

# Drugs, spirits and human rights

Mental health in post-conflict  
Northern Uganda in the  
context of modernization and traditional beliefs



JOHN PAUL II JUSTICE AND PEACE CENTRE



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Kamila Krygier

John Paul II Justice and Peace Centre

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## Acronyms

CSO	-	Civil Society Organisation
DHO	-	District Health Official
DSM	-	Diagnostic and Statistical Manual of Mental Disorders
FGD	-	Focus Group Discussion
HC	-	Health Centre
IDP	-	Internally Displaced People
LC I	-	Chairman Local Council I
LRA	-	Lord's Resistance Army
NGO	-	Non Government Organisation
PTSD	-	Post Traumatic Stress Disorder
RRH	-	Regional Referral Hospital
UN	-	United Nations
VHT	-	Village Health Team
WHO	-	World Health Organisation

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## Chapter 1: Introduction and Background

### 1.1 Introduction

***"Insanity - a perfectly rational adjustment to an insane world."***

(R. D. Laing, British psychiatrist, 1927-1989)

This highly controversial statement, which shocked people in the 70's would be no less contentious today. Mental health or mental ill health, the human mind is still little understood as we try to battle the causes and the devastating consequences of mental disorders in the 21<sup>st</sup> century. However, the above quote comes back to mind in the context of war, conflicts and mass violence that are usually linked to a much higher prevalence of mental illness (Mollica, Cardozo, Osofsky, Raphael, Ager, & Salama, 2004; IASC, 2007). In other words in an insane environment the likelihood of developing mental health problems is much higher than in a peaceful and secure setting. Considering the fact that even outside the context of war and mass violence 14% of the global disease burden have been attributed to neuropsychiatric disorders, making them the most burdensome of all diseases (Prince, et al., 2007), or the estimate that by 2030 depression will become the most common illness, overtaking by far HIV or cancer (Network for Mental Health, 2012), then the scope of the problem becomes apparent.

At the same time mental health is a largely neglected topic within the development sector. The majority of health projects focus on HIV/AIDS or on tropical diseases such as Malaria. Mental disorders are complex, and long-term, and addressing them does not provide the straightforward outcomes and success indicators many donors are looking for to measure the impact of their projects. Meanwhile, many governments of developing and low-income countries do not perceive mental health as a priority. Over 50% of the low-income countries do not have a policy specifically dedicated to mental health (WHO, 2011). This in turn frequently contributes to various human rights violations and abuses towards people suffering from mental ill-health, as the protection of their rights is not ascertained by a particular legislature (Dhanda & Narayan, 2007). In contexts of war or post-conflict settings, human rights violations of people living with mental illness further multiply and extend their excessive suffering, of having lived through violence and displacement.

Uganda is a low-income, post-conflict country that exemplifies the above mentioned problems. There is a mental health policy but it is outdated (last revised in 1964) and offensive to people with mental health problems (Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010). The new mental health policy, which represents a positive development towards improving the situation of persons with mental ill-health, has remained in draft for a considerable number of years. The expenditure on mental health in Uganda is less than 1% of the health expenditure and 55% of this total amount is dedicated to the National Mental Health Hospital in the capital city of Kampala (Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010). Meanwhile, studies conducted in the post-conflict region of northern Uganda report a large number of people suffering from PTSD and

depression with estimates ranging from over 40% up to above 70% (Pham, Vinck, & Stover, 2009; Roberts, Ocaka, Browne, Oyok, & Sondorp, 2008; Vinck, Pham, Stover, & Weinstein, 2007). There is widespread stigmatization of people with mental disorders leading to aggressive behaviour towards them, exploitation, abuse and discrimination in various areas of life even after they have recovered (Cooper, Ssebunnya, Kigozi, Lund, Flisher, & Consortium, 2010; Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009). It has been found in Uganda that the stigma of mental illness is frequently associated with belief systems of evil spirit possession or punishments for bad deeds (Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009).

Although it certainly seems that there are some positive developments in improving the situation of people with mental health problems and mental health service users in Uganda it is not clear to what extent the situation and daily life of this group improved in reality, and especially in the post-conflict area of northern Uganda.

## 1.2 Background

### 1.2.1 Context and problem statement

The civil war in Northern Uganda has been one of the most brutal and longest conflicts in Africa, characterized by numerous killings and mutilations of civilian population and abductions of children (Pham, Vinck, & Stover, 2009). Over 90% of the population in Northern Uganda, specifically in Acholiland, has been forcibly relocated to IDP camps, under the pretence of protection which, however, resulted in making it easier for the LRA (Lord's Resistance Army) rebels to abduct large numbers of children from the camps (HUR�PEC, 2003).

The people in IDP camps experienced a high number of traumatic events, such as witnessing killings and abduction or being subject to abductions themselves which, as mentioned above, has been associated with the high prevalence of PTSD and depression among this population (Pham, Vinck, & Stover, 2009). Moreover, the lack of basic goods and services, common in the IDP camps, has been shown to have a significant association with PTSD and depression (Roberts, Ocaka, Browne, Oyok, & Sondorp, 2008).

The cessation of hostilities in 2006 led to the end of the war within Uganda, though the final peace agreement between the LRA and the Government of Uganda was never signed and the LRA continues the fighting and abductions in neighbouring countries. During and after the conflict there has been a number of reception centres for returning abductees. This was, however, by far not enough to attend to the needs of the population and by now, the majority of the reception centres have closed (IRIN News, 2013). Moreover, attending a reception centre does not seem to have had an impact on depression or PTSD symptoms (Pham, Vinck, & Stover, 2009).

Now, as people are returning or recently returned from the IDP camps they again face insecurity with regard to poverty and the widespread land conflicts leaving the most vulnerable groups dispossessed and unsafe. The ones suffering from mental illness are confronted with additional discrimination and stigmatization. Meanwhile the government mental health facilities are inadequate and insufficient, especially in more remote rural areas, while the number of NGOs dealing with this problem is extremely small compared to the high prevalence of mental disorders (UN Peacebuilding Programme, 2011).

Local beliefs in rural Africa regarding mental illness are mostly associated with spirit possession or witchcraft. Such beliefs might contribute to discrimination either due to fear, a conviction that the people themselves are to be blamed for their mental illness or in form of drastic treatment attempts (Read, Adiibokah, & Nyame, 2009; BBC News, 2013). Also in Northern Uganda many of those traditional beliefs regarding mental health and illness are common (UN Peacebuilding Programme, 2011).

As stated by the WHO – “there is no health without mental health” (theme of the 2010 Mental Health Day) and there is also no development without health. Unfortunately, many of those silently suffering people with mental health problems are not in the position to speak for themselves and for others this is an uncomfortable topic and they are inclined to look the other way.

The population in Northern Uganda suffered brutality and gross human rights violations during the civil war. Many wounded or mutilated people bear the lifelong scars from those injuries. But there are also scars other than the physical ones. Yet, as they are less visible, they tend to be forgotten in the aftermath of a conflict, focusing on reconstruction and recovery.

### 1.2.2 Local versus international understanding of mental health

As a result of globalization all sectors of life are subject to a rapid change. In developing countries mostly western approaches are adopted indiscriminately in various public sectors such as health, education and others. In mental health the diagnostic systems used in African countries are no different from the ones used in Europe or the US, though it has been recognized a long time ago that cultural perceptions and even symptoms of mental disorders differ<sup>1</sup>. Many of the traditional beliefs, especially in rural areas, represent a very different understanding from the western concepts.

While very common, those local systems of understanding and categorizing mental illness have not been systematically studied. There is a number of studies focusing on the local perceptions in the Acholi sub-region but none, to our knowledge, dealing with the same subject in the Lango area. The UN Peacebuilding Program study pointed out five major mental health problems as described by the communities in the Acholi region: madness (apwoya), spirit (cen) possession, neurological disorders (mainly referred to as epilepsy), over-thinking (two tam, par, kumu and ma lwor) and over-drinking. Over-thinking seems to resemble depression and dysthymia syndromes or mixed depression and anxiety symptoms, while spirit possession has some similarities with Post-Traumatic Stress Disorder. Madness has been differentiated in that study into two categories, one resembling severe mental disorders such as psychosis. The other, having increased as result of the war experience and resulting from unresolved spirit possession, over-thinking or over-drinking. There have also been descriptions of a conduct problem, gin lugero or kwo maraca, that has some similarity with the DSM IV-TR criteria of Oppositional Defiant Disorder or Conduct Disorder (UN Peacebuilding Programme, 2011; Betancourt, Liesbeth, Onyango, & Bolton, 2009).

Taking into account those differences and diagnostic challenges as well as limited research on this topic, especially in the Lango area, this study focuses more on the situation of the people living with mental illness, their treatment by families and communities as well as the

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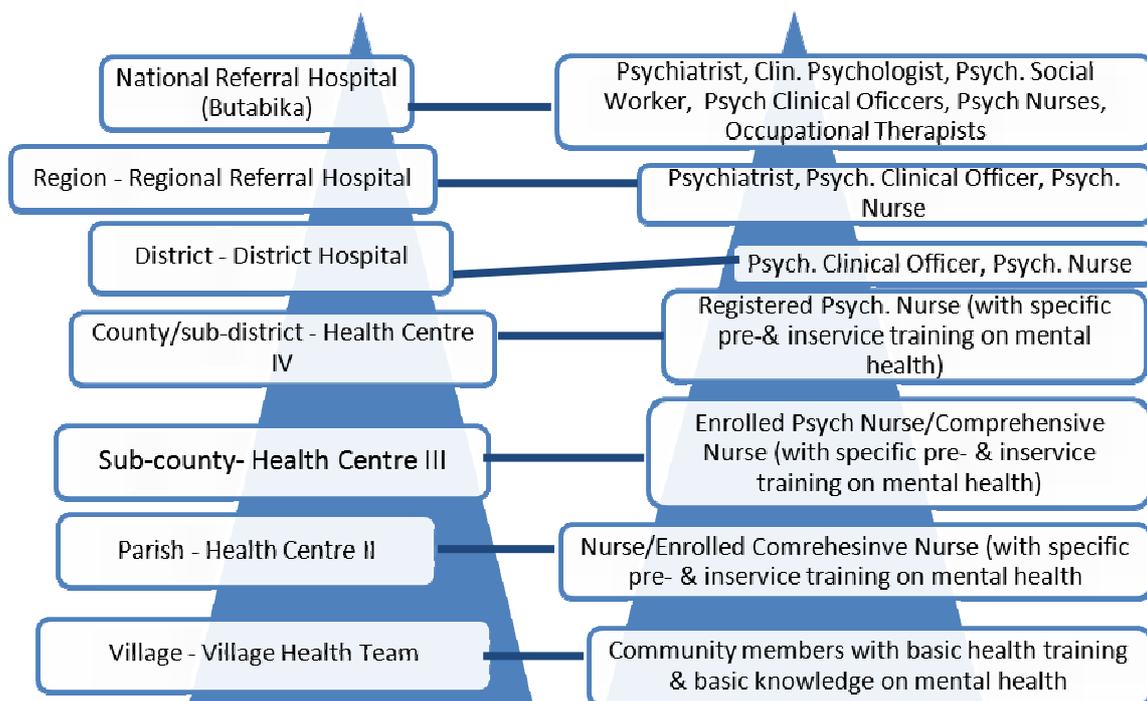
<sup>1</sup> Already in the DSM III-R (Diagnostic and Statistical Manual of Mental Disorders, the version from 1987) the different meaning of some symptoms depending on the cultural background has been recognized.

availability of services, mostly leaving aside the question of the type of mental disorders. However, since local beliefs might have some impact on the way people are treated, questions regarding beliefs and perceptions of mental illness have also been included.

### 1.2.3 Brief overview of the health system structure in Uganda

In Uganda there is a hierarchical health system structure starting from village up to the national level. The level of knowledge, professionalism and the variety of available services increase at each stage.

**Chart 1: Hierarchical health system in Uganda**



Required type of staff at each level of the health facilities

This chart shows the types of health services as well as the kinds of health workers and their level of knowledge on mental health required at each health facility in Uganda (Ndyabangi, Basangwa, Lutakome, & Mubiru, 2004). A study carried out in the Acholi sub-region in 2011 already found that this is more an ideal than a real structure with only half of the general health workers having received pre-service training on mental health care and none of the Village Health Team members (VHTs) reporting any kind of training on that topic (UN Peacebuilding Programme, 2011).

