

Self-care in leprosy from the perspective of groups: a qualitative approach

Autocuidado em hanseníase sob a ótica de grupos operativos: uma abordagem qualitativa
Autocuidado de la enfermedad de Hansen desde la perspectiva de grupos operativos: abordaje cualitativo

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ABSTRACT

Objectives: To analyze a self-care support group for people affected by leprosy from the perspective of operative groups. **Method:** A qualitative study of the explanatory type, carried out in a health unit in a municipality of Pernambuco. Content analysis was carried out, in the thematic analysis proposed by Bardin. **Results:** The results indicated characteristics of the group related to the six vectors of the Pichon-Rivière theory: affiliation and belonging, cooperation, pertinence, communication, learning and tele. **Discussion:** The monitoring of a self-care group in leprosy provides a range of meanings and reflections. Being part of a group increases the opportunities for rebuilding self-confidence, self-esteem and insertion in the community. **Conclusion:** The leprosy self-care support group in focus is characterized as an operative group. Studies that investigate the implicit factors of the SCGs are still needed, especially with regard to the characteristics of the groups in the different health units.

DESCRIPTORS: Leprosy; Self-care; Group Structure.

RESUMO

Objetivos: Analisar um grupo de apoio ao autocuidado para pessoas acometidas pela hanseníase sob a ótica de grupos operativos. **Método:** Estudo qualitativo do tipo explicativo, realizado em uma unidade de saúde em um município de Pernambuco. Foi realizada a análise de conteúdo, na modalidade análise temática proposta por Bardin. **Resultados:** Os resultados apontaram características do grupo relacionadas aos seis vetores da teoria de Pichon-Rivière: afiliação e pertença, cooperação, pertinência, comunicação, aprendizagem e tele. **Discussão:** O acompanhamento de um grupo de autocuidado em hanseníase proporciona uma abrangência de significados e reflexões. Estar inserido em um grupo aumenta as oportunidades de reconstrução da autoconfiança, autoestima e inserção na comunidade. **Conclusão:** O grupo de apoio ao autocuidado em hanseníase em foco se caracteriza como um grupo operativo. Estudos que investiguem os fatores implícitos dos GACs ainda são necessários, sobretudo no que diz respeito às características dos grupos nas diferentes unidades de saúde.

DESCRITORES: Hanseníase; Autocuidado; Estrutura de Grupo.

RESUMEN

Objetivo: Analizar un grupo de apoyo para el autocuidado de personas afectadas por la enfermedad de Hansen (lepra) desde la perspectiva de los grupos operativos. **Método:** Estudio cualitativo de tipo explicativo, realizado en una unidad de salud de un municipio de Pernambuco. El análisis de contenido se realizó según la modalidad de análisis temático propuesto por Bardin. **Resultados:** Los resultados indicaron que el grupo tenía características relacionadas con los seis vectores de la teoría de Pichon-Rivière: afiliación y pertenencia, cooperación, pertinencia, comunicación, aprendizaje y telé. **Discusión:** El seguimiento de un grupo para el autocuidado de la enfermedad de Hansen ofrece una cobertura de significados y reflexiones. Formar parte de un grupo aumenta las oportunidades de reconstruir la confianza en uno mismo, la autoestima y la inserción en la comunidad. **Conclusión:** El grupo de apoyo para el autocuidado de la enfermedad de Hansen se caracteriza, principalmente, por ser un grupo operativo. Aún se necesitan estudios que investiguen los factores implícitos de los GAC, especialmente en lo que respecta a las características de los grupos en las diferentes unidades de salud.

DESCRIPTORES: Enfermedad de Hansen; Autocuidado; Estructura de Grupo.

INTRODUCTION

Leprosy is a chronic disease that mainly affects the skin and peripheral nerves, also affecting the eyes and the organs. Due to its clinical condition, leprosy has a high disabling power, being able to interfere in quality of life⁽¹⁾.

One of the main strategies for the prevention of disabilities is self-care, characterized by the individuals' act of taking care of themselves and understanding their body and mind regarding their difficulties and limitations, through actions aimed at the adoption of healthy habits, control of risks and health problems and, consequently, improvement of quality of life. Self-care can be operated in individual care or with a group approach⁽²⁾.

