SELF CARE: A CATALYST FOR COMMUNITY DEVELOPMENT

Hugh Cross,* Ramesh Choudhury**

ABSTRACT

This paper presents salient findings from an evaluation of a programme designed to address the issue of leprosy related stigma in Southern Nepal. The programme under the acronym STEP (Stigma Elimination Programme) adopted an approach that was dependent on the empowerment of people affected by leprosy. Empowerment was facilitated, primarily through self-care group association. The premise was that, as people became increasingly self confident, as an effect of self-care, their focus could be shifted from the pursuit of personal goals to activities that could be undertaken for the benefit of their communities. As the self-care groups evolved, all 10 groups adopted a community development agenda. This paper outlines the projects that the groups planned and initiated and describes the method used to validate their efforts. It also gives results of surveys conducted to assess the impact of the programme on stigma, activity limitation and impairment.

INTRODUCTION

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 realise 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" (1). In the International Classification of Function (ICF), environmental factors are given a broad definition which includes the physical, social and attitudinal parameters of existence (2). Stigma is a social malaise which does not only impede the development of individuals, but impoverishes their entire communal environment, by the creation of deviant identities and unproductive roles (3,4). It was recognised by the Nepal Leprosy Trust (NLT) that an intervention was necessary which would target environments compromised by stigma in South East Nepal.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

NLT was unconvinced by conventional stigma reduction strategies that focused primarily on education, because it considered such strategies to be based on Eurocentric logic, that stigma was a simple correlate of ignorance. The studies of Heijnders and Hyland (5, 6, 7), demonstrated that the complexity of stigma in Nepal, was related to culture specific health beliefs which are more closely associated to magic or superstition, than science. With such findings as those of Heijnders and Hyland, consolidating earlier suggestions by Waxler (8), Berreman (9) and Valencia (4), it was accepted that if stigma in Nepal was modelled on an alternative logic, then intervention should identify and target a core belief. In the context of Southern Nepal, people affected by leprosy were commonly believed to have been cursed and were also considered to be a curse on their families and communities. This understanding was derived from a common derogatory term used to identify leprosy affected people in Nepal: "*khori*" which is translated as curse. NLT developed a strategy to facilitate the transformation of the local image of leprosy affected people, from those who were a curse, to those who were a boon. The strategy was that community development would be effected by and through the empowerment of people who had been marginalised due to the stigma of leprosy. The strategy was developed into a programme which adopted the acronym STEP (Stigma Elimination Programme).

DEFINING THE PROGRAMME

The process of community development usually involves an external agent that has its own perspective of a target community's needs and problems and works in partnership with the community to bring about development. Community empowerment is characterised by capacity building so that community members become their own change agents. With community empowerment programmes, external agents are still involved, but as facilitators that increase community skills and abilities so that they can develop themselves (10, 11, 12).

The concept of STEP was primarily influenced by Paulo Freire's theory of conscientisation: i.e. that marginalised people can go through a process which enlightens them to the latent power they have, to address problems. As they become enlightened and start to utilise that power, they become their own change agents. As such, STEP fell within the conceptual framework of community empowerment. However, STEP was conceptualised and activated

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

by an external agency (Nepal Leprosy Trust) with the ultimate vision of engineering positive structures (physical and psychological) within certain target communities. As such, STEP also fell within the conceptual framework of community development; although it had a stronger tendency toward the concept of empowerment rather than development. This came about because NLT considered people stigmatised by leprosy, in Nepal's Terrai region to be so profoundly debilitated that, as a population it could hardly maintain a foothold in the base level of Maslow's heirarchy of need (13). Thus it was that the organisation felt compelled to be the stimulus to initiate the process of conscientization. Further to facilitating conscientization, NLT had planned to offer material support to help develop infrastructure, environment enhancement or even personal advancement, but that it would not make any suggestions to that effect. The groups that formed would be able to approach NLT with proposals for assistance as they might approach any NGO with a development agenda.