### 1.2.4 Mental health and international human rights

While the “right to health”, as it is generally called, is enshrined in the International Convention on Economic, Social and Cultural Rights (ICESCR), one of the earliest human rights treaties (UN, 1966), the recognition of a specific affirmative right to mental health developed much slower. Some scholars argue that mental and physical health cannot be

treated separately (Gable & Gostin, 2009) and indeed, the right to mental health is clearly mentioned in Art. 12 of the ICESCR:

*“The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”*

However, in many cases that does not seem to have helped improve the human rights situation of people living with mental health problems. Over time some additional instruments developed taking into account the special situation of those people. The most prominent document is the “Principles for the protection of persons with mental illness and the improvement of mental health care”, commonly called MI Principles, developed and finally adopted by the General Assembly in 1991. The principles stipulate the general rights and freedoms of people with mental disabilities, stressing that they should enjoy these rights in the same way all other people do and should be protected from any kind of discrimination. For example the first principle dealing with the general rights and freedoms states among others:

*All persons with a mental illness, or who are being treated as such persons, have the right to protection from economic, sexual and other forms of exploitation, physical or other abuse and degrading treatment.*

and

*There shall be no discrimination on the grounds of mental illness. “Discrimination” means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights.*

(UNHCHR, 1991)

The later part of this document focuses mostly on the treatment of patients in mental health facilities, emphasizing their right to be treated with dignity and respect, especially as voluntary in-patients or in involuntary detention. The MI principles highlight the patients’ right to information with regard to their health status, as well as the need for their informed consent to the treatment, their right to privacy, to education facilities and to the least restrictive treatment possible – just to name a few. Later, in 1996, the application and practical implementation of the MI Principles has been further clarified in the “Guidelines for the Promotion of Human Rights of Persons with Mental Disorders” (WHO, 1996).

In 2006 the Convention on Rights of People with Disabilities came into being which included people with mental disabilities. Yet people with mental health problems have always been and continue to be, marginalized within the disabilities rights movement due to common negative beliefs about their condition (Gable & Gostin, 2009). The widespread misconception that people with mental health disabilities are generally aggressive, less

competent and potentially dangerous present this group with very different challenges with regard to stigma and discrimination compared with people with physical disabilities

Therefore, while there has been some progress achieved and there are countries and regions where the living conditions and treatment of people with mental disabilities has considerably improved, their general human rights situation remains poor. The World Health Organization has recently described it as a “global human rights emergency” (WHO, 2013). This situation is even more serious in many developing countries, which are struggling with limited material, financial and human resources and consequently focus rather on lethal or infectious diseases. Unfortunately, most donors active within the health sector also seem to concentrate on HIV/AIDS or Malaria, where successes might be more visible and tangible than in an area like mental health.

Thus, while recognizing the considerable developments in the mental health and human rights sector, there is still a long way to go before people with mental disabilities enjoy all their human rights.

#### 1.2.5 Objectives

The overall objective of this study was to examine the living situation of people with mental health problems in Northern Uganda, but also of other stakeholders such as their families or mental health professionals.

Our interest was to assess the scope of the problem, the perceptions and beliefs regarding mental illness in the communities, the treatment, the attitudes towards people living with mental illness and the availability and accessibility of treatment options. We also endeavoured to assess the perception of mental health professionals and to develop recommendations based on the suggestion of the interviewees. Specifically the objectives focused on:

- Assessing the human rights situation of people with mental health problems within mental health institutions, and the mental health service delivery in Northern Uganda (Acholi and Lango sub-regions)
- Assessing the perception and working situation of psychiatric staff
- Assessing the treatment of people with mental ill-health within the communities, and how they are perceived by the community members
- Developing approaches and recommendations on how to improve the human rights situation and the well-being of this particularly marginalized and vulnerable group

## Chapter 2: Methodology

This research is mainly qualitative, exploring the assessment, estimates and understandings of community members, people affected by mental ill-health and health professionals. The methodologies used include literature review, key informant individual interviews, focus group discussions, written questionnaires and some observation done while the data collection and interviews were conducted.

The data collection took place in April 2013 in the districts of Gulu, Amuru, Lira and Oyam and mainly in the sub-counties of Awach, Koro, Amuru, Pabbo, Lira, Amach, Ogur, Aber, Loro and Oyam Town Council (apart from situations where the nearest health facility was located in another sub-county).

The following groups of respondents were interviewed in the Northern Region: LC1's, Village Health Team members, district health officials, traditional healers, people with mental disabilities, care takers and relatives of people with mental ill-health, health workers from Health Centres II, III, IV and 2 private hospitals, mental health professionals from Regional Referral Hospitals and NGO staff. There were 8 focus groups discussions conducted, 2 in each district. Finally, the Principle Medical Officer in charge of Mental Health and Control of Substance Abuse of the Ministry of Health and current or former mental health workers of the National Referral Hospital Butabika have been interviewed or answered written questionnaires. The total number of respondents was 329, with 313 from the Northern Region and 16 from Kampala. The sample size is representative with a confidence level of 95% and a confidence interval of 5.5, which applies to questions answered by all respondents. Some questions were specifically directed only at some key informants having detailed knowledge on the issue in question.

The sub-counties were randomly selected as well as the participants for the focus group discussions, paying attention, however, to gender balance and excluding persons directly affected by mental illness. The reason was that those people have been interviewed separately as key informants, and the participation of people living with mental illness or their close relatives might have made the discussion less open and potentially biased.

The research assistants, who carried out the interviews, have been selected from the Acholi and Lango regions respectively, ensuring that they were fluent in the local languages and had some experience in research, data collection in the area of social sciences. All research assistants have been trained and the tools pre-tested on the ground making the necessary adjustments.

One limitation of the study was the number of locations. It would have been good to include even more rural or remote areas. It would also have been beneficial to interview even more stakeholders from other sectors, such as security and education. Due to the complex nature of the topic it was also not possible to determine the nature and type of the mental

disorders. It would have been interesting to see how many of the people suffered from PTSD and depression as opposed to other mental health problems. But it was firstly, beyond the capacities of this study and secondly, most of the people affected do not know their own diagnosis or have a very different concept of their condition, which is not compatible with western approaches. Since the decision was to focus on the human rights situation of the people with mental health problems the diagnosis, for this research, was secondary.

Finally, although the predominant methodology was interviews, we were not able to conduct interviews in Butabika. Instead we have been instructed to submit questionnaires that have been answered in writing by the respondents. This change of methodology might reflect on some findings as we will elaborate later in the sub-chapter dealing with the National Referral Hospital.

## Chapter 3: The Findings

### 3.1 Is mental health really a concern?

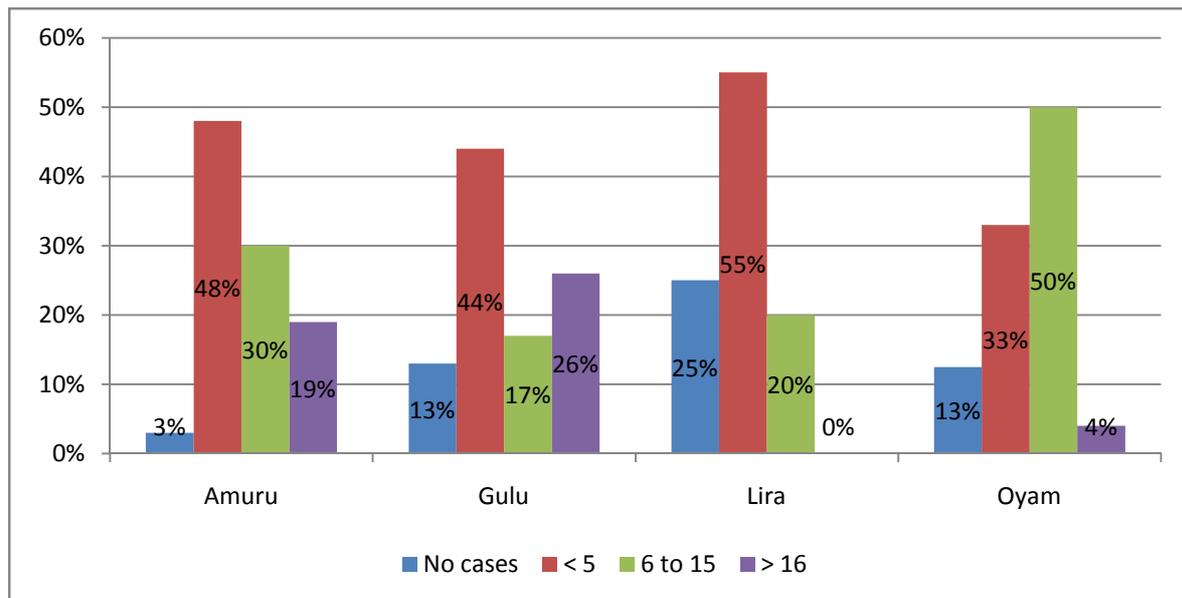
Some of the studies cited in the first chapter indicate a high or even extreme prevalence of mental illness in Northern Uganda, specifically in the Acholi sub-region where most of the research has been carried out (Pham, Vinck, & Stover, 2009; Roberts, Ocaka, Browne, Oyok, & Sondorp, 2008; Vinck, Pham, Stover, & Weinstein, 2007). However, some time has passed since the data collection for those studies has been done and there are indications that especially conditions like PTSD might considerably reduce over time (Silove, 2004). Then, what is the perception of the people themselves? Do they perceive mental illness as a serious concern and an issue that needs to be addressed? The responses of Village Health Team members and LC I's as well as the NGOs working on the ground, provide an insight into the perception of the communities in the Acholi and Lango sub-regions on this topic. While most of the health workers in the Health Centres visited have only been employed there for short periods of time making it more difficult for them to provide estimates about the extent of mental disorder prevalence, the LC I's, the VHTs and most of the NGO staff have been working in that capacity and within the communities for many years (majority for over 5 years) giving them an in-depth insight into the situation of the people in the villages.

Out of the 47 LC I's interviewed the majority (43) stated that they perceive mental illness as a serious concern in their home area. Only 4 reported not having any cases of mental illness in their village.

Nine of the 52 VHT respondents reported not having any cases of mental illness in their villages – 5 of them from Lira, 2 from Oyam and 1 from Gulu and Amuru each. Almost half (22) of the VHT respondents reported up to 5 cases. 7 interviewees, all from Gulu and Amuru districts, gave an estimate of over 16 cases of mental illness in their villages.

The chart below displays the combined estimates of LC I's and VHT members of mental illness cases in their respective villages.

**Chart 2: Estimated number of mental illness cases**



Mental health has been perceived by almost all informants as a serious concern. In Gulu and Amuru there are more villages with extremely high numbers of cases as compared to Oyam and especially Lira. None of the respondents in Lira estimated the number of cases being 16 or more in their village and the majority of those who reported cases, assessed the number to be 5 or less. In Gulu, Awach sub-county appears to have an extremely high number of mental illness cases, followed by Amuru sub-county in Amuru district. This corresponds with the reports of the participants of the focus group from Awach, who stated that their sub-county is leading in mental illness cases.

The participants of all 8 focus group discussions from all 4 districts stated that they perceive mental health as being a serious concern. Some described the number as alarmingly high or as increasing.

The respondents from HC's III and IV reported receiving cases of people with mental disorders regularly, mostly on a daily basis. The 16 informants from HC's II also all deal with mental health cases (except one respondent from Aber) regularly, though slightly less frequently than the HC's at a higher level. Some respondents reported daily cases but others stated receiving cases rather on a weekly basis. The reason might be that patients try, if possible, to reach HC's III and VI, who usually employ staff more qualified on mental health.

All of the 8 interviewed traditional healers also said they receive people with various mental disorders. However, the numbers of cases varied greatly. Some reported only 10 cases or less yearly and others 30 and above.

All NGO staff interviewed were of the opinion that mental health is a serious issue and also all mentioned PTSD as the most common diagnosis, followed by depression. The high occurrence of PTSD was mostly associated with the war. The answers to the question whether numbers of cases are increasing or decreasing were, however, inconclusive. Some

think that numbers appear to be increasing due to raised awareness and more available treatment opportunities. Others were of the opinion that the numbers of cases are really going up and attributed the increase to limited service provision and to people not going for treatment. The ones who reported reduced numbers believe it might be due to the war being over, more people seeking help and more services being in place.

Finally, the respondents living with mental illness agreed that mental illness is a serious concern.

