

**THE EFFECTIVENESS OF SELF-CARE SUPPORT GROUPS
IN THE PREVENTION AND MANAGEMENT OF ULCER:
AN EVALUATION STUDY IN ETHIOPIA**

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ABSTRACT

A sixteen-item pre-tested structured interview was used to assess the attitude of self-care group members (n=61), involved in the self-care programme of All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (ALERT). An open-ended item for assessing the opinion of health personnel working in leprosy affiliated institutions and case-studies, was also used to collect data. Results showed that beneficiaries have a positive attitude towards the various aspects of the programme.

Health personnel also favoured the programme in many ways, despite their disappointment regarding the organisation and management of the programme. Analysis of coping efforts employed by the self-care group, revealed the importance of behavioural modification techniques, followed by the use of material sources as important strategies in the area of prevention of disability. Recommendations for future research and intervention are made, based on results obtained.

INTRODUCTION

A major issue in the treatment of leprosy, is the prevention and management of ulcers, particularly plantar ulcers (1). Plantar ulceration is a major complication of leprosy. Untreated simple ulcers will develop into complicated, chronic ulcers, resulting in bone infection and destruction, further impairment and even amputation, often with extended periods of hospitalisation (2). Even after completion of treatment, the 'care tradition' also continues through the provision of antiseptic, vaseline, bandages, wound trimming and dressing which has resulted in an increasing number of people becoming dependent on institutional based services and thereby, resulting in a big drain of resources (3).

In Ethiopia, in the course of multi-drug therapy (MDT) implementation, between 1983-1999, a total of 107,311 patients have been released from treatment as cured (4). This means, taking the average disability grade I and II (5) recorded among these people (that is 20%), other things being equal, about 21,462 released from treatment as cured, would require life-long care for the management and prevention of their ulcers. Moreover, given the current

incidence rate of leprosy in the country (0.75 per 10,000 population), about 4000 new patients are detected yearly, of whom, conservatively 18% (720) have some disabilities grade I and II. Many of these people would require the "usual" care for their ulcers, provided by the health workers from health institutions.

In response to this demand and due to the shift from bio-medical to the bio-psycho-social approach, a new line of thought emerged, as a tool to guide research and explain health related problems. The integration of behavioural and bio-medical knowledge, thus emphasised a patient's continuous contribution to his/her own existence, health and well-being. From an interactionist and developmental perspective, the patient or client is seen as one who is biologically and socially functional and primarily responsible for his/her health (6,7). Hence, active participation and contribution of individuals to maintain overall well-being, is highly encouraged as a health promotion activity.

The formation of support groups was found to be a useful coping strategy. Under such shared environment, where love, companionship and emotional bonding between the support group members are developed, collective action with regard to common health concerns is better achieved (8). Support groups cultivate individual and collective responsibility and maximum (efforts towards) striving for self-determined health activities (8,9). They also enhance the adoption of a wide variety of cognitive and behavioural efforts to manage internal and external demands, that tax resources at their disposal (9). Empirical studies elsewhere, have shown that the use and choice of health services is better understood and communicated, among self-care support group members (10).

It is in the light of this conceptual framework, that ALERT launched a self-care group programme, using a community based rehabilitation approach. In its unpublished material, the ALERT research team reported that, "a comparison of the foot ulcer situation at intake in two sub-groups (420 group members followed for six months and 173 followed for 28 months), against the situation in all 474 group members at intake, showed significant changes in terms of ulcer healing count: 'it was able to reduce their [members'] total number of ulcer count at intake, by almost 68%' (3).

An evaluation study was conducted on the cost-effectiveness and psychological changes brought about by the self-care programme, in the management and prevention of ulcers. The effectiveness of a health programme can be evaluated partly by the change it has brought about in the attitude (belief system) of the clients. A shift from the conventional approach that encourages dependency on an institution, to a self-care approach, and encourages the use of better coping mechanisms, is an aspect of the health programme evaluation. This paper attempts to answer the following questions:

- Has the self-care programme brought about any change in the attitude of clients in wound healing?
- Is there statistically significant attitudinal difference between the two settlement patterns?
- What coping mechanisms do clients employ, in order to alleviate their ulcer problem?

