

A study of the linkage of poverty alleviation with self-care in South Central Nepal

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Accepted for publication 29 June 2017

Summary

Background: RECLAIM CDR was an empowerment project implemented by the Nepal Leprosy Trust (NLT) in four districts of Nepal. It ran from 2011 to 2016. The RECLAIM methodology reflected that of an earlier STigma Elimination Project that was implemented under the title of “STEP”. What follows in this paper are the salient findings of an independent evaluation of RECLAIM that took place in April 2016.

Objectives: The main objective of RECLAIM CDR was to ascertain the extent to which the STEP methodology might impact on poverty alleviation.

Method: Quantitative data relating to: impairment status, participation, self-efficacy, and relative poverty was analysed. Qualitative methods were also used for triangulation and to gain perspective.

Results:

- 50 of the self-care groups (SCG) that were established progressed to become self-help groups (SHG) with a total membership of 866 people.
- The median score on the Grameen Progress out of Poverty Index (PPI) rose from 27 to 38.
- There was an improvement in levels of social participation with 44% of beneficiaries reporting “no restriction”.
- “Eye Hand and Foot” scores suggested that 68% of leprosy affected SHG members neither experienced improvement or deterioration in impairment status.
- The median self-efficacy score rose from 20 to 29.
- 47 of the 50 SHGs had organized and managed a variety of activities that demonstrated commitment to social responsibility.

Conclusion: The outcomes of the project suggest that self-care, as applied by groups of people affected by leprosy does enhance perceived self-efficacy and that the energy generated by such perceptions leads to more productive and fruitful lives generally.

The study was undertaken at Lalgadh Leprosy Hospital and Services Centre, Janakpur, Nepal.

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Limitations

This is a study of a field implemented project and lacks, therefore, the scientific rigour that would be a feature of an experimental trial. The various assessments that were conducted were carried out by trained field workers, but no inter-rater procedures were followed to establish the reliability of data. Wherever possible, validation of data was sought through triangulation with verbal contributions from SHG members and local government officials.

Introduction

RECLAIM CDR is an acronym for Releasing the Energy and Capability of Leprosy Affected Individuals and other Marginalised people. It was a project implemented by NLT in four districts of the Central Development Region of Nepal - hence the suffix "CDR". The suffix serves to differentiate the RECLAIM project implemented by NLT from a near duplication of the methodology implemented by Nepal Leprosy Fellowship in the Eastern Region of Nepal. That project was implemented under the title RECLAIM EDR. The RECLAIM methodology was essentially a replication of an earlier project that was implemented by NLT under the title of STEP (an acronym for "Stigma Elimination Project"). The focus of RECLAIM, however, was not stigma reduction, but poverty alleviation.

The essentials of the STEP method that were replicated in RECLAIM were as follows:

- People who were impaired by leprosy but were known to adhere to self-care advice were identified by NLT staff. On further assessment, those who were found to have positive attitudes and who demonstrated empathy and problem solving skills were offered an opportunity to be trained as self-care group facilitators. (Further than prevention of disability, training also emphasised empowerment principles, rights and responsibilities.)
- As trained facilitators they were encouraged to return to their communities where they might establish SCGs. The identification of and approach to other people affected by leprosy was left to the facilitators. (Facilitators received a modest stipend for their activities).
- The logistics of SCG meetings (frequency, time and place) was decided by the group members.
- Monitoring of group self-care practice and general group dynamics was undertaken by personnel from the Community Development Department (CDD) of Lalgadh Leprosy Hospital and Leprosy Services Centre (LLHLSC).
- When the CDD staff responsible for monitoring a self-care group made an assessment that a group was functioning successfully and that people were beginning to report positive outcomes of self-care, that group was encouraged to develop savings and loan facilities. At that juncture self-care groups were also encouraged to register as self-help groups.
- Engagement between the self-help groups and the communities in which they were established was encouraged, but was not compulsory. Ideas for "civic responsibility" projects were generated by the self-help groups themselves.

