


Beliefs, stigma and discrimination associated with mental health problems in Uganda: Implications for theory and practice

International Journal of
Social Psychiatry
2014, Vol. 60(6) 554–561
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0020764013504559
isp.sagepub.com


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Abstract

Background: There are major gaps in knowledge about beliefs, stigma and discrimination in Uganda, including the relationship between different cultural beliefs and stigmatising responses, how stigma and beliefs result in discrimination and the impact of social factors such as gender, poverty and ethnic conflict.

Aim: This exploratory study aims to understand beliefs, stigma and discrimination associated with mental health in Uganda in more depth from the perspectives of different stakeholders.

Methods: Focus groups and interviews were undertaken with mental health activists, policymakers, practitioners, non-governmental and human rights organisations, journalists and academics.

Results: Stigma was reported by individuals, families, communities and institutions, including health services. The study also found stigmatising beliefs linked to traditional, religious and medical explanatory frameworks, high levels of ‘associated stigma’, common mental health problems rarely medicalised and discrimination linked to poverty, gender and conflict.

Conclusions: The findings suggest the need to address stigma in their cultural and social context, alongside other human rights initiatives.

Keywords

Uganda, mental health, stigma, beliefs

Introduction

Health-related stigma exists across cultures (Deacon, 2006), creating social exclusion within families and communities and discrimination in employment, education and housing (World Health Organization (WHO), 2001). Goffman (1963) defined stigma as ‘a mark that is deeply discrediting’ and identified the role of social interaction in stigma, including the acquisition of negative labels and the process of stereotyping. However, others suggest that stigma persists across societies because it serves to reinforce social order and solidarity among the ‘insider’ majority (Falk, 2001). Link and Phelan’s (2001) modified labelling theory outlines the co-occurrence of labelling, stereotyping, separation, status loss and discrimination and the fact that social, economic and political power is necessary to stigmatise. Stigma relating to mental health problems is associated with substantial societal burden (Evans-Lacko, Henderson, & Thornicroft, 2013) and occurs at a range of levels, including self, family, community and structural

discrimination (Corrigan, Markowitz, & Markowitz, 2004). For example, stigma results in people with mental health problems receiving poor treatment from health-care staff (Henderson, Evans-Lacko, & Thornicroft, 2013).

Studies in high-income countries demonstrate a range of negative stereotypes, including dangerousness, unpredictability, recovery pessimism, incapability, pitifulness (Corrigan & Penn, 1999), shame and blame (Scrambler, 2009), which vary according to the type of mental health problem (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). However, it is argued that regardless of patterns and strength

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of stigmatising beliefs – or the causal explanations that underlie them – that patterns of discrimination across cultures remain similar (Van Brakel, 2006). Stigma can also affect people associated with the out-group member, described as ‘courtesy stigma’ (Goffman, 1963), with key components including blame, shame and contamination by association that severely affects many families (Byrne, 2001; Larson & Corrigan, 2008).

However, most approaches towards stigma have been developed in the context of high-income countries using Western constructs of mental health. This research seeks to understand and conceptualise stigma relating to mental health problems in Uganda.

Mental health problems in Uganda

Uganda is situated in East Africa, sharing borders with Kenya, Sudan, Democratic Republic of the Congo (DRC), Rwanda and Tanzania. Of the 30 million population, 5% are displaced by war and 31% live in poverty (United Nations Population Fund (UNFPA), 2008; UNHCR, 2009). Long-standing mental health conditions affect up to 30% of the population (Kasoro, Sebudde, Kabagambe-Rugamba, Ovuga, & Boardman, 2002). Poverty and poor mental health are intrinsically related, particularly in rural areas where poverty is higher and the majority of the population reside (Flisher et al., 2007; Patel, 2007; Siddiqi & Siddiqi, 2007).

