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ORIGINAL ARTICLE

PERCEPTION OF PATIENTS WITH LEPROSY ABOUT THE SELF-CARE GROUPS PERCEPÇÃO DE PACIENTES COM HANSENÍASE ACERCA DOS GRUPOS DE AUTOCUIDADO PERCEPCIÓN DE PACIENTES CON HANSENIASIS ACERCA DE LOS GRUPOS DE AUTOCUIDADO

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ABSTRACT

Objective: to analyze the perception of leprosy patients about self-care support groups. **Method:** qualitative, descriptive study, carried out in a reference health unit for the treatment of leprosy with 11 patients. Data was collected through a semistructured interview using the Content Analysis Technique. **Results:** the findings were classified into two categories: << Importance of self-care for the prevention of physical and psychosocial disabilities and << contributions of self-care support groups in coping with the difficulties and limitations of people affected by leprosy >>. **Conclusion:** self-care support groups provide the reduction of physical disabilities through preventive measures, health education, adherence to self-care and treatment. In addition, these groups raise self-esteem, overcome prejudice, and enable the therapeutic link between patients and professionals. This study assists in coping with the difficulties and limitations of people affected by leprosy. **Descriptors:** Self-care; Leprosy; Prevention; Disabilities; Health Education; Self-Help Groups.

RESUMO

Objetivo: analisar a percepção dos pacientes com hanseníase acerca dos grupos de apoio ao autocuidado. **Método:** estudo qualitativo, descritivo, realizado em unidade de saúde de referência para tratamento da hanseníase com 11 pacientes. Os dados foram coletados por meio de entrevista semiestruturada, e realizada a Técnica de Análise de Conteúdo. **Resultados:** os achados foram classificados em duas categorias: << Importância do autocuidado para a prevenção de incapacidades físicas e psicossociais e << Contribuições dos grupos de apoio ao autocuidado no enfrentamento das dificuldades e limitações das pessoas atingidas pela hanseníase >>. **Conclusão:** os grupos de apoio ao autocuidado proporcionam a redução de incapacidades físicas, por meio de medidas de prevenção, educação em saúde, adesão ao autocuidado e tratamento. Além disso, esses grupos elevam a autoestima, proporcionam a superação de preconceito e possibilitam o vínculo terapêutico entre pacientes e profissionais. Este estudo auxilia no enfrentamento das dificuldades e limitações de pessoas atingidas pela hanseníase. **Descritores:** Autocuidado; Hanseníase; Prevenção; Incapacidades; Educação em Saúde; Grupos de Apoio.

RESUMEN

Objetivo: analizar la percepción de los pacientes con hanseniasis acerca de los grupos de apoyo al autocuidado. **Método:** estudio cualitativo, descriptivo, realizado en unidad de salud de referencia para el tratamiento de la hanseniasis con 11 pacientes. Los datos fueron recolectados por medio de entrevista semiestructurada y realizada la Técnica de Análisis de Contenido. **Resultados:** los hallazgos fueron clasificados en dos categorías: << Importancia del autocuidado para la prevención de incapacidades físicas y psicossociales y << Contribuciones de los grupos de apoyo al autocuidado en el enfrentamiento de las dificultades y limitaciones de las personas afectadas por la hanseniasis >>. **Conclusión:** los grupos de apoyo al autocuidado proporcionan la reducción de incapacidades físicas, por medio de medidas de prevención, educación en salud, adhesión al autocuidado y tratamiento. Además, estos grupos elevan la autoestima, proporcionan la superación de prejuicio y posibilitan el vínculo terapéutico entre pacientes y profesionales. Este estudio ayuda en el enfrentamiento de las dificultades y limitaciones de las personas afectadas por la hanseniasis. **Descriptor:** Autocuidado; La lepra; Prevención; Discapacidad; Educación em Salud; Grupos de Autoayuda.

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INTRODUCTION

Leprosy is an infectious disease caused by the intracellular bacillus *Mycobacterium Leprae* (*M. Leprae*). It is a disease of a chronic, slow, treatable course and its form of transmission occurs through the upper airways. Contamination occurs through direct and prolonged contact with the carrier, which is not being treated.¹ The disease has a high infectivity rate, but low pathogenicity, ie it infects a large number of people, but few become ill.¹

The bacillus has an affinity for peripheral nerves, mainly affecting the skin and mucous membranes. This neural tropism is responsible for the incapacitating potential of leprosy, which, when left untreated or treated late, can result in deformities and disability. The degree of disability can be determined from the neurological evaluation of eyes, hands and feet. Its result is expressed in values ranging from 0 (zero) to II (two), where 0 (zero) does not indicate the presence of neural involvement and II (two) indicates the presence of disabilities and deformities.²

