Addressing Livelihood Issues among Persons with Severe Mental Disorders in a Rural Community Using WHO CBR Management Cycle

James JW¹, Sivakumar Thanapal², Jagadisha Thirthalli³, Santhosh S⁴, Manjula R⁵, Dundappa Doddur⁶, Janardhana AL⁷, Naveen Kumar C⁸

¹Ph. D. Scholar in Mental Health Rehabilitation, NIMHANS, Bangaluru,
²Associate Professor, Department of Psychiatry (PRS), NIMHANS, Bangaluru,
³Professor of Psychiatry and Head I/C Psychiatric Rehabilitation Services, NIMHANS, Bangaluru,
⁴Co-ordinator, Community Mental Health Program, Association for People with Disability,
⁵Executive, Community Mental Health Program, Association for People with Disability,
⁶JRF, Community Based Rehabilitation for Severe Mental Illness Project, NIMHANS, Bangaluru,
⁷Assistant Director, Association for People with Disability,
⁸Additional Professor, Department of Psychiatry, NIMHANS, Bangaluru.

ABSTRACT

Background: Persons with severe mental disorders are a very vulnerable population. They are at a higher risk of being discriminated in access to health care, social services and employment. Objective: The study looks at describing about how livelihood as a component of community based rehabilitation can help in rehabilitation of persons with severe mental disorders and the challenges faced in implementing it. Methodology: A CBR project for severe mental disorders was initiated with the help of Association for People with Disability and the local health and disability welfare department in Jagalur taluk of Davangere District in 2015. The CBR management cycle given by WHO is used in this study this follows the principles of action research. Results: The CBR framework given by WHO is useful in conceptualising the project and using locally identified resources for livelihood related rehabilitation of persons with SMD. Conclusion: Livelihood is an essential part of every individual and it plays an essential role in the recovery process of people with severe mental disorders. As emphasised in the WHO CBR guidelines using locally available resources in the process of rehabilitation is essential.

Keywords: Persons with Severe Mental Disorders, Rural Community, WHO CBR

INTRODUCTION

Livelihoods are a set of activities, assets and strategies required to make a living. Some people with mental illness may not be able to work because of their illness and others because of discrimination. This leads to people being denied opportunity to work or even lose their existing job’s. To overcome the barriers employment and income generation opportunities must be created locally(“WHO | Mental health, poverty and development,” n.d.). Participating in livelihood activities like skill development, self employment, wage employment, financial services, and social protection is an important aspect of recovery process. Apart from income generation livelihood opportunities can promote independence, establish social networks, improve self esteem, and give control over one’s life (“WHO | Community-based rehabilitation guidelines,” n.d.).

Persons with severe mental disorders are a very vulnerable population and are at a higher risk of being discriminated in access to health care, social services and employment. Severe mental disorders have a life time prevalence of 1.8 % and the treatment gap for these disorders in India is above 70 % (Gururaj G et al., 2016). People with severe mental disorders come with diverse needs and livelihood is considered as a felt need for most
persons (Nagaswami, Valecha, Thara, Rajkumar, & Menonr, 1985; Pillai et al., 2010). Although there are high unemployment rates in persons with severe mental disorders it is seen that most people want to work. It is also seen that employment improves the outcome by increasing self esteem, alleviating psychiatric symptoms and reducing dependency and relapse (Lehman, 1995).

A CBR project for severe mental disorders was initiated with the help of Association for People with Disability and the local health and disability welfare department in Jagalur taluk of Davangere District in 2015. The project involves working with different stakeholders in the community to provide treatment and rehabilitation which is easily accessible, freely available and locally acceptable for persons with severe mental disorders.

There is paucity of literature in the field of livelihood of persons with severe mental disorders in the community. The objective of this study is to describe about how livelihood as a component of community based rehabilitation can help in rehabilitation of persons with severe mental disorders and the challenges faced in implementing it.

**Process**

CBR programs can be conceptualised using the CBR management cycle. In this study we would discuss about what was done for livelihood of persons with severe mental disorders according to the management cycle in Jagalur.

