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# Contextual analysis of health care at discharge in leprosy: an integrative review

Análise contextual da atenção à saúde na alta em hanseníase: uma revisão integrativa Análisis contextual de la atención a la salud en el alta en lepra: una revisión integradora

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## ABSTRACT

**Objective:** To analyze contextual relations of health care in the discharge of leprosy.

**Method:** An analytical, reflexive study based on the theoretical framework of context analysis, elaborated through an integrative review of literature in the databases SCOPUS, PUBMED, LILACS, SCIELO and BDENF, with uncontrolled descriptors Leprosy and Patient Discharge, obtaining 14 publications.

**Results:** The immediate context addresses health care at discharge in leprosy; the specific context treats leprosy as a public health problem; the symbolic conceptions and marks involving leprosy are encompassed by the general context; and in the metacontext are described the health programs and policies that subsidize the care of leprosy patients.

**Conclusion:** The contextual elements emphasize the need to guarantee universal coverage of cases of leprosy, from diagnosis to the post-discharge, reinforcing leprosy as a public health problem. Despite the limitations of the bibliographic studies, these have relevance for the health area.

**Keywords:** Leprosy. Patient discharge. Disabled persons. Comprehensive health care. Nursing.

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## **RESUMO**

Objetivo: Analisar as relações contextuais da atenção à saúde na alta em hanseníase.

**Método:** Estudo analítico pautado no referencial teórico de análise do contexto, elaborado mediante revisão integrativa de literatura nas bases de dados SCOPUS, PUBMED, LILACS, SCIELO e BDENF, com descritores Hanseníase e Alta do Paciente, obtendo-se 14 publicações.

**Resultados:** O contexto imediato aborda a atenção em saúde na alta em hanseníase; o contexto específico trata da hanseníase como problema de saúde pública; as concepções simbólicas que envolvem a hanseníase são abarcadas pelo contexto geral; e no metacontexto estão descritos programas e políticas de saúde que subsidiam o atendimento à pessoa com hanseníase.

**Conclusão:** Os elementos contextuais ressaltam a necessidade de garantir a atenção em saúde para os casos de hanseníase, do diagnóstico até o pós-alta, reconhecendo a hanseníase como problema de saúde pública. Apesar das limitações dos estudos bibliográficos, estes possuem relevância para a área da saúde.

**Palavras-chave:** Hanseníase. Alta do paciente. Pessoas com deficiência. Assistência integral à saúde. Enfermagem.

## RESUMEN

**Objetivo:** Analizar las relaciones contextuales de la atención a la salud en el alta en lepra.

**Método:** Estudio analítico, pautado en el referencial teórico de análisis del contexto, elaborado mediante una revisión integradora de la literatura en las bases de datos SCOPUS, PUBMED, LILACS, SCIELO y BDENF, con descriptores Lepra y Alta del Paciente, obteniendo 14 publicaciones.

**Resultados:** El contexto inmediato aborda la atención en salud en el alta en lepra; el contexto específico trata a la lepra como problema de salud pública; las concepciones simbólicas que envuelven la lepra son abarcadas por el contexto general; y en el metacontexto se describen los programas y políticas de salud.

**Conclusión:** Los elementos contextuales resaltan la necesidad de garantizar una cobertura universal en casos de lepra, desde el diagnóstico hasta el post-alta, reforzando la hanseniasis como problema de salud. A pesar de las limitaciones en los estudios bibliográficos, estos tienen relevancia para el área de la salud.

**Palabras clave:** Lepra. Alta del paciente. Personas con discapacidad. Atención integral de salud. Enfermería.

## INTRODUCTION

Leprosy, as an infectious disease, has peculiarities in its physiopathology, with heterogeneity in its territorial distribution recognized by the World Health Organization (WHO), which recommends the improvement of the coverage of actions in endemic countries<sup>(1)</sup>. This recommendation is aimed at early diagnosis, the treatment with polychemotherapy (PCT), the development of actions aimed at health promotion and prevention of leprosy through active search<sup>(2)</sup>.

