

Self care groups and Ulcer prevention in Okegbala, Nigeria

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Summary

Objective To assess the impact of the three self-care Groups on ulcer prevalence and readmission rates in Okegbala hospital.

Design A retrospective, descriptive study. The evaluation combined four data collection methods namely (i) records survey, (ii) semi-structured interviews of individual members of self-care groups, (iii) group discussions and (iv) key informant interviews.

Results Record surveys show that the ulcer prevalence has decreased by almost 75% since the adoption of the self-care group; admissions to hospital for ulcer care have reduced, and the mean interval between admissions has increased by 7 months. Semi structured interviews and group discussions show that all members have a greater sense of control of their ulcers and general health; and that self-care groups have a potential of catalysing community solidarity and development.

Conclusions This small study shows that self-care groups are valuable for reducing ulcers and giving members a greater sense of control of their ulcers and general health resulting in fewer hospital admissions. We recommend a multi-centre, controlled, prospective study incorporating different settings (e.g. urban, rural, near hospitals, within field leprosy programmes) to test these findings. Such a study has the potential of influencing policy and health-service reorientation of ulcer care in future.

Introduction

Plantar ulcers are a familiar problem in people affected by leprosy with nerve damage. Simple ulcers left untreated can develop into complicated, chronic ulcers, become infected and result in further impairment.¹ Ulcers are still the most common reason for admissions at leprosy

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hospitals. In 2007, 55% of all admissions to hospitals assisted by The Leprosy Mission were for ulcer management, with 37.5% being re-admitted within 12 months.²

Interventions to promote wound healing and to prevent the occurrence of wounds are vital in any leprosy control programme. These interventions include both those to be carried out by the health workers, and more importantly those to be carried out by the person at risk of ulcers (supported by family and community), that is, self-care.

Self-care can be defined as 'the range of behaviour undertaken by the individuals to promote, or restore health',³ or 'the process of enabling people to increase control over, and to improve, their health'.⁴ These broad definitions encompass self-care actions in either the presence or absence of medical supervision recognising its significance in both health and illness. In self-care the affected person takes control of the management of their condition. They are supported by a team of health and social care workers who are facilitators that empower individuals to solve problems themselves. The Ottawa Charter for Health Promotion,⁴ and The Innovative Care for Chronic Conditions (ICCC) Framework⁵ both stress the importance of self-care in the management of chronic conditions.

Self-care in the prevention of disability in leprosy is one of the main components in the WHO Global Strategy for reducing the leprosy burden and sustaining quality leprosy services (2006–2010).⁶ Similarly, the Consensus Statement on the Prevention of Disability (POD) 2006 states 'Self-care is a key strategy in the prevention of disabilities and is a vital component of leprosy control'.^{7,8} Despite this the practice of self-care has been poor for many decades as Hugh Cross has stated in his paper: 'A focus on the issues associated with implementing self-care as an intervention'.⁹

Self-care groups (SCG) are based on the belief that wound healing is the responsibility of those directly affected, and uses the group dynamics of encouragement and accountability to support one another in wound management and obtaining wound healing materials.^{1,10} The Stigma Elimination Programme (STEP) in Nepal has already demonstrated that self-care is a valid approach to the sustainable management of impairments, due to leprosy.¹¹

STUDY AREA AND RATIONALE OF STUDY

Okegbala Hospital was founded by Service in Mission (SIM) in the 1950s as a leprosy hospital for the mid-western states of Nigeria. Now owned and managed by the Evangelical Church of West Africa (ECWA), Okegbala is the leprosy referral hospital for Kwara State. The hospital is surrounded by three villages (Alabe, Ayekale and Oloruntele) which grew over the years from small leprosy settlements into proper villages, home as well for people not affected by leprosy. There are about 50 people affected by leprosy with permanent visible deformities secondary to nerve damage living in Okegbala. Okegbala is situated 8 km from Omu-aran town which has a huge market and mosque which attracts beggars. Some people affected by leprosy travel daily to Omu-aran to beg, a journey with a potential of perpetrating plantar ulcers.

