

A Brief Overview of Community Based Rehabilitation for Severe Mentally ill: an Indian Perspectives

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ABSTRACT

Community Based Rehabilitation (CBR) is implemented through the combined efforts of people with Severe Mentally Ill (SMI) themselves, their families, organisations and communities, as well as the relevant governmental and non-governmental sector, education, vocational, social and other services. country like India has a unique geographical area, limited recourses, utilization of available infrastructure, available negative attitude and social stigma pull the CBR for the mainstreaming and welfare of SMI as well as reduce the burden of their family members/care givers in India. The purpose of the study is to provide information about emergence of Severe Mentally ill. Literature has been searched of both electronic databases including PubMed and manual searches. CBR emphasis to encourage the community to create awareness about negative attitudes and behaviours towards people with SMI and their families, that the community is supportive of them, and that people with SMI is mainstreamed across all development sectors. There is right time to work together and also needed strong liaisons between various stock holders those are working in the area of chronic mentally illness.

Keywords: *Community, Rehabilitation, Mental illness, Family*

A wide variety of very different and complementary approaches are taken in developing countries, such as India, to adequately respond to the needs of persons with severe mental illness. Community Based Rehabilitation (CBR) programs are considered fundamental for improving the well-being of persons with severe mental illness, and for fostering their participation in the community and society at large [1,2]. It has been promoted internationally for more than 30 years as a strategy for improvement in the quality of life and services for people with severe mental illness. CBR programs are considered to be the most cost-effective approach in improving the well-being of persons with severe mental illness, in comparison with care in hospitals or rehabilitation centers [3]. It is categorically based within a community development framework. The strategy of CBR places equal emphasis on inclusion, equality and socio-economic development as well as rehabilitation of all people with disabilities as well as chronic mental illness. CBR is implemented through the combined efforts of people with disabilities themselves, their

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families, organisations and communities, as well as the relevant governmental and non-governmental sector, education, vocational, social and other services. [4]. CBR promotes collaboration among community leaders, people with disabilities, their families, and other concerned citizens, to provide equal opportunities for all people with disabilities in the community. CBR is considered the most cost-effective approach for improving the wellbeing of persons with disabilities and for fostering their participation in the community and society at large. The UN Convention on the Rights of Persons with Disabilities [5] also states that comprehensive rehabilitation services involving different types of interventions including medical and social are needed to ensure the equal rights and participation of persons with chronic mentally ill in societies. Mental disorders were the second leading cause of disease burden in terms of years lived with disability (YLDs) and the sixth leading cause of disability-adjusted life-years (DALYs) in the world in 2017, posing a serious challenge to health systems, particularly in low-income and middle-income countries.[6]

Mental problems of a chronic nature result in a lifelong impact. This impact lasts for a protracted period, gradually resulting in a poor quality of life for such individuals and their families. Mental disorders contribute to a significant load of morbidity and disability, even though few conditions account for an increasing mortality. As per Global Burden of Disease report, mental disorders accounts for 13% of total DALYs lost for Years Lived with Disability (YLD) with depression being the leading cause². Previous reviews, meta-analysis, studies and independent reports have indicated that nearly 100 million persons in India are in need of systematic care based on data³ that are a few decades old and have serious methodological limitations.[7]

Roots of CBR

In the beginning, CBR was primarily a service delivery method making optimum use of primary health care and community resources, and was aimed at bringing primary health care and rehabilitation services closer to people with disabilities, especially in low-income countries. Some also introduced education activities and livelihood opportunities through skills-training or income-generating programs. [8.] In 1989, WHO published the manual *Training in the community for people with disabilities to provide guidance and support for CBR programs and stakeholders*, including persons with disabilities, family members, schoolteachers, local supervisors and CBR committee members [9]. In 1993 the UNDP published estimate of different type of disabilities and the possible role of CBR in answering needs of these persons. The 2004 position paper redefines CBR as “a strategy within general community development for the first CBR Joint Position Paper was published by ILO, UNESCO and WHO, which was followed by many other publications such as *CBR and Health Care Referral Services and Promoting CBR among urban poor populations*.

In 2003, an international review of CBR was organized in Helsinki. In 2004, the ILO, UNESCO and WHO updated the first CBR Joint Position Paper to accommodate the Helsinki recommendations. rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities” and promotes the implementation of CBR programmes “...through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services” (joint paper 2004). Therefore, CBR can be seen as a multi-sectoral, bottom-up strategy where the community involvement is an essential element of the development process – a development perspective that coincides almost entirely with the concept of human development.[10]

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Goals of CBR:

These are the following goals of CBR for the person with Severe Mental Illness (SMI):- (A) To promote inclusion of people with mental illness into societal activities (B) To facilitate the generic services as well as appropriate support to people with mental illness.(C)To promote and protect the rights of people with mental health problems (D)Reducing self-stigma of persons with SMI (E) Improving community attitude towards persons with SMI.[11]

Needs of CBR:

The emergence and needs of CBR for the person of SMI are the followings:(A)_CBR activities are designed to meet the basic needs of people Severe Mental Illness, reduce poverty, and enable access to health, education, livelihood and social opportunities (B)_CBR programs empowered Patients and Families to become informed partners in planning and implementation of rehabilitation strategies that were ecologically feasible (C)_Community processes, full participation, equal opportunities, social inclusion, are some of the key common elements of CBR work. Community Mental Work is no different so the programs integrate well together.(D)CBR programs can have a positive impact on the lives of Person with Mental Illness, their families and on the situations in which people live by including people with psychosocial disabilities in the CBR programs.(E)There are a limited number of Mental Health Professionals and Mental Health Services in India, Making Community Based Rehabilitation strategy will empower the community level stakeholders to take action (F)Community Based Rehabilitation strategy help in achieving the goal of continuity of care and Inclusion of people who are mentally ill into the community.

CBR in an Indian Perspective

Indian community is known for its diversity of cultures, race, cast, class, language, religion and has a unique geographical area. Emergence and growth of psychosocial rehabilitation in India can be divided into two phases. In the **First Phase**, comprising of the first 25 years since independence, most of the services were hospital based and largely confined to the government mental hospitals. The emphasis was on keeping the long-stay patient occupied with some form of work or activity.It is the **Second Phase**, from the early 70's onwards that saw concerted efforts made to reintegrate the patient with the family and the community. This period is characterized by several initiatives taken by non-governmental organizations (NGOs). The community based initiatives have largely come through Non-Governmental Organizations (NGOs). The first half way home in India was started by the Medico-Pastoral Association in Bangalore in 1972, and the first day care center, also in Bangalore, was started by a group of housewives in 1974, coming together under the name of FRIENDS of NIMHANS. Today there are more than 50 such centers located in different parts of the country. Although, a majority is concentrated in the southern states, it is heartening to note that such facilities are available in Kolkata, Gauhati and Gurgaon. One of the centers in Kolkata (Paripurnata) is unique because it was primarily started to address the rehabilitation needs of women with mental illness in judicial custody. Yet another first is the starting of a day care center by family caregivers at Chennai (Aasha). In response to concerns expressed by caregivers, many of the NGO's have started long stay residential facilities. *Sourabha* CBR program project near Bangalore identifies severe group of disabled people, and allocates CBR workers on regular visits to meet their specific needs. *Association of People with Disabilities Bangalore* is providing training to groups of young women and girls with disabilities to live together independently in a rented accommodation close to an industry where they work. It has increased their confidence to live independently and work in the

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employment as a group. The state government of Andhra Pradesh is supporting the inclusion of children with disabilities and special needs in mainstream schools. This has been implemented as a pilot project covering 30–40 schools under the district primary education program. An individual education program is prepared by the team of appropriate specialists for every child with disability. Teachers are sensitized to the needs of the children with disabilities through a focused training program. Free mobility, hearing, and other aids are also provided where required. *Amarjyoti Disabled Persons Association* in Kanakpura, has initiated several advocacy drives in order to earmark 3% budget of the local panchayat of villages for rehabilitation schemes. It is a block level federation of disabled persons with more than 500 members, 10 self-help groups, and 5 rehabilitation committees at the mini block level. CBR is still in its infancy in India and developing countries but enjoys wide acceptability. Disability rehabilitation is primarily considered to be the responsibility of the family. The significant place of family, religion, and traditions to an individual cannot be overlooked in the success of any CBR movement in India.[12]

Barriers to Practice CBR Approach for PWMI in India

These are some barriers, which creates obstacle in the implementation of CBR :- (I) Lack of Co-Operation from Families of Persons With SMI: Often CBR Worker do not receive support from the beneficiaries' families. It was revealed that families of persons with mental illness thinks that if their family members receive services form the CBR it may mean that their psychosocial disability grant will be taken away or psychosocial disability grant beneficiary maybe changed. Some members of the families have given up on their members with severe mental illness and they are switching all the burden to CBR caregivers as they are tired of caring for their family member who has mental illness [13]. (II) Lack of Intervention by Government Departments: The government departments don't get involved in trying to solve challenges that are faced by CBR workers neither to show a little support or intervention to the challenges. It has revealed that the partnerships with government is inadequate as the government used their position as providers of funding to dictate how programs should be run, and did not consult with the NGO around changes made to programs. It has also noted that the government is not interested in consultation and dictatorial and there is no relationship and partnership between the government and NGOs which includes CBRs [14] (III) Shortage of Human Resources and Other Materials: CBR caregivers often face the ongoing barriers to implementation, including lack of resources, and limited opportunities. It was revealed that the resources needed in the CBRs are human resources, material resources, and financial resources and they may not be always available [11]. A study conducted in Ghana revealed that shortage in human resources is a challenge in CBRs and these leads to high workload of caregivers.[15]. It has also seen in the study of rural India revealed that female individuals with severe mental illness do not access rehabilitation services due to lack of female caregivers to assist them. Female caregivers were available but they are just dropping out and this leads to lack of human resources [16]. (IV) Poor Funding System: It has found that some caregivers (CBR Worker) receive stipends from the Department of Social Development but is not enough as they receive it in a quarterly basis and they have families to support [17]. It was also supported by (DSD, DWCPD and UNICEF, 2012) that, CBR caregivers are faced with challenges for category of personnel as the level of training and skills are inadequate; stipends are low; and CBR is still a contested concept [18]. The Department of Social Development has acknowledged difficulties with the funding of services provided by CBRs at the national level. The well-being of many persons with disabilities is not well-protected because of the lack of funding of CBRs. As a result, it is not easy for CBRs working in the disability sector

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to access government funding. Some organizations are faced with a challenge that even when a service level agreement is in place, funding does not always come through, as agreed. (v) Emotional Challenges of CBR Workers: Some CBR workers are affected negatively by seeing those persons with severe mental illness every day and knowing that there is nothing they can do change the situation, more especially those from poor families. It was evident and the role of caregivers may have a negative impact on their emotional health. A study revealed that caregiver's physical and emotional dysfunction were experiences linked with the care giving activities. Physical and emotional health of caregivers is negatively impacted by the demands of caregiving. [19]

Impact Of CBR Programs

CBR program had a significant positive impact on several outcomes of interest promoted by the WHO, namely individual mobility, activities of daily living, communication skills, emotional wellbeing, social participation and employment. The findings suggest that CBR programs can improve livelihoods and wellbeing of persons with Mental Illness and other disabilities. In the study the highest positive impact is also observed on emotional wellbeing.[20]. Another important effect of the program was observed during the study is on social participation which encompasses important dimensions of social life. The CBR empower social participation and reduce prejudice, such achievement also contributes to the principle of "full inclusion and participation in all aspects of life" promoted by the article 26 of the UNCRPD. CBR programs have a positive impact on the wellbeing of persons with disabilities in most areas of intervention such as health, livelihood (including opportunity for employment), disability rights and social participation.[21] It has seen that participation in CBR has an impact in terms of changing mentalities and fighting prejudice and exclusion. In point of fact, participation in the program has a positive effect on the ability to express one's opinion and on the opportunity to participate in the community's decisions. CBR programs have positive impact on the community area at village level and for single individuals such as caregivers. CBR is a feasible model of rehabilitation for people with schizophrenia even in economically deprived settings, and that outcomes are better, at least for those who are treatment compliant.[22] Lack of mental health professional has been seen in the country like India and other developing countries (especially in rural settings). The CBR method offers a model which involves active local community participation and low levels of technical expertise to deliver services. Mental health professionals can contribute to enlarging the capacity of existing non-governmental organizations that already operate in such areas to initiate services that draw upon the resources of the community.

Strengths of CBR

The CBR method was more efficient in overcoming the economic, cultural and geographical barriers and was more effective in retaining patients and their families in the program, as reflected in the significantly better compliance rates. It is plausible to speculate that the mental health workers made a significant contribution by providing a range of services at home. Being members of the local community, they communicated effectively with patients and families, using shared cultural idioms and thus promoting greater adherence to treatment. The mental health workers worked closely with the families and supported them in coping with the appropriate management of the illness. Community based rehabilitation relies on the engagement of communities in the management of disability. Patients and their families were empowered to become informed partners in the planning and implementation of rehabilitation strategies that were ecologically feasible.

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CONCLUSION

CBR is respectful approach as well as a process for the person with severe mental illness, in which information should be provide to people (and, if appropriate, to their family members) about their mental health problems without imposing unnecessary labels. They (patient and their family) have to also ensure that they are aware of their human rights and how to exercise these rights. In this process, people is to make aware of the available treatment and support options in their community to enable them to make informed decisions about actions they want to take. Self help group can also play a key role in the CBR process. Professional, these are working in the area of CBR should encourage and support self-help groups to advocate for the development of accessible, affordable and acceptable community mental health services. Collaborative and holistic approaches can also play vital role for achieving the goal of CBR especially for the SMI.

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Conflict of Interest

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