Mental health problems are understood in the context of indigenous, religious, biomedical and social explanatory models. Indigenous and religious beliefs influence the way mental health problems are viewed (Kasoro et al., 2002; Ndyabangi, Basangwa, Lutakome, & Mubiru, 2004). There is the view that most people with mental health problems initially consult traditional healers (Ovuga, Boardman, & Oluka, 1999) and believe mental health problems are caused by evil spirits, witchcraft or ancestral spirits (Ovuga et al., 1999; Teuton, Bentall, & Dowrick, 2007). There is some evidence that biomedical constructs are more common in urban areas (Teuton et al., 2007), although some studies suggest the use of formal mental health services remains low due to cultural beliefs about causation (Ndyabangi et al., 2004) and difficulty accessing services (Basic Needs/MHU, 2009). Medical approaches can often be used alongside traditional healing (Ovuga et al., 1999).

Stigma in Uganda

Self-stigma can lead to delayed help-seeking, rejection and shame (Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009). People can be alienated by their families, who fear the person is bewitched or under the influence of spirits (Byaruhanga, Cantor-Graae, Maling, & Kabakyenga, 2008; Kasoro et al., 2002). Within communities, people can be seen as dangerous or evil, and traditional beliefs can reinforce stigma by viewing them as deserving punishment for

wrongdoing (Teuton et al., 2007). However, traditional beliefs can also discourage harassment within communities (Ndyabangi et al., 2004). Many families go to extreme lengths to keep mental health problems hidden (Kigozi et al., 2008) due to the consequences of disclosure. People with mental health problems and their families may experience more difficulty in getting married, and harassment from the community is common (Byaruhanga et al., 2008).

Studies suggest negative attitudes are exhibited from health-care professionals and structural discrimination is manifested in a lack of consultation and consent about treatment (Ani & Ani, 2008; Ndyabangi et al., 2004). Uganda has no national body for assessing human rights of users in mental health services (Kigozi et al., 2008). Many individuals with a mental health diagnosis do not have the right to vote or inherit property and may lack basic needs, including food, shelter and clothing (Basic Needs/MHU, 2009; Ndyabangi et al., 2004; Ssebunnya et al., 2009). Women with mental health problems are more likely to experience sexual abuse and are sometimes not allowed to look after their children (Basic Needs/MHU, 2009). Many mental health activists reported losing their job because of a mental health diagnosis (Ssebunnya et al., 2009).

Social factors cause mental health problems and magnify stigma. Studies highlight the trauma of civil wars on both the victims, those displaced and child soldiers (Annan, Blattman, Carlson, & Mazurman, 2008; De Jong & Kleber, 2007; Neuner et al., 2008). Roberts, Ocaka, Browne, Oyok, and Sondorp (2009) highlight the mental distress of internally displaced people in Northern Uganda, where women and children are particularly vulnerable (Desjarlais, Eisenberg, Good, & Kleinman, 1995; Kasoro et al., 2002; Leibling-Kalfani, Marshall, Ojiambo-Ochieng, & Kamembo, 2007; Lustig et al., 2004).

Poverty may both cause mental health problems and reinforce stigma. People with low incomes may have limited access to services, transportation and treatment (Basic Needs/MHU, 2009; Ndyabangi et al., 2004) and are likely to avoid seeking help until conditions become chronic. This in turn exposes the individual to increased stigma (Lwanga-Ntale, 2003; Ssebunnya et al., 2009).

There are major gaps in knowledge about beliefs, stigma and discrimination in Uganda, including the relationship between different cultural beliefs and stigmatising responses, how stigma and beliefs result in discrimination and the impact of social factors such as gender, poverty and ethnic conflict. This exploratory study aims to understand beliefs, stigma and discrimination associated with mental health in Uganda in more depth from the perspectives of different stakeholders.

Methods

The study adopted a qualitative methodology placing a priority upon understanding the social world through the

interpretation of participants. We used individual, semi-structured interviews and two focus group discussions with key informants. Semi-structured interviews were selected to capture individuals' views and experiences and offer the possibility of modifying one's line of enquiry, following up interesting responses and investigating underlying issues (Robson, 2002). Focus group discussions were selected as they have the advantage of enabling the researcher to examine the ways in which people in conjunction with one another construe stigma (Bryman, 2004). The same questions were asked in the interviews and focus groups, and the schedule covered several areas: how are mental health problems understood within the community, what do people believe are the main causes, the main sources of stigma towards people with mental health problems, the impact of stigma on people and how to address stigma. The interviews were flexible enough to allow the researcher to explore issues in depth with interviewees.