METHODS

Description of study area

The study was conducted in Shashemene and Wolkeite, that are semi-urban and rural areas respectively of Ethiopia, where the ALERT self-care programme had been actively engaged in promoting a pioneering leprosy control strategy. (As of January 1, 2001, the programme is being run by the respective regional TB/leprosy control programmes, integrated with the general health services).

The inhabitants of Shashemene are settled in nearby located villages, called "colonies". In Wolkeite, they live in scattered groups, integrated within the larger community. Therefore, this settlement pattern is assumed to bring about "attitudinal differences" in accepting a novel leprosy control Prevention of Disability (POD) strategy. The entire population in the two areas where the ALERT self-care leprosy programme is active, comprises 302 males and 177 females.

Sample

Nineteen in Shashemene, and nine in Wolkeite, self-care groups were functioning at the time of the study. Each group comprised of 9 - 13 members. Five out of nineteen, and four out of nine self-care support groups, were randomly selected. The attitudinal measurement interview was administered to 61 self-care group members who were available during their monthly session.

All 61 cases have been released from treatment for leprosy. Forty-seven of them, claimed to have taken dapsone (DDS), and to have been released from treatment before, or, at the start of MDT (1983) in their area. The remaining fourteen, had taken MDT ranging from periods between 6-24 months, and released thereafter. The sample population consisted of "cold cases", who were released from treatment for leprosy long ago, the minimum time being 13 years ago.

To rank their coping mechanisms in the order of merit, all 9 groups were presented with 5 strategies. The members in each group discussed the relative importance of the five coping strategies and put them in the order of merit, reached by a consensus.

Health personnel serving in leprosy affiliated organisations, were grouped into nine different strata, based on their profession. Twenty four respondents out of 51, were taken on a proportionate random sampling technique from ALERT, Shashemene TB/Leprosy unit, Shashemene Hospital, GLRA Medical Department and the Shashemene branch of the Ethiopian National Association of Ex-Leprosy Patients (ENAELP).

Data Collection

To achieve greater methodological validity, a mixture of qualitative and quantitative techniques of data gathering was used. The instrument used in this study has two parts that include the following sections: a measure of attitude towards self-care leprosy control programme and a measure of coping mechanisms used by self-care groups.

By incorporating ideas suggested by the programme holder and adopting attitudinal statements taken from current literature (6,11), sixteen items for surveying the attitude of self-care group members was prepared. The attitude measurement instrument included aspects like self-care programme efficiency, its contribution in bringing change in the belief system, the role of the support group in ameliorating ulcer problems and other related issues as perceived by respondents. The attitude schedule was also augmented by open-ended items to dig out additional information regarding problems, encountered since their establishment and suggestions concerning other socio-economic development programmes, that could go side-by-side with the health programme, meant to bring change in the living condition as perceived by the respondents.

To ensure validity, the schedules were thoroughly examined and commented upon by programme holders and by experts in the area, for content, item wording, choice of words and ambiguity, and pre-tested on randomly selected fifteen leprosy affected individuals, during April 5 -7, 2000. The items used in assessing the attitude of respondents had three choices i.e. 'agree', 'undecided', 'disagree', with weights three, two and one respectively. The statements were written in such a way, that reaction to the positives are weighted three, two and one and the negatives as one, two and three. These two kinds of statements were distributed alternatively. Statements phrased in such a way reduce response bias (12).

As a measure of reliability, Crombach's alpha was computed for the sixteen items. The computed reliability coefficient was found to be 0.952. This result is evidence for the internal consistency of the attitude measurement schedule.

A four-item open-ended self-report questionnaire was distributed to health personnel, to assess their opinion about health management, especially on the management and prevention of ulcers (of leprosy), or of chronic diseases in general. The perception of the health personnel about the buffering effect of self-help and support groups against distress resulting from

leprosy, is essential in implementing such a health programme. It is because of this general assumption that their opinion was surveyed (questionnaire appended).