STRATEGY AND IMPLEMENTATION

The general strategy to reach the STEP goals was to transform the image of leprosy affected people by facilitating the creation of an environment in which they could become positive change agents. The premise was, that having reached a level of inner development such that they were characteristically interdependent, they would begin to engineer developments in their villages (consistent with empowerment theory).

In March 2002, 10 people affected by leprosy were appointed to act as facilitators to develop self-care groups in their villages. They were all people who had undergone self care training at the Lalgadh Leprosy Services Center (LLSC) (14). 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, the groups had developed and had taken on the form of Self Help Groups with characteristic credit unions and micro enterprise development. The Self Help groups

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

expanded criteria for membership to include other marginalised and disadvantaged people. It was at this juncture that the Self Help Groups began to take initiatives to pursue development agendas 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.

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 at that time (they also all planned to proceed with requests for NGO status at District and then National level).

EVALUATION OF THE PROGRAMME

In February 2005, three years after the programme had been initiated, it was evaluated.

The following data collection procedures were undertaken:

- Participatory exercises with 39 community leaders of the 10 villages where STEP was implemented.
- Listening surveys with 5 of the 10 Self Help Groups.
- Focus Group discussion with the 10 Self Help Group facilitators.
- P Scale survey of leprosy affected people in all the SHGs and a control group comprising people affected by leprosy who do not live in STEP villages.
- Green Pastures Activity Scale survey of leprosy affected people in the SHGs (cohort study)

GENERAL COMMUNITY PERSPECTIVES

39 Representatives from the 10 villages where STEP had been established, attended an inquiry at LLSC. The representatives included head teachers, social workers, assistant health workers, members from NGOs and the VDC secretaries. The objectives of the inquiry were:

- To establish the context in which the programme functioned (impressions of village development profiles and development issues).

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

- To establish what the extent to which STEP activities were consistent with development concerns.
- To assess the attitudes of village representatives towards people affected by leprosy and STEP

A VISUAL ANALOGUE RATING OF VILLAGE DEVELOPMENT

A simplified account of Maslow's hierarchy of needs was explained to the participants. They were then requested to group themselves with other representatives from their respective villages. 10 small groups were thus organised. The groups were presented with a visual analogue representing a 10 rung ladder. It was explained that the bottom most rung of the ladder represented communities where only basic human needs were met: i.e. the need to satisfy, hunger, thirst and sex (based on Maslow's theory). The ninth rung represented communities characterised by people who could expect to fulfill their aspirations. Rungs between the two represented developments on a continuum from basic survival to self actualisation. Groups were asked to consider which level on the analogue best represented their own communities. Feedback was collected from the participants and was used later to assist in developing a contextual profile of the STEP villages in general (see Figure 1).

MODIFIED NOMINAL GROUP EXERCISE TO DETERMINE KEY ISSUES AFFECTING VILLAGES IN DHANUSHA AND MAHOTTARI

Whilst in small groups, the participants were also requested to suggest what the key issues were, that affected life and development in their villages. Comments and suggestions were offered from the floor verbally (a deviation from normal nominal group exercises) (15). Ten suggestions were contributed which were recorded on a white board. After a period of reflection and clarification, the participants were asked to agree, within their small groups, on how the suggestions should be ranked to represent priorities in their villages. Rankings were then submitted by each group for analysis.

Ten groups submitted ranking for the ten issues suggested (1 was the most serious issue). The issues were listed with the range of ranking, ascribed to them. The median rank for