A conclusion drawn from STEP in 2006 was that the empowerment approach adopted was an effective method for reducing the effects of leprosy stigma (this was based on an assumption that improvement in social participation was a valid proxy for stigma reduction). The

approach also appeared to have a positive effect on the adherence to self-care practice which, it had been suggested, explained the good results that had been recorded for impairment status. Members of SHGs had also demonstrated commitment to numerous civic responsibilities through which they had enjoyed an elevation of status in their communities.^{1,2} The project, however, did not include any assessment of the effects on poverty that the empowerment approach might have. The Nepal Leprosy Trust (NLT) decided to attempt to address that shortcoming through the implementation of RECLAIM CDR (Central Development Region). RECLAIM was essentially a scaled-up replication of STEP, but the primary outcome of interest was poverty alleviation (it was assumed that other beneficial effects, that had been outcomes of STEP, would also feature with RECLAIM).

It is widely agreed that poverty is multidimensional, but there does not appear to be a consensus on how it should be measured. In the context of RECLAIM, poverty was defined by the following dimensions: being asset poor relative to others; being restricted in the participation of social activities; being unable to control disabling impairments and having a low conviction that individuals could cope with personal challenges.

MEASURING RELATIVE POVERTY

An instrument that has been developed to measure relative poverty is the Grameen Progress out of Poverty Index (PPI).³ It comprises a set of 10 simple questions that can be answered by a competent household member. The questions all relate directly to observable household characteristics. The answers to the questions are scored and the score then indicates the likelihood that the household is functioning below the national poverty line. The score can also be used to determine the household's likelihood of falling below any one of a range of other internationally recognised poverty lines.

Desiere *et al.* conducted a validity assessment of the PPI and concluded that "*the PPI does a remarkable job in estimating poverty levels*" and that it can be considered a SMART indicator even though they did express some reservation regarding the "Relevance" component within the SMART framework. In the context in which they conducted the assessment, they showed that whilst it accurately distinguished poor from non-poor households (making it a useful reporting tool) its sensitivity to changes in poverty status was limited; this, they suggested, could restrict its usefulness for evaluating the impact of development projects in some countries.⁴

MEASURING SOCIAL EXCLUSION

Restriction in the participation of social activities can be measured on the Participation Scale (P Scale). The scale was developed by van Brakel *et al.* who also presented evidence to show that a P Scale score is a reliable and valid indicator of the extent of social exclusion experienced by people affected by leprosy.⁵ The properties of the P scale have since been examined by other researchers. (Carlijn *et al.*,⁶ Peters RM⁷). A study which was particularly relevant to RECLAIM was that undertaken by Stevelink *et al.* who showed that the psychometric properties of P Scale were valid in the cultural context of Eastern Nepal.⁸ The P Scale has been used by numerous researchers and practitioners and has become a standard indicator in many programmes.

MEASURING LEPROSY RELATED IMPAIRMENTS

The Eye, Hand and Foot score (EHF) has come into common usage as a method to measure leprosy-related impairments. The reliability of this simple instrument, based on the WHO three point grading system, was established by Brandsma and van Brakel in 2003.⁹ There are, however, issues related to the definitions of impairments that commonly cause confusion among health workers and can lead to incorrect classification. In an attempt to reduce that confusion a Delphi exercise was undertaken by Cross *et al.*¹⁰ They presented a consensus on operational definitions and an accompanying set of guidelines to which health workers can refer so that common impairments might not be misclassified.

MEASURING SELF-EFFICACY

Perceived self-efficacy is an expression of optimism regarding an individual's sense of personal competence. It appears to be a pervasive phenomenon which finds support as a factor that explains the motivation some people have to achieve ambitious goals. Schwarzer and Jerusalem suggested that self-efficacy determined whether people believed that they could perform challenging tasks, or the extent to which they could cope with adverse situations. Perceived self-efficacy, they suggested, facilitates goal-setting, effort investment, persistence in face of barriers and recovery from setbacks. The General Self-efficacy scale which they developed has been adapted to 31 languages.¹¹ Scholz *et al.* studied the psychometric properties of the instrument through an examination of findings relating to 19,120 participants from 25 countries. Their hypothesis was that the General Self-efficacy scale could be configured across cultures equivalently. Their findings supported that hypothesis and confirmed the universality of the underlying construct.¹²

Materials and Method

A mixed method was designed in which a combination of quantitative and qualitative techniques was used to describe and analyse the outcomes of the project.