In Brazil, leprosy is presented as an endemic, neglected disease, linked to the condition of poverty, which keeps alive the memory of moments of exclusion of the patient at the time of compulsory hospitalization<sup>(3)</sup>. The recognition as a public health problem caused the Brazilian Ministry of Health (MOH) to take the commitment to establish actions to reduce the burden of leprosy<sup>(4)</sup>.

The main strategy reaffirms the need to organize a Health Care Network (HCN) capable of following the user's demands through the linkage between Primary Health Care (PHC) and secondary and tertiary levels of care. It reinforces the importance of actions aimed at early diagnosis, drug treatment, disability prevention, contact surveillance and rehabilitation<sup>(5)</sup>.

Although leprosy is treated and curable<sup>(6-7)</sup>, there is the possibility of recurrence and the appearance of leprosy reactions that develop and aggravate the after-effects after discharge, so that the problem does not end after the conclusion of the PCT<sup>(8)</sup>. The repercussions of the disease on the world stage confirm the problem after discharge medication, emphasizing the importance of discussions about what has been done in relation to health care for egresses of PCT specific to leprosy<sup>(9)</sup>.

Faced with the need to establish care services and effective actions for those who have completed drug treatment, it is questioned: What are the contextual relations inherent to health care that interfere with the discharge of leprosy?

The context is seen as the inherent aspects of a given situation that allow to understand its whole, discovering its meanings through a mutual, purposeful and systematic relation existing between the elements involved with the studied phenomena. According to the references used in the present study, the contextual levels are divided into four distinct and interrelated interactive layers: the immediate context, the specific context, the general context and the metacontext<sup>(10)</sup>. In this perspective, the objective of this study is to analyze the contextual relations of the attention to health in the discharge in leprosy.

Thus, it is intended to contribute to a greater approximation between the attention given to the individual who was discharged for cure in leprosy and the context around this phenomenon, with a view to a better understanding of the problem in the post-discharge period, as well as aiming at awakening in the professionals the need for practices involving the promotion and recovery of health, as well as the prevention of diseases before, during and after PCT.

### METHOD

It is an analytical study<sup>(11)</sup>, based on the theoretical framework of context analysis<sup>(10)</sup>. The context is established by interactive layers that congregate different extensions of meanings related to the phenomenon, linked by points of intersection, providing a spiral vision of the problem contextualized<sup>(10,12)</sup>.

In this way, the contextual analysis favors a growing understanding of the phenomenon that goes from the immediate context where the situation is described as such, goes through the specific dimension, besides analyzing subjective aspects in the general context. The macro aspects involve sociopolitical and theoretical elements, established in the metacontextual considerations<sup>(10)</sup>.

In order to compile information for the preparation of the contextual analysis study of health care at discharge in leprosy, an integrative literature review was developed<sup>(13)</sup> guided by the question: What is the knowledge about the discharge of the leprosy patient? Through the elaboration of the search protocol<sup>(13)</sup>, the strategy of collecting and analyzing the results was established. Therefore, the integrative literature review study was initially developed in order to seek information in a systematized form, for later analysis of the compiled materials and description based on the contextual layers.

The search for studies was guided by the eligibility criteria: complete articles available through the use of the *proxy* of the Federal University of Rio Grande do Norte, in the Portuguese, Spanish and English languages, and addressing the issue related to discharge in leprosy. Editorials, letters to the editor, abstracts, expert opinions, theses and dissertations were excluded.

The selection made by two researchers, independently, occurred in the months of June and July of 2017, in the SCOPUS and PUBMED databases, using descriptors indexed in the *Medical Subject Headings* (MeSH); in addition to the bases Latin American Literature in Health Sciences (Literatura Latino-Americana em Ciências da Saúde (LILACS)), *Scientific Electronic Library Online* (SCIELO) and Nursing Database (Base de Dados de Enfermagem (BDENF)), by means of Health Sciences Descriptors (DeCS). In case of divergence of opinion on the inclusion of certain material, a third researcher was consulted.

The search was made without using a temporal cut-off related to the year of publication of the studies and was performed using the indexed descriptors Leprosy and discharge (or *Leprosy* and *Patient Discharge*, for selection via MeSH), associated with

the Boolean operator *AND*, obtaining a total of 145 publications. After exclusion according to the eligibility criteria and repeated publications, 14 articles<sup>(14-27)</sup> were included for the study, as explained in Flowchart 1.