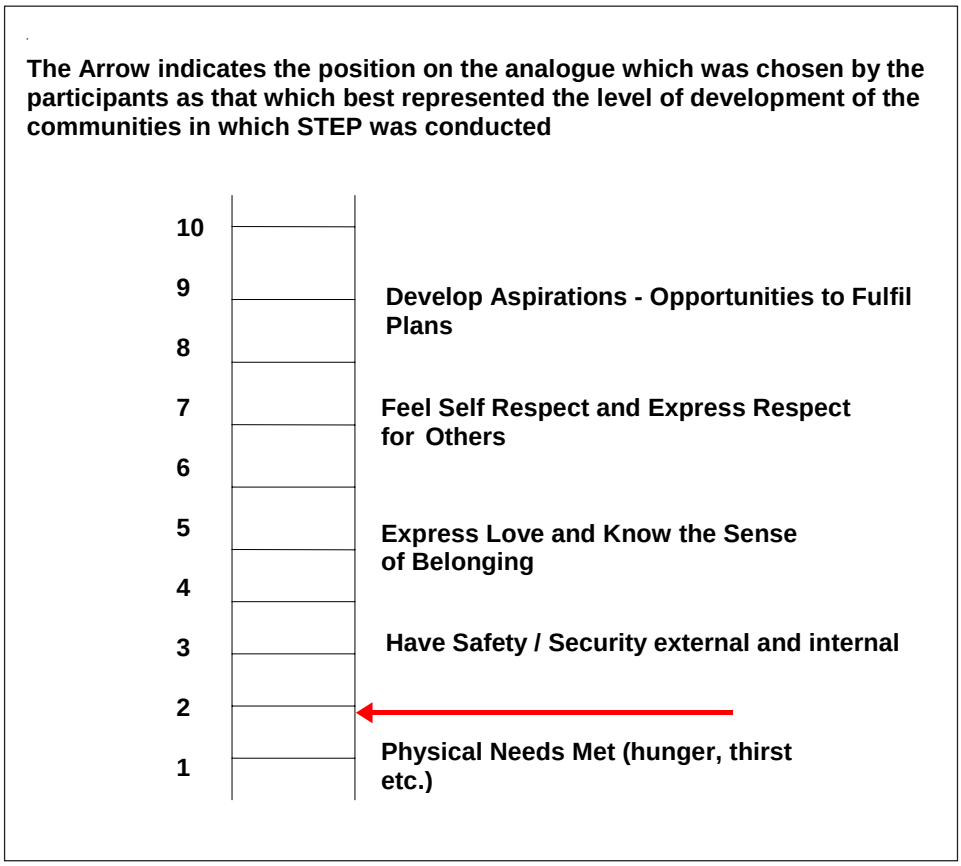
J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

each suggestion was taken as that suggestions position on a scale of importance. Where five or more people had agreed on the ranking the result was considered a consensus. This exercise further helped to develop an impression of contextual factors. The issues and the priorities accorded them (as reflected by the ranking) are presented in Table 1.

RESULTS

Figure 1.

The Visual Analogue Rating Village Development in Dhanusha and Mahottari



J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Table 1. The Key Issues Affecting Villages in Dhanusha and Mahottari (as determined by community representatives)

Issues	Median	Rank
Education and Unemployment (2 issues with identical ranking)	2	1
Security (protection)	3.5	2
Population Growth	4.5	3
Health Issues	5	4
Environmental Sanitation	5.5	5
Drug and Alcohol Abuse	6	6
Stigma and Discrimination (not leprosy specific)	7	7
Planning and Infrastructure	8	8
Human Trafficking	9	9

Community Opinions of STEP

31 of the 39 participants indicated that they knew about STEP. The two features of the programme that had been particularly admired were the organization and supervision of non formal education (particularly the establishment of Early Child Development programmes) and efforts to improve village environments. Participants also expressed their admiration for the vigor and resolve that the groups demonstrated in their determination to overcome the disadvantageous affects of leprosy.

PARTICIPATORY METHODS

Self Help Group Perspectives

Table 2. Self Help Groups Surveyed

Village	Number of People in Attendance
Gaushala	30
Aurahi	25
Lohana	20
Prakauli	7*
Rupaitha	22

* The team arrived at Prakauli late. Most of the SHG had already left.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Self Help Group Listening Survey

At each venue, the same semi structured interview was applied. Two principle questions that were put to the groups were:

- What benefits have you had from being in this group?
- What have you done together as a group, that has been for the benefit of others?

What benefits have you had from being in the group?

