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Article

Co-production of a pictorial recovery tool for people with psycho-social disability informed by a participatory action research approach—a qualitative study set in India

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Summary

Mental health problems are recognized as a leading cause of disability and have seen increased allocations of resources and services globally. There is a growing call for solutions supporting global mental health and recovery to be locally relevant and built on the knowledge and skills of people with mental health problems, particularly in low-income countries. Set in Dehradun district, North India, this study aimed to describe first, the process of co-production of a visual tool to support recovery for people affected by psycho-social disability; second, the key outputs developed and third, critical reflection on the process and outputs. The developmental process consisted of participatory action research and qualitative methods conducted by a team of action researchers and an experts by experience (EBE) group of community members. The team generated eight domains for recovery under three meta-domains of normalcy, belonging and contributing and the ensuing recovery tool developed pictures of activities for each domain. Challenges to using a participatory and emancipatory process were addressed by working with a mentor experienced in participatory methods, and by allocating time to concurrent critical reflection on power relationships. Findings underline the important contribution of an EBE group demonstrating their sophisticated and locally valid constructions of recovery and the need for an honest and critically reflective process in all co-productive initiatives. This study generated local conversations around recovery that helped knowledge flow from bottom-to-top and proposes that the grass-root experiences of participants in a disadvantaged environment are needed for meaningful social and health policy responses.

Key words: community-based participatory research, mental health, Asia, qualitative methods

INTRODUCTION

Mental disorders have been reported as contributing 11.8% of the total burden of disease in India (Patel *et al.*, 2011) yet <1% of the national health budget is allocated to mental health service provision (World Health Organisation, 2011). The Global Mental Health

Movement launched in 2007 (Lancet Global Mental Health Group, 2007), built on a public health approach grounded in bio-medicine, made a prominent call for resources to increase access to mental healthcare. This attention to mental health is badly needed, though emerging voices from social scientists suggest we must give greater priority to the political, economic and social determinants of mental health, community resources and local solutions and balance the prevailing biomedical approach (Campbell and Burgess, 2012; Kirmayer and Pedersen, 2014; Jain and Orr, 2016).

One potentially powerful response to the lack of focus on social determinants of health and biomedical frameworks is the recovery approach (Slade *et al.*, 2012). Recovery is a term that is utilized broadly in the mental health field, with its application to date largely focused on remission of symptoms and a return to previous employment and roles (Slade *et al.*, 2012). However, mental health service users have suggested recovery is a 'way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Anthony, 1993). Within the field of global mental health, there have been calls to ensure bottom-up, service user driven approaches to recovery, thus ensuring the cultural and social validity of services (Aldersey *et al.*, 2017).

Recovery is also an approach of learning from people in recovery about 'what works' and also refers to the broader recovery movement, a values-based endeavour by people in recovery, practitioners and others to transform and develop mental healthcare and services (Roberts and Boardman, 2013). Supporting this approach, recovery 'tools' such as the Illness management and recovery program (Mueser *et al.*, 2002) and Wellness Recovery Action Planning (WRAP) (Cook *et al.*, 2010) have been evaluated empirically to show improvement in symptoms, hope and quality of life (Slade *et al.*, 2014).

In India, some mental health professionals have adopted recovery frameworks constructed in Europe and North America, yet recovery approaches as a first step need to reflect the local cultural context and identify local concepts of 'recovery', to allow a shared understanding of what recovery is and how it is 'practiced' in that place (Gopal and Henderson, 2015; Bayetti *et al.*, 2016). Indian studies have identified the importance of community resources such as temple healing (Raguram *et al.*, 2002), knowledge and inclusive attitudes (Shidhaye and Kermode, 2013) and carer perspectives on recovery (Janardhana *et al.*, 2018), and have called for a greater emphasis on recovery(Chaturvedi and Thirthalli, 2015; Agarwal and Sinha, 2016). However, there remains a large challenge in developing vernacular concepts of recovery contextually valid in India in the community (Gopal and Henderson, 2015; Bayetti *et al.*, 2016; Janardhana *et al.*, 2018) and that build on frameworks of clinically applied anthropology among mental health professionals (Jadhav, 2013).

A key component of locally and contextually valid approaches to recovery requires a knowledge production model that strongly represents the perspectives of 'experts by experience' (EBE) (traditionally on the receiving end of medical research). Growing numbers of publications have demonstrated the value of a co-production process that collaboratively builds on the knowledge of EBE 'with the knowledge of health or science professionals, and thus honour the right of people to participate in any knowledge creation that ultimately affects their lives (Ottmann *et al.*, 2011; Gillard *et al.*, 2012; Loewenson *et al.*, 2014). Benefits of co-production include improved quality and responsiveness of services, more effective and cost-efficient services, strengthened social capital and citizenship (Ottmann *et al.*, 2011) and further, space for dialogue between service users and service providers which can increase the possibility for critique of bio-medical discourses which have dominated interventions for the last century (Gillard *et al.*, 2012).

