

Hansen's disease patients' perception of self-care from the complexity perspective

Autocuidado na percepção de pessoas com hanseníase sob a ótica da complexidade

Autocuidado en la percepción de las personas con enfermedad de hansen en la óptica de la complejidad

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ABSTRACT

Objective: This study aimed to understand how patients with Hansen's Disease perceive self-care from the complexity perspective. **Methods:** Qualitative, descriptive and exploratory study based on the Collective Subject Discourse. **Results:** Sample composed of 15 subjects, most of whom were married males (66.6%) with a mean age of 52.3 years and were classified in the polarized forms of the disease. The following themes emerged from the DCS synthesis: having Hansen's Disease, drug therapy, self-care and lifestyle. The study provided visibility to the vertical model, which is largely hegemonic in the tradition of public health care policies, showing concern about only treating the disease, disregarding the complex relationships involved. **Conclusion:** Acknowledging these limitations and setting strategies to change them in favor of the dialogue among interprofessional team members are challenges to further develop self-care practices and to empower patients in relation to treatment and disease.

Keywords: Hansen's disease; Leprosy; Self care; Philosophy in nursing.

RESUMO

Objetivo: Compreender a percepção das pessoas com hanseníase em relação ao autocuidado, sob a ótica da complexidade. **Métodos:** Pesquisa qualitativa, descritiva e exploratória alicerçada no Discurso do Sujeito Coletivo (DSC). **Resultados:** Amostra constituída de 15 sujeitos, idade média de 52,3 anos, maioria masculina (66,6%), casados (66,6%) e classificados nas formas polarizadas da doença. Pela síntese do DSC emergiram os temas: ser portador de hanseníase, terapêutica medicamentosa, autocuidado e estilo de vida. O estudo deu visibilidade ao modelo verticalizado, largamente hegemônico na tradição das políticas públicas de saúde, mostrando preocupação em tratar apenas a doença, desconsiderando as relações complexas que a envolve. **Conclusão:** Reconhecer estas limitações e ter estratégias para transformá-las em favor do diálogo entre os membros da equipe interprofissional são desafios para fazer avançar as práticas do autocuidado e do empoderamento do portador em relação ao tratamento e à doença.

Palavras-chave: Hanseníase; Lepra; Autocuidado; Filosofia em enfermagem.

RESUMEN

Objetivo: Comprender la percepción de las personas con lepra en relación con el autocuidado bajo la óptica de la complejidad. **Métodos:** Investigación cualitativa, descriptiva y exploratoria, con base en el Discurso del Sujeto Colectivo. **Resultados:** Muestra constituida por 15 sujetos, mayoría masculina (66,6%), edad media 52,3 años, casados (66,6%) y clasificados en las formas polarizadas de la enfermedad. Por la síntesis del DSC, emergieron los temas: ser portador de lepra; terapéutica medicamentosa; autocuidado; estilo de vida. El estudio le dio visibilidad al modelo verticalizado, largamente hegemónico en la tradición de las políticas públicas de salud, mostrando preocupación en tratar solamente la enfermedad y desconsiderando las relaciones complejas que la involucran. **Conclusión:** Reconocer estas limitaciones y tener estrategias para transformarlas en favor del diálogo entre los miembros del equipo interprofesional son retos para hacer avanzar las prácticas del autocuidado y del empoderamiento del portador en relación con el tratamiento y la enfermedad.

Palabras-clave: Enfermedad de Hansen; Lepra; Autocuidado; Filosofía en enfermería.

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INTRODUCTION

Scientific progress and new therapies have contributed to making the cure of Hansen's disease possible. In that sense, it is important to highlight the training and recycling of professionals to ensure early diagnosis, treatment, prevention of physical disabilities and discontinuity of the epidemiological chain of the disease¹.

Other aspects should be considered though, such as physical, psychological, social and environmental effects, which have a systemic and dynamic relationship and go beyond the biomedical sphere. In order to do so, one must take a fresh look at human beings and consider them as an open system with possibilities for exchange and interaction within those spheres. When one considers health a process that only makes sense when individuals act as the lead character in their own reality, they cannot be disconnected from their relationships with their environment².

