Creation and development of support groups for leprosy self-care in a state in the northeast of Brazil

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Abstract: **Objective**: To understand the creation and development of support groups for leprosy in a state in the northeast of Brazil. **Methods**: Qualitative study conducted with three groups in northeast Brazil, from February to December 2019. Data collection included interviews, participant observation, and document analysis. Data were analyzed using the content analysis technique, considering preestablished topics: implementation, organization, and continuity of the groups. **Results**: The most common reasons presented by the groups for the implementation were the needs to expand care and optimize working time. The stigma and service organization issues were obstacles to implementation. The most relevant factor for the continuity of groups was the involvement of the coordinators in the activities. Support from external actors, such NGOs and universities, was relevant to implementation and continuity. **Final considerations**: Similarities and differences among groups are related to participants, actions to foster the groups, health policy support, and interference from external actors. Support groups for leprosy self-care are spaces that strengthen the practice of care. This study contributed to implement or reorganize self-care support groups.

➤ **Keywords:** Leprosy. Self-care. Self-Help Groups.

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Introduction

Leprosy is a century-old disease that is still a serious public health hazard in Brazil. Its presence among the poor is notorious, and it has a social impact on individuals and families, with negative consequences in many different dimensions of their lives. These aspects require more technical, scientific, and financial investment from public policies, so the disease can be eradicated, or its effects minimized, considering the current Brazilian context.

Brazil is the 2nd country with the highest rates of detected new cases of the disease. Also, among American countries, it concentrates 92% of cases (Brazil, 2019). Leprosy is an infectious disease with dermatological-neurological involvement, which has a high chance of leading to disabilities if the diagnosis is late (WHO, 2017). In 2019, there were 23,612 new cases notified in Brazil. 82% of them were evaluated regarding Degree of Physical Disability (DPD) at time of diagnosis. Of these, 1,984 presented a DPD of 2, and 5,826 presented a DPD of 1 (Brazil, 2020).

In this context, self-care stands out as a conceptual model that involves a series of anticipatory and timely actions carried out by individuals to take responsibility for their own care. A rational attitude is necessary for a person to be able to make decisions and carry out planned, coordinated, and integrated daily actions (Chompré, 1994 apud Batista; Vieira; Paula, 2014). In the context of disease, self-care involves individual decisions in day-to-day actions, in order to prevent, control, or reduce the impact of the chronic conditions that affect them (Cavalcante; Oliveira, 2012).

The practice of self-care support, in the context of leprosy, can be carried out in individualized actions or in leprosy self-care support groups (SSSG). Some countries around the world have reported the presence of SSGs, including Brazil (D' Azevedo *et al.*, 2018; Pinheiro *et al.*, 2014), Mozambique (Deepak; Hansine; Braccini, 2013), Indonesia (Susanto; Dewi; Rahmawati, 2017), Nepal (Cross; Beise; Choudhary, 2017; Langen, 2012; Pryce *et al.*, 2018), and the Netherlands (De Vries; Groot; Van Brakel, 2014).

Regarding the impact of SSGs on the lives of users, studies have shown a significant increase related to physical deficiencies and social participation, emphasizing that the benefits of this practice go beyond physical care (D' Azevedo *et al.*, 2018; Deepak, Hansine; Braccini, 2013; Pinheiro *et al.*, 2014; Susanto; Dewi; Rahmawati, 2017). Thus, these groups show improvements in the clinical conditions of the individuals who participate, with a consequent increase in the quality of life of these people and their families.

In 2010, the Ministry of Health of Brazil published a guide (Brazil, 2010), which provides orientations regarding the creation of support groups in the country. Ever since, there has been an increase in the number of groups created. In December 2017, the Ministry of Health promoted a meeting including the representatives of more than 70 SSGs from different Brazilian states (Brazil, 2018). Although this shows that these groups have been advancing in Brazil, there have been few papers about the experience of SSGs, analyzing whether they are sustainable, what their results are, and whether they can help build new care strategies.

