STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal

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Summary This paper focuses primarily on the extent to which a Stigma Elimination Programme (STEP) affected the social participation of people affected by leprosy in southern Nepal. The Participation Scale (popularly known as The P Scale) was applied to compare leprosy affected people who participated in STEP groups with a control group comprising leprosy affected people who lived in villages where STEP had not been implemented. It was found that STEP participants had significantly higher levels of participation compared with controls and that their levels of social participation were higher than would be expected even for the general population. It was also found that leprosy affected people without visible deformity or ulceration (whether in the STEP group or not) do not appear to suffer participation restriction in southern Nepal.

Introduction

There are a number of health conditions that bear the burden of stigma, but perhaps the most powerful image of stigma is that related to leprosy; still a common metaphor for stigma. Weiss recognized this reality and to lay emphasis on it, he disclosed that leprosy had been the only condition for which explicit and exclusive studies of stigma had been supported by the WHO Special Programme for Research and Training in Tropical Diseases (TDR). Considerable resources have been invested in information and education campaigns (IEC), following which it was claimed the stigma of leprosy had been reduced. On examination, however, it appears that the surveys used to measure impact may have missed the mark. Recourse to earlier studies on stigma show that it is not the disease per se that invokes negative responses. It is the disfigurement and disability caused by the disease that results in rejection. In his study, which included observations at treatment centres in the Chingleput district of Tamil Nadu, Rao reported that even people who were being treated for leprosy disassociated themselves from others on treatment who had disabilities, particularly ulceration. Arole et al. devised a stigma scale and used the findings from focus group discussions and rapid rural appraisal methods to investigate the issue of stigma in Maharashtra. They concluded that where people, deformed by leprosy, lived in communities...
where there was an integrated health service, they did not suffer negative effects of stigma. They also reported, however, that there were high levels of stigma in communities where a vertical approach to leprosy control had been maintained as was the case in Chingleput when Rao undertook his study.1

Knowledge, attitude and practice (KAP) surveys have been used to ‘measure’ stigma.2 Giving the benefit of her considerable experience, Hyland voiced her skepticism over the validity of KAP surveys for that purpose. She suggested that KAP surveys are not able to reflect the multiple and multi-layered notions related to health behavior which can confound logic.7 Heijnders’ research elucidated the complex dynamic nature of leprosy related stigma and as such it further explains why simplistic methods to measure it are inappropriate.5,6 In his comprehensive review of publications on the topic of stigma measurement, van Brakel concluded that, ‘the similarity in the consequences of stigma in many different cultural settings and the crosscutting applicability of many items from stigma instruments suggest that it would be possible to develop a generic set of stigma assessment instruments’.11

The P Scale is an instrument that has been validated through an exhaustive process of testing and re-testing in a multinational, multicentric initiative. It does not measure stigma per se, but it does measure the extent to which people participate in common social events. Since the key issue of stigma is that it excludes people from participating in such events, it is suggested here that the ‘P Scale’ is a valid proxy measure for stigma. (The construction of a generic measure for stigma is now a principal objective of the International Consortium for Research and Action Against Stigma (ICRAAS) that was launched in the Netherlands in December 2004.).

**STEP**

Stigma may be ‘enacted’ (negative actions conducted by others to the detriment of labeled individuals), perceived (an individual assumes that his label will incite negative affects from others) or ‘self imposed’ (an individual enters a state of self loathing due to the label). However, regardless of the type of stigma, an individual’s well-being will be adversely affected. NLT sought to develop a novel strategy to tackle stigma; that strategy was STEP (Stigma Elimination Program). STEP sought to combat ‘enacted’ stigma by transforming the image of leprosy affected people from ‘victims’ to positive change agents. It also sought to combat the issue of perceived stigma and self stigma through the emphasis on empowerment. The process of empowerment is one in which identity is established, the value of life is enhanced and the potential for a dynamic future is constructed. Empowerment was at the core of STEP.