In order to make it possible to cure and break the chain of transmission of the disease, the World Health Organization (WHO) introduced polychemotherapy (PCT) for the treatment of leprosy in the 1980s.³ New related requirements, such as the reduction stigma, promoting the social reintegration of these patients and the quality of life. Social issues and human rights of people affected by leprosy were considered in public health policies related to the disease.³

Leprosy has a significant disabling potential, which can result in several inconveniences for the performance of the patient's daily life activities. Such disorders can be avoided through early diagnosis and treatment.⁴ In this sense, there is a strategy in progress in Brazil for the implementation of self-care support groups in health services, supporting people affected by the disease. The central proposal of self-care support groups is to bring together people with the same grievances and interests, who wish to learn to cope with their difficulties, through the exchange of experiences.⁴

Leprosy Self-Care Support Groups (SSGs) are an indispensable tool in the prevention of disabilities and in maintaining treatment.⁴ The groups also promote social interaction, exchange of experiences among their members and help overcome difficulties related to diagnosis of the disease.⁴ In addition, they make it possible to optimize the time that professionals would lead to

individual self-care guidelines, by performing them in a group.⁴

Thus, it is important to understand patients' perceptions about the development in SSG and its contribution to its treatment. This perception will enable the understanding of the potentialities and limits of groups, as well as the reorganization of the work process. In addition, it provides an overview of the performance of teams, who are involved in healing, prevention and rehabilitation, under the patient's eye.

OBJECTIVE

♦ To analyze the perception of leprosy patients about self-care support groups.

METHOD

A qualitative, descriptive study, carried out from February to June, 2016, in a support group for self-care in leprosy of the Otávio de Freitas General Hospital (OFH), located in the city of Recife / PE, Brazil. The field of study was selected for offering ambulatory care to patients with leprosy. In addition, the hospital develops disability prevention activities through two self-care support groups (SSG) since 2012, with approximately fifteen patients each.

As a criterion of inclusion in the study, patients with a diagnosis of leprosy, SSG participants for at least six months, were aged at least eighteen years and had attended at least three meetings of the group. The research population consisted of thirty-four patients enrolled in the SSGs (twenty men and fourteen women). From this number, those who met the inclusion criteria participated and accepted to be part of the study. Thus, the study sample was of the random type until the saturation of the information, totalizing eleven patients.

Data collection was performed through a semi-structured interview, which addressed the following topics: the importance of SSG, SSG contributions in the therapeutic process, SSG activities and motivation to participate in the group.

The interviews were recorded, then transcribed in full. The data was analyzed through the Bardin Content Analysis.⁵ The research was developed after approval of the Ethics Committee, with CAAE opinion 641,926, governed by resolutions 466/2012 and No. 510/2016 of the National Health Council of the Ministry which guide research involving human beings. Participants were guaranteed confidentiality and identity anonymity. All of them signed the Informed Consent Term, after

receiving information on the subject, object and objective of the study.

RESULTS

Eleven people (eight men and three women) were interviewed, from the Metropolitan Region of Recife and the interior of the State of Pernambuco. The interviewees were between the ages of 30 and 60.

The characterization of the participants reveals the predominance of males among the study participants, being 73% of males and 27% of females. Regarding the clinical form, 82% are of the multibacillary Virchowian type and 18% of the pure neural form (present the peripheral nervous compromise, as the first manifestation of mononeuropathy type). Regarding the degree of disability, we observed 36% of degree of disability I and 64% of degree of incapacity II. All interviewees had some degree of disability already in place.

From the analysis, the interviews were organized in the following thematic units: therapeutic contributions, changes after SSG and professional performance. Subsequently, the units were classified into two categories: importance of self-care for the prevention of physical and psychosocial disabilities and SSG contributions in coping with the difficulties and limitations of people affected by leprosy. The two categories are presented below:

♦ Importance of self-care for the prevention of physical and psychosocial disabilities

Self-care support groups contribute to building competence and awareness about the need for self-care practices in the routine of patients. The interviewees revealed that the guidelines discussed in the groups are fundamental for improving the health condition, as can be seen below:

Always take the medicine right [...], wash your feet [...], take care ..., give moisturizing oil [...]. Self-care all [...]. Sometimes we do not do everything completely, because it's a lot for us to do [...]. When standing in front of the television, put your feet in the water for ten minutes [...] and then [...] hydrate [...]. Then we feel better. (page 04)

Look, I learned to take care of the eyes, to take care of the nose, right? [...]. Up to your ear, eh? And the very voice, which is [...] the throat of the people, is a little dry. And we must also be careful, be guided and [...] heard as well as members, right? Nerves, arms, feet ... these things [...]. All this we could handle better, right?". (p. 06)

