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Multiple dimensions of healthcare management of leprosy and challenges to its elimination*

Múltiplas dimensões da gestão do cuidado à hanseníase e os desafios para a eliminação

Múltiples dimensiones de la gestión del cuidado de la lepra y los desafíos para su eliminación

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ABSTRACT

Objective: To analyze assistance provided to people affected by leprosy through multiple dimensions of Care Management. **Method:** Exploratory single case study with a mixed methods approach conducted at a referral service in a Southern Brazil municipality. Content analysis and webQDA software were used for data treatment. **Results:** Participants included health professionals, people with leprosy and their family members. leprosy incidence was found to indicate its dissemination in the study setting, despite its low endemicity. Predominance of multibacillary cases and diagnoses with grade 2 disability indicate shortcomings in early detection efficacy. Contradictions were found in multiple dimensions of Care Management, leading to the understanding that the challenges in fighting leprosy are not only biological, but also socially determined. **Conclusion:** The presented challenges demonstrate the health care network's frailty regarding lowering this disease's rate and the need for effective public policies to confront diseases that, similarly to leprosy, are determined by social inequality.

DESCRIPTORS

Leprosy; Public Health Nursing; Health Management; Nursing Care; Social Inequity; Neglected Diseases.

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INTRODUCTION

Leprosy continues to afflict disfavored social classes in historically endemic areas. It leads to high percentages of physical disability, compromising the working capacity and lives of those affected and perpetuating the stigma related to this condition[1-2].

Along with the 200,000 cases notified per year worldwide, which show no clear signs of reducing in the near future, there are undetected and untreated cases, which jeopardize even more this disease's control, since such cases represent a hidden reservoir of infection. The World Health Organization (WHO) considers that there are yet additional challenges, such as the limited impact of actions for controlling and preventing leprosy transmission, the continuity of stigma of this disease, and evidence of delayed detection of new cases, given that diagnoses include physical disabilities[3-4].

Worldwide charge of grade 2 disability (G2D) is estimated to afflict one million people in 2020. Its related suffering encompasses not only pain and discomfort strictly from physical damage, but also a high psychological and social impact, which reinforces the need for implementing more effective disease control strategies[3,5]. By considering leprosy a chronic condition, health policies must focus on maintaining its control rather than its elimination[3].

Brazil presents the second highest number of new leprosy cases worldwide. In 2018, 28,660 new cases were notified, which amounts to 1,785 more cases than those of the previous year[6]. Regarding prevalence and overall detection rates, Brazil had 1.35 cases per 10,000 inhabitants and 12.94 per 100,000 inhabitants, respectively[7].

Leprosy is among global diseases considered as neglected. It predominates in conditions of poverty and contributes to the perpetuation of inequality, since it represents a strong hindrance to the development of countries[1-2].

Given this context, Historical Dialectical Materialism (HDM) was employed as this study's theoretical and philosophical framework. Also, to establish a dialogue with public policies on the inclusion of leprosy patients in the Brazilian healthcare system, Healthcare Management (HM) was adopted as a methodological framework. This is defined as the provision or availability of health technologies in accordance with individual needs in different moments of each person's life[8].

Healthcare Management is conducted in six dimensions: individual, family, professional, organizational, systemic, and societal. Each presents a specificity, which can be known for purposes of reflection, research, and intervention[8].

This study aims thus at analyzing assistance provided to people affected by leprosy through the multiple dimensions of Healthcare Management.

METHOD

Study type

This is an exploratory single case study with a mixed methods approach which was developed in two concomitant phases.

Scenario

A municipality which hosts a Healthcare Regional center of a state in Southern Brazil was chosen as the study scenario. This municipality accounts for 30% of new leprosy cases notified in this Regional center and has a referral service for case follow-up.

Selection criteria

In the qualitative phase, intentional sampling was adopted for selecting research participants, which were organized into three groups: health professionals, people with leprosy and relatives.

The six health professionals forming the care team for people affected by leprosy in the referral service were invited to participate. These included a dermatologist, a physiotherapist (who was also a coordinator in a municipal program for leprosy control), a psychologist, a social assistant, a nurse, and a nursing auxiliary.

