

An intensive self care training programme reduces admissions for the treatment of plantar ulcers

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Summary This paper describes, in detail, an intensive 14 day Self Care Training Programme that is conducted at Lalgadh Leprosy Services Centre in Nepal. An evaluation of the programme was undertaken in which hospital admission for infected plantar ulceration was the outcome measure. It was found that those who had undertaken the programme were less likely to have been admitted for hospital treatment in a 3-month follow-up period ($\chi^2 = 5.1$, $P = 0.02$). An odds ratio of 1:1.8 (95% CI = 0.15–0.01) was also calculated. This paper presents an overview of the issues related to impairment, a description of the Self Care Training Programme, an analysis of the evaluation results and a discussion of the findings.

Introduction

It was Waxler's¹ contention that the tragedy of leprosy has little to do with the bacillus *per se*. In her opinion the patient's experience of the disease is profoundly affected by the social beliefs and expectations of the society in which the individual participates. For similar reasons, Valencia² cautioned that conventional models should not be used to assess the affects of leprosy, because it is not simply a physiological dysfunction: it is a complex psycho-social phenomenon with profound consequences for the affected person, his/her family and the community. According to Parsonian theory, it is in the course of social interaction that values and rules are constructed. He suggested that in all societies there are pre-existing cultural systems of ideas that are used to construct and modify the labels that direct societal behaviour towards those affected by disease.³

In the Indian subcontinent, the term '*Illness of Untouchability*', as coined by Berreman,⁴ is apt because it resonates with cultural meaning that helps to define the social effects of the disease. In his study of leprosy in the Chingleput district of Tamil Nadu, Rao⁵ stated that, '*The general perception of leprosy within a community is confined to conditions associated with deformity*'. (This observation is repeated with emphasis throughout the literature.) Rao demonstrated that 81% of respondents in his survey did not recognize that hypopigmented patches or nodules were a symptom of leprosy. However, 89.6% of the same group associated leprosy with deformity or ulceration.

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Clearly the chronic nature of the disease, with its potential to inflict gross deformity, is traumatic primarily for the patient but also for his/her social environment. In the Indian subcontinent there is no strong concept of 'self'. It is the corporate need of the body of the family (closely followed by the need of the community) that is significant rather than the individual in isolation. Accordingly, when individuals are denied a role in the family and community their lives are perceived as essentially meaningless.^{6,7}

For the reasons suggested above, it is essential that every effort is made to limit the extent to which secondary complications of leprosy extend to cause deformity, limitation of activity and restrictions in social participation. The principal agent in the control of his or her illness will be the affected person him/herself, which is why every effort must be made to empower the affected person adequately for the challenge. Self care has been the mainstay of prevention of disability for many years. Watson⁸ has vigorously promoted the concept and has striven to encourage programmes to emphasize the necessity for teaching pragmatic methods of self care.

Ethiraj *et al.*⁹ conducted a study of the effects of community based self care. They compared the affects of community education on one group of people affected by leprosy, and individualized input from trained field staff on another group. They reported that self care behaviour in both groups was better than a control group that received no input. Mathew *et al.*¹⁰ reported that the prevalence of simple ulcers was reduced by 50% after intervention from trained field staff who taught home based self care procedures to people impaired by leprosy.

Kemper *et al.*¹¹ conducted a comprehensive review of self care interventions. Their focus was primarily on self-initiated responses to symptoms of acute illness and as such, their results were not appropriate for comparison with this study. However, they did review papers that focussed on self care education programmes (primarily educated communities in America) and in summarizing their findings they concluded that, generally, research had indicated the effectiveness of self care education as a means to reduce health care utilization. They also emphasized the consistent reporting that self care had not resulted in dangerous practices.

The Lalgadh Self Care Training Centre

A recent innovation at the Lalgadh Leprosy Services Centre (a project of Nepal Leprosy Trust) has been the development of the Self Care Training Centre (SCTC). The centre provides an environment, separate from the medical services, which focuses on prevention of impairment and disability and enhancement of social participation. This is accomplished through imparting effective self care strategies and social skills within a quasi-educational rather than a medical environment.

