

Self-care groups of leprosy-affected people in Mozambique

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Summary

Introduction: In 2011, the national leprosy control programme in Mozambique decided to promote the setting up of self-care groups (SCGs) for prevention and care of disabilities.

Objectives: To present an overview of the national SCG strategy and to understand the perceptions of people with leprosy regarding the benefits and challenges of participating in the SCGs in Mozambique.

Methods: Semi-structured group interviews were carried out with 22 SCGs involving 299 leprosy affected people in Nampula and Manica provinces.

Results: SCGs are involved in different activities and do not limit themselves to activities related to disability care. The majority of respondents expressed satisfaction about their participation in SCGs. Apart from perceived benefits in relation to their disabilities, the majority of SCG members also reported benefits in social participation. Lack of training, insufficient resources for income generation and long distances were the major challenges for SCGs, especially in the Manica province.

Conclusions: People affected with leprosy perceive SCGs as useful in self-care for prevention of disabilities and social participation.

Introduction

Between 1985 and 2008, globally around 15 million people with leprosy were treated and cured. However, physical disabilities caused by the disease, as well as the impact of social prejudice and discrimination, continue to be important challenges.¹

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REGULAR CARE FOR LEPROSY-RELATED DISABILITIES

With regular care, worsening of existing disabilities and the appearance of new disabilities due to leprosy can be prevented.²

The Innovative Care for Chronic Conditions (ICCC) programme promoted by the World Health Organization (WHO) takes note that adherence to long-term treatments among people with chronic conditions is remarkably low. As the management of chronic conditions requires lifestyle changes, ICCC suggests that the emphasis should be shifted from relying on care by health care personnel to a person's own central role through self-care.³

An ILEP publication on prevention of disabilities⁴ suggested setting up self-care groups (SCG) to 'encourage disabled people to meet together to talk about solving self-care problems and to practice self-care together.' It also suggested that 'SCGs can be found in communities where a number of leprosy affected persons live close to each other (people should not have to walk too far to meet others).'

Different studies on the impact of SCG participation among people with leprosy have suggested improvements in wounds and ulcers, better self-care activities, an improved self-concept and more sense of control over their bodies, and decreased use of health services.⁵⁻⁷

SELF-CARE AND SELF-HELP GROUPS IN LEPROSY

Historically, leprosy programmes have maintained a distinction between the 'self-care groups' linked to care of disabilities and the 'self-help groups' that focus on poverty reduction, income generation and advocacy.⁸

More recently, the Community-Based Rehabilitation Guidelines⁹ look at self-care as one of the activities of a self-help group and propose that people with similar health-care needs, can benefit from support and advice received from their peers. They suggest that people with disabilities should be connected to existing self-help groups to meet their specific health care needs.

There are experiences in other countries where self-help groups are used both for self-care as well as for other socio-economic activities. For example, in Indonesia, "The SCG is set up to become a catalyst of community empowerment. It tries to help the members and the communities become the agents of change through capacity building. Health workers support this process externally as facilitators in building up of capacity."¹⁰

LEPROSY-AFFECTED PEOPLE IN MOZAMBIQUE

The national campaign for reducing the prevalence of leprosy to less than 1 per 10,000 through improved MDT coverage was launched in 1996. This objective was achieved at national level in 2007. In this period, more than 100,000 people were diagnosed and treated with MDT, while the percentage of new cases of leprosy with Grade 2 disabilities at the time of diagnosis varied from 6.6 to 14.8%. A leprosy monitoring exercise in 2008 showed that about 20% of all the patients had a visible disability.¹¹

Historically, Nampula province in the north of the country had the highest prevalence of leprosy in Mozambique.¹² In the Makhuwa language spoken in Nampula, leprosy is called *Marreetha* and people affected by leprosy are called *Namarreetha*, which means 'a moribund person.' Use of such words contributes to the negative image of the disease in the community.

