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RESEARCH

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HANSEN'S DISEASE PATIENTS' PERCEPTIONS ON THEIR ALTERED FUNDAMENTAL HUMAN NEEDS: INDICATIONS FOR SELF-CARE

Percepção de pacientes com hanseníase sobre suas necessidades humanas básicas alteradas: indícios para o autocuidado

Percepción de pacientes con hanseníasis sobre sus necesidades humanas fundamentales cambiadas: indicaciones para el autocuidado

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ABSTRACT

Objective: The study's main purpose has been to analyze Hansen's disease patients' perception on their altered fundamental human needs. **Methods:** It is a descriptive research with a qualitative approach, which was performed with ten patients who were registered in the National Hansen's Disease Control Program at a Health Unit, in *Belém* city, *Pará* State, Brazil. Data collection took place over the period from August to September 2017, through the use of semi structured interviews and patients' medical reports. The data was organized and analyzed from the perspective of content analysis. The research was approved under the No. 2.148.415/06.23.2017 by the Ethics Committee of the *Escola de Enfermagem Magalhães Barata* [Nursing School]. **Results:** There were identified five altered needs, specifically: physiological, security, love and/or social, esteem and self-actualizing needs. It was noticeable that the perception of altered needs stimulates self-care actions, therefore, pointing towards achieving satisfaction. **Conclusion:** The nurse should provide humanized care towards patients bearing Hansen's disease, motivating them to achieve autonomy and self-care, hence contributing to an improvement in their quality of life.

Descriptors: Nursing care, Hansen's disease, Health education, Self-care, Nursing theories.

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RESUMO

Objetivo: Analisar a percepção de pacientes com hanseníase sobre suas Necessidades Humanas Básicas alteradas. **Método:** Pesquisa qualitativa e descritiva, realizada com dez pacientes inscritos no Programa Nacional de Controle da Hanseníase em uma Unidade Básica de Saúde em Belém-PA. Dados coletados de agosto a setembro de 2017, por meio de entrevista semiestruturadas e prontuários dos participantes. Os dados foram organizados e analisados na perspectiva da análise de conteúdo. A pesquisa foi aprovada, sob o nº 2.148.415/23.06.2017, pelo Comitê de Ética da Escola de Enfermagem Magalhães Barata. **Resultados:** foram detectadas cinco necessidades alteradas: necessidades fisiológicas, de segurança, de amor e/ou sociais, de estima e de autorrealização. Evidenciou-se que a percepção das necessidades alteradas estimula ações de autocuidado, com vistas a sua satisfação. **Conclusão:** O enfermeiro deve prestar cuidados humanizados ao paciente com hanseníase, motivando-os para a autonomia e para o autocuidado, contribuindo para a melhoria da qualidade de vida.

Descritores: Cuidados de enfermagem; Hanseníase; Educação em saúde; Autocuidado; Teorias de enfermagem.

RESUMÉN

Objetivos: Analizar la percepción de los pacientes con hanseníasis sobre sus necesidades humanas fundamentales cambiadas. **Método:** Investigación descriptiva cualitativa, realizada con diez pacientes inscritos en el Programa Nacional de Control de la Hanseníasis en una Unidad Básica de Salud en Belém-PA. Los datos fueron recolectados desde agosto hasta septiembre de 2017, por medio de entrevistas semiestructuradas e historial clínico de los participantes. Los datos fueron organizados y analizados en la perspectiva del análisis de contenido. La investigación fue aprobada bajo el número 2.148.415/23.06.2017 a través del código postal de la Escuela de Enfermería Magalhães Barata. **Resultados:** Fueron detectadas cinco necesidades cambiadas: necesidades fisiológicas, de seguridad, de amor y/o sociales, de estima y de autorrealización. Fue evidenciado que la percepción de las cambiadas estimula acciones de autocuidado con el objetivo de alcanzar su satisfacción. **Conclusión:** El enfermero debe ofrecer cuidados humanizados a los pacientes con hanseníasis, motivándolos a todos para la autonomía y para el autocuidado, contribuyendo para la mejoría en la cualidad de vida.