Asked about the reason why they perceive mental illness as a concern many of the community members mentioned the constraints for the families and communities. Due to the high numbers of mentally ill people in some villages the interviewees perceive the challenge as not merely individual but concerning whole communities. They mentioned examples of people displaying difficult behaviour, being aggressive, destroying property, neglecting themselves, undressing etc.

Although the question of exact numbers as well as the question if cases are increasing or decreasing could not be established conclusively, it seems clear that mental illness is perceived by the majority of people in the Acholi and Lango regions as a very serious concern. This corresponds with findings of the above mentioned studies, which found a high occurrence of mental illness particularly in the Acholi region, where the majority of the studies took place. It appears, however, that even in the Lango region mental health is of high concern, though the numbers of cases are estimated as slightly lower. There also seem to be some differences within the districts, with some sub-counties having much higher mental illness prevalence than others. Since all those numbers are estimates this information would need to be verified and the reasons for those differences established. Apart from the suffering of the affected people themselves the widespread occurrence of mental illness places considerable constraints on families and whole communities, which appears to be quite overwhelming for many of them.

### [3.2 The situation of people living with mental illness in their communities and common beliefs about mental illness](#)

Though there is still a limited number of studies and research on the topic of mental health in Uganda, in recent years there have been some publications dealing with service delivery for people with mental disorders. Their daily life and experiences in their homes and communities have only been mentioned marginally, emphasizing stigma and discrimination (Cooper, Ssebunnya, Kigozi, Lund, Flisher, & Consortium, 2010) or giving a brief overview of the challenges people with mental health problems are facing (Ssanyu, 2007). Widespread stigmatization of people with mental ill-health and its consequences have been described in the Western world (Corrigan & Watson, 2002) as well as in some African countries (Read, Adiibokah, & Nyame, 2009). However, there is little detailed information, from Northern Uganda, on the daily life situation of people with mental health problems regarding family

care, their level of integration into local communities as well as general beliefs regarding mental illness and its causes.

### 3.2.1 Family care and community attitude

The predominant picture appears to be that the attitudes to, and treatment of people with mental illness vary. There are a number of families who take care of their relatives when they develop a mental disorder. Not surprisingly the majority of the interviewed care takers and relatives of the mentally ill reported rather positive examples of family care. Most other informants from within the communities report both - positive and negative examples. The interviewed district health officials as well as NGO staff are more critical listing more negative than positive cases. It seems to depend on the family, their values, their level of knowledge on mental illness but also the extent to which their ill relative presents a burden to them. The participants of one focus group discussion stated that some families try to provide at least minimal care, like food or clothing so that their relative will not die of neglect since they fear a curse on the family. Many informants specifically stated that mothers usually try to provide for their children while men frequently do not care.

Although there has been a number of cases reported where families lock or chain their relatives it seems to be much more common that people suffering from mental illness are just abandoned to roam on the streets trying to survive on their own. According to a number of respondents many families try to help their relative by taking them either to health facilities, to witchdoctors or to churches for prayers or sometimes trying all those options. When there is no improvement and the relative becomes more and more a burden or is perceived as disturbing, the families give up on him or her and abandon them. According to an LC I from Gulu district, older people especially are left on their own as families do not have much hope for their improvement. In some cases, when the mentally ill relatives are still young, they are at least provided with basic necessities but still separated from the rest of the family. In one of the villages visited by the researchers a teenage girl has been fed by the wife of her uncle after the parents stopped taking care of her. However, she was staying in a small hut by herself in quite some distance from the home of her uncle, since she was 13 years old. She was not provided with any furniture or other items and was staying in the empty hut sleeping on the floor.

Even when families try to provide for them, people with mental health problems are often perceived as useless and when they get sick with Malaria or other physical diseases they are frequently not cared for in the same way as other family members. Many respondents stated that a mentally ill person in the family is perceived as particularly burdensome if there are small children or babies in the family as the parents fear for their baby's wellbeing.

Verbal abuse is rather common and there have also been a number of respondents reporting extreme mistreatment and beatings. Several informants also stated that people with mental health problems are exploited by their relatives and forced to work very hard leading to breakdown or exhaustion.

Although a number of cases has been reported when people living with mental illness are accepted and well integrated into the community in most cases they are feared or avoided and often also attacked or beaten. The behaviour of the community members has been largely attributed to the behaviour of the people with mental ill-health. The ones, who are perceived as aggressive or dangerous are frequently beaten and abused, the others are left alone and mostly ignored. One respondent from Gulu Regional Referral Hospital reported that a former patient of the Mental Health Unit has been killed by the community after discharge from the hospital.

Most of the NGO respondents and hospital staff working in mental health units highlighted mistreatment, stigma and discrimination by the communities. The fear of stigma prevents some of the people with mental health problems from accessing treatment, as their families do not want to get exposed, NGO staff and hospital workers reported.

Several respondents described people with mental ill-health as a nuisance for the communities as they “do not bathe” and are “dirty”, “walk aimlessly and speak incoherently”, “undress” etc. Many pointed out, that adult community members, who understand that the people are suffering from an illness, are friendly. Children and youth, however, are frequently aggressive and abusive. Children often abuse people with mental health problems verbally or throw stones at them. Especially disturbing were the repeated reports of sexual abuse of women living with mental illness. Instances of rape seem to be common and in one case the rapes of the mentally ill female community members became so rampant that most of them left the area and moved to another parish. There was not a single testimony of follow up or reporting of abuses and criminal offenses against people with mental ill-health. One respondent from an NGO narrated the following example:

*“There has been a child defiled in Bungatira. She was 13 years old and mentally ill. No one bothered about her. Even the police did not take action. We took up the case but it was too late. We took the case to the police and they said they will follow it up but they did not. People with mental illness are not taken seriously by the community or by the law. They cannot access legal help. These days even clan leaders are not bothered.”*

In one FGD the informants highlighted the exploitation of people with mental disorders and stated that sometimes they are made to work hard in the field and after they have finished the work they are chased away without any compensation. One person living with mental illness reported having been taken advantage of by having to pay more by taxi drivers or being cheated by shop owners.

Children, who developed a mental illness, are mostly excluded by other children not allowed to play with and often their education is discontinued. Adults are treated like “social outcasts” as one respondent from a Health Centre II explained; they are not allowed to drink or eat with others and are chased away from public places.

Half of the users of mental health services stated that even after they have improved they still do not feel they are treated the same way as other community members. One informant told us that she is still being treated like patient, which makes her feel uncomfortable and another reported that most of her family and friends think she will relapse again.

Dr. Sheila Ndyabangi, the Principle Medical Officer in charge of Mental Health and Control of Substance Abuse explained that there are representatives of people with disabilities, which includes people with mental disorders, in the Ugandan Parliament. However, people with mental ill-health never get elected into those kinds of representative positions because they are perceived to be incapable. Only people with physical disabilities are perceived as competent enough to perform political leadership roles. Dr. Ndyabangi gave this as an example of discrimination even within the group of people with disabilities.

As emphasized at the beginning of this paragraph, there are also positive examples. According to one NGO respondent an estimated 1/3 of persons with mental health problems are supported by community members. Interestingly, the majority of the interviewees with mental health problems reported positive experiences. Some informants described situations in which the community supported someone, who has been abandoned by the family, or in which community members got involved when families were mistreating or neglecting their ill relative, giving food, clothing or support in reaching a health facility. However, this does not seem to be as common as verbal and physical abuse, fear and isolation. Moreover, people with mental ill-health are completely at the mercy of their families and the communities, and are dependent on the people's understanding of their situation and their good will. There is no authority or institution to help, protect or support them if the families and communities refuse to do so, which unfortunately happens rather often. Finally, it has been shown in other studies that many people living with mental illness develop self-stigma, which results in negative beliefs about self, leading in some cases to a failure in pursuing various life opportunities (Corrigan & Watson, 2002). This group might, therefore, not perceive discrimination and prejudices for what they are and consequently not report discrimination, since they agree with those negative attitudes due to the self-stigma. This could be even more common in Northern Uganda, where it seems that many people developed PTSD and other mental disorders as a result of the conflict. Some witnessed, experienced, and also committed atrocities. The memories haunting them may possibly contribute to feelings of guilt, worthlessness and low self-esteem. As one of the district health officials stated:

*Those who were abducted, and then killed people feel they are not worthy of life in the community.*

### 3.2.2 Perception of mental illness

All community respondents have been asked what they perceive as the causes of mental illness. The questions were formulated as open ended and all informants could give several responses if they believed mental illness can have various causes. The table below summarizes the most common responses of 157 individual community members including VHT members, LC l's, people with mental health problems, their care takers and relatives as well as traditional healers.

**Table 1: Community perception on causes of mental illness**

Response	Frequency
It is the result of past experiences	54
It is inherited	52
It is due to witchcraft	32
It is like any other illness	27
It is a curse	25
It has a supernatural cause (unburied bones, spirits etc)	21

A few respondents also mentioned untreated Malaria or Meningitis and alcohol or drugs as causing mental illness<sup>2</sup>.

In the 8 focus group discussions the answers regarding causes of mental illness varied between supernatural causes (such as curse, witchcraft, spirits or seeing unburied bones) mentioned in all FGD's, "untreated Malaria", mentioned in 6 FGD's, "inheritance" causes mentioned in 5 FGD's and finally substance abuse and result of past experience in 4 and 3 FGD's respectively.

The conclusion of those divergent responses is that in general, people in rural communities have very little knowledge regarding mental health. Mostly, they have some ideas, beliefs or theories. The answers that are related to some kind of supernatural cause are still rather common. However, the notions that experiences during the war might result in mental disorders are also very widespread. 1/3 of respondents mentioned "past experiences" as a cause for mental illness by which the majority meant traumatizing events experienced during the two decades of the armed conflict. Many community members related the occurrence of mental illness to specific cases in which people had to witness atrocities committed on their relatives. Several respondents pointed out the cases of returnees, who have been abducted by the LRA and forced to kill and commit atrocities themselves. According to them very many of those returnees developed some form of mental illness. This is consistent with the findings of several studies carried out, which found high prevalence of especially PTSD but also depression in former abductees (Bayer, Klasen, & Hubertus, 2007; Pham, Vinck, & Stover, 2009).

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<sup>2</sup> The people who mentioned those causes were fewer, and therefore the table only shows the major responses

Also several of the cases attributed to supernatural causes can be linked to the armed conflict. A number of respondents mentioned seeing unburied bones as a cause for mental illness or evil spirits (cen), which follow people who committed or sometimes just witnessed killings and atrocities. Several of the relatives and people with mental ill-health themselves also perceived the cause as resulting from the war.

The problem with some of those beliefs is that they may lead to blaming the person with mental health problems, which reduces the compassion, empathy and subsequently the support of the community. The belief that mental disorders are contagious was also mentioned several times, although it appears to be even more common with regard to epilepsy. The contagion is sometimes perceived as physical similar to other diseases and sometimes as “contagion in a spiritual sense”, when the evil spirit haunting the affected person can move to others in close proximity to the mentally ill person.

It is not difficult to imagine how those perceptions can affect behaviour towards people with mental ill-health. Especially children, being generally more susceptible to adopting the beliefs of the adults around them, might get scared of people possessed by evil spirits, fearing their condition might be contagious. Believing this is an evil person they might throw stones and chase such people away. The close association or even causal relationship between some of the local beliefs and the stigmatization of mentally ill people has been mentioned in other studies highlighting the resulting exclusion, alienation and poverty, which in turn contributes to the stigma (Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009).

The following people within the health sector have been asked about their perception of mental illness: staff of the Health Centres II, III and IV as well as district health officials. The NGO staff have also been included in this table, as they are working professionally in that area and most have had some kind of professional training on mental health.