There is growing recognition that psycho-social interventions in particular, are more likely to be effective where people are engaged in developing and implementing the intervention (Greenhalgh, 2009; Ruggeri and Tansella, 2013). A further extension of the co-production process is participatory action research (PAR) which seeks to transform power relationships inherent in the research process. PAR builds on the idea that participation in the research process is a continuum that can range from compliant participation to a research process that can 'free' participants from traditional power relations and hierarchical structures, meaning that the research process itself can be 'emancipatory' (Loewenson *et al.*, 2014). This can offer an alternate model to hierarchies built on identity axes such as caste, age, gender and disability (Nayar, 2007; Mehrotra, 2012; Jadhav *et al.*, 2016). As these hierarchies and their associated mechanisms of social exclusion are of themselves determinants of mental ill-health, PAR is a potentially health-promoting methodology in this setting(Chung and Lounsbury, 2006). The core idea of the participatory approach to research is that, 'knowledge is built out of the collective comparison of subjective experiences of reality by groups of people commonly exposed to, acting on and/or with first-hand experience of that reality' [(Loewenson *et al.*, 2014), p.

20]. This participatory process can thus honour the right of people to participate in any knowledge creation that ultimately affects their lives (Greenhalgh, 2009; Ottmann *et al.*, 2011; Loewenson *et al.*, 2014).

Northern India, with a Hindi speaking population of 650 million, has a poorly resourced and largely ineffective public health system, which has particularly limited access to care for people with psycho-social disability (PPSD) (Patel *et al.*, 2015). Implementation of India's National Mental Health Programme typically depends on a psychiatrist who operates out of a district hospital with visits to rural health centres for out-patient clinics. This programme has been criticized as ineffective in engaging communities around mental health due to its biomedical orientation (Jain and Jadhav, 2008) and includes very limited psycho-social interventions which are emphasized as central to effective care in global mental health practice guidelines such as the World Health Organisations' mhGap 2.0 publication (World Health Organisation, 2016). The Department of Empowerment of persons with disability, within the national Ministry of social justice and empowerment is the Government of India body charged with supporting skill building and community-based rehabilitation (including psycho-social support) for people with disabilities. These services are currently primarily available in larger metropolitan cities although there are plans to expand their reach (Ministry of Social Justice and Empowerment, 2018). To our knowledge, there have been few accounts of locally developed tools or resources for 'recovery' co-produced with PPSD and carers, developed in India (Lloyd *et al.*, 2016). In this paper, we build on a framework of health systems research (Loewenson *et al.*, 2014), with a focus on recovery in the field of global mental health, for which we used participatory processes (PAR) and report here on the co-productive aspect.

In this paper, we aim to: (i) describe how a PAR approach was used to guide the process of co-production of a pictorial tool to support recovery for PPSD and carers; (ii) describe the key outputs (recovery tool domains and components) developed through this process and (iii) critically reflect on both the process and the outputs with respect to the psycho-social context, power relations and constructions of recovery that emerge.

MATERIALS

Setting

This study was set in the busy, green valley of Dehradun, which has 2 million inhabitants and is part of the North Indian state of Uttarakhand. At the time of this study implementation of the National mental health programme had not started and there were six Government psychiatrists working in the state, four of them located in Dehradun, the state capital. Table 1 shows Dehradun district as more urban and literate population than the mean for India, but with indicators showing greater structural gender inequality that disadvantages women, revealed in uneven measures of sex ratios (ratio of male to female babies at birth) and the gender literacy gap.

The project was implemented by Burans, a partnership project which works broadly in community mental health promotion and health system strengthening, led by the local non-profit Emmanuel Hospital Association organization and written up as a case study (Mathias *et al.*, 2017). Burans works in four communities of Dehradun district with a target population of 100 000 people. In each community five employed team members work with volunteer community members working to promote mental health by through increased knowledge, safe social spaces and partnerships for action (Campbell and Burgess, 2012; Mathias, 2016) and by strengthening the public mental health system. Over the first 4 years, 950 PPSD were registered in the programme.

The team

An eight-member EBE group was formed and included carers as well as people with lived experience of mental illness. Co-author KK was an EBE group member and also works for Burans as a team leader. Participants were offered a small payment for their contribution. The EBE group worked collaboratively in co-production with the research team comprised of KM, a New Zealand public health physician who has lived in India for two decades, PP, a Dehradun based health professional, SJ, an Indian-origin social work academic based in Scotland, and RG, an Indian public health professional living in South India. The profile of people represented in the EBE group is provided in Table 2.