The Leprosy Self-Care Groups (SCGs) created with the objective of being a space where their members develop skills to recognize health problems and complications, how to prevent or care, in addition to allowing for the exchange of experiences among people with needs and interests in common. It is noteworthy that the group is also important for the integration between the health network and the users, in order to improve comprehensive health care⁽²⁾.

The SCGs are proving to be an innovative strategy with regard to the work on clinical issues, self-esteem, empowerment and social participation. Self-care is one of the goals of the 2016-2020 Global Leprosy Strategy, which aims to achieve "a world without leprosy" in

the long term⁽³⁾. A number of studies address the importance of implementing SCGs in health services and bring positive results to the lives of users on several issues, such as, for example, with regard to social participation, self-esteem, socioeconomic rehabilitation and clinical aspects of the disease⁽⁴⁻⁶⁾.

When it comes to the operationalization of group work, Pichon-Rivière, an Argentine psychiatrist and psychoanalyst, elaborated the theory of the operative group. He defined an operational group as a set of people, interconnected in time and space, centered on an objective, which explicitly or implicitly proposes a purpose, a task, behaving like a network of roles, establishing links between them⁽⁷⁾.

Consequently, the theory attributes major importance to the social ties, which are the basis for the communication and learning processes⁽⁸⁾. The author built a dialectical spiral, which encompasses the group process. This is represented by an inverted cone and, in this graphical representation, there are the six vectors of analysis: affiliation and belonging, cooperation, pertinence, communication, learning and tele⁽⁷⁾.

The affiliation and belonging vector represents the relationships and the degree of identification among the participants in the task and the feeling of belonging to the group. Cooperation is characterized by the actions of one individual towards the other and mutual

help, contributing to the group task. Relevance consists of the group's ability to focus on the task. The communication vector evaluates the communication networks existing in the group, which can be verbal or non-verbal. Connected to communication is the learning vector, which accounts for the information of all members. Tele refers to the feeling of sympathy or dislike existing in a group⁽⁷⁾.

Within the perspective of the SCGs, there are existing gaps regarding the understanding of the functioning logics of these groups, since they are gradually configured depending on the actors involved. In this sense, studies that seek to advance the understanding and development of these groups, through established theories such as operative groups, become relevant. This knowledge can contribute to a better understanding and strengthening of the SCG strategy.

The operative group theory proposed by Pichon-Rivière is capable of promoting a better understanding of the group process that the SCGs have been developing. In addition, the analysis of the functioning of these groups based on this theory innovates studies already carried out on this theme. Given the above, this study aims to analyze a self-care support group for people affected by leprosy from the perspective of Pichon-Rivière's operative groups.

METHOD

This is a qualitative study of the explanatory type, as it seeks to describe the phenomenon through explanations and theories about how and why things happen, deepening the knowledge of reality⁽⁸⁾. It was carried out in a leprosy self-care support group located in a municipality of Pernambuco. The number of participants in the group is variable, between six and eight participants per meeting, with regular participation of a mean of five participants.

The location was chosen because it is a reference service for the treatment of patients affected by leprosy, for having a self-care group implemented three years ago, and for being part of research and extension projects at the University of Pernambuco, the linking institution of the authors. The number of participants in the group is variable, between 6 and 8 participants per meeting, with regular participation of a mean of 5 participants.

Data collection was carried out from November 2017 to November 2018. For data collection, two techniques were used: participant observation and semi-structured interviews.

Participant observation consists of integrating the researcher into the reality he intends to observe, becoming one more of the group⁽⁹⁾. 10 participant observations were conducted with records in field diaries. The instrument contained questions about the dynamics of the group, topics covered, physical space of the meetings, and behavior of the professionals

and users. The meetings were held once a month. During this stage, the study subjects were selected, as well as key informants whose selection occurred following the intentionality criterion. This criterion takes into account the quality of the information; therefore, the oldest participants in the group with the most regularity in the meetings were selected, being the subjects who would make possible a better contribution to the phenomenon under study⁽⁹⁾.

The semi-structured interview consisted of pre-formulated questions, directed to the study subjects, about the activities carried out, the importance for the participants, the dynamics developed, and the topics addressed in the group⁽⁹⁾. Five interviews were conducted: one with the unit's health professional, who coordinates the group, and four with SCG participants, these being the oldest subjects in the group and with the best attendance records in the meetings.

