Mental illness - stigma and discrimination in Zambia

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Abstract

Objective: The aim of this qualitative study was to explore the presence, causes and means of addressing individual and systemic stigma and discrimination against people with mental illness in Zambia. This is to facilitate the development of tailor-made anti-stigma initiatives that are culturally sensitive for Zambia and other low-income African countries. This is the first in-depth study on mental illness stigma in Zambia. **Method:** Fifty semi-structured interviews and 6 focus group discussions were conducted with key stakeholders drawn from 3 districts in Zambia (Lusaka, Kabwe and Sinazongwe). Transcripts were analyzed using a grounded theory approach. **Results:** Mental illness stigma and discrimination is pervasive across Zambian society, prevailing within the general community, amongst family members, amid general and mental health care providers, and at the level of government. Such stigma appears to be fuelled by misunderstandings of mental illness aetiology; fears of contagion and the perceived dangerousness of people with mental illness; and associations between HIV/AIDS and mental illness. Strategies suggested for reducing stigma and discrimination in Zambia included education campaigns, the transformation of mental health policy and legislation and expanding the social and economic opportunities of the mentally ill. **Conclusion:** In Zambia, as in many other low-income African countries, very little attention is devoted to addressing the negative beliefs and behaviours surrounding mental illness, despite the devastating costs that ensue. The results from this study underscore the need for greater commitment from governments and policy-makers in African countries to start prioritizing mental illness stigma as a major public health and development issue.

Key words: Mental health; Stigma and discrimination; Qualitative study; Zambia

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Introduction

Mental illnesses worldwide are accompanied by another pandemic, that of stigma and discrimination. Mental illness tends to strike with a double-edged sword, with those affected having to deal with the symptoms and disabilities of their illness on the one side, and widespread stigma and discrimination on the other. Evidence from North America and paralleling findings from research in Western Europe suggest that stigma and discrimination are major problems in the community, with negative attitudes and behaviour towards people with mental illness being widespread.[1-6]

Stigma and discrimination towards mental illness have been said to be less severe in African countries.[7-8] It is unclear however whether this finding indicates that Africa represents a geographical region that does not experience stigma, or whether there is a dearth of research in these

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societies.[9] Indeed, studies elucidating mental illness stigma and discrimination derive mainly from Western countries, with a paucity of comprehensive studies having been conducted in Africa, particularly in Sub-Saharan Africa.[7,10] The few studies conducted in Africa have suggested that the experience of stigma by people with mental illness may in fact be common.[11-12]

For example, in their study investigating knowledge and attitudes of the general South African public towards mental illness, Hugo and colleagues found that knowledge was low and stigma was high. Such stigma appeared to be associated with the fact that mental illnesses were understood as a lack of willpower, and stress-related, rather than medical illnesses.[13] Another example can be seen in Nigeria, where the first large-scale, community representative study of popular attitudes towards mentally ill, found stigma to be widespread, with most people indicating that they would not tolerate even basic social interactions with someone with a mental illness.[9] These preliminary findings thus confirm Corrigan and Watson's assertion that the lack of empirical data in African countries may explain the speculation that stigmatisation and discrimination towards mental illness is less common in these societies.[14] More studies on the continent are needed in order to avoid ill-informed assumptions, and to prevent uncritical transposition of findings from western contexts to Africa, given cultural and structural regional differences.

Besides this geographical gap that appears to characterize the mental health and stigma/discrimination literature, other theoretical and methodological biases have also been noted. From a theoretical perspective, various scholars have argued that understandings of stigma and discrimination pertaining to mental illness have been far too narrow. Most studies tend to understand stigma and discrimination from an ''individual or psychological level'', that is individual beliefs, attitudes and behaviour that usually evolve from ignorance and erroneous beliefs.[15-16] The focus has thus been on identifying and examining the nature of the beliefs that come to be associated with ''category members'' and the ''category label'', and the way in which such people are treated as a consequence of such attitudes.[17]

Most certainly, such models have helped to explain some of the causes and effects of mental illness stigma.[15] However, these approaches tend to neglect more macro-level stigma and discrimination. Thus, various scholars have argued that understandings of stigma and discrimination need to be broadened, incorporating structural or systemic factors that arise at the level of the institution and reflect economic, political, and historical forces.[16,18] Structural or systemic stigma and discrimination represents the policies and behaviours of private and governmental institutions that intentionally or unintentionally hinder the rights and opportunities of stigmatized groups.[18] These include for example, restricting the voting and employment rights of the mentally ill, as well as structurally disadvantaging mental health services through its unequal distribution of resources in health care.[19,20]

From a methodological perspective, it appears that studies, globally, which have explored stigma and discrimination associated with mental illness have been predominantly quantitative, relying heavily on opinion polls, surveys and structured questionnaires.[21] Very few qualitative studies have been done on the stigmatization of and discrimination towards mental illnesses. It has been argued that given that stigma may be a more subtle and elusive object of research than commonly assumed, qualitative methodologies are needed to help tap into the more nuanced forms of stigma and discrimination.[21] Furthermore, it has been argued that survey-type research may fail to capture the possible social, cultural and political forces that lie at the heart of mental illness-related stigma and discrimination.[16] More qualitative studies are therefore needed in order to explore some of the more subtle, complex and multidimensional dynamics possibly at play.