GENERAL AIMS

The responsibility for the management/prevention of impairment and disability and the empowerment of the individual to act within his/her society will be shifted from the health professional to the individual. In this way, dependency effects will be reduced and individual control will be strengthened.

SPECIFIC AIMS

1. To establish and reinforce essential measures of self care for people impaired by leprosy.
2. To enable people impaired by leprosy to self monitor changes in nerve function.
3. To enable people impaired by leprosy to recognize other indications for self referral (e.g. renewal of footwear and appliances).
4. To enable people impaired by leprosy to conduct activities of daily living effectively and independently.
5. To empower people psychologically for the challenges of living in a potentially hostile environment.

HUMAN RESOURCES

The SCTC Facilitator has responsibility for demonstration and advice on all self care activities related to the prevention/management of impairments. He identifies special needs and directs accordingly. He also leads group discussions, undertakes an active role in training of social skills and counselling. He is aided by two full-time assistants.

A major emphasis in the self care programme is safe methods of daily labour. For this purpose land has been made available within the Lalgadh Hospital compound for the purpose of small scale farming activities. A sound understanding of the common causes of secondary impairments enables the facilitator to advise trainees in methods to adapt implements and/or adjust methods of work. Buffalo husbandry is also conducted. Apart from the obvious focus on self care the farming activities also evoke familiarity. This has been a deliberate move to enable people to associate self care procedures with normal activities of daily living.

The initial assessment of people who fulfil the criteria for entry to the SCTC is conducted in the Outpatients Department at Lalgadh Hospital and through other contact situations. The ward manager of the Inpatients Department (IPD) also identifies people who fulfil the criteria for transfer to the SCTC. Candidates from the IPD are recommended to the facilitator who assesses the person and decides whether he or she should be offered a place in the SCTC.

MATERIAL RESOURCES

Dormitories

A purpose built Centre was constructed. The Centre can accommodate 24 persons in two dormitories (one female and one male). The Centre also comprises a multipurpose room for teaching/discussion purposes. To reduce the semblance of a hospital, the interior decoration of the accommodation dormitories was painted with a wash that resembles the colour of village dwellings. Simple bamboo and webbing beds have been provided.

Kitchen

A building was converted to resemble a typical village kitchen (dung and clay walls and floors, clay ovens and storage facilities). Village cooking equipment and other utensils have been provided. Cooking is undertaken by participants, thereby providing an essential learning environment, particularly for women.

SCTC PARTICIPANTS

Entry criteria

Those considered for participation in the programme are:

1. People newly diagnosed with leprosy who present with anaesthetic hands and/or feet and/or muscle paresis or paralysis.
2. People being treated or released from treatment presenting with early signs of deformity or ulceration.
3. People under 55 years of age (unless they show an unusual degree of motivation).
4. People at high risk of type 1 or type 2 reaction.
5. People for whom prednisolone treatment has been prescribed.
6. People showing signs of depression.

Particular effort is made to persuade women to participate because in the socio-cultural context of the study, women are traditionally discriminated against and are therefore considered by the authors to be more vulnerable. Where possible, spouses are also encouraged to enter the programme and to participate in it.

Participation

During a 14-day stay, trainees are expected to participate in an organized programme. The programme rotates continuously so that people enrolling at any stage in the 14-day programme will still benefit from the full programme (details of the programme are given in the Appendix).

On concluding the programme, participants are asked to complete a post-training assessment. On departure, they are presented with a certificate of participation and a gift which includes a small mirror, a comb and a 1 m² sheet of polythene (polythene sheeting is used to line holes made in the ground for foot soaking).

Materials and methods

STUDY GROUP

Subjects for the study group were obtained by analysing records from the SCTC. All trainees who had completed the 14-day intensive training programme between July 1998 and July 1999 were selected. A requirement was that all subjects met the inclusion criteria of the SCTC as previously outlined. The study group comprised 254 trainees (66 females and 188 males). The female to male ratio (1:2·8) closely reflected the ratio of registered cases at LLSC at that time (1:2·6). Mean age of the group was 35 years.