Initiating and agreeing upon the recovery tool development process

The idea of developing a pictorial recovery tool was initiated by KM, SJ and the Burans team in reviewing tools developed in high-income countries (HIC) that were not easy to use for people with low literacy, and that did not adequately connect with the context and experiences of PPSD and carers in Dehradun (Mathias *et al.*, 2017). The research team (KM, PP, SJ and KS) elected to use a PAR framework that built on a health systems strengthening framework, hoping to use a process of

Table 1: Socio-demographic profile of the study district, with state-level and national comparison data

Indicator	National—India	Uttarakhand	Dehradun
Total population (million people)	1200	10.1	1.7
% population rural	72.2	69.5	44.5
% population under 15 years	34.9	28.9	26.9
Sex ratio (female to 1000 males)	940	963	902
Literacy (% literate female)	65.5	70.1	78.4
Literacy (% literate male)	82.1	87.4	89.4
Maternal mortality	178	292	178

Table 2: Socio-demographic profile of EBE group members

Variable	Detail	PPSD	Carer
Sex	Women	3	4
	Men	1	
Age	Range	30–40	35–62
	Mean age	36	44.75
Literacy and educational level	Low or no literacy	2	3
	Literate	2	1
Residence	Small town	3	3
	Dehradun city	1	1
Employment status	Working as community mental health professional	1	1
	Not in paid work	2	2
	Employed in low-income fields	1	1

'empowering co-investigation' in the participation continuum outlined by Chung and Lounsbury [(Chung and Lounsbury, 2006), p. 2131] and Gillard *et al.* (Gillard *et al.*, 2012). All participants gave informed consent. The study was approved by the Emmanuel Hospital Association Institutional Ethics Committee in January 2017.

RESULTS

The results are presented in three sections corresponding to the study aims. First, an in-depth discussion of the *process* for developing the key domains of the Swasthya Labh Saadhan recovery tool (literally 'health benefit tool') (SLS tool), second, *summarizing* the eight domains identified for the SLS tool and third, *critically reflecting* on the tools' acceptability, process and output.

Process of developing the key domains of the Swasthya Labh Saadhan (SLS) tool

To develop domains of recovery the EBE first held two full day workshops and then held six shorter meetings. Participatory methods including telling stories of recovery, discussing photographs, drawing pictures and discussing pictures drawn, collecting symbols, focus group discussions and participant observation to generate key domains of recovery. In-depth interviews were also held with EBE participants. Key terms agreed upon included: *swasthya labh saadhan* (recovery tool for health), *theek hona* (to be well) and *swastha rehna* (remain in good health). Triangulation, using a process of review, analysis and comparison of the diverse forms of data collected, verified and strengthened the findings.

Figure 1 demonstrates the co-production process, building on the spiral process of PAR [(Loewenson *et al.*, 2014), p. 13].

Data analysis

EBE members and researchers used the generated data to analyse and develop domains of the SLS recovery tool following a framework described by Gillard *et al* (Gillard *et al.*, 2012).

Stage 1—Preliminary analysis

EBE members generate concepts of recovery by discussing facets of recovery for themselves, their household or in their community then grouping concepts to describe key areas for recovery.

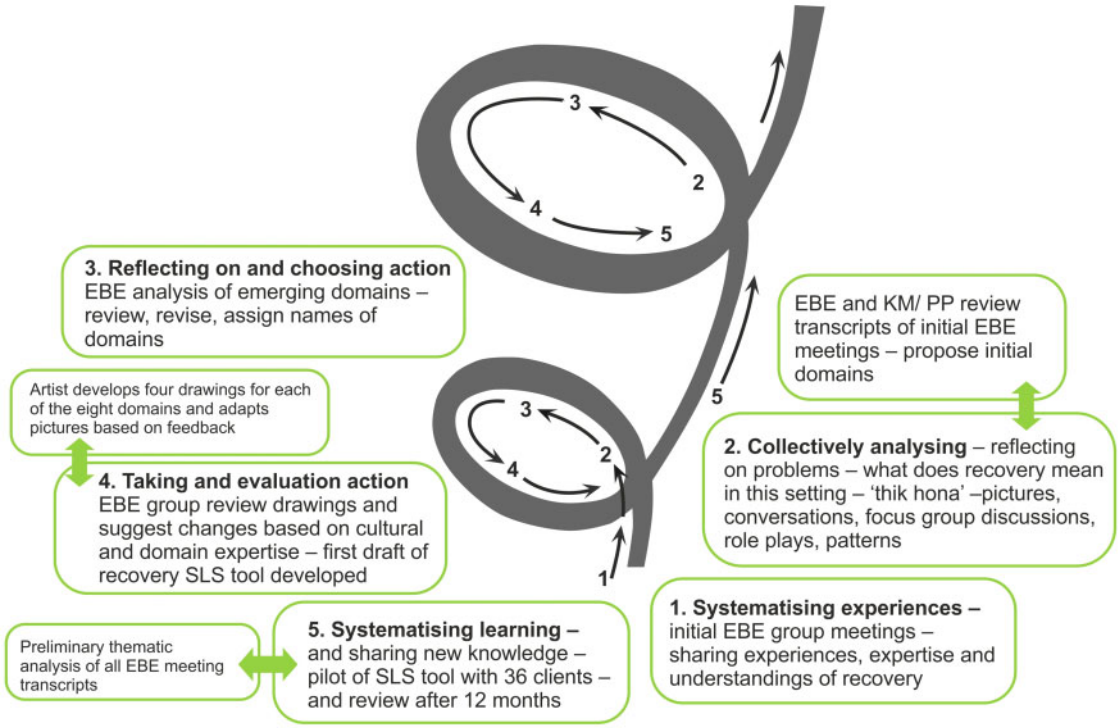

Fig. 1: Flow chart of the tool development and analysis process.