A list of coping mechanisms assumed to have a wound healing effect, was also prepared and included as data gathering tool.

Questionnaires were distributed to self-care groups and members, and the authors distributed all case-discussions held with cases. The actual data collection in Shashemene area was carried out from April 15 to 20, and in Wolkeite area from May 2 to 5, 2000.

Statistical methods

Descriptive statistics like frequency count, percentage, ranking and t-test were analytical methods used in the study.

Analysis of Results

Self-Care Group Members' Attitude towards the Programme

Table 1: Results of a questionnaire based attitude survey among members of prevention of disability self-care groups in Ethiopia (N=61)

Item no	Attitude measurement items	Agree		Undecided		Disagree	
		n	%	n	%	n	%
1	The skill/knowledge/ acquired in the self care programme has largely improved my health status	35	57.4	11	18.0	15	24.6
2	Personally, I feel satisfied with the treatment of ulcer exercised in the self-care programme	38	62.3	10	16.5	13	21.3
3	Self-care programme is an alternate to treating ulcer/wound in hospitals/ health centres	30	49.2	9	14.8	22	36.1
4	The use of self-care programme to deal with ulcer management /treatment/ is one of urgent needs of ulcer patients	45	73.8	10	16.4	6	9.8
5	The service I get from support group is better than the service I had been getting from health centres	20	32.8	13	21.3	28	45.9

Item no	Attitude measurement items	Agree		Undecided		Disagree	
		n	%	n	%	n	%
6	It is my belief that I should continue to participate actively in the self-care health programme	40	65.6	9	14.8	12	19.7
7	The service I get from self-care programme is not as such different from the service I had been getting from health centres	21	34	11	18.0	29	47.5
8	I didn't see any new thing in the self-care programme to treat and manage ulcers	32	52.5	13	21.3	16	26.2
9	Since my involvement in managing my own wound my self-esteem is boosted	40	65.6	11	18.0	10	16.4
10	Members of the self-care group are very helpful to me in ameliorating my ulcer problem	45	73.8	6	9.8	10	16.4
11	Since my participation in the self-care programme, I feel my health is improving gradually	38	62.3	12	19.7	11	18.0
12	Ulcer treatment and management is better achieved individually than working in groups	43	70.5	10	16.4	8	13.1
13	The wound became more painful after I started managing it in the self-care programme	42	68.9	6	9.8	13	21.3
14	It is very difficult to learn and apply ulcer treatment skills learned in the self-care programme	52	85.2	2	3.3	7	11.5
15	It is waste of time to discuss health related problems in the self-care programme group	42	68.9	9	14.8	10	16.4
16	I feel relaxed when I work together and share experiences with my colleagues in the support group	38	62.3	8	13.1	15	24.6

Items 1,2,3,4,5,6,9,10,11,16 are positively stated items

Items 7,8,12,13,14,15 are negatively stated items

To assess the degree of positive or negative trends associated with the self-care programme, frequencies were counted on a 3 point response scale (agree, undecided, disagree). The distribution of frequencies along the continuum showed that relatively few respondents fall under the 'agree' category, for the positive statements. Comparatively, counts were relatively higher under the 'disagree' category. This distribution indicates, that the majority of respondents seem to be in favour of the programme. In the case of item 5 and item 7 the respondents' rating is different from the rest of the frequency distribution.

Regarding distribution of the respondents' suggestion on strengthening the programme in the future, 44% expressed that health education (facilitation by the programme holders) needs to continue. It is interesting to note here, that this figure is in line with the high percentage value falling under the 'agree' category in item 1. Concerning other development activities likely to be incorporated as part of the main health programme, 79% of the respondents suggested incorporation of credit facilities.

To investigate the difference between the two study sites with regard to their attitude towards the programme, mean comparison was made using the 't'-test. Though the analysis did not reveal a statistically significant difference between the two study sites, the mean value for Wolkeite was larger than that of Shashemene. This result is interesting in itself. In Wolkeite, the researchers came across some self-care group members travelling two or more hours on foot, or on horseback, to attend their scheduled meeting. Tolerance to hardship and such commitment, is further evidence for the programme beneficiaries' positive attitude towards the health/self-care programme. Results are given in Table 2.