1 Control of their impairments. They expressed great satisfaction in finding that they were not powerless to prevent deformity and that they could do so independently of medical services (this was expressed by all groups).

2. Emotional and practical support from other group members. Examples ranged from group pressure on rights issues (access to a temple) through encouragement, to continue self-care activities, to provide support through times of personal or domestic crises (this was expressed by all groups).

3. Community acceptance (this was expressed by five groups).

4. Literacy. The groups related that the main impact of literacy is that people could avoid the practices of unscrupulous loan sharks. It had become possible for people to avail of legitimate banking services (this was expressed by four groups).

5. Women were no longer compelled to seek agricultural, daily wage work. Micro-enterprise had generated sufficient income for many of the women to be released from the dependency on such employment. (this was expressed by three groups).

What has been done together as a group, that has been for the benefit of others?

Each group had been encouraged to participate in village surveys, to ascertain local needs and to then develop their own programmes with the aim of addressing what they perceived to be, priority needs. Funding and support for any chosen initiatives came from a combination of sources which included SHGs, local government sponsorship, LLSC and other NGOs. All support was sought by the SHGs themselves. All actions were initiated by the SHGs and all negotiations and bureaucratic demands were handled by the SHGs independently.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Projects included:

- Early Child Development (primarily targeting Dalit[1] children).
- Non formal adult literacy.
- Building community and domestic toilets.
- "Care Haven" for abandoned elderly people (in process).
- Leprosy awareness campaigns (mobilizing schools to conduct village parades).
- Defaulter tracing and case detection (for many local people, SHGs are the first consultation point when leprosy is suspected. Over 238 people suspected to have leprosy were referred by SHGs to Health Posts, where 215 cases were confirmed. 54 treatment defaulters were restarted after being traced and counselled by group members).
- Installation of wells and hand pumps.
- Small scale environmental hygiene projects (village tidying).
- Creating access to public areas (pathways) for underprivileged groups .
- The groups combined efforts and resources to establish a stall at a major Hindu festival in Janakpur. From the stall, they offered free snacks to a considerable crowd of devotees. (A banner identifying them as leprosy affected people was prominently displayed).

The Facilitators

The SHG facilitators participated in a focus group discussion, which sought to ascertain what had been the most positive affects of STEP in their perspective. LLSC had initially recognized that the STEP facilitators would be required to invest a significant amount of time and emotional energy to establish their groups. In recognition of this, LLSC paid them an allowance to compensate for wages they might otherwise have earned. They had also availed of opportunities to establish micro enterprises for income generation. At the time of

[1] Dalits are an unscheduled caste. They were traditionally considered "untouchable". In some Terai areas, close proximity with Dalits is considered a threat to the ritual purity of higher caste groups. In some of the STEP villages Dalit children were barred from attending schools where they might "contaminate" higher caste children.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

the evaluation, the facilitators had ceased to receive allowances, but continued in their roles for the prestige that the roles offered them (by their account).

The most common outcome of these group discussions amongst the facilitators, was that they had developed courage. They had confidence to dialogue with officials at VDC and District level. Some had negotiated their way through bureaucracy to register their groups with local authorities. Others had managed to support group members through the process of citizenship registration and subsequently registration as disabled people (with disabled person's registration people are entitled to statutory benefits). Another facilitator had advocated on behalf of destitute widows until the VDC agreed to release allowances for them. Some had persevered with authorities until land was released for building public meeting houses, or until they were given permission to utilise abandoned government buildings for SHG meetings.

STIGMA REDUCTION

The Participation Scale (Popularly known as The P Scale) is an instrument that has been validated through an exhaustive process of testing and re-testing, in a multinational multi-center initiative. It is suggested here, that as a measure of social participation, The P Scale is a valid proxy measure for stigma.

