Overcoming Discrimination: Social Responsibility Towards People with Mental Illness[1]

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Abstract

The reduction of stigma and discrimination attached to mental illness has become a priority concern for mental health policy in Sri Lanka. The main objective of this paper is to examine where the responsibility to combat discrimination lies in different situations where people with mental illness are being discriminated against. The paper argues that people with mental illness have been excluded from mainstream society not because of problems with those who have the illness but because of prejudicial attitudes that society holds toward them and because of the nonavailability of social arrangements that facilitate their community living.

Keywords: Discrimination; Mental Illness; Recovery; Social Responsibility; Stigma

Introduction

People with mental illness have been stigmatized and discriminated against throughout history and in many societies (Foucault, 1988; Sartorius & Schulze, 2005). The social stigma affects not only the people with mental illness but also their families (Lefley, 1992). Family members tend to institutionalize their relatives with mental illness because of the societal discrimination it brings to the whole family. Over 70% of the service users who live in the psychiatric institutions at Mulleriyawa, Angoda, and Hendala have the potential to live in the community and actively participate in socioeconomic activities (Wipulasena, 2012; World Health Organization, 2008). But even though many years have lapsed since their discharge, they still remain at the psychiatric institutions, since their family members are not willing to accept them. The relatives gave false contact information at the time of the institutionalizations, and these relatives do not respond to requests made by the psychiatric institutions to accept their family members back. Stigma is considered one of the reasons for the nonacceptance of discharged service users by their relatives.

The stigma gives rise to negative consequences for the individual's self-concept and social well-being, which in turn affects the causes of mental illnesses (Markowitz, 2005). Stigma is considered a great hindrance to a better quality of life for the people who have the illness and for their family members. Therefore, combating stigma is a high policy priority in many countries (Sartorius & Schulze, 2005), and it is one of the prime objectives of the mental health policy in Sri Lanka (Mental Health Directorate, 2005). The objective of this paper is to examine where the responsibility of combating discrimination lies in different situations where people with mental illnesses are being devalued.

There is a lot of criticism about the very use of the term, "stigma" (Chamberlin, 2006; Sayce, 2000). Some criticisms leveled against it say that the concept of stigma is itself stigmatizing and that the problem of stigma is located within the individuals who have the problem. Those who have experienced serious mental health problems indicate that instead of the term, "stigma," concepts such as prejudice, discrimination, and exclusion describe their experiences more accurately (Chamberlin, 2006; Sayce, 2000). Chamberlin (2006) explains the above concepts, according to her own experience, in the following manner:

"Prejudice refers to the unwarranted negative attitudes people hold towards us based on their own beliefs and preconceptions, rather than on our specific individual attributes. Discrimination defined in terms of the societal codification of such attitudes, as expressed in laws and customs that result in us having a lower social status and fewer rights than non-labeled people." (p. xii)

Sayce (2000) shows how discrimination manifests through the exclusion of persons with mental illnesses by a lack of economic and social participation. Most definitions of stigma focus on attributes of the individual who is being devalued (Goffman, 1968; Pilgrim & Rogers, 2005). When stigma is defined in terms of specific attributes of the person with mental illness, an exact answer is not provided as to how other members of the family who do not have the illness are subjected to discrimination. Chamberlin's (2006) view is that discrimination against persons with mental illness is related to external factors, such as people's own beliefs and prejudices, rather than to specific attributes within the person with mental distress. Sayce (2000) argues that questions raised by the critiques of the use of different concepts are not merely semantic. Different conceptual models point to different understandings of where responsibility lies for the problem and to different prescriptions for action.

Methodology

The study was based on service users attached to a counseling center at Piliyandala and to a voluntary home with long-term residential care facilities for people with mental illnesses, at Horana. Field work was conducted from January 2011 to December 2012. The initial data collection commenced with a random group of service users attached to the above centers. Preliminary interviews were held with this random group, consisting of forty service users and some members of their families. The initial analysis was begun by making reflective notes on data collected from preliminary interviews. Open coding was used in order to generate initial concepts from the early empirical data. In the next stage of data analysis, these codes were further linked to each other in theoretical and conceptual models.