**Table 2: Health professionals and NGO staff perception on the causes of mental illness**

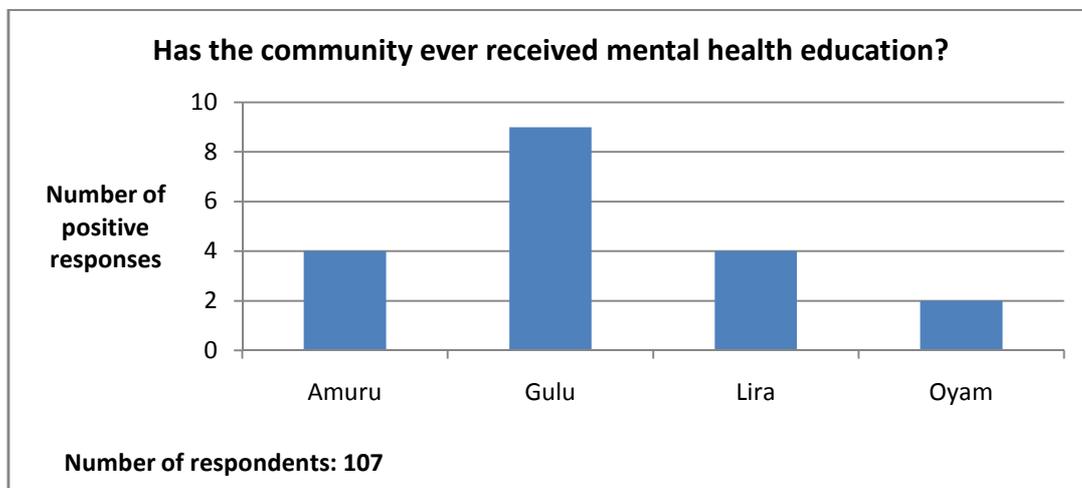
<b>Response</b>	<b>Frequency</b>
It is the result of past experiences	26
It is inherited	19
It is like any other illness	17
It is due to witchcraft	7
It is a curse	2
It has a supernatural cause (unburied bones, spirits etc)	2

Out of the 44 respondents more than half mentioned past experiences as a cause for mental illness and several specifically highlighted the war and experiences of violence, killings and abductions. Interestingly, even within the health sector there have been some respondents, who mentioned supernatural causes for mental illness.

Several respondents stated the lack of understanding and knowledge on mental health as reasons for mistreatment and discrimination. Moreover, some pointed out that after awareness raising on mental health, community members better understood the nature of mental disorders and then the attitudes and behaviour towards people with mental health problems changed for the better.

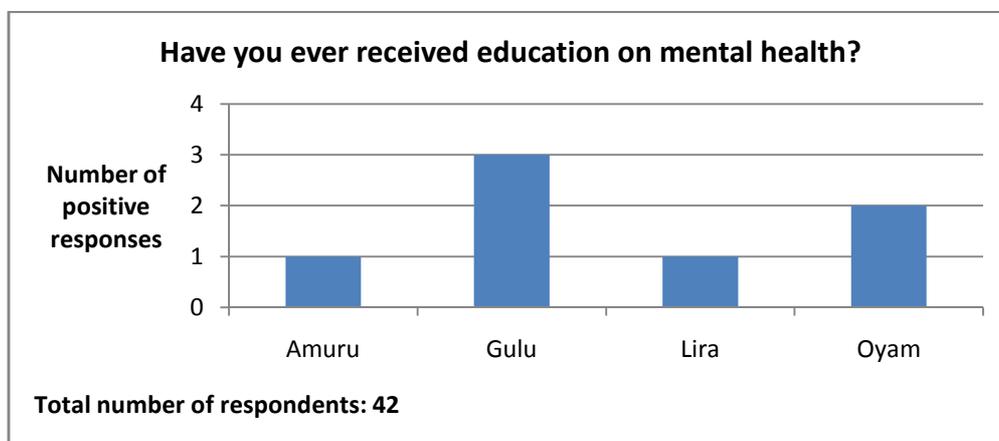
Consequently, community members have been asked about mental health education in their area. Where education or sensitization sessions were reported to have taken place, they were asked when and by whom. Out 107 respondents including LC I's, VHT members as well as people with mental ill-health, only 19 mentioned any kind of mental health education carried out in their community that they are aware of.

**Chart 3: Mental health education in the communities**



Additionally, the care takers and relatives of mentally ill people have been asked if they personally received any kind of education on mental health. Out of 42 respondents only 7 responded positively.

**Chart 4: Education on mental health for relatives and care takers of people with mental ill-health**



According to the respondents the majority of those few trainings or awareness raising activities have been carried out by NGOs. TPO (Transcultural Psychosocial Organisation) has been mentioned by several respondents, 2 respondents mentioned a World Vision training and 1 respondent from a VHT reported a training by CARE, carried out in 2012. Only a very small number has been done by health workers from a hospital or a health centre.

It seems that there have been almost no awareness raising activities directed at the whole community. Some care takers or relatives participated in a training specifically carried out for them or have been given some general information about the appropriate care for their relative upon discharge from the hospital. There has also been some training carried out targeting the VHT's. This already seems to show some improvement, since in the UN study carried out 2010/2011 none of the VHT members reported having received any kind of training on mental health (UN Peacebuilding Programme, 2011). It also corresponds with our findings, as out of the few who have been trained most stated the trainings took place 2012. However, recognizing those positive developments this is far from enough. Still the majority of the VHT members have no mental health background at all and they never received even a basic training on that topic. In communal settings it is, moreover, crucial to involve all community members in sensitization activities, instead of only focusing on some specific target groups.

### 3.3 Service delivery – formal and informal

Service delivery in the mental health sector in Uganda has been described in several studies as deficient. The challenges include lack of qualified staff (New Vision, 2012; Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010), abusive treatment of patients by hospital staff (Cooper, Ssebunnya, Kigozi, Lund, Flisher, & Consortium, 2010), lack of drugs (Baingana & Mangan, 2011) and general underfunding of the sector (Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010). Upcountry the problems are even more severe. In the Acholi sub-region where some surveys were carried out, the lack of qualified staff has been described as more pronounced, funds and drugs are wanting and the VHT members lack any basic knowledge on mental health (UN Peacebuilding Programme, 2011).

The following section examines the assessment of the quality and accessibility of services by community members, people with mental ill-health, their relatives and care takers as well as health workers in the Acholi and Lango regions.

#### 3.3.1 Quality of government mental health services

The assessment of the quality of services varied. This might be attributed to the individual opinion or belief of what “good quality services” actually mean. Generally the care takers and relatives as well as people with mental health problems described the services in rather positive terms and the behaviour of hospital staff as friendly.

Yet, when asked if they felt they have been treated with dignity and respect less than half of the former patients responded positively. Several respondents also reported being always

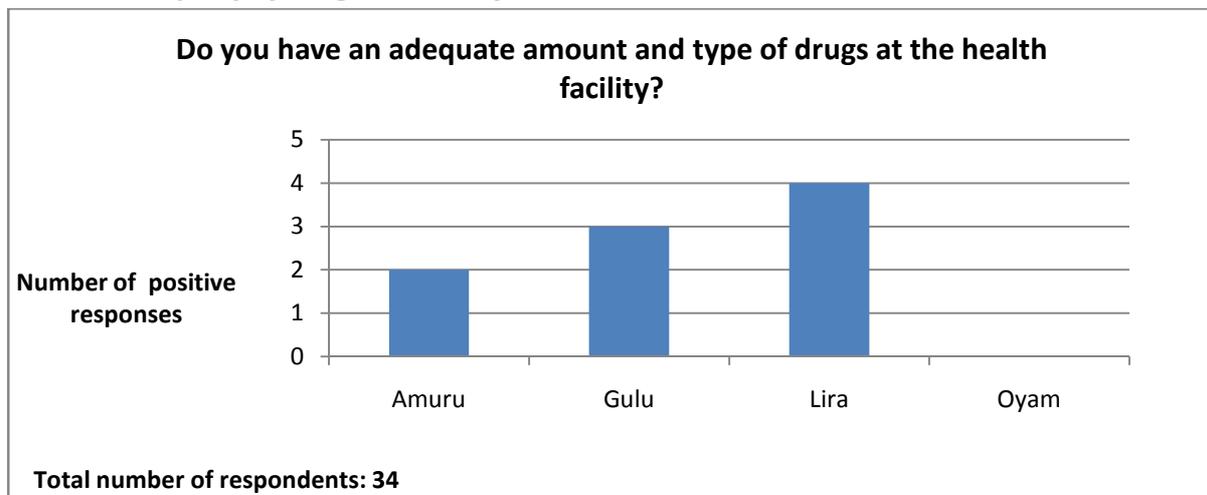
put on drug dosage, which they experienced as too high. Others mentioned poor bedding, hostility and shouting by the staff, frequent locking up of patients in a small room without proper care and physical abuse by other patients.

The NGO staff were more critical about the services, with the majority assessing them as being fair or very poor. However, more than half of them also described the hospital staff as rather friendly.

It seems that the professional care of the patients by the staff depends considerably on the patients' behaviour. The limited number of human resources presents a challenge making it difficult for the staff to really engage with patients. Gulu Regional Referral Hospital was reported to have 1 psychiatrist, 6 psychiatric clinical officers and 3 psychiatric nurses but no clinical psychologist. There was a fluctuating number of other staff, working there temporarily as part of their medical training. In Lira there was no psychiatrist or clinical psychologist, 3 psychiatric clinical officers and 4 psychiatric nurses.

All staff of health facilities have been asked if they perceive the amount and type of drugs as sufficient and adequate. Only 9 replied positively to this question.

**Chart 5: Adequacy of drugs in health facilities<sup>3</sup>**



Several respondents stated that although drugs are available, it is usually the older type with more side effects, and that they do not have all the drugs they need for the different disorders.

While the majority of health workers from HC III level upwards ascertained that they inform the relatives and/or patients about the diagnosis and the effects and side effects of the drugs, less than half of the people affected by mental illness reported knowing their diagnosis or having been given detailed information about the drugs apart from when and how often to take them. Though the hospital staff all affirmed giving detailed information about the drugs, a nurse in one of the referral hospitals told us the following story.

<sup>3</sup> The respondents in Oyam did not answer this question.

*A mentally ill girl has been discharged from the hospital upon insistence of her family and given drugs to take at home. One of the side effects of the drugs has been an extreme swelling of the tongue. The family tried to push the tongue back inside the mouth and after failing they decided to visit a witchdoctor, thinking it must be witchcraft. The witchdoctor also failed but in the course of trying to push the tongue back in it got infected and the girl died from the infection.*

Clearly, the family was not aware of this particular side effect. Though health workers know they should give all the information they frequently do not have the time to do so and just dispatch some very general instructions. As the example above shows, this can have tragic consequences.

Further, community members and health sector employees have been asked what they perceive as the main challenges in accessing formal treatment. The table below shows the answers of all 114 respondents.

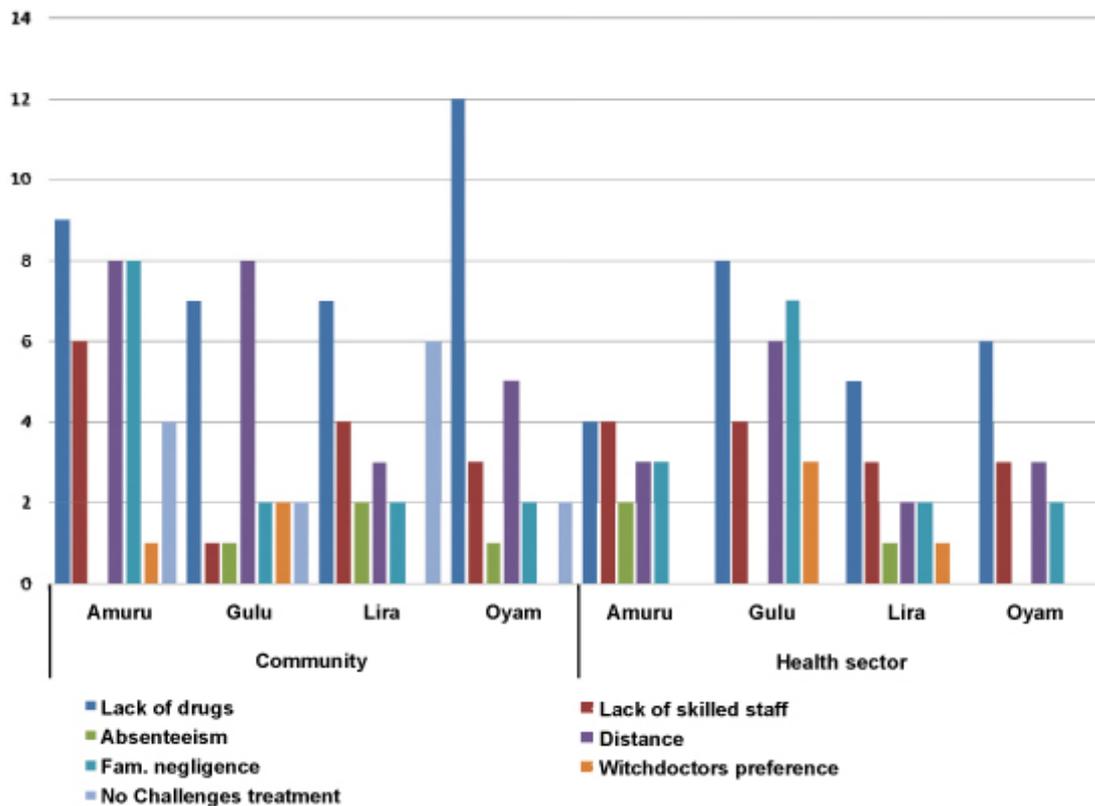
**Table 3: Challenges in accessing formal treatment**

<b>Response</b>	<b>Frequency</b>
Lack of drugs	58
Distance to health facility	38
Family negligence	28
Lack of skilled staff	28
No challenges	14
Preference of witchdoctors	7
Staff absenteeism	7

Only a very small number did not see any challenges for people with mental health problems to access formal treatment. Around half of all respondents mentioned lack of drugs, followed by distance to the health facility. Regarding the distance to health facilities several respondents stated the problem of transport. This is of course especially challenging in the case of mental disorders, where most drugs need to be taken continuously and very regularly.