Descriptores: Cuidados de enfermeira; Hanseníasis; Educación para la salud; Autocuidado; Teorías de enfermería.

INTRODUCTION

Hansen's disease is a chronic and infectious disease and is still a public health issue, being related to stigmas and prejudices, which can cause biopsychosocial problems,[1] as well as altering their Fundamental Human Needs (FHN) and interfering with people's life quality.

Nonetheless, subjective issues are neglected during treatment, emphasizing only objective and clinical aspects, which are also necessary, but we must also think about psychosocial aspects, for humanized care focused on their real needs.[2]

The stigma attributed to Hansen's disease patients generates prejudice and exclusionary attitudes, which may arise within their own family ties and has serious repercussions on their personal life, including psychological distress, leading them to attempt to hide the disease to avoid rejection.[1]

Maslow hierarchized the FHN into the following needs: physiological; security; love/relationship; esteem; and personal fulfillment. Imbalances about and around you generate needs and the human being seeks to satisfy them. Satisfaction is important for physical and mental health, and skilled care is needed to address their deficits.[3]

Therefore, the practice of self-care in Hansen's disease consists of activities that the patient performs at home. To this end, they should be properly guided through health education by professionals to avoid complications and to reduce the risk of injury and accidents that could cause them to mutilate and/or lose body parts.[4]

Intending to broaden the justification of the study in question, a search was made in the databases of the Virtual Health Library (VHL), having as a temporal cut, articles from 2010 to 2016. The evidence pointed to a gap in the knowledge of articles related to the addressed object of study, in other words, the Fundamental Human Needs and Hansen's disease.

The above-mentioned endorses the need for research related to the theme/object, mainly because Brazil is the second country in the world in absolute numbers of Hansen's disease cases, second only to India. In 2015, 28,761 new Hansen's disease cases were diagnosed in Brazil, and the *Pará* State was responsible for 2,889 of these cases, equivalent to 10% of the country's total cases.[5]

The impact of this study is in the field of nursing and also in other health areas, which are interested in this matter and are dedicated to caring with an emphasis on health promotion and prevention of physical and psychosocial disabilities of Hansen's disease.

Bearing the aforesaid in mind, the following objectives were defined: to analyze Hansen's disease patients' perception on their altered fundamental human needs, and what they do in order to satisfy those needs.

METHODS

It is a descriptive research with a qualitative approach, which targeted an audience of 17 patients who were registered in the National Hansen's Disease Control Program at a Health Unit, in *Belém* city, *Pará* State, Brazil.

Inclusion criteria were as follows: any gender or age and living in *Belém* city, *Pará* State, Brazil. The following were excluded: associated comorbidities and psychic problems that made it impossible for them to answer the interview questions. A total of 10 patients have participated by meeting these criteria, and seven patients were excluded because they were associated with other comorbidities.

Participants were coded by the letter P, followed by the number corresponding to the order of the interviews, (P1, P2 ...). The approach was for convenience and was conditioned on their attendance at the unit. They were invited to participate in the research at the end of the nursing consultation, being informed about the objectives of the study and asked about their interest in participating in it. If so, they were directed to an office in the unit itself in order to conduct the interview, paying attention to the preservation of confidentiality, comfort, and privacy of the participants. The interviews began after the signing of the respective Consent Terms, as well as the consent to record their statements in electronic media (voice recorder). With those who were not available to grant the interview at the same time, another day was scheduled at the Health Unit.

The individual interviews took place over the period from August to September 2017 and lasted an average of 30 minutes, containing questions concerning the participants' socioeconomic profile and subjective questions, which would allow their perceptions vis-à-vis their Fundamental Human Needs to be met or affected as regards to Hansen's disease. Subsequently, the statements were transcribed and analyzed according to the Bardin's thematic content analysis.[6]

This study was approved by the Research Ethics Committee of the *Escola de Enfermagem Magalhães Barata* [Nursing School] (Legal Opinion No. 2.148.415/06.23.2017).