Stage 2—Developing an initial domain framework

The group proposed a framework of broad 'domains' of recovery, within which practical activities for PPSD and carers would be detailed. After the second EBE meetings KM and PP reviewed the data generated in Stage 1 to condense the themes into seven preliminary domains.

Stage 3—Probing the domains

In the third EBE meeting there was a lengthy discussion of proposed domains and the domain of 'Engaging spiritually' was added while two other domain names were changed to better reflect nuances of group generated data.

Stage 4—Defining each domain's framework in pictorial form

EBE members proposed four or more activities related to each domain which were illustrated with line drawings by the artist, a 14-year-old student studying in Dehradun district. Pictures were reviewed by EBE members to assess their cultural appropriateness, comprehensibility and generalizability and revised in response to feedback. Examples of EBE feedback are provided below:

> The woman depicted is peeling onions, but she is kneeling with her legs underneath her, which suggests she is praying. It would be better to have her squatting.
> The picture of the child going to school shows the child carrying the backpack. Her father should be carrying the school bag.

Stage 5—Piloting the domains and refining the tool

The final tool format was developed by KM and PP, in discussion with EBE members and comprised of an A4-sized plastic folder with paper sheets, which portrayed the eight domains in pictorial form. A client and community team member could select their preferred activities for recovery for the ensuing fortnight. Pictures could be cut-out and pasted into their own activity folder and reviewed by the community worker, client and carer 2 weeks later. Preliminary piloting of the tool suggested it was acceptable, easy to understand, used primarily by PPSD directly and practically useful. A further adaptation suggested by an EBE was that coloured pencils and colouring in the pictures could enhance tool engagement.

Stage 6—Thematic analysis of transcripts

In-depth analysis of transcripts (EBE workshops and in-depth interviews) to understand concepts by KM and SJ involved reading and re-reading transcripts to seek consistent patterns inherent in the data, and critical reflection. These were summarized into three meta-themes.

Critical reflection

Group members were initially resistant to the idea that they had any expertise or knowledge to offer and as described below

> We are not experts of any kind. We are just people who have so many problems in our families and we are trying to find a way to get by. You people, (from Project Burans) are the ones who are the experts, so it is you who should be telling about this project and our SLS work we have been doing together. You are the ones who have guided us all.

Early in the process KM, SJ and PP submitted an abstract about the SLS tool for a conference, yet had not thought to discuss the abstract development and submission process with the whole group. Six weeks later when the abstract was accepted for presentation, the researcher team critically reflected to recognize that this process was not jointly developed. The researcher team apologized for their non-collaborative conference application process, which was discussed with the EBE group. We queried whether any EBE members would be interested to participate or to co-present with a pre-made video or a Skype link however the group responded with 'It is our tool but it's your project and your *rozi roti*' (daily bread) i.e. that the SLS tool belonged to the EBE group, the researcher team and the community but the public and paid presentations of the collaborative work could be done by the researchers.

The components of the Swasthya Labh Saadhan recovery tool

The eight domains developed and agreed upon in the EBE group, with the underlying concepts and verbatim quotes, are presented in Table 3 with a further analysis of these themes by the researcher team, into three meta-domains of normalcy, belonging and contributing.

An example of the pictorial nature of the tool is shown in the line drawings used for the domain titled 'Having fun' in Figure 2.

Thematic analysis of all the transcripts by two of the researchers, KM and SJ, demonstrated a prevalent construct of mental health as primarily social and cultural (vs. biomedical). This analysis distilled three key ways that a PPSD and their household engages with the domains described below:

Recovery is achieved and evident through activity

Being busy and active was repeatedly described as a marker of wellness and as a pathway to recovery. Four of the domains described above include components of being engaged in different ways. An example of 'Being spiritually engaged' was supported by an illustration that showed someone ringing a temple bell while 'Being an active family member' was illustrated by a family sitting and eating a meal together. 'Being an active community member' was exemplified by a picture of a man going to mosque at communal prayer time. Furthermore, community members identified actions as the most practical way to start a recovery journey. Participants described the benefits of activity as distraction from emotional difficulties and as providing a sense of achievement:

> *GM5*: Well I get a little bit of peace. I wash up and bathe. I do rituals and take grandchildren to school.
>
> *GM3*: In such times, we forget our troubles, right?
>
> *GM5*: Yeah. a little bit. I cook and knit a little. () then my mind does not wander here and there. (FGD3)

Activity in the early morning brought a sense of inner peace and was important for well-being as well as fitting with gendered societal expectations for women to rise early for purposeful (sweeping) or less purposeful (devotional practice) types of activities.

> I feel good when I get up a little early in the morning. I feel peace early in the morning. Sometimes I feel good reading a book. Going out somewhere and speaking to someone good. Doing rituals and fasting feels good sometimes. (GM1, FGD2)

Recovery is supported by the physical environment

Participants underlined the importance of their physical environment for recovery. Access to quality housing, space for cooking and play areas were described as important for being mentally healthy.