Descriptive data relating to all 866 members were used to compile the demographic profile of the project population.

A complete set of quantitative data for each individual comprised scores on all of the following: Grameen Progress out of Poverty Index (PPI), Participation Scale (P Scale), Self-efficacy Scale, and Eye-hand-foot Impairment (EHF was only used for people affected by leprosy). Complete sets of quantitative data recorded at baseline and at final evaluation were available for 495 SHG members. ("Baseline" in this context refers to data that was recorded when individuals became group members.)

Qualitative, participatory methods were used to gain deeper insight on the impact of the project, and for the purpose of triangulating quantitative data. Methods used included the following:

- *Drama*: At their meetings SHG members were asked to participate in either a drama or drawing exercise to express what they liked best or what they do not like at all, in relation to their groups. All groups and members chose drama. The members were divided into 2–3 teams and each team was asked to enact their impressions of RECLAIM outcomes.

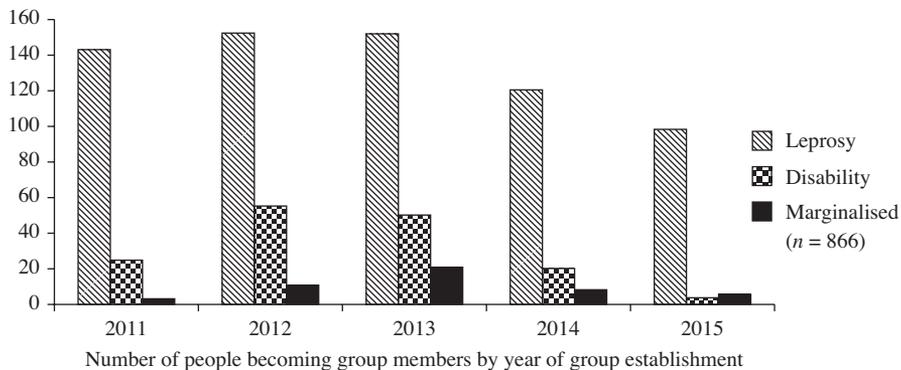


Figure 1. Self-Help Groups: Types of Members.

- ‘What we like most’: Four sheets of paper were presented on each of which was one of four drawings depicting self-care, social participation, community development activities and income generating projects. Participants were requested to form a circle and the four sheets were placed on the floor in the middle of the circle. Each member received four tokens and all were asked to distribute the tokens on whichever picture(s) represented aspects of the group’s achievement that was of greatest value to each individual. Participants could choose to put all four chips on one sheet, distribute them evenly, or in any other manner. People affected by leprosy, disabled and marginalised people received chips of different colours so that preferences of members with non-leprosy related disability and/or marginalised members could be tracked (it seemed reasonable to assume that only leprosy-affected members might value self-care).
- Group discussions: At a routine facilitator meeting the 50 SHG facilitators were divided into five groups and asked to discuss and report group feedback on questions that had been prepared for them.