RESULTS

Participants' profile

The age group of the participants ranged from 21 to 63 years old, and the majority group (60%) was between 21 and 34 years old. People in this age group are more likely to be affected by Hansen's disease, which might be explained by increased exposure to the conditions that lead to the disease.[7]

Considering the 10 participants, six (60%) were women. Patients with stable union predominated (common-law marriage), six (60%), which is a positive aspect for coping with the disease, since family and spouse support plays an important role regarding patient support during the diagnosis and treatment of Hansen's disease and from other diseases.[9]

The monthly family income ranged from one to seven minimum wages: considering the ten participants, six (60%) received up to three wages and two (20%) received between one and two wages. This result differs from other studies,[10] which point to the low socioeconomic level as a conditioning factor to acquire the disease.

The clinical therapeutic profile of the patients indicated a mostly multibacillary group (70%). Regarding the degree of disability, 50% of the cases were not assessed. This finding is in line with the recommendations of the Brazilian Ministry of Health, which recommends early diagnosis and treatment to avoid physical disabilities, such as limitations in the eyes, hands, and feet of patients.[11]

The perception of altered needs and self-care

Physiological needs

Physiological FHN comprise the existence and survival of the individual and are related to oxygenation; elimination; nutrition; hydration; mucosal cutaneous integrity; discoloration of epithelial, subcutaneous and mucosal tissue; and sexuality.[3]

The mucosal cutaneous integrity was the most mentioned by the participants due to the characteristic signs and symptoms of the disease, such as: spots, dryness, skin darkening, and reduced thermal, tactile and pain sensitivity.[11]

> *I remember the spots that appeared on my body. Not long ago my back started to get full of light spots and I was very worried. Now it's getting better.* (P2)

The lack of guidance on food intake was mentioned by another participant:

> *The information was very good, I just said nothing about food, if I could eat any kind of food, and I forgot to ask, so I deprived myself of eating a lot at the beginning of the treatment and lost a lot of weight.* (P4)

Nevertheless, other information was received and also praised, as reported below:

> *The guidelines given by the professionals (doctor, residents, nursing, and physiotherapist) were very good, they explained about the disease and treatment. They informed me of the precautions I should take, such as using sunscreen, moisturizer, and healthy eating. Things I didn't do before.* (P3)

> *About the guidelines, I was informed to choose suitable shoes, not to drink alcohol, not to sunbathe and to keep the skin always hydrated.* (P5)

Security need

The need for security involves physical and psychological security related to individual protection against dangers and threats involving health, safe work, social security, and social order.[3]

> *It started with light spots on the legs and back, I had tests, I took to the doctor, but did not certify anything. I went often after consulting with a dermatologist and never got it, meanwhile, the spots started increasing.*

> *So, I was forced to pay for a private doctor who requested a smear-positive for Hansen's disease.* (P10)

For some participants, most self-care actions are protective, in other words, they aim to minimize body changes, making the disease invisible to others, thus reducing the possibilities of sequelae and prejudice.[12] The following reports may show what was wanted to express:

> *I use sunscreen and moisturizer, I'm careful with my feet, I wear comfortable shoes because, because of the lack of sensitivity, I already got hurt and didn't feel it, I just realized it because I was bleeding. I'm careful when I cook too, because of the temperature. I do not want to be discriminated against by anyone.* (P10)

The search for the invisibility of Hansen's disease is what some patients seek to hide the marks of the disease, especially those that are exposed and noticeable to others.[1]

> *So, I started wearing longer clothes and long pants to cover this spot on my thigh.* (P9)

> *I get annoyed because of this I use a sunscreen based to slightly smooth the imperfections on my face and, as I work with the public, it ends up giving a bad impression to other people.* (P6)

Love and/or social needs

The need for love and/or social is related to life in society and includes the needs for meaningful living, respect, friendship, leisure, social participation, and affection.[3]

Hansen's disease is still a disease that causes mutilation and deformities. Such factors cause prejudice, objectified by the fear of others to approach and touch the Hansen's disease patient.[2] As can be seen below:

> *There is prejudice and lack of information because Hansen's disease is an apparent disease and people are afraid to approach. It is considered an ugly disease because it causes deformities in the body, skin, atrophy of muscles and nerves and is biblical. Very much mentioned as a disease without a cure.* (P9)