**Situation analysis**

Table 1 Situation analysis at Jagalur (Details collected from people registered for treatment camps at Jagalur 2015-16)
Jagalur consist of 135 villages which are largely agrarian who cultivate maize and millets and are totally dependent on rainfall. Since the time the project had started the rains have failed consecutively. Because of this there is a tendency that people migrate to towns and cities to find employment as they do not find jobs locally.

The initial part of the project focused on providing treatment but during various interactions (follow up visits, home visits, family meetings, and residential camps) with the persons with SMD and caregivers they came up with livelihood related needs.

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Persons with SMD</strong></td>
<td>During various interactions like follow up visits, home visits, family meetings, and residential camps some of them came up with the need that they are willing to work but require help in finding employment. There were few persons with SMD who felt that they are happy with what they are currently doing and do not need any livelihood related needs.</td>
</tr>
<tr>
<td><strong>Caregivers</strong></td>
<td>While interacting with caregivers during follow up visits, home visits, family meetings, and residential camps some of them felt that if the persons with SMD are given work then they would do it. And they also came up with the need that they wanted help in procuring disability certificates. Most of the other caregivers also mentioned that with only medication most people have gone back to carry out the work that they used to do earlier.</td>
</tr>
<tr>
<td><strong>Accredited Social Health Activist (ASHA) workers</strong></td>
<td>Over a period of time ASHA workers also agreed that persons with mental disorders can work and be productive like other individuals and they helped spread this message in the local community. They are also an important resource in identifying patients in the community, following them up and building community awareness</td>
</tr>
<tr>
<td><strong>Health and disability welfare departments</strong></td>
<td>Provision of disability certification is important for availing many welfare schemes. Liaison from APD team was done with the district hospital psychiatry team who issue disability certificates for mental disability. Information about welfare schemes for the disability from the disability welfare department was given.</td>
</tr>
<tr>
<td><strong>Local leaders</strong></td>
<td>The Zilla Panchayath leader had been invited for important functions held during the course of the project. They have been supportive towards helping out in providing permissions to use local governmental resources and conduct programs and rallies. Local panchayaths also have the resource of reserved funds for disability related work.</td>
</tr>
<tr>
<td><strong>CBR workers</strong></td>
<td>APD plays the important role of implementing the management cycle of the CBR program. As they are from the locality they have built the trust of different stakeholders with their goodwill and dedicated work. Two community workers along with the help of the CBR manager facilitate each step of the management cycle. They act as the liaison between different stakeholders and address the needs of the persons with SMD and their family.</td>
</tr>
</tbody>
</table>
Stakeholder analysis

This step involves identifying important stakeholders and ensures their partnership to establish a sense of community ownership. It involves discussing with different stakeholders about livelihood opportunities, which are available locally, their utilisation and what they can contribute. This is an ongoing process.

Problem analysis

A problem analysis helps in identifying the main problems and the root cause and effect or consequences. Person with SMD and caregivers expressed diverse needs. On discussion with different stakeholders it was decided that on priority few components of livelihood such as financial service, skill training and social protection can be done during this cycle.

Objective Analysis

- Disability certification
- Skills training
- Information about welfare benefits

Planning and design

This stage involves deciding about what the CBR program needs to do to address the problems and issues and planning how to do it.

Disability certification was taken up as it helps in getting other welfare benefits and it can be done in a relatively short period. It was also seen that some caregivers and persons with SMD were eager to take up self employment but did not have financial support. To acquire loans one of the requisite was to have skills related to a particular field following which the skill development centre for unemployed youth were contacted.

Implementing and monitoring

As planned the camp for disability certification was conducted during a residential camp for caregivers and patients. Twenty two persons who had valid documents had been assessed and were asked to visit the district headquarters to finish the certifying procedure. Once the certification was done it took about two to three months for the completion of verification process and to get the monthly pension.