CONTROL GROUP

Hospital main files were checked for exclusion criteria for the control group, i.e. patients who had been transferred out, those who had been in the SCTC and defaulters. Remaining files were checked and all patients with impairments who would have been eligible for the SCTC but who did not enter the programme between July 1998 and July 1999 were selected. From these, 254 files (75 females and 179 males) were randomly selected to form the control group. The mean age of the group was 39 years.

FOOT IMPAIRMENTS

A further selection was then performed: all files were checked to determine the number of subjects with foot impairment in each group. In the study group, 192 subjects had foot impairment, whilst in the control group, 206 subjects had foot impairment. Further analysis was undertaken using data describing these sub-groups.

The outcome considered was whether or not subjects had been admitted for the treatment of complicated, infected ulceration within a period from July 1998 to October 1999. (Three months beyond the closing date for inclusion into the study was given to allow for possible hospitalization of people who had participated in the programme at the end of the review period.)

DATA ANALYSIS

Hypothesis

People who did not undergo training in the SCTC were more likely to have been admitted for hospital treatment of complicated infected ulcers than people who had undertaken the SCTC programme.

Null hypothesis

There will be no difference in the number of admissions for the treatment of complicated infected ulcers between people who had undertaken the SCTC programme and others who had not.

Results

No significant differences were found between the study and control group when compared on leprosy status and gender, however, a statistical difference was found between groups on age ($P = 0.006$) (Tables 1, 2 and 3).

The number of subjects in the study group with foot impairments totalled 192 (76%), and of this group, 24 had been admitted to hospital for treatment of a complicated foot ulcer. In the control group, 206 (81%) of subjects had foot impairment, and of this group, 43 had been admitted to hospital for treatment of a complicated foot ulcer.

When compared on admissions, the groups were found to be significantly different

Table 1. Comparison between groups on leprosy status. There were no significant differences between groups

	Care after cure	Registered patients	Total
Study	71	121	192
Control	77	129	206
Total	148	250	398

Table 2. Comparison between groups on gender. There were no significant differences between groups

	Male	Female	Total
Study	141	51	192
Control	142	64	206
Total	283	115	398

(Table 4). However, because of the difference in age distributions among the groups the groups were further broken down and an age-wise comparison was made.

Only one person in the Control group under 21 years had been admitted and four people in the same age group from the Study group had been admitted. Further comparison therefore was restricted to those over the age of 20 years (Study group, $n = 171$, Control Group, $n = 199$).

With the difference between the Study and Control groups still being significant, we suggest that the findings were therefore not biased by the age differences between the two groups (Table 5).

ODDS RATIO (OR)

An OR of 1.8 (95% CI = 0.15–0.01) was calculated. This suggests that people with impaired feet who did not undergo training in the SCTC were nearly twice as likely to be admitted for treatment of a complicated ulcer than people who did participate in the programme.

On the evidence cited above, we reject the null hypothesis of no difference and suggest therefore that the SCTC programme at Lalgadh Leprosy Services Centre (LLSC) may have a significant effect in reducing admissions for the treatment of infected complicated ulcers among people with foot impairments.

Discussion

The prevention of plantar ulceration is not the only reason for including people in the self care training programme. We therefore accept that it is only a partial measure of efficacy. However, our contention is that the necessity to admit people for hospital treatment is partly an effect of the dominant causal and recovery belief system that influences an individual's

Table 3. Comparison between groups on age

	<21 years	>20 years	Total
Study	21	171	192
Control	7	199	206
Total	28	370	398

$$\chi^2 = 7.5, P = 0.006.$$

Table 4. Comparison between groups: hospital admissions for complicated plantar ulcers

	Yes	No	Total
Study	24	168	192
Control	43	163	206
Total	67	331	398

$$\chi^2 = 4.4, P = 0.03.$$

self care behaviour. We suggest that ulcer prevention indicates more than skill or knowledge; it also indicates attitude and self-esteem.¹²

Although established guidelines and recommendations⁸ had been implemented at LLSC, it was found that almost 20% of all people who were registered with foot impairments were being admitted for the treatment of infected plantar ulceration (many of these will have multiple admissions). Apart from the scale of medical and technical interventions that this patient load demands, the dilemmas of dependency and debilitation are also recognized as problems. Although the follow-up period for this study was relatively short (3 months), it was demonstrated that of those who did participate in the SCTC programme only 12% were subsequently be admitted for treatment.