> No one should ever think that they should stay far from a sick person. The environment at home and in the neighbourhood should be good. (GM2, FGD3)

Table 3: Eight domains developed through co-production process, with supporting quotes and actions

Domain terms in Hindi	Domain-English	Meta-domain	Core concepts discussed in EBE group for this domain	Sample verbatim quote by EBE member	Exemplary actions or activities proposed
Apna Khayal Rakhna	Taking care of oneself	Normalcy	Being well enough to carry out the activities of daily living such as bathing, washing hair as well as activities to look good e.g. hair-cut or makeup Self-care included taking medicines or attending counselling for one's own mental health	When we talk about self-care and its importance it includes eating well ( ) because its' not just that. It's like doing extra things like nail polish and dressing up. Every time I think next month I will do this or that and let it go. It is all a symbol of being well.	Completing activities of daily living e.g. bathing Activities for personal grooming e.g. get a hair cut Actions for physical health e.g. go for a morning walk Making space for quiet alone time e.g. read a book
Nashe Se Dur Rehna	Being addiction free		Being addiction free critical for recovery and mental well-being Alcohol primary concern Means to leave addictions difficult	My husband is an alcoholic. He refused to let me even come here. He is drunk right now. All my troubles are caused by him. He had an infection in his brain because of which he used to be adamant and want alcohol.	Reducing number of cigarettes Turning away from bottle of alcohol and instead play cricket Turning away from an alcohol shop and sit with wife
Adhyatmik Rup Se Sakriy Rehna	Being spiritually engaged	Belonging	Being spiritually engaged as a route to and marker of recovery Importance of religious rituals and prayers for healing Combined approach with bio-medical treatments and prayers (*Dawa* and *dua*)	We light a diya (a small cup shaped oil lamp) every day in my house. But sometimes, when that is not possible, wherever I am, I join my hands to pray to God. (kahin bhi hun, haat jod deti hun) Then we get peace and it feels like we have done something.	Spend time in devotion (e.g. sit and pray with cup of tea) Go to a place of worship (e.g. temple, mosque, church) Do something prayerful (prayer flags, prayer meetings) Celebrate a festival (e.g. Diwali, Christmas, Ramzan)
Maza Karna	Having fun		Being able to laugh, forget troubles and have fun an important marker of recovery Emphasis that being able to play with children is a central indicator of this domain More avenues for men to have fun (carom, cards, sports) than for women	I like playing with children. Now that I am unwell I get irritated a bit. Otherwise, I like playing with kids, annoying them and having fun. I like this a lot, from the beginning. I even imitate others with the children. I like this and it makes me happy when I do this. But since I fell ill, I am staying far from these things.	Listen to music/watch a movie Play a sport with friends (badminton/cricket) Try something new (e.g. making a new recipe) Go somewhere new (e.g. visit a waterfall with friends)

(continued)

Table 3: (Continued)

Domain terms in Hindi	Domain-English	Meta-domain	Core concepts discussed in EBE group for this domain	Sample verbatim quote by EBE member	Exemplary actions or activities proposed
Parivar Me Sakriya Sadasya Hona	Being an active family member		Relationships and regular communication with family both near and far emphasized Core concept of doing things together like eating, visiting and communicating well. Underlined that a well person has a responsive relationship with children	I also like talking to people on the phone. Early in the morning, the first thing I do is call my mother (in Delhi) and talk to her. I entire day goes well if I talk to her first thing in the morning. On days I do not talk, I feel very burdened that day.	Participate in conversation together Eating together Play with children (e.g. play games, teach cooking) Participate in a joint family decision
Dost Hona	Being a friend		Friendship important to as availability of someone who can listen and help problem solve Also valuable is the companionship of others to do things with Friends important to provide perspective and relationship outside the household	Another thing that has been helpful for me is my friends. I needed some people to share my frustrations with and all that I was going through. And luckily, I had a circle of friends who understood. (. . .) I do feel that this social circle, and the festivals, (..) has been helpful for me.	Ask others how they are/start a conversation Call friend on phone Arrange to meet with friends for chai or a walk Give a present to a friend or take their children to school
Ghar Ke Karya Me Yogdan Karna	Contribute to the household	Contributing	Contributing with shared work or income important for self-esteem, and to show consideration and connection for others in household Contribution described as important to wider community perceptions of the whole family and possibly, as a way to reduce stigma or social exclusion	It's important to contribute to your family because how else can one live? ( ) . . . People look at a family member who isn't earning or contributing in any way as a burden. It's looked at as an honour issue . . . ( ) There's a lot of stigma attached to anybody in the family who is like this.	Clean/wash own clothes and plates Help clean and sweep house Go shopping for household things/pay bills Seek income with employment or handicraft
Samuday Me Sakriya Sadasya Hona	Being an active community member		Citizenship as a marker of recovery was highlighted Includes doing ones' duty e.g. sweep in front of house, or help neighbours out	I like keeping things clean. I like to keep my neighbourhood clean. ( ) We can keep our homes clean, but we need to keep our neighbourhood clean too.	Join in community functions—marriages, funerals Greet and talk to shopkeepers and neighbours Making community a better place-picking up garbage Joining together/taking action with others