Through the rural development and self employment training institute (RUDSET) a program was organised in dairy farming for the youth as it was more feasible in the agrarian community. There were initial apprehensions that persons with mental disorders might not be suitable for training. Among the persons who expressed livelihood needs only thirteen of them showed interest in skill development program and among them eight persons from Jagalur had participated in the program. The rest did not participate as they could not leave their home as they had other responsibilities at their home and caregivers were apprehensive about them staying away from home. The program took place in the district headquarters where people had to stay for close to two weeks and it was found that persons with mental disorders were equally competent. All of them along with people from other taluks had completed the training successfully and were given certificate for the same.

<table>
<thead>
<tr>
<th>Issues and problems</th>
<th>Things to be considered</th>
<th>Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability certification</td>
<td>Most people request for getting disability pension</td>
<td>Request disability certifying authority to conduct a camp in the community.</td>
</tr>
<tr>
<td>Training and employment</td>
<td>Adequate number of people with SMD who are willing to undergo training. Identify potential training personals/centres</td>
<td>Training in animal husbandry with certification through unemployed youth scheme.</td>
</tr>
<tr>
<td>Information about financial service</td>
<td>Identify patients and caregivers motivated to ask for financial service and identify potential resources</td>
<td>Educate about schemes provided by the government and how to access them.</td>
</tr>
</tbody>
</table>
Information about financial services like getting loans was provided in monthly meetings. One of the requisite for getting loans was to have bank accounts. Information about 3% reservations for persons with disability and other state and central schemes was provided along with guidance about how to avail them.

**Evaluation**

As the procedure for getting disability certificate requires the persons with mental disorders to be available at the district headquarters there were no future camps conducted for certifying disability. Persons who were eligible for evaluation were asked to visit the district headquarters on Thursdays. APD staff would help them in the paper work. Almost forty persons who had severe mental disorders only required medication and had gone back to be functional like other individuals. Around ten individuals who did not have documents of earlier treatment had difficulty in getting disability certification. Eight of the individuals who were eligible to get disability certificate had issues related to accessing the district headquarters as they couldn’t afford it or had no one to accompany them. Three of them were clubbed with other patients and caregivers to visit the district headquarters. However 34 persons with severe mental disorders have been issues disability certificate after the initiation of addressing the livelihood related needs and all of them have been getting monthly pension of 500 or 1200 depending on the percentage of disability.

The persons who had gone through the dairy farming training had to open bank account. But some of them were hesitant in opening bank accounts and wanted APD staff to do everything for them. The APD staff however wanted them to take up the responsibility as it helps in empowering them. Some of the bank authority had doubts about the capability of a person with mental disorders to maintain a bank account. The bank officials were oriented that they would be able to maintain their account and they would also have a caregiver as a joint account holder. Once the bank accounts were open the next step was to request for loan with the bank officials. But most of the bank officials had doubts about the repayment and the whole process took more than a year to materialise. Currently all the individuals have their own bank account or a join account with other family member. Four of the individuals family had unpaid loan due to which they were not eligible to get another loan until they repay the existing loan. Other individuals mentioned that it would be difficult for them to rear cattle as feeding the cattle during drought is difficult. However five of them help their family in agriculture during the seasonal rains and the rest work in others field as daily waged labourers.

Caregivers and patients were encouraged to request for support from the 3% reservation funds at the panchayath for availing loans and housing related schemes. Most panchayath officials did not know about the 3% reserved funds and had to be oriented about it.

The management cycle would continue to address the issues that come up in the evaluation phase. The issues like sensitising from higher officials to get orders to use the panchayath funds reserved for disabled have been carried on. Utilising schemes like MGNREGA in future for employment guarantee and sorting out issues related to it is ongoing.

**Case vignettes**

Ms. S and Mr. K patients from one of panchayath were granted goats through animal husbandry and veterinary services scheme. After receiving the goats within few weeks they had sold it for a higher price as they mentioned that it is difficult to take care of the goats in that season of the year. They used the money to lend for interest and paid back the loan.