Furthermore, it has been argued that globally, most studies have tended to focus on the attitudes and behaviours of the general community, whilst neglecting the views and actions of specific population groups.[7] One particular group that has been largely ignored is that of health care professionals, both in the general and mental health fields.[7,22] This is cause for concern, as the few studies that have explored this area have found that such professionals frequently hold negative attitudes towards mentally ill patients which can have a material effect on the quality and quantity of services that are offered.[20,23,24] In addition, stigma as experienced by those who suffer from mental illness has been inadequately explored.[16] This may be one of the reasons why many anti-stigma programmes and initiatives have, in part, been criticized for being largely uninformed by the lived realities of people with mental illness.[20]

Putting these geographical, theoretical and methodological gaps aside, it is also important that increased attention is given to researching and addressing the stigmatization of mental illnesses and the discrimination of those affected. Stigma and discrimination towards the mentally ill have pernicious implications for prevention and treatment of mental illnesses, as well as the rehabilitation and quality of life of those who suffer from mental disorders.[14,25,26] There is much evidence to suggest that stigma and discrimination ensuing from it can have adverse effects on those with mental disorders' willingness to access appropriate care and adhere to treatment regimes.[20,27] The personal and social costs that result from untreated mental disorders are also considerable, including lost employment and reduced productivity, together with possible suicide, homelessness and the disruptive influence on family life.[21,28] In addition, stigmatization and discrimination of those suffering from mental disorders hinders their ability to integrate into society and ultimately recover from their illness, due to the frequent personal harassment, social isolation and economic exclusion they experience.[5,13] Forms of structural and systemic discrimination, such as limited allocation of resources to psychiatry, also hinder advances of the profession.[2] All of these issues in turn pose major barriers to alleviating the already significant public health burden of mental health.[29-31]

A promising sign is that in recent years, the elimination of stigma and discrimination of mental illness has been taken on board as a central target by various agencies and governments internationally. The World Psychiatric

Association has recently initiated a global programme against stigma and discrimination, and twenty countries are participating in the programme.[20] The European Union's recent consultation about mental health promotion identified the fight against stigma as an important area of work for European countries, and the World Health Organization has highlighted the need to combat stigma and discrimination.[22,32] More initiatives, particularly in Africa are however urgently needed.

The aim of this qualitative study was to explore the possible presence, likely causes and potential means of addressing stigma and discrimination against the mentally ill in Zambia. In line with approaches proposed by Thornicroft et al and Link and Phelan, the current study employed a broad understanding of stigma and discrimination in relation to mental illness, including individual attitudes and behaviours, as well as more macrosocial systemic stigma and discrimination.[16,27] These issues were explored by assessing the views and attitudes of a number of specific population groups, including mental and general health care providers, policy makers, users of psychiatric services, teachers, police officers, academics, and traditional healers. Being based in Sub-Saharan Africa, utilizing qualitative methodologies, performing micro- and macro-level analyses, and focussing on specific populations, this study speaks directly to many of the geographical, theoretical and methodological gaps germane to the contemporary mental health stigma literature. Based on the insights drawn from this study, recommendations will be provided on how such stigma could be addressed in Zambia and other low income African countries.

Method

The data collection for this study formed part of a situation analysis of the current status of mental health policy, legislation and services in Zambia which was conducted as part of the first phase of the Mental Health and Poverty Project (MHaPP). The MHaPP, which is being conducted in four African countries, Ghana, South Africa, Uganda and Zambia, aims to investigate the policy level interventions that are required to break the vicious cycle of poverty and mental ill-health, in order to generate lessons for a range of low- and middle-income countries.[33]

This particular study focuses on the qualitative data obtained from the MHaPP situation analysis. Fifty semi-structured interviews and six focus group discussions were held with policy makers (from the Ministry of Health and elsewhere), health and mental health care professionals, users of psychiatric services, teachers, police officers, academics, members of three NGOs and traditional healers. In total, the study sample was 65 respondents, who were sampled from three districts in Zambia (Lusaka, Kabwe and Sinazongwe). The fieldwork for the study was conducted in 2005 and 2006.

The sampling of respondents for the semi-structured interviews and focus group discussions was purposive. Respondents were selected mostly because they were known to be resourceful people and had the experience that was particularly relevant to the study. The participants were also selected based on the principle of maximum variation, in order to provide as wide a range of perspectives as possible on mental health policy development and implementation in Zambia.

The duration of the interviews and focus group varied between 45 – 120 minutes. Six focus group discussions were conducted with no less than six participants and not more than eight at the most. A focus group consisted of homogenous participants (with nurses alone, clinical officers alone and patients alone), although in two instances focus group discussions were conducted in the company of nurses and clinical officers. Clinical officers are front line staff in the delivery of mental health care in primary health care units in both long stay facilities and daily outpatient facilities. Such staff members are at a level higher than nurses but lower than doctors, with the law inhibiting them from administering psychotropic drugs.

