

ORIGINAL RESEARCH

Lived Experience of Psychosocial Disability and Social Inclusion: A Participatory Photovoice Study in Rural India and Nepal

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ABSTRACT

Purpose: *This study aimed to investigate the experiences of people living with a psychosocial disability in rural India and Nepal, and to highlight key barriers and enablers for inclusion.*

Method: *Participatory action research approaches and Photovoice methodology were employed to investigate the lived experience of 32 participants in rural India and Nepal. There were 12 participants and 4 caregivers of people with psychosocial disability from each of the two countries. Semi-structured interviews with study participants were transcribed and analysed thematically to answer the study question.*

Results: *The findings revealed themes related to various supports, meaningful engagement in activity, and community awareness. Among these categories were both enabling and impeding factors to inclusion, the presence or absence of which was typically associated with improvements or worsening of symptoms respectively.*

Conclusions and Implications: *This study underscores the need for integrated community-based approaches that are multisectoral, inclusive of family, and strengthen community responses. Photovoice was also shown to be a feasible research methodology for providing insights into the lived experience of people with psychosocial disability and for fostering their empowerment.*

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INTRODUCTION

The inclusion of people with disabilities is increasingly being prioritised in development programmes and national agendas (Saran et al, 2018). While the inclusion of people with mental illness and psychosocial disabilities tends to be lower on the agenda, the World Health Organisation's Mental Health Gap Action Programme (World Health Organisation, 2018), the Sustainable Development Goals (Votruba et al, 2014; Izutsu et al, 2015; Mills, 2018) and the Global Mental Health Movement are helping to raise its profile.

There is now a well-recognised body of evidence about the importance of shaping services and programmes according to consumer voices and aspects of lived experience, and the value of participatory process in recovery and inclusion (Rose et al, 2011; Evans et al, 2012; Sweeney et al, 2012; Ennis & Wykes, 2013; Salzer & Baron, 2016). This evidence has been predominantly in high-income countries however, and there is very little documented evidence of the experiences of people and families affected by psychosocial disability in low- and middle-income countries (LMICs) (Semrau et al, 2016). Accompanying this evidence gap, there is also a practice gap in as much as community-based programmes in LMICs could play a role in modelling inclusion and engagement of people with psychosocial disabilities (Menil & Glassman, 2016; Salzer & Baron, 2016).

Photovoice methodology has traditionally been used as an investigative research tool for a range of public health and social concerns. The utilisation of Photovoice in the area of mental health is reasonably recent and, to date, relatively uncommon. A scoping review of the use of Photovoice in mental illness was published in 2016, with only 7 studies fitting the inclusion criteria of primary data collection investigating the lived experience of mental illness (Han & Olliffe, 2016). Photovoice has been used to identify mental health concerns in participants post-disaster (Annang Ingram et al, 2018); to investigate the experience of using mental health services (Tang et al, 2016); and to explore factors that contribute to inclusion and wellbeing (Reid & Alonso, 2018). However, all published Photovoice and mental health studies to date have been completed in high-income countries, with a dearth of literature on lived experience of mental illness in low- and middle-income contexts.

Creating platforms for people with psychosocial disabilities to have a voice in their communities increases general understanding about mental illness, reduces stigma, and improves outcomes for people with psychosocial disability (Mathias et al, 2015; Carroll et al, 2016). Photovoice has been shown to be a robust method for achieving these aims (Han & Oliffe, 2016). Thus, the authors of the current study undertook a participatory action research utilising Photovoice to explore the lived experience of people with psychosocial disability in Nepal and India.

Building on the existing qualitative literature, and acknowledging the gap in such literature in LMIC settings, this paper discusses how the voices of those with lived experience can inform development programmes and promote inclusion.

Ethical Considerations

The research was undertaken by TEAR Australia in partnership with the University of Melbourne's Nossal Institute for Global Health, Emmanuel Hospital Association (EHA) in India, and the Centre for Mental Health and Counselling (CMC) in Nepal. Approval for the research was obtained from University of Melbourne's Human Research Ethics Sub-Committee, the Nepal Health Research Council and Emmanuel Hospital Association Institutional Ethics Committee.