Based on the theoretical relevance of ideas generated through the analysis of data collected from the preliminary interviews, sixteen service users were selected for the sample. It was also possible to

interview one or two of their families. The interviews with some of the respondents were held at their homes as per the information obtained from them during the preliminary interviews. The unstructured interview method was used to collect qualitative data. Presented with general guidelines such as, "Tell me what you think about your future," "What are your experiences in public places," and "What happened after you came to the voluntary home," the respondents were given the opportunity to express their views openly. The sample consists of the service users who had been diagnosed by psychiatrists as having "severe mental illnesses" (N=9) as well as "mild mental health conditions" (N=7).

In addition, secondary sources were also used to develop this paper. Research papers and literature in social work were used in order to present descriptions of more progressive approaches used in the field of mental health at present. This literature was useful for making comparisons between the mental health approaches used in Sri Lanka and those used in other countries, where more progressive approaches are being adopted.

Discriminatory Experiences of the Family

The prejudicial attitudes attached to mental illness have caused detrimental effects not only to persons with mental illness but also to the other members of their families who do not have the illness. According to this study, there are a number of ways in which discrimination is experienced by members of a family due to the mental illness of their relative. The experience of the majority of families, 81%, was that they could not invite friends to visit their homes. This was due to the fear that the mental health condition of their family member would be revealed to the friends or that they would face an awkward situation in front of the friends because of the "inappropriate behavior" of their relative who had mental health difficulties. However, except for two families, no other family in the sample had as yet undergone such "embarrassment" in front of their friends. This indicates that they had excluded themselves from social relationships all on their own, even before they faced any experience of discrimination from others.

Another experience for other members of the family who did not have the illness was the difficulty faced when seeking marriage partners. This was experienced by the members of two families in the

sample. The parents of the proposed partners had expressed their dislike of the marriage proposal after the disclosure that one of the family members had a mental illness. In nine families, the members were worried that they would have difficulty finding marriage partners for other members of their families. According to the respondents, there are a number of reasons why people reject marriage proposals coming from families with persons who have mental illnesses.

a) Having a matrimonial tie to a family with a mental patient is considered disgrace to the social status of their own family.

b) Dislike on the part of the relatives of letting one of their family members undergo the hardships borne by the members of a family with a mental patient.

c) Belief on the part of the relatives that a successful married life could not be achieved due to the responsibility held by such a family regarding the patient.

A family's ability to cope with mental illness depends in large part on the adequacy of community support available to them (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). The family may attempt to be free of such responsibilities if community support is not available. Of the sample population, 44% of the families providing home care would have preferred to board their relatives in a place away from home. This includes five families with individuals who were diagnosed by psychiatrists as having mental illnesses that were not severe. Reasons mentioned for demanding residential facilities included difficulties in caring for ill family members due to financial hardships, the negative impact created on the roles of other members of the family as a result of their being at home, and the feelings of fear, irritation, and shame that were consequences of stigma. Szmukler (1996) has argued that framing care givers' problems in terms of "burden" is pejorative and unhelpful, because the lack of economic and social participation of the people with mental illness are a matter of prejudicial attitudes attached to the illness (Deegan, 1993; Repper & Perkins, 2003; Sayce, 2000). Structural social work theorists view social problems as an inherent part of the social order rather than as failings of individuals (Mullaly, 1997).

