“Participatory research: factors in inclusion from the lived experience of the psychosocial disability studies across three Low and Middle Income Countries (LMIC)”

Ram Lal1, Emily Allan, Raj Kamal, Rachel Raj, Helen Fernandes & Becca Allchin.

Introduction:
Mental illness often causes numerous disadvantages such as high levels of stigma, deprivation of adequate care and participation restrictions in social, cultural and work situations. It is even higher in a country having low or middle income status like Nepal, India, and Afghanistan. Disability affects many people around the world and often access to health care and social inclusion is very poor for people with disability. There is limited information about the everyday experiences of people with psychosocial disability and what stops people from being included into the community and what helps people to be included. Multiple studies have focused on the experience of stigma and discrimination (Corrigan, 1998, Corrigan et al, 1999, Wahl, 1999), but not the wider experience and how other factors influence the lived experience. This research adopts a social model for understanding mental illness, as its goal is exploring broader lived experiences. Therefore, the research frames mental illness as “psychosocial disability”, which creates space for acknowledging the environmental and social factors that shape the lived experience. It includes study population from three south Asian countries having low middle income status (LMIC).

Methods:
Three mental health community development projects from India, Nepal and Afghanistan collected lived experience data, and findings were developed specific for each context. Lived experience data was extracted from individual narratives – a total of 30 people with psychosocial disability and 7 caregivers across three countries. In Nepal and India, photo voice was used to gain insights into the lived experience of people with psychosocial disabilities, whilst in Afghanistan, due to cultural and privacy restrictions, semi-structured interviews were employed. Participants were asked about the significant barriers and enablers to inclusion that they face. The interviews, photos and the commentaries provided with photos from India and Nepal were transcribed and translated looking at barriers and enablers. Within each country the data was analysed to identify key themes of enablers and barriers for people living with psychosocial disabilities for inclusion.

Results:

1. Access to adequate MH services
“Improvement in my mental illness after taking medication regularly.” – Participant from Nepal

“I used to hit everyone, my children and my husband. I told them I would burn the house down and leave them. I asked for a divorce. I thought my head would explode. I went to many doctors and then my husband told me there is a new clinic opening, and I came to this clinic. They gave me just 1 tablet that only cost 80afs and I became better” – Participant from Afghanistan

“This person helped me a lot and helped me go to the doctor and get free medicines for three months after which we were able to buy the medicines.” – Participant from India

2. Connection of supportive community (encouraging participation) and;
“The person who supported us in bringing together people with mental health problems and their family members for the development of a group.” – Participant from Nepal

“This person is a traditional healer and he did not have much [of an] idea about mental illness but when the project held meetings on mental illness, he had attended the meeting and obtained information. So when we had an issue of mental illness in my family, he encouraged us to go to the hospital and take proper treatment rather than go for traditional healing practices.” – Participant from India

3. Support and care from Family
“The support of my wife helped improve my situation. I was able to deal with my illness because of her support. If she had behaved badly like all the others, our family would have broken up. With her support, our bad situation had a positive outcome.” – Participant from India

“Mental illness can be cured by the love and support of family members.” – Participant from Nepal

4. Economic Stress
“I went to a mental health doctor once or two times but due to poor economy I couldn’t continue visiting the doctor.” – Participant from Afghanistan

“I experience more financial difficulty now because the person who used to bring income into our family now has a mental illness and doesn’t work.” – Participant from Nepal

Discussion:
While access to adequate mental health care is an expected enabler and its absence a barrier, the results highlight the significance of connection to supportive community and support from family as enabling and their absence as barriers. Personal coping mechanisms, meaningful contributions and participation in religious activities have been identified as enabling and should be leveraged as key factors in wellness, recovery and inclusion. Economic stress as a barrier highlights the relationship between poverty and mental illness and the costs involved in health seeking in these contexts. The results point to a need for organisations to not only focus on enabling adequate access to mental health services but also to be building inclusive communities that support families and take account of access to development and economic pathways. In conclusion it is important to consider creating enabling environment for people living with psychosocial disability.

Limitations:
• People with psychosocial disabilities were not included in the collective analysis and prioritization
• Participants may have not wanted to speak too negatively against close family members or activities connected to the organisations’ project work.

Conclusions:
The results point to a need for organisations to focus on enabling adequate access to mental health services as well as providing community mental health liaison workers to support this focus. There is clearly benefit in developing a broader understanding of mental health concerns in the wider community through education which could be implemented through existing community structures such as schools, religious communities, community meetings, and existing community groups. Alongside education within the wider community, it is possible to build inclusive communities that support individuals and families, taking into account access to development and economic pathways.

References:

1. Corresponding author email: ramlal@mos.com.np

Results - Most Significant Barriers

1. Unsupportive attitudes and behaviours from the community

“Some people say I have an evil spirit and I totally don’t believe that. Some people think I am not fast, but am slow. Some people think I am making excuses for myself when I tell them that I have a medical condition, perhaps they don’t believe me.” – Participant from Afghanistan

“My neighbors who troubled me too much. These are my neighbors who spoke ill of me. Both they and their husbands both troubled me. They made statements like ‘let her die don’t help her’” – Participant from India

“This photo represent the community people [who] are humiliating me and making fun of me so this makes me feel unacceptable …[and] is one of the most significant barriers to inclusion in my community” – Participant from Nepal

2. Difficulty in accessing appropriate care

“They encouraged me to see some faith healer. In the past I believed this would help me so I went to many faith healers but got no positive effect. I spent lots of money, paying faith healers but I got no help.” – Participant from Afghanistan

“In our village, there is no treatment available for mental illness and the available treatment is far away and without access to proper transportation, The road is also bad and it is difficult to travel. If I had my own vehicle, it would have made my life easy. I had to depend on others when I fell sick as well.” – Participant from India

3. Low MH literacy

“Due to the false beliefs about mental illness, it is difficult [for me] to participate in society. And there is an ancient belief that if the body is swept by a broom then the person will be cured but in my case, it didn’t work at all. I tried this method [under the influence of] ancient belief. This tradition has aroused many difficulties during my mental illness” – Participant from Nepal

“This is my son who I tie with a chain when I go to work. He runs away and disturbs other people and people come and complain about him. I don’t like to do this but often he runs away and disturbs people and this leads to other complaints and fights” – Participant from India