Search with uncontrolled indexed descriptors SCOPUS: 91 publications PUBMED: 34 publications LILACS: 3 publications SCIELO: 11 publications BDENF: 6 publications Total: 145

Final sample SCOPUS: 7 publications PUBMED: 1 publication LILACS: 2 publications SCIELO: 1 publication BDENF: 3 publications Total: 14

**Excluded publications** By eligibility criteria: 128 By repetition: 3 Total: 131

**Flowchart 1 -** Articles included in the study. Natal/RN, Brazil, 2017 Source: Research data, 2017

In order to carry out the analysis, in addition to the articles selected, we also searched for convenience, in a non-systematized way, publications<sup>(4,28-34)</sup> of the authors' knowledge, because it is seen necessary and relevant for contextual analysis.

Once the references for analysis were defined, all the material was analyzed, distinguishing elements that characterize the publications (database, periodical, title and year of publication), as well as the identification of information for discussion of the contexts under analysis, concerning the discharge in leprosy. Therefore, the presentation of the results in relation to the objective of this work is done in a descriptive way, by discussing the content identified in the selected studies to compose the integrative review at each of the contextual levels: the immediate context, the specific context, the general context and the metacontext.

## **RESULTS AND DISCUSSION**

The selected articles<sup>(14-27)</sup> to compose the present integrative review present different levels of evidence. According to the level of evidence proposed by Melnyk and Fineout-Overholt<sup>(35)</sup>, two studies were classified in level IV (related to evidence from a cohort study)<sup>(14,24)</sup> and 12 studies were considered at the level of evidence VI, i.e., those that include evidence derived from a single descriptive or qualitative study<sup>(15-23,25-27)</sup>.

The year of publication of the articles selected ranged from 2000 to 2016, with predominance of seven publications (50%) inserted in the SCOPUS database. The journal that obtained the largest number of studies included in this review was the *Journal of the Brazilian Society of Tropical Medicine (Revista da Sociedade Brasileira de Medicina Tropical*), with a total of two articles<sup>(14,17)</sup> (14%).

Of the total articles selected, three<sup>(21,24,26)</sup> (21%) were published in international journals and indicate that post-discharge physical disabilities suggest late diagnosis and inadequate patient follow-up after completion of PCT, suggesting continuity of care for primary health care, in addition to emphasizing early diagnosis of leprosy as the main means of preventing such disabilities<sup>(21,24)</sup>. When considering the possibilities of isolation and depression caused by leprosy, the literature also affirms the need for psychological support to patients who were discharged from leprosy<sup>(26)</sup>.

Following the division proposed by the theoretical reference<sup>(10)</sup> and according to the summarization described in Chart 1, the *corpus* of this study is defined through the immediate context, which addresses health care at discharge in leprosy; the specific context in that it treats leprosy as a public health problem; the symbolic conceptions and marks that involve leprosy and are allocated in the general context; and the metacontext, where health programs and policies that subsidize care for the person with leprosy are concentrated.

CONTEXTUAL LAYER			
Immediate: Attention to health in the discharge in leprosy	Specific: Public health problem	General: Symbolic conceptions and trademarks	Metacontext: Programs and policies of health
Attention focused on the physical incapacities, relapse and leprosy reaction, with structuring of a system of reference and counterreference.	The high magnitude of the disease, its biological repercussions and the socioeconomic profile of the patient make leprosy a public health problem in Brazil.	Prejudice and stigma in the face of the history of divine punishment, isolation, fear of contagion and physical disability, besides the non-recognition of the treatment.	Guarantee of universal coverage, evaluation of the program and incentive to research, favoring the fight against leprosy, its complications and discrimination.

**Chart 1** - Identified knowledge about the discharge of the leprosy patient from the selected publications Source: Research data, 2017.

#### Considerations on health care in discharge in leprosy: immediate context

The criteria for termination of treatment for leprosy defined by the MOH relate to the number of doses of MDT administered in a given period of time, whether paucibacillary (PBs) or multibacillary (MBs). At the conclusion of the drug therapy, called discharge by cure, ceases to be an infectious disease and moves to the scope of chronic diseases<sup>(15-18)</sup>.

