the patient is forced to take a chance on whatever drugs are available, or go find and pay for the successful drug. At smaller hospitals and health centers the problem is even more pronounced. To make matters worse, psychiatrists do not always consider the patient’s or family’s economic situation when prescribing medications. In an attempt to give the patient the best prognosis, a doctor may prescribe the medication that he or she knows is most effective, but is not on the list of drugs provided by the government. When the family can’t afford to buy the medications, however, they cannot help no matter how much better they are. Families are reluctant to admit to doctors or authority figures that they cannot afford the medication, so they will keep quiet and the patient will go without necessary drugs. On the other hand, some psychiatrists take the necessary time to assess the economic status of the family and prescribe accordingly.⁹⁶

The patients themselves can also be an economic strain to families and caretakers. In all MHUs (excluding Butabika), attendants are required for admission. This means that

⁹⁵ Participant 112-114. 17-18 November 2008.

⁹⁶ Participant 108, 116. 3, 28 November 2008.

the caretaker is removed from economic activity for the period of hospitalization. Once at home, it is often still necessary for someone to forego work in order to care for the patient. Wandering is an extremely common symptom of mental illness in Uganda, meaning careful observation of the patient is often necessary. In some cases, someone is needed to be vigilantly watching the patient for signs of relapse, which can distract from work or chores. A relapse may also result in property destruction, such as the mother of a patient whose family is without bedding because the patient destroyed what was there. Finally, patients often become financially dependent on family members, at least for a period of time, which leaves the caretaker with an additional dependent, one who would otherwise be living independently or supporting himself or herself. In cases where the patient is a mother, the family (usually the patient's mother) steps in to care for the children, meaning even more dependents and work for the caretaker.⁹⁷

Caring for a mentally ill person can cause emotional and psychological stress. Most caretakers are somebody very close to the patient. Seeing a close friend or relative in serious distress often causes distress. In particular, it can be very upsetting for parents or older family members to see the patient's chances at success in school and work diminish. As one psychiatrist explained, it is hard for family members to accept the fact that the patient "is not going to become the person that they thought they were."⁹⁸ Furthermore, the mental illness will put strain on, and possibly damage the relationship between the two people. In some cases, family members (particularly mothers) blame themselves for the illness. Similarly, the community may blame the caretakers. Communities also stigmatize the family or people living with mentally ill persons. Many Ugandans, for example, consider epilepsy contagious, and so people will stop visiting the home or family members of an epileptic.⁹⁹

Unfortunately, the mental health system is not equipped to address the psychological needs of family members and caretakers, but there is some attempt to. The previously mentioned group sessions for parents of children with a mental illness may be offering some solace to family members. Family therapy is also used fairly often when the patient is a child. In addition, the community mental health program seeks to ensure a

⁹⁷ Participant 108, 304, 315, 317. 3-21 November 2008.

⁹⁸ Participant 115. 27 November 2008.

⁹⁹ Participant 102, 106, 107, 112, 114, 203. 28 October- 18 November 2008.

healthy social environment for patients by counseling family members when necessary. The financial problems of the community mental health program still apply to these attempts, however, and therefore they are not extensive. In general, the formalized mental health system is not addressing the needs of informal caretakers.¹⁰⁰

It is organizations that provide mental health services that are currently most successful in the role of caring for the caregivers. Hope After Rape (HAR) provides both individual and group counseling to family members of victims of sexual abuse. It is considered a necessary step because the distress caused by having a family member who is a victim, and a family member who is mentally ill as a result, can make it difficult for family members to care properly for victims. The Transcultural Psychosocial Organization (TPO) also makes stabilizing the family and social environment a priority, through group counseling and community awareness.