In this perspective, interaction with patients with Hansen's Disease should be based on the valuation of their feelings and permit the possibility to exchange both experience and lessons learned³. Dialogical relationships between the patients with Hansen's Disease and the multidisciplinary team are an essential resource to recognize the importance of self-care, as well as the development of potential and autonomy.

In this sense, self-care is a process that permeates life and is therefore dynamic and fundamentally depends on the commitment of the individual. In that respect, it is worth mentioning the importance and recognition of biopsychosocial changes that result from the disease process, which is the case of Hansen's Disease.

Clinical practice is where a human being's needs are holistically acknowledged and enables individuals to be valued in their essence. Thus, interdisciplinary and horizontal practices contribute towards the changing of the Cartesian paradigm and displacing of the conventional fragmented approach. This manner of looking at the world moves away from the stiff logics of care that is focused on complaints and only values the biological sphere, and therefore loses the depth within subtleness.

Adopting this practice will dynamically facilitate the inter-relationship and give the multidisciplinary team a new insight on welcoming and bond building⁴. However, for this process to be successful, however, both professionals and people with Hansen's Disease needs to collectively share the knowledge, allowing for interpretation, which is a fundamental tool for understanding and troubleshooting.

Given the above, the question is 'What meanings do people with Hansen's Disease attribute to self-care?'. Based on what has been said, the aim of this study was to understand, from the perspective of complexity, how people with Hansen's Disease perceive self-care.

This research is justified by the professional and academic contact with patients with Hansen's Disease receiving care at a specialized outpatient clinic. This relevant study is extended to healthcare professionals, including managers, since the implementation of holistic care requires breaking with the paradigms of the biomedical model. Furthermore, the intention is to contribute to qualified and innovative nursing care.

METHODS

This descriptive, exploratory and qualitative study was conducted in the Hansen's Disease Control Program at the Outpatient Clinic of the Teaching Health Center at Botucatu School of Medicine, *Universidade Estadual Paulista*.

Hansen's Disease patients previously screened based on a consultation of their medical records were individually invited to participate in this study when they were waiting for their medical appointment in the waiting room of the abovementioned outpatient clinic. Treated patients who returned for follow up after being discharged were excluded from the study.

Following the medical appointment, semi-structured, individual and privately held interviews were carried out in July and August 2010. For the participants to disclose their experience, the following guiding questions were elaborated: What is it like for you to live with Hansen's Disease? What changed in your life after you received the diagnosis? What does self-care mean to you? Who taught you about self-care? Do you have information about the medication you used or that you have been using? How do you evaluate your self-care?

On finding no further variance in the phenomenon under study, the sample size was determined at 15 participants. Recorded interviews obtained with the consent of the participants were transcribed and reviewed, using the methodological strategy Collective Subject Discourse (CSD)⁵. The method consists in selecting key expressions from each individual response, relevant excerpts that correspond to core ideas which are the synthesis of discursive content. By means of that combination, synthetic discourses are constructed using the first person singular, which represents the ideas of the group or of the collective subject⁵. Discourse review was carried out based on the epistemological perspective of the Theory of Complexity according to Edgar Morin⁶.

This project received approval from the Research Ethics Committee at the aforementioned institute under Process # 3537/2010.

RESULTS

The sample consisted of 15 subjects, mostly men (66.6%), with a mean age of 52.3 years, who were white, married (66.6%), had not completed secondary school (60.0%) and had been classified in the multibacillary (66.6%) and paucibacillary (33.3%) forms of the disease.

The following are the themes and core ideas that composed the Collective Subject Discourse.

Theme 1 - To be a person with Hansen's Disease Core idea - Experiencing the disease Synthesis of the Collective Subject Discourse

We have to accept it as if it were part of life because there is no other option. I have suffered a lot with it. It is awful to have leprosy. I was shocked to see the huge patches on my body and did not know what they were. I am always embarrassed and afraid of what people are going to think

and many people end up staying away. People used to ask what I had and I used to cope with the asking as well as I could until, one day, my wife said it was all very embarrassing. My legs went numb, I couldn't walk anymore and they still haven't gone back to normal. I don't think they will ever be the same again but, if they do go back to being what they were, what are things going to be like? When I am on the streets I don't go near people anymore, you see, people look and they are afraid of catching it...