Starting from the premise that these groups can contribute to minimizing the impact of leprosy, it is important to understand how they are built within health services, and how the relationships between participants have been established. Thus, this study aimed to understand the process of creation and development of groups to support self-help in leprosy in a state in the Brazilian northeast, aiming to gather elements that can contribute for the formation and consolidation of SSG strategies, in order to provide a more comprehensive health care for people affected by leprosy.[1]

Methodology

This is a qualitative study, focused on the SSGs in the state of Pernambuco, in the Brazilian northeast. There have been groups in the state since 2012. During collection, there were six active groups in the state. We selected three, which had been acting the longest and had more frequent meetings. These groups were invited to participate in the study after their goals were presented during previously scheduled regular meetings.

Data were collected using a triangulation of collection techniques, including participant observation, in-depth interviews with key informants, and document analysis (Minayo, 2010). The researcher responsible for the observation has experience with these groups since 2014, through university extension activities aimed to monitor and improve the SSGs. This facilitated access to the groups.

At first, the participant observation was carried out with the aid of a field diary, in which information about the meetings was recorded (number and profile of participants, topics and themes addressed, interactive activities conducted, forms of participation, types of relationship, and conversations that took place). The thirty-four meetings conducted from February to December 2019 were observed.

The observations helped select the subjects of the study, which were identified as key informants. The selection of these participants was intentional, meaning these subjects were chosen according with the relevance of their discourse and the meanings expressed about the study object (Navarrete *et al*., 2016). After observation and enumeration of selection criteria, three users, one per group, and four coordinators of the groups — one of the groups has two coordinators, and all coordinators are health workers — participated in the next methodological step: in-depth interviews. With this goal, we prepared a script with topics about implementation, organization, and continuity of the groups. In this stage, the interviews were recorded and transcribed in full. For document analysis, we considered the minutes of the meetings, provided by the groups — one book each. This is the only type of formal record the groups use.

The collected materials were submitted to content analysis, with a pre-analysis exploring the material, and a categorization through a thematic content analysis (Bardin, 2011). Thus, the analysis of the collected materials was carried out, at first, with three pre-established thematic categories, defined according to our study object: "Implementation of leprosy self-care support groups"; "Organization of leprosy self-care support groups"; and "Continuity of leprosy self-care support groups". In this stage, the analysis attempted to uncover, in the materials found in data collection, units of meaning that corresponded to pre-established categories.

Later, through an analysis of the material collected in the thematic categories, eight new categories of analysis emerged from the identification of new units of meaning, corresponding to the topics determined. Three of them were related with the topic of implementation of leprosy self-care support groups ("Reasons to implement groups", "Factors that lead to SSG implementation", and "Obstacles to implement groups); three were related with the topic of organization of leprosy self-care support groups ("Profile and number of participants", "Admission and permanence of participants", and "Planning and carrying out activities"); and two were related with the continuity of leprosy self-care support groups ("Aspects that favor continuity" and "Aspects that hinder continuity").

This study is a part of the research "The social experience of participants of leprosy self-care support groups and the possibilities of care", approved by the research ethics committee of the Hospital Complex of the Teaching Hospital Oswaldo Cruz / Cardiac Emergency Room of Pernambuco – HUOC\PROCAPE. Opinion number: 1932.6919.6.0000.5192. The subjects of the study signed an informed consent form. To preserve their anonymity, participants were identified by the word "professional" or "user", followed by a number. SSGs were identified using numbers from 1 to 3.

Results and Discussion

The choice of working with three different groups allowed analyzing different sets of experiences. All of them were based on health services and were coordinated by health workers. Group 1 had existed for three years, had a mean of 10 participants and monthly meetings in the specialized center; Group 2 had existed for five years, with a mean of 15 participants and monthly meetings at the reference center; and Group 3 had existed for seven years, with a mean of 25 participants and bimonthly meetings at a hospital.

The experiences of creation and development of these groups will be presented and discussed according to the thematic categories established and the corresponding subcategories that emerged from them.