Support groups are an extremely valuable method of assisting caretakers. BasicNeeds Uganda (BN) has helped organize several caretakers groups. Not only do these groups offer support to each other, some have formed drug banks. Drug banks are groups of caretakers in which each member contributes some money so that the group can buy expensive drugs in bulk, thereby saving each member money. The Schizophrenia Fellowship (SF) has formed similar groups. SF is a membership organization based in Masaka and Jinja. The Jinja group is based at Bugembe HCIV, and is run by the health center's PCO. Most members are parents or relatives caring for someone with mental illness. All of the respondents who were members from SF reported that they were having a difficult time caring for their family member, and that they were unhappy for a while. They also all responded that since joining the group, while they still face difficulties, they are much happier. They described the group as "a place to laugh and feel relieved", a place they feel "embraced", "at peace", and "a lot of joy."¹⁰¹

Ignorance and misunderstanding is a dilemma for both caretakers and mental health care workers. The general public has a much different conception of mental illness than formally trained professionals do. First of all, mental health professionals have sometimes found it difficult to explain to family members and patients that mental illness

¹⁰⁰ Participant 102, 106, 108, 112, 113, 114. 28 October- 18 November 2008.

¹⁰¹ Participant 204, 314-319. 21 November 2008.

is, in most cases, a chronic disorder. There are certain cultural expectations of doctors in Uganda. Namely, people expect medication in the form of pills or injection. They expect the medication to work quickly, and that once the symptoms are no longer visible the disorder is cured, making the drugs unnecessary. As a result, drug therapy is often terminated much too early, indeed in some cases it is needed for the duration of the patient's life. It is easier for the patient to accept that he or she must take medication permanently because they are able to observe what happens to them without medication. In the case of Butabika patients, they are also interacting with mental health professionals on a daily basis, and can see other patients that are there because they have relapsed. Once they are in the home, however, the patient is subject to pressure from the caretaker or family. It can be difficult for families to accept that the patient is not cured because of the aforementioned cultural preconceptions and because it is upsetting news. When the caretaker is encouraging a patient to discontinue medication, the patient often acquiesces.¹⁰² So, if caretakers were made to accept the long-term nature of mental illness, it would reduce the quantity of patients that relapse. There is, however, a Catch-22. It has been shown that societies that conceptualize mental illnesses as curable as opposed to permanent have better treatment outcomes.¹⁰³ More research is needed to determine how best to inform patients and caretakers about the medications.

As mentioned earlier, violence is the most likely symptom to prompt hospitalization. This fits into a general tendency for people to recognize and identify behavioral symptoms over emotional ones.¹⁰⁴ The Group 3 participants were asked about how they knew the patient was ill, and what happened when the patient became ill. Besides violence or uncontrollable behavior, the most common responses were “over-talking”, “over-walking”, disrupted speech, etc. When asked about the cause of the illness, the Group 3 participants also have a very consistent view. The fact that the patients are in the hospital is an indicator that most of the caretakers have accepted that it is not caused by cultural or spiritual factors. Only one attendant cited the cause as being “bewitched.” Instead the explanation usually begins with environmental factors, like too

¹⁰² Participant 109, 110, 112, 114, 116. 5-28 November 2008.

¹⁰³ Good 1997: 233.

¹⁰⁴ Okello, Elialilia. “Cultural explanatory models of depression in Uganda.” Thesis for doctoral degree (PhD.). Kampala: Makerere University and Karolinska Institutet, 2006. 1-43.

much work or stress. The patient is unable to deal with the circumstances, and the result is “too many thoughts” or “over-thinking.” In summary, the vast majority of the Group 3 participants had the following conception of mental illness:

Environmental stress → Cognitive disruption → Behavioral symptoms
 (too much stress or work) (“too many thoughts”) (violence, “over-talking”)

While most of the Group 3 participants were sympathetic to the patients, this sample is biased toward this result because the caretakers have taken the time to seek treatment and participate in treatment. There are, however, some families that will actually blame the patient for the illness. As shown above, biological or organic causes do not factor into the common conception of mental illness, which is also confirmed by the observations of Group 1 and 2 participants, and Dr. Elialilia Okello’s work on the cultural construction of depression in Uganda.¹⁰⁵ It becomes the responsibility of the mental health workers and community sensitization programs to explain that the patient is not at fault. In order to do remove blame, Ugandan psychiatrists have found it useful to explain the organic causes of mental illness. Although medical terms are not always easily or effectively translated from English to local languages, there are certain semantic constructions that have proven useful. One experienced psychiatrist explains mental illness as a result of “imbalances” in the “fluids” in the brain.¹⁰⁶ Other phrases that have been valuable are “the illness disturbed the brain”, the illness is “in the blood”, or “runs in families.”¹⁰⁷ It is important that mental health workers take the time to translate and explain mental illness in terms that are not only easy to understand, but culturally significant to patients, families, and communities.

