Original Research

The Stigma of Mental Illness in Sri Lanka: The Perspectives of Community Mental Health Workers

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Abstract

Objective: To gain an understanding of how stigma associated with mental illness exists in Sri Lanka from the perspectives of community mental health workers and to explore their views on how stigma may be tackled in the future.

Methods: Purposive and snowball sampling methods were used to recruit community mental health workers for this small qualitative study. Nine semi-structured interviews were conducted using an interview guide. The data were analyzed using the 'thematic framework' approach.

Results: Stigma is associated with the family unit; there is strong faith in traditional beliefs and healers; and negative attitudes and behaviours exist regarding mental illness. Community mental health workers are influenced by poor health seeking behaviours and low prioritization of mental health services in the country.

Conclusions: This study provides insight into how stigma exists in Sri Lankan communities and influences the work of community mental health workers. Findings reinforce existing international health literature and thus convey that stigma is an important issue that must be tackled globally.

Implications: Community mental health workers can contribute to reducing stigma by increasing awareness of mental illness in various ways but increasing the availability of services within Sri Lanka is also a key to reducing stigma.

Keywords: mental health, Sri Lanka, stigma, qualitative research

Introduction

Approximately 5–10% of the Sri Lankan population is thought to be suffering from mental illnesses requiring medical attention (Castillo, 2009). Sri Lanka has one of the highest suicide rates in the world with rates higher than 20 per 100,000 (Hendin *et al.*, 2008; Siva, 2010). Enduring civil war conflict for over 30 years and the devastating 2004 South-East Asian tsunami may have had repercussions on the mental health of the population (Mollica *et al.*, 2004; Mahoney, Chandra, Gambheera, De Silva & Suveendran, 2006; Neuner, Schauer, Catani, Ruf & Elbert, 2006; Wickrama & Wickrama, 2007; Catani, Jacob, Schauer, Kohila & Neuner, 2008).

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Mental health care in Sri Lanka, as in many other low and middle-income countries, is plagued by poor funding, scarcity of trained human resources, and reliance on tertiary care (Saxena, Thornicroft, Knapp & Whiteford, 2007). There is only one psychiatrist for every 500,000 people (Siva, 2010). By comparison, Switzerland has 150 psychiatrists per 500,000 people (World Health Organisation, 2011). The deficit of trained mental health workers is worsened by geographical inequity, with the majority located in urban settings (Zolnierek, 2008; Siva, 2010).

Community based mental health services have been offered as a solution to this problem (Mollica *et al.*, 2004; Mahoney *et al.*, 2006; Prince *et al.*, 2007). These services are recommended as a way of increasing accessibility and reducing reliance on tertiary care (Mollica *et al.*, 2004; Mahoney *et al.*, 2006; Prince *et al.*, 2007). Community based

mental health services are available in some areas of Sri Lanka on an ad-hoc basis, but there is no formal system in place nationwide. However, according to the mental health policy of Sri Lanka (2005–2015) psychosocial trainers and community mental health education officers are to be recruited to staff community resource centres to provide primary care mental health services (Mental Health Directorate and Ministry of Health and Nutrition, 2005).

The other overarching barrier prevalent, not only in Sri Lanka, but worldwide, is stigma. Stigma associated with mental illness has been described as the *main obstacle to the provision of care for people with (mental illness)* (Sartorius, 2007, p. 810). Stigma has been defined as the combined effect of prejudice, ignorance and discrimination (Thornicroft, Rose, Kassam & Sartorius, 2007). Though international health literature acknowledges how stigma can act as a barrier to the accessibility of mental health services, there is paucity in the literature specifically regarding how stigma associated with mental illnesses exists and its impact among health workers in Sri Lanka. This study therefore sets out to explore how stigma exists in Sri Lanka and acts on the services offered by the community mental health workers from their perspectives.

Methods

Setting and Context

Apart from a non-governmental organization called 'Basic Needs' that utilizes community mental health volunteers in the Hambantota district; community mental health workers are mainly a mixture of different health professionals who provide community based mental health services in Sri Lanka. As yet, there is an absence of an organized system of community mental health workers throughout the country.

Design

The study design was qualitative. Semi-structured interviews were carried out with nine community mental health workers in Sri Lanka. Semi-structured face-to-face, confidential interviews were chosen as a feasible method of collecting the relevant data to answer the research question whilst also allowing participants the freedom to express themselves more or less on a particular topic. Individual interviews were carried out instead of group interviews or focus group discussions. A group situation may not have allowed for an in-depth discussion of the participants' individual experiences and thoughts, particularly given the sensitive nature of discussing mental illness (Green & Thorogood, 2009). Moreover, a hierarchy may exist in a group which may silence some members who feel they have less authority and less popular perspectives may not be fully explored.