Theme 2 - Self-care

Main Idea: Perception of Self-care

Synthesis of the Collective Subject Discourse

I don't know much about that self-care stuff, I look after my body well and I shower. I think it has to do with knowing how to look after yourself well and live according to the instruction we are given. One has to protect well the skin and feet to not get hurt. I follow the instructions very carefully and I think that is what self-care means so one doesn't make things worse. I have taken the medication because of the skin lesions and they are disappearing, I think that, if I had not looked after myself, I wouldn't have gotten better. The thing I cannot do is rest because I am not a retired person yet. Although I do a lot, it is still not enough, I have to take greater care but I find it difficult. But I really don't care that much about that stuff, I don't really take care, I have to work out in the field, cook lunch and dinner, life carries on as usual...

Theme 3 - Drug Therapy

Main Idea: Knowledge about drug therapy

Synthesis of the Collective Subject Discourse

I don't know the difference. I take a little red one and a little white one and I know they are for Hansen's Disease but I don't know what they are for, I know they eliminate the problem. It is a drug that kills the microbes in the body, the bad guys. When I take a corticoid it is to stop the pain in my nerves and then the bumps disappear from my body. Thalidomide was the drug I most took which is for inhibiting the problem in the nodes...

Theme 4 - Lifestyle of a person with Hansen's Disease

Main Idea: Changes in lifestyle

Synthesis of the Collective Subject Discourse

The truth is nothing has changed. I started the treatment and it is one extra thing I need to remember to do every day. I used to do things that I cannot do anymore, I cannot work, I don't have any strength in my arms anymore nor in my legs like I used to have. I had to start water aerobics lessons, I had never practiced any walking exercises nor stretching. My legs, arms, toes, fingers and joints in my arms hurt for a while and then it stops. At first I was a bit

depressed. My wife almost left me, she dumped a lot of stuff on me. It was as if she put me down and stepped all over me...

DISCUSSION

Epidemiological data from this study are similar to the literature and show that economically active individuals diagnosed in polarized forms of the disease are subject to the disease⁷. This is a concern as it shows the late diagnosis of the disease, which both increases the possibility of spreading the bacillus and the risks regarding disability and sequelae.

The World Health Organization (WHO) states that two to three million individuals around the world present physical disabilities resulting from the disease, which affect social, economic and cultural aspects⁸.

Hansen's Disease is most frequent in the less favored social and economic classes, where there are lower standards of living, which contribute to the development of the disease^{2,9}.

The method used allowed us to unveil the understanding of the disease by people with Hansen's Disease. It was made evident that the experience is distressing and marked by pain, which hinders routine actions. Pain is a subjective, universal, complex and unique experience for each individual. In Hansen's Disease, pain is associated with the inflammatory process in peripheral nerves, a salient feature of the disease that can trigger physical disabilities and deformities and compromise quality of life¹⁰.

In addition to the aspect of pain, Hansen's Disease still carries strong stigma. Despite it being a curable and referenced disease since biblical times, it lies in the imaginary realm of people's minds nowadays. In the attempt to try to reduce stigma in Brazil, the terminology was changed from Leprosy to Hansen's Disease, but in vain¹¹.

Another factor observed in the testimonies is the neglect of the signs and symptoms, which delays the diagnosis. This can be attributed to the absence of physical pain, which is commonly observed in people with chronic diseases who are socially rejected, as is the case with Hansen's Disease, in which the disease is hidden from all out of fear of rejection and abandonment¹¹.

To evolve, man depends both on the cultural and biological context⁶. In that sense, man has to be considered in a broader context to understand the changes that occur in his living space. In the case of Hansen's Disease, the reality most Hansen's Disease patients live in shows that they fall short of social and cultural access to get updated on issues related to the disease¹².

Regarding perception of self-care, subjects are notably restricted by the difficulty in understanding how to develop self-care independently and very often for not being aware of the severity of the disease. Furthermore, it becomes evident that subjects do not fully apply the instructions they receive and that, therefore they do not benefit from self-care.

The subjects condition life in a limited way and do not understand the seriousness of the disease and the need for adjustments after the diagnosis. Therefore, the transformation of this reality

crucially depends on their context and life experience, which permits autonomously choosing what suits them better.