The coordinator of the Regional center's program for leprosy control and the Epidemiologic Surveillance coordinator for this Healthcare Regional center participated in this research by referral from the municipal program coordinator. Users and their relatives were referred by the municipal program coordinator, who established contact and scheduled the interview.

Selection criteria for the group of participants with leprosy were: an individual who had recently started treatment, one halfway through the time allocated for each therapeutic scheme and one whose treatment was concluded. In the group of participants corresponding to relatives, the inclusion criterion was selecting and inviting one relative of each person afflicted with leprosy. In the quantitative phase, leprosy cases notified in the study scenario between 2007 and 2016 were included.

Data collection

The interviews were conducted between March and June 2017, directed by a semi-structured script developed specifically for each participant group. In the qualitative phase, recommendations by the Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed.

The quantitative data on the notified cases were provided by the program's municipal coordinator, along with data from the reporting forms of this research's participants.

Data treatment and analysis

The interview recordings were transcribed and the resulting material was analyzed using a qualitative analysis software, webQDA®, and content analysis[9]. Empirical categories were developed from the multiple dimensions of Healthcare Management: societal, systemic, organizational, professional, family, and individual[8]. The categories of analysis comprised forty-five Tree Codes, which branched into fifteen Codes and thirty Sub-Codes. Descriptive statistics was employed to organize and analyze

quantitative data. The data were inserted into Excel® version 2016 spreadsheets.

Ethical aspects

The project was approved by Universidade Estadual do Centro-Oeste's Ethics Committee in Opinion number 1.864.051/2016 and followed ethical recommendations from National Health Council's Resolution 466/2012.

RESULTS

Study participants included the six health professionals who worked in the referral service, two coordinators of the leprosy Control Program for that Healthcare Region, seven people afflicted with leprosy (one starting treatment, two halfway through treatment and three who had already been cured and discharged) and four relatives.

The description of results aimed at presenting the multiple dimensions of leprosy Healthcare Management and providing an understanding of the categories for empirical analysis, which were developed for this study based on the adopted methodological framework.

In the Societal Dimension, stigma related to the historicity of leprosy is still present. According to the participants, the prejudice they experience often comes from people afflicted with leprosy themselves.

(...) there is still that stigma; leper is no longer used, but unfortunately laypersons and uneducated people still use that word. This makes people walk away (P5).

(...) And from patients themselves, undoubtedly, because patients have a lot of prejudice against themselves due to historical issues of leprosy (P6).

Between 2007 and 2016, socioeconomic characteristics of newly reported cases in the study scenario predominantly comprised low education, urban residence, low income, informal jobs – especially agricultural work – or unemployment, and lack of pension rights. Precarious socioeconomic conditions were found to impact self-esteem and people's decision to timely search for health services and have leprosy diagnosed.

(...) when you have self-esteem, you take care, you eat properly, you have a good residency status. Even if you are infected by this bacterium and it manifests, you have some pride and you try to find out what is going on with you, and eventually you find out. You persist. But when it comes to very humble people, under very precarious conditions, do you think they worry about something that doesn't even hurt? (P2).

Regarding the Systemic Dimension, this study's scenario was found to be in the Healthcare Regional center which accounts for the highest number of new cases, despite leprosy low endemicity. In 2016, 21.43% of them had G2D in their diagnosis, which indicates a high parameter (above 10%) for the effectivity of actions for early detection. These indexes demonstrate the preoccupation reported by participants with the abandonment of leprosy control program.

(...) we have noticed that incentives from above to maintain this service do not come any longer, because they are unnecessary. They say that less than one case per ten thousand inhabitants means this has been eliminated as a public health issue. And we are eliminated because we do not amount to the necessary number. (...) yes, the number of cases has had a significant reduction, but these people still need care (P2).

In this study's scenario, a healing rate ≥ 90%, along with a < 10% treatment abandonment rate for leprosy patients, was found to indicate high care quality and case follow-up until treatment termination. Surveillance of household contacts was considered a main strategy of action by the Region's program for leprosy control. Between 2007 and 2016, a desirable parameter (≥ 90%) for examined contacts was achieved.