An interview guide was used to gain consistent and comparable sets of data between participants. The interview guide consisted of five open ended questions and several probing questions to use if needed. 'Stigma' was not directly referred to initially to prevent 'leading' questions. Case vignettes were also used to understand how the community mental health workers would help in stigma-related situations. Case vignettes are an ethical method of exploring reactions to hypothetical situations whilst preventing participants from recounting their own experiences, which may prove emotionally difficult (Green & Thorogood, 2009). The interview guide and case vignettes are available from the author upon request.

On initial approach of enquiring about participation, six community mental health workers offered to conduct the interview in English because they were fully competent and this was accepted to reduce potential translation errors. Three interviews were conducted in Sinhala (one health professional and two non-health professionals), with an interpreter present. Before the interviews, the interpreter was briefed about the interview guide and throughout the interview clarified meanings. No participants were excluded from the study due to the language they spoke. The interpreter translated the Sinhalese responses as the interview went along. These English translations were transcribed following the interview.

Nine interviews were conducted lasting between 40 min to an hour. By the last interview, the data were saturated so the interview process was stopped. The interviews took place confidentially in clinic rooms at Katugastota Community Mental Health Centre and Angoda Hospital or participants' homes (Corrigan, 2004; at each).

Interviews were recorded and then transcribed within 24 h. The transcriptions were anonymous, stored on an encrypted memory stick and the audio files were destroyed.

The study has ethical approval from the Leeds Institute of Health Sciences Research Ethics Committee and the University of Sri Jayewardenepura Faculty of Medical Sciences Ethics Review Committee.

Sample

Initially, the sampling method was purposive to ensure that the participants were appropriate for the study with suitable experience in mental health, to attempt to gain diversity of opinion, and to obtain a sample in a reasonable time period. The Institute for Research and Development provided contact details of two key

informants at Katugastota Community Mental Health Centre and Angoda Hospital that could act as gatekeepers in recruiting participants. Health professionals and non-health professionals who were involved in providing community based mental health services were selected as participants. Following initial interviews, participants were asked to suggest further potential participants (snowball sampling), to reduce selection bias that may have been introduced by using gatekeepers whilst continuing to contact suitable participants.

All participants were given time to read and consider an information sheet and if willing, were asked to sign the consent form. Participants were assured that their confidentiality and anonymity would be maintained, and that they were able to withdraw from the study at any point. None of the approached potential participants declined to take part in the study. All nine participants provided written consent.

Results

Participants

Of the nine participants interviewed, there were only three non-health professionals. This included two doctors, three nurses, one occupational therapist, one development worker, and two volunteers. Their experience in providing community based mental health services ranged between 2 and 14 years (mean 7.6 years). No noticeable differences in responses were found between health and non-health professionals.

Results are loosely organized under the questions used. However, due to the nature of the interviews with open questioning and participants being encouraged to discuss and elaborate on their thoughts freely, there was overlap of significant points between questions. Hence presentation of the results has been adjusted to bring more structure for the reader.

1. How stigma associated with mental illness exists in Sri Lankan communities

Family

All participants stated that the community's views of a person with mental illness seem to be inherently linked with the view of the person's family. As one individual said: *It is severe in the community; there is stigma, not only towards the ill person, but towards the family.* Participants expressed how families hide relatives with mental illnesses. Some participants thought that because of lack of information about mental health services in rural areas, families keep mental illness hidden. Conversely, some considered that rural communities were more open about mental illness

than urban communities. For example, one participant felt that relatives *keep the person inside* being *overprotective* and concerned for the safety of the individual and others, rather than hiding the person away. This participant stated that this reasoning is more common amongst lower class families, whilst high society families are more likely to hide away an unwell relative due to shame. Shame and fear of how revealing mental illness would affect social status were more of a problem among high society.