Its chronic evolution is often associated with the development of reactional episodes for up to five years after completion of PCT. In post-discharge neural damage occurs and the consequent installation and worsening of physical disabilities, indicating the need for qualified and comprehensive care for these patients considered cured<sup>(16-20)</sup>.

On the one hand, the MOH emphasizes the importance of returning to the health unit if new skin lesions are observed, neuralgia with or without worsening of the sensory function, associated or not with changes in motor function, for prevention and treatment of disabilities, and as a differential diagnosis between leprosy reactions and recurrences<sup>(4)</sup>. On the other hand, the literature cites the inexistence of well-defined actions in the care network focused on the operationalization of care in the continuity of care directed to the egresses of PCT<sup>(16,18,21-22)</sup>.

Although the recommendations for follow-up in the discharge period involve three groups of clinical conditions: physical disabilities, relapse and leprosy reaction<sup>(4)</sup>, many professionals and users confuse discharge of PCT with discharge by cure, hindering the continuity and maintenance of the patient in the care network. When considering the different possibilities of clinical manifestation of the disease at discharge, it becomes preponderant the organization of the program of elimination and control of leprosy with systematization of the monitoring and regular monitoring of these patients<sup>(15-16,18-19)</sup>.

Using an integral and longitudinal approach in a perspective of continuity of care with a view to the prevention of physical disabilities, rehabilitation, early diagnosis of cases of relapse and leprosy reaction, it becomes fundamental the patient's vigilance<sup>(19,21,23)</sup>. In this sense, it requires the structuring of institutions of reference and counter-referral flow with guarantee of consultations, tests and procedures for prevention and rehabilitation of physical disabilities, involving a multiprofessional health team at the three levels of assistance<sup>(18)</sup>.

The health services should be located close to the patient, with follow-up of the care by regular scheduling of return for consultations in a period of five years after discharge<sup>(19,24)</sup>, having as main entrance door in RAS the APS<sup>(28)</sup>.

A qualified team is responsible for promoting and ensuring the development of diagnostic, treatment, harm and injury prevention actions, health promotion and

biopsychosocial rehabilitation<sup>(18,20-22,26)</sup>. Therefore, neurological assessment, activity delineation, risk awareness, and social participation restriction are actions that improve the quality of health care for people who have completed PCT of leprosy<sup>(16,20,24,27)</sup>.

The attendance of the egresses of the drug treatment for leprosy with the PCT requires the standardization and elaboration of protocols, going beyond the coverage geared to attend the leprosy reactions, putting in practice the integrality of the care within the scope of the Unified Health System (SUS), of contribute to the social reintegration of individuals and provide universal assistance according to the specific needs of each case<sup>(15,23,25)</sup>.

### The insertion of leprosy as a health problem: specific context

Characterized as a chronic, slowly evolving infectious-contagious disease, leprosy has high disabling power by affecting skin and peripheral nerves, leading to limitations and physical disabilities. Its biological and social repercussions associated with the high magnitude of the disease in the Brazilian territory make it a public health problem<sup>(15-16,20,22,24-25)</sup>.

WHO has implemented treatment with PCT since the 1980s. It is recognized as one of the most important measures to eliminate leprosy as a public health problem and to achieve the goal of elimination, i.e. reducing the prevalence of the disease to less than one case per 10,000 inhabitants<sup>(18,20-21)</sup>.

Despite the existence of treatment and cure, Brazil is the country with the highest prevalence in the entire American continent, ranking second in the world *ranking*, with 25,218 new cases diagnosed, of which 1,696 were in children under 15 years of age in  $2016^{(30,36)}$ , prevailing as a relevant and worrying information when considering that detection in children under 15 years of age is an indicator of high endemicity<sup>(16,25,27)</sup>.

The recognized efficacy of PCT for the elimination of the bacillary load of the organism is not sufficient for the effectiveness of the treatment, which depends on the actions to be taken when considering the incapacitating potential, with consequent problems entailed in addition to the presence of the bacillus in the organism, as reduction of work capacity, socioeconomic restriction and psychological problems<sup>(15-16,20)</sup>.