METHOD

Setting

The study was conducted in locations where Emmanuel Hospital Association (EHA), India, and the Centre for Mental Health and Counselling (CMC), Nepal, currently implement community-based mental health projects. The study took place over four rural field sites in the two countries, following Hergenrath's ten-point framework for Photovoice (Hergenrath et al, 2009).

Photovoice is a qualitative participatory action approach that combines photographic images with narrative, and recognises local knowledge and the experiences of those most affected by the issue in question (Reid & Alonso, 2018). In this research, Photovoice methodology was employed to answer the research question: "What are the key barriers and enablers for social inclusion in rural north India and Nepal?"

Sample

Thirty-two research participants were selected through purposive and convenience sampling. They were 12 people with lived experience and 4 carers, from each country.

Selection criteria:

- over 18 years of age;
- ability to follow instructions and communicate verbally;
- lived experience of psychosocial disability for 6 months or more;
- for carers, more than 6 months of experience of caring for a person with psychosocial disability.

While 32 people were invited to participate, two declined. Written informed consent was obtained and two more participants later withdrew due to personal reasons. Participants were trained in using a digital camera and photography, and then instructed to take photos, over a four-day period, of perceived barriers and enablers to community inclusion.

After the four days, researchers interviewed participants, using an approved interview guide. Participants nominated their six most representative photos – three barriers and three enablers. Researchers asked participants to identify the two most significant pictures from those six (one key enabler and one key barrier). Participants discussed these two with the researchers, and gave a descriptive title to the remaining four photos. The interviews were audio-recorded, transcribed and translated.

Data Analysis

Thematic analysis of the data utilised a multi-stage grounded theory approach. The data was collated into response type (e.g. “India participant primary barriers”, “Nepal carer secondary enablers”), and codes were developed. Two researchers coded the data independently. A high degree of inter-researcher consistency allowed the team to arrive at the final themes.

RESULTS

Thematic analysis revealed three categories of response: supports, meaningful engagement, and stigma and community awareness/attitudes. Under each

category, a number of themes emerged as enablers and barriers to social inclusion. The themes are captured in Table 1.

Table 1: Themes denoting Enablers and Barriers to Social Inclusion

Category	Enablers to Inclusion	Barriers to Inclusion
Supports	Family, friends' and neighbours' emotional and practical support promotes mental health	Mental health of individuals affects other family members' wellbeing and participation
	Nature, religion and safe places enable recovery and mental health	Economic stress exacerbates psychosocial disability
	Access to treatment is important for recovery	Barriers to treatment inhibit wellbeing and inclusion
Meaningful Engagement	Engagement in meaningful activity facilitates positive emotions, meaningful time use, self-efficacy and economic contribution	Limited contribution to family and community life is a barrier to inclusion
Stigma & Community Awareness/ Attitudes	Community awareness and acceptance enhance participation	Stigma and discrimination hinders inclusion
	Advocates promote awareness and inclusion	Decreased sense of wellbeing and self-worth limits inclusion

1. Supports

Supports were natural, medical and economic in nature. Here 'natural supports' is defined as the natural environment, religion, home and family and friends (Sidebotham, 2014).

Family, friends' and neighbours' emotional and practical support promotes mental health

The positive support of family members was the most significant enabler to inclusion. Many photos portrayed family members who had supported the

person with lived experience in emotional and practical ways. These were spouses, children, parents and grandparents, siblings and uncles. Emotional support encompassed caring for, helping and listening to the person with psychosocial disability. Practical support included help to purchase medication, to take medication on time, to access treatment, and financial contributions.

“This is a photo of my son. He is the one who took care of me and the family throughout my illness and also took responsibility of the medical expenses.” (NUMA06)

In some cases, support was perceived to promote positive mental health outcomes.