A control group comprising leprosy affected people not in STEP villages was interviewed, but because of the logistical issues related to insurgency activity at the time, it was not possible to generate a random sample for interview. "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 Out Patients data base and field workers were dispatched to find and interview as many of those people as could be found. 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. At the time of the evaluation, there were a total of 184 leprosy affected people in the SHGs; 83% were interviewed.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Table 3. Sample Details

	STEP n = 152		Non-STEP n = 102		TOTAL
Mean Age	Male 47	Female 44	Male 42	Female 34	
Visible Deformity	48	28	71	10	157
No Visible Deformity	48	28	13	8	97
	96	56	84	18	254

P SCALE RESULTS

It was found that only 7% of people in STEP groups still suffered significant participation restriction, whereas, 40 % of Non-STEP controls reported significant levels of restriction. It can be assumed that 15% of the general population would have restriction (scores greater than P Scale score 12). By comparison with the general population, therefore people in STEP groups suffered significantly less participation restriction (Full details are given in another paper: "STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal." Cross H and Choudhary R; submitted, Leprosy Review).

IMPACT ON DISABILITY

On inclusion into a SHG, monitoring staff from LLSC interviewed new members using the Green Pastures Activity Scale (GPAS), to give baseline information relating to individuals' activity levels. Impairments (with exclusion of eye impairments) were also recorded.

A list of all people who had been questioned on entry into the SHGs, was compiled. It was then planned to meet as many of those people as could be encountered to request them to contribute to a follow-up survey. There were 171 GPAS entries in an Access database. These represented most of the people who had joined SHGs, since the programme began. Names and addresses were retrieved from this list and field staff were dispatched to find, interview and examine those people. 129 people were found and interviewed.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Table 4. Impact on Impairment

Impairments	March 2002	March 2005		
		Resolved	Improved	Worse
Ulcers	54	47	7	0
Fissures	9	9	0	0
Claw Fingers	7	4	3	0

GPAS scores at Baseline and Scores at Follow-up were compared to ascertain whether there was a difference in activity levels. It was considered that the length of time that people had been active in the SHGs could affect the outcome (i.e. longer periods of participation may have effected better results). For this reason, subjects were grouped according to the time period when they joined their respective SHGs.

Subjects were allocated to 1 of 4 groups:

a) People who had joined SHGs between October and December 2001.

b) People who had joined SHGs between January and April 2002.

c) People who had joined SHGs between August and October 2003.

d) People who had joined SHGs between June and August 2004.

A non parametric analysis of variance was applied to test differences within and between groups.

Group A (n = 21)

	Minimum	25%	Median	75%	Max
Baseline	0	0	1.5	6.5	40
March 2005	0	0	2	5	30

Difference: Not significant

Group B (n = 65)

	Minimum	25%	Median	75%	Max
Baseline	0	0	1.5	8	40
March 2005	0	0	2	6	44

Difference: Not significant

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Group C (n = 36)

	Minimum	25%	Median	75%	Max
Baseline	0	0	2	10	47
March 2005	0	0	1	4	33

Difference: Not significant

Group D (n = 7)

	Minimum	25%	Median	75%	Max
Baseline	0	6	14	18	29
March 2005	0	1	3	8	10

Difference: p=0.04

The difference between groups was not significant.

The improvement in impairment status was notable. There was however, only a marginal improvement in GPAS scores.This was perhaps a reflection of the harsh reality within which the people were compelled to function, regardless of impairment. What the findings also suggest, is that self care (which includes activity adjustment) can enable people to conduct activities in a harsh environment, without further impairment.

DISCUSSION

Validation of STEP was established through participatory exercises, undertaken with the cooperation of community representatives active in the 10 villages. They presented a perspective of the general level of development in their villages and a consensus on the issues, that in their opinion, needed to be addressed. The actions initiated and implemented by the SHGs were considered in that context and were found to be consistent with the needs expressed. The SHGs' community oriented activities, therefore, will have contributed to village development objectives. The population of the villages where STEP had been implemented was in the region of 90,000. That the 39 significant community representatives were not only aware of STEP groups, but could relate their key activities, indicated that the groups had achieved high profiles in their communities.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

The high regard in which the STEP groups were held in their communities, was not only considered a reflection of the social responsibility they assumed, but was also an expression of admiration for the personal resolve of members to gain control over disadvantages of leprosy related impairments. It is therefore not social responsibility alone that has gained recognition; self-care with its connotations of self respect, have won high regard for leprosy affected individuals in those groups.