Studies attribute some universal characteristics to the majority of people affected by leprosy, which concern populations with low purchasing power, low education and productive age. Such peculiarities reinforce the visibility of the disease to the social and economic scope, so that the affected persons have less access to health actions and services and, as a consequence, greater difficulty in following the treatment<sup>(15-16,18,20,25)</sup>.

The post-discharge sequel of neural damage is itself a health-care problem. It is estimated that 20% of newly diagnosed cases present some degree of incapacity and 15% of those under treatment may develop it during the use of PCT or after discharge by cure<sup>(16-17,21,24)</sup>. The loss of neural function is associated, on the one hand, with the action of the Hansen bacillus in the body, on the other, with the reactional immunological events that may occur before, during or after the drug treatment with PCT<sup>(14,17-18)</sup>.

The involvement of the autonomous, sensitive and motor nervous system, with changes in muscle tone, motor power and sensitivity increase the possibilities of ulceration, infection and destruction of structures such as skin, tendon, ligament, bone and muscle<sup>(19)</sup>. Such modifications lead to the development of physical deformities and disabilities, with negative interference in work capacity, social life and self-esteem<sup>(16,18,20,23)</sup>.

It is recognized that the presence of physical disabilities increases concomitant to the time of disease evolution and that the evolution of the degree of deformities after high medication reflects the need for organization and structuring of health services with a focus on integral care, involving rehabilitative and restorative conducts<sup>(16,20,27)</sup>.

Thinking on reducing the worsening of disability, the importance of early diagnosis of leprosy cases and identification of physical disabilities is also reinforced for treatment<sup>(20,22,24)</sup>, which can be facilitated through actions of health education and improved access to health services, which should be able to develop actions aimed at the control of leprosy<sup>(22)</sup>.

It is important that managers ensure the technical qualification of the health team and organization of control services in the territory, with a broader coverage of the patients, favoring treatment, vigilance and rehabilitation actions to advance the elimination of leprosy as a public health problem as well as in the negative and stigmatizing denotation of leprosy<sup>(18-19,25)</sup>.

## Symbolic conceptions and trademarks involving leprosy: general context

Leprosy is a millennial disease cited in biblical texts, often associated with divine punishment, whose sequelae caused fears among the healthy population, with consequent remission of the patient to peripheral areas. For many years, the practice of isolation was considered a measure of disease control<sup>(20,25)</sup>.

The former legacy of leprosy carries inhuman marks of horror which, coupled with the incapacitating potential, negatively impacts the person affected by the disease. It can be synthesized from two points of view: the symbolic meanings attributed to the disease and the functional and bodily impairment of the affected person.

From the point of view of symbolic meanings, coexistence with stigma and prejudice attitudes reflects on the quality of physical well-being, the psychological and socioeconomic status of patients and occurs mainly in the population's response to fear of contagion and the possibility of developing some kind of physical disability, as well as the conceptions associated with conditions of poverty and low level of education<sup>(16,21)</sup>.

The evolution of neural damage impairs bodily functionality by restricting the development of activities, making it difficult to establish social relations<sup>(15,24,27)</sup>. The functional limitations and stigmatizing attitudes in the context of leprosy are a driving force in restricting social participation, establishing difficulties in the workplace and consequent economic problems<sup>(15,21-22)</sup>.

It is mentioned<sup>(16)</sup> that attitudes of prejudice, stigma, discrimination and rejection are negative consequences of late diagnosis and poor physical and psychological rehabilitation of patients with leprosy. In addition, the lack of information on the part of the population regarding the existence of treatment, with a break in the transmission chain and healing, reaffirms the stigma surrounding the disease and the patient<sup>(23)</sup>.

The illness process carries the historical marks of the disease because it involves complex aspects that influence treatment, such as prejudiced ideas or lack of information<sup>(20)</sup>. In the routine of health services, there is the fear of people with leprosy as the uncertainty and the possibility of infecting others. In this sense, reinforcing the need for dialogue among patients, family members and health staff in order to clarify doubts and favor improvement in social interaction<sup>(20,23)</sup>.

The activities of health education are presented as a facilitating tool for the promotion of health care. It is essential to disseminate information to discourage stigma, favor early diagnosis and appropriate treatment in a timely manner to prevent physical disabilities, as well as periodic evaluation and continuity of treatment after medication discharge<sup>(23,25)</sup>.