Although advances have been made in Hansen's disease and its signs and symptoms, a large part of the population remains lay about it, especially concerning the forms of contagion and the possibilities of cure, reinforcing the maintenance of stigma and prejudice, leading to isolation of the patient, affecting their sociable need for friendship and family and social life.[13] The following can be evidenced as follows:

> *It is a contagious disease. That's what the hospital staff told me, and I couldn't be around anyone. I was with my daughter hospitalized and they isolated me from her, and I was already doing the treatment.* (P7)

To avoid social exclusion and embarrassment in interpersonal relationships related to the clinical externalization of the disease, many patients prefer to hide the diagnosis as a form of self-protection against possible discriminatory attitudes that often contribute to the interruption of treatment.

> *I didn't tell almost anyone, only close friends and family, because of the prejudice that still exists. People often move away because they do not know about the disease.* (P2)

> *I was afraid of being prejudiced, I didn't tell, and I walked away from everyone.* (P4)

Esteem needs

One aspect of Hansen's disease that should not be overlooked is the emotional one, since it is a socially stigmatized disease, because it can cause changes and disruptions in body image, manifested by mucosal cutaneous lesions. In this way, it changes the patient's image and feeling of himself.[2,14]

Self-image is the way one sees and perceives oneself; self-esteem, in turn, is the feeling one has about one's self-image. It is noteworthy that the involvement of more exposed areas of the body, such as the face and hands, causes more embarrassment, because the lesions are more noticeable and therefore generate a need to hide what society considers ugly.[14]

> *The imperfection that bothered me the most was that of my face. As I had not before, it drew a lot of attention. I used a lot of makeup to hide it, now it's almost gone. I was devastated, feeling very ugly.* (P4)

> *The Hansen's disease reactions made me look like a monster. Looking at myself in the mirror horrifies me.* (P6)

Self-actualizing need

This need includes spirituality, acceptance of facts, potential and problem-solving skills. Many patients use spirituality to go through painful and chaotic situations, such as Hansen's disease. The search for spiritual support can increase life's sense of purpose and resistance to suffering as a way to deal with illness. Spirituality is then considered a Fundamental Human Need.[15]

> *I was totally lost at first, I was asking God not to let me lose any limbs.* (P1)

> *Only God to support me and help me in this treatment. Without him, I would have given up on the first reaction.* (P5)

DISCUSSION

Diseases such as Hansen's disease constitute imbalances in the body, altering various FHN, such as: physiological, safety, love and/or social needs, esteem and self-fulfillment. These needs require adaptation to meet the resulting changes. Accordingly, the level of lifestyle changes depends on the severity and stage of the disease, the willingness to self-care, and the resources available to meet these needs and regain homeostasis.[4]

The skin is an important organ of interaction with the environment and with other people. Hence the clinical changes in Hansen's disease, especially the spots and reactions, stigmatize the patient, referring him to the image of someone whose approach should be avoided, because he has a mark that disqualifies him.[1]

Still, on the physiological FHN, nutritional status is one of the main influencers of the innate and adaptive immune response, compromising the body's defenses, and is directly influenced by infections. Hansen's disease is known to be linked to immunity, so because of exposure to the bacillus, depending on the efficiency of the immune response, the organism may prevent the development of the disease or generate milder or more severe clinical forms.[12]

The medications used to treat Hansen's disease can cause complications, such as anemia, and impair the absorption of nutrients such as iron, calcium, and zinc, leading to weight loss due to its interaction with food. Although in Hansen's disease treatment there is no contraindication to a specific diet, adequate nutrition is essential for health promotion and protection, thus improving immunity.[12]

Considering this framework, Hansen's disease care involves several professionals and many areas of knowledge. Educational guidelines should occur in a horizontal and participatory manner, contributing to the patient's adherence to self-care practices and, consequently, to the prevention of disabilities, since self-care is only possible if the patient knows its importance and makes a commitment to the improvement of your health status.[4]