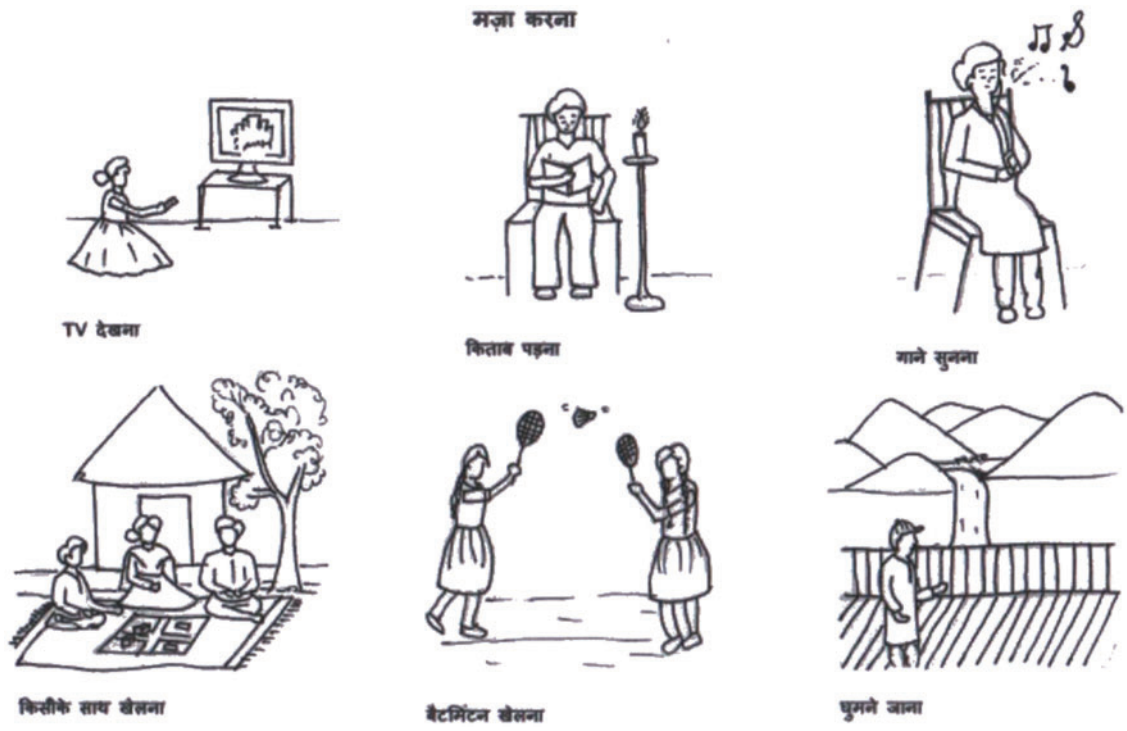

Fig. 2: The domain titled 'Having fun' (maza karna) and associated pictures in SLS.

Table 4: Matrix table showing how the meta-domains interact with the meta themes

	Taking action for recovery	Supportive physical environment	Supportive economic and social resources
Normalcy	Taking care of oneself Being addiction free Being spiritually engaged	Having fun	Contributing to the household
Belonging	Being a friend Being an active family member	–	Being an active community member
Contributing	Being an active family member	Being an active community member	Being an active community member Contributing to the household

Recovery is supported by economic and social resources

Participants described mental distress because of the lack of employment and low income, and shared their aspirations for a better life:

> I have a lot of problems. All my life I have had only troubles and difficulties. (…) Other people go to work. I keep running behind work. Everybody gets work, only I don't. (…) I want to be like the other women I see, have money and buy whatever they feel like. I also want to do that. (…) I have been trying to get a job that will pay better. (…) I feel overcome by these troubles, and then I also have an alcoholic husband, and the place where I stay is not good. (GM4, FGD1)

In describing their efforts to find employment, EBE members outlined how they navigate between hope, hard work and despair:

> I feel that hard work is all we have. We have to keep our spirits up, keep believing in our heart, and do not commit suicide. Still, I do think about suicide sometimes. (GM4 FGD1)

Social resources, and specifically social inclusion was described as a key factor impacting participation and

social engagement. The participant below described how community members consider mental illness as contagious:

> Nowadays the situation is that people see each other and get irritated. They say that this person is sick so stay far away, or we will also get sick. But people don't realize that anyone can get sick at any time. (.). No one should ever think that they should stay far from a sick person. (GM2, FGD3)

The way these themes interact the meta-domains is summarized in Table 4.

The domains identified in the SLS as a co-produced tool were acceptable and legitimate for the team who participated in co-producing this resource. The acceptability and legitimacy is examined in a further study (currently being written up) where this research team evaluates the tool in a pilot study of 26 PPSD.

DISCUSSION

Using a framework of PAR to co-produce a recovery tool, this study shows ways in which a group of community members with lived experience of psycho-social disability were involved in knowledge production.

