

Zero Leprosy Best Practices

Best Practice: *Support Groups to Reduce Stigma Associated with Leprosy*

Subthemes

- Reduction of stigma, discrimination, and exclusion

Target Audience(s)

- Health staff
- Persons affected by leprosy
- Other partners such as NTD NGOs

Contributors

Contributing organization: MORHAN (Movement for the Reintegration of Hansen's Disease)
Rio de Janeiro, Brazil

Key Messages

Support groups and educational groups can take different forms and can serve to reduce stigma for people affected by the disease, their family members, and their communities. These groups can be arranged in different ways in terms of who is involved and what are the goals.

Key Informant / Date Submitted

C. White
Georgia State University, United States
December 2019

Description of the Best Practice

Introduction

Support groups have great potential in terms of sharing information that can reduce leprosy-related stigma. In the late 1990s, the non-profit organization MORHAN (Movement for the Reintegration of People Affected by Leprosy) facilitated different types of support groups in Rio de Janeiro, Brazil. As part of an ethnographic research project, I had a chance to conduct participant observation in self-help groups and educational meeting groups. Here, I will describe the structure of these two types of meetings and the potential positive outcomes. Although I do not have data that demonstrate the effectiveness of these types of meetings over the long term, there are examples from other cultural contexts of the success of these types of groups.

Objectives and Methodology

In the late 1990s in the state of Rio de Janeiro, Brazil, MORHAN volunteers collaborated with healthcare professionals to organize “*grupos de auto-ajuda*” (self-help groups) that were usually facilitated by a

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volunteer but were composed primarily of people who were in treatment for leprosy or who had completed multidrug therapy (MDT) but were still in treatment for leprosy reaction. These self-help groups took place at outpatient treatment facilities. MORHAN's main objectives for these groups were to increase self-esteem, provide emotional support, decrease fear and anxiety related to the disease, resolve doubts, and provide information that participants could share with family members and other contacts.

MORHAN staff, social workers, and psychologists also held "waiting room" educational sessions at what was then the State Institute of Sanitary Dermatology in Rio de Janeiro, which was on the grounds of the former hospital-colony community of Curupaiti. People in the wider community of Jacarepaguá knew about the existence of the leprosarium and were sometimes fearful of coming to the clinic for treatment of other dermatological conditions because of the stigma associated with the location. Therefore, the objectives for this group were to destigmatize the location for people coming for outpatient treatment.

In 1998-1999, I attended two self-help groups at a health post in São Gonçalo and six waiting room meetings in the State Institute of Sanitary Dermatology in Jacarepaguá. Facilitators of the meetings had backgrounds in nursing, social work, physical therapy, and psychology. Because I was an ethnographer focusing on the experience of leprosy treatment in Brazil at that time, my primary methods were participant observation and interviews. I conducted in-depth interviews with some of the professionals who led these groups.

Implementation of Practice

For the self-help groups I observed, people who went to the health post for leprosy treatment were encouraged by clinic staff to attend these monthly meetings. A MORHAN volunteer (who was also a health professional) would usually begin the session by talking about some of the biomedical understandings of the causes of leprosy, its treatment, and its potential complications. They would also discuss the fact that there is no need for persons with leprosy to live separately from others or to separate personal items in the household. Family members were invited to come in to learn more about the disease. Participants shared their stories and asked questions.

The educational meetings were held in the waiting room of a clinic among people waiting for their dermatology appointments (for a variety of conditions, including leprosy). A social worker, sometimes accompanied by a nurse or physical therapist, would direct the group, although participation and questions from people in the waiting room were encouraged. The focus was usually on popular beliefs about leprosy and on fears that people might have about contagion, particularly their fears associated with Curupaiti. The social worker would talk about the fact that the residents of this hospital-colony were cured many years ago and could not transmit the disease to others. The fact that the probability of contracting leprosy outside the gates of this facility was higher than inside them was frequently mentioned. The social worker would also mention that although some of the residents had severe disabilities, most of them had contracted leprosy before the development of MDT.

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According to Vieira (1), MORHAN lost a primary source of funding in late 1999 and was not able to continue with self-help groups. They were able to reestablish these and other educational activities in 2004 through a partnership with the government (Secretary of Health Education).

Results—Outputs and Outcomes

In terms of concrete results, I did have a chance to observe people (in the short span of a self-help group or educational meeting) express relief and/or interest in learning some of the information about leprosy that was shared in the group or by the facilitator. I did not do follow-up interviews with people who attended these meetings, although this would be an important research project to demonstrate the impact of these types of meetings. Vieira (1) has documented MORHAN's work over the years.

Lessons Learned

The availability of physical space—an empty room near the clinic in the case of the self-help group and a large waiting room at the State Institute of Sanitary Dermatology—was one thing that made these groups possible. While educational groups related to leprosy could be held in public spaces like a clinic waiting room, a more private space is probably necessary for a group that mainly serves people affected by the disease so that privacy and confidentiality can be maintained.

Although funding may be necessary in some cases to make these groups happen, they could also be facilitated by trained volunteers including healthcare professionals and people affected by leprosy.

Replicability and Scalability

Support groups in many forms have been implemented in many different cultural contexts. Although other projects use the terms “self-help” and “self-care,” these can be defined differently and meet different needs of people affected by leprosy. DAHW-Brasil currently sponsors support groups, including a women's group in Mato Grosso that is led by a woman affected by leprosy and has over 40 members and “deals with both social and clinical aspects of leprosy” (Reinaldo Belcher, DAHW-Brasil, personal communication, 2019). In some cases, these groups involve more than just sharing information and allowing a safe space for conversation although this alone can provide great emotional and psychological support to people affected by leprosy and can function to decrease stigma. There are examples of self-help and self-care groups that also facilitate the development of things like micro-business (2). Support/self-care groups in Ethiopia were established mainly to help people affected by leprosy have greater access to information on wound management (3).

Conclusions

Support groups and self-help groups have the potential to decrease enacted and perceived stigma related to leprosy. In collaboration with healthcare professionals and/or people affected who might be trained as facilitators, group discussions might identify needs or problems within families, with employers, and in communities related to leprosy stigma or stigma associated with disabilities. These groups, particularly those comprised largely or solely of people affected by the disease, can also be the starting point for community organization or the development of economic enterprises, though this might be more relevant in certain settings (for example, in a town or village setting where members of

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the group live close to one another, as opposed to an urban area where participants might live in different communities).

Educational/waiting-room meetings in healthcare settings where leprosy and other diseases are treated and/or that are located on the grounds of a leprosy community, as in the case of Curupaiti, have the potential to decrease fear and stigma of community members. This type of activity takes advantage of waiting-room settings for educational purposes. It is different than a support or self-help group in that its purpose is to educate the wider community about leprosy and does not provide the privacy of a support group. However, it is a kind of meeting that is relatively simple to implement. Leaders of these meetings could be healthcare professionals or trained volunteers, including people affected by the disease with a healthcare or social work background or who are trained in leprosy education.

Both types of groups would benefit from participation of people affected by leprosy as facilitators. It is particularly important for facilitators or leaders to be aware of local perceptions and beliefs about leprosy and its treatment, cure, and management and to be aware of the local culture, gender roles, and daily life circumstances of the local population.

Further Readings

References

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Other

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