Key informants included members of six SHGs and all 50 SHG facilitators. Verification was also sought from local government officials. SHGs were selected to represent a broad spectrum of differences. Selection was based on the following criteria:

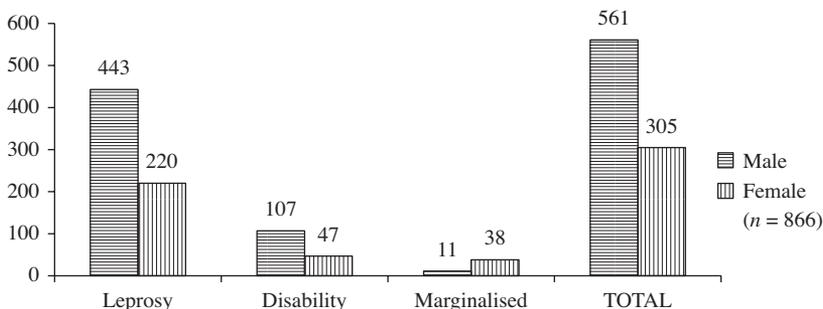


Figure 2. Gender Distribution by SHG Type of Member.

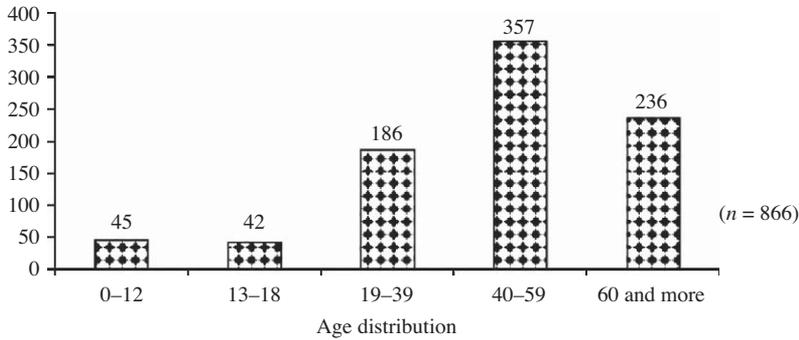


Figure 3. Self-Help Group: Age Distribution.

- Different start years over which groups were established
- Different districts
- Different levels of strength
- Reasonably accessible for an investigator to visit

All 50 SHG facilitators attended a feedback meeting at Lalgadh Leprosy Hospital and Leprosy Services Centre.

Results

Between 2011 and 2015, 50 self-care cells had developed to become self-help groups with a total membership of 866 people. Each group comprised people affected by leprosy, people with non-leprosy related disability and people who were marginalised in their communities (primarily abandoned or widowed women). Please see Figures 1, 2 and 3.

Progress out of Poverty

At baseline the median Grameen Progress out of Poverty Index (PPI) was 27; that score indicated a 75% likelihood that that households reporting the median score were living below a \$1.25/day poverty line (based on Purchasing Power Parity (PPP) in 2005). People with PPI scores lower than 27 were almost certain to fall below that line.

Table 1. Distribution of PPI Scores

	n*	Minimum	25%	Median	75%	Max
Baseline	482	0	16	27	38	90
End evaluation	482	0	26	38	50	90

(*of 495 data entries 7 were invalid)

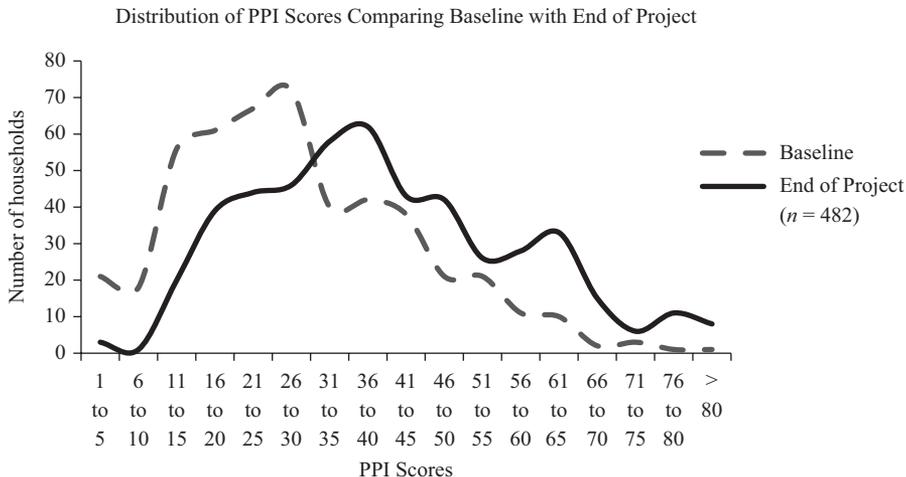


Figure 4. The distribution of PPI scores Comparing baseline with End of Project (n = 482).