How does the 'Swasthya Labh Saadhan' (SLS) recovery tool compare with recovery tools from HIC?

Several domains of SLS map directly or indirectly onto recovery domains in tools developed in HIC. 'Household responsibilities', 'self-care', 'reducing addictive behaviour' and 'social networks' also feature in the Recovery Star tool (MacKeith *et al.*, 2010). The Canadian tool 'Do-Live-Well' (Moll *et al.*, 2015) also includes 'self-care', 'connecting with others', 'experiencing pleasure and joy' and 'contributing to community and society'. Using a similar approach to the WRAP tool, SLS proposes that a PPSD identify new actions that may increase mental wellness from recovery domains similar to the 'Wellness Toolbox' to build into daily rhythms (Copeland, 2002).

Differing from HIC recovery frameworks, this tool uses a visual approach to recovery which increases the tool accessibility in a setting where there is low literacy and education. Use of pictures or pictographs has been found to enhance recall and engagement with health-related tools in low literacy settings (Houts *et al.*, 1998). The domains generated in this tool provide a strong focus on the role of the PPSD such as 'Being a friend' or 'Being an active family member' reflecting the relational understanding of mental well-being prevalent in South Asia (White, 2010). SLS also gives greater attention to one's role within a household and a community, (the domains 'Being an active family member', 'Contributing to the household' and 'Being an active community member'). Themes of productive activity and skills for community participation, were similarly found in a recent study in India assessing carer priorities for recovery (Janardhana *et al.*, 2018). The domain of spiritual engagement has not been a feature in most recovery tools developed in HIC but was regarded as a core component by the EBE group in the North Indian context, which was also described in another Indian study (Raguram *et al.*, 2002). Notably absent in the eight domains of this tool is any mention or expectation of access to care, medicines or social or health services that would support recovery. This seems likely to reflect a context with almost no accessible mental health services, or medicines, or community-based services, suggesting that these supports to recovery were not imagined or expected.

These findings of convergent and divergent components between our tool and existing HIC tools reflects societal and psycho-social contexts and was also described in another study which compared concepts of recovery held by PPSD in Chennai and Perth (Gopal and Henderson, 2015). The substantive value of our approach lies in the co-production process that we have taken which seeks to embody local concerns and understandings (Kohrt *et al.*, 2016). This process builds on a community mental health competencies approach (Campbell and Burgess, 2012), where community members have experiential knowledge developed within a safe social space, and in collaboration with partners of a local organization, to develop a contextually valid recovery tool (Campbell and Burgess, 2012; Mathias, 2016). We would expect the SLS to contribute to greater utility and effectiveness in the implementation phase. This user-led approach has been critical for the development of recovery movements in locations as diverse as Scotland and Hong Kong (Bradstreet and McBrierty, 2012; Slade *et al.*, 2012).

How did co-production impact the form and process of the research?

By using a participatory process generating knowledge with an EBE group, this study can critique the dominant discourse, where knowledge production relies on a subject expert who has acquired knowledge through academic qualifications and study (Chung and Lounsbury, 2006). For the EBE group, there was a growing realization of the implicit knowledge that they could offer as

they participated in knowledge co-production. For example, the seemingly amorphous data of pictures, stories and symbols generated by the group was transformed through analysis and discussion into the eight domains. For the researcher group, who believed we were using empowering approaches, we were surprised to become aware we had inadvertently made several unilateral decisions (e.g. in submitting a conference abstract). This challenge was surprising and uncomfortable.

The other key contribution of a co-productive process with the EBE was in underscoring the centrality of activity, the physical environment and social and economic resources for recovery. The critical role of mental health determinants has been well described yet steps to address the physical, social and economic environment are not strong in other recovery tools. 'A focus on social justice may provide an important corrective to what has been seen as a growing over-emphasis on individual pathology. Mental health is produced socially: the presence or absence of mental health is above all a social indicator and therefore requires social, as well as individual solutions' [(Friedli and World Health Organization, 2009), p. 5].

CHALLENGES TO ENABLING EMANCIPATORY PAR?

The SLS tool development used an engaged and participatory process that was dynamic, but did not fully accomplish the goal of emancipatory PAR which seeks to develop 'egalitarian partnerships with community members that equalize decision making power between researchers and community members' [(Chung and Lounsbury, 2006), p. 2131]. The researcher team represented the joint work by sending a conference abstract and made decisions about the SLS implementation processes without consultation with the EBE group. Difficulties in making the research process fully participatory and emancipatory included EBE participants recognizing themselves as expert. The term 'EBE' originates from high-income settings with 'services' that are 'expert driven'. The EBE term is perhaps a reaction in part to the nature of vertical hierarchies where traditionally professional health providers are regarded as experts. However despite the lack of mental health services in India, it is likely to be relevant in the Indian context, given the top-down nature of biomedical services (Jain, 2016). In this context 'patients' however, might instead be conceptualizing themselves in different ways as suggested by an EBE group member 'just people ... trying to find a way'. The concept that being a 'patient' might be constructed by biomedical service providers has been discussed with respect to people with little access to services in Guatemala (Harvey, 2008) and seems useful to consider with respect to forms of participation in this Indian context.