On the other hand, the fragmented, mechanical and linear form of care in health conditions an individual to repeat old patterns and promotes dependence on healthcare professionals. The individual is diverted and begins to believe that reason and action do not have an influence on reality and any action that leads to self-care is hindered.

Thus, a person with Hansen's Disease has to be taught not only conventional treatment practices, but also self-exploration, so that electing the best lifestyle after the disease diagnosis is a possibility, directing self-care.

Classical science has often been questioned for making a difference between mind and body. In that sense, when only the physical/material aspects are analyzed, some human concerns are not explained and there is a lack of fulfillment in the way humanity lives¹³.

Therefore, the concern with increasing a client's autonomy should be part of any therapeutic process where better understanding of the body, disease and its relationship with the social environment occurs and better quality of life is promoted.

And, thus, the Theory of Complexity invites us to value common sense knowledge and practical sense, which guide our daily actions and give us a sense of purpose in life. It is essential to promote health and self-care practices to awaken an ethical approach to life and responsibility and concern with life.

Drug therapy in Hansen's Disease is composed of bacteriostatic and bactericidal action drugs that comprise multidrug therapy (MDT), and which may trigger adverse effects on several body systems¹⁴.

It became evident that MDT drugs are unknown to the patients, who only identify the drugs based on their color and define them as drugs taken to fight the agent causing the disease. This fact may be attributed to the daily and constant use of the drugs during a period of six to 12 months, depending on whether the patient was classified as multibacillary or paucibacillary.

On the other hand, knowledge is observed on the action mechanism of certain drugs used to treat signs and symptoms, which can appear before diagnosis, during or after treatment. As these reactions occur with a certain frequency, patients have knowledge about Thalidomide and corticosteroids due to their immediate action mechanism. Thus, in that context, every drug that leads to resolution, especially related to alleviating pain and discomfort, is seen from a different dimension.

That information makes reference to a complex phenomenon, as it has rational notions and no concern with the harmful effects of a drug. Morin emphasizes the uniduality of human beings, who are completely biological and cultural at the same time¹⁵. Issues related to drug therapy, however, are elucidated early in treatment when drug actions are highlighted.

In this sense, there is a need to foster creativity and curiosity to awaken a new look based on the diagnosis, and not simply to remain at the mercy of orders, myths and beliefs but to acquire the freedom of spirit¹⁶. A process that can be achieved when

healthcare professionals broaden their views on humanity and do not limit themselves to just transmitting information and contribute to building contextualized knowledge in line with the reality of people in a critical and conscious fashion¹⁷.

Disease represents disruption of daily routines and brings about unexpected lifestyle changes. Individuals have their own characteristics of understanding a situation and react in different ways when the diagnosis is given and treatment proposed. Considering the integrative and dynamic characteristic of human beings, individuals do not get sick due to biological factors only, but a disease can cause suffering and affect spheres beyond the physical realm.

Most chronic diseases are associated with the combination of social, cultural, environmental and behavioral factors. Thus, while not having impending life-threatening risk, it causes a substantial burden on the individual with social and economic impacts¹⁸.

In the field of this context, there is need for structural changes in the life of a person with Hansen's Disease, since the disease can cause deformities and disabilities, which are socially compromising and require the patient to recognize and adjust their new reality. Thus, the act of thinking permits innovations and adjustments following a phenomenon, it fosters change and provides a new look on the world according to his/her needs as a thinking being¹⁶.

CONCLUSION

The study granted visibility to ways of living with the disease, understanding of self-care and of drug treatment, in addition to the lifestyle of people with Hansen's Disease from the perspective of vertical model, a largely hegemonic tradition of public health policies, which disregards the complex relations involving the disease.

Recognizing these limitations and establishing strategies to transform them in favor of a dialogue among the multidisciplinary team members are challenges to make progress in the practices of self-care and empowerment of people with Hansen's Disease with regard to treatment and disease.

A major contribution of this study is considered as the possibility of providing a guidance framework to build assessment tools for services specializing in the treatment of Hansen's Disease, as well as identifying gaps and possible strategies for the reorganization thereof, in order to strengthen the network of healthcare and improve healthcare.

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