The participants who were interviewed individually included stakeholders from various sectors as follows:

- Directors: Ministry of Health: 5
- Directors: Ministry of labour: 1
- Director: Ministry Home affairs: 1
- Director: Education: 1
- Director: Ministry Community Development & Social Services: 1
- Director: Ministry Local Government & Housing: 1
- Commission of Prisons: 1
- HMIS specialist: 1
- Director (DHMT) Lusaka: 1
- Provincial clinical care specialist: 1
- Medical doctors: 4
- Clinical psychologists: 1
- Clinical officers: 4
- Nurses: 6
- Mental health NGOs: 5
- Family members: 3
- Users: 3
- Social workers: 1
- General psychologist: 1
- Teachers: 3
- Policemen: 2
- Traditional healers: 1
- Prison warden: 2

The interviews were loosely structured, consisting of open ended questions that broadly defined the area to be explored, and from which the interviewer or interviewee could diverge in order to pursue an idea on a specific issue in more detail.[34,35] The semi-structured interviews and focus group discussions were tailored according to the specific individual being interviewed. The following generic areas were mostly covered in both the semi-structured interviews and focus group discussions:

1. The general health context in Zambia
2. Key challenges facing the health system
3. Perceptions of mental health and persons with mental disorders
4. Mental health needs and priorities in Zambia
5. Key challenges facing the mental health system
6. The general policy making processes
7. Process of mental health policy development.

8. Role of various stakeholders in mental health policy
9. Content of the current mental health policy and legislation
10. Mental health policy implementation
11. Mental health research

Various scholars emphasize that the major advantage of focus groups lies in their ability to mobilize participants to generate their own questions in their own vocabulary and to respond to and comment on each other's contributions on their own terms.[36] Statements are challenged, extended, developed, undermined and qualified in a way that generates rich and in-depth data. This is particularly pertinent for the current study because as highlighted earlier, stigma research has tended to ignore the social and structural underpinnings of stigma. Thus, the utilization of focus groups allowed the researchers to tap into how representations and meaning systems in relation to mental illness are articulated, formed, changed, negotiated, censured, justified, diversified and jointly constructed within social networks and social interactions. Furthermore, the focus groups may shed light on certain shared norms and communal understandings, as well as discrepant and divergent views. For this reason, the data collected from the focus groups both enhanced and expanded upon some of the issues that emerged within the individual interviews.[37,38]

Permission to conduct the study was obtained from the Ethics Committee of the School of Medicine, University of Zambia and the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town, South Africa. We provided detailed information to participants concerning participation and the consequence of the study, and thus participation was voluntary. With the consent of individual participants, all sessions were digitally recorded and transcribed verbatim. All digital recordings were erased following transcription, and all identifying information was removed from all transcripts. Confidentiality and anonymity was thus ensured. Transcripts were entered into Nvivo 7 which was used for coding and analysis.

The analysis was undertaken using a grounded theory approach. As the name implies, grounded theory refers to generating theory and understandings which are 'grounded' or which emerge from the data that is systematically gathered and analyzed.[39] The objective is to build and expand, rather than test theory, allowing for the discovery of new insights and enhanced understandings that are derived from the coded categories, themes and patterns. Grounded theory is useful in undertaking local research where it may not be wise to transfer theory generated in more western settings onto an African context.[40]

Grounded theory enabled the researchers to inductively identify categories, themes and patterns that emerged from the data, as well as interpreting and contextualizing the text at greater depth to uncover deeper meanings and themes. A broad generic coding list was created by the study team, where after more refined codes were formulated inductively.

Results

Widespread stigma and discrimination

The results revealed that mental illness stigma and discrimination is widespread in Zambian society. This surfaced in three different ways. For the most part, this emerged when participants were asked directly whether stigma and discrimination of mental disorders occurs. On other occasions, a number of the stakeholders spontaneously volunteered their thoughts on these issues. Finally, when reading each interview as a whole, in their entirety, it became clear that some of the interviewees themselves had certain stigmatizing tendencies. Discourses of stigma seemed to speak through the participants' talk of mental health.

Within the general community:

> *''This is a mad person, so what is he doing in the community...''*

An overriding theme amongst participants from all of stakeholder groups interviewed was that stigma towards the mentally ill is rife in Zambia. The interviews were saturated with comments that people with mental disorders are ''stigmatized'', ''feared'', ''marginalized'' and ''labelled in exclusively negative terms''. It was emphasized that such people were commonly seen as ''rejectees'', ''stupid'' ''embarrassments in the community'' or the ''laughing stock of the community'', and thus relegated to the identity of ''just a Chainama case''. Chainama is the main psychiatric hospital in Lusaka. The list of the negative ways in which the mentally ill appear to be perceived in the general community was incessant. One mental health nurse most succinctly captured community attitudes when she articulated:

> *'You know a mentally ill patient is always stigmatised, wherever she goes, whenever she does anything, people in the community would say cofuntha [you are mad].'*

These views were confirmed by some of the mental health service users themselves that were interviewed. For example, one mentally ill patient, who suffers from depression lamented:

> *'My association with Chainama aggravated the stigma in the community. So, I came in contact with stigma and discrimination and that introduced me to life of misery, you know you can't get a job...you can't be accepted. I couldn't see hope and my future was chopped off. I live a life of loneliness'.*

This patient highlights some of the kinds of discrimination that appears to ensue from such widespread community stigma. Indeed, a number of respondents indicated how the mentally ill are frequently ''discharged from their duties'' and ''kicked out of employment''. Furthermore, a social worker explained that *''You find people with mental problems are attacked, and then you find the community just stands around cheering, bullying and throwing stones at them''.*

Many participants emphasized that such widespread stigma in the community also frequently extends to

everything that is associated with mental illness. Family members of the mentally ill were perceived by many of the respondents to experience stigma themselves, as articulated by a member of a mental health NGO:

> *'Stigma associated with mental illness is transferred to their afflicted family members. They too are affected in a big way... it is assumed that the whole family is mad.*