Some countries have attempted to respond to the above issues by facilitating caregivers in accessing services such as respite care services, home treatment/crisis resolution teams, day centers,

drop-ins, etc. (Geiser, Hoche, & King, 1988; Thornicroft & Tansella, 2003). Mobile services are provided through home treatment/crisis resolution teams. Crisis resolution teams with intervention skills for crisis situations support caregivers in controlling crisis situations faced in home caring. Through respite services, the responsibility of caring in the community setting is taken over by trained service teams in instances where family caregivers are in need of relief (Geiser et al., 1988). Respite services are provided in the homes of service users as well as in institutional settings. It is important that mental health and social services are available to family members or caregivers in order to deal with a wide variety of situations that often require coping with. This can prevent making mental illness a "burden" to the functioning of the family. Instead of removing persons with mental illness from the social and economic mainstream, mental health workers can assist them in performing social roles, activities, and work required for ordinary community living. Discrimination on mental health grounds could be minimized by providing people with mental illnesses the opportunity to take up socially valued roles (Wolfensberger, 1983).

Another experience that family members have to face is the teasing by others in public places. All respondents in sample who had undergone this experience were children studying at schools in rural areas. Their right to maintain privacy in the school environment was limited, as the majority of the students in their school came from the same area that they lived in. For this reason, it was difficult for them to conceal the health condition of their family member. They were subjected to teasing by their peers in places like the playground at school, due to the mental illness of their family member. It is important to implement programs against prejudice and discrimination focusing on diverse social segments. In 1996, the World Psychiatric Association (WPA) began an international program to fight the stigma and discrimination associated with schizophrenia, focusing on teenagers, high school children, etc. (Sartorius & Schulze, 2005). Through these programs, the WPA attempted to construct positive and helpful social attitudes against existing prejudicial attitudes connected to mental illnesses.

Discriminatory Experiences of Persons with Mental Illness

The experiences of discrimination faced by persons with mental health problems were different from those faced by members of their families. A majority, 89% of the people who were living with their

families underwent this experience in the family itself. There are several ways in which they were excluded from the family:

a) They were excluded from the decision making process of the family.

b) They were removed from the social roles they had previously performed in the family and had been turned into passive dependents.

c) The family members did not communicate with them the daily occurrences that took place in the family.

The ideas presented above were expressed by the people in the sample in various ways. A 52-year-old woman said, "My relatives used to visit me at home those days. But nobody visits me now. My son and daughter-in-law do not allow my grandchildren to even come into my room. My daughter-in-law does not like it even if I go into the kitchen to help her. She thinks that I mess things up everywhere I go. Earlier, my son used to inform me every time he steps out of the house. Now, I do not know where they go or what they do."

A 72-year-old retired school teacher shared his experiences in the following manner: "I do not have an illness that requires any medication. Sometimes, I lose track of what I say and do. But that does not happen often. Earlier I used to sweep the compound every morning. At such times, my acquaintances walking on the road used to come near the gate and talk to me. But now, if I go to the compound, my wife and daughter are asking me whether I am trying to embarrass them. They are worried that I would say unnecessary things with the neighbors. Therefore I stay in my room."

A 35-year-old woman staying at the voluntary home said, "Nobody at home would listen to me. If I speak, they think I am blabbering nonsense. I am very happy to be at the voluntary home. People here can understand what I say. I think this is the best place for me to live. I do not think I can ever go back home or to my job again."

This study reveals the manner, in which persons were compelled to become dependent, even the individuals diagnosed by psychiatrists as having only mild mental health problems. One person who received psychiatric treatment for a mild condition of depression and returned to work in the same place at which he was earlier employed was covered in this study. He was 52 years old and was

employed as an accountant at a government institution. He shared his experiences at the place of work when he returned after psychiatric treatment, in the following manner: "I took three months leave, obtained treatment and went back to work after recovery. Those at office are aware that I obtained psychiatric treatment. Now, I am assigned a lesser amount of official duties. In most occasions, I am assigned to support the work done by other accountants. Others do not look at me the same way they did before. Everybody takes pity on me. They check on me, ask me whether I have eaten. Now I feel as if I am a different person. The juniors who used to ask my advice for work related things are now looking at me with pity. I feel that I am helpless. I am trying to obtain a transfer and go to another office as soon as possible." The above statement indicates the diversity of discriminatory experiences that people face. Even through sympathetic responses, a person can experience discrimination. That is because the sympathetic responses symbolize that he is a "weak" person deserving the help of the others and "not a person suitable" to give advice to juniors regarding official work. Persons are devalued by sympathetic responses, because these responses hamper equal rights to experience or share normal respect for the individual, the right to self-determination, and standards in the community (Nirje, 1999).

