

A Study on Community-based Approaches to Reduce Leprosy Stigma in India

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Abstract

There is a global awareness that reduction of leprosy stigma is not at par with the technological developments and the resulting cognitive changes pertaining to leprosy, which can be attributed to lack of active community participation in the programmes. With a major aim of identifying the best methods using active participation of the society, the Leprosy Mission in India initiated a multi-state community-based interventional trial of leprosy stigma reduction in 2 similar rural blocks located beyond 25 km. from the three hospitals, from 3 states, at Faizabad in Uttar Pradesh, Purulia in West Bengal and Champa in Chhattisgarh of India during 2005. A baseline survey was done which confirmed a high level of leprosy stigma. A stigma reduction organizing committee (SROC) in each village, thus a total of 60 SROCs from 3 states @ 10 from each block were formed. One trained social worker appointed by the project as community organizer in each block acted as a facilitator for all the stigma reduction activities taken up by the committees. The outcome of the project shows, the SROCs' interventions are well accepted by the communities. Education and counseling through SROC members in local circumstances are very much feasible and effective.

Key words: Leprosy, Stigma, SROC, Multi-state study

Introduction

Community participation is an essential ingredient in any successful public health or development programme (Neuhauser et al 1998) and a large number of accrued benefits are usually attributed to such participatory processes (Zakus 1998). Published literatures on community based approaches deal largely with economic uplift and socio-economic issues involving self help groups (SHGs),

micro-finance, land development etc. (Mayoux 1998). Also community-based approaches are used in rehabilitation programmes again for socio-economic developments (Pollard and Sakellariou 2008).

However, one needs to distinguish between mere community orientation and active community based participation, where the community becomes the driving force from initiation to implementation of the

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programme (Shrestha 2002, Asadi-Lari et al 2005). Community-based interventions in health programmes are a more recent phenomenon and the experiences in the successful family planning projects or food supplementation programmes or childhood immunizations or even in conducting preventive trials in HIV have shown that active role of the people are quite cost effective and sustainable (Khan et al 2005, UNAIDS 2007, Klemm et al 2008).

Health is a biosocial issue and efficient management of health problems must deal with both the medical and social aspects (Park 2002). A strong social component is inherent in many serious health issues (Petryshen et al 2001, Egbert et al 2004). History records the failure of several technological developments to improve health unless the communities concerned were closely involved in their planning and implementation (Peters et al 2007). Leprosy is a prime example of great societal stigma resulting in discrimination, isolation and injustice (Gilman 1999, McCurry 2004, Chen et al 2005). Thus despite the powerful multi-drug therapy (MDT) and steroids, reconstructive surgery and other medical advances, leprosy patients still delay reporting or default due to social stigma, resulting in physical deformities and debilitation (Bekri et al 1998, Chen et al 2000). It is, therefore, imperative that urgent steps should be taken to address social dimensions of leprosy using community based approaches.

The Leprosy Mission in India initiated a community based leprosy stigma reduction study in 3 states of India during 2005 with a major aim of identifying the best methods using active participation of the society. In this paper, we describe our experiences and identify potentially effective methods to reduce leprosy stigma.

Material and Methods

The Leprosy Mission (TLM) in India has been actively involved with caring for leprosy affected over the past century. Today, it has stated as its goal the eradication of the causes and consequences of leprosy both physical and social. With its head quarters in New Delhi, it has nearly 20 hospitals and an equal number of community projects all over India.

In 2005, a multi-state community-based interventional trial was initiated in 2 similar rural blocks located around three of its hospitals at Faizabad in Uttar Pradesh, Purulia in West Bengal and Champa in Chhattisgarh states.

A baseline survey was done to capture the essential demographic and socio-economic features of the nine blocks, followed by an in-depth interview survey of leprosy patients and community representatives on the prevalence and correlates of leprosy stigma. The baseline study included men and women as well as representative sections of the population. The survey confirmed a high level of leprosy stigma (TLM Trust India 2007). The methodology for this project consisted of utilizing 6 qualified social science post graduates who were trained in social aspects of leprosy to live in the selected rural areas and serve as 'community organizers'. They established good rapport with the community through house-to-house visits and carried out general discussion about leprosy as well as about the objectives of the research project.

To be truly community based, the public must be fully involved in the initiation of ideas, planning strategies, implementation, monitoring and evaluation. The mandate of the COs was to explore with formal or informal community leaders as well as with other important persons in the community

their attitudes to leprosy stigma and how the community can get involved in the stigma reduction activities. Frequent individual and group meetings were held in each state and were shared among the community organizers and senior scientists to formulate field strategies to encourage community participation. The ideas suggested by the community were discussed in small group meetings of community leaders and in due course, it became clear that a stigma reduction organizing committee (SROC) should be formed in each village to spearhead leprosy stigma reduction activities. It was felt that wherever possible, such a committee should have a wide representation of the community including leprosy affected persons, meet frequently, keep minutes, delegate responsibilities and generally approve plans and programs. The optimal size of the committee was suggested to be 15 to 20. We now describe our efforts in this direction.

Results

Methods of formation : A village meeting was held when the leaders explained to the public about the problem of leprosy and the stigma associated with it, which was causing a hindrance in the proper treatment and prevention of disabilities. During the discussions, volunteers and nominations were called from the public to be the members of a committee to implement stigma reduction activities. The community organizers met the potential nominees at each visit and solicited their cooperation and acceptance to be a committee member. Further, at each visit the community organizers requested the potential nominees to suggest other names, who were also contacted. All those accepted were called for a meeting by the panchayat president at an acceptable time on a suitable date. A large number gathered at this meeting, where the

guidelines for the functioning of the committee were drafted and the dates of next meetings decided. Despite the great interest, attendance of members fluctuated at each meeting and some members just couldn't be regular due to various pre-occupations.