Similarly, a social worker explained, *'The community also rejects the family. The whole family is seen as tainted, so the community does not accept the family and the individual'.*

It seems that the Chainama mental hospital is itself a source of widespread negative attitudes. As a general medical doctor explained:

> *'Some patients have told me that they would love to change the name Chainama into something else like probably Kenneth Kaunda Hospital. Why do they say this? Because Chainama has always been stigmatized...Just the name is seen as negative'.*

The all-embracing nature of mental illness stigmatization in Zambia was most aptly revealed by a general nurse's comment that even a neighbourhood can be stigmatized if a patient is known to have lived there:

> *'You will find that once there is an illness in the neighbourhood, the neighbours will not want to stay there, because they will be saying that ''apa pali cimunthu cofunta'', meaning there is a mad person here'.*

Amongst family members of the mentally ill:

> *''Family members themselves are indeed culprits in this area...''*

Although widely acknowledging that the relatives of those suffering from mental disorders are frequently stigmatized, many respondents also suggested that family members themselves often hold very negative views about mental illness, and treat their family members affected very badly. Many allied mental health professionals indicated that the mentally ill are frequently *''viewed as subhuman by their own flesh and blood''* and *''discriminated against by their closest friends and family''.*

It seems as if abuse of the mentally ill within the family is widespread, as indicated by this social worker:

> *'You find that even in their own homes they are being troubled by their relatives. I remember when I was called to go and see a patient who was kicked up within the home once he was discharged'.*

Many respondents highlighted how many mentally ill persons are ''abandoned by their relatives'' or ''not accepted by their family''. A mental health service user said that ''I experience discrimination, especially from my relatives''. A similar view was expressed by another mental health service user:

> *'To some extent, they [family members] also promote this human rights violation. I remember when we had a focus group discussion and a lot was coming out that family members themselves are indeed culprits in this'.*

It seems that a mentally ill child suffers particularly pernicious stigma by their family. One policy-maker in government movingly stated that if a parent has a mentally disabled child, and you ask them how many children they have, it is common for them to reply ''we have three and then there is that unusual one''. Similarly, a school teacher remarked:

> *'Some parents wouldn't want to be recognised that they have such children. These children are unwanted. These days...they wouldn't want to keep their children and not wanting to be seen that they have such people in their homes'.*

Amid general health care providers:

> *''Why are we occupying mental patients because it is said that an idle mind is the devils workshop...''*

In the interviews and focus group discussion with general health care practitioners, it became clear that these individuals may possess certain, albeit more subtle, stigmatizing tendencies. Stigmatizing discourses appeared to seep through some of the stories that they told, and the remarks that they made. For example, the above quote by a general health nurse illustrates this point while talking about the under-staffed and over-burdens hospitals in Zambia. In expressing her frustration over her own workload, the negative views this nurse holds about mental patients is clearly revealed. Similarly, when talking about a meeting she attended with mental health patients, another general health nurse articulated:

> *'I attended a workshop run by _____ [NGO] and like, we look at these people [people with mental illness] as if they can't do anything. But at this meeting, I mean I forgot that we were dealing with mental patients, they came up with ideas, a lot of ideas. I was so surprised at how intelligent they actually are...'*

Although this nurse is providing an account of a situation where her negative views about mentally ill people were challenged, the denigrating assumptions she usually holds about such individuals is starkly revealed. One is struck by the surprise she displays in relation to how ''intelligent'' this group of mentally ill people were. Similarly, when talking about how she sympathizes with families who have a mentally ill relative, another nurse emphasized:

'They are a burden to their relatives...if they can be more independent, they will be respected as human beings'.

The negative views that some general medical practitioners appear to hold was confirmed by comments made by other stakeholders who were interviewed. For example, in describing a situation when he had to take a person with a mental illness to a general hospital, a prison warden exclaimed:

'These patients are rarely attended to when they go to general hospitals. All of the staff their will just say, ''nichofunta ichi chiyende ku Chainama'' meaning that's a mad person let him/her be attended to by the Chainama guys'.

This view was shared by a few mental health nurses, who said that when they have taken a mental patient to the general hospital, the staff there ''don't want mental patients'', ''are rude to them'', remark that ''this is a Chainama case so it's not there problem'' and thus frequently ''do not attend to the person''.

This lack of care afforded to people with mental illness in general hospitals was reiterated by a mental health user suffering from depression, when he described an incident when he went to get medicine at a general hospital:

'I went to _____ clinic, and oh dear me, a nurse came out so strong and said 'who told you that we stock medicines for mad people here'?

Amongst mental health care staff:

''It's like they don't see that you are a person like everybody else...''

Although expressing great uneasiness with the way in which many general health practitioners' appear to perceive and treat the mentally ill, it became apparent that some mental health care professionals themselves may not be exempt from possible stigmatizing tendencies. At times, this was revealed in quite an overt manner. For example, when describing some of the staff in the mental hospital, a psychologist exclaimed:

'If their relatives bring them food, they can't put it in fridges, because they are perceived that they are sub-human. If they look at them, they are perceived that they cannot even suffer from malaria hence, no mosquito nets in those wards'.

In addition, accounts given by mental health patients and their families revealed that mental health professionals do not always think about and behave towards patients in the most amicable ways, as indicated by a family member of a mental health service user:

'He is treated really badly at the hospital... For instance, he told me how he was being beaten when he was admitted. These people who work with the patients should be more knowledgeable...Even the nurses say iwe yenda ku Chainama [hay you are just a Chainama case]'.