Studies in Mozambique have revealed that affected people are ashamed of showing their skin patches, are worried about infecting their close relatives and have lowered self-esteem.¹³

An evaluation of the leprosy programme in Nampula and Niassa provinces in 2007 concluded that “The quality of the programme activities needs further improvement, especially POD and rehabilitation.”¹⁴

SCGs OF LEPROSY-AFFECTED IN MOZAMBIQUE

The WHO Global Strategy 2011-15 had proposed setting up SCGs of people with leprosy for care of disabilities. The Regional Leprosy plan for the period 2013-2015 in Africa noted as one of its challenges, ‘the lack of effective prevention of disabilities through early detection, management of complications and support of patients for self-care.’¹⁵

The target of the National Leprosy Control Programme (NLCP) in Mozambique is to reduce the number of newly diagnosed leprosy-affected people with a visible disability in 2011 by 50% by the year 2014. In 2011, the NLCP also decided to promote the setting up of SCGs of leprosy-affected people in all endemic provinces ‘to benefit from peer support’ for prevention of disabilities.¹⁶

The NLCP’s manual on leprosy control provided the following information on setting up of SCGs: “The volunteers, guided by the local health staff and the district supervisor, will help in organizing self-care groups. It is the policy of the NLCP to support and encourage the development of these groups. Important aspects are: the development of self-care and socio-economic groups within leprosy-affected communities; collaboration of partners in self-help groups as well as socio-economic groups to develop the groups’ sense of ownership and abilities to resolve problems using locally available resources; group and individual teaching and practice of self-help skills.”¹⁷

PREVIOUS EXPERIENCES OF SCGs IN MOZAMBIQUE

A few years earlier, some non-governmental organisations (NGOs) working with leprosy-affected people had already started promoting SCGs in Mozambique. Thus, SCGs started in Cabo Delgado province in 2008 with three main objectives: to heal wounds and prevent worsening of existing deformities; to increase self-esteem; and to develop economic activities as a kind of income generation.¹⁷

A guide-booklet for SCGs of leprosy-affected people was prepared in Cabo Delgado.¹⁸ The guide was in Portuguese and provided the following information:

- Principles of self-care for preventing new disabilities and taking care of existing disabilities.
- Different roles in a SCG including coordinator, facilitator, group leader and members.
- Setting up a group and criteria for selecting members.
- Activities during group meetings.
- Training of group members.
- Specific activities including socio-economic rehabilitation, referral services and protective footwear.

SCGs IN NAMPULA PROVINCE

Nampula province is located in the north-eastern part of Mozambique. SCGs in Nampula province of Mozambique were started by two local NGOs in 2010. The SCG guide from the

Cabo del Gado province was photocopied and distributed to the SCGs in Nampula province. The local association of people with leprosy called 'the IDEA group of Nampula' was also involved in training of SCG members.

In 2011, following the NLCP's decision, the Provincial Department of Health also started to promote SCGs in the remaining areas. As a result of these activities, in 2012 there were 64 SCGs of leprosy-affected people in Nampula province with a total of 808 members.

SCGs IN MANICA PROVINCE

Manica province is located in the central-west part of Mozambique. Leprosy incidence is much lower in Manica, compared to Nampula province.

With support of local NGOs, SCGs of people with leprosy were started in 2008. The association of persons affected with leprosy called 'the IDEA group of Manica' was also involved in training of SCG members.

In 2011, following the NLCP's decision, the Provincial Department of Health in Manica also started to promote SCGs of people with leprosy. As a result, in 2012 there were a total of 40 SCGs of leprosy-affected people in Manica province involving a total of around 700 members.

Methods

A study was planned to understand the viewpoints of persons affected with leprosy who are members of SCGs, with the aim of improving and strengthening the SCGs.

The research proposal was approved by AIFO's ethical committee. A simple questionnaire for a semi-structured interview was prepared to collect information from the SCGs. The questionnaire was translated in the local language and then checked by reverse translation.

The purpose of the research was explained, prior consent was obtained and the questionnaire was administered to seven SCGs in Nampula province in May 2012 by the local leprosy supervisor or the local NGO staff. For each question, the group was asked to discuss and to express its collective opinion.

Later, the same questionnaire was also proposed to the leprosy programme in Manica province. On the suggestion of the local partners in Manica, an additional question about the distance from the meeting place was added to the questionnaire. After informed consent, the updated questionnaire was used for interviewing fifteen SCGs. In Manica also, for each question, the group was asked to discuss and to express its collective opinion.

A purposive non-random sample of SCGs was selected for the research from the two provinces. Out of the total 104 SCGs in the two provinces, a sample of 22 SCGs were interviewed (21%) with a total of 299 members. In each province, the partners were asked to select at least one SCG in each district of the province, and to ensure a mix of different characteristics such as duration of the group, meeting place of the group, and distance from the provincial headquarters.