Table 2: Mean comparison between the two study sites

Study sites	n	Mean	SD	df	t
Shahemene	41	37.22	10.63	9	1.235*
Wolkeite	20	40.10	7.33		

$P > 0.05$

Analysis of health personnel response

In general, qualitative data analysis showed that majority of the respondents (about 78%) were in favour of the self-care programme for the prevention and management of ulcers, despite the fact that only five respondents criticised it for its vertical organisation, where planning, implementation and monitoring of the programme was carried out by few staff members without adequate participation and consultation of other concerned partners. They also commented that the programme was lacking in well-defined guidelines and feedback resulting from continuous assessment.

Analysis of coping mechanism

Five coping mechanisms frequently used by self-care programme groups that were identified during the pilot study, were ranked in the order of their potency to alleviate ulcers /wounds. The most efficient coping mechanism being ranked 1 and, the least efficient being ranked 5.

Table 3: Coping mechanisms frequently used by self-care programme groups

Code	Coping mechanisms
A	Changing some routines and habits, which cause and aggravate ulcer problem. (Not to walk without shoes, always inspect that shoes are free from foreign substance i.e., gravel, sand; not to walk long distance etc)
B	By learning more about the treatment and management of ulcer from the group members and the health personnel [facilitators] (soaking, trimming, bandaging)
C	By talking (discussing) over the problem situation with family (husband, wife, children)
D	By talking (discussing) about ulcer problem with other friends/people 'in the same boat'
E	Accepting (admitting) limits and shutting oneself in home

Table 4: Coping mechanisms ranked in their order of merit

Self care groups		Coping mechanisms				
		A	B	C	D	E
G.K Group	Rank	2	1	4	3	5
W.Y Group	Rank	3	2	4	1	5
M.K Group	Rank	2	1	3	4	5
M.T Group	Rank	1	2	4	3	5
A.E Group	Rank	2	1	4	3	5
N.S Group	Rank	2	1	3	4	5
J.M Group	Rank	3	1	4	2	5
C.N Group	Rank	1	1	4	3	5
M.A Group	Rank	1	2	4	3	5
Sum of ranks		17	12	34	26	45
Order of merit		2	1	4	3	5

As can be easily observed, the self-care groups make use of a mixture of psychological and material resources as palliatives to confront their ulcer related problems. The emphasis appears to rely more on personal and inter personal resources rather than passively waiting for miracles to happen. The finding suggests that coping mechanisms employed by the self-care groups has two aspects. First, it is concerned with changing attitude and the belief system – psychosocial stigma with leprosy. Secondly, it suggests the importance of social support activities, such as talking over ulcer related problems with friends/husband/wife and using others as a sounding board. The fact that the coping mechanism which states, “accepting limits and shutting oneself in the home,” and ranked 5th by all support groups, testifies that mature coping mechanisms seem to have considerable importance, than defensive attempts that precipitate ulcer related problems.

DISCUSSION

As is evident from the analysis of the self-care group members’ attitude, only two items were found to veer towards the negative side. From this result we can safely conclude, that the overall evaluation of the programme beneficiaries’ attitude towards the self-care programme, showed the potency of the programme.

Although it is difficult to ascertain as to what extent the response of the respondents reflects in their day-to-day activities, which shows how they actually behave in real life situations, the results however, indicated that the programme has brought about a modification in their thinking and life style.

This general explanation, however, should not shadow exceptions. Although results of the data analysis revealed the overall strength of the programme, it cannot be said that the programme is free from any shortcomings. The response of health personnel to the open-ended items substantiates this idea. Health personnel were asked to give their opinion regarding the concept that the self-care leprosy control programme, is an alternate strategy to healing wounds/ulcers. Apart from enhancing a patient’s own responsibility for his/her own well-being and its cost-effectiveness, some respondents criticised it for its vertical organisation where planning, implementation and monitoring of the programme is carried out by a few staff members without adequate participation and consultation of other concerned partners. In addition, the programme was said to be lacking in well-defined guidelines and feedback, resulting from continuous assessment.

