“Pictures make it easy” co-production and piloting of a pictorial tool for mental health recovery in North India

Summary

Mental health recovery requires the participation of people with mental health problems, and approaches that fit with the culture, language and place they belong. The ways that social recovery takes place, what aspects of recovery are most important (e.g. work, self-care), the measures of social recovery, and the types of support that people with mental health problems would like, vary in different contexts. This project piloted a process to work together with people with mental health difficulties and carers to understand the domains of recovery in Dehradun, North India, and together co-produced a tool, Swasthya Labh Sadhan to help people to develop their own recovery journeys. The tool includes culturally relevant domains of recovery including taking care of one self, being spiritually engaged, having fun, being an active family member, contributing to the household, being a friend, and being an active community member.

This study illustrates ways in which community members with lived experience of psycho-social disability can be involved in knowledge production and the challenges and enablers of such processes. The Swasthya Labh Sadhan tool was trialled among 28 community members with mental health problems over a five-month period. The process of developing the tool and the tool itself has potential for being adapted to other mental health programmes in and beyond India.

Background

A central problem in Indian mental health care relates to the social inclusion of people with psycho-social disabilities in their families and communities. In many parts of India, there are also major gaps in accessibility of biomedical treatment for mental illness. Both these problems provide an opportunity to develop biomedical, psychological and social approaches to mental health (bio-psycho-social approach). This project addresses the social recovery of people with psycho-social disabilities (PPSD) in Uttarakhand state. The first aim of this study was to understand the areas of social recovery that were important to people with experience of mental health problems, and together to design a pictorial tool to help them undertake social recovery journeys, paying attention to how the process could be participatory. The second aim of the study was to pilot this study with people with mental health problems in the community and to assess how useful the tool was for recovery.
Methods

This project was set in Burans, a partnership mental health project led by the Emmanuel Hospital Association (www.eha-health.org) in rural and semi-urban communities in Dehradun district, Uttarakhand state, India.

How we went about developing Swasthya Labh Sadhan

- Experts by experience (EBE) who were people or carers of people with experiences of a mental health problems worked together with the research team in the knowledge production process using a framework called participatory action research.
- We used participatory methods which included games, discussion and pictures to understand the key domains of recovery that were important to them.
- The group explored activities associated with these domains, to support design of a visual recovery tool. An artist developed line-drawings for each of the domains and EBE members gave feedback on these.

How we piloted Swasthya Labh Sadhan

- The SLS tool was piloted among 28 community members with mental health problems between June and November 2017
- Participants were existing clients of Burans project (total n = 11) or service users of psychiatric outpatient department of Selaqui state mental hospital (n = 17)
- Participants all had a moderate or severe score of mental distress (12 or higher with the SRQ tool)
- Burans community team members were trained in the use of social recovery approaches, and worked with six to ten clients
- Participants used the pictorial tool to choose a domain for mental recovery, and a focus activity. They kept their own files and met up with their Burans community worker every 2-3 weeks.
- The research team observed and supported visits, collecting data using participant observation and a research

Results - Developing Swasthya Labh Sadhan

The process used for tool development required a five-step process which was iterative and participatory, and is shown in Figure 2.

Figure 2. Flow chart of the tool development and analysis process

<table>
<thead>
<tr>
<th>Type of activity</th>
<th>Endline</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Systematising experiences</td>
<td>initial EBE group meetings – sharing experiences, expertise and understandings of recovery</td>
</tr>
<tr>
<td>2. Collectively analysing</td>
<td>reflecting on problems – what does recovery mean in this setting – ‘thik hona’ – pictures, conversations, focus group discussions, role plays, patterns</td>
</tr>
<tr>
<td>3. Reflecting on and choosing action</td>
<td>EBE and KM/ PP review transcripts of initial EBE meetings – propose initial domains</td>
</tr>
<tr>
<td>4. Taking and evaluation action</td>
<td>EBE group review drawings and suggest changes based on cultural and domain expertise – first draft of recovery SLS tool developed</td>
</tr>
<tr>
<td>5. Systematising learning</td>
<td>and sharing new knowledge – pilot of SLS tool with 36 clients – and review after 12 months</td>
</tr>
</tbody>
</table>

Sample verbatim quote

There's a lot of stigma as an honour issue... ( )

It's looked at as a burden. It's looked at as an honour issue... ( )

It's important to contribute or earning in any way. People look at a family how else can one live? ( )

My family is not very attached to anybody in the family who is like this.

Domains of recovery developed by the EBE group included: taking care of one self, being spiritually engaged, being a friend, and being a member who isn't earning or contributing in any way. People look at a family member who isn't earning or contributing in any way. People look at a family member and all those things have helped us spiritually.

These domains useful

- Taking care of one self
- Being spiritually engaged
- Being a friend
- Being a member who isn't earning or contributing in any way

Benefits likely supported by

- Literacy was a factor
- Active listening
- Psychiatric medication
- Recreation
- Engagement

Results – Piloting SLS

Participants all had a moderate or severe score of mental distress (12 or higher with the SRQ tool). The SLS tool was piloted among 28 community members with mental health problems between June and November 2017. The research team observed and supported visits, collecting data using participant observation and a research. The SLS tool was piloted among 28 community members with mental health problems between June and November 2017.

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Domains of recovery developed by the EBE group included: taking care of one self, being spiritually engaged, being addiction free, having fun, being an active family member, contributing to the household, being a friend, and being an active community member. Table 1 provides an example of three of the EBE contributions that gave priority to a domain, the domains developed and the types of activities proposed by EBE members and the final pictorial tool output.