The data collected from all 22 questionnaires was entered through Excel and analysed. The results were shared with the partners in the two provinces and their comments have been incorporated in the preparation of this article.

Results

PROMOTER OF SCG

The sample in Nampula province included three SCGs started by the Provincial Health Services and four SCGs started by NGOs. In Manica province, the sample included 11 SCGs initiated by the Provincial Health Services and four started by NGOs.

SELECTING A NAME FOR THE SCG

All the groups have a name in their local language and all the groups felt that having the right name for the group was very important. For example, a SCG in Sussundenga district of Manica province is called Chinguirirai (Be strong, have courage) and the group said that the name of the group is important because 'it encourages its members to face the difficult situations of their lives.'

GENERAL INFORMATION ABOUT SCG MEMBERS

The seven sample SCGs in Nampula province had 109 members (51.3% male and 48.7% female), while the 15 sample SCGs in Manica province had 190 members (50% male and 50% female). Thus, in terms of gender, the sampled groups had almost equal numbers of men and women.

The average number of members in the SCGs was 15.5 in Nampula province and 12.6 in Manica province.

In terms of the age of the SCG members, in Nampula province the age varied from a minimum of 20 years to a maximum of 72 years (median 43 years). In Manica province, the age range was larger, a minimum of 13 years and a maximum of 93 years (median 47 years).

Finally in terms of marital status of the SCG members, the situation was as follows: in Nampula province, 73.5% of group members were married while only 1.8% were divorced; in Manica province, 51.5% of group members were married and 33.1% were divorced. Thus in the sample SCGs in Manica the percentage of divorced people was much higher compared to Nampula and the difference is statistically significant ($p = 0.0141$).

DURATION OF THE SCGS

In Nampula, the duration of the sample SCGs, that is, the period that they had been functioning, varied from 19 to 43 months, with a mean duration of 31.4 months (median duration 32 months).

In Manica, the duration of sample SCGs, had a much larger variation, from 6 to 120 months, with a mean duration of 43.4 months (median duration 38 months).

EVOLUTION OF SCG MEMBERSHIPS OVER TIME

In both the provinces, Nampula and Manica, the group memberships had increased over time.

In Nampula province, initially the total number of members in the sample SCGs was 83 people, while at the time of the interview, the total membership had increased to 109 members (an increase of 33%). In Manica province, initially the total number of members in the sample SCGs was 112, while at the time of the interview, the total membership had

increased to 190 (an increase of 69%). The difference in the increase in the membership in the two provinces was not significant statistically ($P = 0.6713$).

In both provinces, groups said that very few people had left the SCGs mainly for problems related to poor health, large distance from the meeting place, difficulties of transportation and death. Only one group out of the 22 interviewed, mentioned one person who had left because of conflict with another group member. At the same time, almost all the SCGs had attracted new members from the local communities.

MEETING PLACE FOR SCGs

SCGs were asked about their group meeting place and if the place had been changed in the past. In Nampula, all the seven groups had started meeting close to their villages and they continued to meet there, though some of them had changed specific meeting places in their communities.

In Manica province, 80% of the groups had started their meetings in a hospital or in a health centre, while the remaining were meeting closer to their villages, often in the house of a SCG member. At the time of interview, about 40% of the groups continued to meet in a hospital or a health centre, while the remaining 60% met closer to their villages.

The SCGs of Manica were also asked about the maximum distance between an SCG member and the group meeting place. This question was not asked in Nampula province.

The average maximum distance for a group member in Manica to reach the meeting place was 5 km for those SCGs that met in their communities, 11 km for those SCGs that met in health centres and 25 km for those SCGs that met in a hospital.

FREQUENCY AND DURATION OF SCG MEETINGS

The groups were asked the number of times they met in a month when they had started and at the time of the interview. They were also asked about the average duration of their meetings.

In Nampula province all the SCGs usually met four times a month when they were formed and the frequency of the meetings remained unchanged at the time of interview. In Nampula, the meeting duration varied from 2 to 6 h (average duration 3.9 h).