Similarly, a mental health service user sadly explained:

'Sometimes the way we are treated in the wards, it's like they don't see that you are a person like everybody else, sometimes you are even beaten, we were being beaten and insulted. You can't like it'.

Some of the negative views certain mental health care practitioners appear to hold were also revealed in more subtle ways. For example, when asked whether service users should be included in policy development, one clinical officer in psychiatry rather tentatively replied:

'Well, um, I mean, I suppose, like they are not always sensible...you know they can't really function properly, so it will be very difficult for them to come up with comprehensive ideas'.

Similarly, in answer to the same question, a mental health nurse exclaimed:

'I am not sure, but I think as care takers we know what is good for them and what is not. Often they choose something that is not good for them, so they should have a limit there'.

Although submerged in uncertainty, both of these mental health practitioners' remarks tend to be to link to the rhetoric of incapability and powerless so characteristic of views about people with mental illness.

At the level of government:

''Mental health...is the Cinderella of the health services, as it is the last aspect of it...''

It became clear that more structural forms of discrimination are rife at the level of government. This was most aptly revealed in respondents' discussions around the current mental health law, as well as the limited funding allocated to mental health. A number of respondents indicated that the mental health law is ''old fashioned'' and uses ''very ancient and derogatory terms like imbecile and idiot''. It was emphasized further that this current law ''does not protect the rights of the mentally ill'' because the ''patient has no say when it comes to the law''. The degrading nature of the current mental health law in Zambia was most pertinently revealed in one mentally ill patient's narrative about stigma:

'One of the biggest problems is the law itself...it actually deposits a person with a mental illness as a dangerous person, as a person with no worth. The way law describes me. Who am I? The identity that I am given by the law is an imbecile, an idiot...'

Other health professionals commented on the way in which psychiatry is sidelined through its unequal or scanty distribution of resources in health care. During an interview with a district health officer, the interviewer remarked that he thought that a certain amount of money was specifically dedicated for mental health. The respondent replied:

> *'I have never heard of that money, that is news to me. I have never come across a budget allocated to the district for mental health care... Mental health...is the Cinderella of the health services, as it is the last aspect of it... The monies which come here are just not adequate'.*

The limited funds dedicated to mental health was reiterated by a psychologist when she explained,

> *'There is the complete neglecting of mental health issues. I think we devote less than 1% of health expenditure to mental health which is a sad state of affairs'*

Possible causes of stigma and discrimination

Having shed light on the omnipresent nature of stigma and discrimination within Zambian society, we now turn to exploring some of the possible reasons for such widespread negative views and behaviours.

Constructions of mental illness aetiology:

> *''So it all starts with the definition itself...''*

It became clear that dominant views around what causes mental illness in Zambian society may play a significant role in producing stigmatizing attitudes towards people with such disorders. Firstly, hegemonic cultural explanatory models of mental disease aetiology appears to be a major contributing factor towards mental illness stigmatization and discrimination, particularly amongst those not in the fields of general or mental health care. There was a great deal of consensus amongst respondents that mental illness in the general community tends to be understood as ''bewitchment'', ''Satanism'' and ''evil spirits'' and that the individual has ''been cursed'' or ''possessed by demons''. A number of participants explained that it is commonly believed that the individual has done something wrong in the community, such as ''stealing'', ''telling lies'', ''committing atrocities with other innocent people'' or ''getting with another man's wife'', and as a result, the person or a member of their family, is bewitched. As described by one mental health nurse,

> *'When mental illness is in the family, it is seen as a sign that one of the relatives in the family did some thing which is not supposed to be done. So, its like an omen or an abomination, so they are punished, bewitched, through poor mental health, through mental illness. Like a curse from God'.*

As indicated by this nurse, given understandings of mental illness aetiology, the supposed resulting mental illness is consequently perceived to be divine punishment for immorality. A few respondents made the link, explicitly, between this cultural authority of traditional constructions of health and illness and stigmatization. For example, after talking about dominant understandings of the causes of mental illness, a member of a mental health NGO concluded:

> *'So, generally, the picture is that, because of the way people understand mental illness, the community has been persecuting the mentally ill and that is why these people have never enjoyed the comfortable life'.*

In a similar way, a clinical officer in psychiatry remarked:

> *'People still think that mental illness is caused by evil spirits. They believe that any person suffering from mental illness is demon possessed. And these explanations affect the way they perceive mentally disabled people... So it all starts with the definition itself'.*

In addition to dominant cultural explanatory models of mental disease aetiology, drug and alcohol abuse was highlighted, particularly amongst participants in the general and mental health fields, as an additional causative factor for mental illness. This perception also appears to contribute to the stigmatization of mental illness.

A number of health professionals explained that drug and alcohol abuse is a major cause of mental illness. In the participants' descriptions, it became clear, that such views translate into the notion that mental illness is self-inflicted. This in turn appears to elicit blame, rather than understanding or compassion. For example, one clinical psychiatric officer elucidated:

> *'So many of the disorders are from substance abuse...they abuse alcohol, they abuse these illicit drugs, cocaine and related ones, and then they wonder why they get mentally ill...'*

Through this account, this health care provider implied that mental illness is a calamity one brings upon oneself, and is thus condemns mentally ill patients for ''inexcusably'' imposing risk upon themselves. Similarly, a mental health nurse described a patient she knew who ''had no direction'' and thus ''just sat around smoking dagga'' and then ''expected people to feel sorry for him when he fell ill''. The sentiments of disapproval and blame are clearly revealed by these remarks. A few other mental health care workers also recounted stories with similar morally punitive undertones.