An additional challenge to participation was related to literacy and education meaning illiterate group members initially contributed less in discussions. Furthermore, the majority of EBE members had no prior politicization or contact with any user movement and had also had limited literacy and education, which perhaps led to them feeling unqualified to challenge or engage with the power relations in the co-production process.

In addition, as a first 'experiment' with both co-production and PAR, there was a developing consciousness in both the EBE and the research team about what constituted participation, with the processes evolving en route. The EBE understanding that the tool was theirs, but that the research and Burans team could use it to generate their 'daily bread' illustrates this well. The actual process was closer to engaged co-production (knowledge production) and the timelines did not permit (or we did not allow them to permit) genuine and deep engagement in power relations, although it was dynamic and moved with time (Chung and Lounsbury, 2006). We identified key points in the tool development process at which co-ownership could be enhanced. These include early and explicit discussions about how the process could be co-owned, what each group's expectations and hopes were, and identifying key junctures where critically reflective discussion could be held.

What are the implications for policy and practice from this study?

This study has several key implications for mental health policy and practice in India, and for future directions of global mental health more broadly. First, it suggests that people with lived experience of mental health difficulties have sophisticated and diverse understandings of what recovery means to them. Mental health programmes should prioritize involving community members with lived experience of mental health difficulties in designing mental health promotion, programmes and policies, and resources and seek to use participatory approaches at national, state, district, organizational and community levels.

Employing an honest and critically reflective process can also ensure that participation is genuine so that programmes and policies benefit from local knowledge.

Second, use of a co-developed mental health recovery tool in this study generated local conversations around recovery that expanded horizons for all participants.

Training lay and professional mental health workers to engage in co-productive and participatory ways helps knowledge flow from bottom-to-top which can enhance trust with communities and provide avenues to improve mental healthcare delivery. Third, a participatory methodology ensures that the grass-root experiences of participants in a disadvantaged environment, conceptualize mental health as both a social and a medical concern, requiring both social and medical policy responses. The meta-themes of this study underline the importance of psycho-social interventions that address behavioural activation (keeping busy) (Patel *et al.*, 2013), and addressing macro determinants of health including the physical, social and economic environment such as housing, employment and gender equality (Kirmayer and Pedersen, 2014; Patel *et al.*, 2015). Fourth, the SLS tool provides a framework where the recovery approach can be taught and practically used in engagement with PPSD, who are or are not literate, by psychiatrists, nurses, carers, community workers and others implementing the National mental health programme and policy in India (Government of India, 1982). Implementation research that examines ways this and other co-produced tools could be used practically in training, community-based rehabilitation as well as in development of policy and programmes is needed.

Fifth, this tool could potentially open new spaces and connections for people across social boundaries such as empowering women with PSD to engage in new activities outside of established gender roles; and this could be an overt focus with community workers enabling such processes. Another area of potential development could be in addressing recovery from the impacts of multiple marginalities. For example, a woman from an oppressed caste with a mental health problem may experience the benefits of greater social participation and increased mental health also impacting on other sources of marginality and more community/social connections potentially re-shaping power relationships. These hypotheses require further research to examine the impact of locally contextualized approaches to recovery on social power and marginality.

Methodological considerations

Methodological weaknesses in this study include underrepresentation of men and people from a Muslim faith tradition in the EBE group and insufficient time for deep, power-shared participation. We incorporated four strategies to address the trustworthiness of the findings of this study (Lincoln and Guba, 1985): credibility, transferability, dependability and confirmability. Triangulation by using different sites and analyses by authors with different ethnic backgrounds increased the study's credibility. Dependability and confirmability of study results were increased with rich, extensive group discussions and individual interviews with PPSD's and carers, and with incorporation of feedback on tool utilization with pilot testing. We provided detailed contextual information to maximize transferability, in particular, to urban and peri-urban settings in Hindi-speaking North India. We acknowledge that the transferability of the tool domains should be evaluated critically in different contexts with different languages and cultural contexts, such as in rural North East India.

CONCLUSION

Mental health recovery tools and approaches have been dominated by Western frameworks and values, and there is an urgent need for contextualized tools to support recovery among people living in low- and middle-income countries. This paper outlines the process used to co-produce a recovery tool, *Swasthya Labh Saadhan*, and the key domains of that tool, in the context of peri-urban North India. The eight key domains outlined in the SLS tool can provide a clear framework for lay and professional community workers in South Asia, to support rehabilitation and recovery among people with mental health problems. The pictorial nature of the tool is particularly helpful for people with low literacy. The three meta-domains identified as central to recovery were normalcy, belonging and contributing. Mental health programmes at policy, organizational and family levels should prioritize involving people with lived experience of mental health difficulties in designing mental health programmes and policies, and use a critically reflective process to ensure that it is participatory. Working with lay and professional health workers in co-productive and participatory ways will enhance trust with communities and strengthen mental health systems and delivery of care.

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