The chart below shows the detailed answers categorized by type of respondents (Health worker or community member) and the district.

**Chart 6: Major challenges in accessing formal treatment**



The required type of staff (see chart 1) with professional knowledge on mental health seems to be mostly present at Health Centre IV level. At the 4 HC IV visited all informants reported that they have had some specific training on mental health. At the HC II and III level the required type of staff was present in three quarters and half of the cases respectively. Roughly half of the interviewed staff of HC II's and III's reported having some kind of pre- or on-service training on mental health. Of the VHT members interviewed almost half had not received any kind of training on mental health. The group that had received some training was mostly trained in counselling.

The majority of health workers refer people with mental health problems to the next higher level. Sometimes VHT members or HC II staff refer directly to a HC IV or even the Regional Referral Hospital, for a more specialized treatment of mental disorders. In Lira RRH some staff reported referrals to Gulu RRH since there is a psychiatrist present. In Gulu RRH two staff reported referring patients to NGOs for further help or counselling, especially after discharge from the hospital. They specifically mentioned World Vision, Peter C. Alderman Foundation, TPO and Caritas Counselling Centre. None of the health centre staff reported any referrals to NGOs. The NGOs working in that sector seem to mostly conduct trainings, and several operate within the mental health unit premises – such as TPO or Peter C. Alderman Foundation in Gulu.

Seeing that there has been a number of disturbing cases where people with mental ill-health have been severely mistreated by their family or community members, we have enquired if there is some kind of protocol or guidelines to inform the decision making of health workers in such cases in order to protect the patients. In the HC's most of the respondents admitted not having any written guidelines for those cases. Dr. Sheila Ndyabangi confirmed that a document of this type is not there and added that they are waiting for the new mental health policy to pass. Interestingly, the staff of the RRH's ascertained the existence of such guidelines although no one could produce a copy.

Finally, the referral hospitals have been asked about their discharge procedures and the conditions upon which in-patients are released to go back home. Though the majority cited improvement, several informants also mentioned cases when patients are perceived as "too difficult to manage", in cases when they destroy hospital property or threaten staff or there is no care taker. Lack of food or clothing, which are supposed to be provided by the care taker have also been mentioned as reasons for discharge.

In general it appears that although some services are there and it certainly seems that the accessibility and availability improved, it is still not enough. Especially in the lower level health facilities many health workers do not have sufficient training and knowledge. The drugs are a problem and the ones that are there are old type drugs with severe side effects, of which the relatives and patients are frequently not aware. Acquiring newer drugs does not seem to be a priority at all. They are expensive and people suffering from mental disorders have to take them continuously and in most cases for a very long time. Therefore, as has been pointed out by some health workers, buying those drugs is not considered "sustainable". Moreover, as transpired during the interview with Dr. Sheila Ndyabangi, the government does not perceive the newer drugs as necessary as they are, according to her, "sometimes worse than the older type drugs" with more negative effects.

It was unfortunately not possible to establish the specific budget for mental health. Most officials and health workers explained that there is a general budget for health, medication etc. and it is not possible to specify, what amount is used for psychiatric medication and mental health issues in particular. Although one study, co-authored by Dr. Sheila Ndyabangi mentioned that only 1% of the total health budget is spent on mental health (Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010), when asked directly she said that the budget for mental health could not be specified. Nevertheless, it seems that whatever the exact percentage the budget is clearly too small. According to health staff and officials upcountry, mental health is clearly less of a priority than other health sectors. Several district health officials stated that mental health education in the communities, or even needs assessments, cannot be carried out due to limited funds. In most cases no education takes place and in the few cases where it does, it is part of general health sensitization sessions and does not get the attention and time necessary. One of the interviewed mental health focal persons of one district stated that his position is mainly a title and there is no budget attached to it. He tried to carry out some of the duties that should be part of a

mental health focal person's work, but realizing that he would need to fund it from his private money he was not able to continue. Most of the district health officials lamented the lack of funds for mental health and several stated that the focus is mainly on lethal diseases while mental health is neglected.

It also emerged that without a strong family support, people with mental health problems have very little or no chances to improve and get any kind of help. This might be the reason why the key informants with mental ill-health have been mostly positive about their family and community support. The health situation of the others probably deteriorates till they just barely survive on the streets.

The in-patient facilities are very limited in the whole region of Northern Uganda. The patients not only have to be brought there by their relatives but need a constant care taker, who provides them with food and other necessities. This is usually a very high burden for rural families, which lose not only the sick family member but also another person to take care of the patient. Some families therefore are reluctant to bring their mentally ill relatives to the hospital or do not want them to stay for long periods of time. At home, however, they frequently face the challenges of negative attitudes of community members, especially if their mentally ill relative is perceived as dangerous or disturbing. This presents an even bigger problem for families of people with a very severe mental illness. A person with mental ill-health that is destructive or becomes aggressive has virtually no place to go. The communities mostly do not accept those people, the families cannot manage and even the mental health units, which are supposed to be there for the most severe cases of mental disorders reportedly discharge patients who are too difficult or aggressive. This is where the government services fail to provide for their most vulnerable members of society. Those people are left on the streets, frequently beaten or sexually abused, which probably contributes to their aggressiveness as they try to defend themselves.

The only place where in-patients can stay without a care taker is in the National Referral Hospital Butabika. However, reaching Kampala from upcountry towns is a big challenge and even more so from a remote village. Therefore, the distressed families end up abandoning their relatives perceived as "hopeless cases". As all stakeholders feel unable, overwhelmed and helpless, government public services fail to take up their role and people with severe mental disorders end up alone on the streets, eating from garbage bins, sometimes helped but frequently beaten and abused.

### 3.3.2 Non-government services

In the four surveyed districts there are three private hospitals: two in Gulu district, Gulu Independent Hospital and Lacor Hospital and one in Oyam, the Pope John XXIII Hospital in Aber. Due to time and distance the research team could only visit Gulu Independent Hospital and Lacor Hospital. For the two in Gulu, both have staff specialized in mental health. They do not have in-patient, but offer some out-patient services such as diagnosis (Lacor), drug administration, counselling and referral. The referrals are mainly to Gulu RRH.

Both hospitals reported that they have drugs for mental disorders,adequate in type and amount. Their assessment of the government services for mental health varied. While the staff of Lacor Hospital assessed the treatment of in-patients at government hospitals rather positively, the staff of Gulu Independent Hospital had a more negative opinion, mentioning patients being locked up, abused verbally and largely neglected.

Gulu Independent Hospital reported that they rarely receive mental health cases, while Lacor Hospital staff received cases on at least a weekly basis.

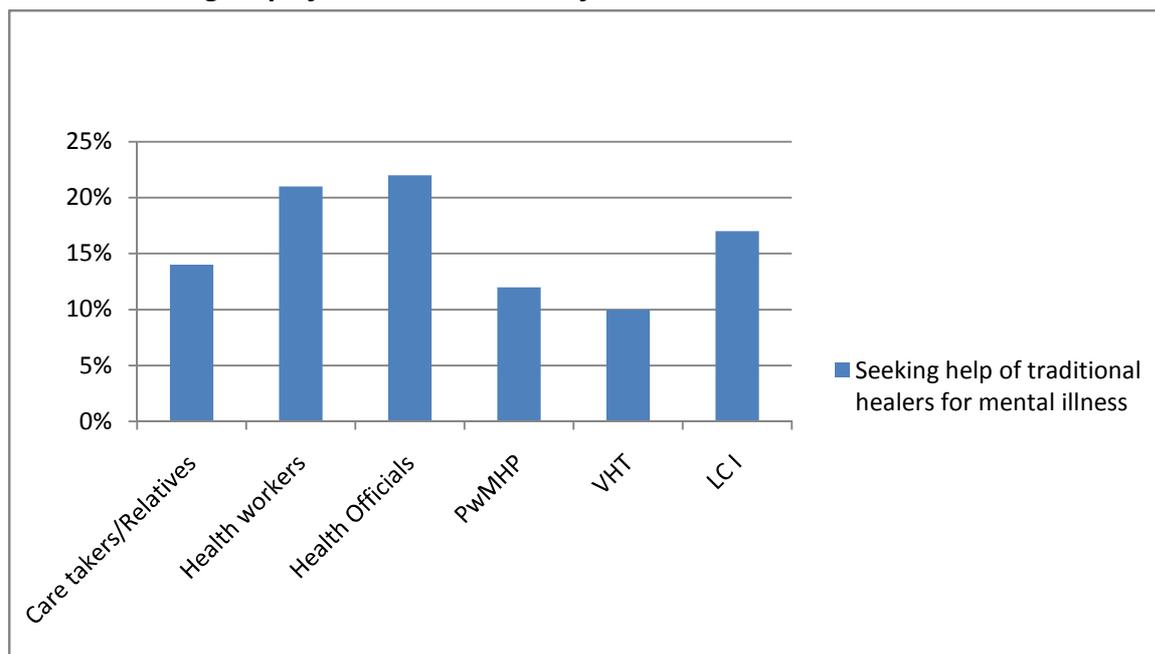
Almost all of the interviewed NGOs stated doing counselling services and around half carry out some form of training either for health workers or community sensitization. The other services mentioned included psycho-social support, referrals to RRHs, some specific forms of therapy (cognitive, play therapy or Narrative Exposure Therapy for trauma) or diagnosis and administering of drugs.

Although the non-government services offered cover a good range of possible mental health interventions, the majority of those NGOs are centred in the major towns of Lira and Gulu. There are very few NGOs working on mental health based in Amuru and only one could be found in Oyam. There are some NGOs based in Gulu or Lira which operate in Amuru or Oyam but those services are not comprehensive and scarcely sufficient for districts that are already disadvantaged with regard to government services. It is unfortunate that NGOs tend to focus on the same central places, which are already more privileged, instead of trying to support regions that are more remote and marginalized.

The informal services most frequented by the community are traditional healers and churches, where mentally ill people are brought to be helped through prayers. It was difficult to establish reliable numbers regarding people seeking the services of traditional healers in mental illness cases.

Below are the percentages of respondent groups, who mentioned traditional healers as a common way of seeking help by families with a mentally ill relative; the percentage of family members who reported having taken their relative to a traditional healer; and the percentage of people with mental health problems (PwMHP) who reported having been taken to a traditional healer by their family members.

**Chart 7: Seeking help of traditional healers for mental illness**



The next table shows the responses of traditional healers interviewed when asked how many cases of people with mental illness they have received last year. The total number of traditional healers interviewed was 8. Out of those interviewed all received people with mental illness but only 2 reported more than 30 cases.

**Table 4: Mental illness cases received by traditional healers in the last year**

Values	Amuru	Gulu	Lira	Oyam	Grand Total
Not Receiving M/H cases					
0-10 cases (last year)	1	1	2		4
11-20 cases				1	1
21 - 30 cases			1		1
30 and above	1	1			2

Bringing the mentally ill relatives to priests and churches for prayers has been mentioned occasionally by several respondents but less so than traditional healers.

It appears, that, while frequenting traditional healers or using prayers to cure mental illness is not unusual it might be less common than expected and possibly less common than it used to be, though we do not have any data or reports to compare current help seeking behaviour with earlier tendencies. Those findings also contradict statements of some health officials, who said that people tend to first visit traditional healers, secondly go for prayers and only as the last resort they would seek help at a public health facility.