By the End of Project the median PPI had risen to 38; a score which indicated that the likelihood that households reporting the median were living below the \$1.25 /day poverty line had dropped from 75% to 47%. On comparing Baseline with End of Project PPI Scores the improvement was significant (Mann-Whitney U Test, Z-Score = 10.0121, $P < .05$).

The shift toward greater asset prosperity that the population reported generally is illustrated in Table 1 and Figure 4.

Social Restriction

Group members who were willing to respond could choose whether to respond to the Nepali or the Hindi versions of the P Scale. Responses from 482 people were analysed. Please see Figure 5 and Table 2 for results.

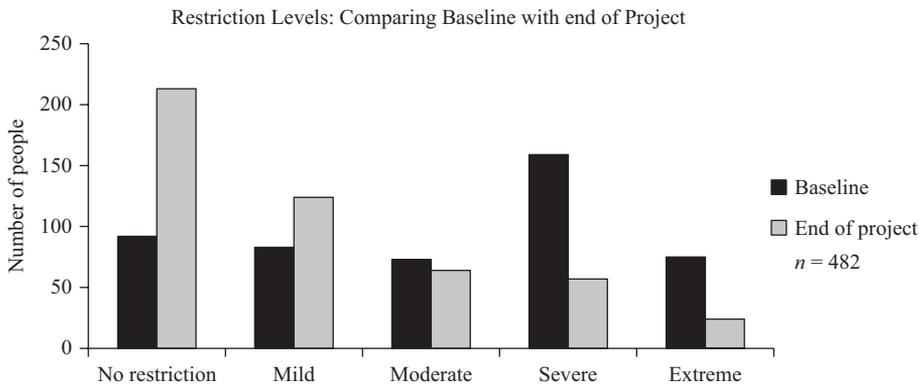


Figure 5. Shift in levels of social restriction.

Table 2. Distribution of P Scale Scores

	<i>n</i> *	Minimum	25%	Median	75%	Max
Baseline	482	0	17	31	46	90
End evaluation	482	0	2	16	26	90

(* of 495 data entries 13 were invalid.)

Mann-Whitney "U" Test, Z score = 10.8432, $P < 0.05$.

Impairment Control

The physical effects of self-care were measured on Eye Hand and Foot scores, the assumption being that if self-care was being applied adequately, scores would not worsen and that they might improve (most WHO Grade 2 impairments are irreversible whilst some, e.g. wounds, might heal).

EHF scores had been recorded for all group members who were affected by leprosy including those who did not have apparent impairment on joining groups. People affected by leprosy who did not have physical impairments, but were offered group membership included people who were considered particularly vulnerable, i.e. people with a history of reactions and people known to be marginalised due to the stigma of leprosy. Of those affected by leprosy who did not have any apparent physical impairment at baseline ($n = 101$), three people did proceed to present with impairment at the end of the project. Further analysis of impairment here, however, is restricted to people who did present with measurable physical impairment at baseline ($n = 272$). Please see Table 3 for results.

The impairment status of the majority (68%) of people who presented with measurable impairment at baseline had neither improved nor worsened when group members were assessed at the end of the project.

SELF-EFFICACY

A Hindi version of The General Self-Efficacy Scale was used. It comprises questions which probe an individual's perception of their own level of self-efficacy. Respondents ($n = 476$) were asked to rate their responses to each question on a scale of 1 to 4: 1 = Not at all true 2 = Hardly true 3 = Moderately true 4 = Exactly true. With 10 questions, the lowest score possible was 10 and the highest score possible was 40 (Please see Table 4 for results).

363 people reported higher self-efficacy; 90 reported no difference and 29 reported lower self-efficacy.