STEP became fully operational in March 2002, when 10 people affected by leprosy were appointed to act as facilitators to develop self-care groups in their villages. The 10 people chosen had all availed of the self-care training which is a core feature of the programme run by the Nepal Leprosy Trust (NLT) at the Lalgarh Leprosy Services Centre (LLSC). They were chosen on the basis of character and perceived potential to conduct the activities that were envisaged as the foundation of STEP. Following facilitator training, the facilitators were issued with names of people affected by leprosy in their villages. Their first task was to contact those people and to encourage them to initiate self-care groups with the primary aim of impairment control.
By March 2003, when it was apparent that the self-care groups had continued to develop and become increasingly cohesive, the groups took on the form of Self Help Groups with characteristic credit unions and micro enterprise development. The Self Help groups expanded criteria for membership to include other marginalized and disadvantaged people. It was at this juncture that the unique feature of STEP was also introduced, i.e. that the Self Help Groups began to take initiatives to pursue a development agenda for the benefit of their wider communities. They were not merely the recipients of donor aid, but they became donor partners offering opportunities and services for the development of their villages.

Since 2003 the Self Help Groups have brought to fruition a variety of initiatives that have been consistent with the development agendas of the villages where STEP has been operational. Perhaps the most significant projects have been the organization and supervision of non-formal education, but other projects have also been notable, e.g. provision of wells and water pumps, environmental development (hygiene and access), concern for the distressed aged, and advocacy.

By February 2004, the Self Help Groups were gaining greater independence concurrent with increasing local recognition. Some were successfully registered as NGOs at the Village Development Committee (VDC) level; others are still in the process of registration. Having achieved recognition at VDC level, the groups intend to proceed with requests for NGO status at District and then National levels (two groups were in the process of District level recognition at the time of the evaluation programme). The plan is for the groups to register, under the title of one organization, at National level.

A broad assessment strategy was devised and undertaken to evaluate STEP in March 2005. Diverse participatory methods were used to establish an impression of the context in which STEP was implemented. Community representatives from the 10 villages where STEP was established, contributed to a process of village profile development. Senior District Officers contributed perspectives on key health and education issues in the two districts in which the villages are located. Members of the STEP Self Help Groups (SHGs) contributed information through listening surveys and STEP facilitators contributed through a focus group discussion.

‘P Scale’ was used as a proxy measure for stigma. Validation of the result was supported by triangulation with qualitative data collected through the diverse participatory exercises.

ASSUMPTIONS

Inherent to the design of STEP was the following hypothesis: ‘When individuals who had been marginalized as an effect of leprosy are transformed into positive change agents in their communities, the stigma associated with leprosy will be negated in those communities.’

In the Ottawa Charter it is stated that ‘To reach a state of complete physical mental and social well-being, an individual or group must be able to identify and realize aspirations, to satisfy needs and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life not the objective of living.’ Whether it is enacted or perceived, or self-imposed, stigma compromise an individual’s path to the objective of ‘complete physical mental and social well-being’. The publication of the International Classification of Function in 2001 broadens the perspective of ‘environment’. In the ICF, environmental factors are given a broad definition which includes the physical, social and attitudinal parameters of an individual’s existence. The significance of these publications for the evaluation of STEP was that evidence of exchanges of generous attitudes and actions between leprosy affected
people and others in their communities would be indicative of a community where stigma could not be an issue.

Evidence was therefore sought to ascertain whether individuals affected by leprosy in villages where STEP has been implemented participated in their communities at significantly higher levels of participation than similarly affected people in ‘non-STEP’ villages.

The use of the ‘P Scale’ provided empirical evidence of levels of participation expressed by the people interviewed. The assumption that a difference in social participation could be attributed to the program was validated by a process of triangulation. ‘Triangulation’ in this paper refers to an approach to data collection in which evidence was deliberately sought from a wide range of different, independent sources and often by different means. As a validation strategy it follows precedents sometimes used in qualitative research where interviews, focus group discussions or other participatory methods are used to contribute to the evolving analysis. During the evaluation period focus group discussions, Nominal Group exercises and listening surveys were conducted. Using such methods, the context in which the program was conducted was described by community representatives. Village development priorities and attitudes were established. It was also ascertained that STEP had a high local profile, that participants were highly regarded, and that expansion of the project was highly desirable. Details have been reported elsewhere.

Materials and methods

It was regrettable that during the planning stage of STEP, the P Scale was still undergoing development. It was not possible, therefore, to describe pre and post programme effects on participation for the target population. A comparison of participation levels between STEP groups and a control group from non-STEP areas was designed as an alternative.

In preparation for the evaluation, a copy of the P Scale questionnaire was sent to LLSC with instructions for the translation process. The questionnaire was subsequently translated into colloquial Maithili. On arrival at LLSC, the staff of the Community Development Department and three Maithili staff from the Hospital Outpatients Department were trained in the application of the scale. A pilot exercise was conducted to establish whether there were any issues that required to be addressed. Some of the interviewers required further instruction to avoid inadequate data collection, but there were no insurmountable issues.