We adopted working definitions of 'beliefs,' 'stigma' and 'discrimination' at the beginning of each interview and focus group. We defined 'beliefs' (about mental health problems) as 'a firmly held opinion that you believe to be true' and asked participants about the sources of influence of their opinions. We defined stigma as negative attitudes towards people with mental health problems and discrimination as unfair treatment. In defining these terms, we recognised that there is not a linear relationship between these concepts.

The study adopted purposive sampling (Duggal, Punter, & Fordwour, 1999), although there was an element of convenience sampling and snowballing as initial participants in the study recommended other stakeholders that it would be useful to approach to gain a richer picture of the issues. Participants were selected to ensure adequate representation from a broad range of stakeholders spanning policy-makers; human rights organisations; psychiatry, psychology and social work practitioners; mental health activists; national non-governmental organisations (NGOs); community workers; journalists and academics from a range of disciplines. This was achieved with 16 key informant interviews and two focus groups discussions, each with 12 mental health activists. In order to achieve this broad representation, a range of individuals and organisations (from NGO, government, academic and private sectors) were identified and approached via email to participate in the study. One focus group consisted of mental health activists from all regions of Uganda, who had experienced mental health problems, linked to a national mental health NGO, Mental Health Uganda. The other focus group was a group of mental health activists based in Kampala who undertook awareness raising work within communities. Both groups were selected through a major NGO to ensure there was a proper support structure in place for participants. Provision was made for interpreters when required. Interviews were

conducted until saturation point was reached and no new themes emerged.

All of the individual interviews were conducted in English as the interviewees could all speak English fluently, which was checked out in advance. Both of the focus groups were conducted in a language all of the participants could understand and translated. A translator was recruited for each of the focus groups. The translator understood both the indigenous language adopted for the focus groups and English. In addition, the translator had a good knowledge of mental health problems. This insider knowledge was invaluable in facilitating a good understanding between the interviewers and focus group participants on these issues. Both the interviews and focus groups were audio-recorded with participants' consent and transcribed, to ensure accuracy and reliability of the data. Notes were also taken for each interview with participants' consent by a note-taker, who was present at all the interviews and focus groups.

The data from all the interviews were transcribed by the same person and then analysed to enable the identification of key themes and issues. A systematic approach to analysis was taken, which involved coding the data, adding comments and reflections, identifying similar themes, elaborating a set of generalisations that cover consistencies in the data and finally linking these generalisations to a formalised body of knowledge in the form of constructs and theories (Miles & Huberman, 1994). This primarily followed the framework provided by the topics covered in the interview schedule but was sufficiently flexible to allow for new issues to be identified.

Results

Participants described mental health problems, stigma and discrimination as complex in nature, needing to be understood in relation to the cultural, social and economic context of Ugandan society.

Beliefs about mental health problems: concepts and causes

Concepts of mental health. All respondents reported that common mental health problems such as depression and anxiety were rarely seen as mental illness within Ugandan society but as part of life, a response to difficult circumstances:

Depression, anxiety and common mental health problems are not seen as mental illness and lost in the scale of social challenges. (Interview 8, academic)

Accordingly, they do not attract significant stigma and are usually only addressed if they become disabling. Another issue relating to the construction of mental health problems is the lack of differentiation between mental health problems

that are more severe by the public, 'it's just madness' (Interview 4, academic).

Tradition and faith. All participants felt that traditional cultural explanations for mental health problems are commonly held. Possession by evil spirits is a common belief, as a punishment or curse, due to wrongdoing:

Cultural explanatory models of mental illness see it as a curse, not appeasing ancestors, or witchcraft. (Interview 5, policymaker)

Another explanation is that mental health problems occur when spirits are released. All respondents reported witchcraft as a common social belief. These beliefs impact treatment, with traditional treatments or faith 'cures' being commonly sought:

Severe mental illness is seen as clan spirits or social spirits getting angry and therefore they tend to invoke different types of treatments. (Interview 1, academic)

Traditional beliefs often coexist with social, biomedical and religious explanations. For many participants in Christian and Muslim communities, mental health problems were seen as having a religious cause, being attributed to sin or the 'will of God'.