Fear:

> *''People are just scared...and fear always makes people behave in negative ways''*

It became clear that mental illnesses have induced an emotional context of fear and anxiety in Zambian society.

People within the general community, as well as some health care practitioners appear to harbour immense fear towards mental illness. Such trepidations appear to stem from perceptions that mental illness is contagious and transmittable, and that mentally ill people are dangerous. For example, participants described how many people in society ''believe that mental illness is contagious''. As a member of a mental health organization said:

> *'Most of the organizations that we came across have a belief that a bite from a mental patient affects the other person to be mentally ill. Now with such kind of beliefs, do you expect the community to give proper care to the patient?'*

The way in which such fear translates into negative attitudes and behaviour is clearly revealed by this respondents comment. Other respondents highlighted that many people in Zambia believe that mental illness is genetically transmissible. Consequently, people are afraid to marry someone from a family where mental illness exists, in case the new children get ill, as described by a teacher:

> *'Others think it's an inborn thing that is passed from generation to generation, meaning that, if there was a mentally ill patient in a family, then this will get passed down into subsequent families...So people are scared...'*

Although there most certainly is evidence supporting the contribution of genetic factors to mental illness, the way in which this evidence is interpreted and the fears stemming from this, contributed to the stigmatization of mental disorders and those affected. In conjunction with fears of infection and transmissions, other participants, particularly in the general health field, expressed immense fear around the supposed violent and aggressive nature of people with mental illness. A few general medical doctors provided in-depth narratives about how dangerous and risky mentally ill people can be:

> *'It is very risky for you to be working in the psychiatric ward...you really have to be very careful because it is risking. Patients can end up beating you so you need to be very tactful...Either you will be physically attacked.*

Similarly, in talking about why mental health patients should not be treated in the general health care sector, another general health officer

> *'You see, these mental patients when they get sick they become violent so they threaten the people that we keep here...They become so aggressive...'.*

It thus seems that a myriad of fears are associated with mental illness, which may contribute to the widespread stigmatization of people with mental disorders. Indeed, as a man suffering from anxiety explained:

> *'People are just scared. I can see that they are afraid of me, and fear always makes people behave in negative ways.'*

Association with HIV/AIDS:

> *''People's views about AIDS accounts for a lot of why mental illness is seen as so negative''*

The stigma surrounding mental illness appears to be buttressed and/or produced, at least in part, by HIV/AIDS stigmatization. General and mental health practitioners and policy-makers emphasized a significant link between mental illness and HIV/AIDS, indicating that many people suffering from mental disorders are also HIV-positive. As a clinical officer in psychiatry exclaimed:

> *'Nowadays there are so many patients who are mentally ill with HIV... I would say that from my own experience, I have seen that many people, particularly women suffer from HIV/AIDS related mental disorder'.*

This was reiterated by a policy maker in government who said:

> *'With HIV pandemic, there are now a lot of people with mental disorder due to HIV/AIDS.... lets say 80% of them could be HIV related... AIDS is a catalyst for mental health so you can't separate HIV from mental health'.*

It seems that the mental health and HIV/AIDS link is widely known in the community, with a common prevailing perception being that HIV/AIDS causes mental illness, as indicated by this mental health nurse's remark:

> *'Most people think that mental illness is because of HIV/AIDS, although others think they have just been bewitched'.*

Indeed participants in the general health field indicated that people ''often assume that if one is a mental patient, one also has HIV''. Given this epidemiological profile, together with the common assumptions it evokes, a few respondents explained that mental illness stigmatization is produced by HIV/AIDS-related stigma. A mental health NGO member argued:

> *'I think that people's views about AIDS accounts for a lot of why mental illness is seen as so negative... If people see a patient from Chianama, they will say, 'Oh, he must have AIDS'... And, we still face a lot of stigma with AIDS...'*

Similarly, a psychiatric officer explained:

> *'Sometimes they would say mental illness is because of infections which are HIV related or other infections like syphilis and you know these kinds of diseases carry a lot of stigma already...'*

Challenging mental illness stigma and discrimination

Respondents from all stakeholder groups interviewed, emphasized that increased attention and commitment towards addressing the widespread stigma and discrimination surrounding mental illness in Zambia is urgently needed. Community sensitization and public awareness campaigns were indicated as the primary approaches that should be used. It was stated that people need education about ''the causes of mental illness'', ''how mental illness can affect anyone'' and how ''with the right treatment, people can be cured and function as normal''. It was emphasized that this is essential for people to ''start accepting mental illness'' and ''perceiving the mentally ill as human beings''. For example, a general medical doctor suggested:

> *'We need to sensitize people in the community to make them understand what mental illness is all about. They need to know that they [the mentally ill] are sick just like any other illness'.*

Other respondents emphasized particular groups that may need to be targeted for awareness campaigns. For example, a policy-maker in government highlighted that employers need to be targeted, so as to avoid inappropriate discrimination:

> *'Employers need to be educated that there is a certain level where someone can continue with his job and contribute effectively to the organisation. So I think that the target should be the employers, the people with the authority to keep someone in the organisation'.*

