

**THE ROLE OF SUPPORT GROUPS IN RAISING THE
SELF- CONCEPT OF PEOPLE AFFECTED BY LEPROSY:
AN EVALUATION STUDY IN ETHIOPIA**

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ABSTRACT

A pre-tested structured interview was administered to a sample of twenty-four pairs of leprosy affected self-care group members and matched subjects around Shashemene, to evaluate any perceived changes regarding themselves, and their disease resulting from membership of the self-care leprosy control programme, undertaken by All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (ALERT). Besides this, a case study and observation reports were used, to complement the quantitative information from an interview questionnaire. The 24 self-care members perceived themselves and their ulcer problem more modestly than their counterparts not in the programme. The difference between the mean 'self-concept sum scores' was significant ($t=10.19$, $P<0.005$ $df=46$, and $x=30.083$, $P<0.001$ respectively). Case and observation reports qualified this finding, indicating that the health promotion activity undertaken by the self-care programme has raised the clients' sense of worth and self-esteem. Further recommendations have been given for conducting studies of a similar nature in the future.

INTRODUCTION

A factor of cardinal importance in understanding the dynamic component of health, is the client's sense of worth (1,2). Different authors have suggested that a person's sense of place in a community, is central to understanding how health can be achieved and maintained, and how illness can be overcome. They stated that people tend to lose assertiveness, become less alert, develop more illness and are more likely to die, when they are deprived of making their choices (1, 2,3).

Individuals who have a positive self-concept and appraise their environment realistically, tend to use more mature coping strategies, than individuals who view their environment passively (4, 5). Linda K. George, cited (4) in Menaghan, stated that "more education appears to foster a cognitive complexity that facilitates realistic stress perception and problem -

solving skills". Other investigators also found on the one hand, a strong relationship between sustained education and on the other hand, a more positive self-perception, greater readiness and intellectual flexibility to deal with complex and novel situations"(4).

The effectiveness of any health promotion programme can be evaluated in terms of the relative value the individual places on himself and his social environment. A potentially important variable in assessing the effectiveness of a self-care programme, is the change it has brought in self-esteem or, more generally speaking, self-concept among beneficiaries. Self-concept is operationally defined in this study as, "overall evaluation of leprosy affected individuals about themselves and their environment, in light of the social stigma associated with the disease" (4, 5). To investigate whether the programme has brought about any meaningful behavioural change with regard to ulcer management and prevention among the self-care group members, it was considered essential to compare samples of people who had participated in the programme, with those who had not.

Though variations in methodology designs can be attributed to purposes and resources available at hand, most social action evaluation studies, make use of surveys, case studies and field experiments in an attempt to fulfill objectives stated in the respective studies. Project evaluation research designs, reviewed by different authors show that interviewer or questionnaire techniques, use of documents and observation techniques, are principal data gathering tools (6).

METHODS

Sample

Cases: the primary sampling unit for the case (self-care group members) comprises a total of 35 self-care support groups working in Shashemene. From this first level sampling frame, nine groups were randomly identified. Twenty-four individuals were selected with proportionate random sampling from the nine groups.

Matched groups : the selection of subjects who had not participated in the self-care programme was facilitated by a social worker working for ALERT - Ethiopia Leprosy Control. Household selection proceeded systematically, until twenty-four household heads matched for sex, age and occupation with the case subjects. Where selected individuals were not immediately available for interview, the next household head was taken. All interviews were conducted in private.

Data collection

Construction and Development of the Instrument: A thirteen - item interviewer questionnaire was developed, pre-tested and completed by the authors. The items were framed on a three choice response dimension (questionnaire appended). Themes included ability to maintain self-control, level of efficiency in wound management, overall perception of the self and environment. To assess validity, the initial form of the schedule was examined by the self-care programme managers and by experts for content, item wording, choice of words and ambiguity. After shaping the initial form, the schedule was administered to fifteen randomly selected, leprosy-affected individuals from April 5 to 7, 2000. The pre-testing, highlighted ambiguity and deficiencies in wording the items and the average time needed to complete the schedule. This prior adjustment, provided the necessary quality control and minimised the occurrence of error in administering the final form.

Translation from the English language to Amharic (a local language) and translation back to English, was done by two experts who could speak and write the two languages fluently. Later, differences in translation were identified and discussed between the translators, which enabled them to reach a consensus. To minimise the problem of interview bias, the schedule was administered to the comparison groups in a constant manner, by one interviewer.

The total score for each subject was obtained by summing up the assigned weights to all items. The maximum possible score becomes 39 and the minimum 13. A respondent's total score was computed from the score sheet. As a measure of internal consistency, Crombach's alpha was computed and found to be 0.72, indicating that the instrument would suffice the purpose of the study. Frequency counts; median, 't' and chi-square tests were used to crystallise quantitative data.

Case Study

A case with an interesting history was identified during the interview session. Open-ended questions were formulated by the researchers, to elicit information. A summary of the case report is included in the analysis.

Observation

The researchers observed the proceedings of the nine self-care groups' weekly sessions, recording all the events that took place from the introductory part of a session to the closing coffee reception, which features the warm and affectionate attachment among group members. Events were systematically recorded, organised and analysed.

ANALYSIS OF RESULTS

Self-care and matched group comparison

It is hypothesised that the self-care groups, which have undergone extensive health education, would have acquired knowledge and skills that eventually raised their self-esteem. Hence, only a one-tailed significance test was done. The mean difference of 8.08 was found statistically highly significant at 0.0005 level ($t = 10.19, P < 0.0005$ $df = 46$).

The median sign test was used to compare the level of self-concept of the two groups. The means of the two groups were pooled together, and a common median was found. If the programme had no effect on the perception of the self-care programme participants about themselves and their environment, it was expected that half of the scores in the two independent samples should lie above and half below the common median.