The interviews took place in the health service, on the days of the self-care support group meetings, in an appropriate place and at a time agreed upon with the study participants. These were recorded and transcribed in full for later analysis.

The data from the interviews and field diaries were analyzed through content analysis, in the thematic analysis modality, which followed the phases of floating reading, pre-analysis, exploration of the material, coding and categorization⁽¹⁰⁾.

The analysis was performed through pre-established categories, defined from the perspective of Pichon-Rivière's group process⁽⁷⁾. In this sense, the six vectors for categorization were considered: affiliation and belonging, cooperation, pertinence, communication, learning and tele. In the text, to describe the results, the subjects were identified as Participant 1 to Participant 4 and as Professional.

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RESULTS

In data analysis, it was identified that the group practices were related to the characteristics of the vectors identified in the operative group theory⁽⁷⁾. The group studied has the central task of working with self-care supported among the participants. In this sense, the results are presented according to each of the six vectors proposed by Pichon-Rivière.

Affiliation and belonging

Affiliation and belonging are essential indicators for the development of operative groups and were present in the participants' testimonies when citing the creation of bonds between members, as noted in the following statements:

It's a family that we chose, a family that we created here. Then I feel like I'm part of a family... (Participant 2).

I'm really enjoying this group, I'm really enjoying it. I even said: I was discharged, but I will not leave you (Participant 3).

It was observed that the users feel free to share their trajectories about the disease, experiences and difficulties, feelings, opinions, ideas and desires for the future, as they know that there they find support from the coordinator and other participants, as seen in this excerpt from the coordinator's speech:

And then it was very interesting to hear that we're a family, right? We welcomed a patient who reported, who felt free to report, who has a homeless situation, who has nowhere to live, who has no family, the only family is a daughter he has and she's in prison. Then the others, automatically, right? they put themselves to say "We are your family now" (Professional).

In the observation, it was possible to see that the participants feel at ease, hug each other, expose doubts, talk to each other about different subjects and demonstrate efforts to

be present. Behaviors related to the attachment that the members have for the group were also observed, many found the affection, solidarity and respect that, as reported in the meetings, they did not obtain in their own family. The conviviality and shared life at each meeting provided the feeling of belonging within the SCG under study, giving new meaning to the users' presence in the meetings.

Cooperation

Through the analysis of the field diaries, this vector was identified through the proactivity and collaboration of the users in carrying out activities developed in the SCG, in addition to the willingness to share and teach each other their individual skills, aiming to contribute to the learning of the large group.

Cooperation was also identified at times when the SCG members effectively participated in dynamic activities, such as making decorated boxes and vases in income-generating workshops, selling clothes in an organized bazaar to acquire resources for activities of the group, and at the moments of mutual help and welcoming among the users, as highlighted in this speech by the coordinator:

We talk about self-care because they start to take care of themselves, to think about themselves, but it's also a place for caring for others, right? We have a lot of the importance that we give to the other, right? What the other is doing... (Professional).

The participants' feeling of belonging, identified in the first vector studied, is related to cooperation, since the users feel part of a family, in which they aspire to growth and mutual help:

I never had these friends like these... I live alone, right? That I have no friends. But after I came here I got a lot of sister. A lot of... a complete family and lives in here ... this family lives here inside me. Friendship I have with these people. I like you a lot, I love you (User 2).

Pertinence

It was possible to observe that the SCG coordinator plays an important role in sustaining the task, interconnecting factors, placing them in a condition of empowerment, as subjects capable of participating in the corrective process, since the group is a basic structure of interaction:

What I try to look for is that there is always an argument, right? To try to find them, to talk... to praise, to listen, to show that opinion is important. And that's it. It's not just showing, it really is. That they... that they are participating, that they feel they are actors in that process, not supporting people. That they feel they are primary participants in that process. My quest is this, to try to get them to participate, to be there (Professional).

Communication

Regarding the participants' behavior in

relation to the conversations existing in the group, the users report different experiences. Some assume the role of listeners and others are more expressive, with conversations and exchange of experiences among the members, as shown by the following reports:

No, I never say no. My way is to keep silent just listening. I just listen. When I was there I never spoke. Sometimes I speak. Once. Sometimes I don't even speak. I'm only listening, I know how to say no (Participant 1).

