

Nursing care experiences with Hansen's disease patients: contributions from hermeneutics

Experiências de cuidado dos enfermeiros às pessoas com hanseníase: contribuições da hermenêutica

Maria Cristina Dias da Silva¹
Elisabete Pimenta Araujo Paz¹

Keywords

Leprosy; Health services, Nursing care;
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Descritores

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Abstract

Objective: To analyze the experience of caring for Hansen's disease patients in the practice of nurses in the city of Rio de Janeiro.

Methods: Qualitative study based on philosophical hermeneutics conducted in the programmatic areas of health in the city of Rio de Janeiro, which presented high or medium rates of Hansen's disease detection in 2014. Services with the following profiles were selected: exclusively Family Health Strategy (FHS), services with specialized clinics, and hybrid units in which the FHS and the traditional care model coexist. Nineteen nurses working in the primary and secondary health services of these areas participated in the research. The inclusion criteria were having at least five years of experience in following up Hansen's disease patients, and technical ability acquired from specific training. Exclusion criterion was being absent from work during the whole data collection stage, which happened between February 2015 and March 2016. Interviews were scheduled in agreement with participants and recorded with their authorization.

Results: Two categories were established: For nurses, care for Hansen's disease patients lost its quality, and nurses recognize stigma as a problem that compromises Hansen's disease treatment and cure.

Conclusion: Treatment of Hansen's disease patients was limited to eventual actions, where the professional-user relationship has a fragile link. The stigma and discrimination that harm treatment are still present in attitudes and behaviors of health professionals, and represent an obstacle for reestablishing health.

Resumo

Objetivo: Estudo qualitativo fundamentado na hermenêutica filosófica que teve como objetivo analisar a experiência de cuidar de pessoas com hanseníase na prática de enfermeiros do Município do Rio de Janeiro.

Métodos: Estudo qualitativo desenvolvido nas áreas programáticas de saúde do município do Rio de Janeiro, que apresentaram alto ou médio coeficiente de detecção de hanseníase em 2014. Foram selecionados serviços com os seguintes perfis: exclusivamente ESF, serviços com clínicas especializadas e unidades mistas que se caracterizam pela coexistência da ESF e do modelo tradicional de atendimento. Participaram da pesquisa dezenove enfermeiros que atuavam nos serviços de Atenção Primária e Secundária destas áreas. Os critérios de inclusão definidos foram possuir experiência de pelo menos cinco anos no acompanhamento de pessoas que receberam diagnóstico de hanseníase e, qualificação técnica por treinamento específico. Como critério de exclusão, estar em afastamento laboral durante toda a etapa de coleta de dados que ocorreu no período de fevereiro de 2015 a março de 2016. As entrevistas foram agendadas em comum acordo com os participantes e gravadas com autorização dos mesmos.

Resultados: Elaboraram-se duas categorias: Para os enfermeiros, o atendimento da pessoa com hanseníase perdeu em qualidade e os enfermeiros reconhecem o estigma como um problema que compromete o tratamento e a cura da hanseníase.

Conclusão: O atendimento às pessoas com hanseníase ficou reduzido à uma ação eventual, onde a relação profissional-usuário tem vínculo fragilizado. O estigma e a discriminação que comprometem o tratamento ainda estão presentes nas atitudes e no comportamento dos profissionais de saúde, e se constituem em obstáculo no restabelecimento da saúde.

Corresponding author

Maria Cristina Dias da Silva
Afonso Cavalcanti Street, 275,
20071-003, Rio de Janeiro, RJ, Brazil.
mariacrisdias@uol.com.br

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¹Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro, Rio de Janeiro, RJ, Brazil.

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Introduction

Hansen's disease is a chronic disease whose etiologic agent is the *Mycobacterium leprae*, a resistant acid-fast bacillus that prefers skin and peripheral nerves located in higher and lower limbs and the face. The bacillus is highly infectious, however, with low pathogenicity.⁽¹⁾ Most people do not get sick in contact with carriers, even if they are not being treated.