Families also kept mental illness hidden from the community for fear that it would negatively impact on other family members' chances of marriage. *Some people think, if the brother has a mental illness, sister won't be able to get married so they want to keep the mental illness a secret.* Within the family, relatives with mental illnesses are viewed negatively if they are unable to contribute financially to the household. *If the person is inactive or non-productive, the family might think of that person as a burden to the family. Thus, part of the stigma is that the person is useless and doesn't contribute to the family.*

Behaviours and Attitudes

Participants agreed that while communities generally behave negatively and have negative attitudes towards people with mental illnesses, in some cases, community members try to understand and sympathize with people suffering from mental illness. One participant felt that, despite a lack of understanding, Sri Lankan close knit communities look after the mentally ill, and that the varied religious culture help to care for people. *The community takes people to temples, shares food, that whole system is very well established in this country.*

Nevertheless, participants also described how community members socially exclude people with mental illnesses; the main reason being that people with a mental illness are viewed as violent. *Some people in society are <u>scared</u> of people with mental illnesses; they are scared they will get hit, so they don't even go near them (emphasis added).* In addition, many participants stated that community members will assault and tease people with a mental illness. *More people treat them badly, making jokes, doing harmful things, attacking and neglecting.* All participants provided examples from their own experiences of the negative ways in which people with mental illnesses have been treated in the community, including community members running away from people with mental illness, throwing stones and using derogatory names. Such maltreatment was often secondary to religious beliefs about the causes of mental illness, and that the unwell person warrants punishment as he or she must have behaved badly in the past. One participant explained that when intentionally irritated, someone with a mental illness may become aggravated or violent, reinforcing fears of the mental ill in communities.

Another significant problem was the lack of awareness among authorities including the police. One particular high profile case in Colombo was referred to several times where members of public, and then subsequently the police, responded with violence to an individual who was throwing stones at cars. He ended up running away into the sea and drowning. Though he was known to mental health services, they were not contacted during the events.

Participants also agreed that the Sri Lankan media contributed to stigma associated with mental illness. Examples sited included poor reporting of news events where mentally ill people had been involved, and portrayal in films of *people with mental illness hurting children and things*. Though some considered that the media were improving, and programs promoting mental health awareness and providing advice were becoming more prominent.

Beliefs about Causality
All participants offered a number of beliefs about the cause of mental illness that exist in Sri Lankan communities. The most common response was that 'Gods and Devils' cause the development of mental illness. 'Paying for mistakes in a past life' was also a common but not unanimous response: *One might think that way for a physical illness like when someone becomes paralysed. But not for a mental illness.*

One commonly described belief was that spirits may cause mental illness. *They think that someone like a dead father, their spirit will take over you and cause the illness.* It was thought that this might be because community members commonly observe individual's mental state deteriorating following the loss of a loved one. 'Academic problems', through which a person develops mental illness because they are 'over educated' (young people who spend too much time studying**)**, fail to pass exams, or gain employment, were also expressed as potential causes. Similar to the reasoning behind the belief in being possessed by spirits, one participant attributed the association of mental illness with academia as likely due to peoples' observations of individuals becoming unwell during periods of intense stress, such as exams. These beliefs illustrate a lack of knowledge about the medical causes of mental illnesses in Sri Lankan communities. Stigma may be increased by these beliefs as they place blame on the person suffering from a mental illness, or 'outside' uncontrollable factors.

2. How stigma associated with mental illness impacts on community mental health workers

Health Seeking Behaviours
All participants cited 'poor health seeking behaviors' as a difficulty in providing community based mental

health services. Poor knowledge about mental illnesses and treatment options prevented people from seeking community based mental health services. *I feel that many people in the community are not aware about mental illness, the treatment or lack the knowledge about mental health.* Participants also linked the lack of awareness about treatment options to traditional beliefs regarding the cause of mental illness discussed earlier. *They think mental illness cannot be treated with drugs or therapy.* Alternatively, as one participant stated, *First of all, they* [society] *believe in Karma, so they think that life cannot be manipulated. All things we have to accept and suffer.*

Given these traditional beliefs, community members often prefer to seek help from traditional healers first. *Once they get the illness they first go to a spiritual healer to cut the influence of bad spirits. They come late to us. That is the problem.* One individual described how they go *through the track;* a *social stream* where an individual may see the village head person (gamarala), a fortune teller, a spiritual leader (katadirala), and god master (kapurala, devala), each with differing roles in traditional medicine, before considering 'Western' medicine. This causes a significant delay in reaching allopathic services creating a cycle whereby the delay causes late diagnosis and reduced efficacy of allopathic medicines, further enhancing the belief that these medicines are ineffective, and thus causing these services to remain low in people's priority when gaining help. Additional difficulties accessing those suffering from depression were brought up by three interviewees. They stated how depression in particular is not identified as being a psychiatric disorder. *They don't see it as an illness, they might say, this woman is very cruel, and she's always crying.*

Place within the Health System
Services for mental illnesses were not considered to be a priority in Sri Lanka compared to other kinds of health services. *Even in the health sector, mental health is treated differently; priority is given to physical illness.* As a result, some felt stigmatized as community mental health workers. *When I go to hospital for my own medical problems and the medical staff asks, I say I am working in mental health, they laugh and make jokes about mental illnesses, asking "Are you not ok, are you still taking treatment?"* For these reasons, participants felt that their services were only valued by services users and not others in the community.