(...) Treating patients and isolating them is ineffective. If they are discharged – we are talking about a contagious disease – they are cured, which means no more medicine and no more protection. They will get infected again if informants are not well examined (P5).

(...) This is one of the most demanded indexes here in Vigia-SUS regarding informants, contact evaluation. We really try to achieve it (P6).

Basic Care was pointed by the interviewed health professionals as a strategy to increase the potential of the program for leprosy control. However, the following processes were found to weaken the maintenance of a decentralized model of leprosy care: high personnel turnover and low commitment by health professionals; this disease's low endemicity, which contributes to longer intervals between newly detected cases; the emphasis on attending epidemiological emergencies and overload of actions for meeting scheduled demands in the basic health units.

(...) How can the units deal with such a situation if there is only one case every five years? It is very rare. (...) They fall out of practice because they provide care only once and never see this again (P2).

(...) The more centralized a service is, the more likely it is for a patient to experience access difficulties and come more deformed because it takes longer, which does not happen in the health unit (P5).

In the Organizational Dimension, new multibacillary cases, more advanced clinical forms of the disease (dimorphous and Virchow's) and diagnosis including G2D were found to predominate between 2007 and 2016. Such numbers lead to the inference of shortcomings in the early detection of leprosy in the study scenario. Also, a delay between initial contact with health service and diagnosis confirmation was identified.

(...) I do not understand it because some cases come to us at such an advanced stage which could have been treated at the beginning; you check patients' records and you find out they have looked for care many times already (P3).

(...) I guess I have been through more than ten doctors. And I had got no answer. I even did an allergy treatment, which the doctor from the unit near home said would work. (...) It took me four years to get to the (referral service) (I5).

Difficult access, lack of physical resources and frequent doctor turnover were pointed as factors which contribute to late diagnosis.

(...) one of the biggest problems (...) is the issue of medical professional turnover in this service. We have trained some people last year, and now we have new people already; we cannot possibly train everyone and this sometimes ends up being neglected by the service. (...) And there is really a lack of sensitivity towards leprosy. Diagnoses are not performed early because of that, because they say it is just an allergy, it is anything, you should just use an ointment; they don't think it might be leprosy and don't forward the patient to our service (P6).

Health professionals at different levels of healthcare are remarkably unprepared to diagnose leprosy. Reported misdiagnoses led to wrong treatments and disease worsening. Also, people were noticed to take long to seek a health unit due to a lack of knowledge on signs and symptoms of leprosy.

(...) leprosy is a chronic condition which is not prioritized by patients because it does not hurt, it does not bother. Patients usually seek help for other problems. (...) early diagnosis is still very difficult. (...) Why do they arrive disabled? Why isn't this diagnosed earlier? It is usually because the patient had been to the health unit with a spot, with some alteration, and it did not receive sufficient attention (P5).

Early diagnosis was demonstrated to be the main manner of preventing disabilities due to leprosy.

(...) Fast intervention and perception is a preventive service. For instance, like I said: he called, we did it, we followed-up, had him examined, then immediately talked to the doctor. She attended him while we made a dorsiflexion device, which is an apparatus to enable him to move properly because he was limping already, with spine and hip problems, because he had to turn his hip completely to change pace. All these interventions are part of prevention (P2).

Participants reported noticing a positive impact from individual and collective health education activities, especially in seeking health services, examining contacts, and adherence to treatment, also playing an important role in breaking the stigma.

The teamwork conducted in the referral service was pointed as a positive feature for the effectivity of the leprosy control program in the study scenario. All interviewed users and family members reported being satisfied with the attention provided by the team.

In the Professional Dimension, according to participants, few professionals from Basic Care were capable of properly conducting early detection of this disease. As barriers for training health professionals, frequent personnel turnover, and the disease's low endemicity in the study scenario were mentioned.

(...) Because college does not teach much. Because this disease is not emphasized. When it comes to HIV, for instance, there is a trend (P1).

(...) Demanding from the health system that these doctors continue to receive continuous training (...) you need to remind them of the disease and their obligation of treating, of diagnosing and treating, leprosy (P5).

Despite the trainings and support offered by the referral service's team, reduced participation, lack of interest and prejudice from the Basic Care teams regarding leprosy have been reported, which leads to often unnecessary referral to the referral service.