“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.” (KANK09)

Several carers recognised the importance of their own role in providing support, with one carer taking a photo of herself and adding the caption:

“Only a mother can take care of her son... no matter how hard it is.” (HUSH06)

Though less frequent a response, the support of friends and neighbours was perceived as valuable for reasons similar to family support.

“It is very easy to participate, as friends have accepted me and they listen to my feelings and support me.” (NSP6)

Conversely, the lack of family support created a barrier to inclusion and participants perceived the absence thereof to exacerbate symptoms and negative emotions, and as a barrier to accessing treatment.

“Due to the false beliefs and unsupportive behaviour from my family members, I was not permitted to get treatment.” (NSP3)

Absent family support or negative family responses in the form of violence or restraint was also present in some participants' captions.

Economic stress exacerbates psychosocial disability

Participants with lived experience said that stress, negative emotions and symptoms were exacerbated by economic factors. Carers and participants expressed household economic stress due to the inability to work of both/either themselves and/or the person they were caring for.

“When I am sick, I can’t work and can’t earn money. I need work to earn money, but I don’t have either.” (KASK09)

Economic stress was also linked to access to treatment and services, and the associated expense. Participants spoke of the financial burden and the extensive efforts required to obtain effective treatment.

“We face financial difficulties in affording the medical treatment required for both of us – my husband and myself – because we both have mental illness.” (NDP6)

“...My parents are the ones who ... took me to India for my treatment, spending two million rupees. They got that money from selling gold and buffaloes. When all our assets were used for my treatment, my mother would cry a lot. Despite all these difficulties they continued my treatment and made me well.” (NDP5)

Mental health of individuals affects other family members’ wellbeing and participation

Participants noted that mental illness affected the lives of family members and carers.

“My children’s school studies are hampered by my mental illness... I was afraid that my situation would create depressive symptoms in my daughter when there was very much depression and sadness. Probably this time she was studying at grade 5 or 6, she used to be afraid and cry a lot and sometimes she used to study. Due to my illness there was disturbance in her study.” (NSP1)

“I got depression because my husband has mental illness.” (NDP6)

Nature, religion and safe places enable recovery and mental health

Participants felt that feelings of peace, happiness and safety result from experiences in nature, religion/religious practice and safe places.

“Happiness after seeing the greenery and blooming flowers.” (NDP3)

Religious rituals were associated with peace and receiving strength.

“I feel peace after chanting the Gayatri mantra (a devotional song). ... As far as I know I should meditate this mantra to be relaxed and fresh.” (NDP4)

Home and places of worship were both mentioned specifically as safe spaces. However, there were also several exceptions wherein the home was identified as an unsafe place of restraint and exclusion.

Access to treatment is important for recovery

Treatment support is defined here as including availability of medical services, transport, treatment affordability and supply, and support in taking medication. Participants expressed that treatment support helped to reduce symptoms, increase positive emotions and therefore promote social inclusion.

“Improvement in my mental illness after taking medication regularly.” (NDP6)

Barriers to treatment inhibit wellbeing and inclusion

The absence of treatment was among the most significant barriers to inclusion. Many participants described difficulties in access, citing varying reasons such as environmental barriers.

“In our village, there is no treatment available for mental illness and the available treatment is far away, and without access to proper transportation I was unable to take proper treatment. 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.” (KASK09)

However, barriers to treatment were also compounded by lack of family support to access medication, by economic factors and by lack of awareness of treatment options. These compounding barriers have been discussed under other theme headings, but reiterate the value participants placed on accessing treatment.

2. Meaningful Engagement

Meaningful engagement included activities such as parenting and caring roles, livelihood activities, household tasks and participation in religious and community events. Participants pointed to a number of benefits of engaging in meaningful activity.

Engagement in meaningful activity facilitates positive emotions, meaningful time use, self-efficacy and economic contribution

Meaningful engagement helps participants deal with symptoms and promotes positive emotions such as ‘enjoyment’, ‘accomplishment’ and ‘feeling at peace’.