3. Steps to reduce stigma associated with mental illness

All participants thought that spreading awareness and understanding of mental illnesses was key to tackling its associated stigma, focusing on the fact that psychiatric disorders are illnesses like heart disease or diabetes, and that treatment is available and effective. *Like any*

organ can get diseased, it is the same with the mind; people can try and understand that it is curable, controllable.

Those in positions of authority, such as police, and students at school or university were identified as primary targets. In addition, several participants highlighted the importance of reducing stigma in the medical profession, and all felt that further training in stigma would be beneficial so that health professionals have a better understanding in order to take a more holistic approach to their patients. *Medical students don't see the patient as a human being, they see them as a 'case'. They never relate that to real humanitarian things.*

The value of promoting success stories was also emphasized in order to demonstrate that mental illnesses can be treated effectively. All participants thought that the media has significant potential to help reduce stigma. *We can give good examples through the media. They could be used in a positive way instead, saying mental illness can be treated, here are the places; instead of negative things.* One caution was also raised. One participant was wary of promoting mental health awareness too heavily in the media until more community mental health services were organized and available. *First of all there should be some system, where to go, what to do.* From this perspective, the priority should be to improve services so that people are treated effectively, leading to local success stories, and communities spreading awareness by word of mouth. *They had a problem, he went there and they sorted him out, you better go there and see.*

Several interviewees expressed the view that the focus of service development should be in communities and that sustainability would best be achieved by 'ownership' – working with and involving community members. In addition, more could be done to liaise with traditional healers to help reduce the delay in diagnosis and effective treatment, such as full time consultants in communities. It was noted that the Health Ministry was putting processes in place to *decentralize mental health services to the community and provinces.* Greater government priority for mental health was also noted. *It is important for mental health to be more on the government priority because mental illness prevalence is increasing.*

Relating to the importance of contributing financially in families, two participants noted that vocational rehabilitation may be of particular significance to reducing stigma of mental illness in Sri Lanka, *because part of the stigma is that the person is useless and doesn't contribute to the family. Now we must do something on vocational rehabilitation.* Several participants commented that stigma in mental health appeared to be lessening significantly in recent times. One participant stated that Sri Lanka is in an *era of transformation* with regard to views on mental health.

Discussion

This study has provided insight into how stigma associated with mental illness exists within Sri Lankan communities from the perspectives of community mental health workers. As well as affecting the person with a mental illness, stigma affects the patient's families through stigma by association (Goffman, 1963; Ng, 1997; Lauber & Rösser, 2007; Larson & Corrigan, 2008). This affects family members marital and employment prospects (Phelan, Bromet & Link, 1998). Stigma by association linked to mental illnesses is likely to be more prominent in Asian countries, Sri Lanka included, where communities are family-orientated (Ng, 1997). Many Sri Lankan families hide mental illness from society to avoid discrimination in terms of marriage engagements, a finding which reinforces existing literature (Ng, 1997; Lauber & Rösser, 2007; Larson & Corrigan, 2008). Research shows that negative effects on marriage chances was the greatest concern of Indian family members interviewed about their relative with a mental illness (Raguram, Raghu, Vounatsou & Weiss, 2004). This leads to poor health seeking behaviors; a major barrier to the provision of mental health services internationally. Even when help has been sought, evidence shows that there is poor reintegration into families following treatment at a psychiatric institution in Sri Lanka (Zolnierek, 2008), possibly attributed to the fear of stigma by association. This leads to a vicious cycle whereby people with a mental illness continue to go untreated and subjected to stigma, particularly if action is not taken to understand and support their families experiencing stigma by association. Furthermore, while stigma by association continues, people with success stories will be less likely to come forward publicly as they may be concerned that it would affect their family's status in society. Elsewhere, role models who have experienced a mental illness, such as John Kirwan (New Zealand Rugby 1984–1994), have worked hard to break down barriers in health seeking behavior.