Table 1 gives the scores of the two groups. A positive sign indicates a score above the common median and the negative sign a score below the common median. The common median was 29.50.

Table 1: Median test applied to self-care and matched groups (N = 48)

Self-care group members (n=24)				Matched group members (n=24)			
Score	Sign	Score	Sign	Score	Sign	Score	Sign
37	+	35	+	26	-	27	-
32	+	37	+	19	-	21	-
31	+	33	+	22	-	30	+
34	+	34	+	27	-	21	-
35	+	37	+	27	-	23	-
33	+	35	+	22	-	22	-
30	+	37	+	24	-	26	-
33	+	31	+	25	-	30	+
28	-	32	+	28	-	28	-
30	+	31	+	22	-	25	-
33	+	29	-	24	-	26	-
32	+	32	+	26	-	20	-

From Table 1 in the self-care group, 22 observations are above the common median value. In the matched group, exactly the opposite, is observed.

A chi-square with correction for small samples was computed from the two by two contingency table based on data from Table 1. A statistically highly significant value ($\chi^2 = 30.083, P < 0.001$) was obtained, indicating that self-care programme participants have a better level of self-concept compared to the matched subjects, as measured by the questionnaire.

Case result

Analysis of case information from a 52 year old self-care group member, who had been taking dapsone for more than ten years and admitted twice for an ulcer problem, further substantiated the result obtained from quantitative data.

The integration of leprosy control with TB and the general health services coupled with the introduction of the self-care programme, were the driving motives to treat ulcer problem through support groups. In spite of this new approach and all sorts of help offered from colleagues, the 52-year case subject claimed that he was saved from amputation. As a concluding remark the subject stated: "Ah! We would have benefited more from such 'health group' [self-care] had we had it some fifteen years ago".

Observation

Unlike other self-care groups (e.g. diabetes, cancer, AIDS associations etc.), ulcer-care discussion is not dominated by health professionals or social workers. Instead, each member was encouraged to share his/her practice of ulcer management used at home. As a procedure, every member was invited by the chairperson to inspect, comment and suggest on the status of eyes, hands and feet of his/her colleagues. Improved ulcer condition was rewarded by the group. If no progress has been made since the last session, the individual is criticised. Punishment involves withholding of moral rewards, and at times it goes to the extent of fining some amount of money.

The progress in self-concept can be witnessed in individuals, by no sign of reservation in their comment and no sign of hesitation to touch cracked, dirty and wounded feet of someone whom he/she had not known for years and had not had close relationship with. It is here that an outsider would observe the emotional attachment prevalent among self-care members. One member said, "It is such support or emotional attachment that controls my behaviour".

DISCUSSION

Evaluation of the level of self-concept between self-care and matched groups revealed that self-care group members were found to have a better image and assessment of themselves and their ulcer problem.

The degree to which one values oneself has certain implication as far as health is concerned. Low self-esteem on the part of matched group members might imply fewer competencies in manipulating their environment and less ability to manage and treat their ulcer.

What the authors found to be uncertain, though, is that it is difficult to state emphatically the cause and effect relationship. Whether lowered self-concept as measured by the items among the matched group might be attributed to a lack of health education (through participatory learning and action method), or any other disadvantageous position compared to the self-

care group, is not exactly known. Since multivariate analysis was not within the remit of this research design, explaining the intricate relationships between the selected variables was not possible. Like any other exploratory surveys of similar nature, the purpose of this study was to describe events in a simple way and to provide information on the psychosocial environment under which the programme is run. Yet, it is the authors' belief that they threw fresh light on the strengths of the programme that would furnish programme holders to make decisions as objective as possible, in the future.

In the future, there is a need to develop a valid instrument and see the interrelationship between selected variables and weigh the net effect of these variables, by employing a multi-variant statistical analysis.

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APPENDIX I :SELF-CONCEPT QUESTIONNAIRE (FOR SELF-CARE GROUP MEMBERS AND MATCHED GROUPS)

	Self concept measurement items			
1	To what extent do you easily get upset when you think of your ulcer problems?	Very much	Moderately	Not at all
2	How often do you have negative feelings such as despair, anxiety and depression?	Very often	Sometimes	Not at all
3	To what extent do you feel inferior to other people in the community when you think of your ulcer?	Very much	Moderately	Not at all
4	How strongly do you feel trust, worthiness and optimism in you?	Very much (strongly)	Moderately	Not at all
5	How satisfied are you with your ability to perform your daily living activities?	Very satisfied	Mildly satisfied	Not satisfied
6	Are you currently enjoying life ?	Yes I do	Undecided (I don't know)	No I don't
7	To what extent do you believe that ulcer treatment can be done independently with minimum aid from the health personnel?	Strongly believe	Somewhat believe	Don't believe
8	Do you now admit your limits more easily than when you first experienced (saw) ulcer on your body?	Yes I do	Undecided (I don't know)	No I don't
9	Do you believe that health personnel's daily supervision is very indispensable for the management of ulcer?	Believe	Undecided (I don't know)	No I don't
10	Do you agree that ulcer/wound/ need not be exposed to non-leprosy affected people other than the health personnel?	Agree	Undecided (I don't know)	Disagree

	Self concept measurement items			
11	To what extent do you believe that the support from family and friends (colleagues) helps to cope with ulcer problems?	Strongly believe	Somewhat believe	Don'tbelieve
12	How suitable is the condition of your living place for the management of ulcer?	Very suitable	Moderately suitable	Not at all
13	How satisfied are you with your personal Relationship with people not affected by leprosy?	Very satisfied	Moderately satisfied	Not satisfied

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