In Manica province, the SCGs met one to four times per month when they had started (mean frequency 2.1 meetings per month). At the time of interview, the frequency of meeting varied from one to three times in a month (mean frequency 1.6 meetings per month). In Manica province, the meeting duration varied from 1 to 6 h (average duration 2.7 h).

Thus in Manica province, the meetings were less frequent and shorter than the meetings in Nampula province.

TRAINING AND MATERIALS FOR SCGs

The SCGs were asked if they have received any training on group management, wound care and prevention of disabilities and if they had received any manuals, booklets or other printed materials.

In Nampula province, 29% of the groups had received some training on management of different SCG activities while 86% had received training on care of wounds and prevention of disabilities. 58% of the groups had also received printed leaflets and learning materials on self-care.

In Manica province, none of the groups had received training on management of different SCG activities, while 86% had received training on care of wounds and prevention of disabilities. Finally 23% of these groups had received printed leaflets and learning materials on self-care.

PROTECTIVE FOOTWEAR AND TECHNICAL APPLIANCES

72% of the SCG members in Nampula had received footwear (sandals) in the previous 12 months, while in Manica, only 8% of the members had received sandals in the same period. No SCG member had received any other technical appliances in the past 12 months in both Nampula and Manica provinces. The difference between the two provinces for the access to sandals is statistically very significant ($P = 0.0082$).

PERCEIVED BENEFITS FROM THE SCG MEETINGS

The groups were asked their opinions about the benefits of being part of a SCG.

In Nampula province, one SCG did not answer this question. Among the remaining six SCGs, the perceived benefits of being part of the groups were as follows: better care of disabilities and wounds (100%), ability to fight for rights (100%), socialising and meeting with friends (83%), economic benefits (83%), to have fun and enjoy together (83%), to receive sandals (83%), better care of the eyes (17%) and an opportunity to go out of the house (17%).

In Manica province, the perceived benefits of being part of a SCG were as follows: socialising and meeting friends (93%), better care of disabilities and wounds (80%), able to fight for rights (73%), to have fun and enjoy together (67%), economic benefits (40%), opportunity to go out of home (27%) and to receive sandals (20%).

MAIN CHALLENGES FOR THE GROUPS

The groups were asked about the main challenges they faced for which they needed support. In Nampula, all the SCGs asked for more support for income generation activities.

In Manica also, all the SCGs asked for more training, economic assistance and funds for income generation activities. In addition, in Manica, 80% of the groups asked for support for transport for participating in the meetings.

Discussion

Different findings from the research - the perceived benefits, the increase over time in SCG membership, and the low number of people leaving the SCGs, all point towards satisfaction of leprosy-affected people from the SCG participation.

In both Nampula and Manica, the perceived benefits were related to practical issues (better care of disabilities and receiving sandals) as well as to social participation (meeting friends, enjoying an opportunity to go out of the house).

In Manica province a larger percentage of SCG members were divorced compared to Nampula province. The significance of this finding was not clear and requires a specific study to understand it.

In Nampula province, all the sample SCGs were based in local communities, while in Manica province, most SCGs started under the health services were based in health centres or hospitals. Thus, in Manica province, a key finding was the large distances and the difficulties of transport and consequent difficulties in participation, for SCGs that meet in a health centre or a hospital. Meeting in a health centre or a hospital probably facilitates support from health services, but the transportation problem suggests that the SCG meeting places should be shifted to somewhere closer to the communities where the members live.

Access to protective footwear and to training are other challenges in the Manica province. Finally, in both the provinces the SCGs ask for strengthening of income generation activities. Thus the research shows that implementation of SCGs may be different in different provinces.

Over the past decade many leprosy programmes have initiated integration of leprosy control services with the primary health care services. Many programmes have expressed concern about inadequate attention towards activities of prevention of disabilities and rehabilitation in the integration process. On the other hand, promoting SCGs for disability care has been mainly seen as an activity of NGOs. In this scenario, the decision of NLCP in Mozambique to promote SCGs in all endemic areas can be seen as an innovative step that merits research.

This research focused only on the perceptions of leprosy-affected people. More comprehensive research on the implementation of SCGs strategy in Mozambique is needed.

LIMITATIONS

The research did not collect any empirical data on impairments and related improvements among the SCG members. This kind of information can be important to assess the effectiveness of SCGs in prevention of disabilities and for planning training and capacity building of SCGs.