Table 3. EHF Scores ($n = 272$)

EHF scores did not change	EHF scores improved	EHF scores worsened
185	76	11

The difference in the sample attributed to "improvement" was significant (Kruskal Wallis Test, $\chi^2 = 10.352$, $P = 0.0013$), but the difference attributed to worsening was not (Kruskal Wallis Test, $\chi^2 = 0.169$, $P = 0.68$)

Table 4. Self-Efficacy Score

	<i>n</i> *	Minimum	25%	Median	75%	Max
Baseline	476	10	14	20	26	40
End evaluation	476	10	22	29	33	40

(* of 495 data entries 19 were invalid)
 Mann-Whitney “U” Test, Z score = 12.1692, *P* < 0.05.

SOCIAL PARTICIPATION

Reports from the field had shown that of the 50 SHGs groups 47 reported that they had organised and implemented at least one activity aimed to enhance community life. A list of such activities included:

- building multi-purpose meeting houses
- installation of dustbins
- feasts prepared and served by SHG members to which community members were invited
- village clean-up programmes
- tree plantation
- installation of hand water pumps
- installation of low-cost toilets
- road repairs
- organising and overseeing non-formal education classes
- organising street drama (a method for delivering health messages)

All the groups reported that they were active in at least one activity that enhanced the Department of Health leprosy control programme. Reports revealed the following:

- 285 people had been sent to the health posts by group members for further examination.
- 122 of the 285 people suspected as presenting with leprosy were confirmed as leprosy cases at local health posts.

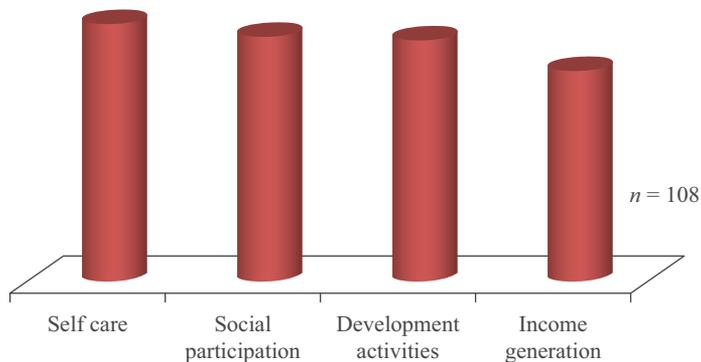


Figure 6. Rank order of regard for SHG activities (types of members combined).

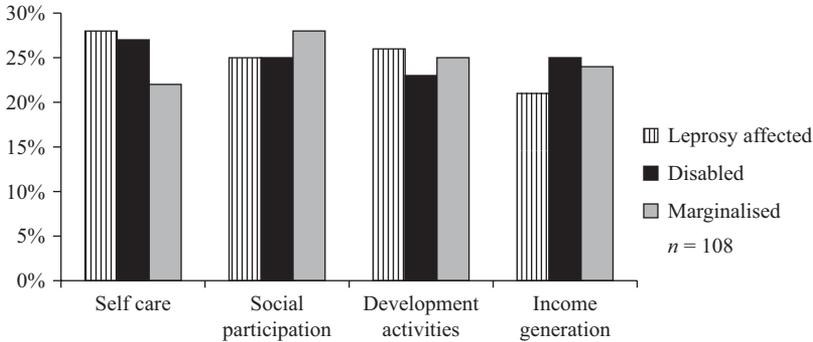


Figure 7. Rank order of regard for SHG activities by types of members.

- 2 people affected by leprosy who had technically defaulted had been counselled by group members to re-start MDT treatment. There were also reports that others who were irregular consumers of MDT had been encouraged to adhere to treatment more diligently.
- Most groups routinely approach the health posts in their area and ask for lists of newly diagnosed leprosy patients. Such people were visited to provide counselling and self-care information, some were also invited to join groups.

