

CHALLENGES IN LEPROSY REHABILITATION

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ABSTRACT

'Multiple drug Therapy' (MDT) has transformed the outcome of leprosy in people affected by it. Leprosy affected persons develop much less disfiguring disabilities after use of MDT. As a result leprosy services are now becoming integrated into general health services. When this integration becomes stronger, leprosy rehabilitation is also likely to adopt methods followed by general health services. Vertical, stand-alone services, based on single aetiology like leprosy, will require some adaptation to fit in with the environment of general health services. The authors speculate that changes in leprosy rehabilitation could make 'community based rehabilitation' (CBR) an important method for the vast majority of leprosy patients who need rehabilitation. This paper discusses some of the concerns regarding the suitability of CBR for leprosy rehabilitation.

INTRODUCTION

With the use of 'Multiple Drug Therapy' (MDT), leprosy affected persons now develop less disfiguring disabilities compared to a decade earlier (1) and as a result, stigma attached to leprosy has diminished considerably. In the past, leprosy was viewed as a severely stigmatising condition that progressively devalued and marginalised the affected persons; finally to culminate in segregation, away from homes and society in colonies of similarly deformed people. During this process not only did society devalue them, but they also rated themselves lower on the value chain.

The scenario is different today. The integration of leprosy services into general health services has initiated a transformation in leprosy rehabilitation from being a vertical, stand-alone service, based on a single etiological factor, to an integrated service along with other general health services (2). As the process of integration has picked up pace of late, leprosy rehabilitation has started using strategies adopted by other health services, such as 'Community Based Rehabilitation' (CBR). The recent changes in management of leprosy have also led to changes in rehabilitation and its philosophy. It has changed from a medical model where prevention and reversal of deformities were the prime focus of interventions, to a psychosocial model with emphasis on integration, economic rehabilitation, and access to services and human rights. Interventions in leprosy rehabilitation have shifted beyond traditional prevention, treatment and surgical reconstruction to others such as community based rehabilitation, socio-

economic rehabilitation and formation of self-help groups for affected persons and families. Thus, leprosy rehabilitation has refocused its emphasis from a purely 'client-centred programme' to a 'client and community centred programme' (3).

CHANGING SCENARIO OF LEPROSY REHABILITATION

Even though the strategies in leprosy rehabilitation have been modified to suit the present situation for sometime now, it is still unclear as to who needs rehabilitation and which services are best suited for different groups of patients (4). In an analysis of studies on leprosy, Srinivasan reported that 21% to 45% of all persons affected by the disease deteriorated economically. A high proportion of this group had deformities. Yet, not all persons with deformities deteriorated economically. Conversely, some persons without deformities also deteriorated economically. The dilemma is to identify 'who amongst leprosy affected persons need community level rehabilitation to address the economic and other psychosocial impact of the illness'. Are they persons with deformities? Or are they leprosy affected persons with some other parameters that are not yet identified? Likewise, it is yet unclear what kind of rehabilitation is most acceptable to leprosy affected people. For example, only a very small number of people with deformities are finally fit and willing for reconstruction surgeries. Similarly, a substantial number of economically deteriorated leprosy affected people show no interest in seeking available rehabilitation schemes. Objective evidence pertaining to acceptance and appropriateness of rehabilitation services in leprosy is scanty and is an area of concern.

The transition of leprosy rehabilitation from medical to psychosocial and from institutional to community based processes require certain changes in governance. Traditionally, health care institutions used a 'top-down' approach in service delivery and governance. In some cases the systems became so autocratic that 'needs' of clients were ignored and they never became empowered to choose their goals. In contrast, 'community based organisations' do not have highly differentiated structures or systems of communication that are imposed on clients. They use a 'bottom-up' approach that allows client participation in strategy development. The major difference between institutions and community-based organisations is that institutions discouraged people from accessing services if they disagreed with the institutional goals. In community-based organisations any such differences are settled through a change in programme plan to make it more client-centred. Leprosy rehabilitation until recently was more institutional and top-down. However of late, some programmes have become 'bottom-up' in approach, and as a result have started using 'participatory needs analysis', 'participatory decision making' and so on. These are approaches that are quite different from what these institutions were used to earlier.