In the meetings of the group are discussed topics that approach the knowledge about the disease, the difficulties experienced in the day to day and the coping strategies. Patients reported changes related to the understanding and acceptance of the disease, as well as the improvement in self care after participation in the SSG, as reported below:

Maybe today I had some injury because of lack of information [...], if I had not joined the group [...]. I believe, that the information [...], That made me today had no sequel. (p.66)

I believe even Hansen's behavior changes, have you? The way we behave with our own disease, so that it does not cause great harm and without self-care we would not be able to. It changed because, in the case, if I had not participated, I would not have information on how I would get rid of this easy disease, right?. (p. 07)

When asked about the motivation to participate in the groups, respondents reported recognizing the importance of accountability with the therapeutic process and support among SSG participants, as noted in the following statements:

When I come here, I feel better and we talk, try to know things. There was one time that I wanted to stop taking the medicine, because I take medicine and never get well. I kept thinking: no, it's better to do what has to be right. (page 07)

Like this [...]. Since I have the disease and those people have it, [...] we are debating: what is better [...], what can I do [...]. (p. 02)

SSG provided patients with social interaction as well as the ability to recognize that they need to adopt self-care. This has led some to take a stand to support and sensitize others to self-care.

♦ Contributions of the SSG in coping with the difficulties and limitations of people affected by leprosy

The interviewees reported that they felt worry and fear when receiving the diagnosis of the disease. However, when they entered the SSG, they were well received and properly targeted. They emphasized the importance of the reception performed by health professionals and other participants of the group, as approached by one of the interviewees:

I was crying in the room [...]. You do not know how hard it is to get here. And the way she [healthcare professional] welcomed the patients hugging, kissing, when she gave me the first hug I thought: she kissed me! I was horrified! This woman must be crazy or she must have the disease right? (p. 11)

Patients reported that when the diagnosis was discovered by friends and family, there was a move away from these people and that was one of the reasons they hid the diagnosis. They were restricted only to their environment, for fear of people's reactions and this isolation brought innumerable damages to social relations, as pointed out below:

And there are people who, like me, go away [...]. I think because of the prejudice [...]. I am no longer ashamed to say [...]. Before I had, then the group helped me a lot. (page 02)

At first there was a lot of prejudice, but after I joined the group, we made new friends. That attracted a lot of good things, because before I felt everything out there [...]. After the group, I accepted the disease better. (p. 05)

Patients with feelings of sadness and hopelessness reported that they lived in isolation and without much social interaction. After participating in the group, however, there was a reduction of these symptoms. Because they succeeded in interacting with others in the same situation, they achieved an improvement in self-esteem. The sharing of experiences and established links strengthened self-confidence. In the group, the patients realized that they could be themselves, without hiding their injuries, physical disabilities or limitations, as we see in the following reports:

I lived very depressed [...], I lived thinking. I said, my God, take care of me, Lord [...]. But then I'm glad to be coming here to the group. (page 01)

It has changed in my life that sometimes, when I come here myself, I feel better. We talk and look for things. (page 07)

Just the fact of coming and participating in the group, seeing that there were people with more difficulties than I, with more weaknesses that I had and was there strong and strong, why I could not be? (p. 11)

Thus, in view of all the stigma, fear and low self-esteem reported by the patients, it was possible to identify that the self-care group contributed to the acceptance of the disease and the stigma confrontation. It is worth noting that the group facilitated the exercise of social interaction, as it worked as a support for people, in the search for autonomy and self-esteem.

DISCUSSION

Leprosy, when diagnosed and treated late, can result in physical disabilities. The disease can lead to decreased work capacity, social problems, mental disorders and limitation in

the accomplishment of activities of daily living.⁶ It is possible to emphasize in this study that the interviewees already had some type of installed incapacity, which reflects the diagnosis late disease.⁷

The degree of disability is determined from the neurological evaluation of the eyes, hands and feet and their results vary in values from 0 to II. The assessment of disabilities is extremely relevant for the education and promotion of self-care. In this case, the central objective is to avoid the installation of post-discharge disability.⁸

The prevention of incapacities is done through procedures and exercises, which the individual, properly oriented, encouraged and trained, should perform regularly at home, during treatment and after discharge. For this, it is necessary to have a behavior change, with a relationship of trust between the patient and the health team, besides the incorporation of self-care in the routine of individuals.⁹

Support groups for self-care in leprosy (SSG) arose from the perspective of preventing disabilities and physical and psychosocial limitations, as well as combating the stigma and prejudice suffered by people affected by the disease. SSGs also function as an important health education tool.¹⁰

The groups play a very important role in disseminating information about leprosy. In the majority of the interviewees' speeches, it was recognized the importance of the SSG as an information vehicle, capable of promoting adherence to treatment. In addition, it is a channel for listening and health education, which results in greater adherence to the achievement of self-care.