Many researchers have demonstrated the discriminatory experiences in public of people with mental illnesses (Read & Baker, 1996; Sartorius & Schulze, 2005). However, a majority, 69% of the sample did not have experiences of being unfairly treated, teased, or bullied in public places. That was because they had limited opportunities to develop social relationships with the wider society outside their homes. Except for the annual trip organized by the home, the service users of the voluntary home did not have any opportunity to engage in social activities. To those who received home care, social activities were mainly limited to trips taken to the hospital to obtain treatment. This group included not only persons who had been diagnosed by psychiatrists as having severe mental illnesses but also persons with mild mental health difficulties. In this regard, the following are among the views expressed by members of the families of persons with mild mental health problems:

- "We are worried to take him anywhere. We do not know what he will do and when he will do so."

- "If we take her out and if she creates a commotion, we shall have to face reproach from other people."

- "We are worried to send him anywhere on his own. Someone from home must accompany him if he is to go somewhere."

The medical perception and the lay perceptions of the severity of mental illnesses are constructed as distinct entities (Bruce, 1999). The distinction between the lay perception and the psychiatric perception of the severity was clearly evident in the above statements of family members of individuals who were diagnosed by psychiatrists with mental illnesses that were not very severe. These individuals' health problem had been identified by themselves as well as by their family members as a "madness" that made it impossible for them to actively engage in community life, rather than as a mild health problem that would enable them to actively participate in economic and social activities like any other person not labeled as a "mental patient." Therefore, they undergo a greater pressure than that which should result from the psychiatric reasoning on the severity of their illness. Mental health workers must understand the manner in which the pressure induced by the mental illness is experienced by the person, beyond the limits of the explanations provided by psychiatry. That is because lay constructions of the severity of the illness are far more important than the meaning given by psychiatry when supporting them in their daily living in the community. The lay construction of the severity is largely based on people's own beliefs and prejudice. The lay conceptualizations directly impact a person's everyday experiences in the community.

It is widely believed that even some psychiatric explanations about "mental illnesses" are based on prejudicial judgments (Perkins & Repper, 1998; Sayce, 2000). These explanations have been criticized and challenged by most of the personal accounts of recovery submitted by persons who faced experiences of serious mental health problems (Chadwick, 1997; Deegan, 1993). These personal narratives show that even the "chronic patients" who have been accepted by conventional psychopathology as unresponsive to treatment (Corrigan & Ralph, 2005) hold the potential to recover. Greenberg, Greenley and Benedict (1994) reveal that many persons with severe mental illnesses play positive roles in their families. Drake and Deegan (2009) show that the incapacity to make decisions is rare even among persons who have experienced severe mental health problems. As argued by Sayce (2000), if not for prejudice and

social exclusion, persons diagnosed with mental illnesses do have the ability to perform actively in various roles as full citizens. Anthony, Rogers, Cohen and Davies (1995) state that although a moderate relationship has been found between symptomatology and work skills, symptoms should not be considered a proxy measure for vocational functioning among persons with severe mental illness. Although the direction of causality is not clear, studies of schemes to get people with severe mental illness into work suggest that work is related to a reduction in symptoms and hospitalizations and that it promotes a better quality of life and self-esteem (Boardman & Killaspy, 2010; Bond et al., 2001).

Researchers point out the manner in which even people with serious mental illness are able to achieve more positive employment outcomes through follow-up services provided within work settings (Bond et al., 2001). Now it is accepted that traditional approaches to vocational rehabilitation such as skills training, prevocational training, and sheltered workshops have very little impact on employment outcomes (Becker & Drake, 2003; Bond et al., 2001). Instead, a wide variety of new supported employment approaches have been introduced in some countries where more progressive community mental health services[2] have been implemented (Bond et al., 2001).