Another limitation of the research is that information was collected by the same people who normally support the SCGs. Thus it is possible that at least some of the SCGs were unable to frankly express their opinions about the SCGs. It also asked for collective opinions of the groups about different issues and thus, might have missed variations in specific concerns and challenges of individual group members.

Conclusions

Self-care activities can have a fundamental role in the care and prevention of progressive worsening of leprosy-related impairments. Peer support through self-care groups is a useful strategy for promoting the active engagement of people with disabilities. Its benefits go beyond self-care and distribution of materials such as protective footwear, and include better social participation.

At the same time, self-care groups of people affected by leprosy need support in terms of training, income generation activities and access to services. Finally, SCG activities need to be organized in, or close to, the communities where members (and potential members) live.

Usually SCGs are organized at the local level by NGOs. Promoting SCGs through the NLCP in Mozambique should be considered as a pioneering effort to complement the integration of leprosy control services in the primary health care and merits more research.

Conflict of interest

All the three authors worked for Italian NGO AIFO that supports leprosy control and SCG activities in Manica and Nampula provinces of Mozambique. None of the authors received any specific funding for conducting the research or for preparing this article.

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References

- ¹ Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy, p. 3–4, WHO Regional Office for South-East Asia (SEARO), Delhi, India, SEA-GLP-2009.3.
- ² Watson J. Preventing disability in leprosy patients, p. 16, TLMI, Middlesex, UK, 1986.
- ³ Innovative care for chronic conditions - Building blocks for action, WHO, WHO/MNC/CCH/02.01, Geneva, Switzerland, 2002.
- ⁴ How to prevent disability in leprosy – Learning guide four, ILEP, London, UK, 2006 (pp 29 and 52).
- ⁵ Benbow C, Tamiru T. The experience of self-care group with people affected by leprosy: ALERT Ethiopia. *Lepr Rev*, 2001; **72**: 311–321.
- ⁶ Abera M, Lemma G. The effectiveness of self-care support groups in the prevention and management of ulcers: an evaluation in Ethiopia. *Asia Pacific Disability and Rehabilitation journal*, 2003; **14**(1): 43–50.
- ⁷ Cross H, Chaudhury R. Self-care: a catalyst for community development. *Asia Pacific Disability and Rehabilitation journal*, 2005; **16**(2): 102–116.
- ⁸ Guidelines for the social and economic rehabilitation of people affected by leprosy, pp. 18, ILEP, London UK, 1999.
- ⁹ CBR Guidelines – Health module, p. 17, WHO, ILO, UNESCO & IDDC, Geneva Switzerland, 2010.
- ¹⁰ Arief F. Self-care group in leprosy programme in Indonesia – thesis for master of public health, Royal Tropical Institute, Amsterdam, Netherlands, 2008.
- ¹¹ Report “Avaliação Do Program Nacional Para A Eliminação Da Lepra Em Moçambique” (Leprosy Elimination Monitoring), WHO and ILEP, Maputo, Mozambique, 2008.
- ¹² Benfica A. História do Programa de Controle da Leprae em Moçambique, Maputo, Mozambique, 2007.
- ¹³ Palhota M. A. Lepra em Namaíta, Província de Nampula: Uma Reflexão Sobre Representações Socioculturais, thesis, anthropology dept, Universidade Eduardo Mondlane, Maputo, Mozambique, 2012.
- ¹⁴ Feenstra P. Report of Evaluation of leprosy programme in Nampula and Niassa provinces, NLR, Amsterdam, Netherlands, 2007.
- ¹⁵ The WHO African Region Strategic Plan for Further Reducing the Burden of Leprosy 2013–2015, WHO Regional Office for Africa, Brazzaville, Congo, 2013.
- ¹⁶ Relatório do Biénio 2008–09, pp. 17 Escritorio Nacional da OMS em Moçambique, WHO-Mozambique, Maputo, Mozambique, 2010.
- ¹⁷ Schreuder P. Review of The National Leprosy Control Programme of Mozambique And Its Implications For Future Directions of The Programme, pp. 15, September 9–25, 2011, Maastricht, Netherlands.
- ¹⁸ Guião de grupos de auto cuidado, A missão contra a Lepra Internacional, Cabo Delgado, Sede em Pemba, Mozambique, 2009.