Mr. T diagnosed with Bipolar affective disorder has been availing treatment form the camps and has attained symptom remission. He had difficulties in finding jobs and had requested for finding help in starting a business. With minimum funds arranged by his family he started to sell buttermilk during summer in Jaglur town bus stand. He was good at his business and had got enough
profit to maintain his everyday needs and provide for his family. But once summer had passed he couldn’t continue the business. He was not open to sell tea instead of buttermilk stating it was difficult to sell. He was encouraged to reach out to the panchayath to request for loan from the 3% reserved funds for disabled. After long wait he has been recommended forgetting subsidised loan from a scheme of krishimantralaya to start dairy farming. He has been eager to get the loan and start dairy farming but the procedure in getting the loan and surety of repayment have been issues that have been delaying the process.

Mr. S husband of a patient with schizophrenia had made job cards for his family under the MGNREGA rural employment guarantee scheme. Using the job card for the disabled individual in the family Mr. S had worked under the scheme and earned close to 20000 Rs.

DISCUSSION

Action research is an orientation to knowledge creation that arises in the context of practice and requires researchers to work with practitioners. Its purpose is not only to understand social arrangements, but also to effect desired changes as a path to generate knowledge and empowering stakeholders (Bradbury-Huang, 2010). The CBR management cycle given by WHO used in this study also follows the same process as action research. (Chatterjee, Patel, Chatterjee, & Weiss, 2003) Found that CBR model is feasible model of care for persons with chronic schizophrenia in a resource poor setting.

Most people with SMD when given treatment tend to be less disabled and are willing to work. Similar results in community study was reported by (Thirthalli et al., 2010). It was also seen that when people with SMD start to get back to work it helps in reducing the financial burden of the family and community members are more accepting.

Disability pension is the most desired welfare benefits among persons with mental disability in rural population (Kashyap, Thunga, Rao, & Balamurali, 2012). Handholding in acquiring disability certification is needed for most people with SMD. Single door access to all welfare benefits would help in reducing the formalities in accessing different welfare benefits.

Providing training for livelihood related activities should be in acceptance with the local culture and also consider the ground realities. The training in dairy farming was culturally centred but the process taken for opening a bank account, requesting for loan and the paper work requires time and hand holding from on field staff Providing livestock to the members during drought would be difficult to feed and maintain.

Information about locally available funds like the 3% reservation in Panchayath funds and loans available from different departments can help in livelihood related activities in the community. Meeting with the district collector to voice the needs of patients and caregivers was facilitated. An order was passed to all the Panchayaths that the 3% reservation in funds should also be utilised for persons with mental illness.

Implications and Limitation

The whole CBR process has to be an ongoing consultation which has to be in sync with ground level realities. The management cycle will keep continuing and as the work continues there will be more clarity about the needs and challenges that are present. The CBR framework given by WHO is useful in conceptualising the project and using locally identified resources for rehabilitation of persons with SMD. The interventions followed would be unique to this area as it doesn't have any other form of livelihood available in the community. This is a descriptive paper to explain about some of the ground realities. The larger study that is being carried out would give more quantitative data along with descriptive information for better conceptualisation.

CONCLUSION

Livelihood is an essential part of every individual and it plays an essential role in the recovery process of persons with severe mental disorders. As emphasised in the WHO CBR guidelines using locally available resources
in the process of rehabilitation is essential and very much helpful. The CBR staffs working in the community play an important role in making recovery a reality and carrying forward the process of community base rehabilitation.

**Ethical clearance**

- Ethical clearance has been approved by the NIMHANS ethics committee and informed consent has been taken from persons with SMD and caregivers.

**Funding and support**

- The CBR project for SMD at Jagalur under principal investigator Dr. T Sivakumar, Associate professor, Psychiatric rehabilitation services, Department of Psychiatry, is funded by NIMHANS.
- Association for People with Disability funds the community mental health program with the help of Live Love Laugh Foundation.
- Chittasanjeevani Charitable Trust provides psychotropic medication free of cost for the Jagalur project.
- The source of funding for the Ph.D research is from UGC Junior research fellowship.

**REFERENCE**


Corresponding Author: Dr. Sivakumar Thanapal, Associate Professor, Department of Psychiatry (Psychiatric Rehabilitation Services), NIMHANS, Bangaluru (Karnataka) Email: drsivakumar_mmc@yahoo.co.in