COMMUNITY ULCER CARE

For decades, people with wounds in Okegbala who didn't need or refused admission had attended the ulcer shed within the hospital compound for their ulcer care. The responsibility for ulcer care at that time was firmly with the hospital staff, many of them former patients of the hospital and resident in the community themselves. In 2004, the physiotherapist at the hospital began a new initiative in the management of ulcers, by starting ulcer-care groups in the three

communities. However, these ulcer-care groups were still managed by staff at the hospital who trimmed, dressed and cared for ulcers in the three villages. The health staff chose the date and time and sent for the people with ulcers to come. In effect the ulcer shed had moved location.

SELF-CARE GROUPS

In April 2006, the principles of SCG as described by Benbow and Tamiru¹⁰ were introduced to the groups. The only exception is that beggars are welcomed as members on the understanding that they demonstrate a desire to heal their wounds and contribute positively to the group. The first and main principle of SCG is that the group members and not the health staff own and run the group meetings. The group members take responsibility for their own care and that of the other members of the group. Group members are trained as part of the SCG programme.

SCG programmes are made up of the Coordinator, the facilitators, the group leaders and group members. The SCG Coordinator is a member of the health staff with specific POD training. Coordinators receive training in group dynamics and coordination. At present the SCG coordinator in Okegbala attends 6-monthly refresher training meetings with SCG coordinators from other projects. Facilitators are either community health assistants or community members. The group leader is a member of the group who has been chosen by the members and is trained locally by the Coordinator and facilitator. Group members are people affected by leprosy who are at risk of further impairment who have voluntarily committed to attend regularly. The facilitators and group leaders were trained locally by the coordinator in October 2006 and are supervised by the coordinator. All training material was adapted from the materials developed at ALERT, Ethiopia. For group leaders, the appropriate materials were translated into the local Yoruba language.

Since the start of the community ulcer care programme in 2004, there had been no formal evaluation. This evaluation aimed to assess the impact of the three SCGs on ulcer prevalence and readmission rates in Okegbala hospital.

Material and Methods

STUDY DESIGN

This was a retrospective, descriptive study conducted to establish:

- (a) The trend of ulcer prevalence among group members in Okegbala since the establishment of self-care groups,
- (b) The impact of self-care on re-admission for ulcers,
- (c) The perception of group members about self-care.

STUDY POPULATION

As this was the first study exploring the influence of SCGs on ulcer prevention in Nigeria, a purposive sample of 24 participants was recruited from three self-care groups in Alabe, Ayekale and Oloruntele communities of Okegbala. Criteria for inclusion were people affected by leprosy who have been members of the self-care groups since 2004 irrespective of gender or age.

DATA COLLECTION AND ANALYSIS

Over a 4 day period in August 2007, the evaluation combined four data collection methods namely (i) records survey, (ii) semi-structured interviews of individual members of self-care groups, (ii) group discussions, and (iv) key informant interviews. Nine key informant interviews were conducted by three health staff specialising in leprosy POD and fluent in the Yoruba-a language spoken in study area. The interviews took place in the homes of the participants. The time taken to complete each interview ranged from 40 to 60 minutes. The interview questions included: why members joined the groups; how they would describe the experience of belonging to the group; and what they personally thought were the benefits of self-care groups. Each question included prompts. Quantitative Data was entered into a database using Microsoft Access and analysed with EpiInfo. MS Excel was then used to generate frequency tables and plot charts. Qualitative data from interview transcripts was analysed for content. The content was grouped into main themes which were then counted and tabulated to obtain frequencies. The combination of semi-structured and key informant interviews with record surveys was adopted to enhance the credibility of the findings of the evaluation. The findings were further cross-checked several times by the authors to ensure the interpretations of the narratives of SCG members reflected their lived experiences.

Approval for the study was obtained from The Leprosy Mission-Africa Research Committee, Kwara State Ministry of Health and the Head of ECWA Hospital Okegbala. Permission to enter the villages was given by the village heads of the Okegbala Community. All interviewees gave informed consent for their data to be included in the study. All data was confidential, with no client names used throughout the study.