A logistical issue that did affect data collection was the imposition of movement restrictions by Maoist insurgents which were active in Nepal. At the start of the evaluation period, road traffic movements outside LLSC were restricted to emergency vehicles only (ambulances or vehicles conveying sick or wounded people). When the movement restrictions were eventually relaxed a curfew remained enforced for the duration of the evaluation period. The imposition of the curfew restricted travel because field workers were compelled to return to LLSC before nightfall. Such impositions restricted the areas that could be reached to those within a limited radius of LLSC. The restrictions also impacted on the number of leprosy affected people attending LLSC to avail of services. The availability of leprosy affected people that could be interviewed was smaller than had been hoped.

A decision was made to interview as many leprosy affected people in the STEP groups as could be reached. A control group comprising leprosy affected people not in STEP villages was also interviewed, but because of the logistical issues reported above, it was not possible to generate a random sample for interview. The groups were not matched but all subjects
were from rural, agricultural environments. ‘Non-STEP’ villages within a reasonable radius from LLSC were identified (i.e. villages that could be reached by field workers with near certainty of them being able to return before curfew). Names and addresses of all leprosy affected people living in those villages were extracted from an outpatient data base and field workers were dispatched to find and interview as many of those people as could be found. All data relating to STEP subjects and controls were gathered by one group of six field workers. It is stressed here that apart from the logistical restrictions imposed, there was no further selection bias. In both groups, only people between the ages of 15 and 65 were included for interview. None of the people interviewed were employees of Lalgadh Leprosy Services Centre. At the time of the evaluation, there were a total of 184 leprosy affected people in the SHGs, of whom 83% were interviewed.

Ethical approval for the study was given by the trustees of the Nepal Leprosy Trust. An explanation of the interview process and the rationale for the study was explained to every individual that was interviewed. An interview only proceeded on the agreement of the individual to participate.

Results

The sample details are shown in Table 1.

**ANALYSIS OF P SCALE SURVEY**

Kruskal-Wallis test for two groups was used to analyse differences between groups (Table 2). STEP and non-STEP groups and subgroups scoring below the threshold of 12 (i.e. no different from the general population) were cross tabulated, and Yates corrected \( \chi^2 \) was used to test significance (Table 3).

It has been established that 95% of the general population is likely to score between 0 and 12 on the P Scale (van Brakel et al., *Disability & Rehabilitation*, vol. 27, 2005, accepted for publication). Therefore, only scores over 12 indicate significant levels of participation restriction. The study areas in which the P Scale was developed included Nepal and parts of rural Uttar Pradesh. In the absence of a local threshold, therefore, the cut-off of 12, representing the 95th percentile reported by the authors of the study was considered acceptable for the areas where STEP was implemented.

By the above criterion, it was found that only 7% of people in STEP groups still suffer significant participation restriction, whereas 40% of non-STEP controls reported significant

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levels of restriction. It can be assumed that 5% of the general population would have
restriction, by comparison, people in STEP groups did not suffer significantly less
participation than the general population. This was a very remarkable finding.

Further investigation sought to establish whether people with visible disability were more
disadvantaged than those without disability. It was found that even when people in STEP
groups did have disability only 10·5% suffered participation restriction. By contrast, 38% of
the non-STEP controls with visible disability reported restriction.

It was also established that where there was no visible deformity, only 2% of the STEP
subjects reported participation restriction compared with 19% of people in non-STEP
villages.

Although not detailed in this paper, STEP has had a significant impact at community level
and is recognized as a positive force by district level officials of HMG Nepal. As direct effects
of SHG activity, a considerable number of individuals have benefited: 1060 people have had
some basic education, many people now have access to clean water, some have the benefits of
improved sanitation and others have improved physical access to amenities, over 200 people
are now generating income from their own micro enterprises. Infrastructure development was

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<th>Table 3. Comparison of P scale scores &lt; 12</th>
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not particularly notable given the size of the population and the extent of need, but the strides towards equity and the dismantling of prejudice were significant.  