The vocational training programs conducted for people with disabilities in Sri Lanka by the Ministry of Social Services and psychiatric institutions are mainly based on traditional approaches. The traditional models use a "train and place" approach, offering training in sheltered workshops to individuals and later placing them in work settings. Supported employment models use the reverse approach, in which clients are placed in jobs and are then trained by on-site coaches (Becker & Drake, 2003). The supported employment programs are closely integrated with the mental health treatment teams. The mental health workers of the supported employment programs find individualized job placements according to client preferences, strengths, and work experiences and integrate people with mental health problems into work settings with follow-up support (Becker & Drake, 2003; Bond et al., 2001). Follow-up supports are useful for them, since they are especially sensitive to the negative effects of the workplace. The workplace is one of the key environments that can have a significant impact on mental stress (Tausig & Fenwick, 2011).

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2. *Community mental health services focus on assisting people with severe mental health problems who have been excluded from mainstream society, and who have been offered care within a large institutional setting, to start living in a local neighborhood.*

Of the sample population, 63% had either resigned from their jobs or had not made any attempt to be employed for reasons of feelings their incapacity to work, feelings of stress and anxiety, fear of disclosing that they were undergoing psychiatric treatment, fear of being isolated in the workplace, or fear about not having any idea about how to acquire a job. However, except for people with mild mental health conditions, all the others who had undergone in-house treatment at psychiatric institutions had obtained vocational training while being institutionalized. They had no access to support services that facilitated job acquisition and provided ongoing support from skilled mental health professionals within the work setting. Supporting mental health service users in accessing employment is a crucial aspect of the inclusion of people with mental illness in the social mainstream and as a strategy for combating discrimination, because work is more than just a source of income, it provides social contact and social support, social status and identity: a means of structuring and occupying time, activity and involvement, and a sense of personal achievement (Repper & Perkins, 2003).

Recovery and Self - Stigmatization

The recovery model became the new vision of the mental health service system in the 1990s in most of the countries where more progressive mental health approaches are being adopted. According to the recovery model, medical treatment is not considered mandatory for recovery. One assumption of the recovery model is that recovery can occur without professional intervention (Anthony, 1993; Corrigan & Ralph, 2005). Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributive life even within limitations caused by illness (Anthony, 1993). The recovery model emphasizes each individual's potential for recovery. It assumes that the factors that support recovery are different from one individual to another, and it emphasizes the service user's expertise in identifying and defining factors that enable recovery (Anthony, 1993; Deegn, 1993). Personal narratives on recovery presented by individuals experiencing severe mental health problems have heavily influenced the development of the recovery model (Chamberlin, 2006; Deegan, 1993). Through their own recovery experiences, these individuals have explained how their recovery was enabled through opportunities given to them to actively participate in socioeconomic activities, to spend satisfying and hopeful lives, to gain control over their lives, and to move past the discrim-

inatory experiences they had to face due to the label of "mentally ill."

In this study, except for a very few, the service users' responses to the question, "What helps you in your recovery," did not take a narrative form based on their own perspectives. A 52-year-old individual who was currently employed as an accountant at a government institution said, "I am recovered now. But the others at the office think that I am still unwell. My problem is that they do not accept that I have recovered." Three persons expressed similar views. According to their view, they have already recovered from the "illness," but they will achieve complete recovery only after others have accepted that they have recovered. This is the horrific result of labeling someone as a "mentally ill" person. That means that others will continue to regard him/her as a "mental patient" even after the "symptoms" have gone. Experiencing continuous regard from others as a "mental patient" may in turn be the cause of further mental health problems (Markowitz, 2005). Two persons in the sample stated that they received medicine in time and that they had now been discharged from the hospital, as they had recovered. Three persons mentioned a few things that they needed in their recovery such as medicine, relaxation, and involvement in religious activities. For all others in the sample, the determination regarding their recovery was based on the opinion of the doctors.