Poverty. Many participants felt mental health problems were caused and perpetuated by poverty, for example, through creating distress from the burden of being unable to provide for one's family:

Poverty directly leads to mental ill health, for example the burden of being unable to provide food, education fees for a large family this uncertainty can lead to breakdown. It's not simple; even if medication is free many poor people can't afford the transport to pick it up regularly. People can only afford old medications which have bad side effects that affect the person's ability to work. (Interview 2, NGO)

This is exacerbated by the lack of any safety net if someone loses his or her job. This creates a cycle of poverty if someone falls ill, due to the costs to the family of providing treatment and the lost income as a result of the person with mental health problems being unable to work. Respondents reported a strong relationship between inaccessible health care and rural poverty:

It's not simple, even if medication is free, which is rare, then many poor people can't afford the transport to pick it up regularly. People can only afford old medications which have bad side effects that affect the person's ability to work. It also affects the ability to recover and increases relapse. (Interview 2, NGO)

Trauma and conflict. The other social factor identified by two individual respondents from NGOs was the impact of trauma related to conflict:

Remember that 80% or more of the population have experienced severe trauma in the last 40 or 50 years. There is war in the north for over a decade with many displaced and traumatised people, but there is also the conflicts linked to the Congo, Central Uganda suffered under Amin and the Luwero triangle still recovering from massacres. There is lots of national trauma. (Interview 12, NGO)

Conflict impacts on communities through dual stigma. Ex-soldiers find it difficult to integrate back into their communities. Many men have been kept in camps and reliant on support, making them feel that they are not providers. Many women have been raped, which has led to them being rejected by their communities as well as coping with the trauma.

Stigma and discrimination

Mental health activist and NGO respondents described stigma towards people with mental health problems in Uganda as widespread and devastating for the person affected. Stigmatising beliefs include perceptions of danger, unpredictability, incapability and figures of fun. High levels of blame towards people for their illness were linked to religious beliefs and traditional cultural explanations: 'They believe that I committed great crimes that caused mental health problems' (focus group (FG) 1, mental health activists). This included beliefs that mental health problems were contagious, particularly epilepsy, inheritable and that people do not recover:

Once mentally ill always mentally ill, it goes through generations so doomed forever and limits chances of marriage. (Interview 5, policymaker)

Self-stigma. Self-stigma was described by all mental health activists. A number of issues emerged that contribute to self-stigma, including shame, feeling guilty about their role in the family and a lack of worth in abilities to contribute or work and in terms of relationships. The impact of self-stigma leads people to have a poor self-image and results in withdrawal of the person with mental health problems:

Self-stigma is the biggest. It begins with yourself, then the way it levels on you, you end in no man's land, isolated. (FG 1, mental health activists)

Family stigma and discrimination. Family stigma was seen as the most common and distressing source of stigma. Participants explained this in terms of the importance of their family to them, giving greater impact to any rejection, such as blame that the person has caused the mental health problems through sin or offending spirits and ancestors. The shame of having mental health problems taints the family and reduces opportunities for marriage due to beliefs that it is contagious and inheritable:

People believe it is inheritable, which affects marriage prospects so people are hidden so that not all of the family are tainted. (Interview 2, NGO)

The impact of this stigma was described in a number of ways. Stigma can result in a loss of liberty, which in some cases leads to people being hidden or locked away for many years by their families. People's rights were often abused, with many people found in chains or living in squalid conditions or found naked:

We have experience of removing people from chains. It's one thing when the community call you mad, you can kind of understand, but when it's your children it hurts more. (Interview 12, NGO)

There was also exclusion from the family itself, where people with mental health problems could be made to eat separately or even forced onto the streets. Relationships suffer, where people are seen as being a burden by their parents or siblings or as inadequate partners. However, families could also be very supportive and protective:

Protection may be positive and negative. Negative, as they will try to keep this member of the family away from the rest of the community but positive in showing a lot of care. (Interview 3, NGO)

Community stigma and discrimination. Community stigma was reported as widespread by every respondent. People are commonly seen as figures of fun or pity and lacking in capability. People are also shunned due to beliefs that they are dangerous, to blame or contagious, and this was particularly apparent in rural areas.