“Taking care of my child helps me and keeps me happy.” (SASD09)

“Working has helped me forget my problems at least for that short time and focus on the work. This also gave me happiness.” (BESA10)

Participants drew direct links between livelihood activities and community insofar as running a business helps participants meet and interact with others, for example. Moreover, livelihood activities, along with study, were tied to future-related prospects, which alleviated financial stress, increased motivation and helped participants “move ahead in life”. Such benefits engendered a sense of self-efficacy.

Meaningful engagement also had benefits such as the perception of time well spent. For example,

“We two brothers used to travel to different places and this helped me to utilise the time of my sadness in the right way.” (NSP1)

Livelihood or gainful employment also fostered increased economic security.

“This business has helped me to increase my self-esteem and my motivation in life. It is one of the important parts of my life which helped me to move ahead while I was in financial crisis.” (NSP5)

Limited contribution to family and community life is a barrier to inclusion

On the other hand, suspended livelihood activity exacerbated financial stress, symptoms and exclusion. Being unable to engage in activities that participants felt were meaningful was linked with negative emotions.

“I did not have a livelihood and my mind was empty and hence I started thinking about various things which further added to my stress and mental illness. If I am busy and involved in livelihood activities, it would reduce my stress.” (KANK09)

“I feel bad that I am unable to do a lot of work in the house. Since I am not able to do the housework, the burden falls on other members of the family.” (SASD09)

3. Stigma and Community Awareness and Attitudes

This category of response encompasses self-stigma as well as knowledge, attitudes and discrimination by the community.

Decreased sense of wellbeing and self-worth limits inclusion

Participants identified a decreased sense of self-worth as being a barrier to inclusion and affecting interactions with family and friends, self-perception and motivation to participate.

"My illness isolated me from everyone. ... I always prefer to be alone and not even interact with my family even when they want to talk to me." (NUMA06)

Symptoms affected how participants felt about themselves, whether lonely, 'better off dead' or useless to society. Thoughts of one's value or one's achievements relative to others caused self-stigma. Often symptoms prevented participants from involvement in activities that they valued, such as socialising, housework and enjoying nature.

"I am not able to interact with other women...When a lot of women are sitting and talking, I am unable to interact properly. Sometimes I say inappropriate things which affect other people. I feel bad that I am not able to talk to people properly, especially with relatives and guests when they visit." (HAME09)

Community awareness and acceptance enhance participation

Participants placed value on community awareness and described how it promoted acceptance, which enabled inclusion. For example,

"...the society should be encouraged to involve (people with mental illness). As a result, mentally ill people can feel part of the society." (NSC1)

Several participants further articulated the enabling role of support/self-help groups for economic and social support.

"This group has helped me in interacting with other people and has provided an opportunity and created a forum to listen to the difficulties of others." (NSP6)

"The saving and credit co-operatives have supported building good rapport in the community by collecting and utilising cash. Whenever I need a loan, the group members support me to pass the loan (test), which provides assistance in my work." (NDC1)

Stigma and discrimination hinders inclusion

The most pervasive barrier to inclusion was social distance. Most participants expressed this, describing feelings of criticism, judgement, discrimination or isolation.

"... people in the community are humiliating me and making fun of me, so this makes me feel unacceptable ... (and it is) one of the most significant barriers to inclusion in my community." (NDP1)

The social distance experienced by participants was often the result of the behaviour of an unnamed individual or group of individuals in the community.

“This picture reminds me of a person who always created obstacles to stop me receiving treatment and participating in the community.” (NSP4)

Some participants related exclusion to specific community events.

“When there was a market fair in this place, I was not allowed to go there.” (NSP5)

Social distance was linked to negative traditional beliefs and practices, and a perceived lack of awareness about mental illness in the community. Some participants described the negative traditional beliefs and practices that they believed caused worsening mental health, recurrence of the mental illness, and/or reduced access to treatment pathways.