Results

Table 1 shows groups in Okegbala community comprise an elderly population with a mean age of 62.5 years, the youngest member of the groups is 35 years old, and the oldest is

Table 1. Demographic data of members of 3 self care groups in Okegbala community ($n = 24$)

	Alabe	Ayekale	Oloruntele	Total
Members per group	7	9	8	24
Female	5	6	7	18
Male	2	3	1	6
Mean age in years (age range)	62.5 (52–71)	64 (63–71)	58 (35–72)	62.5 (35–72)
Marital status				
Single	1	2	0	3
Married	3	0	2	5
Widowed	3	4	5	12
Not given	0	3	1	4
Occupation				
Begging	3	3	3	9
Trading	2	1	2	5
Farming	0	2	1	3
Labourer	2	0	1	3
None	0	0	1	1
Not given	0	3	0	3

72 years. Ayekale has the oldest members with a mean age of 64 years. This elderly population is also reflected in the marital status; 60% of the 20 members who gave their marital status are widowed. Seventy-five percent of the group members are female. Nine group members (43%) were beggars. Eight of the members have benefited from the community based rehabilitation (CBR) programme in Okegbala and have started trading and farming for a living. The paragraphs that follow utilise qualitative and/or quantitative data to answer the research questions of this evaluation.

ULCER PREVALENCE

In these three groups 18 of the 24 members (75%) who have been in the group since the onset had ulcers when they joined. By December 2007, only five (20.8%) still had ulcers as depicted by Figure 1.

This was confirmed by SCG members who claimed the biggest impact of the groups is the healing of ulcers.

Figure 1 shows a minimal reduction in number of people with ulcers from 18 to 16 between December 2003 and December 2005 when ulcer care was driven by the health staff. The number of ulcers decreased rapidly following the adoption of the principles of self-care groups in April 2006. Figure 2 shows that the reduction in the number of ulcers has been sustained.

RE-ADMISSION INTERVAL

Four of the nine key informants (hospital staff) have observed that the admission rate for ulcer care has reduced among the self-care group members. This is confirmed by admission records which show that only four of the 24 group members have had recurrent admissions for plantar ulcers since 2004. Looking at the admission trend for these four people from 2000 to

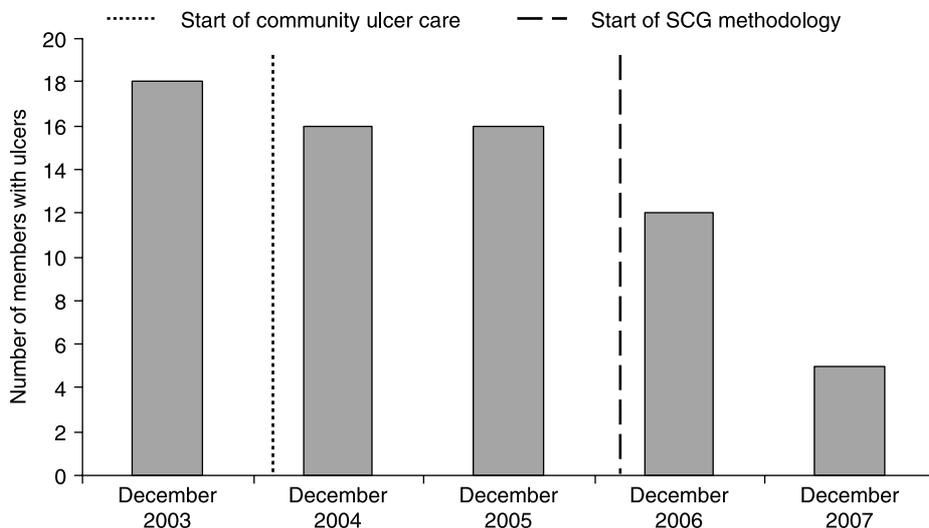


Figure 1. Ulcer prevalence among SCG members (2003–2007) (n = 24).

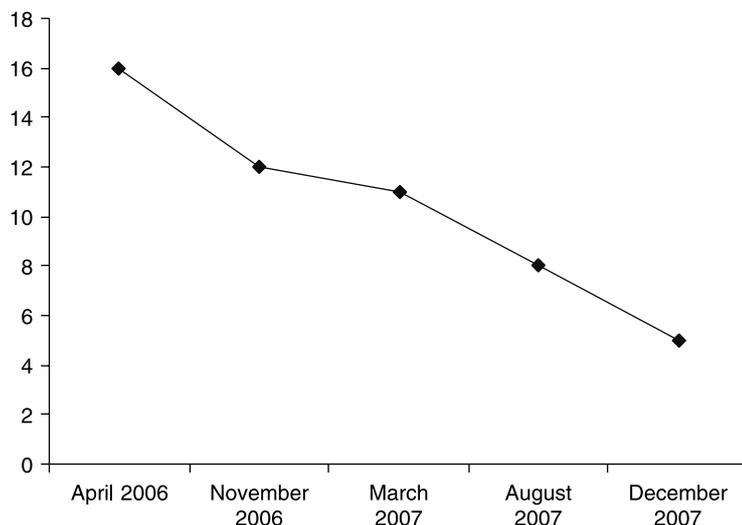


Figure 2. Ulcer trend among group members since April 2006 ($n = 24$).