Therapeutic groups have as their primary objective to improve illness situations, which affect individuals, both physiologically and mentally. The benefits and advantages of bringing together people with common illnesses or similar difficulties are numerous. Patients are able to perceive their problems when viewed in others. Thus, the groups allow greater therapeutic adherence, besides serving as a stimulus for self-care.¹¹

According to the interviewees' statements, it is possible to identify that the SSG provided the exchange of knowledge and the improvement in motivation for life. The groups contributed significantly to the construction of patients' autonomy and responsibility, in their care and, respectively, in their welfare. They provided learning as well as providing self-care support. Through SSGs, participants are able to identify

behaviors that need to be changed or corrected, as well as reinforce the exchange of experience between them.¹²⁻³

Relevant information identified in the interviews was the confrontation of the disease stigma after insertion into the SSG. It is known that stigma in leprosy is directly linked to issues that correspond to the body, or to body image with sequelae. Historically, the social isolation of leprosy patients has strengthened the spread of widespread fear, stigma and prejudice in society in relation to leprosy.¹⁴

Stigma causes difficulty in social acceptance and, as a result, there is a reduction in quality of life. The patient becomes discriminated against, which results in social isolation. Difficulties are observed in the relationship of the stigmatized with family and friends, as well as in social relations. This was a situation reported by the interviewees.⁷

It can be seen that coping with stigmatizing situations requires the work of health professionals, who have a relevant role in guiding and disseminating information on leprosy. They should demystify their negative image, as experienced and reported by the participants of this study.¹⁵

The lack of health education actions keeps the society unknowing about leprosy and, consequently, prejudice. Therefore, it is essential to carry out educational actions in health, so that people can better understand and understand the disease. Thus, the insertion of the patients into the SSG provided greater knowledge and made it possible for the patients to demystify information about the disease through social interaction with other people under treatment.¹⁶

Leprosy is considered a chronic disease. Depending on the disability and the disabilities it can cause, in addition to the stigma involved, it can lead to an increased risk of mental disorders, especially depression.¹⁷

This study pointed out that some interviewees reported a feeling of sadness, faced with difficulties with the diagnosis of the disease. It was also observed the importance of the group, as a supporter for the change of feelings and attitudes, facing this problematic.

Sadness and depression are frequent conditions in people who are diagnosed with chronic diseases, because they compromise the individual's functionality and adaptation to social life. The high incidence of depression and the numerous impacts it causes have been considered serious problems of this 21st

century, appearing as public health problems. Depression is significantly higher in people with chronic diseases, who need special and more specialized attention from the professionals involved in their care.¹⁸

Chronic diseases need permanent treatment and, therefore, their patients need habits that promote awareness for self-care. In this sense, adherence to treatment is essential for the success of therapy. This adherence refers to the behavior of the patient, in relation to the recommendations of the professionals, the frequency of consultations or changes in their lifestyle. Failure to adhere to treatment results in therapeutic failure. For this reason, many professionals are concerned about patients adhering to treatment, since this failure affects their quality of life and the care they provide.¹⁹

The performance of the health team can be the differential in adherence to the therapy, through the reception. Encouragement is a key factor so that the patient can achieve the knowledge and the necessary skill in the incorporation of new habits favorable to self-care.⁴

The relationship between professionals and patients depends on the professional's ability to establish interpersonal relationships. Numerous experiments have shown that some patients' complaints could be avoided or diminished if they had been heard, understood, accepted, considered and respected.²⁰

Health team professionals, especially those involved with SSG, are coparticipants in the process of patient commitment. They should tailor their language to the public, inform and clarify their questions in a clear and direct way, stimulating them to self-care.¹⁷

CONCLUSION

The study allowed the identification of the importance of self-care support groups, from the perspective of the patients participating in the SSG. The group contributed to the reduction of their physical disabilities, as well as to adherence to self-care and treatment. SSG was also important for raising patients' self-esteem, enabling a greater therapeutic bond between them and professionals and helping to overcome prejudice to the disease.

Patients' perceptions about SSGs allowed us to identify the relevance that these therapeutic groups have over the life of each participant, as well as their potential contribution in encouraging adherence to self-care practices. Studies on group activities for

the treatment of chronic comorbidities and stigmatizing diseases are extremely relevant. Research on the functionality of therapeutic groups will provide subsidies to policy makers and those involved in the treatment of chronic diseases. The studies aim at the physical and psychosocial improvement of the participants and are good tools for coping with these diseases, which require specific and prolonged follow-up.

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