An interesting finding is that while a considerable number of people attributed mental illness to some supernatural cause, the number of people who actually seek the help of a traditional healer/witchdoctor seems to be small. A possible answer might be that many of

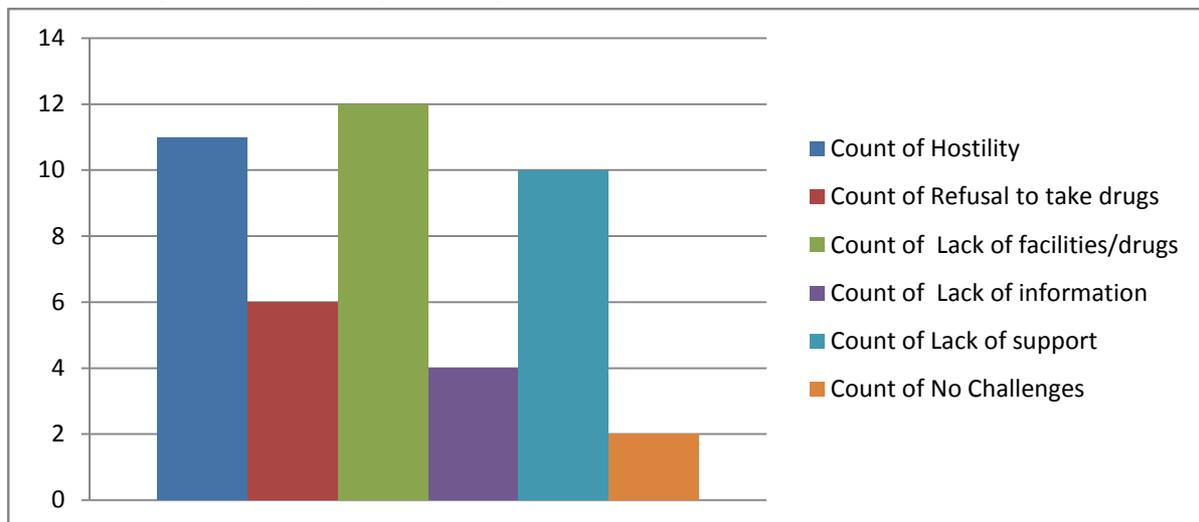
those who believe in supernatural causes do not take their relatives anywhere, or just abandon them. Since many seem to have very vague ideas about mental illness, it is also possible that they try different options for help and did not mention all in the interviews. It is an interesting question why people, who believe the cause of mental disorders is supernatural, still try health facilities for help.

### 3.4 Major challenges reported by care takers and relatives of people with mental illness

While this study is focusing on the situation of people with mental health problems and the challenges they commonly face, the burden this type of illness places on the families should not be ignored. Many families, who abandon their relative with mental health problems, do not do so for lack of empathy or love. Often they are overwhelmed and simply unable to provide for other family members, work, take care of the children while at same time watching over a relative who might be unpredictable, who might run away or is aggressive. They are mostly not informed or educated on how to deal with people who have mental disorders, many have little resources and moreover face hostility from the neighbouring communities. Sometimes the families are divided. Some family members try to take care of the mentally ill relative while others would rather get rid of him.

One of the questions given to relatives and care takers of people with mental ill-health has been what they perceive as major challenges particular to this kind of illness. The most common answers of the 42 respondents are summarized in the chart below. Only 2 respondents stated not having any particular challenges.

**Chart 8: Major challenges reported by care takers**



There were also other challenges mentioned such as the difficulty of reaching the health facilities due to lack of money and transport or of working in the field, while having someone at home who needs constant supervision.

Mostly, the families are left alone with their burden. The health facilities are far away, especially the ones with specialized staff such as HC IV or the Regional Referral Hospitals. The social cohesion, more common before the conflict and before the communities got

scattered in IDP camps, got disrupted. As there is no other support available, the care for a mentally ill relative sometimes just becomes too much.

### 3.5 Stigma and the situation of mental health professionals

The stigma against people with mental ill-health has been described in several studies. The consequences are fear, avoidance and denial of job or other life opportunities leading to poverty (Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009). Sometimes people with mental health problems develop self-stigma and thus begin sharing those negative attitudes and beliefs about themselves (Corrigan & Watson, 2002).

This raised the question about the situation of mental health professionals. Does the highly stigmatized field of work also reflect on them? How are they being perceived by the general population or by their fellow health professionals? Do they feel their profession is very different from other health sectors?

The majority of the key informants including mental health professionals from HC III, HC IV, Regional Referral Hospitals, Butabika National Referral Hospital, the district health officials and Dr. Sheila Ndyabangi, the Principle Medical Officer in charge of Mental Health and Control of Substance Abuse, were of the opinion that the situation of mental health professionals is very different from other health workers.

Some of the informants perceived the differences in positive terms. Dr. Ndyabangi for example stated that they are highly respected and frequently “stolen” for other positions. Others emphasized the highly complex and specialized nature of their profession, explaining that a “critical mind” and patience is needed as they do not have laboratories or equipment for diagnosis, for example. Some felt that working with difficult, sometimes aggressive patients, who might refuse to take drugs, and dealing with emotions requires more skills than other health professions.

The majority, however, highlighted challenges and widespread stigma from the general public, also, very frequently, from other health workers. Of the 20 mental health professionals working in mental health units in Regional Referral Hospitals or in the National Referral Hospital Butabika 12 stated that the community and mostly the other health professionals perceive them in a similar way as their patients. Many explained that there is a prevalent belief that people working in the mental health sector have themselves mental health problems. Some felt they are not being taken seriously and that their unit receives less attention, funds and resources. One respondent pointed out, that due to the widespread stigma many of her colleagues do not choose this profession voluntarily but only if they have no other choice.

Several informants emphasized the risks that are part of this profession while dealing with aggressive patients, who sometimes attack the health workers. There has been some anecdotal information about very serious events within the mental health units, such as

rapes of health workers by patients. Evidently, their security and safety is not always guaranteed. The atmosphere of insecurity or fear can in turn lead to health workers overreacting to some smaller misbehaviour of patients or, as reported by some informants from one of the mental health units, to premature discharges when health workers feel threatened by a patient.

The majority of the district health officials interviewed expressed their concern of the whole mental health sector being marginalized, receiving little funding and the extremely limited number of specialized staff recruited by the government. Several of the respondents pointed out that the numbers of mentally ill people in their districts is overwhelming, yet the mental health professionals are few and the funds for drugs are little.

Many of the mental health professionals as well as the district health officials maintained that mental health is a particularly marginalized sector and also Dr. Ndyanabangi agreed that the budget allocation for mental health is too small. She was, however, of the opinion that this is true for all health sectors. She also stated that the number of mental health professionals is small because the work is not appealing and much less lucrative than other health professions.

Concluding, the general situation seems to be much more challenging for mental health workers than for other health professionals, although the health sector in general is suffering from underfunding. The specialized staff are even fewer than in other sectors while, at least in some regions, they have to deal with huge numbers of very difficult patients (New Vision, 2012). In Northern Uganda there is reportedly only one psychiatrist, working in a mental health unit (some others are exclusively lecturers). Unfortunately he did not agree to be interviewed.

In addition to their difficult work conditions, mental health professionals face widespread stigma and discrimination, not only among the general public but frequently within their own health profession. Clearly, it is very difficult to advocate for better working conditions and more resources for a sector that is perceived negatively and where the health professionals themselves are not taken seriously.

### [3.6 Suicides](#)

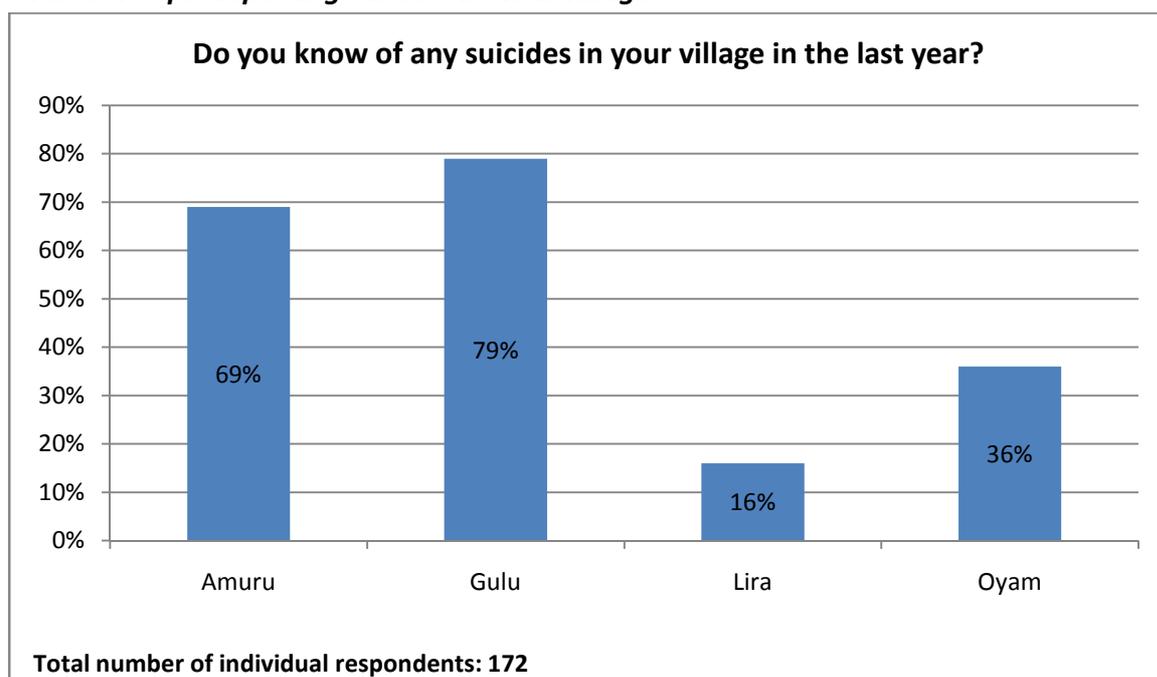
The issue of a rising number of suicides in the post-conflict region of Northern Uganda has recently had some attention. The scope of the problem is so worrying that local leaders called for a workshop in February this year to discuss this new crisis and develop some ideas on how to deal with it (Acholi Times, 2013). In the workshop, with the title “Taking Action - The Rising Spate of Suicides in Post-Conflict Northern Uganda”, the LCV Chairman presented some very disturbing statistics. According to him Gulu district alone registered 51 suicides between October 2012 and January 2013. This excludes the attempted suicides (Ojara, 2013).

Although drawing a causal relationship between mental health and suicide rates was beyond the capacities of this study, there are a considerable number of reports that link suicides to mental ill-health (Washington State Coalition for Mental Health Reporting, 2013; Sunday Vision, 2013). According to various estimates, although the majority of people who experience mental illness do not die from suicide, of those who do commit suicide around 90% have a diagnosable mental disorder. In his opening remarks the LCV Chairman of Gulu, Hon. Ojara Martin Mapenduzi, also clearly linked the high number of suicides in his district with mental illness.

While it was not possible to study such a complex subject in detail, the purpose in this study was to generate a broad comparison between the 4 districts, and to find out what community members report to be the reasons for suicides or attempted suicides.

The figures clearly show a much higher prevalence of suicide cases in Amuru and Gulu as compared to Lira and Oyam, with Gulu district being the highest (79% of respondents reported at least one suicide in their village).

**Chart 9: People reporting suicides in their village**



Percentage of people reporting suicides in their village out of the total number of respondents from the respective district

Though the data is not sufficient for assuming a causal relationship, it is nevertheless an interesting observation that the prevalence of suicides per district corresponds with the estimated numbers of mental illness cases, whereby Gulu was leading, followed by Amuru, Oyam and finally Lira (see chapter 4.1).

All respondents were asked if they know the reasons for the suicides in their villages. The majority reported various cases of domestic quarrels such as land wrangles, quarrels over

money, extramarital affairs, jealousy or impotence. It appears that in the majority of cases there has been some involvement of substance abuse – sometimes drugs but mostly alcohol. Many respondents, explaining details of the type of quarrels, gave a very similar scenario: the wife refused her husband money (for example after a harvest) that he wanted to spend for drinking. And that was the reason he killed himself.

Another reason frequently mentioned, were suicides related to HIV status. Either the person who committed suicide discovered that he/she is HIV positive or one of the spouses found out that the status of the other is positive.

Poverty has been mentioned by several respondents as a general reason. Sometimes a specific event triggered the suicide such as being unable to pay back debts or loans, losing family property etc.