“Due to the false beliefs about mental illness, it is difficult (for me) to participate in society. A broom is shown in this photo. 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.” (NDP4)

Advocates promote awareness and inclusion

Throughout the collected data, respondents identified key advocates who facilitated inclusion. Advocates were people who were valued for their knowledge about mental illness and for support provided to the participant and their family. Advocates included family members, NGO staff and volunteers, health clinic or community health workers, traditional healers and sometimes neighbours. Advocates provided support by raising awareness, bringing people together in groups, strengthening networks of people with psychosocial disability, facilitating access to treatment, as well as listening and understanding. For example,

“(These are) the right people who provided the right information at the right time to take treatment for my mental illness. They are my neighbours and the volunteers from the project, and they helped me go to the hospital. They helped me at the right time and took me to the right place.” (KASK09)

Participants described the importance of NGO staff or volunteers’ work in creating community action and awareness about mental health. For example,

“He is the first person who (shared) ...with our society that the mental illness can be treated. He visited every area, every house and provided information that this can be treated and this is not due to God or ghost but this is an illness which can be cured with treatment. He raised awareness on this issue...” (NDC2)

DISCUSSION

The photos and accompanying narratives gathered through this study point to the importance of natural supports, access to treatment, stable household economics, meaningful activity, community awareness and advocates who promote inclusion. They describe exclusion through stories of stigma and discrimination stemming not only from negative traditional beliefs and practices in the community, but also from poor mental health generating self-stigma and self-discrimination.

Internal and External Contributors to Inclusion

While this study yielded a range of responses to the research question, the key themes raised by participants were highly consistent among those experiencing psychosocial disability and among carers, both in Nepal and India. The role of symptoms was central. Many of the identified barriers and enablers related to a person’s state of mental health, which contributes to or infringes on one’s self-worth and associated propensity for inclusion. The social environment (community attitude and awareness, advocates) was also identified as a significant factor in inclusion, confirming the understanding that inclusion is derived both from within an individual and from the environment. Indeed, the framework for the International Classification of Functioning, Disability and Health highlights the non-linear, dynamic and complex interactions between impairment, function, environment and participation (WHO, 2001; Sánchez et al, 2016). The voices of those with lived experience of psychosocial disability in this study have conveyed the importance of ensuring both specific supports for people with psychosocial disability to strengthen internal factors which influence inclusion, as well as the importance of addressing existing environmental barriers.

The Importance of Natural Supports and Treatment

A requirement to be noted is the need to assure specific supports in order to promote inclusion. One of the most significant of these is access to treatment, which was expressed in terms of the consequences of its unavailability, i.e.,

without treatment, symptoms worsen and the individual loses the capacity to engage in family and community life. Kermode et al (2010) acknowledged that the exacerbation of symptoms can increase stigma and psychosocial disability, stressing therefore that access to effective treatment is still a vital issue for many people with psychosocial disabilities. This issue of access to treatment, however, was more complex than unavailability of services, and included the family's role, transport issues, economic factors, awareness and community acceptance of treatment options. These results reiterate the importance of understanding the different factors preventing or enabling access, and of developing tailored programmes which frame access to culturally-appropriate healthcare as a human right, which contributes to full social participation (WHO, 2013). Appropriate treatment should be seen through a rights-based lens that promotes participation, contextual understanding, choice and person-centred approaches (Eaton, 2018).

Social and Economic Outcomes of Meaningful Activity and Livelihood

The notion of meaningful engagement is closely tied up with life in the home, livelihood and family roles. It commonly links with economic contributions to family and society. As such, participants portrayed the cyclical relationship between financial hardship and mental health: financial hardship was a cause of mental ill-health, and mental ill-health resulted in lost productivity and/or associated treatment costs. This finding aligns with growing international evidence that mental ill-health and poverty interact in a negative cycle in LMICs (Lund et al, 2010; Patel et al, 2010; Lund et al, 2013). According to the findings, participation in gainful employment, livelihood or economic activities as well as household responsibilities and support groups, enables wellness and inclusion. Livelihood activities create opportunities for positive social connection, and generate positive emotions, a sense of meaningful use of time, self-efficacy and a positive orientation towards the future. These broader benefits of including livelihood and income-generating activities in inclusion approaches have also been documented elsewhere (Raja et al, 2012; Tew et al, 2012; Lund et al, 2013; Carroll et al, 2016).