(...) I think health professionals have a lot [of prejudice]. *(...) It comes more - I guess - from this population than from family or from people* (P1).

(...) It is routine, because this is an old disease that has always been around, but the prejudice is like "this is to be treated in the [referral service]. *This is not ours"* (P2).

(...) There is [prejudice], *mainly among health professionals. I think we do not have a way of making professionals more sensitive and this leads to more prejudice* (P6).

As flaws in the work process of the referral service's team, the following stand out: inappropriate physical structure, which does not favor privacy, lack of reception and administrative services personnel, reduction of material and financial costs, high professional turnover, which makes training difficult, the fact that the leprosy program is not among priorities of the municipality's government, and lack of time.

The following were mentioned as potentialities: involvement and compromise by all team members regarding care, the construction of bond and confidence on users, proper headquarters for the referral service, facilitated access to specialists and collaboration from Basic care teams.

In the Family Dimension, support and participation by relatives on home care practices were emphasized.

(...) we talked. I was always supportive and so were my mother and sisters, and she started to relax, worrying only about making progress with her treatment (F4).

Finally, in the Individual Dimension, people afflicted with leprosy and their relatives were found to have little or no knowledge on this condition.

(...) I did not know much about this disease. (...) they said it is very dangerous (I6).

Among the processes that increase personal adherence, the following were mentioned: care provision by all team members of the referral service, the establishment of bond and confidence, active search for absent people, a desire for healing, family support and orientations offered by each health professional, specially the nurse.

As processes that weaken treatment adherence, the following were mentioned: interest in maintaining an assistance benefit, mental disorders and/or dependence on alcohol or other drugs, precarious socioeconomic conditions, resistance to treatment, medication adverse effects, non-acceptance of the disease as chronic and absence of follow-up by the health service.

DISCUSSION

These findings, which are in accordance with the literature, suggest that leprosy is associated with social inequality, due to its concentration on disfavored social classes. Stigma and fear associated to this disease contribute to the delay in starting treatment and to the reduction of individual economic productivity, perpetuating poverty[10-13].

This disease, considered as age-old and neglected, illustrates the close relation between life conditions and the health-disease process. Therefore, protective processes may include lower social inequality, higher human development, broader health coverage and income transfer programs[11-12,14-17].

Social programs can produce benefits to vulnerable people, stimulating the use of health and education services and improving school attendance and health indexes while aiming at emancipating families in conditions of extreme poverty. Thus, countries with high leprosy endemicity and low human development should prioritize investment in research on its social determination, incorporating poverty eradication as an important component of health policies[11-12,14-15,17-18].

The results of this study are in accordance with the literature, which points to a long construction of stigma related to leprosy as a phenomenon deeply and historically rooted in societies. Discrimination and prejudice were found to persist even among health professionals.

Studies show that prejudice commonly comes from people afflicted with leprosy themselves regarding their body image, and is expressed by fear of other people's reaction, anger, shame, and non-acceptance of the disease. As social subjects, these individuals reproduce and feed the disease stigma, which in turn makes the fighting process and self and social acceptance even more difficult[11,19-23].

Conceptions of leprosy are usually associated to previous knowledge related to past experience, cultural prejudice and information obtained from the media. Biblical narratives which associate it to impurity and the need for exclusion and isolation, as well as the use of the term leper, collaborate for the construction and consolidation of this disease's social imaginary[11,19,23-24].

The means and conditions for fighting leprosy in different social classes also differ on access to health services, work, information, proper living conditions, social support network, among other aspects[11].

One of the contradictions pointed out was the concern about the uninterest from managers to invest in leprosy care in states not presenting hyperendemic parameters, while the detection of new cases in the study scenario has demonstrated more severe forms of the disease and/or physical disability in the diagnosis.

The WHO recommends decentralizing leprosy programs to Basic Care units in municipalities. This proposal is still considered one of the biggest challenges for achieving disease control, given that, even though care and control of leprosy are Basic Care attributions, centralized care is still predominant in specialized attention. This contributes to the maintenance of hidden prevalence[21].