Supernatural causes have also been reported, for example, of people having committed a crime and being cursed or bewitched and committing suicide as a result of that. There was one story repeated by several respondents relating to an occurrence in Koro sub-county during the war. A group of soldiers crossing a bridge fell into a river and drowned. In this particular village the number of suicides seems to be particularly high, with many people killing themselves by drowning in that same river where the soldiers died. Many people believe that the ghosts of the soldiers are haunting the people of this village making them commit suicide. According to one respondent, those cases became so common that when someone even mentions “going to the river” the person is brought to the police station as neighbours or relatives fear this might mean an attempted or planned suicide.

Mental illness has also been given as a reason by a number of respondents, predominantly, by respondents with some background and knowledge on mental health, such as NGO staff or health workers. Some informants emphasized the traumatic events people have experienced during the war, witnessing, or being forced to commit, atrocities.

The reason mental illness as cause might not have been mentioned more often by community members is that some of the mental disorders commonly associated with suicides, such as major depression or bipolar disorder, are difficult to identify by someone not knowing the symptoms.

The extremely high involvement of substance abuse in the majority of reported suicide cases, apart from being a mental disorder itself in cases of addictions, could also suggest a connection with other mental disorders. Substance abuse is a frequent comorbid disorder, especially associated with mood or anxiety disorders, such as depression or PTSD, and especially common among adolescents (Deas & Brown, 2006; National Institute on Drug Abuse, 2010).

Whatever the causes, the number of suicide cases in Gulu and Amuru is disturbing, even in a recovering post-conflict society. It is of utmost importance to examine the background and reasons for such an alarming occurrence of suicide.

### 3.7 Butabika

Butabika Hospital is the only National Referral Hospital in Uganda. It has a capacity of 500 psychiatric beds<sup>4</sup>. It offers a bigger variety of services compared to Regional Referral Hospitals including for example occupational therapy, psychological therapies offered by clinical psychologists and psychosocial interventions by social workers. Most staff reported more or less regular refresher trainings and capacity building on various issues related to mental health.

Although the present research focused on the post-conflict setting of Northern Uganda, the decision to include Butabika Hospital, was based on the fact that as a National Referral Hospital it serves all people from all regions of Uganda and at the same time it represents the “last resort” for most complicated and difficult cases. As this is a big hospital, the present survey could only offer a small insight in order to outline some issues and highlight a few challenges. A thorough description of the hospital would require a separate research focusing fully on that particular health facility.

There is not much literature detailing the conditions in Butabika Hospital, specifically from a human rights point of view. The information available is very positive, pointing out the praise Butabika receives for its services, though adding that the researchers might have been associated with the hospital and the responses could, therefore, have been biased (Cooper, Ssebunnya, Kigozi, Lund, Flisher, & Consortium, 2010).

As mentioned in the methodology chapter, this study also faced some challenges, as it was not possible to conduct interviews and information has been given by respondents filling out written questionnaires. Those questionnaires have then been collected by the Deputy Director and forwarded to the research team. Such an approach limited the level of anonymity necessary for honest and critical responses. Additionally, the research team interviewed two former psychiatric nurses of Butabika Hospital. Interestingly, the information provided by the currently working staff and the former staff was very different.

The general information regarding staff and the number of patients was as follows: The estimated number of in-patients is around 700. According to the respondents there are 6 psychiatrists, 2 clinical psychologists, 2 occupational therapists, 3 social workers, 8 psychiatric clinical officers and, according to the deputy director more than 300 psychiatric nurses.

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<sup>4</sup> <http://www.emerald-project.eu/the-group/consortium/butabika-national-referral-and-teaching-mental-hospital/>; <http://www.prime.uct.ac.za/index.php/research-uptake/prime-in-the-media/75-prime-launches-with-partners-in-uganda.html>

The respondents in Butabika were asked to assess the behaviour of health workers in general towards people with mental disorders and then specifically to assess the behaviour of Butabika staff.

The responses were overwhelmingly positive about the general conduct of health workers in various health facilities towards patients with mental ill-health and even more so about the relationship between staff of Butabika and the patients. They described the behaviour of Butabika staff as professional, following ethical guidelines and regularly inspiring praise by patients.

Only some interviewees expressed a slightly less positive opinion stating that in some health facilities patients with mental disorders are stigmatized, that there are instances of negative attitude or that due to human resources and financial restrictions the physical interaction with patients in other mental health units might be restricted or there might be constraints in drug supply. One respondent stated, that due to such drug shortages some patients might think that drugs have been misappropriated. A few respondents have been somewhat less enthusiastic about the relationship between staff and patients in Butabika Hospital acknowledging that it depends on the individual health workers, some are empathic and others judgemental or rude and that it depends on the nature of the patient. One respondent admitted that sometimes the rights of the patients are abused by undressing them and locking them in a side room (sometimes for a night without a blanket, as has been witnessed upon a visit in the hospital).

Almost all of the current hospital staff asserted that drugs are adequate with regard to quality and amount. Only one respondent acknowledged that some drugs are too expensive for the hospital so it is mainly the cheaper and older drugs that are being provided.

The discharge circumstances were also described as taking place either upon improvement or against medical advice upon demands of the relatives.

The rate of re-admission could not be established exactly but almost all respondents agreed that it is very high and that the majority of patients are re-admitted at some point.

One challenge is the issue of escapes. While the exact information on the average number of escapes per month could not be established the estimates ranged from 10 to 50. The standard procedure reported differed slightly depending on the respondent but the majority stated that the Head of Nursing Staff is informed, the hospital administration and the Executive Director. An escape form is filled, the police is informed and the relatives are called. There is also a search conducted on the hospital ground and in the neighbourhood. Through calling the relatives it is established if the patient has returned home and in some cases radio announcements are being broadcasted.

The statistics regarding the numbers of patients from the Northern Region could not be reliably obtained. The Deputy Director explained that data about patients is not compiled

specifying the place of origin and, therefore, it is rather difficult to estimate the number of patients from the North or the most common diagnoses of patients from that area. A number of respondents attributed the causes of most mental disorders in Northern Uganda to the war, but it was rather an educated guess or personal opinion and not based on available patient statistics.

Finally, it was established that Butabika Hospital offers a number of outreaches, follow-ups of patients and psycho-education but all those activities are limited to an area in and around Kampala and are severely limited by available resources, funding, transport etc.

As already highlighted above some of the information given by former health workers of Butabika as well as collected from families of previous patients or gathered through own observations during visits to Butabika, contradict this predominantly positive picture given by the current staff of the hospital.

In at least one case of a patient escaping the hospital, there was no thorough search conducted and the relatives have not been informed. Since they were from a distant region they only found out by co-incidence when a friend of the family went to visit the patient in Butabika and it transpired that the patient has already escaped some days ago. Only then a very superficial search within the hospital grounds has been carried out. Some former patients or relatives interviewed were neither aware of their diagnosis nor about the details of the side effects of the medication given.

The former psychiatric nurses reported that medication was not enough, there was no time for patients and some of the health staff were verbally or even physically abusive to the patients. They stated that the number of beds is too small and the quality and amount of food is not adequate. One respondent reported that many cleaners would beat patients and there have been instances of sexual harassment and rape by some guards, which in the majority of cases have not been followed up. Only in one case a guard has been fired. The rude behaviour of cleaners was also reported by a former patient, who stated they would frequently pour cold water on patients in the morning to make them leave their beds. A former Butabika nurse further described an event, when a pregnant patient of Butabika delivered the baby without any assistance, since there was no mid-wife and the nurse that was supposed to be present was absent. The baby died.

In another case the drugs prescribed by the doctor to a patient were too expensive for the hospital and the family refused to pay for them or to come and collect the patient. According to the respondent, a nurse called the family, lied to them that the patient died and when they came the staff forced the patient upon the family.

The interviewee stated that when patient files were misplaced or forgotten the nurses would distribute any available medication to patients. She also stated that health staff steal medicine, like painkillers, "in broad daylight" and there is little or nothing left when patients become physically sick.

Clearly, the pictures given are extremely different and it is difficult to establish the truth in an environment that is not easily accessible. A number of reports, even of former patients, were rather positive about the hospital. Butabika seems to have better conditions and better service delivery standards than most other health facilities that are available to people with mental disorders. However, even if those incidents reported by the former staff were rather isolated cases, they should be thoroughly investigated. Further, the staff of a national mental health hospital should have at least general knowledge and basic training on human rights, so that they always act within an accepted human rights framework, respecting and protecting the rights of the patients entrusted to them. Even one case of sexual harassment of a patient would be one case too much and the follow up of such accusations is the responsibility of the hospital.

As stated above, it was not the core purpose of this study to assess the conditions within the National Referral Hospital. The little insight acquired through interviewing some current and former staff as well as some former patients and the observations made during the visits shed a light on a number of challenges within the hospital, including the very high number of escapes as well as the attitudes towards the patients, the infrastructure, drugs and other resources. It would be important to have an objective study looking into those challenges to provide the Butabika administration, management and staff with some recommendation on how to improve their services.

## Chapter 4: Discussion

The topic of this research was very broad and complex and it was difficult to cover all aspects of mental health and human rights in Northern Uganda. Nevertheless, a number of issues as well as suggestions on how to address them clearly emerged as a result of the present study.

It was a consensus of the majority of respondents that mental health is a great concern in all areas where the research took place, however, it seems an even greater burden in the Acholi sub-region. While it was beyond the capacities of this study to establish causal relationships and ascertain that the main reason for a high number of mental illness cases could be attributed to the long term brutal civil war, the conflict, suffered for such a long time, certainly plays a role. Several studies found extremely high prevalence of depression and PTSD in the Northern Region of Uganda, and also in other countries that share a similar history, increased occurrence of PTSD and depression is common (Betancourt, Liesbeth, Onyango, & Bolton, 2009; Roberts, Ocala, Browne, Oyok, & Sondorp, 2008; de Jong, et al., 2001). While the violence and atrocities witnessed, suffered and committed are an obvious cause for wide-spread mental ill-health, other consequences of long-term conflicts also play a role. For example, mental ill-health in post-conflict regions has been partly attributed to daily stress arising from poverty (Buvens & Lagen, 2013; Schryver, 2013), while at the same time other research shows that mental illness can lead to poverty (Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009). This has been consistent with our findings, since many respondents mentioned poverty as one of the reasons for mental illness as well as traumatic experiences during the war. Such intertwined factors create a vicious circle and downward spiral for people with mental health problems and their families, which is almost impossible to escape without external support

Unfortunately, the majority of interventions focus on one specific topic ignoring the complexity of a post-conflict setting. While the Government tries to provide some kind of minimum service provision for all citizens, NGOs also tend to have very narrow projects and objectives instead of pursuing a more holistic approach. For example, though the basic medication and mental health services are provided free of charge, the affected people are frequently unable to reach them.

When the health facilities, such as Health Centres or an RRH could be reached many families are still overwhelmed by the constant need of care of their relatives with mental health problems. Many poor families simply cannot afford to lose, not only one pair of hands, of those with mental health problems, but also of the care taker. The regular travelling to health facilities to collect the medication is time consuming and too expensive for many and it gets even worse in cases when the person with mental health problems needs constant supervision at home or the care taker has to accompany them in the mental health unit. Those challenges have been pointed out by the majority of respondents, who

recommended accessible and adequate supply of drugs and stressed the problems of distant health facilities and transport. Very many informants emphasized that services should be closer to home at community level. The economic difficulties have also been mentioned by the majority of informants, who suggested support in form of clothes or food for people with mental health problems and financial or livelihood support for the families. A number of respondents mentioned vocational training or education opportunities for people with mental ill-health pointing out that they should be enabled to “make use of their talents”.

This is, however, only a part of the problem. When asked for suggestions on how to improve the living situation of people with mental health problems the majority highlighted the need of community education. Even if families resolve to take care of their relative with mental ill-health and even if they manage to survive economically, they frequently face rejection, prejudice, hostility and fear from their community. Those negative attitudes could be addressed by intensive community sensitization, awareness raising and involvement of all stakeholders, including community members in managing the challenges presented by mental disorders. The reduction of prejudice and discrimination attached to the whole area of mental health in the communities could also help to mitigate the stigma towards mental health professionals.

There is not only a general lack of knowledge but also a pervasive confusion with regard to mental health. The perceptions of mental illness present a blend of traditional, cultural, religious and western perspectives on the topic, with people seeking help from traditional healers, priests or health facilities – sometimes all of the above. This information gap on the side of affected families as well as communities is combined with a widespread lack of cooperation or even recognition on the side of those formal and informal service providers.