And here among the colleagues we talk. One says what he's feeling or an improvement he has had from then on. (Participant 4).

There was also a complaint from another user to the group colleagues when expressing that there is lack of commitment when an activity is organized and the group members do not attend the meeting, which can be characterized as "misunderstanding".

In the group under study, these questions can be seen as a possibility for strengthening pertinence. This is due to the fact that these issues such as divergences and difficulties are agreed upon and dealt with during the meetings, and actions around the group task are defined by them, the absence of a member causes difficulties for its success.

Learning

In the group under study, learning is consolidated through health education dynamics that add interaction of all

participants and mainly address the theme of self-care.

Communication and interaction are revealed as fundamental elements for the effectiveness of the teaching-learning practice, being reported in the following statements:

One of the main [activities carried out in the group] is to talk about the disease, how we're reacting, about what we should and should not do, taking care of the body, treating the body, taking medication at the right time, among other things (Participant 4).

We talk about... we learn to exercise, we learn to do, like, care about the knife, about the fire, because there are a lot of people who have numbness in their hands (Participant 3).

It's more about the theme of the feet, hands, eyes, eye care, throat. You show all of this to us here (Participant 3).

In the dynamics of self-care with hands and feet performed in this group, for example, it was observed that learning is built through the exchange of knowledge and the display and reproduction of care by the users, who from then on report being more attentive to daily self-care. Topics such as the importance of the medications, myths and truths about the disease, and rights and duties were also addressed. In addition to that, there were moments of discussion of documentaries about Leprosy and social gatherings, which adds great interest and excitement to the participants, as they are able to learn through

a more accessible and interactive language.

Tele

In the observations made, it was possible to observe moments when small groups with some members of the SCG interacted with each other, talking about issues in their personal lives, showing interest and attention to the speech of the other. Although there are no conflicts and not interfering with the functioning of the SCG, there are those participants who interact more with some than with others. This point was also identified from the following report:

Let's suppose, there's a group of 10 or 15 people, there's always one that is not close to the person and the person is not close to him (Participant 4).

Within the operative group there is greater approximation between some members, which, in other words, represents the formation of subgroups within the group itself. In relation to the group under study, these relationships are important because they also develop the feeling of belonging. Consequently, the participants feel able to create close bonds and friendships for being with people who share the same experiences and difficulties, thus building tele.

DISCUSSION

The monitoring of a self-care group in leprosy provides a range of meanings and reflections. The narrowing of affective bonds in this space

is justified by the need for social and emotional support of the individuals affected by the disease when considering the prejudice and stigma caused by leprosy⁽¹¹⁾.

In Pichon's theory, the narrowing of ties is categorized as Affiliation and Belonging. The feeling of affiliation is transformed into belonging, where the identification of the subject with the group is perceived, the feeling of "us", becoming part of the whole and the desire to be present and to commit to the task⁽⁷⁾.

A research study carried out with an operative group of mothers who take care of children with disabilities is in line with this study when it confirms that the group, based on the establishment of bonds, is characterized as a welcoming place for people who face the same reality. The group becomes a space of comfort, where its participants feel safe to exchange experiences and reframe their life experiences. The creation of these social bonds is fundamental to the learning process⁽¹²⁾.

Social exclusion in individuals diagnosed with leprosy sometimes becomes heavier than the clinical manifestations of the disease. In addition to social reintegration, the group also favors the participants' transition back to their community; participants in self-care groups demonstrate better control of the disease and of its origins⁽¹³⁾. Feeling part of a group can be a contributing factor to the user's empowerment process in the fight against the

disease⁽¹⁴⁾.

Cooperation is another important point for the establishment of the group. The users' proactivity and collaboration is a factor routinely found in the meetings of the group under study. Mutual support is a characteristic that is also found in a support group for self-care in leprosy in Nepal, even though individual counseling exists, the participants share experiences and former participants practice preventive self-care measures with the patients. The study shows how this exchange of information between participants of the same origin and with similar experiences is positive when it comes to leprosy⁽¹³⁾.