August 2007, the mean interval between admissions has increased by 63.6%, from 11 months (2000–2003) to 18 months (2004–2007).

REASONS FOR JOINING GROUPS

Twenty-two of the 24 group members agreed to be interviewed about their perceptions of self-care groups. Of these 22, 19 (86.4%) reported joining the SCG to improve their health and specifically heal their ulcers and remain ulcer free. The remaining three (13.6%) said 'because of leprosy', 'I was encouraged to join by the health worker' or 'I joined in solidarity with my friends'.

MEMBERS OVERALL EXPERIENCE WITH GROUPS

All SCG members reported a positive experience in the SCG; there were no reports of negative experiences. All felt they had acquired sufficient knowledge/skills from the SCG to take care of their own bodies and prevent and heal ulcers. When asked about how being a member of the SCG had improved their health, the majority (95.5%) stated their physical health had improved and their ulcers had healed, while one person says he now has peace of mind through mutual support of the group.

COMMUNITY CHANGES DUE TO GROUPS

When asked about the changes the self-care groups have brought to the community, if any, 50% of members mentioned that the fact SCG members had managed to heal their ulcers was a benefit to all the community. Another three people (13.6%) mentioned that the community is much more united and the community members support one another more. Two people (9.1%) said that the groups had been a catalyst for community development and another two

people (9.1%) said the general hygiene of the members and the community is much improved. Four people (18.2%) were not specific in their answer of the type of community improvement brought about by SCG.

CHANGES IN ACTIVITY AND PARTICIPATION

When asked about changes in activity and participation since joining the SCG, 14 members (63.7%) claimed they had less activity limitation and participation restriction, five members (22.7%) claimed to be the same and three members (13.6%) could not give a specific answer to this question.

FUTURE EXPECTATIONS

The majority of SCG members interviewed expected good health (50%) and socio-economic benefits (41%) in terms of access to micro-finance and vocational training as a result of being members of the SCG. The remaining 9% (two people) gave self-help and continuity of the groups as their main expectation.

Discussion

The Leprosy Mission started promoting and supporting self-care groups in villages neighbouring leprosy hospitals in Nigeria in 2003. Initially starting with five groups, by May 2008, there were 86 groups reported by five hospitals and eight leprosy control programmes. A total of 951 people regularly attend these 86 groups. This study reports the results of an informal evaluation of three self-care groups in Okegbala Community.

WOUND HEALING

The effect on both ulcer prevalence and the re-admission rate for ulcers has been remarkable. The number of people with ulcers has reduced by almost three quarters in 24 months. This compares favourably with similar reports from China, Ethiopia and Nepal.^{1,9,10}

The SCG members and the staff report that members are able to prevent ulcers more effectively and when small wounds do occur, they are able to carry out simple home-based wound care and heal the wounds quickly on their own with the group's support and without hospital admission.

In the Ethiopian groups, the number of wounds reduced most notably in the first 6 months, but in Okegbala, the reduction has been sustained steadily over 18 months. This could be because a number of members had multiple ulcers at the beginning and the data collected by the group leader is the total number of people with wounds, rather than total number of wounds.

From observation, the five people who still have chronic ulcers will probably need orthopaedic reconstruction of their feet to promote healing. They have not yet consented to this surgery. In the meantime their ulcers are smaller, clean and well taken care of at home. Any time there are signs of complications in these wounds they are recognised by the group and referred to the hospital by the group leader.