For demographic and resource reasons, it is unrealistic to aim at a clinician to client ratio that might be sufficient to ensure adequate control over the incidence of infected plantar ulceration. For this reason, the most significant agent to take responsibility for the prevention of secondary impairment is the client him/herself. The facilitation of essential skills and attitudes to accomplish this objective should therefore be given high priority. Care should be taken when setting such an objective not to be too ambitious. It should be accepted that not all who complete the programme will be motivated. Attitude is a very complex phenomenon that is affected by many variables.

The programme aims to bring impairment prevention and participatory skills to all aspects of the clients' lives. The potential benefits in terms of control, heightened self-esteem, and confidence that may result from the acquisition of knowledge and from affirmative interaction during the course has not been assessed. However, it is possible that the development of subsequent social skills may have a far more profound impact on the lives of those who complete the course than simply learning physical damage limitation skills.

The aims and objectives of the Self Care Training Centre being wide and varied have

Table 5. Comparison between groups: >20 years of age who had hospital admissions for complicated plantar ulcers

	Yes	No	Total
Study	22	149	171
Control	42	157	199
Total	64	306	370

$$\chi^2 = 5.1, P = 0.02.$$

stimulated a number of investigations that are currently in process. These studies are aimed to give further objective evidence to support or refute the hypothesis that the Self Care Training Programme enhances the quality of life of those participating in it. The effects of the programme on activity levels and social participation will hopefully also give insight into the association of impairment and ability. Sound science has established the validity of the Green Patures Activity Scale,¹¹ which has facilitated the collection of further relevant data. It would also be useful to conduct a gender analysis to ascertain the extent to which gender issues are affected by the programme.

In conclusion, the study has demonstrated that an intense period of self care training does appear to effect positive behaviour. The proportion of people admitted for treatment amongst those who underwent the SCTC Programme was significantly less than a control group. We recommend, therefore, that an intense period of training is an effective means by which clients can be enabled to take control over the effects of leprosy.

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Appendix

OBJECTIVES

1. On completion of the SCTC programme, participants will be:
 - a) Aware of essential self care procedures for their specific impairments.

- b) Able to identify and use appropriate materials and resources to effect adequate self care.
- c) Able to discuss the implications of self neglect.
- 2. On completion of the SCTC programme, participants will be:
 - a) Able to conduct and monitor basic sensory and voluntary muscle testing for hands and feet.
 - b) Able to conduct a basic eye examination.
 - c) Aware of indications for self referral for early neuritis.
 - d) Discuss the implications of failing to report changes.
- 3. On completion of the SCTC programme, participants will be:
 - a) Able to assess their footwear and hand or foot orthoses.
 - b) Able to discuss the implications of wearing unsuitable footwear/appliances.
- 4. On completion of the SCTC programme, participants will be:
 - a) Able to use assistive devices competently.
 - b) Able to suggest/identify appropriate alternatives/replacements.
- 5. On completion of the SCTC programme, participants will have:
 - a) A positive self image.
 - b) A desire to return to their home environment.

14-DAY PROGRAMME

Sunday to Thursday

6 a.m. to 8 a.m.	Soaking, oiling and scraping of feet and hands
8 a.m. to 9 a.m.	Cooking activities and breakfast
9 a.m. to 10 a.m.	Exercises
10 a.m. to 11 a.m.	Group discussion (from Monday to Thursday, a different impairment related problem is discussed. On Sunday, social issues are discussed).
11 a.m. to 12 noon	A different health related topic is presented each day, e.g. nutrition, vomiting and diarrhoea, family planning, personal hygiene
12 p.m. to 1 p.m.	Lunch
1 p.m. to 2 p.m.	Basic literacy (the objective is to teach participants how to write their own name)
2 p.m. to 4 p.m.	Farming or domestic skills
4 p.m.	Review of day's activities

Every Friday a social programme is planned to enable participants to develop and express normal socio-cultural skills.