COMMUNITY BASED REHABILITATION AND LEPROSY

Among the strategies adopted for rehabilitation, 'community based rehabilitation' (CBR) is of special interest for leprosy because general health services in many countries have already adopted this strategy as a viable alternative to reach disabled persons from rural areas. Planners can no longer ignore the strategic importance of this method that has evolved over the past two and a half decades (5,6). Over the years, there have been many changes in the way CBR is conceptualised and implemented. The major changes have been the transition from an individual orientated focus to a community orientated one, and from the medical model to the social one. It has now moved away from being merely a form of 'therapy in community' to an approach that promotes community participation and ownership of programmes. The emphasis is on equal access to disabled people to all services that are accessible to others in the community. More recently equal opportunities, protection of rights, advocacy and formation of self-help groups have also become major areas of interest for CBR. The goals of CBR are now widened to include enhancement of activities of daily life; creation of awareness, achievement of barrier free environment, attainment of human rights; and a context where community can participate and assimilate the process of their development.

Now that CBR has become a community development process, the debate whether it should be initiated by outsiders or started by the community has been of interest. Votaries of the former view advocate starting delivery of services without waiting for the community to participate. Because community ownership, where people take responsibility for planning, implementing, monitoring and risk sharing, is a slow process. The alternate view is that concerned groups themselves should initiate CBR because it is a developmental process. If CBR is externally initiated, communities can remain passive and do not develop capacity to manage their own affairs. 'Community participation' is the central and essential tenet in the social model. However, communities are often quite heterogeneous, with wide differences in socio-economic, educational, religious and ethnic status. This diversity can cause friction, because some groups have different needs and priorities compared to others. Similarly, needs and priorities of people with disabilities are not always at the forefront when competing issues occur simultaneously. People in some developing countries also expect benefits from their governments as doles, and as a result show a reluctance to take charge of their affairs. Decentralisation and 'bottom-up' strategies become difficult to implement in these circumstances.

The emphasis in CBR today is on integrating disability into the development processes. Votaries of integration conclude that it is cost-effective, promotes better social integration and ensures access to people with disabilities as much as others in the community. Besides, community participation is greater when the majority rather than only a minority share its

benefits. At the same time, unplanned integration of disability into development can ignore 'real rehabilitation' needs of people with disabilities and segregate them further. During the last few years, integration of disability into community development programmes have shown some tangible benefits and some problems. Poor organisational capacity to integrate two functionally different streams of interventions and lack of familiarity with rehabilitation on the part of community development organisations, have acted as major barriers for integration. Lack of mobility, education and other skills also prevent disabled people from being part of the broader development process. In addition, people with disabilities expect doles and are poorly motivated to assume responsibilities. Integration of rehabilitation into development programmes needs a high degree of co-ordination and collaboration between different sectors such as health, education, employment and others. Barriers in this process have to be removed before such collaboration can succeed and make the social model of CBR effective.

CBR was promoted to gain wider coverage at affordable costs. In order to reduce costs many interventions were shifted to families of disabled persons and community. Although CBR appears to be cheaper, in reality much of the costs are transferred to the consumers. If the consumers' costs are also included in computing the expenditure, it may turn out to be much higher than what is generally assumed. Many families in developing countries do not have the means to support their disabled members. In an environment of increasing difficulty to access resources, these families are more likely to choose their 'normal' members to support than their disabled relatives.

About 30% of people with disabilities in CBR have severe and multiple disabilities. Sometimes severely disabled persons get neglected while CBR focuses on issues such as 'community participation' and equal 'rights'. When they are neglected, programmes tend to gloss over their shortcomings as a 'limitation of CBR'. Women with disabilities are another group whose needs are not adequately addressed. They face unique disadvantages simultaneously, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services provided by male service providers.

The problems of community volunteers illustrate how difficult it is to translate a theme like 'community participation' into practice. Volunteers are difficult to find, their turnover is high, large resources are required to train them continuously, they lack motivation and do not perform if incentives or small salaries are not paid. However, there are programmes that have successfully used volunteers, though they are the exceptions.

CONCLUSION

'Community based rehabilitation' evokes different perceptions in different people. Many feel that it is the only hope for the majority of people with disabilities in developing countries.

Others see CBR as a process of development with ill-defined boundaries. Some feel that CBR would disappear after a while. If one ponders for a moment on alternatives to CBR for people with disabilities, including people affected by leprosy in poor countries, it would be clear that it is difficult to ignore the role of CBR in leprosy rehabilitation.

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