

community health centres. If this idea is implemented, other patients and users of health services will have the opportunity to meet and interact with people who have psychiatric disorders. By these means we hope to reduce the prejudicial attitudes that stigmatise people who are psychiatrically ill as dangerous and threatening. It will help to ensure they are regarded in future simply as members of the community, just like everyone else.

Conclusion

The adoption of resolutions regarding universal access to health and universal health coverage by PAHO and WHO member states as well as by the United Nations General Assembly provides a unique window of opportunity for us to promote the universality of psychiatric care. It can assist in our fight against the stigma that psychiatric patients currently experience in so many regions

of the world. But to eliminate stigma, we need to identify and to implement specific evidence-based strategies. Changing the model of medical care, with a focus on integrating psychiatric care into the everyday practice of primary healthcare and promoting exposure of psychiatric patients to other users of health services, should be a centrepiece of those strategies.

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Stigma and recovery in the narratives of peer support workers in Rio de Janeiro, Brazil

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Stigma attaching to mental illness has been considered a major challenge to public policies, to the provision of care and to the well-being of people who live with the experience of mental illness worldwide. Here we discuss narratives from peer support workers which we obtained during the assessment of a new psychosocial intervention programme in Rio de Janeiro. We used a range of focus groups, in-depth interviews and clinical supervision notes to derive these narratives, which covered topics such as the peer support workers' perceptions of family and social views, their sense of self and the experience of being stigmatised. We conclude that stigma appears to be a barrier to recovery. Peer support work for people with severe mental illness is a strategy that may help them to overcome stigma and discrimination. Fostering mutuality and hope in the context of peer support helps affected individuals to make sense of their being in the world and can facilitate their recovery.

Background

Stigma presents a challenge to public policies, to the provision of care and to persons worldwide

who live with the experience of mental illness (Saraceno *et al*, 2007; Sartorius, 2007). Characterised by negative thoughts and attitudes, stigma results from lack of knowledge (ignorance), prejudicial attitudes and discriminatory behaviour (Thornicroft *et al*, 2007). The experience of stigma decreases self-esteem, which in turn reinforces negative attitudes and increases the risk of social exclusion (Sartorius, 2007). Stigmatisation is a devastating experience that negatively impacts upon self-identity and creates a barrier to recovery, to accessing health services, to getting a job and to education and housing. Whereas an important step to recovery is accepting one's illness, on the other hand, the label of a psychiatric diagnosis can lead to internalisation of stigma and a sense of hopelessness (Davidson, 2003; Farkas & Anthony, 2010).

In the last decade, the need to tackle stigma has been included in both global and local mental health policies and research agendas (Saraceno *et al*, 2007). Psychosocial interventions that include peer support work give positive results in reducing stigma among persons with mental illness and professionals (Farkas & Anthony, 2010). Peer support work is based on the principles of mutuality and hope. It is also based on the belief that persons with mental illness who have gone through difficult situations, and have overcome them, can be

helpful to others who have similarly experienced such situations. It aims to encourage affected individuals to think positively about their future and about their prospects for recovery (Davidson *et al.*, 2012; Stastny, 2012). Personal narratives, which are a component of peer support work, have an important role in overcoming stigma (Jenkins & Carpenter-Song, 2008).

In Brazil, there have been recent improvements in the care of people with mental illness that were engendered by legislation passed in 2001. There are new psychosocial care centres (centros de atenção psicossocial, CAPS) across the country, strategic services that provide mental healthcare and promote the social inclusion of people with severe mental illness (Ministério da Saúde, 2011, p. 106). In 2008, Brazil ratified the United Nations Convention on the Rights of Persons with Disabilities, banning any kind of discrimination against persons with mental illnesses. Yet, despite all this, stigma is still a challenge in the country (Spadini & Souza, 2006; Saraceno *et al.*, 2007).

Clinical experience reveals that stigma and prejudice are still prevalent aspects of perceptions and social representations of mental illness, from the perspective of users, families and professionals (Spadini & Souza, 2006; Moreira & Melo, 2008; Vicente *et al.*, 2013). Vicente *et al.* (2013) investigated family members' perceptions of mental illness in southern Brazil. They found that a lack of understanding makes it difficult for people to accept mental illness in family members or in the community. Stigma negatively influences relationships within families and between families and society, and can even lead to interpersonal and institutional violence. Moreira & Melo (2008) analysed the lived experience of stigma among in-patients with mental illness in Fortaleza (a city in north-eastern Brazil). They described a feeling of uselessness and powerlessness, reflecting the internalisation of stigma and a negative self-perception. People with severe mental illness tend to try to disguise their mental health problems because they fear negative reactions from others. In a review of Brazilian publications about societal attitudes to mental illness, Spadini & Souza (2006) emphasise that a lack of awareness of the problem reinforces prejudice.