6.4 The importance of psychoeducation

Psychoeducation has been found to be the most effective method of improving informal caretaking practices and fighting stigma, and has the added benefit of being inexpensive. Psychoeducation, as it exists in Uganda, essentially consists of revealing the nature of mental illness, the causes of mental illness, and the forms of treatment for

¹⁰⁵ Okello 2006: 1-43.

¹⁰⁶ Participant 115. 27 November 2008.

¹⁰⁷ Participant 109, 110, 115. 5-27 November 2008.

mental illness. The primary sphere of influence is the mental health worker to the patient and caretaker. As discussed earlier, many problems result from misunderstandings and misconceptions on the part of caregivers. Most, if not all, psychiatrists attempt to perform some degree of psychoeducation during consultations, but for some reason it is not always getting through to caretakers. The attendants that were Group 3 participants were quick to praise the staff at Mulago. However, of those that were asked¹⁰⁸,

- a. “What do the doctors tell you about your family member’s illness?
- b. What do the doctors tell you about why your family member is ill?
- c. What do the doctors tell you about your family members treatment?”¹⁰⁹

none of the respondents could answer all three questions. Over half were able to answer the third question by saying that the patient was on medication, or that the patient was to take drugs regularly. Others, however, said “nothing” or “not yet.” These were also the most common responses for the first and second questions. None of the respondents had been informed of the biological nature of mental illness, and only two reported having been given any information about the cause of the illness. Before these questions were introduced, the interviewees were still being asked if he or she knew what caused the illness. Again, none mentioned biological causes

From these findings it seems clear that more psychoeducation is needed for caretakers at MHUs. Psychiatrists, however, are facing serious time challenges. They are forced to see many patients, and often don’t have time to explain details and causes. Many are also forced to work at private clinics because of low pay. Some report that they only explain the details and causes of the illness if the patient or caretaker asks, or if it is necessary because the caretaker is blaming or stigmatizing the patient.¹¹⁰ It is possible that there is an additional justification for withholding the organic nature of mental illness. Many caretakers reported that because the illness was caused by stress, they made sure to help the patient avoid stress. Many of the illnesses seen in Uganda are brought on or exacerbated by environmental circumstances, so this practice is extremely helpful. More research is needed to determine exactly what should be included in

¹⁰⁸ Eight of the fourteen attendants were asked these three questions; the other six were interviewed before the question were included.

¹⁰⁹ See Appendix II- Interview Questions

¹¹⁰ Participant 106, 108, 114. 3-18 November 2008.

psychoeducation, and if or when explaining biological origins of mental illness is necessary. What is not in question is that caretakers should be advised on how to care for the patient, that the patient is not to blame, and that it is extremely detrimental to stigmatize or marginalize the patient.

Psychoeducation is also an effective solution to stigma in the community. The Ministry of Health has taken some steps in this direction by promoting public awareness on the radio and posters. The community mental health program is also helping by working in communities and outreach centers. HAR, BN, and TPO are all involved in community education programs like health talks or awareness promotion session. These methods have been found effective. A new approach is also yielding impressive results. It is actually more like an old approach with a new appreciation. Family members of the mentally ill are uniquely positioned within society to promote awareness and fight stigma. The community is less likely to discount what they are saying because they are not ill, as opposed to patients themselves. Caretakers have also been exposed to psychoeducation through the mental health system and different organizations. In addition, they can offer compelling testimonies to make the community understand important messages, like that the mentally ill should not be blamed for their illness, for example. Possibly most importantly, they have a strong motivation to end stigma. SF in Jinja has had considerable success in using family members to educate communities. Their grassroots approach is ideal for communities which cannot be easily convinced by a poster or meeting. The members themselves are proof of the success. A few of the members are simply concerned citizens, who were recruited by caretakers. They report that they are involved even though they are not related to a mentally ill individual because they recognize mental illness as the community's responsibility, and because they know it could happen to anybody.¹¹¹ There is an increasing awareness among mental health professionals and organizations that family members are perfect contact points for community psychoeducation. With encouragement and assistance from the mental health system and organizations caretakers could be at the forefront of fighting stigma and raising awareness from mental health issues.