In the effectiveness of group development, it is essential to undo stereotypes and interrupt the resistance to change on the part of the participants to improve the learning and communication process within the group, often caused by of the participants' insecurity. For a group, pertinence is an important point for its effectiveness and continuity⁽¹⁵⁾.

Regarding the role of the coordinator in strengthening pertinence, one of its functions is to identify and monitor components for the construction of meanings of the task within the group. The coordinator becomes a fundamental part to strengthen relationships and enhance group activity, monitoring the creation of bonds, providing individual and collective self-knowledge by identifying movements and attitudes of the participants

that hinder group integration and synthesis⁽¹⁵⁾. There is evidence that the feeling of welcome in a self-care group favors mutual support and recovery of self-esteem⁽¹⁶⁾.

In this process of strengthening the group, the spokesperson is identified, the one who expresses the feeling of the group since, gradually, questions, reflections and other subjective issues arise among the group participants⁽¹⁷⁾. Bringing the analysis to the group under study, the different roles of the participants in the communication allow us to infer a good relationship and interaction between them, even though there are divergences. Pichon explains that "misunderstandings" arise from a failure in the communication circuit, common basic issues in group integration, often due to the difficulty in sending a message or to the lack of understanding of those who receive it⁽⁷⁾.

In another study, conflicts and divergences that can emanate in operative groups were also pointed out due to the differences between the people who compose it, stating that this allows people to deal with their individualities, building collective learning. With regard to Pichon's theory, he states that overcoming learning and communication difficulties is one of the purposes of the operative groups⁽¹²⁾.

With regard to learning, a study⁽¹⁸⁾ developed in 2018 with a group of people with Diabetes Mellitus and hypertension, the message conveyed enabled the participants to re-

elaborate the information transmitted to the group, improving the work of the group process by promoting better integration among the participants and questioning about themselves and the other. The study shows that this communication is fundamental for learning, making it possible to internalize effective lifestyle changes through this interaction and knowledge sharing in a way similar to our analysis.

The health education strategies used by the group coordinator are important for the participants' learning process. Reflections from a study in Operative Groups of the Luis Amigó Foundation show that, in an operational group, the coordinator identifies the current needs of the participants and uses methodological strategies that revolve around the verbalization possibility of the participants, neutralizing the distraction or avoidance process. In the case of leprosy, there is a need to adapt health education to the sociocultural level of the patients for it to be effective⁽¹⁹⁾.

In addition to health education, the group under study also included an income-generating project in the community; making decorative boxes and vases was important for the recognition of their self-ability and confidence. Members of a group in Nepal who got involved in a similar activity verified the opportunities obtained from the project, contributing to greater social acceptance and to better opportunities of active participation

in the life of the community in which they are inserted⁽¹⁶⁾.

The last vector, *tele*, consists of the positive or negative distance among the group participants, both between themselves and with the coordinator. That is: It is necessary to note that a negative tele is harmful to the group in relation to the task. This fact is due to the affinity and to the greater willingness to interact more with one of the members, and even with the coordinator⁽⁷⁾.

When it comes to leprosy, this point is important when it comes to social relationships. Being part of a group increases the opportunities for rebuilding self-confidence, self-esteem and insertion in the community.

In addition, over time, the users begin to recognize the importance of self-care and in continued participation in these groups⁽¹⁶⁾.

CONCLUSION

In view of the results presented, it is possible to characterize the support group for self-care in leprosy under study as an operative group, taking into account the vectors of the group process of the dialectic spiral. The technique of the operative group is important for the performance of nurses and other health professionals as it highlights the relevance of communicative processes and their benefits among group participants and their coordinators. The study elements reinforce the idea that the SCGG can be a space for active

participation and empowerment for the users, corresponding to their health and affective needs.

The work with Pichon's theory can bring about elements that collaborate with the improvement of groups focused on self-care in leprosy as a tool for their coordinators with regard to strengthening and contributing to their creation and/or continuity, since the theory covers essential factors of a group. Studies that investigate the implicit factors of the SCGs are still needed, especially with regard to the characteristics of the groups in the different health units.

The study was carried out in a self-care group with limits related to the generalization of SCGs as Pichon-Rivière's operative groups, making it necessary to study experiences in other realities.

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