Peer support work for severe mental illness

Here we report on the analysis of narratives we obtained from peer support workers, focusing on the issues of recovery and stigma, in the city of Rio de Janeiro. During 2014 and 2015 we carried out a project entitled RedeAmericas (RA), which was designed to build capacity among young researchers and lay workers for a novel intervention service, and to assess the effectiveness of that psychosocial intervention through a randomised clinical trial. We called the intervention 'critical time intervention – task shifting' (CTI-TS). It was delivered jointly by a peer support worker and a community mental health worker to CAPS users.

This was the first time peer support work had been used in Latin America (concurrently in Chile) (Susser, 2012). Because it represented a novel approach to formal mental healthcare and utilised a workforce in Brazil (Stastny, 2012), we decided to obtain, and to analyse qualitatively, narratives from peer support workers about their experience of delivering care and how it interacted with their recovery process.

Ten potential peer support workers, aged between 25 and 54 years, were initially nominated by CAPS, and after participation in a short course organised by the research team, assistants were selected to work on the CTI-TS trial, providing they met the following criteria: a history of mental illness, a minimum of 8 years of education, and their own participation in active treatment. Four peer support workers were selected and were expected to dedicate 20 hours each week to undertaking the following activities: accompanying designated patients in their daily lives; attending clinical supervision sessions; and completing records regarding interventions. There was on-the-job training. We used audio-recordings of focus groups, in-depth interviews and clinical supervision notes to gather information about the work that had been done with clients. We codified their narratives and organised them into broad categories.

Our work was approved by a local ethics committee and all participants gave informed consent. Participants' names in this paper are fictitious.

Sense of self: from embodied stigma to recovery

From the perspective of the peer support workers we had appointed and trained, their family is the foundation of their world, although they remarked that prejudice begins at home ('the biggest prejudice is within the family'). Grace (54 years of age, female and married) stated that her family life is 'turbulent'. She said she was often abused by her husband, who said 'that I'm too ugly, that I'm the worst of everything' and that she herself thought the members of the research team were 'crazy' for having selected her as a peer support worker. She asked us, 'How come you could believe in us? Nobody believes in us; everybody fears us.' Grace believed she was not a person, after hearing such harsh remarks from her husband, because he often called her an 'animal':

I was an animal ... now I'm not an animal anymore. I used to think I had no brain, nor body ... that's why I never understood geography, because I never understood the map. So, just now I got to find out what a map is ... before, I never understood about it. Look, I don't know if I've really lived during the past 40 years. I guess I hadn't really lived. I didn't live! I think I started to live 3 years ago. I have started to live now! Now I am getting a life!

Grace reconstructed her sense of self by recognising that she does have a physical presence, and came to accept that it was possible to be experienced as a distinct and valued being. Dance classes and peer support work helped her to make sense of herself and aided her recovery:

I never could imagine that [dance classes] were so important. I discovered that my life wasn't a prison anymore. Like now, you are teaching me how to walk ... I am another person, today I am walking differently.

Grace particularly valued supervision meetings and told us she believed her function as a peer support worker was 'to help, to be able to explain my experience in overcoming my difficulties to other people'.

According to another peer support worker, Leo (33 years of age, male and single), his family gave him support, despite the fact that 'people from outside do not understand us'. For many of the peer support workers, their family and social relations could be supportive but, paradoxically, they could also be a source of discrimination and stigma, and that sense of stigma was often internalised. From Leo's perspective, he 'became a teacher' out of his own experience:

I realised that I can help other people ... so this job is helping me a lot; now I know how to approach people, how to express myself properly.

In another example, a former service user, Michael (43 years of age, male and single), when asked about his new role as a peer support worker, explained:

What I've understood about peer support work is that we help people who in Brazilian society's eyes should be given nothing.

In terms of the work he was doing with people who were experiencing severe mental illness, he explained that 'we try to rescue their sense of citizenship, their sense of inner love, their self-esteem'.

Sammy (29 years old, female and single) told us that being a peer support worker, having 'gone through difficulties oneself', offered an opportunity 'to share those experiences with people, to know that one can take pills and despite that one can have a normal life'.

Conclusion

In the narratives presented here, stigma clearly influences self-esteem and self-confidence, and can present a barrier to recovery (Davidson, 2003). Our peer support scheme offers an important strategy that can help to overcome stigma and discrimination, because it gives peer support workers a new role within a social milieu. We must, however, bear in mind that family and social relations also play a central role in helping to overcome stigma, even though they themselves present a potential source of discrimination and negative attitudes (Thornicroft *et al*, 2007) that can lead to symbolic violence (Vicente *et al*, 2013). Prejudice and negative beliefs – expressed in words such as 'ugly', 'crazy', 'animal' – were used in peer support workers' discourse when talking about society's attitude towards them. Internalised stigma can be conceptualised as a dialogical game between the ideas of being 'normal' and 'crazy', as noted in Grace's narrative: 'there's no problem in calling

me crazy, because I cannot be normal ... because I think nobody is normal'.

Participants incorporated the main principles of mutuality and hope. Peer support work helped them to make sense of themselves, by recognising their embodied experience and enabling them to think in different ways about their being-in-the-world; they became their own educators in this role. We are confident that peer support work is, possibly, a light on the path that will overcome stigma.

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