We aimed at a total of 60 SROCs, 20 in each state. Among the total, 16 committees were small (8-10 members), 39 were of medium size (11-15 members) and 5 were big (16-20 members). Out of 60, 20 committees had the Sarpanch/ Panchayat member/ Pradhan as the Chairman of the committee, 6 had teachers, 10 had the village doctors, 10 had SHG leaders and 14 had Gram Vikas Samiti Workers or social workers. Seven committees constituted of males only, 5 were exclusively female dominated but majority of those (48) consisted of both males and females. In 26 committees, leprosy afflicted persons were included.

The activities by SROC are process outputs as per the objectives of the study, since the initiatives and management was done by SROC without any external help. The inputs by SROC by way of programs would be proof of their capacity building and would lead to impact outputs thereby reducing stigma.

Activities of the committee : At each meeting, the committee discussed the problem of leprosy stigma and how to organize the reduction activities. Almost all the committees decided to visit the TLM hospital to familiarize themselves with leprosy, its treatment, the hospital activities and the nature of integrated services where non-leprosy patients were also treated. They met the Superintendent and staff and visited various Departments including the laboratory and the pharmacy. These visits enhanced their understanding of leprosy as a bacterial disease and the powerful drugs now

available to cure the disease and its complications. The positioning of leprosy and non-leprosy patients in the same ward allayed the fears of SROC visitors about easy communicability of leprosy.

At each of the meetings, ideas on better education were suggested, discussed and a variety of programmes were organized through various communicating actions about the disease process leading to nerve damage. This included cricket matches, school children rallies, health camps and *melas* etc. The community members themselves organized folk-dramas, dances, etc. primarily aimed at better awareness of leprosy and the undesirability of stigma and discriminatory actions against the affected persons.

Table 1 shows a comparative account of the community based activities carried out by the SROCs in each block. Highlights show that activities such as providing counseling and moral support to leprosy afflicted person

and his/her family members, education through banner, referring leprosy suspected to TLM by SROC, use of IEC materials and video etc. have been commonly practiced by many committees. A comparison shows majority of the committees in Uttar Pradesh and Chhattisgarh used IEC methods as means of stigma reduction whereas West Bengal proceeded through referring the leprosy suspected to the treatment centres and counseling of the leprosy afflicted individuals and their families.

Monitoring and evaluation : All these activities were supervised and informal feedbacks were obtained, which were discussed by the committee and further programmes were arranged. As part of the monitoring process, the committee members verified, using observation method, the changes in patients' restrictions reported by their family members. The committee also helped in early detections and reporting for starting treatment promptly and to be

Table 1 : Community-based activities carried out in each block

Community-based activities	Uttar Pradesh	West Bengal	Chhattisgarh	Total
Education through Banner	13	7	19	39
Use of IEC materials (pamphlets, posters, booklets etc.)	13	2	15	30
Health camps by SROC in the villages	4	0	2	6
Organize the village level meetings inviting leprosy patients	7	12	7	26
Screening camp	3	6	5	14
Rally with local school students	13	3	13	29
Referring leprosy suspected to TLM by SROC	5	21	6	32
Follow up of active cases	5	9	6	20
Video show	9	6	15	30
School education	6	5	7	18
Group discussion	4	5	7	16
SROC <i>mela</i> /convention	4	2	-	6
Counseling and moral support to leprosy afflicted and family members	6	27	12	45
Counseling of family members of leprosy afflicted persons	-	9	-	9

regular. The grade of disability of new patients when they reported for treatment was used as an indicator of early detection. Likewise, MDT regularity and completions were identified as important impacts of the committee efforts. The committees are now in the process of developing a formal evaluation of the programme and deformity rate among new cases in the intervention area could be monitored as a parameter for evaluation of the impact in future.

Discussion

Due to prevailing confusion and conflicting terminology, it becomes necessary to define a 'community' in a particular context as well as 'community participation' (MacQueen et al 2001, Cornish and Gosh 2007). The role of Community Advisory Boards in involving communities has been well documented in HIV trials (Strauss et al 2001). The success or failure of such committees depends on how the partnerships between the community and the institution is built on respect, transparency (Israel et al 1998). Arnstein (1969) has described a 'ladder' of citizen participation that can be adapted to different circumstances.

The origins of stigma for any health event can be traced to the physical/medical aspects as well as to socio-religious teachings (Heijnders 2004). The sociological dimensions are inter-related and change over time as the awareness increases and more effective medical treatments are designed (Rafferty 2005). This may be a long-drawn process and may not entirely change the image of leprosy as a disabling disease warranting continuation of stigma. When community-driven active participation occurs, the potential for positive impact is clearly shown, although there is a need for a sustained action for longer period.

Stigma arising out of fear or revulsion (or fear of ugly ulcers or bad smell) must be handled differently from stigma arising out of ingrained beliefs on the supernatural causes of leprosy. While the former needs to be tackled by competent, user-friendly preventive and curative medical care whereas the latter can only be addressed through building awareness of the nature of the disease, its inception, incubation period, pathology, availability of powerful drugs, and the link between late detection/reporting and progression of irreversible disabilities (Nicholls et al 2006, vanVeen et al 2006). Thus intensive efforts through community-driven activities can promote early detection and regular treatment with MDT and will surely sever the link between leprosy and deformity.

Community participation in all stages is the key element in the success or failure of any control programme, even so for leprosy, where a strong social component exists. This paper suggests one model; many others should be identified and widely promoted. The key factor is the involvement of various important elements of society, young and old, men and women, high and low social strata etc. and inclusion of the cured leprosy patients. The top agenda must be early detection and regularity of treatment. Government as well as NGOs should modify existing operational guidelines (WHO 2006) to include active community participation.

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