Leprosy, regarding its chronicity and the need for continuous care through well-structured case surveillance, requires planning health services for controlling it as an endemic condition to provide broad coverage. Leprosy has increasingly been integrated to Basic Care in most countries where it is endemic, except for treatment centers aimed at this disease, establishing a reference and counter reference system within the services[25].

However, corroborating studies conducted in Santarém, Pará state[10] and João Pessoa, Paraíba, state[13], predominance of clinical multibacillary forms (dimorphous and Virchow's) and a significant share of people with G2D indicate late diagnosis for this disease, from which it can be inferred that the basic health care network still faces difficulties in early detection.

This fact seems to be associated to insufficient training of health professionals for essentially clinical leprosy diagnosis, contributing to disease worsening, disabilities, and consequent ongoing transmission of the etiological agent[10,19].

Successful implementation and execution of leprosy control program depend both on effort and technical education for health teams involved and on the quality of health service access of the basic network by users[26].

Uninterest and reluctance from Basic Care professionals in providing care to people affected by leprosy was pointed out. This leads to unnecessary referral to the referral service. Such finding corroborates a study conducted in Africa, reinforcing that this attitude strengthens the stigma associated to the disease, while also contradicting the WHO's incentive for the inclusion of leprosy among the primary health care services[22].

Such difficulties jeopardize the maintenance of a decentralized model for leprosy care while hindering disease control. In the study scenario, people affected by the disease were found to usually encounter many barriers to receiving an early diagnostic, contrary to directives from the Ministry of Health[27].

Such a finding corroborates other studies that consider the path of people afflicted with leprosy to be a long one from perception of the first symptoms to starting treatment. People commonly move through more than one service before this disease is mentioned as a hypothetical diagnosis. Patients' expedition in search of proper diagnosis and treatment is related to the lack of knowledge from professionals and population on this disease, as well as delays in diagnosis, negative exams, and incorrect diagnosis[19,26].

The emergence of disabilities in people diagnosed with leprosy indicates shortcomings in disease control. These include early detection, the impact of actions such as collective comprehension of this disease, the health system's capacity of recognizing early clinical manifestations and, to a certain extent, service coverage, as well as social aspects of people afflicted with leprosy[6,15].

Knowledge on leprosy and the understanding of orientations, preventive measures and therapeutic measures influence the autonomy of subjects regarding care, which is crucial for the coverage of preventive actions[15]. Attention should be paid to low education, since it is directly related to a lack of understanding of this disease and, consequently, to postponing seeking the health service, while also being considered a barrier for health education[10,13].

Contact surveillance, one of the key actions for leprosy control, was reported in a study[28] conducted in Ceará state, which found among facilitating factors for examination family involvement and orientation regarding leprosy cases on the importance of performing a dermatological and neurological exam. On the other hand, lack of orientation was reinforced as the main difficulty for conducting the exam. These data reinforce the need for conducting actions that are more based on health education, mainly in Basic Care.

Health education for the population and permanent education for professionals at all levels of health care favor early detection of leprosy, possibly impacting time spent waiting and searching for diagnosis[19].

Care aimed at educational, behavioral, psychic and social aspects of people afflicted with leprosy, as well as those of their relatives and society as a whole, is of uttermost importance for providing successful treatment and, subsequently, reintegrating individuals back into society[21,29].

Family support along with proper follow-up by the health team offers significant support for people afflicted with leprosy and are generally pointed as fundamental for fighting this disease. Reception is thus a crucial strategy to strengthen bonds between users and their relatives, which is also regarded as a relevant measure for providing appropriate care and follow-up of cases until the patient is healed[19-20,29].

Low adherence is still an important obstacle to leprosy control, since those who abandon treatment continue to be possible sources of infection, leading to irreversible complications and resistance to multiple medicine[30].

Precarious socioeconomic conditions were pointed by this study's participants as one of the processes that weaken adherence to leprosy treatment. Such a fact corroborates other studies, which reveal higher prevalence of variables such as gender, education, income, and housing conditions as causes for non-adherence and/or abandonment, which are more significant than levels of knowledge on the disease[26,30], reinforcing the need for approaches to health policies to contemplate social determination to improve control and achieve disease elimination.