Sample verbatim quote from EBE member

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.

My family is not very ritualistic, although we do trust in one form of religion because we were born into it. Otherwise we look at all the religions with respect. ( ) We are much attached to the natural world, my family, so we spend a lot of time planting trees and taking care of them, having pets, and all those things have helped us spiritually.

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.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Type of activity proposed by EBE</th>
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<tbody>
<tr>
<td>Maza karna</td>
<td>Listen to music/watch a movie</td>
</tr>
<tr>
<td>Having fun</td>
<td>Play a sport with friends (badminton/cricket)</td>
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<tr>
<td></td>
<td>Try something new like cooking a new recipe</td>
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<tr>
<td></td>
<td>Go somewhere new like a waterfall with friends</td>
</tr>
<tr>
<td>Adhityamik rup se sakriya rehena</td>
<td>Spend time in devotion (e.g. sit and pray with cup of tea)</td>
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<tr>
<td>Being spiritually engaged</td>
<td>Go to a place of worship (e.g. temple, mosque, church)</td>
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<tr>
<td></td>
<td>Do something prayerful (Put up prayer flags, light a candle, prayer meetings, namaaz)</td>
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<tr>
<td></td>
<td>Celebrate a festival (e.g. Diwali, Christmas, Ramzan)</td>
</tr>
<tr>
<td>Ghar ke karyon me yogdan lена</td>
<td>Clean/ wash own clothes and plates</td>
</tr>
<tr>
<td>Contributing to the household</td>
<td>Help clean and sweep house</td>
</tr>
<tr>
<td></td>
<td>Go shopping for household things/pay bills</td>
</tr>
<tr>
<td></td>
<td>Seek income with employment or handicraft</td>
</tr>
</tbody>
</table>

Results – Piloting SLS
- Significant change in mean SRQ scores suggesting a reduction in self-reported mental ill-health
- Benefits likely supported by
  - Relationship built between PPSD and CW
  - Psychiatric medication
  - Active listening
- Literacy was a factor
  - Low literacy group found pictures more useful
  - Higher literacy group found dialogue around domains useful

<table>
<thead>
<tr>
<th>SRQ baseline to Endline (with Confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
</tr>
<tr>
<td>Endline</td>
</tr>
<tr>
<td>SRQ SCORE</td>
</tr>
</tbody>
</table>
Conclusion

People with lived experience of mental health difficulties have sophisticated and diverse understandings of what recovery means to them. Mental health programmes should prioritise involving people with lived experience of mental health difficulties in designing mental health programmes and policies, and using a critically reflective process to ensure that it is participatory. This ensures that programmes and policies benefit from this local knowledge.

Use of a co-developed mental health recovery tool led to improved mental health and generated local conversations around recovery between lay workers and people with lived experience.

Training lay mental health workers and mental health professionals to work in co-productive and participatory ways will enhance trust with communities, and provide ways to improve mental health care delivery as well as improving recovery and mental health for community members.

This project was a partnership between Burans, of the Emmanuel Hospital Association and the University of Edinburgh.

The Emmanuel Hospital Association is a non-governmental provider of healthcare in India, serving some of the remotest and most underdeveloped parts of the country’s north and north east through its 20 hospitals and 42 projects. Project Burans is a community based mental health partnership initiative of the Emmanuel Hospital Association working with the Uttarakhand Community Health Global Network (CHGN) that works to address the significant mental health problems of the Uttarakhand region in North India. The SLS project is funded by the ESRC Impact Acceleration Account of the University of Edinburgh.

Quotes from partipants in the recovery tool study:

So when I started working with this client she said it is no use trying to talk or listen to her husband. Now, after one month of using the (SLS) tool she talks to her husband, and he talks with her, and they share their feelings. So the tool has been useful.

Community worker (Mussoorie)

What we have noticed is that our son is now talking much more with us, he is even doing his mazdoor (daily labourer) work several days a week now. And last month he went alone to the doctor at Selaqui to get his medicines even.

Parents of a man with mental health difficulties (Sahaspur)

I liked going for morning walk. I never used to do this before. I have started doing this now. I like it. I never used to go for walks before or out before. Since I got this tool, I follow it, and seeing the pictures I go for walks and do things.

Woman with mental health difficulties (Sahaspur)

We noticed is that our son is now talking much more with us, he is is even doing his mazdoor (daily labourer) work several days a week now. And last month he went alone to the doctor at Selaqui to get his medicines even.

Community worker (Sahaspur)

Women mostly do housework, and we tell them about the tool and tell them about benefits of a morning walk, but for them this is a challenge to get out of their house. They usually always stay in their homes and never come from behind their veils. So this is a challenge for

Woman with mental health difficulties (Sahaspur)

Community worker (Sahaspur)

Implications for policy and practice

The study has four sets of implications for mental health policy and practice in India.

1. People with lived experience of mental health difficulties have sophisticated and diverse understandings of what recovery means to them.

2. Mental health programmes should prioritise involving people with lived experience of mental health difficulties in designing mental health programmes and policies, and using a critically reflective process to ensure that it is participatory. This ensures that programmes and policies benefit from this local knowledge.

3. Use of a co-developed mental health recovery tool led to improved mental health and generated local conversations around recovery between lay workers and people with lived experience.

4. Training lay mental health workers and mental health professionals to work in co-productive and participatory ways will enhance trust with communities, and provide ways to improve mental health care delivery as well as improving recovery and mental health for community members.

About the Partners

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