The literature also describes family secrecy to avoid discrimination by employers (Ng, 1997; Lauber & Rösser, 2007). In our study, this was mentioned by one participant who stated that fear of discrimination prevented him from providing employers with information on a diagnoses of mental illness. Interestingly, many participants stated how families view relatives with a mental illness as a burden if they do not contribute financially to the household and stated that gaining employment was seen as an important way of gaining acceptance from families.

These findings also identified many beliefs about the causes of mental illnesses. In Sri Lanka, Buddhist and Hindu beliefs about 'karma' are widespread and may cause mental illnesses to be considered as fated or linked to blame (Tribe, 2007). Stigma may be particularly attached to conditions where the sufferer is considered

to be culpable (Scambler, 1998), therefore, the many traditional beliefs cited by participants (e.g., 'horoscopes', 'Gods and Devils' and 'paying for mistakes from a previous life') have the potential to exacerbate stigma within communities. An interesting finding was the notion that Sri Lankan communities view 'sins from a past life' as a cause of physical illness, but not of mental illness.

Community mental health workers in Sri Lanka perceive stigma as a barrier to people seeking mental health services. Another widely held view among mental health caregivers was the general lack of mental health literacy among patients, friends, and families. Lack of knowledge about the mental health services also was mentioned as a factor that promotes stigma. However, improved mental health literacy would not necessarily transfer into better attitudes (Nordt, Rössler & Lauber, 2006). One concern was that community members often seek traditional medicine first, and then only attend community based mental health services when the traditional methods fail, thereby delaying early diagnosis and treatment. The preference for traditional medicine prior to allopathic services has been reported elsewhere (Ng, 1997; Lauber & Rösser, 2007; Thornicroft, Rose & Mehta, 2010). In developing countries like Sri Lanka where community based mental health services are not readily available throughout the country, traditional medicine may also be the primary choice (Lauber & Rösser, 2007; Siva, 2010).

Traditional medicine is highly respected in Sri Lanka, thus it is wrong to assume that allopathic services will be seen as superior. Instead, links need to be established between community mental health workers and traditional healers. If mutual respect between traditional healers and community mental health workers can be established, the two could co-exist within the community and work together. However, as one participant noted, traditional healers are likely to feel *it may affect their business* and so might not be motivated to cooperate.

Limitations

A small sample size of nine participants was recruited, however, this is typical of qualitative inquiry, and information was saturated. Little additional information was obtained by the final interviews. Purposive sampling leaves one at risk of overweighting subgroups that are more readily accessible, while snowball sampling is prone to bias as those recommended by an initial participant are likely to have similar traits and characteristics. However, as no population list of community mental health workers was readily available, these sampling methods were the best available (Trochim, 2006; Castillo, 2009).

Owing to a lack of time and resources, triangulation of findings with other sources, though desirable (Scambler, 1998; Huxley & Thornicroft, 2003; Thornicroft *et al.*, 2010) was not possible. This may have limited the validity and transferability of the findings. The sample was obtained of community mental health workers from just two districts of Sri Lanka, Colombo and Kandy. Community mental health workers in other districts may have different experiences. Although many of our findings reinforce existing international health literature, though there is a lack of Sri Lankan literature for comparison. Also, the ethnicity and religious composition of the two districts are not dissimilar to the national statistics (Department of Census and Statistics – Sri Lanka, 2001).

Wilks states that participants' responses to case vignettes are not necessarily indicative of reality (Schulze, 2007). Other possible limitations are: courtesy bias, whereby participants give the answer of what they think they *should* do rather then what they *would* do; and recall bias, where the participant recounts a response that does not fit with reality. However, some argue that in qualitative research, the response from the participant is valuable regardless of whether it is 'true' because it is the perspective of the participant being investigated (Scambler, 1998), not their actions. Finally, reflexivity is required to acknowledge the author's 'self' as an influence on the findings and discussion produced. Guidelines were followed (Mays & Pope, 2000; Pope, Ziebland & Mays, 2000; Green & Thorogood, 2009) in an effort to have a uniform approach to developing and discussing findings. However, another analyst may have developed different key findings based on their own 'self' and values; an unavoidable feature of qualitative research.

Conclusion

This study provides insight into a subject in which there is currently a dearth of literature. Stigma associated with mental illness is present within Sri Lankan communities, causing those suffering from mental illness and their families to endure prejudice, discrimination, and the effects of ignorance (Lauber & Rösser, 2007) whilst creating a barrier towards the provision of services by community mental health workers.

Acknowledgments

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