Of these five people, four have had frequent re-admissions for ulcers since 2004, but the mean re-admission interval has increased by 63.6% (from 11 months between 2000 and 2003 to 18 months between 2004 and 2007) showing that they too are learning to take care of themselves at home. The home-based care is simple and feasible in the simplest of settings as set out in *ILEP learning Guide 4: How to Prevent Disability in Leprosy*⁸ and *I Can Do It Myself*.¹²

SLOW START

As with other self-care group programmes in other countries, there was initial inertia and it took a while for the members to understand the concept of self-care. The progress was initially slow and moved step by step. Both the health staff and the group members had difficulty adjusting to the principles. The health staff were used to being 'prescribers' and are now 'facilitators' and the members were used to 'having things done to them' rather than solving their own problems.

Before 2006, the groups were given all the ulcer care material. The health staff trimmed and dressed their wounds during the meeting and then the members went home with a small supply of dressing materials to last until the next meeting. From 2006, however, the only materials supplied were footwear and crutches. Members were taught to use locally available materials for soaking their hands and feet and to dress wounds if needed. Vaseline is readily available in Nigeria and is cheap, so for oiling most people buy it in the market and use it as part of their daily care.

There was some initial misunderstanding by both SCG members and hospital staff that SCG replaced hospital care. The SCG Coordinator had to meet with the facilitators, group leaders, members and the hospital staff to correct this misunderstanding. Self-care groups are an adjunct to, not a replacement of, hospital care for the complications of leprosy.

SUPPORT/TRAINING

The vital role of a properly planned training for the Coordinator, Facilitators and Group Leaders cannot be over-stated. Once everyone understood their role, participation improved and problem solving by the group members themselves became easier. The training and support was more than the transfer of skills and knowledge, but looked at attitude and building up individuals' self image and esteem, with empowerment of group members as the goal.¹¹

In Nepal, self-care was shown to be a valid approach to the sustainable management of impairments due to leprosy when group facilitators are paid an amount of money to compensate for lost earnings.¹¹ However, in the SCG programme in Nigeria, no compensation is paid at all. The findings of this evaluation highlight the feasibility of motivating and encouraging self-care without monetary compensation.

OTHER BENEFITS

Omu-aran has a big market and mosque which both attract beggars. Nine of 21 (43%) group members gave their occupation as begging (see Table 1). The SCG programme in Okegbala is one aspect of the local CBR programme. The self-care groups are seen as cooperative groups who save money in a community purse. The cooperative can also borrow money from the micro-finance programme in the community supported by TLM. This is a similar

development to that described in Nepal.¹¹ Some of the younger members have benefited from this micro-finance and have started trading and farming for a living (see Table 1).

From our observations, and also from the testimonies of the group and community members, the general hygiene of the members has improved greatly. This in turn has led to a greater acceptance by the wider community in the nearby township of Omu-aran where the nearest market and large places of worship are.

LIMITATIONS OF THE STUDY

The authors acknowledge the following limitations of this study. First, the sample size of this study (24 SCG members and nine health staff) could limit the possibility of generalising the findings. However, the triangulation of results of the multi-method study was designed to enhance credibility and provide an account of the context to permit an assessment of the transferability of the findings to other settings.

Second, while the study depended on group members' recollection of their health status and admission records, nevertheless, the fact that the 24 people were SCG members up to the period of the evaluation meant their experiences of SCG were still fresh in their minds. Their narratives can thus be accepted as authentic representations of their experiences of SCGs.

Third, more objective results of the impact of SCGs on activity limitation and participation restriction could have been achieved if we had used tools to measure these dimensions of disability at the start of the self-care group programme.

Fourth, there was no control group of people affected by leprosy who do not participate in self-care groups. Such a comparison would have provided additional evidence to the study, perhaps providing other factors for wound healing.

Conclusion

In spite of the small number involved in this evaluation, the findings from the records review and accounts of respondents generated sufficient evidence to indicate that self-care groups are valuable for reducing ulcers and giving members a greater sense of control of their ulcers and general health, resulting in fewer hospital admissions. We believe issues of group member empowerment, increasing readmission interval for ulcers and community cohesion would be relevant to other self-care groups and other settings.

As there are scores of self-care groups in operation in different countries and settings (urban and rural, near hospitals and within field leprosy programmes), we recommend a multi-centre, controlled, prospective study to test the findings of this report regarding the value of self-care groups for ulcer management and prevention. Such a study has the potential of influencing policy and health-service reorientation of ulcer care in future.

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