Discussion

Considering that it could be expected that 95% of the general population would be free from significant levels of participation restriction, it is very remarkable, given that 47% of STEP members had visible complications that 93% of them were also free from participation restriction. It may be that their relatively recent rise in self esteem, self reliance and community acceptance had generated unprecedented levels of self confidence such that they registered better levels of acceptance than would have been expected of the general population. Although the foregoing suggestion is speculation, it may be supported by considering the comparison of P Scale scores relating to people who did not have visible deformity. It was found that most people who had suffered leprosy, but had no visible sign of the disease, did not suffer significant participation restriction. However, when cross tabulating P Scale scores for STEP and non-STEP groups without disability it was found that people in the STEP group scored significantly less on the P Scale than non-STEP peers, i.e. they were more confident in their communities.

An interesting observation was that leprosy affected people in that part of Nepal do not suffer participation restriction if they do not have visible deformity (i.e. the non-STEP subjects were not different from the general public on comparison of P Scale scores). This has implications for further planning, because it would appear that this group does not need particular focus for intervention.

At the time of writing this article, the districts in which STEP was implemented still had high leprosy prevalence rates (Dhanusha 4.6 per 10,000, Mahottari 4.0 per 10,000). Leprosy was therefore still a significant public health problem. People presenting with leprosy in villages where STEP was implemented were likely to have benefited, directly and indirectly from the programme. Direct benefits would have been due to the activities of the STEP groups who collaborated closely with local Health Post staff. Some of the groups conducted defaulter tracing and case detection activities. Reports were that for many local people, SHGs were the first consultation point when leprosy was suspected. Over 238 people suspected to have leprosy were referred by STEP groups to Health Posts, where 215 cases were confirmed. Fifty-four treatment defaulters were restarted after being traced and counselled by group members. Indirect benefits may have been that the more positive attitude to people affected by leprosy might have created an environment wherein people may have been less inclined to delay presentation for fear of negative consequences.

In the absence of a valid scale for stigma, the P Scale was considered a valid proxy for this study. However, it is acknowledged that participation restriction can also be an effect of activity limitation, geographical isolation or difficult terrain.

It is also acknowledged that although it has been inferred that the enhanced participation among those involved in STEP was an effect of external factors (e.g. the enhancement of village environments attributed to STEP members actions), improvements could have been due to internal factors. Internal factors (e.g. greater self respect as an effect of empowerment) may have lead to a reduction in perceived stigma or to enhanced coping skills. It is the authors’ opinion that the outcome was perhaps an effect of a combination of both internal and external factors.
The reasons why a random sample could not be generated were given above. The authors acknowledge that the unequal distribution of sex and deformity between the groups could be a confounding factor. Compared with the STEP group, a higher percentage of subjects in the non-STEP group had visible deformities (79% non-STEP versus 50% STEP). Because of this, a decision was made to conduct a stratified analysis of groups with and without deformity because evidence from earlier studies does suggest that people with recognizable signs of the effects of leprosy do suffer discrimination, which is likely to affect participation.3,6,9,10,11

Another potential source of bias was that there were more women in the STEP group. Maithili culture appears to be strongly male dominated. The low percentage of women in the non STEP group (17·6%) compared with a much higher proportion (38%) in the STEP group could mean that the positive effects of STEP may have been underestimated, i.e. a relatively high level of participation in the non-STEP group may have been expected due to the low proportion of women. Published evidence that Maithili women are discriminated against, however, is scarce. Heijnders did report that ‘non-decision making’ women did appear to be more susceptible to negative impact as an effect of leprosy than ‘non-decision making’ men. However, the dynamics are complex because from Heijnders’ study it appears that ‘decision making’ men with leprosy suffer the greatest negative impact.6 Further analysis of groups of men and women with and without visible signs of leprosy, therefore, was not conducted.

Conclusion

The hypothesis upon which STEP was based is that: ‘When individuals, who had been marginalized as an effect of leprosy, are transformed into positive change agents in their communities, the stigma associated with leprosy will be negated in those communities’.

On reflection, it should be considered that the initiatives alluded to above had been instigated by people who were all affected by leprosy. Three years prior to the evaluation they were mostly illiterate, physically impaired, stigmatized and marginalized. Given their initial disadvantaged status, their achievements were very remarkable.

The outcomes of the P Scale investigation did present substantial support to suggest that leprosy related stigma had been overcome in communities where STEP had been implemented. It would appear that stigma can perhaps be eliminated as a social malaise where the STEP model is applied in communities similar to that in Southern Nepal.

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