- "I am still not recovered. The doctor has still not stopped my medication." – A 58-year-old woman receiving psychiatric treatment.

- "No one from home would come to take me home until I am recovered." – A 37-year-old woman at the voluntary home.

- "I was asked to rest until I am recovered. I am still taking treatment." – A 31-year old person living at the voluntary home.

- "The children do not allow me even to do household chores. I cannot even take part in household work until I am well. The doctor advised me to continue medicine for some more time." – An 82-year-old woman who was obtaining medical treatment.

The above statements show that they did not sense their own capacities, as they had adapted to the "patient role" successfully imposed upon them based on medical labeling. It is obvious that the intensity of their self-stigmatization was at a very high level.

Self-stigma refers to the state in which a person with mental illness has come to internalize the negative attitudes about mental illness and turns them against himself or herself (Corrigan, Roe, & Tsang, 2011). During this process, a person often "loses" a previously held identity as a student, worker, parent, etc., while the stigmatized "illness identity" becomes dominant (Corrigan, Roe, & Tsang, 2011). The possibility of self-stigmatized persons or persons adapted to negative prejudicial attitudes regarding "mental illness" discovering paths to their recovery through their own subjective approaches is very limited. It is hard for people to set personal goals when they feel that they are not worthy of having goals, and it is difficult to achieve those goals when feeling incapable (Corrigan, Roe, & Tsang, 2011). Through helping the person to occupy roles outside the "patient role," opportunities can be given to them to remove themselves from the status of a "patient with mental illness."

In countries where more progressive approaches are being adopted, now it is increasingly common for people with the experiences of mental illnesses to be involved in mental health care provision (Linhorst, 2006; Perkins & Repper, 1998). It is accepted that mental health services supplied with the involvement or management of persons with experiences of mental illness are more compatible with the needs and interests of the service users than services provided by those who do not have such experiences (Linhorst, 2006; Repper & Perkins, 2003).

In countries where the paradigm shift has taken place from a treatment model in which "patients" are made into passive dependents under psychiatric care within an institutional setting to a whole different level in which users have expertise in identifying and defining factors that enable recovery, this shift indicates the radical transformation that has taken place in ideology in terms of mental health practice and provision. It also shows the radical changes that have been made in power relations between mental health professionals and service users.

Even in a context like Sri Lanka, where mental health services are mainly provided in large psychiatric institutions under psychiatric care, mental health professionals can assist users in devising their own ways of making themselves autonomous from the larger system. Self-stigmatization and discrimination can be minimized by empowering people with mental illnesses. According to Payne (1997),

"Empowerment seeks to help clients gain power of decision and action over their own lives by reducing the effect of social or personal blocks to exercising existing power, by increasing capacity and self-confidence to use power and by transferring power from the environment to clients." (p. 266)

One cannot empower another. People must empower themselves. Yet, others play a critical role in providing individuals with supportive relationships, resources, decision-making opportunities, and other things people need to empower themselves (Linhorst, 2006). Self-stigmatization does not occur in a state where people with mental illnesses have been given such opportunities.

Conclusion

The likelihood of discrimination against a person and his/her family on mental health grounds is minimal in a society where the moral responsibility of caring for people with mental health problems is undertaken by the community. In the present context in Sri Lanka, not only the person with mental illness but also his or her family members experience discrimination based on the psychiatric history or current mental health problems of the person. This shows the negligence of the responsibility of the society toward supporting people with mental illnesses and their families. People with mental illness have been excluded from mainstream society not because of problems with those who have the illness but because of prejudicial attitudes that society holds toward them and because of the nonavailability of social arrangements that facilitate their community living. Instead of removing them from the social and economic mainstream, mental health workers can assist them in performing social roles, activities, and work required for ordinary community living. Through helping the person to occupy roles outside the "patient role," opportunities can be given to them to remove themselves from the status of a "patient with mental illness." Discrimination on mental health grounds could be minimized by providing people with mental health problems the opportunity to take up social roles.

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