Reports of community stigma included being taunted and made fun of and excluded from a range of activities such as church or village activities. In addition, communities were often instrumental in making it known the person was not a suitable marriage partner. Beyond this individual stigma was the concept of 'collective stigma' for the whole family within the community, which leads to further guilt and shame for the person affected:

The community stigmatises. Even family and my own children can keep their distance, parents can see you as a burden and you become isolated. (FG 1, mental health activists)

Institutional discrimination. Discrimination was reported as being common in a wide range of institutions in Uganda. Around half of the mental health activist respondents identified being discriminated in the workplace by employers, resulting in people losing their jobs, or being shunned by colleagues:

If you admit it then recover, workmates may be against you. I was one of the best workers but they said 'no' you can't come back here. (FG 1, mental health activists)

Two activists reported being excluded from schools and universities. In addition, mental health activists specifically reported avoiding services due to stigmatising attitudes from health-care staff:

Institutions labelled me. Despite my long experience they thought I could not do anything. (FG 1, mental health activists)

Negative media reporting about people with mental health problems is common, with radio presenters and newspaper reporters reinforcing negative stereotypes:

Media people come from the community, so have similar prejudices. Some may not be well trained in journalism ... radio presenters calling names and giving abuse, stops it being seen as a problem. (Interview 11, journalist)

The political environment was also seen as negative, with several respondents highlighting a case where a serving member of parliament was prevented from taking up a cabinet post based on reports that she had attended a psychiatrist.

Stigma and discrimination not experienced equally. Participants reported that stigma is not experienced equally within Ugandan society. People living in poverty were felt to be more vulnerable than those with high income due to a lack of good-quality treatment. This can lead to active psychotic symptoms and means that people are more likely to be rejected by their families and end up on the streets:

If you contribute nothing you can become an outcast in every sense, especially in a village community. (FG 2, mental health activists)

Gender is also an important social factor: 'Women experience stigma differently and may define the pain differently' (interview 12, NGO), with women experiencing mental health problems subject to domestic abuse and sexual exploitation. This creates additional stigma in a patriarchal society:

Women suffer more; many are taken advantage of by men. Have HIV, children with different fathers. This increases poverty and reinforces stigma. (Interview 14, NGO)

Conflict both causes mental health problems and exacerbates the associated stigma. Migrants from the conflict in the North can experience stigma from being disfigured or orphaned, which can exacerbate stigma arising from the mental health aspects of trauma. Rather than acknowledging their experience of trauma, many people from the North were blamed for their circumstances. Equally within the North, former soldiers and women who had been raped during the conflict experienced discrimination when they resettled within their communities, which creates blame and barriers to support:

In northern Uganda you look right, left, nothing but war. They are stigmatised and on the streets. (FG 2, mental health activists)

Finally, the experience of stigma was seen to depend on the nature of the mental health problem. Stigma tends to be lower for common problems, which are often not viewed as mental health problems, and high for epilepsy (which was seen as a mental health problem in Uganda) and psychotic illness.

Discussion

This study aimed to address major gaps in what we know about beliefs, stigma and discrimination by exploring these areas from multiple perspectives in relation to the cultural, social and economic context of Ugandan society. The findings raise a number of important issues in challenging our concepts of both mental health problems and stigma.

The relationship between beliefs and stigma is complex. Social, medical, religious and traditional explanations are often held in parallel at all levels of society. Traditional and religious belief systems contribute to blame by linking mental health problems with possession due to wrongdoing or sin. While attributions differ, this essentially still corresponds to Scrambler's (2009) model of blame linked to individual deviance. However, traditional beliefs are much more complex than this and in some cases also diminish stigma, by portraying the person as carrying a burden on behalf of the clan.