The several reasons why the diagnosis and treatment of Hansen's disease are late are related to the lack of knowledge of the population about the clinical manifestations of the disease, the failures in health services, due to the lack of training of professionals to diagnose and treat the disease early or disability. services in meeting the health demands required by the population. This delay leads to the evolution of the disease and the aggravation of body changes, altering the FHN safety against health risks.[16]

In most cases, the Hansen's disease patient goes to various health services for diagnostic investigation and treatment for his problem, although in most cases he has very specific signs and symptoms of the disease (such as paresthesia, neuritis, spots on the skin). In Brazil, 75% of patients are diagnosed when they already have physical disabilities.[16]

In this sense, late diagnosis and treatment have direct interference with safe FHN: in disease control, transmission occurs from untreated bacilliferous patients, increasing the risk of physical disabilities, which are responsible for severe neural injuries that make individuals more susceptible to accidents, also compromising their psychic, moral and social aspects.[14]

Therefore, considering the magnitude of Hansen's disease, information on the disease should be intensified; train health professionals to act in demystifying stigmas; and foster greater demand for health services early, ensuring adequate diagnosis and treatment.[16]

It is noticed that the interviewees, especially women, who are more rigorously judged for their aesthetics, had to create protection strategies to hide the imperfections on their body, and thus protect themselves from possible prejudice that may come to suffer.[2] The use of makeup and longer clothes means to care not to denude the disease in the eyes of others, guarding the consequent repercussions on their personal, professional and social lives. Consequently, the feeling that the patient attributes to his self-image reflects on the attitudes towards his body, because when this need is not met, the person feels inferior and undervalued.[14]

Some professionals still have difficulties to act in front of a person with Hansen's disease and often end up contributing to the negative representation of the disease, isolating them and changing the patient's love and/or social FHN. This attitude goes against what is advocated by the Brazilian Ministry of Health, which emphasizes that from the first dose of polychemotherapy the patient ceases to be the transmitter of the disease, and for no reason that might just drive him away or cause embarrassment.[11,16]

Stigma is a term used to refer to an attribute, trait, or disease in a derogatory manner, considering a person as different from normal, and involves stereotypes and prejudices. In this sense, the characteristic that makes it unequal to other people becomes grounds for exclusion from the group to which it belongs, altering the Fundamental Human Need to belong to a group.[18]

The need for esteem involves self-confidence, self-esteem, and self-image, utility, purpose, and self-satisfaction, such as independence, recognition, dignity, subjective equality, respect and opportunity.[19] Altered self-image and self-esteem interfere with coexistence, considering the fact that body image is one of the fundamental components of identity. In the case of visible changes in the skin, there may be stigmatization and damage to psychosocial relationships, which can turn the body into something repulsive, considering that we live in a society that values the beautiful and presents strict aesthetic standards.[20]

Spiritual well-being is considered a dimension of people's health and was defended by Wanda de Aguiar Horta when proposing the Theory of Fundamental Human Needs. So, such need should also be prioritized in consultations with Hansen's disease patients and may positively influence the course of treatment or create barriers to adherence.[15]

Consultations for the supervised dose are scheduled every 28 days and this opportunity should be used to guide the disease to ensure understanding, adherence to treatment and self-care. Neglecting any kind of care regarding the disease is a risk that might lead to prolonged treatment and even the appearance of deformities.[17]

The limitation of this study relates to its execution in only one scenario, which reduced the number of participants and prevented a broader analysis in a larger universe. However, considering the scope of this subject, further studies with larger samples and in other regions are also needed.

CONCLUSION

Herein, it was found that the discovery of Hansen's disease triggers several feelings, negatively affecting the quality of life of patients, changing their fundamental human needs: physiological, safety, esteem, love and/or social and self-actualizing needs. The way they perceive such changes encourages them to perform the educational actions taught by the health team (self-care) in order to satisfy the altered FHN and improve their quality of life.

In providing care to Hansen's disease patients, nurses should focus their attention not only on physical problems, but especially on psychosocial problems, prioritizing sensitive listening that enables patients to express their subjectivities and thus their altered FHN.

Hence, it is intended that the results of this study can support reflections on nursing care provided to Hansen's disease patients and serve as a basis for new care strategies focused on their real health needs.

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