In Brazil, in 2014, Hansen's disease had a prevalence of 1.27 cases per 10,000 people. A decreasing tendency has been recorded for the disease, with North, Northeast and Center-West presenting the highest rates of infection compared to other regions. The general detection coefficient for new Hansen's disease cases in the same period was 15.32 per 100,000 people, corresponding to 31,064 new cases, which means high endemicity. Among these, 2,341 were under 15 years of age, which represents a detection coefficient of 4.88 per 100,000 people, considered very high.⁽²⁾

In the city of Rio de Janeiro, the specific rates of Hansen's disease detection for those under 15 years presented a decreasing trend in the period of 2001 to 2015, which seems to point to a decrease in the levels of transmission of the disease. However, the rate of detection for this age group in 2015 was still in the medium endemicity level (from 0.50 to 2.99 cases per 100,000 people).⁽³⁾

As for the operational aspect of the Hansen's disease Control Program, the contact exam stands out, being employed to increase the timely diagnosis of new cases of the disease. By the end of 2015, analysis of the proportion of examined contacts of new Hansen's disease cases diagnosed in the years of the cohorts – 2013 for multibacillary cases and 2014 for paucibacillary – revealed that, in the city of Rio de Janeiro, only 63.6% of these contacts had been examined. Nine programmatic areas also presented results in this range, varying between 44.9% and 73.3% among them. Only one programmatic area reached 100% of contacts.⁽³⁾

In Polyclinics and Municipal Health Centers, professionals handle problems in care, concerning low risk Hansen's disease cases when they are

referred to treatment and follow-up in the Family Health Strategy (FHS), since it is uncertain if patients will accept and adhere to therapy. Generally, "they did not accept" to keep or resume treatment in other services. When receiving patients for treatment, professionals seldom employed strategies for bonding or coordination with mental health in cases of drug addiction or psychopathies.⁽⁴⁾

Other difficulties involve the wrong assumption from professionals who think health promotion does not concern care for Hansen's disease; the fear of infection when attending Hansen's disease patients and the claim that excessive workload makes it impossible to accommodate these individuals and their families. As for the work process, a speech from a director of a Municipal Health Center on the nurses who practice at the service stands out: "They get too involved with embracement and, therefore, they cannot keep up with the program's activities, they cannot keep up with the programs closely, they leave them aside, dedication to the programs decreases, waiting rooms and groups decreased".⁽⁵⁾

As observed in the meetings with Hansen's disease patients, which are necessary for the therapeutic process, nurses can interact with users and build a care relationship based on true and humanized care. However, it is frequently observed that professionals miss this chance for an intersubjective practice when they reduce their actions to technical and normative procedures.

In order to reconstruct health practices based on care that aims for the healing of people affected by infectious disease and the reestablishment of the health balance, the opinions from health professionals must be appreciated as regards their actions, since they can help each user in the healing process. Regarding user treatment and considering FHS as a substitutive health care model in which care comprehensiveness must be the model for health services, which care experiences of nurses in the Hansen's disease Control Program are unique features?

Based on the presented situations, this study had the objective of analyzing the practice of nurses when caring for Hansen's disease patients in health services of the city of Rio de Janeiro.

Methods

A qualitative study was conducted in the programmatic areas of health 5.3, 3.3, 3.1 in the city of Rio de Janeiro, which presented high or medium rates of Hansen's disease detection in 2014: 15.20, 4.77, and 4.85 per 100,000 people, respectively.⁽⁵⁾ Services with the following profiles were selected: exclusively FHS, services with specialized clinics, and hybrid units in which FHS and the traditional care model coexist.

Nineteen nurses working in the primary and secondary healthcare services of these areas participated in the research. The inclusion criteria were having at least five years of experience in following up Hansen's disease patients and technical ability acquired from specific training. The exclusion criterion was being absent from work during the whole data collection stage, which took place between February 2015 and March 2016.

Initially, the administrators of the health units were contacted so the research objectives could be presented as well as the favorable rulings from the Municipal Management of the Hansen's disease Program. This meeting was the first step toward the identification of professionals that could participate in the research.

Semi-structured interviews with a question script was the chosen data collection technique. In this type of interview, there is a possibility for the interviewer to address the theme at hand, without adhering to the proposed question. It is a conversation with a purpose, that allows access to facts reported by interviewees.⁽⁶⁾

Interviews were scheduled in agreement with participants and recorded with their authorization. In order to maintain anonymity, nurses were identified with the letter N followed by the number of their interview, which varied from one to nineteen.

Data were considered sufficient by the saturation criterion, when new elements ceased appearing in responses from professionals. This criterion concerns knowledge acquired by the researcher on the field, understanding of the group's internal logic, or still, by evidence resulting from empiric material, with no recurrence of new meanings in the speeches addressing the phenomenon.^(7,8)

Data analysis used the philosophical hermeneutics, a resource for the comprehension of meaning that occurs in communication among humans that employs language as a means and object of the experience that enables understanding and comprehension.⁽⁹⁾ In the first stage, interviews were transcribed and repeatedly read, with later organization of excerpts containing similarities in content, forming units of meanings.