Implementation of leprosy self-care support groups

Reasons for implementing the groups

The three SSGs were implemented due to the need to provide more care to the users, that is, health workers were attempting to find different strategies of care that went beyond physical aspects.

> These were issues connected to their needs; I noticed they didn't only have physical needs, but emotional ones too (Professional 4).

This finding is in accordance with what Ayres (2017) calls a new movement in the scope of health, the emphasis put on care in the last few years, and the refusal to objectify people and relationships. In this sense, health workers seem to be seeking "new" strategies to rethink the health care provided, in an attempt to go beyond merely physical elements, as the report indicates.

Another reason to create a self-care support group was the possibility of working collectively, since it allows optimizing the working time of the professional by providing self-care orientations to users as a group, as opposed to an individual treatment, thus expanding their possibilities. This was the reason for the formation of SSGs 1 and 3.

> To reduce time, really, to manage to provide the same information to many people; it's a way of optimizing time, which we don't have much (Professional 1).
>
> One [reason] is that we believe in the creation of the groups, and in the benefits a group brings to people, which are often much more than individual attention, or an additional different benefit (Professional 1).

The interviews above highlight that professionals feel the need to optimize time spent working, considering all their demands. The overwork of professionals in Brazilian public health services has a negative effect on work processes, and professionals need to make choices regarding the services provided that are not always in accordance with the decisions that best attend the needs of the users. Therefore, the work process must be reconsidered, in order to focus on the quality of practices as opposed to their quantity, searching for a more effective and efficient care which focuses on responding to user needs. This type of care takes place as the user is seen and treated as an actor in their therapeutic process, through meetings where desires, beliefs, and knowledge of users are expressed in conversations and recognized by health workers, and spaces where there is a joint exchange of therapeutic possibilities (Ayres, 2009).

Another issue is that self-care practices should be facilitated by the creation of groups (Oliveira; Andrade; Chagas, 2013), which allows working in a space where social, subjective, and biological human dimensions can be articulated. In this regard, it becomes a privileged practice to empower individuals and the collective (Franco; Silva; Daher, 2011). This aspect is extremely important to develop an understanding of the biopsychosocial risk of people affected by leprosy.

Factors that lead to SSG implementation

An important factor for the creation of SSGs, pointed out by groups 1 and 2, was the participation of professionals in specific courses about the formation of these groups, offered by the State Health Department (SES) of Pernambuco and the Universidade de Pernambuco (UPE), where professionals got in touch with documents produced by the Ministry of Health (Brazil, 2010) that included guidance on the formation of SSGs.

> The group was made after we were trained, by the health department, about the formation of these groups (Professional 2).

This finding reiterates that the continued education of health workers is essential for new practices to be implemented in the services, in addition to highlighting the importance of creating and disseminating educational materials that support the training processes of municipal administration and the work process of professionals.

Another element that led to the formation of SSGs was the support from external actors. The Universidade de Pernambuco, the Movement for the Reintegration of People Affected by Leprosy (Morhan), and the Non-Governmental Organization (NGO) NHR (Netherlands Hanseniasis Relief), as well as the Municipal Leprosy Coordination of the SSGs 1 and 2 were mentioned as external actors that contributed for the implementation of the groups. This support took the form of guidance to conduct the groups, supplies, participation in the planning of activities, and experience exchange.

The involvement of NGOs in the formation of SSGs is also a reality in other countries, as is the case in Ethiopia and Mozambique (Benbow; Tamiru, 2001; Deepak; Hansine; Braccini, 2013). For diseases that are often neglected, such as leprosy, which mostly affects poor countries, it is common for NGOs to participate in health policies, since the State is often unable, in these territories, to fulfill its role in the promotion of efficient health policies. Furthermore, the involvement of university projects in the implementation of SSGs shows the importance of university to promote social transformation within health services. The relevance of social participation also stands out in the form of organizations of people affected by leprosy that foster actions such as those of the SSGs. According to the World Health Organization (2011), as people affected by the disease and their families become participants, collaborators, or facilitators of actions implemented in health services, users receiving care reap more benefits.