In addition to awareness campaigns, a number of respondents indicated that redressing stigma and discrimination requires a strong and relevant mental health law and policy. As one clinical psychiatric officer explained:

> *'I think that if the government could come in and strengthen the policy on mental health probably the stigma would go down.'*

This was reiterated by a mental health service user, who movingly supplicated for policy and law transformation to promote stigma reduction:

> *'Please, plead to pioneers to take the issue of policy and law very seriously if we are to move... The law needs to start looking at mental health from the human rights point of view....'*

Other respondents emphasized that appropriate law and policy is not enough, as reducing stigma and discrimination that ensues from it requires actually supporting the rights of people with mental disorders, as one mental health NGO member explained:

> *'There is need to actually promote the equalisation of opportunities. They need to participate in decision-making, full participation. There is need for opportunities in employment, education and rehabilitation services. These steps need to accompany awareness campaigns.'*

Discussion

This study provides qualitative insights into the presence and possible causes of stigma and discrimination in Zambian society, as well as shedding light on what key stakeholders perceive to be the best ways of addressing such stigmatization. To our knowledge, this is the first in-depth study on mental illness stigma in Zambia. This study is also novel in its attempt to explore the attitudes and beliefs of a number of specific population groups, including general and mental health staff, family members of mental patients, as well as government officials. It also attempts to give agency to the views of those actually suffering from mental disorders, voices which are frequently neglected in research. As Link and Phelan argue, stigma research is frequently conducted by researchers ''who do not belong to stigmatized groups, and who study stigma from the vantage point of theories that are uninformed by the lived experience of the people they study''.[16]

The results from this study revealed that stigma and discrimination towards mental illness and those affected are ubiquitous and insidious across Zambian society, prevailing within the general community, amongst relatives of patients, amid general and mental health care providers, and at the level of government. Such stigma also appears to be all-embracing, being directed not only towards those labelled as mentally ill, but also extending to their family members across generations, and even to the mental hospitals themselves. This corroborates findings from other studies, which have also shown that stigma extends to family members and mental hospitals.[2,19,41-42] This picture thus contrasts with assertions that have been made that stigma and discrimination of mental illness is less severe in African countries.[7-8]

Although mental illness stigma appears to be present across Zambian society, the nature of such stigma most certainly differed between different stakeholder groups. The results revealed that stigma residing within the general community and amongst family members is extremely blatant, with a plethora of negative labels being assigned to, and a range of abusive and neglectful behaviours being directed towards, the mentally ill. These findings confirm the results from the few other studies which have been conducted in Africa, which have also shown community stigma and discrimination surrounding mental illness to be overt and pernicious.[7,9,11-13]

The results revealed that some, although not all, general and mental health practitioners may also hold certain negative attitudes towards the mentally ill. Most certainly, such perceptions appear to be more subtle and less crude those residing within the general community. Nonetheless, certain stigmatizing tendencies do appear to be present amongst health care providers. This was revealed by the accounts given by service users and their families, as well as through some of the actual remarks made by such practitioners in the interviews. Schulze indicates that possible stigma amongst health care providers has been a neglected area of research, and a blind-spot in anti-stigma initiatives.[20] A handful of studies that have explored this area have found that health and mental health professionals may contribute to the development and reinforcement of

mental illness stigma.[22,24,32,43] As was the case in this current study, these studies also found that such professionals may use derogatory terms for mental illness, may refuse to treat physical illness in those with mental illness and frequently assume that people with mental illness are incapable and powerless to make decisions.

A disheartening finding from this study concerns the systemic discrimination that prevails at the level of government and policy. This study revealed that mental health legislation contributes to the very disparaging labels assigned to people with mental disorders in Zambian society. Furthermore, mental health appears to be structurally disadvantaged, being allocated inadequate funding. These findings are confirmed by quantitative research carried out in Zambia which found the law to be outdated, and funding insufficient to meet even the basic mental health needs of the country.[44] This situation is not unique to Zambia. WHO Mental Health Atlas revealed that many low income countries in Africa have mental health legislations that are outdated and not in accordance with international human rights standards.[45] In addition, inadequate funding for mental health is an insidious problem affecting many low-income African countries.[31,46,47]

This study also shed light on some of the possible causes of this widespread stigma and discrimination. For the most part, respondents were not asked directly, nor did they spontaneously provide an explanation, as to why such stigma and discrimination exists. Although a direct link was not always made, when reading the respondents' narratives, possible rationales for the ubiquitous stigma materialized. The manner in which stories are told, the emphases and links made, the morals drawn and the details, justifications and conclusions made, are all very revealing often beyond the storytellers' intent.[48] For example, a respondent may be talking about the link between mental illness and drug abuse, and then subsequently conclude with negative characteristics about the person. Thus, by putting the pieces of data together, and contextualizing them with the interview as a whole, more subtle insights can be gleaned.