In the second stage, there was the interpretation of speeches in search of meanings. The researchers' points of view were considered, since, when trying to understand something we read, we anticipate meanings for the whole from a projection based on the pre-comprehensions of the interpreter, and this projection is confronted with the text. Interpretation refers to the recontextualisation of the object of interpretation from the perspective of the interpreter.⁽⁹⁾

The hermeneutic circle was adopted as reference in order to reflect on the comprehension of meanings that rise from a text. This comprehension is only possible given the movement that happens when reading parts of the text and its whole and from interpreters' preexisting concepts, from the anticipation of a meaning for the whole, which is systematically reviewed during further deepening in the meaning. Thus, a new meaning is constructed, produced by the comprehension of an interpreted text.⁽¹⁰⁾

The research was submitted for analysis by the Human Research Ethics Committee of the Anna Nery School of Nursing, Federal University of Rio de Janeiro and the Rio de Janeiro Municipal Department of Health, receiving approval in rulings 905.240 and 956.763, respectively.

Results and Discussion

The interviewed nurses worked in fourteen health units. Regarding social characteristics, eighteen were women and one was a man; six nurses were aged between 30 and 39 years, twelve between 40 and 59 years and one was over 60 years. As for their programmatic area of practice, four nurses were as-

signed to programmatic area 3.1, three to programmatic area 3.3 and twelve to 5.3. On their time of practice at their programmatic area: eight had been working there for five to ten years and eleven for over ten years. Nine had been working there for five to ten years, ten over ten years at the Hansen's disease Control Program and all nurses claimed to have participated in trainings. Twelve were trained and thirteen were included in refreshing courses. From the information contained in the nurses' speeches, two empirical categories were constructed involving analytic dimensions for this group.

Category 1: For nurses, care for Hansen's disease patients lost its quality

When questioned about their work at the health service, nurses responded that there is little attention given to Hansen's disease patients and that this situation results from work overload and the large variety of activities that befalls them. They believe there are losses regarding the discovery of new cases and treatment follow-ups, since care is frequently limited to administering supervised doses with no further assessment of users.

[...] Today I am working on admission, I assist cases of sporotrichosis, tuberculosis, I am on vaccination, hypertension, diabetes, on syndromic approach, I am on patient embracement, on supervision. N4

[...] Then the person administers the dose, but does not ask how the patient is doing. [...] you see that people limit themselves to giving the dose. [...] I believe there are people who are not being detected. [...] and sometimes, reports are minimal, such as: "Dose administered". [...] People do not get involved anymore. [...] People do things automatically. N12

For nurses, care for Hansen's disease patients is reduced to an approach that emphasizes impersonality in practice, which results from distortions in managing the health system and in the work process, producing dissatisfaction for both and little consideration for particularities. They see this approach as loss of quality in care, a subtraction in the right for healthcare. The hegemonic biomedical model is still determinant in the routine of care

practices, although structuring public policies that go beyond technical rationality are being implemented, but which are insufficient to modify the dynamics of health services.⁽¹¹⁾

Results demonstrated that there is no harmony between actions that are recommended and conducted at the Hansen's disease Control Program, which is not coherent with the social practice of nursing.⁽¹²⁾ The nurses began conducting more general activities, focused on receiving all service users, not only focusing on specific Hansen's disease Control Program activities. It seems to be harder to transcend the normative dimension toward the creation of ties, due to the distancing resulting from the work routines in the FHS, which prioritizes low-risk cases that present no interurrences.⁽¹³⁾

Many FHS teams, according to reports from nurses, have not taken up care for Hansen's disease patients due to the turnover at the FHS; the physicians' lack of experience in diagnosing and treating Hansen's disease; the low credibility for cure, and the limited discussion in services addressing these users' situation.

[...] they (FHS professionals) do not take over these patients. [...] They think its too hard, and they always say when I am going to train physicians "oh! Hansen's disease is too hard!". [...] nurses? They do not watch patients, I think they do not take over patients. They do not think patients are part of the team. N5

[...] I was seen as a reference nurse and I was never called for anything related to Hansen's disease. They never asked me for a skin smear, never asked me to clear doubts, an assessment, never. I got to a training, [...] they did not know that I was a nurse, that I performed so many procedures [...] N13

The results in this investigation are similar to those in an assessment study conducted in the state of Pernambuco, which aimed to comprehend how FHS professionals who were trained perceived the individual and organizational effects of Hansen's disease training. The study demonstrated that nurses and physicians were insecure when taking responsibility for presumptive diagnosis.⁽¹⁴⁾

Difficulties in communication among professionals of primary and secondary units was mentioned as a barrier for accessibility and a problem in the assessment of users during and after polychemotherapy, interrupting care. The findings in a research performed in a city in the state of São Paulo agree with the results in this study. The former pointed out difficulties in the integration and communication among workers of primary healthcare unit and other levels of health care.⁽¹⁵⁾ Such limitations can result in disbelief in the substitutive model of health care both for users and for professionals who feel impotent when facing problems that compromise comprehensiveness.