If, on one hand, these findings show that networks formed by the State and other actors are important for the configuration of new strategies of care, on the other, groups are recommended to become autonomous, not depending on external actors. To do so, the role of health management is paramount, including the support from municipal leprosy coordination to form these groups.

In SSGs 2 and 3, the participation of the health team was an important factor for the implementation of the groups. Teamwork is an essential aspect for the effective implementation of new practices in health services. The performance of the teams also helps to avoid the personification of a strategy, increasing its sustainability.

Obstacles to the implementation of the groups

Problems related to the organization of the services and the ancient stigma associated with the disease were found to be obstacles to the creation of the groups. SSG 3, for example, had no support from the management of the unit where it took place, and had trouble setting aside a location for the group to hold its activities, since the people in the group have leprosy.

> Why would no one let us? Because it was a contagious disease. At first, I requested the auditorium, but it was promptly denied because it was leprosy and this auditorium was also used by workers, so he said we could not (Professional 4).

The report above shows that the stigma associated with leprosy was very relevant. It is an element that makes actions related to the disease substantially more difficult, including the formation of SSGs. This group works in a reference hospital for leprosy, where discriminatory practices should not exist.

The stigma against leprosy is associated with the physical manifestations of the disease; with its history, which associates it to punishment and penalties; to cultural and social questions involving the people and groups affected; and to the fear of the transmission of the disease (Sermrittirong; Van Brakel; Bunbers-Aelen, 2014). Furthermore, the users with the most advanced forms of the disease often suffer more with stigma and discrimination (WHO, 2017). These are the users that most often participate in the SSGs.

In addition to the stigma, physical structures inadequate for their activities, and the lack of health workers were challenges to implement the groups. The meetings of SSG 1 take place in a limited space, with lighting and heat issues noticed during the meetings, which the statement of a coordinator reflect:

> The main obstacle here is the structure. Another issue I think is the lack of human resources, because there are no other professionals in the service that can help in this process (Professional 1).

An adequate environment for health services is considered to be an essential element for the humanization of health practices, and is possible when healthy and welcoming environments are available (Bender; Petry, 2019). These are difficult to implement in many SUS services. In the case of leprosy, these issues can be made even worse by the stigma attached to the disease, as this study showed.

Organization of leprosy self-care support groups

Profile and number of participants

The three groups counted on the participation of people with leprosy, registered in health services, under polychemotherapy (PCT) treatment or after it, and their companions. There was no one with other diseases. Studies on the possibility of integrating users affected by other SSG diseases were conducted in the Netherlands, with people affected by diabetes mellitus (De Vries; Groot; Van Brakel, 2014), and in Nepal, with users affected by lymphatic filariasis (Pryce et al., 2018). In a second study, most users with lymphatic filariasis considered participated in an integrated group, which may be related to the integration of users affected by diseases that are stigmatized. In the first study, only 17% of interviewees with diabetes mellitus showed interest in participating in combined groups. This low level of adherence may be explained by the different characteristics of leprosy and diabetes, regarding the distribution of these diseases in social classes and stigma levels. A study from Indonesia about intersectionality and stigma in health found that people with diabetes report fewer experiences of stigma than those affected by leprosy, HIV, and schizophrenia (Rai et al., 2020).

The SSGs in this study could consider including people with other diseases, since these groups are coordinated by health workers who certainly have the competence to monitor these users. However, to do so, they must consider the specific aspects of each group, such as the operational capacity to welcome these members and the position of the participants. The so-called “inclusive groups”, whose implementation imposes the presence of users with leprosy and other diseases in the same group, can lead to situations of stigma.

There was a significant variation in the number of participants in the groups studied. SSG 3, the most studied, had twenty-five users. In this group there were meetings where users were not attentive to the discussions, either because they did not understand what the others were saying, or because they had little interest in the issues discussed. This was noticed in the observation of their body language, the fact they did not look continuously at the person speaking or did not participate when there was an opportunity to do so. These findings can be associated to the high number of people in the meetings and to the way in which meetings were conducted by the coordinators, since these issues were not observed as frequently in groups with less participants, and in groups that promoted more participative dynamics.

Admission and permanence of participants

In all SSGs, participants were invited to participate. Some criteria were used to select those invited (except for SSG 3, where all leprosy patients who used the service were invited): users with a high level of disability already installed; who were likely to develop disabilities; who had trouble adhering to treatment; or had some sign of mental suffering. According to professionals, these users are more likely to participate in groups.

> When I see that the person already has some kind of involvement, or disability, or is likely to, we invite them, because it's easier for them to accept it than for those who have no issues (Professional 1).

After admission into a group, a person could remain for as long as they liked. In the three groups mentioned, coordinators pointed at the emergence of new needs throughout the meetings. This, associated with the limited access users have to the health network, contributes for them to remain in the groups, with no time limit. Thus, in the experiences studied, there were participants who attended the group since its implementation, and, as a result, the configuration of the group was not only that of a self-care group. They were also a social micro-space, where bonds were formed and practices, such as mutual help, emerged.

On the other hand, participant observation found that the long permanence of users made it more difficult for new participants to enter the two older SSGs. Thus, in our observations, we found that new users seemed to feel out of place in the meetings of these groups, leading to low adherence. This can be related to the fact that they did not carry out activities targeted exclusively at the new participants.

> Since we invite them, when they get here they enter into the rhythm of the current group, we cannot get... Let's say, if there's one or two new ones, we can't go to that group that's starting now... those people who are starting, and work with them separately (Professional 2).

Coordinators of the groups were referring to the fact that, when the groups were implemented, they expected new participants to enter as time passed. They also expected older participants to leave, in a process renewal.

> When we thought about a self-care group, we thought that, and about a transition... We want new actors there (Professional 3).

In SSG 3, two strategies were used to deal with this issue: the first was concluding the cycle of activities of self-care support with some participants, considering that they understood how to self-care and improved their physical disabilities. As a result, some users left the group. The second was separating them into two groups, one for new participants, and another for older ones. However, there were obstacles to the implementation of both strategies, such as the fact users resisted the idea of leaving the group, and there was not an adequate infrastructure for the implementation of two different groups in the service, in addition to the low number of health workers.

The process of working in a group involves subtle social interaction aspects which, sometimes, are difficult to capture. Additionally, dealing with people means dealing with their weaknesses, sensitivities, and needs (Mendonça, 2014). In this regard, the coordinators, by themselves, did not know how to deal with questions such as the long permanence of users. A closer participation of health management, and training provided to coordinators could help dealing with these issues.

A strategy to be considered by the groups is the emancipation of old users and the creation of other types of groups, outside of the health services. These users can become affiliated with other groups of affected people, such as Morhan, or even form other groups. In this context, the support from coordinators and partners, with strategic actions to make this transition possible, is essential.

Planning and carrying out activities

The analysis of the minutes and our observations showed that the participants gathered at the beginning of each year or semester to choose the topics of futures meetings, organize festivities, and tours. In SSGs 1 and 2 they were planning each meeting before it started. In one of them, the planning was carried out with university students from extension activities. The need for more flexible planning was known, since the group may have to deal with unpredictable demands.

> This is the idea, that we have a plan, but that it is not so rigid, because sometimes the group wants something else, at that moment (Professional 1).

> Sometimes we start considering everything we want, what we imagine the group would be, and then, when we get at the group, it was none of that. Sometimes things are completely different (Professional 2).

Group work help users express themselves and, as a result, new subjects and discussions can arise. This takes place when participants are open to listen, there is space to talk, and moments in the group are actually established, while a true conversation happens, that is, one which emerges from the meeting, that is not directed (Gadamer, 2006). In this regard, groups are potential spaces for conversation.

SSGs change over time. Some issues are solved, others arise. SSG 2, for instance, started with the goal of solving problems related to user wounds; then, it took other forms, due to the meetings that were taking place.

In the records in minutes and field diaries, we found activities that were common to the three groups, such as: discussion of disease-related topics, celebrations, and activities for financial sustainability, to maintain the group. Two groups conducted tours, one had a choir, and another had income-generating activities. Two groups tried to offer income-generating activities, but were unsuccessful, as they did not know how to do so and lacked support. SSG 3, which managed to carry out this type of activity, had support from partners to purchase materials, and volunteers that could teach handicraft workshops.

> So today we are working on this issue of finding resources for them, professional training, so we got them these workshops about sewing and stitching, they learned to make scarves in it, there was a *decoupage* workshop, a furniture wrapping workshop... (Professional 4).

The search for economic activities that allow the participants to generate income is also a reality in other SSGs (Deepak; Hansine; Braccini, 2013; Pinheiro et al., 2014). This is the case because people affected by leprosy, especially those who develop disabilities, often become unable to carry out the jobs they had before becoming ill. This is the case of a user of SSG 3, which worked as a barbecue griller and could no longer carry out this activity. The loss of this “identity” causes suffering in many different forms.

The choir, in one of the groups, started because the companion of one of the participants was a conductor, and made themselves available to coordinate the activity. The groups also promoted tours to touristic spots of the city, planned every semester, which received support from university projects. The presence of the choir and the tours highlights the relevance of leisure activities in the daily life of those dealing with the disease.

> The creation of the choir was great for the self-esteem of the group (Professional 3).

In this regard, the activities conducted in the SSGs evaluated had specific aspects, regarding their length and the number of times they happened. An SSG is a meeting of people, and, as such, can have different characteristics, depending on the people involved and the relationships established, the meetings will define the group.

In the experiences analyzed here, there were no users in the coordination of the groups. Only in SSG 2 did a user participate in the organization of the meetings. This is not the case of the groups from Nepal (Langen, 2012), where the SSGs were coordinated by users. The groups in this study also did not choose leaders among participants, as was the case in Ethiopia (Benbow; Tamiru, 2001). These findings lead to reflections about Brazilian health practices based on the power that has been historically exercised by professionals over "patients", cases in which professionals and health services have difficulties identifying users as actors capable of, for example, coordinating a group. Furthermore, Mendonça (2014) highlights that the presence of leadership withing the groups is essential for them to reach their goals and sustainability, given the complexity of the issues at hand.

The topics addressed in the groups by coordinators or external guests are chosen together with the participants or based on demands noticed that the coordinator. The minutes analyzed showed that most subjects were related to health care: the concept of leprosy; self-care with hands, feet, and face; diet; physical activity; alcoholism; stress; caring for one's wounds; and rehabilitation and medication treatment. Other topics, such as stigma/prejudice and social rights were also identified.

It is worth noting that the manual of the Ministry of Health (Brazil, 2010) offers suggestions of themes and work dynamics for the groups, which were included in the schedule of the SSGs. This shows that the materials were used by the coordinators, and that the training sessions they went through were important for their practice. However, since the publication of this document, 10 years ago, the Ministry of Health published no more materials that would help strengthen these groups. This suggests that group activities are not being prioritized by national policies.

The field diary showed that the topics were addressed by lectures or activities with participative methodologies, using games or interactive activities. SSG 1 used more interactive activities (such as games), while the other groups focused on lectures.

> For example, if the topic is caring for one's feet, we will think about how to address the topic so it isn't monotonous, so I don't just talk all the time and the others only listen; the

> idea is to think about an interactive activity, a game or something that makes them feel interested and make them participate (Professional 1).

In the practice of SSGs, dialogic relationships between users and team are essential resources to recognize the importance of self-care and the development of the potential and autonomy of the users (Souza et al., 2014). This is why groups must have educational practices that allow conversations to take place.

This study found diverse activities and the search for a participatory planning with dialogic relationships, showing that the SSGs elaborated different practices aimed at the wellbeing of participants. This is the case because SSGs are spaces for social relationships. The relationships between participants and among all members of the group determine how the group is going to be (Mendonça, 2014). When the group's way of being is based on the meetings between these actors, considering their subjectivity, it fosters care (Ayres, 2009).

Continuity of leprosy self-care support groups

Aspects that favor continuity

The most relevant factor for the continuity of the SSGs was the involvement of coordinators in the activities. There is a significant effort on the part of workers for group activities to take place despite any obstacles, such as those related to the very creation of the groups. Professional practice, when permeated by feelings of responsibility and preoccupation with another (Ayres, 2009), leads to a greater involvement of the professional with the therapeutic project of the participants of the groups.

The motivation of professionals was related, according to them, with the positive answers they receive from users and the affective bonds formed with the group:

> You hear "if this group wasn't here today I don't know what I'd do with my life", and then you see the importance of the group, of love, of one another (Professional 4).
>
> Another thing that helps is to see the benefits, you know, when we see their stories of improvement, when we see patients telling stories... when we see those things, it's a huge incentive to go on (Professional 1).

Other factors that increased the likelihood that the groups would continue were related with support from partners (university, NGOs, social movements, other health and administrative workers in the service), recognizing the value of the groups, motivation, and the force of will of the users.

> I think that, the group really took off when the partnerships started happening, so, like, we got the partnerships with the university, with the NHR [an NGO] and that's when we reached our maximum potential. I also think it helps the group to survive; these partnerships, the unit too, within its possibilities, support from management, we see an effort and that the group is valued, management and district workers also give support (Professional 3).

> If one day something makes it difficult, we'll gather out there, below a tree, and do it, it's the same, even under a tree (User 1).

The external support from partners, starting with the formation of networks involving NGOs, services from different health care levels, and higher education institutions, is recognized by the WHO as a practice which strengthens the care of people with leprosy worldwide (WHO, 2017) and, thus, should be increasingly sought.

Having resources that will allow users to participate in activities, such as tickets for public transportation and food, was also found to favor the continuity of group activities. In this regard, health services should support users who have financial limitations, so they can participate in the activities.

Empathetic interpersonal relationships, permeated by affection and bonds, contribute to the continuity of these groups. In the interviews, participants reported that the group was a place of "joy", "relaxation", and "friendship", that is, a space for social interaction. They often refer to themselves as a "family". Identifying their own problems in other users, sharing experiences, being open to speak, listen, bonding, and building trust were characteristics of the relationships between participants.

> The group, it allowed patients to exchange, one patient helping the other, so much that they could support each other, they could form a family (Professional 4).

> We all complete each other here, you know? Then it's family. It's a family here. We have our families, but this is a second family (User 1).

The group can be a privileged space to build affectionate relationships, and the interaction between actors leads to multiple possibilities in their encounters. In the groups, users share their experiences, establish bonds, and improve their self-esteem as they interact with others who have similar problems (D'Azevedo et al., 2018).

Aspects that hinder continuity

Regarding the challenges to continue the SSGs, we identified: issues related to poor working conditions for the professionals involved; little professional appreciation; lack of support from management and the health team; little ability to innovate in group activities; issues related to users; and maintaining the motivation of participants.

> These are the challenges, having support, being appreciated (Professional 1).
>
> We have to do new things. Innovating at all times is a challenge for me, implementing new things, thinking about news... this is a challenge, communicating more with management (Professional 1).
>
> Challenges to their limitations, many, their limitations, such as wounds, pains, risks, for example, the tickets... So I think it's more their financial needs (User 2).
>
> The challenge is keeping up the good spirits, because when you have motivation for the group, you'll be able to share, right? (Professional 2).

The experiences reported to the coordinators of SSGs 1 and 3 corroborate the idea that the continuity of the groups is associated to the force of will and courage of the professionals who coordinate the groups, that is, in their absence, the groups would probably be extinguished. SSG 2 was the only group to receive support from health service management. Municipal management discouraged the creation of SSG 1, for example. SSG 3 dealt with several difficulties regarding the work process.

> I have been to management, they encouraged me to give up on the group, they actually asked me to cancel it, because it was too much work. So, then, if someone on management tells you that, that's disheartening, you're there alone, trying, trying... (Professional 1).
>
> Because we reached a point, there was a day I didn't have an esthesiometer, I didn't have a room to attend them, didn't have the auditorium to receive the group, I didn't have a way to print or a snack for the patients. So I said: that's it, I have nothing else, it's just me. (Professional 4).

Corroborating the aspects related to the creation of SSGs, the continuity of the groups was associated with personal aspects of the professionals involved, since this was a personal project, not an institutional one. As a result, sustainability was frail.

Therefore, the lack of management support is an obstacle for the creation and maintenance of the SSGs. Mantellini, Gonçalves and Padovani (2019) emphasize that, despite recommendations from official documents that guide policies to control disease, actions related to physical disabilities, in practice, are almost always treated as secondary, when compared to eliminative actions that focus on screening and treating cases. As a result, inabilities continue to exist and have a negative impact on the lives of those affected.

City and state health policies must support existing SSGs, giving them subsidies to make them stronger and encouraging new groups, while also showing appreciation for the work of these professionals. Furthermore, the national policy to combat leprosy should treat the formation of groups as a priority strategy, in accordance with the role of the State as a promoter of better, more integral health care to those affected by the disease.

Final Considerations

The strategy of working with leprosy self-care in groups has the potential to transform current health practices through a more dialogic, participative health activity, which considers more than just physical issues. The SSGs open a new range of possibilities of practices in the routine of professionals, such as a new way to plan and organize care.

The creation and development of the SSGs analyzed were determined by the motivation of the actors involved (health workers and users), the encouragement and support of health policies, national and local policies to control leprosy, and contributions from external actors, such as a university and NGOs. In this context, the personal motivation of coordination professionals and users had more impact over the creation and continuity of groups than the actions of the State. This shows the need for more effective State actions to consolidate the SSG strategy.

When the implementation of new groups in the national setting is expanded, it is necessary to understand the factors that foster or hinder that implementation, organization, and the continuity of SSGs, as this study showed, contributing to implement or reorganize these groups.

The study was limited to a single Brazilian state. Therefore, it is important to carry out further investigations in other regions, considering the continental size of the country.[2]

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Notes

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[2] R. D. do Nascimento: preparation of the research project, collection and analysis of data and writing of the article. I. M. C de Sousa: preparation of the research project, data analysis and writing of the article. C. P. L. de Melo: data analysis and writing of the article. D. C. M. dos Santos: final draft of the article.

Resumo

Criação e desenvolvimento de grupos de apoio para o autocuidado em hanseníase em um estado do Nordeste brasileiro

Objetivo: Compreender a criação e desenvolvimento de grupos de apoio para o autocuidado em hanseníase em um estado do Nordeste brasileiro. **Métodos**: Estudo qualitativo realizado em três grupos no Nordeste do Brasil, entre fevereiro e dezembro de 2019. A coleta de dados englobou entrevistas, observação participante e análise documental. Os dados foram analisados segundo a técnica de análise de conteúdo a partir dos temas preestabelecidos: implantação, organização e continuidade dos grupos. **Resultados**: A implantação dos grupos apresentou como motivos comuns a necessidade de ampliação dos cuidados, e de otimização do tempo de trabalho. O estigma e questões da organização dos serviços foram obstáculos para a implantação. O fator mais relevante para a continuidade dos grupos foi o envolvimento dos coordenadores nas atividades. O apoio de atores externos como ONG e universidades foram relevantes para a implantação e continuidade. **Considerações finais**: As similaridades e diferenças dos grupos relacionam-se aos participantes, à indução e apoio da política de saúde e às interferências de atores externos. Grupos de apoio para o autocuidado em hanseníase são espaços que potencializam a prática de cuidado. O estudo contribui com a implantação ou reorganização de grupos de apoio ao autocuidado.

➤ **Palavras-chave:** Hanseníase. Autocuidado. Grupos de autoajuda.