The health facilities follow strictly the western approach, using western diagnostic systems and medicine and mostly disregard the services provided by traditional healers or churches and priests. The churches mostly do not accept traditional healers. Those different worldviews exist side by side and instead of availing people with more options they compete, contributing to the general confusion. The few studies on local perceptions of mental illness, including symptoms and categories have not been in any way included or combined with the formal service provisions. On the side of government public health services there seems to be no intention of changing anything in this regard. Dr. Sheila Ndyabangi pointed out that involving traditional healers would be difficult since the quality control of the services could not be ascertained when working with such a diverse group without any official recognition or formal certification.

Consequently many people use the health facilities and take the drugs or give them to their relatives because it might calm them down or make them “easier to manage”. The beliefs and understanding on the causes, however, are mostly very different from the western scientific perspective and although the need to combine those different systems has been

suggested by many scholars (Moodley & West, 2005; Clancy & Hamber, 2008), this seems to be very far from the reality in rural Uganda.

A more holistic approach has been developed for a rural setting in Rwanda, focusing on strengthening families through improving their communication and parenting skills, delivering psycho-education, identifying sources of resilience and, very importantly, involving the whole community through the establishment of community advisory boards (Betancourt, Meyers-Ohki, Stulac, Mushashi, Cyamatare, & Beardslee, 2012). Those structures provide advice on culturally appropriate interventions but at the same time through their involvement, community participation and support is ensured. A similar approach combined with some income generating activities, education or vocational training opportunities for people with mental health problems and their families would be a worthwhile initiative to address the various needs and challenges, which emerged in this study.

The hardships faced by people in post-conflict settings could provide an explanation for the extreme increase in suicides in the Acholi sub-region. Poverty, substance abuse, conflicts within the family or the neighbourhood possibly combined with mental health problems and aggravated by a lack of support and future prospects could lead to a sense of hopelessness and to taking one's life. This emergency situation once more highlights the necessity of holistic approaches targeting psychological, social as well as economic aspects.

Finally, a clear and dramatic outcome of this research is the complete detachment of the whole human rights sector from the topic of mental health. There are few studies on that topic and virtually no human rights organisations in Uganda (to our knowledge) that focus on the rights of people with mental health problems. Meanwhile, the human rights abuses towards people with mental ill-health appear to be horrendous. While the reports regarding the conditions within mental health units were mixed some of the narratives suggest a worse situation than the predominantly positive picture painted by the health workers themselves. There is a lack of information for the patients and relatives and a lack of reliable care, even in the National Referral Hospital, taking into account the many reports of escapes and the lack of follow up on the escapees. People with mental health problems living on the streets are frequently beaten and the women raped and there is no one to protect their rights and report or punish the perpetrators. Almost none of the stakeholders has any kind of basic human rights knowledge including the medical staff or the police, who frequently also have to deal with people with mental ill-health.

It seems that, while other vulnerable groups are at least recognized and have some advocates trying to improve their situation, people with mental health problems and their families are left on their own. And this is the most important message of this research – the necessity of raising awareness of the plight of people with mental ill-health and their families, of the human tragedy that forces many families to abandon their relatives on the streets, of the human rights abuses, extreme poverty and lack of any life opportunities and

finally, of the lack of recognition by government and specifically civil society that this is a vulnerable group, which also needs attention and support, maybe more so than other groups described as marginalized or vulnerable.

## Chapter 5: Conclusion and Recommendations

Mental health is a serious concern in Acholi as well as Lango sub-regions. People with mental health problems suffer discrimination, stigma, human rights abuses, lack of access to services, poverty and lack of most life opportunities available to other people and their families face various challenges that many feel unable to manage. There is a widespread lack of knowledge on mental health on the one hand but also, on the other hand a general confusion, mixing western perceptions with traditional concepts and religious beliefs. At the same time there are no initiatives to integrate those different perceptions or to provide a holistic approach to the diverse psychological, social and economic challenges faced by people with mental health problems and their relatives.

The public and NGO service delivery options tend to focus on some narrow aspects of the problem and to concentrate in urban areas such as Gulu or Lira. There is basically no service provision in rural and remote places making accessibility very difficult or impossible for many people. Poverty, lack of transport and distance to health facilities prevent many from seeking help from public health facilities. The VHT members mostly lack an even basic knowledge on mental health.

As has been emphasized by several respondents, mental ill-health is not an individual problem, especially not in communal contexts such as rural Africa. It is a challenge for families and whole communities. And similarly the consequences are not only individual suffering but poverty, stigma and discrimination affecting entire families. Therefore, any successful interventions have to address all stakeholders and acknowledge the diverse challenges and consequences of mental ill-health.

The government, donors and civil society have to realize that there is no development without health, and no health without mental health. This is even more true in post-conflict settings. The dramatically rising number of suicides should provide a wake-up call, and the realization that economic development is not enough and that peace is not merely the absence of war. The peacebuilding work, including psychosocial interventions, should increase and not stop at the end of the conflict.

Finally, it has to be recognized that people with mental health problems have been marginalized or completely forgotten within the human rights field. Abuse of their human rights need to be addressed urgently by government and civil society actors, within community settings as well as in health facilities, police stations, prisons etc. Moreover, human rights do not only include protection from physical mistreatment – they also include the rights to health, education, work and many other rights stipulated in the International Convention on Economic, Social and Cultural Rights. All those rights pertain to people with mental health problems as to all human beings!

“Perhaps someday it will be recognized that persons who have been diagnosed as mentally ill should have exactly the same rights as other citizens of their countries, most fundamentally the rights to live their lives as they choose and make their own decisions.”

Judi Chamberlin

## **Recommendations**

### **To the Government of Uganda**

- **The services should be brought closer to the people.** Free health care and drugs are not of much help to people in rural areas who cannot afford the transport to reach the health facilities. This is one of the reasons why many people discontinue taking drugs. Mobile teams including a mental health professional reaching regularly the remote areas could be an option when it is not possible for the time being to construct the necessary number of health facilities.
- **Conduct more training for VHT’s.** This is another way of bringing the services closer to rural areas. A number of VHT members had some basic training on mental health but the majority still has not got any training on this topic. This should be made a crucial part of their qualifications.
- **Create a conducive environment for education and vocational training opportunities for people with mental ill-health.** Depending on the severity of the mental health problems it should be possible for people with mental ill-health to join schools together with other youth or children. This would require sensitization or training for teachers. For those with more serious disabilities specific education and training opportunities should be created. Many of the people with mental ill-health are perceived as useless. If they could contribute to the upkeep of the family the perception would change and it would help their integration in the community. Additionally, it would improve the economic situation of the family.
- **Developing guidelines for the police on how to deal with people with mental ill-health.** People with mental health problems are regularly arrested, sometimes kept in prison for a long time and mistreated by other prisoners. Police should be sensitized on this topic. People with mental ill-health should not be subjected to mistreatment and their human rights need to be protected. Those with a diagnosed mental disorder should not remain in a prison but be brought immediately into mental health units.
- **Adoption of the draft bill.** The draft bill on mental health should be adopted. Apart from protecting people with mental health problems from human rights abuses, their rights to work and education and protection from discrimination in work or education places should also be protected by law.

- **Cooperation with informal structures should be initiated.** It should be recognized by formal health service providers that the beliefs of people, especially in rural areas differ from the western approaches and concepts promoted in the hospitals. Some form of cooperation between public health facilities and traditional healers and churches should be encouraged to ensure better service provision. Involvement of traditional healers would also help monitoring and preventing cases of mistreatment or exploitation of people with mental health problems.
- **Assign specific funding for mental health within the health budget.** Mental health is frequently overlooked. There is for example a serious lack of professional staff. The needs of the population with regard to mental health should be assessed, acknowledging the differences between the regions and funding assigned accordingly
- **Establishing reliable statistics regarding mental health needs in Uganda.** During this research we were unable to establish reliable numbers and statistics of mental illness cases. Though some statistics are compiled in health facilities, the ones available are not complete. In hospitals the data is not compiled according to regions and no needs assessments are carried out, at least not on a regular basis. This makes it very difficult to establish the mental health needs in the whole of Uganda as well as the differences between the regions.

#### **To the Management of Health Facilities**

- **Introduction of human rights guidelines in mental health units.** Most of the health staff had no knowledge on human rights. In a sector where so many abuses take place there is a need of guidelines so that the health workers know the rights of patients and patients and care takers are informed.
- **Introduce a structure for patients or care takers to complain in cases of abuses or mistreatment.** Reports of mistreatment should be followed up and there should be a structure within the hospital, for example a committee comprised of hospital staff, which could address such issues.
- **Introduction of guidelines for professionals in cases of suspected mistreatment of out-patients.** Health workers should have detailed guidelines on how to behave in cases they suspect a patient might be mistreated or neglected at home or might show signs of suicidal ideation. At the moment this is left for the individual professional assessment and decision, which is not the right approach for such a sensitive issue.
- **The challenge of stigma of mental health professionals should be addressed.** This topic should be openly addressed within academic institutions and health facilities. An open discussion could help to reduce the widespread prejudices against this profession.

- **The security of mental health workers should be ensured.** While patients need to be protected the staff in mental health units also need to feel safe. Some abuses occur out of fear and could be reduced with increased professional security measures.
- **The escapes of patients of mental health units need to be addressed.** Even the supposedly closed facilities do not provide the necessary care and protection for patients. The ones who escape are in danger. The shortcomings in mental health units should be identified to prevent the escapes that seem to happen frequently.
- **In-patients could be accommodated together for group support according to region or language.** The referral hospitals reportedly do not compile data according to the region the patients are coming from. However, especially in Butabika and particularly in such a multi-ethnic country as Uganda, it could help patients to be accommodated together with others from the same region and speaking the same language. Someone coming from rural Northern Uganda might have problems even communicating with the staff or other patients, increasing the feelings of exclusion and fear of being far away from home.

#### **To NGOs and CSOs**

- **Dispersing and diversifying of services.** Through a proper coordination and cooperation civil society organizations should ensure that they do not all focus on the same topics in the same areas. While urban areas are much better covered, there are virtually no services for people with mental health problems in more remote and rural areas. Those are the places where people are really in need. The approaches should be broader, not only taking care of one aspect of the problem, but also addressing other needs, such as economic challenges. This could be done in cooperation with other organizations which focus, for example, on livelihoods and income generating activities.
- **Human rights organisations should address the neglected topic of the rights of people with mental health problems.** People with mental ill-health should be recognized as a vulnerable group in the same way as others that need special protection are. Criminal offences such as exploitation or rape need to be addressed and should not go unpunished.
- **Conduct trainings in human rights for various stakeholders.** Civil society should develop and conduct training on the rights of people with mental ill-health for all stakeholders involved, such as health workers, police, prison wardens, teachers, LC I's among others.
- **Conduct community education and sensitization on mental health.** This request was mentioned by the majority of respondents. This could contribute

to a better acceptance and to reducing discrimination against people with mental health problems.

- **Conduct training and psycho-education for families of people with mental ill-health.** A more intense involvement focusing on strengthening the family structure and resilience, delivering education on mental health and information on how to deal with the ill relative would help families to manage, instead of abandoning them out of helplessness.
- **Develop inclusive intervention approaches involving community members and combining traditional with western approaches.** Civil society should attempt to bridge the gap between the traditional, religious and western approaches and concepts of mental illness by bringing all those stakeholders together and jointly developing collaborative approaches for better service delivery for people with mental ill-health.
- **Support self-help groups and meeting places for people with mental health problems.** There are few places in Kampala and none (to our knowledge) upcountry where people with mental health problems can meet, discuss and support each other in their daily challenges. Such a place could help them face the widespread discrimination, bring variety into their lives and also provide some relief for the families and care takers.
- **Conduct research on combining traditional with western approaches to mental health in Acholi and Lango regions.** There are a few studies on traditional concepts on mental health within the Acholi region and even less in the Lango region. There are virtually no serious approaches to bringing those very different perceptions and worldviews together. People are caught in between those two worlds moving from one to another. At the same time much better approaches could be developed by trying to merge and combine those methods to develop culturally appropriate services for people with mental health problems.

#### **To development partners**

- **Prioritize the sector of mental health in terms of funding and projects, not only, but particularly in post-conflict regions.** People with mental ill-health should be recognized as a vulnerable group within the development sector and attention should be paid to their needs in the same way as it is done for other vulnerable groups.

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