Common mental health problems were not seen as a medical issue by most Ugandans and therefore less stigmatised. Conversely, stigma associated with severe and enduring mental health problems was high, but seen as a rare occurrence. This emphasises that mental health is an essentially contested concept and challenges the cross-cultural validity of global anti-stigma approaches like '1 in 4' which try to normalise mental health problems. The medicalisation of common mental health problems risks creating stigma for people who may not be currently stigmatised.

Commonly held negative beliefs about people with mental health problems were similar to those found in other international studies in high-income countries such as lack of capability, blame and figures of fun or pity (Corrigan & Penn, 1999), even if the reason for these beliefs differ, for example, blame being linked to sin. However, other stigmatising beliefs were common that are rarely described in high-income countries, such as possession and contagion. These findings support international models of stigma that acknowledge significant variation according to cultural context (Van Brakel, 2006). Furthermore, stigma beliefs varied according to the nature of mental health problems, indicating conceptual development needs to be specific and avoid the generic mental illness construct.

Studies argue that while stigmatising beliefs vary across cultures, the impact of stigma (discrimination) is similar

(Van Brakel, 2006). This study provides some support for this hypothesis, but argues it is too simplistic and fails to account for the strength of discrimination and the accumulative effect of multiple experiences of discrimination – being chained up and hidden away for years – is not captured effectively under a heading of 'social distance.' The absolute nature of poverty and exclusion that people face in low-income countries such as Uganda suggests that models of stigma and discrimination need to be sensitive to massive difference in social conditions.

An emergent finding was extensive associated stigma, with whole families tainted and shunned within communities. Families must be central to efforts in reducing stigma in Uganda. It may highlight that associated stigma is under-researched in high-income countries due to political assumptions of both action theorists (individualism) and structuralists in the disability field who may emphasise individual and group empowerment over benevolent 'carer' concepts.

While there were many areas of agreement on the nature of stigma and its impact, different perspectives emerged on the role of mental health services. There was particular criticism of institutional psychiatric services in perpetuating stigma through long-term exclusion and negative staff attitudes, although this finding only emerged from mental health activists and not from any other stakeholders. This contradicts recent studies (Ssebunnya et al., 2009), suggesting that services are well received. However, this was more nuanced and was not a rejection of mental health services, for example, several service users spoke of the importance of affordable treatment to enhance their quality of life. The lack of reintegration support in terms of work and housing reinforces community perceptions of lack of capability. Conversely, a lack of community mental health support was also seen as a cause of stigma. People in poverty lack the means to travel to access treatment, leading to uncontrolled symptoms and destitution, which reinforces people's bias. Drugs may be outdated with significant side effects, which also creates stigma. Social welfare could be enhanced through developing a greater focus on community-based services.

Finally, stigma is not experienced equally and has had a particularly damaging effect on people living in poverty and their families, for those affected by conflict and war and for women, for example, through sexual exploitation. Stigma within a Ugandan context therefore must be seen through the lens of a human rights and social justice framework.

Strengths and limitations of the study

The study adopts a qualitative approach exploring multiple perspectives. This contrasts with many comparative studies that use scales to measure stigma, which risk failing to capture the impact of stigma, inequalities or how to address

stigma. Adopting a qualitative approach has allowed us to acknowledge different constructs of mental health and consider inequalities and structural discrimination within Ugandan society. Furthermore, it allowed us to gather rich data associated from different perspectives. This approach necessarily creates limitations. The sample size is modest and cannot be assumed to be representative of the whole community, although a wide range of stakeholders was reached. Another weakness of the study was the lack of cross-analysis indicating whether there were different views among the stakeholders, although with the exception of the role of psychiatric services in perpetuating stigma, common themes did emerge from the different stakeholders. The diversity within and between communities in Ugandan society, including urban/rural, ethnic and tribal differences, requires more extensive study.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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