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COMMENTARY

Stigma and discrimination as a barrier to mental health service utilization in India

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Stigma towards, and discrimination against, people with mental disorders is an important barrier to mental health service utilization in India. It contributes to delays in seeking care, impedes timely diagnosis and treatment for mental disorders, serves as an impediment to recovery and rehabilitation, and ultimately reduces the opportunity for fuller participation in life. In India there is a need to generate evidence base for context specific interventions that will address negative attitudes towards people with mental disorders and ensure implementation of these interventions by involving users, care-givers, community health workers and mental health service providers.

Keywords: Stigma, Social distance, Social contact, Help-seeking behaviour, Service utilization, India

In India, the contribution of mental disorders to the overall burden of disease is 11.8%.[1] People with mental disorders remain untreated, and those families who do seek treatment will often turn to non-allopathic providers including practitioners of Indian traditional medicine, religious healers, faith healers and astrologers.[2] It is estimated that only 10% of people with mental disorders are receiving evidence based interventions.[3] The current treatment gap for mental disorders is a result of inadequate coverage of mental health services as well as under-utilization of mental health services by the community.[4] Additionally, the quality of the care delivered in some settings is poor. Widespread stigma towards, and discrimination against, people with mental disorders is an important barrier to service utilization.[5] It contributes to delays in seeking care, impedes timely diagnosis and treatment for mental disorders, serves as an impediment to recovery and rehabilitation, and ultimately reduces the opportunity for fuller participation in life.[6] The concept of 'stigma' is a combination of three related problems: a lack of knowledge (ignorance and misinformation); negative attitudes (prejudice); and excluding or avoiding behaviours (discrimination).[7] This discrimination results in increased social distance: the distance people desire to have between themselves and people with mental disorders in various social situations.[6] Self-stigma, which involves internalisation of these negative attitudes, further compounds these effects.[8] Stigmatisation of people with mental disorders is common wherever it has been studied, and it is clear that these processes present formidable barriers both to social inclusion for affected people and their families, and to proper access to mental health care.[5]

In order to understand the impact of stigma on mental health service utilization in India, it is essential to understand the issues related to stigma in the relevant cultural context. In India, explanations for mental disorders are influenced by biomedicine, systems of traditional medicine and supernatural beliefs.[9] The different explanatory models for mental disorders influence the nature and experience as well as expression of stigma and discriminating attitudes that ultimately affect both help-seeking behaviours and the quality of care provided. Stigma is negatively associated with allopathic help seeking while there is a positive association with previous informal help-seeking.[10] Stigma motivates families to contain the affected person at home in an effort to conceal the condition and the perceived (shameful) causes of the condition (e.g. sins and bad deeds), and this substantially delays or even precludes timely access to treatment.[10] In rural communities in India false beliefs and negative attitudes towards mental disorders are evident which underlines the need to improve mental health literacy in the community.[9] People in India usually attribute mental disorders to a range of social and economic factors rather than supernatural or biomedical causes. Promoting the biomedical model of mental disorders in a setting like this may contribute to greater social distance and increased discrimination.[9]

In India, the Ministry of Health and Family Welfare (MoHFW) is rolling out the District Mental Health Program to all districts in a

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staggered manner, and evidence based models for mental health care delivery are being used to inform the design of this roll-out. In order to have a strong mental health program it is imperative that the gap between community understanding and stigma related to mental disorders and the 'scientific' view is addressed. In India there is a significant research gap regarding the association between stigma and discrimination, professional help seeking, and the quality of the care subsequently delivered. There is evidence of the effectiveness of interventions to reduce stigma and discrimination from high income countries. Delivery of anti-stigma interventions could be through various approaches such as lectures, training programs and social contact interventions. Several randomized controlled trials attest to the effectiveness of live social contact interventions in reducing stigma.[11,12] Social contact interventions in which individuals affected by mental illness share their personal stories have now been developed as common components of mental health anti-stigma interventions.[13,14] Direct social contact has greater impact on attitudes compared to didactic methods imparting education challenging myths which yields only a modest positive impact.[11] A study from India which incorporated a brief educational activity regarding the topic of stigma and discrimination found limited effectiveness of the training program in relation to stigma reduction.[15] Involving people who have previously experienced mental disorders as co-facilitators in this kind of training has the potential to reduce stigmatizing attitudes of participants, as does contact with consumers who have had positive (and realistic) experiences of mental health care, and who are employed and socially included in their communities.[8] Live social contact as an anti-stigma intervention in country like India is difficult to achieve as people with mental disorders most frequently remain hidden and are not mobilized precisely because of the stigma experienced by affected individuals and families.[15]

An alternative approach could be filmed social contact which may have practical and cost advantages and is more easily scaled up for use at the population level. A randomized controlled trial from UK found that filmed and live interventions did not differ in stigma outcomes, the former was more cost-effective and both these interventions were better as compared to lectures.[16] Social contact interventions which will expose people to positive consumer stories should be also combined with providing more information about the effectiveness of treatments. There is an association between confidence in treatment and stigmatising attitudes.[17] It is essential to contextualize these evidence-based interventions and ultimately find the optimal approach for the Indian context.

Stigma is also perpetuated by service providers[5] and it is critical to address this issue in professional training as well as in clinical practice. It is essential to identify the key human resources in the public health system who can deliver interventions to reduce stigma. Community-based health workers play an important role in their communities and are ideally placed to identify people experiencing mental disorders, make appropriate referrals, and to communicate, model and shape positive attitudes if appropriately trained in a context of limited literacy and resource constraints. Civil society organizations and the private sector have both played an important role in the provision of mental health services in India, hence a pragmatic collaboration with these sectors will ensure implementation of evidence-based interventions for reduction of stigma and discrimination. In the long run these efforts should not only address stigma as a barrier to mental health service utilization, but should also engage key stakeholders, in particular people affected by mental disorders and care-givers in a collaborative and participatory manner and ultimately advocate for a rights based approach to care.

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