As shown in other studies views about causation were strongly associated with stigmatizing attitudes towards people with mental disorders.[3,9,49] As with many studies in the West, this study showed that the associations of mental illness with drug and alcohol abuse generate sentiments of blame and condemnation, holding those affected responsible for their illness.[20,32,50] Negative attitudes to mental illness and associated blame also appeared to be fuelled by cultural and religious views about disease aetiology, seeing mental illness as divine punishment for atrocities committed. This confirms Gureje's remark that stigmatization of mental illnesses probably exists everywhere, even though its causes and manifestations may be culturally-specific.[9] More studies are needed to explore the culturally-specific causes, forms and nature of mental illness stigma, so that tailor-made educational campaigns can be more culturally sensitive.[26]

An unexpected finding from this study, that appears to not have been shown elsewhere, was the way in which HIV/AIDS stigma may produce and reinforce mental illness stigma. This was not a major focus of the study, nor was it the main theme that emerged. It was thus not fully explored or unpacked during the interviews. Further probing might have elicited possible reasons for this finding more explicitly. It is possible to speculate on the likely explanations for this relationship. As with mental illness, HIV/AIDS is highly stigmatized.[51] Given that there was widespread belief in Zambian society that people with mental disorders are also frequently HIV-positive, such persons, whether they are positive or not, may suffer twin-stigmatization: HIV and mental illness-related. This clearly reflects Treichler's contention, when talking about AIDS as an 'epidemic of signification', that 'AIDS is a nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce and subvert one another'. More studies are needed to explore this area further.[52]

The myriad of fears surrounding mental illness may also be a contributing factor to its stigmatization. Fears of contagion and transmission as well as the fears of mental patients being violent and aggressive were widespread across the different stakeholders interviewed. Indeed, stereotypes of the dangerousness of people with mental illness appear to be common, and a key factor contributing to stigma and discrimination.[21,48,53]

Various scholars working within a psychosocial perspective have argued that fear might be a driving force underpinning stigma.[54-56] It has been suggested that when people are faced a potential threat, such as mental illness, in order allay the fear it induces, people frequently 'other' or stigmatize the threat and those associated with it. This process helps people to distance themselves from a sense of personal risk and vulnerability.[57-58] Thus, far from being a rational and cognitive process, from this perspective, stigma may rather be a complex unconscious, irrational and emotional process. Thus, despite various assertions that knowledge is a protective factor against stigma, this theory raises questions around the role that information and education may actually play in preventing stigma.[25-26] This understanding of stigma, as related to primal fears and anxieties rather than knowledge, may help one to understand why many health care providers in this study appeared to hold certain, albeit subtle stigmatizing attitudes.

This psychosocial theory may also help one to understand why many people who held stigmatizing views, also emphasized the need for increased attention and commitment towards addressing the widespread stigma and discrimination surrounding mental illness. This apparent contradiction becomes somewhat clearer when one understands that stigma may be an unconscious and unintentional process. Indeed, one was constantly struck by the unawareness so many mental and general health care providers displayed when making certain derogatory remarks.

Many different recommendations were put forward concerning how to address such stigma and discrimination. Strategies suggested included awareness raising campaigns and health education programmes. It was also emphasized that the current mental health law needs to be revamped and transformed, and the social and economic opportunities of the mentally ill expanded.

Anti-stigma initiatives globally have tended to focus on reducing mental illness stigma by changing beliefs and attitudes through three dominant ways: education (which replaces myths about mental illness with accurate conceptions), through contact (which challenges public attitudes about mental illness through direct interactions with persons who have these disorders) and through protest (which seeks to suppress stigmatizing attitudes about mental illness).[21,59-61] The results from this study indicate that such initiatives need to be broadened and expanded.

For example, the results suggest that mental and general health staff should themselves be an important target for anti-stigma initiatives. The results from this study shed light on the fact that challenging mental illness stigma may need to go beyond providing 'correct' information and education, at least amongst health care providers. It may entail providing a space for people to engage with, and be open and honest about the fears and anxieties they may have around mental illness. They need to be encouraged to reflect on their own fears, separating those that are realistic from those that are irrational. Such professionals need to be made aware of, and encouraged to take cognisance of their own attitudes, and the ways in which they may produce and reproduce stigma. This is by no means an easy task, as stigmatization may be serving a deep-seated and frequently unconscious defensive function.

Furthermore, the findings from this study suggest that HIV/AIDS-related stigma may need to form an important component of efforts to reduce mental illness stigma. In addition, anti-stigma initiatives also need to target the structural conditions that create and exacerbate stigma and discrimination. These include developing new legislation, policies, and programmes that are based on international human rights standards for people with mental disorders, securing funding for mental health and promoting the life opportunities of people with mental disorders. All of this will require increased political will from government and relevant stakeholders to promote mental health. These initiatives are essential if we hope to reduce the widespread stigma and discrimination surrounding mental illness in Zambia and other low income countries. Ultimately, the words of one service-user in this study, as highlighted in the title of this paper, are an urgent call to start placing mental heath stigma on the national agenda:

> *'I hope that one day, a person like me could walk head up into a psychiatry unit and say 'look doctor, I have not slept for three to four days please diagnose me'. And I would not feel afraid to say this'.*

Conclusion

Despite the common occurrence of mental health problems, and worldwide anti-stigma efforts, societies continue to hold deep-seated and culturally specific, negative attitudes about mental illnesses. It has been shown that attitudes and behaviours are not fixed and concrete attributes, but have the potential for change. The possibility of reducing stigma thus most certainly exists. Redressing more structural discrimination may be more difficult, as it reflect complex socioeconomic and political forces, directly linked to the wider notions of power, exclusion and control. Ultimately, it requires that policy-makers and other relevant stakeholders start recognizing the devastating personal, social and economic consequences of mental illness, and commit to prioritizing it as a public health and development issue.

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