STEP has demonstrated that self-care is a valid approach to the sustainable management of impairments, due to leprosy. The metaphorical cascade of seemingly inevitable destruction can be prevented, but a simplistic approach is inappropriate. Self-care, demands very much more than the formal transfer of knowledge and simple skills from a health worker with a tick list. Self-care, is perhaps primarily dependent on the potency of an individual's self esteem. What STEP has shown, is that access to self esteem can be found when people are empowered to focus their energy to effect positive developments, that enhance the lives of others.

Considering that 85% of the general population would expected to be free from significant levels of participation restriction, it was remarkable that 93% of people in the STEP groups were also free from 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. Whether STEP will have had a significant long term effect on the communities where it was enacted, remains to be seen.

When reflecting on the findings in this paper, it should be considered that the initiatives had been instigated by people who were all affected by leprosy. Three years earlier, they were mostly illiterate, physically impaired, stigmatised and marginalised. Given their initial disadvantaged status, their achievements can be considered remarkable.

*Box 002, Mail and More, Passeo Marina,
Second Floor, Ayala Centre,
Ayala Business Park, Cebu 6000.
The Philippines
email: hacross@pldtdsl.net

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

REFERENCES

(1) World Health Organisation. ***Ottawa Charter for Health Promotion.*** 1986. Geneva, WHO. Ref Type: Report

(2) World Health Organisation. ***International Classification of Function, Disabilty and Health.*** Geneva: WHO, 2001.

(3) Health Related Stigma: ***Rethinking Concepts and Interventions.: Background Paper: Research Workshop on Health-Related Stigma and Discrimination Royal Tropical Institute (KIT),*** Amsterdam 29 November - 2 December 2004, 2004.

(4) Valencia L B. ***Social Science Research on Social Dimensions of Leprosy: Where are we going from here?*** International Journal of Leprosy 1989; 57(4):847-863.

(5) Heijnders ML. ***The dynamics of stigma in leprosy.*** Int J Lepr Other Mycobact Dis 2004; 72(4):437-447.

(6) Heijnders ML. ***An exploration of the views of people with leprosy in Nepal concerning the quality of leprosy services and their impact on adherence behaviour.*** Lepr Rev 2004; 75(4):338-347.

(7) Hyland J. ***Leprosy and social exclusion in Nepal: the continuing conflict between medical and socio-cultural beliefs and practices.*** In: J Hubert, editor. Madness, Disability and Social Exclusion. London: Routledge, 2000: 168-179.

(8) Waxler N E. ***Learning to be a leper: a case study in the social construction of illness.*** In: Mishler E G, editor. Social Contexts of Health, Illness and Patient Care. Cambridge: Cambridge University Press, 1981.

(9) Berreman JM. ***Childhood leprosy and social response in south India.*** Soc Sci Med 1984; 19(8):853-865.

(10) Laverack G, Wallerstein N. ***Measuring community empowerment: a fresh look at organizational domains.*** Health Promot Int 2001; 16(2):179-185.

(11) Purdey AF, Adhikari GB, Robinson SA, Cox PW. ***Participatory health development in rural Nepal: clarifying the process of community empowerment.*** Health Educ Q 1994; 21(3):329-343.

(12) Williamson J. ***Practical Community Empowerment: Concepts, Organizational Issues and the Process.*** 2000. Menonite Central Committee. Ref Type: Pamphlet

(13) Maslow AH. ***Motivation and personality.*** 2 ed. New York: Harper and Row, 1970.

(14) Cross H, Newcombe L. ***An intensive self care training programme reduces admissions for the treatment of plantar ulcers.*** Lepr Rev 2001; 72(3):276-284.

(15) Cross H. ***Consensus methods: a bridge between clinical reasoning and clinical research?*** Int J Lepr 2005; 73(1):28-32.

J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd