Chapter 9
Community Rehabilitation in Leprosy

Neeraj Agarwal and Abhisek Mishra

Abstract More than 80% of all newly registered leprosy cases in the world are in India, Brazil, and Indonesia combined. According to projections, even if country-level eradication is achieved by 2020, leprosy is expected to remain a concern in high-endemic areas. According to current research, almost half of leprosy patients and their families experience social, physical, or a mix of social and economic challenges, as well as debilitation or destitution. In the broadest sense, disability, which is a symptom of this disease, occurs when people are denied equitable access to resources in their families and communities. The term "rehabilitation" is often suffixed when thinking of a remedial intervention in the context of leprosy since deformities are the most obvious sign of the disease. The physical component of rehabilitation should come first, with the ultimate goal of reversing the physical consequences of leprosy, while behavioral adjustments tailored to individual patients, their families, and their cultures should come second. The case study from India highlights that the affected person is actively spreading the word about leprosy and assuring people that it is curable provided they undergo care in a timely manner. Finally, self-help groups have been found to be effective in resolving the issues that leprosy patients confront. The members of the group are well versed on the difficulties that the patient is dealing with. They learn to love, admire, and encourage one another, which builds trust and self-esteem. People can share ideas and learn from one another at group gatherings.

Keywords Discrimination · Disability · Community-based rehabilitation
Integration · Empowerment

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Introduction

While India rejoices in its polio triumph, another dreaded disease, leprosy, which was eliminated in 2005, continues to haunt the country. Many that are afflicted by the condition continue to be stigmatized and discriminated against in other developing economies as well. It is well evident from the plight of a 30-year-old woman from Banki block, Odisha, which exemplifies the injustice of the stigma and myths of leprosy as reported in December 2020. Since contracting this disease, a year ago, Anita reportedly became untouchable in her village, and her family was forced to relocate to Baghamari in Khordha, about 30 km from Gholapur, where they continued to live in a rented home and struggling for a daily living [1, 2].

Multiple body parts may be involved in this disease such as the face, hands, feet, and/or eyes with characteristic deformities. The deformities result in physical disabilities that find it impossible to carry out everyday tasks, work, or earn a living. The other features include facial plaque of the non-lepromatous patient (especially if in reaction), facial palsy, claw hand deformity, foot drop, or the hypopigmented macules which are conspicuous on dark skin. The individual who is afflicted by ocular morbidity is profoundly distressed and incapacitated [2–4]. This morbidity is more severe than other impairments affecting the hands or feet, even in early stages even before it causes significant dimness of vision. Most notably, it can result in physical disabilities that find it impossible to carry out everyday tasks, work, or earn a living [2, 5, 6]. This can lower the affected person's position in their family and society, leading to psychosocial issues. From the patients' viewpoint, the disorder has an impact on many facets of their lives, including marriage, work, and social contact, especially where noticeable deformities are present.

An analysis of data on 1765 leprosy patients from the Indian Council of Medical Research (ICMR) unit for epidemiology of leprosy at Avadi, Madras, in southern India shows that paucibacillary and multibacillary patients having no impairments to begin with had about 1% and 27.3% risk, respectively, of having some impairment by the time their anti-leprosy treatment was completed [3, 7]. A recent study from Bangladesh found that paucibacillary (PB) and multibacillary (MB) patients who do not have any nerve damage before they begin multidrug therapy had 1.8% and 14.4% risk, respectively, of having nerve function impairment at the time of completion of anti-leprosy treatment. A study of 151 multibacillary cases from Delhi shows that those who had no disability when they began therapy had an 8.33% chance of experiencing any impairment 5 years later [7].

Unlike the biomedical effects, the psychosocial consequences impact not just the individuals involved but also their families. According to a survey of 500 families of two districts in South India, the proportion of families experiencing social and economic challenges has increased from 6% to 57% when the family had a leprosy patient with deformities, compared to families that had a patient without deformities. As per these studies, about 35% of leprosy patients and their families face social, physical, or a combination of social and economic challenges, as well as debilitation or destitution [6–9]. Another big psychological challenge faced by leprosy patients is social isolation, which can be self-inflicted in many cases. In the Avadi study involving 410 persons with leprosy-related deformities, around 8% of people were found to be socially isolated, as demonstrated by not being invited to social or family events. Another research from Orissa found that 308 out of 671 leprosy patients said they were socially alienated to different degrees. Of these, only 150 (48.3%) had some leprosy-related impairments, and the other 158 (51.3%) had no impairments whatsoever [3, 4, 6, 7, 10].

Disability, the characteristic of this disease, in the broadest sense happens when people are refused fair access to resources in their families and cultures. The cultural, social, institutional, environmental, and economic barriers all exist, with attitudinal barriers being particularly important in case of leprosy. Since deformities are the most visible symptom of leprosy, the term "rehabilitation" is commonly suffixed when thinking of a remedial intervention in the context of leprosy [11, 12]. Rehabilitation is an important part of universal health coverage and is a key strategy for achieving Sustainable Development Goal 3—"Ensure healthy lives and promote well-being for all at all ages." The WHO has defined rehabilitation as "the combined and coordinated use of medical, social, educational and vocational measures for training and retraining the individual to the highest possible level of functional ability." The various rehabilitative approaches are like "medical rehabilitation" which refers to provision of anti-leprosy treatment, "surgical rehabilitation" referring to reconstructive surgery, and "physical, social, vocational, economic, and spiritual rehabilitation" which altogether enable the person to lead a meaningful life. There is also a term "preventive rehabilitation" that applies to all treatments necessary to avoid the need for further recovery [13–15].

Assessment for rehabilitation: A screening process may be done at community level to identify individuals in need of rehabilitation service as per existing health program. The frontline workers must be trained periodically for this identification and referral processes from the screening facility. Many chosen for this integration enter a process of periodic appraisal and motivation, which leads to compliance with the rehabilitation plan, which aims to acquire new life skills, social integration, and reputation restoration (Fig. 9.1).

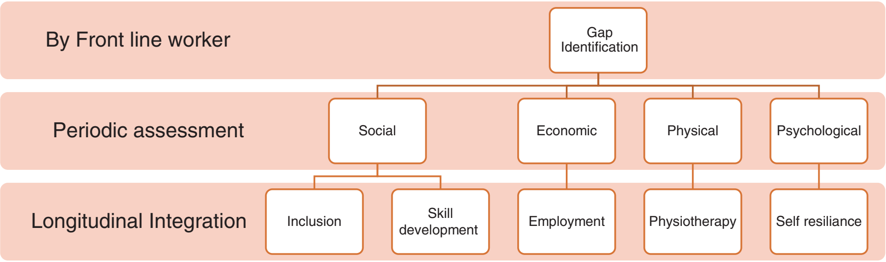

Fig. 9.1 Assessment for rehabilitation in leprosy patients

The Holistic Rehabilitation

The first point of this holistic rehabilitation is the physical component first, where the ultimate aim should be to reverse the physical effects of leprosy, while customizing behavioral changes for particular patients, their families, and their cultures should be the secondary target. The physical rehabilitation of the leprosy-affected has been discussed in the previous chapter.

The International Labor Organisation (ILO), United Nations International Children Emergency Fund (UNICEF) and World Health Organisation (WHO) have both come up with the following concept of community-based rehabilitation (CBR) which is defined as “a strategy within general community development for the rehabilitation, equalization of opportunities, and social inclusion of all people with disabilities” [15]. CBR’s main objective is to help communities take steps to ensure that people with disabilities have the same benefits and resources as anyone else (Fig. 9.2).

Fig. 9.2 Components of the community-based rehabilitation in a nutshell

Case Study from India

Beeramma is 40 years old. She used to be a decent singer when she was younger, and the villagers would ask her to sing devotional songs at festivals and other special occasions. She found patches on her neck about 20 years earlier, and doctors convinced her she had leprosy. She started the medication, but the pills left her ill, so she stopped taking them. She started to lose sensation in her hands and legs over time, and she developed disabilities. When CBR workers visited her village, they noticed that Beeramma kept away from other people. When they asked why she wouldn't join like the rest, she said she was frightened of being humiliated because of her impairment and leprosy. She said "When people tease me, I am really hurt." The staff counseled her and persuaded her to join a new village self-help community. Beeramma agreed to join the group and became one of its leading members. She learned to secure her hands and feet and is now occupied with housework and sheep care. There is no stigma towards her in the community. Looking back, she says "For a long time I lived within four walls. I kept myself apart. Now I realize that people do not think badly of me. I was the one who had an inferiority complex. Now I realize that no one is without value." Beeramma is also actively spreading the word about leprosy and assuring people that it is curable provided they undergo care in a timely manner.

Social Support from Self-Help Groups and in the Form of Microcredits

All the components of the CBR are overlapping with community engagement and social support at its core. The social support mechanism must be put in place not only for leprosy patients but also for other forms of disability [16–18]. Hence, instead of simply including people with leprosy, these groups can include people with a wide range of disabilities in the mainstream by self-help groups. Microcredit loans with a decent and sustainable interest rate have proven to be an efficient way to raise revenue and foster empowerment and self-resilience [9, 18, 19].

Self-help groups have been shown to be successful in a variety of areas in solving the purpose. The members get together on a daily basis to talk about and share issues. They develop trust and self-esteem by learning to love, appreciate, and inspire one another. Group meetings enable people to exchange ideas and learn from one another [20–22]. The existing members assist in needs and skills assessments with new members and may review rehabilitation plans of others. Increased social visibility of group members aids in changing views and encouraging recognition. When members talk as a group, locals and officials are more inclined to listen. Formalizing a group's legal status will help them gain access to political and financial resources. It becomes easier to integrate a small and committed community into conventional self-help groups. As a result, equality and engagement as equal members of the society were promoted [21, 23].

Case Study from India

Sakti the Self-Help Group: In Pallathur, a self-help group with eight people affected by leprosy is being created by the team from the World Health Organization. The WHO team has informed them and their families of the benefits of self-help groups, but the families declined to participate. They did not understand how it would work. People with leprosy-related illnesses, they believed, needed to be supported during their lives. The team held regular meetings, but there was always the question "What do we get out of it?". Then the team had identified eight other people with different forms of disability. One had a physical disability, some were blind, and some had speech or hearing problems. The team had encouraged all 16 people to join in an integrated self-help group. They all agreed, though it took 1 year for the clients and their families to understand the concept. They called the group Sakti, meaning power. They now meet every 2 weeks, and there is no longer any stigma between them. They try to understand each other's problems. When the group was recognized by the government, it was awarded RS 25,000 as a revolving fund, so it is now financially secure.

Another component of self-help and social support is the microcredit programs. It is a social support mechanism where a small amount of loans may be disbursed to the needy as per its financial terms and conditions. A microcredit program is different from a program that is making grants or charity. This loan program must be conducted on commercial terms, with very straightforward terms and simple accounting processes that all members understand [20, 23]. Monitoring of repayments should be included among agreed procedures. It is unrealistic to expect one person to refund the money given to them while another is entitled to have it. The image below has been identified as being important for running a successful microcredit program (Fig. 9.3).

A Delhi-based NGO, Sasakwa-India Leprosy Foundation (SILF), aims to provide available jobs for those who have been impacted by it and their families. Its main focus is on people living in segregated colonies [22]. During 2015–2016, its livelihood program empowered 2044 families, across 18 states in India, in trades such as goat and cow rearing, coir rope making, cutlery making, etc.

Case Study from Odisha

"The women with the Yellow Sarres" The Coir Rope Enterprise, Shantidan Leprosy Colony, Khurda, Odisha. This is an all-women's enterprise for making coir ropes. In 2010, SILF signed off financial support to these women to take over an already running small-scale plant making coir rope. Prior to taking over this factory, all five women relied on low daily pay and part-time work to make ends meet. Their goal was to expand the small factory, which produced rope with basic, manual equipment, to a larger facility that used an electric machine. The strategy was well thought out, and the beneficiaries were enthusiastic; however, achieving their goals was not

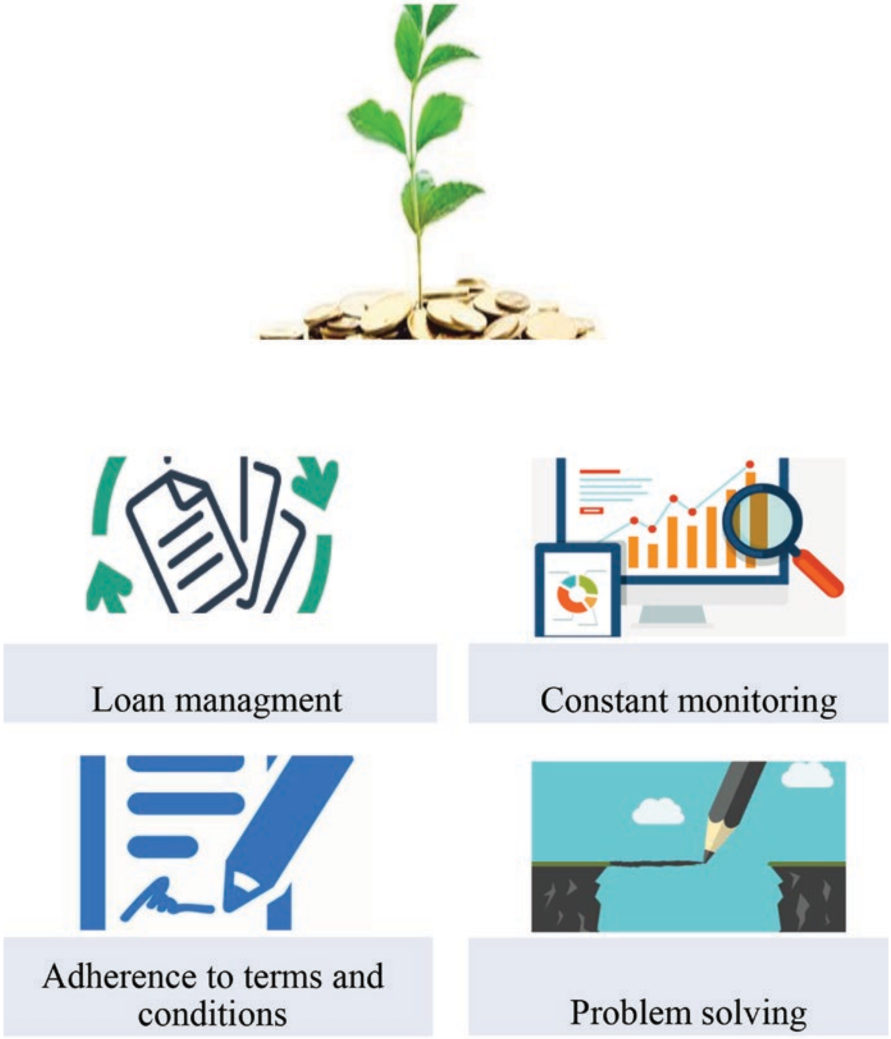

Fig. 9.3 Microcredit programs for rehabilitation in leprosy

as simple as they had expected. With the support of SILF, People's Forum, and their colony leader, these women went to the authorities and convinced them to mount a transformer in the colony. This was a significant move forward, but their trip was far from over. Today the enterprise is well established and profitable, producing more than 50 kg of rope daily. The women's pride in their profession is evident in their optimism and smiles as they arrive at work in their brilliant yellow saris, which they choose for themselves.

In a revamped effort to reduce cases, the government of India recently announced a slew of measures to widen population screening and carry out regular surveillance of this disease. The MoH&FW released operational guidelines in December 2020 that prescribe annual or bi-annual screening instead of occasional campaign drives. Screening has been proposed once a year in areas with prevalence rates lower than 1 per 10,000 populations and twice a year in areas with higher rates. ASHA workers have been contributing to early leprosy case detection across India. They visit house to house to identify people with signs and symptoms of leprosy and refer them to the nearest government health facility for confirmation. Lack of public awareness about leprosy is one of the major problems that India is facing in its efforts against the disease. Screening has been proposed once a year in areas with prevalence rates lower than 1 per 10,000 population and twice a year in areas with higher rates.

Way Forward

Early case detection, regular and complete treatment, and early detection of impairment and disability will play a pivotal role in reducing the disease and disability burden in the community. The challenge is to tackle the research gaps through novel collaborations, to improve operational aspects of the national programs. The medical curriculum needs to be revamped where there is a need to reintroduce leprosy with much focus on mainstreaming of the patients and their rehabilitation. In addition, we must educate children about leprosy in primary schools in order to instill in them the awareness that leprosy is a curable and non-infectious disease. This will help address the problem of discrimination of patients in the society. The legislation and (new inclusive) policies of great importance are themselves to be put in motion for the protection, promotion, and rehabilitation of the disabled person.

As practitioners, we must collaborate closely, particularly with those who lack access to care: those who are unaware of their rights and who often need and want health, social, occupational, and educational services for themselves. To strengthen the functioning of national leprosy services and the feasibility of partnerships with long-term collaborators, implementation analysis is needed. Support organizations providing peer counseling, peer-to-peer networks led by local professionals, social growth, and the participation of people affected in leprosy are there, but it needs to be standardized nationally and internationally. It is equally relevant to increasing the quality of leprosy data that's being generated through existing systems. The strengthening of the public health system at the ground level is necessary to handle this issue in areas where a large number of cases are being reported. An awareness campaign to deal with stigma and discrimination is also necessary so that those infected come forward for treatment and don't feel left out.

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