Category 2: Nurses recognize stigma as a problem that compromises Hansen's disease treatment and cure

The weakening of users, resulting from social stigma related to the disease, was a central aspect in the nurses' speeches.

[...] because, precisely, they (patients) do not want people to know, fearing stigma and rejection. [...] people are afraid, of isolation, patients are already scared of isolation. So, it is a painful thing. N3

We sit down, talk, [...] with the wife, with the husband, we talk to the family. N9

I believe there is still very strong prejudice when you talk about Hansen's disease, even with the name change, it still reminds people of leprosy. This disease still has a stigma today, even with polychemotherapy and everything that has been done for the cure, people still say "oh! He's a leper!" N12

Nurses recognized the complexity of Hansen's disease and that it is almost impossible for users not to bend under the weight of the stigma that affects normal living. Precarious information on the pathology can cause individual and social harm, that is why users, families and health professionals are educated. Similar to the results of this study, an investigation conducted in a city in Minas Gerais showed that patients' reactions were eased by embracement and information.⁽¹⁶⁾

The reestablishment of health, beyond medication and information, depends on the strengthening of social relations, which receives little attention in the services.

An illness means loss of health and it is related to a distancing from the natural routine. Admitting to oneself and to others that one is suffering from Hansen's disease affects individuals at different levels, with social silence or denial being protective attitudes.⁽¹⁷⁾

Episodes of discrimination related to Hansen's disease are not expressed only outside the care environment. Nurses also noticed they are present in the health services, since many professionals manifest attitudes of fear of contagion and rejection of users in care sessions.

[...] in addition to treating the disease, you also have to work the stigma that comes with the disease, the prejudice, you have to work the teams. [...] We can not keep seeing things in boxes, things have to be expanded. N5

She (pharmacist) thought it was weird and did not give the medication, but, she simultaneously felt fearful [...] She was afraid of being contaminated, so she said: "Does he not have that disease. Does he not have Hansen's disease? She spoke directly to me: "I am pregnant". So, she was very scared. Then I noticed she was afraid and I talked to her. N8

Even though treatment is well-designed, the possibility of contamination at work permeates the imagination of some professionals, who do not feel safe when following biosecurity recommendations because they consider that exposure to the bacillus during care is high. Fear of contamination produces tension between following technical orientations and self-protection, which reflects on a distanced care, and this is noticed by patients.⁽¹⁸⁾

The prejudice and segregation against Hansen's disease carriers by health professionals goes against what is recommended by the humanization policy of the Unified Health System.⁽¹⁹⁾ However, it is noticed that such attitudes are also expressed at other care contexts, such as tuberculosis control actions and mental disorders. The natural-

ization of discrimination by health professionals must not be accepted; on the contrary, it must be cause for discussion at health services so they are not perpetuated and vulnerable groups are proactively protected.^(20,21)

Conclusion

Nurses emphasized that at services care for Hansen's disease carriers lost its importance and quality, being limited to eventual, distanced actions. In order to overcome the curativist and short-sighted culture, it is important to value health promotion activities in relation to other activities, since they are frequently in the hands of nurses. In most services, other professionals seem not to prioritize such actions, which results in their low participation. In the speeches of primary and secondary care nurses, it was evident that discrimination toward Hansen's disease patients still compromise treatment, and it is also present in the attitudes and distancing behaviors from health professionals in different categories. In order to overcome this difficulty, employing support social networks can be a strategy to strengthen nursing practices with support from the Support Center for Family Health (Núcleo de Apoio à Saúde da Família - NASF), which has a crucial role in supporting teams. Care centered on individuals is a central aspect to health reestablishment, contributing to reconstruct those who had their natural condition affected by the illness. Increasing family involvement in care for carriers of chronic diseases, and establishing ties to the teams from other health units who are co-responsible for comprehensive care are practices that must be part of the routine of those who practice in the complex care space.

Collaborations

Silva MCD and Paz EPA were equally responsible for the concept of the manuscript; analysis and interpretation of data; composing and critically reviewing its intellectual content and final approval of the version to be published.

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