Furthermore, the need for credit service expressed by a high percentage (79 percent) of the beneficiaries, suggests the need to establish other community based rehabilitation activities that would supplement the target goal. The fact that this health programme should go side-by-side with clinical services, as suggested by beneficiaries and health personnel, indicates

that the programme is not uni-dimensional. In spite of this multi-sectorial feature of the programme, creation of new interests, upgrading of skills and all other working procedures give a purposive direction to programme holders and help the group members to build a positive self-image and live a better life.

Results from this study also highlighted the significance of conscious and rational ways of dealing with ulcer related problems. It is worth mentioning the programme members' coping strategies, which are directed at preventive measures, rather than endeavours to change the aftermath effect of the ulcer. A close scrutiny of the coping strategies in the order of merit assigned, shows that behavioural strategies appear to be more important than the use of material resources. One possible explanation of the prioritisation of the behavioural aspects of coping efforts, might be the participatory method of the health education programme with the aim of promoting awareness. The use of locally available material (for example, the use of 'Zanza', *the soft inner most part of the stem of 'Enset'- false banana.*) as a substitute to bandage and the softening of hands and feet using edible oil or Vaseline, bought from local shops appear to be appreciated. However, there is a need to weigh the side effects, so that the practice of ulcer management would not go astray and possibly aggravate the situation, as suggested by some of the health professionals. Strengthening the referral system and occasional visits by an experienced physician, seems to be an inseparable part of the support group self-care practices. The work of facilitators alone, will not bring the desired outcome.

It may be argued here, that the five coping strategies employed by self-care group members are not adequate enough to meet all needs. Both, self-care group members and health personnel underlined that provision of appropriate, acceptable commercial footwear, is probably as important as other practices in the management of ulcers. Although refraining from walking long distances, is one of the behavioural aspects of coping strategies, without mobility, the chances of earning their daily bread will be difficult. They must be able to get to work from their home and to other community activities. Hence, coping efforts can neither be uniquely behavioural, nor uniquely material, but should be a mutually supportive combination of the two. In other words, footwear provision and the facilitation (health education) programme need to go side-by- side.

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APPENDIX 1 : CASE STUDY (METHOD)

To substantiate the evaluation data, five cases found with special information were identified during interview sessions. Open-ended items framed by the researchers were used to elicit information. Accuracy and reliability of data were maximised by posing counter questions. A sample case study, possessing rich information on the overall aspects of the programme is given below.

Case Study

The person is a 53 year old widowed lady who had contracted leprosy at the age of 14. She lives in Kuyera/ Shashemene leprosy settlement. The case reads:

“I have never been admitted in the hospital nor been treated in clinics, as an out patient, for ulcer case. However, occasionally I used to have small ulcers in my feet, which I mostly treat at home by bandaging for two, three days only. As regards to my occupation, I am a housewife engaged in household activity including farming. Besides, I am engaged in retail trade as side income. I buy and sell farm products (grain, potato, onion and other vegetables) by travelling to open markets in the locality. Especially, after the death of my husband, I am inclined to this trade. I travel a lot, both on foot and by bus depending on the market place. And since my transaction is mostly with other “healthy people” [*people not affected by leprosy*], until recently I used to wear ordinary [*normal*] shoes, even though I knew that I have insensitivity of feet and small ulcers. Because I didn’t want my clients/ buyers to know that I had leprosy and ulcer”.

“Meanwhile, I developed two deep sole wounds in my right foot. I didn’t do anything to them, but I continued to wear same shoes and run for my business. After a few days, the two sole wounds got bigger and deeper and were developing in to one very big and deep ulcer. I went to the clinic and showed to the doctors my ulcer. There, I was told that my ulcer would require a minimum of two weeks treatment with rest to heal; and they advised me to be admitted in the hospital. Since I thought my business would collapse while admitted (and for that matter I didn’t like hospital admission), I refused the admission and came home with one time dressing. But, my wound was getting worse and smelling”.