In this regard, it is important to consider that the path to minimizing such a problem depends both on the personal resources of people afflicted with leprosy and their families and social support, including attitudes by professionals and access to health services[11,22-23].

The limitations of this study are related to the stigma that makes people with leprosy and their relatives not being open to answer interview questions. Also, this study is limited by its comprehension of healthcare management only within the referral service scenario. Studies in the Basic Care scenario along with Family Health Strategy teams are suggested.

This study is thus expected to contribute to knowledge production in a priority area, working with the multiple dimensions in which Healthcare Management emerges, with new tools and technology for strengthening control of leprosy by health services, providing also more depth and comprehension to the social determination of this disease.

CONCLUSION

This study found evidence of contradictions in the management of leprosy care in all six dimensions through dialogues between HDM and HM, leading to the understanding that, to achieve the WHO's goals, the social determination of this disease must be discussed, since the reduction of this disease's charge extrapolates the simple fact that there is medical treatment available.

By considering that leprosy is a historical and socially neglected illness and that absence of diagnosis does not imply absence of disease, the importance of this study is reinforced in face of its unusual approach and the revealing contradictions it pointed out, which open a channel for analyzing overcoming strategies. The study of the multiple dimensions of healthcare management of leprosy is fundamental for nursing practice and teaching, as well as for the comprehension of processes which contribute to maintain this disease's endemicity.

RESUMO

Objetivo: Analisar a assistência às pessoas afetadas pela hanseníase por meio das múltiplas dimensões da Gestão do Cuidado. **Método:** Estudo de caso único, exploratório, com abordagem por métodos mistos, conduzido em um serviço de referência de um munícipio da Região Sul do Brasil. Utilizou-se análise de conteúdo e o software webQDA para o tratamento dos dados. **Resultados:** Participaram profissionais de saúde, pessoas com hanseníase e familiares. Constatou-se que a incidência da hanseníase indica sua disseminação no cenário do estudo, apesar da baixa endemicidade. As lacunas na efetividade da detecção precoce foram evidenciadas pelo predomínio dos casos multibacilares e pela presença de grau dois de incapacidade no diagnóstico. Evidenciaram-se as contradições nas múltiplas dimensões da Gestão do Cuidado, permitindo compreender que os desafios para o enfrentamento da hanseníase não se encontram apenas no âmbito biológico, mas na sua determinação social. **Conclusão:** Os desafios apresentados apontam as fragilidades da rede de atenção à saúde para alcançar a redução da carga da doença e a necessidade de políticas públicas efetivas para o enfrentamento de doenças determinadas pelas desigualdades sociais, como a hanseníase.

DESCRITORES

Hanseníase; Enfermagem em Saúde Pública; Gestão em Saúde; Cuidados de Enfermagem; Iniquidade Social; Doenças Negligenciadas.

RESUMEN

Objetivo: Analizar la atención a las personas afectadas por la lepra a través de las múltiples dimensiones de la gestión del cuidado. **Método:** Estudio de caso único, exploratorio, con enfoque de método mixto, realizado en un servicio de remisión de un municipio del sur de Brasil. Para el tratamiento de los datos se utilizaron el análisis de contenido y el software webQDA. **Resultados:** Participaron profesionales de la salud, personas con lepra y familiares. Se comprobó que la incidencia de la lepra indica su propagación en el escenario de estudio, a pesar de su baja endemicidad. Las lagunas en la eficacia de la detección temprana se pusieron de manifiesto por el predominio de los casos multibacilares y la presencia de discapacidades grado II en el diagnóstico. Se pusieron de relieve las contradicciones en las múltiples dimensiones de la gestión del cuidado, lo que permitió comprender que los desafíos para hacer frente a la lepra no se encuentran sólo en la esfera biológica, sino en su determinación social. **Conclusión:** Los desafíos presentados señalan las deficiencias de la red de atención de la salud para lograr la reducción de su carga y la necesidad de políticas públicas eficaces para hacer frente a las enfermedades determinadas por las desigualdades sociales, como la lepra.

DESCRIPTORES

Lepra; Enfermería en Salud Pública; Gestión en Salud; Atención de Enfermería; Inequidad Social; Enfermedades Desatendidas.

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