Family-centred Approaches

The study also found that reducing exclusion starts in the home. The support of family and significant others was frequently mentioned as important for inclusion. However, not only did those with lived experience need the support

of family, but family and other caregivers also required support. The narratives in this study unveiled family members' experience of family disruption, social disconnection, compounded economic stress, and mental health changes of their own. Multiple other studies on the effects of mental illness on families from diverse low- and middle-income settings note these effects (Shibre et al, 2003; Corrigan et al, 2006; Lauber & Rössler, 2007; McDaid et al, 2008), underscoring the need for family involvement in support and recovery initiatives (Tew et al, 2012). These data highlight the central role of relationships in recovery and the imperative of building mutual understanding and supportive environments for families and households (Wyder & Bland, 2014; Foster et al, 2016; Price-Roberts et al, 2016). The evidence suggests that this support could be offered through individual and family-based counselling, peer support groups, self-help groups and advocacy group membership (Tew et al, 2012; Price- Robertson et al, 2016; Mathias et al, 2017).

Community Mental Health Literacy

Beyond the home is a further identified sphere of concern, where carer-participants in particular placed emphasis on building community mental health literacy for inclusion. They intimated that raising awareness through information sharing helps communities understand mental health in a different way, and helps counter harmful traditional beliefs and practices, stigma and social distance. Mathias et al (2015), Metha et al (2015), Patel et al (2011) and Pinfold et al (2005) agree that emphasis must be placed on increasing awareness of mental health and associated services/treatment, and positive community attitudes. Kermode et al (2010) also suggest incorporating efforts to support access to treatment alongside efforts to address societal attitudes. They meanwhile warn that an excessively bio-medical, illness-focussed approach may worsen stigma and lead to disease labelling. Notwithstanding this, community-based models that integrate awareness and interventions that address upstream determinants of mental health have a positive impact on clinical and social outcomes (Lund et al, 2010; de Menil & Glassman, 2016; Reid & Alonso, 2018). Therefore, programmes could promote inclusion through integrating community mental health literacy alongside rights-based approaches to treatment, while promoting inclusive activities which address multi-dimensional poverty stressors (Lund et al, 2010; Davis et al, 2013; Lund et al, 2013; Trani et al, 2015; Eaton, 2018).

Strengths and Limitations

This study allowed people with lived experience of psychosocial disability to capture and express their lived experience. Participants said that taking the photos and telling their stories was a positive experience, as they felt heard and supported. Consistent with other Photovoice studies, this methodology appears to have been empowering and capable of enhancing self-efficacy, self-reflection and self-awareness (Han & Oliffe, 2016; Reid and Alonso, 2018). While the study results are important for community-based organisations, programmes and services, the process itself has also been a valuable exercise for participants. This suggests that Photovoice is a feasible methodology as both a tool for research and as an intervention in itself.

This study has limitations as to its broad applicability due to the localised focus. As participants were recruited through the work of local mental health projects, results may differ in other settings where there is less awareness of mental illness and access to support. Despite this, the data adds in-depth understanding of a little-studied population and the themes are reflective of the broader literature.

CONCLUSION

Persons affected by psychosocial disability and their carers highlighted the important role of natural supports (family, friends, access to treatment, nature, religion and safe spaces), meaningful engagement, and community attitudes in supporting or deterring mental health, wellbeing and inclusion. These findings align with literature from the region, placing emphasis on the need for multi-faceted holistic approaches to mental health promotion, recovery and inclusion. It is evident that community-based mental health programmes will have greatest impact by taking an integrated approach that accounts for the three categories of response highlighted in this study – supports, meaningful engagement and broader societal knowledge and attitudes.

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