“One day I was travelling with a public minibus to Negele market [near by town]. My seat was almost in the middle of the minibus seats. The mini-bus was full, and because of the rain showers all the windows were closed”.

After few minutes of our drive, I saw the passengers next to me and on other seats, beside and in front, holding their noses with their *netella* (a traditional cloth that people put on mostly over their shoulders.) and handkerchiefs. I was a bit panic by the behavior they showed; I had forgotten about my smelling wound in my foot. Nobody looked at me, and it

seemed that no one had recognised where the smell was from. There is a saying: “own wound will not smell unless you intend to smell it”. I didn’t smell any (wound smell) until I bowed and confirmed that it was mine. I bowed down to my feet [*foot steps*] and inspected my shoe by slightly pressing down the ulcerated-foot with my other foot and take off the back side of the shoe. It smelled very stinky. I was ashamed, but didn’t want to show this up nor did I want the passengers to know that the smell was from my wound. I tried to cover up by holding my nose with my *netella* as others did. Not only this, I loudly said, “Uff! Uff! ... what a smell?... Is there any hide [*animal skin*] in this bus?” No body replied, except some turned their heads towards me and looked surprised. This also disturbed me more. I got frustrated and was disturbed the whole day. This in turn had affected my business on that day, since I was not in the right business-mood to deal with my clients/buyers. After the market I came home but didn’t do any thing to my wound. It remained as it was. Two weeks later, my husband passed away, and per the culture of our community, we have to sit at home for mourning for about 10 to 15 days; a tent will be erected in the compound to accommodate friends and neighbors who come for the mourning. Coffee, tea, roasted beans/grain and food will be served by the *Idir* (a traditional self-help association of neighborhoods the primary aim of which is consoling bereaved families). Unlike men, women sit on the floor- covered with mattresses or carpets—and take off their shoes. Accordingly, as a wife and woman, after the funeral ceremony, I had to sit in the tent, take off my shoes and receive friends and neighbors. So, I sat on the mattress prepared for me and my close friends, exposing my wounds to the public; sometimes I was trying to cover them up with my *netella*, if not to stop the smell.”

“Meanwhile, at night, the daughter of my husband’s friend brought a bucket of water with salt in it and advised me to soak my ulcerated feet for about half an hour. After soaking, she oiled and covered the ulcer with clean cloth. Next morning too, she helped me do same process before I went to sit in the tent. Also at night, I did same thing with her. In two days time the smell went off (had gone). After ten days, my ulcer healed, only a small part (tissue) was left. I said to myself, ‘It is me who spoiled my leg. If I care for it, I can prevent it from destruction and amputation.’”

“Few days later, people affected by leprosy in our neighborhood were approached by ALERT medical team to form a self-care group after they had given us orientation about the programme. In that meeting, I was the first to support the programme, and volunteered to provide my compound and the necessary benches and chairs for self-care group activity. I joined my present group and since then I am actively involved in my self-care group activities.

“To-date I haven’t developed any new ulcers. Inshallah! [*Thanks God*] now I advice, assist and encourage my colleagues and others on the programme. As you can observe, my feet

and hands are 'clean' [*free from ulcer*]; I wear canvas shoes with special sole in it. In my group, we are 10 members, 7 male and 3 female; the group meets here weekly [*i.e. in her compound*]."

APPENDIX 2: QUESTIONNAIRE ON SELF CARE PROGRAMME FOR HEALTH PERSONNEL

Opinion Assessment : Self-Care Programme
[For Health Personnel]

1. Have you heard of (come across) a "support group" in any of the chronic diseases ?
.....
If Yes, (mention)
2. Do you agree that the self-care programme can be an alternate health strategy to healing ulcers/wound ?
If Yes, Why ?
If No, Why ?
3. Do you think the self-care programme is cost-effective than institutioning ulcer ?
.....
4. Generally, how do you appraise the self-care programme of ALERT?
.....

Your profession Specialty (if any)

Position (in your organisation)

Years of service in present organisation/ position