

Ethical issues arising in research with people with mental health conditions

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Case study

Challenges in involvement of people with mental health problems in anti-stigma program in Nepal: lessons from Reducing Stigma among Healthcare Provider (RESHAPE) project

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Description of the research project

REducing Stigma among HealthcAre ProvidERs (RESHAPE)¹, is a research project piloted in Chitwan District of Nepal. In RESHAPE, people with mental health problems or service users were trained to serve as cofacilitators by using a participatory research approach called Photovoice which is a technique in which participants are taught how to use photography as an advocacy and empowerment tool. In RESHAPE, service users contributed personal testimonials of stigma and recovery through the means of photos, led myth busting sessions, and engaged in social contact with primary healthcare workers throughout the WHO's mental health Gap Action Program (mhGAP) training—all the elements associated with successful stigma reduction programs. Service user involvement as cofacilitators is grounded in social contact theory which has shown that facilitated engagement with service users helps to reduce stigma associated with mental illness. The intervention was evaluated through a pilot cluster randomized control trial comparing standard mhGAP training delivered by mental health experts with an mhGAP+RESHAPE training delivered by the mental health professionals along with Photovoice trained service users. The findings showed that RESHAPE intervention improved stigmatizing attitude as well as clinical self-efficacy of primary healthcare workers.

Background

Nepal is a diverse multi-cultural and multi-ethnic country in South Asia with a population of about 29 million. Classified as lower middle-income country, Nepal ranks 147/189 countries in Human Development Index (HDI). RESHAPE was conducted in the context of increased global attention to the delivery of mental health services in low-resource settings. The mental health services in Nepal were mostly institution based provided by limited hospitals located in big cities. The World Health Organization developed the mental health Gap Action Programme (mhGAP), which provides guidelines on training and supervising primary care workers in the delivery of mental health services. In Nepal, mhGAP was piloted in Chitwan District as part of broader package of care developed through the Programme for Improving Mental Health care (PRIME) project. A study conducted under PRIME highlighted that mental health stigma among healthcare providers was one of the biggest barriers to treatment. The RESHAPE project aimed to address this gap by training people with mental health problems and involving them as cofacilitators in the mhGAP training.

Ethical challenges of involving people with mental health problems in RESHAPE project and strategies to deal with them

Risk of harm associated with participation

Systematic reviews and meta-analysis have shown contact-based-approach to stigma reduction, which focuses on facilitating inter-personal contacts between the stigmatised group (such as people with MNS disorders) and the stigmatising group (such as the general population and service

providers), as most effective.² This approach is also used in the RESHAPE project that aimed to reduce health worker stigma by training service users to narrate their recovery story using pictures and interact with health workers during their mental health training. However, the training and interacting components involved disclosure of mental health condition to the health workers and family members. Although disclosure is an unavoidable aspect of service user involvement in contact-based anti-stigma program, this may have unintended repercussions such as additional stigma and discrimination to the service users. This was also highlighted in a qualitative study where service users shared that because of stigma they did not want to participate in research or other activities where they must identify themselves as people with mental health problems.³ Along with risk of harm due to disclosure, there may be additional mental health risks to the participants. Some service users may feel distressed when asked to speak in front of the public, or they might be asked difficult or intrusive questions by the audience that may trigger their distress. Such risk of harm to the service users associated with their participation in programs should be acknowledged and mitigated as this contradicts with the “do no harm” principle of ethics.

Inequity and inclusiveness challenges

Literacy in the Nepali population is low; this is even worse for people with mental health problems who drop out of school or do not engage in literacy programs due to their illness. This lack of literacy combined with their health conditions results in self-stigma and low self-confidence among service users making it difficult for them to participate in mental health programs and research. Contact-based interventions such as RESHAPE assumes that service users are of well-functioning state and can narrate their recovery story and interact with the public with ease. There are limited number of service user advocates who are comfortable doing the presentation and interaction with ease without any training beforehand. Those who are present, are from higher socio-economic background and reside in urban settings. These requirements and assumptions may risk lack of inclusivity and equitable participation of service users in such programs. Participation of female service users was specifically difficult in RESHAPE as they had to travel long distances to come to training centres and as some portions of the training were designed to be residential- they had to stay at the hotel. In Nepal, female mobility is highly restricted, especially unmarried women’s mobility. Therefore, unmarried service users attending training alone in the hotel, sometimes overnight, was not readily accepted by the family and neighbours. Such socio-cultural challenges may limit the participation of marginalized and vulnerable groups among the service users. Implementation of anti-stigma programs involving service users need to be careful that they are selected inclusively and equitably so as to foster representation of not just high-profile advocates but also experiences of local marginalized and vulnerable groups.

Recommendations and conclusion

1. Anti-stigma programs involving service users should be aware about the unintended consequences and potential harm that may be caused while participating in such programs. Participants should be made aware about such potential harm and discussions should be carried out with them, their caregivers, and other stakeholders on what can be done to safeguard them. In the RESHAPE project, service users are trained for 8-10 sessions on disclosure, managing distress, seeking supports, and dealing with difficult questions. Their psychosocial and mental health or any difficulties faced during the period of training or program implementation are checked in each session by trained mental health professionals. Thus, a period of training and preparation may be needed for service users to understand and deal with disclosure and consequences. Constant check-in by mental health professionals also ensures early detection and management of negative consequences or signs of distress. It must also be clearly elaborated and indicated from time to time to service users that any participation in such programs is completely voluntary and they may withdraw their participation at any point without it affecting their regular services.
2. The RESHAPE project borrows from the participatory research approach called Photovoice to help service users create their narrative through their photographs. We trained the service users to use a digital camera and encouraged them to share their story. The service users

could take photographs that represented their understanding of their illness, how it affected them, and what their recovery process was like along with their experiences of stigma. They could then compile these photographs and present them to the health workers to guide their narrative. Learning to use a simple digital camera was literacy friendly and built confidence among service users. Similarly, to foster inclusivity of female service users along with those from wider functioning level, we asked the service users to bring at least one caregiver (family or friend) with them in the training. Caregiver involvement also meant that service users with lower functioning could also be included in the training, which was not possible in the first batch, as the caregivers helped them if they struggled with any activity. Thus, caregiver involvement and adaptation of programs to fit the needs and access of participants may help wider representation of service users.

References

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