Following open discussion SHG members were asked what they liked most or was most important to them about their groups. They were then asked to rank five categories which encapsulated their responses: Self-care, Social participation, Community development activities and Income generating projects (See ‘Methodology’).

Scores from each contributing SHG were summated and the following outcomes were revealed:

- regard for each element was almost evenly distributed,
- regard for self-care was ranked the highest, followed, in rank order, by social participation, development activities and income generation.
- Even the disabled and marginalised members accorded self-care high ranking.

(Please see Figures 6 and 7)

Discussion

Poverty has come to be defined in either relative or absolute terms. “Absolute poverty” describes a situation that prevails when people do not have sufficient money or resources to meet basic needs: food, clothing, and shelter. Relative poverty is a term that reflects the economic status of members of society relative to each other: people are poor if they fall below prevailing standards of living in a given societal context. Both concepts, however, fail to recognise that survival is not solely dependent on access to, or ownership of, material possessions, but that it is also dependent on people’s ability to satisfy the psychological, social and cultural needs that make life meaningful.

Based on the findings presented above we suggest that the lives of RECLAIM CDR group members were generally enriched by participation in the project. We also postulate that it was primarily impairment control, through self-care, that lead to life enrichment. We offer the explanation that if people are able to discover that they can control the secondary effects of leprosy, the perceived self-efficacy that such achievement stimulates is empowering. This suggestion is supported by the findings of Locke and Latham (cited by Shwarzer and Fuchs) who ascertained that people with high levels of self-efficacy choose to perform more challenging tasks and that, not only do such people set themselves higher goals, but they also persevere with them. Schwarzer and Fuchs emphasised that self-efficacy leads to behaviour that is venturesome yet confined to the reach of an individual's capabilities; it does not lead to unreasonable risk taking. Unlike positive illusions or unrealistic optimism, self-efficacy is based on actual experience; it is an outcome of a progression through a course of increasingly ambitious objectives that may start with a relatively modest goal.¹³

We suggest that in the socio-cultural context in which RECLAIM CDR was implemented venturesome behaviour was expressed in the acts of social responsibility that were performed by members of the SHGs. We also suggest that engagement in such activities was enriching because it won the high regard of local people and opened opportunities for greater participation in community life. With social acceptance, opportunities and prospects for income generation projects were also improved. (These suggestions had been verified through statements made by SHG participants and through comments made by local government officials.)

Another important factor that contributed to life enrichment was group identity and solidarity. This was illustrated in a profound manner when group members who were not affected by leprosy still ranked self-care as the most important function of their group. They did not need to apply themselves to self-care, but they appeared to recognise the importance of self-care for the cohesion and continuity of their groups.

Benefits from being associated with a successful SHG appear to be universal and are not culture specific. Benbow recorded that successful self-care groups in Ethiopia reported that belonging to a self-care group increased their confidence to participate in society. Membership also affected the restoration of dignity, self-respect and a sense of belonging within their community.¹⁴ Members of Swedish self-help groups that Adamsen studied comprised people with life threatening diseases, yet they reported that being a group member presented opportunities for the reconstruction of self-confidence and self-esteem which, they considered to be fundamental for the establishment of the mental strength needed for them to gain acceptance in society.¹⁵ In a study of self-care groups in Mozambique, Deepak *et al.* reported that groups had chosen names that expressed powerful identities with one group explaining that a powerful group name '*encourages its members to face the difficult situations of their lives.*'¹⁶

Conclusion

In the RECLAIM CDR project, relative poverty, social restriction, low self-efficacy and poor impairment control were all deemed to be components of the compound challenge that is poverty. The effectiveness of the RECLAIM approach to alleviate poverty, defined in those terms, was assessed by examining each variable independently. Since the values of each variable were found to have improved significantly, we suggest the hypothesis that

RECLAIM would have a multidimensional impact on poverty was supported. We submit, furthermore, that the assessment findings also support a secondary hypothesis, namely, that people who could be shown to exert greater control over adverse physical and social aspects of life were likely to value opportunities to contribute to the development of their communities.

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