¹¹¹ Participant 204-207. 21 November 2008.

7. Conclusion

This study has found that informal caretakers of the mentally ill are involved in several support activities in Uganda. Somewhat like a first response team, they are the ones to recognize mental illness and bring the patient to a hospital or clinic. During and after the hospital stay, informal caregivers provide for the basic needs of the patient, like food, clothes, and shelter. Informal caregivers are also an important asset in treatment, because they can monitor compliance when it comes to medication and follow-up appointments. Finally, they are essential in offering emotional, social and psychological support.

These support activities, however, are only possible if the informal caretakers are sensitized about mental illness. If they are not they may stigmatize, or worse, abuse the patient. Sensitization is also necessary in communities to prevent the community from stigmatizing and abusing the patient. Family members are increasingly involved in community sensitization, and are very effective in this role.

In order to maximize the potential of informal caregivers, they are in need of several types of support. First of all, the government needs to ensure that drugs are available and that the supply is consistent. Mental health care workers and organizations should be lobbying the government for the drugs, as well as providing valuable psychoeducation. They should also encourage and promote networking among caretakers. Caretakers can then form groups to support each other psychologically and financially, if need be. Finally, if all of the aforementioned parties work together to increase community awareness and understanding of mental illness, than harmful stigma can be avoided, and caretakers will gain more outside support.

8. Recommendations

In order for caregivers to receive all of the necessary support, several things must happen. First of all, decentralization is essential to ensure that the mental health needs of the country are being met. The government's current method of decentralization is incorporating mental health into primary health care, which is exactly what is needed. There are several limitations to the practical execution of this plan, however. First of all, there is little to no coordination between the district hospitals and health centers, district level governments, and community based organizations. Furthermore, little effort has been made to ensure that the district level MHUs are fully functional. There is little district funding, only federal, and staffing is inadequate. At a local government level, there is almost no planning or implementation because there is no guidance from the district or national level. Recording keeping at all levels is insufficient, making it difficult to assess community needs and to lobby for services and resources. Finally, NGO coverage for mental health concerns is low. The NGOs that are in existence are operating in only small areas of Uganda, leaving most districts without services.¹¹²

While these issues are being addressed, continued research is required to assess the effectiveness of new measures. In particular, this study has found that there is a need for studies that can determine what methods of psychoeducation are most effective in what settings, and what should be included (or excluded from psychoeducation). In addition, there is good work being done on incorporating traditional healers into mental health care. These studies could lead to important changes and improvements in the way mental health services are delivered in Uganda.¹¹³

Until infrastructure and resources for mental health service delivery is greatly improved, psychoeducation is an inexpensive and effective intervention. If caretakers and family members to the mentally ill are properly and thoroughly informed about mental illness, than they can be much more successful in the caretaking role, even to the point of alleviating some of the burden of the mental health system. Additionally, armed with complete and accurate information, they can serve as a powerful tool in community education and awareness

¹¹² BasicNeeds-Uganda Baseline Study 2004-2005; The Situation of Mental Health in Kamwokya, Masaka, Hoima, and Masindi.

¹¹³ Okello 2006:1-43.

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Interviews

Participant 102. Personal interview. 28 October 2008.
 Participant 103. Personal interview. 29 October 2008.
 Participant 104. Personal interview. 29 October 2008.
 Participant 105. Personal interview. 31 October 2008.
 Participant 106. Personal interview. 3 November 2008.
 Participant 107. Personal interview. 4 November 2008.
 Participant 108. Personal interview. 3 November 2008.
 Participant 109. Personal interview. 5 November 2008.
 Participant 110. Personal interview. 6 November 2008.
 Participant 111. Personal interview. 6 November 2008.
 Participant 112. Personal interview. 17 November 2008.
 Participant 113. Personal interview. 17 November 2008.
 Participant 114. Personal interview. 18 November 2008.
 Participant 115. Personal interview. 27 November 2008.
 Participant 116. Personal interview. 28 November 2008.
 Participant 201. Personal interview. 11 November 2008.
 Participant 202. Personal interview. 12 November 2008.
 Participant 203. Personal interview. 18 November 2008.
 Participant 204. Personal interview. 21 November 2008.
 Participant 205. Personal interview. 21 November 2008.
 Participant 206. Personal interview. 21 November 2008.
 Participant 207. Personal interview. 21 November 2008.
 Participant 208. Personal interview. 21 November 2008.
 Participant 209. Personal interview. 22 November 2008.
 Participant 210. Personal interview. 26 November 2008.
 Participant 301. Personal interview. 29 October 2008.
 Participant 302. Personal interview. 29 October 2008.
 Participant 303. Personal interview. 29 October 2008.
 Participant 304. Personal interview. 7 November 2008.
 Participant 305. Personal interview. 7 November 2008.
 Participant 306. Personal interview. 7 November 2008.
 Participant 307. Personal interview. 7 November 2008.
 Participant 308. Personal interview. 12 November 2008.
 Participant 309. Personal interview. 12 November 2008.
 Participant 310. Personal interview. 12 November 2008.
 Participant 311. Personal interview. 12 November 2008.
 Participant 312. Personal interview. 19 November 2008.
 Participant 313. Personal interview. 19 November 2008.
 Participant 314. Personal interview. 19 November 2008.
 Participant 315. Personal interview. 21 November 2008.
 Participant 316. Personal interview. 21 November 2008.
 Participant 317. Personal interview. 21 November 2008.
 Participant 318. Personal interview. 21 November 2008.
 Participant 319. Personal interview. 21 November 2008.

10. Appendices

10.1 Appendix I- Project schedule

Activity	Sept	Oct	Nov	Dec
Proposal writing				
Submit proposal				
Data collection				
Data analysis				
Report				

10.2 Appendix II- Interview questions

Group 1- mental health professionals

1. Name, gender, age, education level, occupation, residence
2. How long have you been working in the mental health profession?
3. Where did you receive your education?
4. What positions have you held as a mental health professional?
5. Do you diagnose and treat patients?
6. Do you see patients every day?
7. How often do you see your patients?
8. In general, how long is a patient in your care?
9. Could you please describe your research interests?
10. Could you please describe the patients at this clinic?
11. Why do people come to the clinic?
12. What type of treatment is it expected that they receive?
13. What type of family structures and home situations do the patients come from?
14. Who, if anybody, comes with the patient to the clinic?
15. What is your level of interaction with the patient's family members?
16. What information do you give them?
17. How do you explain to the family members the causes of the illness?
18. What information do you ask them?
19. Do you ask them about the family situation or their personal problems?
20. Based on your observations, what are the different roles that the family members play for the patient?
21. In general, how often do friends and family come to see or check up on patients?
22. Who comes most often? (close relations, male vs. female relations, age group, friends?)
23. Do family members get involved in the patient's treatment?
24. If so, how common is it?
25. Have you ever observed a family member intentionally influencing a patient's treatment?
26. If so, what happened?
27. Have you ever observed a family member unintentionally or unknowingly influence a patient's treatment?
28. If so, what happened?
29. Could you please give examples of ways that family members have been able to help a patient's treatment process?
30. Could you please give examples of ways that family members have made the treatment process more difficult?
31. Based on your observations, does the behavior of your patients' family effect treatment outcomes?
32. What is the largest challenge that you face when dealing with family members?
33. What kind of stigma exists towards mental illness in local culture?
34. Have you seen stigma change over time?
35. What is currently being done in this district to overcome stigma?
36. What do you recommend for the future to work on the problem?

37. Is there anything you would like to add?

Group 2- members of organizations that provide mental health services

1. Name, gender, age, education level, occupation, residence
2. How long has your organization been operating in Uganda?
3. What types of services does your organization offer?
4. Who comes to this organization?
5. Why do people come to this organization?
6. If you receive patients, how do they find you?
7. If patients are coming here, who comes with them?
8. Do you see patients?
9. If so, how often and for how long each time?
10. Do you ever interact with patients and/or a patient's family members?
11. Are patients ever brought or accompanied by relatives or friends?
12. Who comes most often? (close relations, female vs. male relations, age group, friends)
13. What are the challenges to delivery of mental health services in this district?
14. Do you see stigma or community attitudes as a challenge?
15. If so, in what ways?
16. Does your organization fight stigma in any way?
17. If yes, then how, and how successful are you?
18. Have you ever observed a family member influencing a patient's treatment?
19. If yes, in what ways?
20. What do you recommend for the future to work on the problem?
21. Is there anything you would like to add?

Group 3- family members of mentally ill patients

2. Name, gender, age, education level, occupation, residence, marital status
3. Who do you live with at home?
4. Who is it that you came here with today?
5. Do you live with this person?
6. Why were you chosen, or did you chose to take care of this person?
7. How did your family member come to be in this hospital?
8. How did you find or hear about the Mental Health Unit?
9. How long has your family member been ill?
10. What happened when your family member became ill?
11. How did you know that your family member was ill?
12. How do you feel about your family member's illness?
13. Why do you think your family member is ill?
14. How do you think your family member can get better?
15. What do you do to take care of your family member?
16. What will happen when your family member recovers and leaves the hospital?
17. What will you do to take care of your family member when you get home?
18. Do you find it difficult to care for your family member? What is difficult?
19. What do you think of the people that work at the hospital? (Remind subject that the doctors will not be told what they say)

20. What do the doctors tell you about your family member's illness?
21. What do the doctors tell you about why your family member is ill?
22. What do the doctors tell you about your family members treatment?
23. Do you think that the hospital is helping your family member?
24. Why or why not?
25. What do you think the hospital could do even better?
26. What do you think the hospital could do that they are not doing now?
27. Is there anything that you would like to add?

NOTE: The participant will be instructed not to reveal his or her relative's name.

10.3 Appendix III- Informed consent forms

Northwestern University

Anthropology

CONSENT FORM

Project Title: Culture and Mental Health in Uganda

Principal Investigator: Kearsley Stewart

Co-Investigator(s):

Student Investigator: Dara Carroll

Faculty Advisor: Kearsley Stewart

Supported by [or Funded by]: Martha Mabie Fellowship for Public Health Research

Introduction/Purpose:

You are being asked to participate in a study that will study the role of community and culture in mental health and treatment. You are being asked to participate in this study because you have a family member who is mentally ill. The purpose of this study is to find ways to improve mental health services in Uganda. We will interview 40 people for this study.

Procedures

Your participation in this study will involve from one to four interviews. In the interview I will ask you questions about your life and your family. I will ask about what you do and who you live with at home. I will also ask about your ill family member, and about his or her illness. Finally I will ask your feelings about the people who are treating your ill family member.

The first interview will be between one and two hours. If you agree to another interview it will last about the same amount of time. All interviews will take place in a private setting, at a time good for you. If you allow, we will audiotape your interview, and take detailed notes during and after the interview. You may switch off the voice recorder, or ask the interviewer to switch off the recorder at any time. You may also ask me to erase the tape, or sections of the tape. After the interview, I will write down the words from our interview. Any information that could identify you will be removed from the written transcript and the tape will be destroyed. If you agree to another interview, we may contact you within two weeks. If you agree to follow-up interviews, we will meet in the same place and I will ask you similar questions. Please remember, at any point in the study, you may cancel your interview from the study, or refuse to continue with the study.

with no risk or harm to you or your family. Nothing bad will happen to you or your family if you stop the interview or cancel some of the conversation on the recorder.

Risks

You may become upset or disturbed when answering some of the questions. You may refuse to answer any question that you do not like. You may stay in the study even if you do not answer all of the questions. If at any time you want to stop the interview, tell me. I will be stop and ask if you want to continue at a different time. You may stop at any time.

Benefits:

There are no direct benefits to you for your participation in this research study. Your participation in this study may help in our understanding of mental illness and the treatment of mentally ill persons in Uganda.

Alternatives:

You can choose not to participate in this research study.

Confidentiality:

Participation in this research study may result in a loss of privacy, since persons other than the investigator(s) might view your study records. Unless required by law, only the study investigator, members of the investigator's staff, representatives of Martha Mabie, the Northwestern University Institutional Review Board, and representatives from the Office for Human Research Protections (DHHS) will have authority to review your study records. They are required to maintain confidentiality regarding your identity.

Results of this study may be used for research, publications, or presentations at scientific meetings. If your individual results are discussed, your identity will be protected by using a study code number rather than your name or other identifying information. All audio records will be destroyed at the end of the study. Your name will not be in the written transcript. Only the principal investigator and student investigator will see the written transcript.

Financial Information:

You do not pay any money to be in this study. You will not be paid for your participation in this study.

Subjects' Rights:

You freely choose to be in this study and you are free to stop at any time. You do not need to answer any questions you do not want to. You may ask that the tape recorder be turned off at any time during the interview if there is something that you do not want to have recorded.

Contact Persons:

If you have any questions about this study you may call me, Dara Carroll, at telephone number **0777-357-844**. If you have any questions about your rights as a research subject you may call the Office for the Protection of Research Subjects of Northwestern University at telephone number +1-312-503-9338. If problems arise evenings or weekends, you may call **0777-357-844**.

Consent:

I have read this form and the research study has been explained to me. I have been given the chance to ask questions and my questions have been answered. If I have more questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a signed copy of this consent form after I sign it.

 Subject's Name (printed) and Signature

 Date

 Name (printed) and Signature of Person Obtaining Consent

Dara carried out her independent study project on mental health. She specifically sought to examine the current role of informal caretakers of the mentally ill. Her objectives included the following; to determine if family members influence the treatment outcomes of the patients. To assess the attitudes, behaviors, and care giving practices that are positive, and those that are detrimental to the treatment of the mentally ill. To recommend specific family interventions in the management of the mentally ill in Uganda.

Dara's study was a qualitative and she triangulated her methods to be able to obtain information that was varied from different people in the shortest time possible. She carried out intensive semi-structured interviews with different categories of the respondents. She provides a detailed breakdown of her research design and an extensive literature in the background section and throughout the study that is very instructive in understanding the mentally ill and the challenges of providing health care to them. In the subsequent sections, she effectively contextualizes the causes of mental health and discusses the different ways in which it has been addressed. The most interesting parts of the study are

the findings in which she discusses the different aspects of the mentally ill.

She found out that family members and close friends often assume the role of caretaker for the mentally ill and carry out multiple chores for the patient like taking them for treatment, ensuring their compliance to the therapy given and for the general welfare of the patients. She explains that In places where family health care givers are not permitted, the doctors urge family members to visit the patient as often as possible. She notes that whereas family members and informal caregivers accept the responsibility to look after the ill, they sometimes neglect or even aggravate the patient. She attributes this neglect and aggravation of the patients to the social stigma that surrounds the mentally ill as well as to the dearth of mental health professionals to deal with the average burden of mental health. The mentally ill are further aggravated by other non-health challenges resulting from poverty, urbanization, torture, war, and displacement. She commends community for the intervention in the management of the mentally ill in resource poor countries. Communities utilize existing infrastructure and human resources available to provide care for the mentally ill very cheaply and at grass root levels.

Dara presents interesting and original research she carried out. She not only covers an impressive range of original documentary sources but also provides documentary evidence on the subject that is drawn from different parts of the world. Dara's study makes a very strong contribution to the general understanding of the challenges that health care gives of the mentally ill face. Her study has the potential to be replicated in other districts. It would be interesting to learn from these districts and compare between them what the good practices are in the handling of the mentally ill. She has also made very good use of elite interviews which take her analysis beyond conclusions, which might be reached through documentary sources alone. Her presentation was very interesting and augmented her findings with statistics and analysis of other related work on health to relay her information.