### **Programs and Policies of Health for Leprosy: metacontext**

The global strategy to combat leprosy is structured around three pillars. The first reinforces the need for the government to offer resources aimed at leprosy control programs, guaranteeing universal health coverage, health surveillance and information systems for monitoring and evaluating the program, as well as incentive to research. The second praises anti-leprosy practices and their complications, while the third pillar is aimed at combating discrimination<sup>(30)</sup>.

It is worth emphasizing that in the Brazilian territory, health care is developed in the scope of SUS in a regionalized network and hierarchized by levels of care<sup>(32-33)</sup>. In the scope of leprosy, the guidelines for vigilance, attention and elimination as a public health problem provide subsidies to professionals who work at different levels of care by developing health care actions<sup>(4)</sup>.

In this perspective, the MOH National Leprosy Control Program establishes and regulates guiding practices to be developed in all instances of health services and systems, in accordance with SUS principles and guidelines to achieve the goals of the global strategy to combat leprosy<sup>(4)</sup>.

It is necessary to structure and hierarchize the network in municipal, regional and state levels, ensuring the flow of reference and counter-referral in the management of integral care to the person with leprosy. The agreements must guarantee the necessary follow-up of the user victim of this disease<sup>(34)</sup>.

Diagnosis and treatment are recommended in APS services, being the responsibility of reference services the conduct of laboratory tests, doubts regarding diagnosis, adverse reactions, reactional episodes, cases of relapses and the need for surgical rehabilitation<sup>(34)</sup>. With regard to the organization and implementation of State and Municipal Leprosy Attention Networks, the MOH included the Comprehensive Leprosy Service in the Specialized Services of the National Registry System of Health Establishments<sup>(29)</sup>.

In the context of the care network and in the perspective of reducing the burden of disease, the development of activities that include health education, early diagnosis with immediate treatment and its interface with the actions of epidemiological surveillance, prevention, treatment of disabilities and control of contacts are relevant when highlighting the lack of specific protection for leprosy<sup>(4)</sup>.

In order to intensify the active search for cases, MOH encourages the development of campaigns in the school environment, especially the "National Leprosy, Verminoses and Trachoma". The dissemination of leprosy-related information to elementary and middle school students is a way of encouraging early diagnosis, as well

as the propagation of information through involvement with family members through the self-image form<sup>(31)</sup>.

At the ministerial level, guidelines for the elimination of leprosy as a public health problem were also developed, with the aim of standardizing patient care in the various health care settings, through the standardization of guidelines for surveillance, care and elimination of leprosy<sup>(4)</sup>.

#### CONCLUSIONS

Based on the contextual analysis, it was possible to identify contexts in which the phenomenon of health care is inserted in the discharge in leprosy, constructing an itinerary by which the patient leaves the active registry of leprosy cases and occupy the space of chronic diseases.

In the analysis through the contexts of the methodological framework, therefore, the phenomenon under study is identified as something complex involving leprosy as a public health problem in Brazil. And it is associated with social inequalities and inequities, such as: poverty conditions, the difficulties for integral treatment, physical and social repercussions, as well as the subjective aspects linked to the history of segregation.

At the level of health programs and policies, it was discussed the service to the person with leprosy, in the metacontextual aspects, reinforcing the political commitment to guarantee the universal coverage for the treatment of cases of leprosy, from diagnosis to the post-discharge, the search active, early diagnosis, contact control, treatment, cure and continuity of attention upon completion of PCT, according to the needs of the patient.

In addition to the contextual analysis study, which presents limitations since it is a bibliographical work, it is suggested to conduct research aimed at evaluating the organization of services for users who have completed PCT for leprosy. This approach would provide support to identify the limitations that the health system and services directed to the person with leprosy may present. By including gray literature, it might be more appropriate to opt for the *scoping review*, this being another limitation of the study.

The relevance of the theoretical studies for the development of health research, especially in nursing, is emphasized by compiling the state of the art with regard to the subject under study, serving as the basis for the identification of a certain problem that is intended to study more deeply. Likewise, its relevance to nursing education and care is brought to the fore by reflecting on the context in which health care is inserted in the discharge of leprosy, raising awareness in the student in training and the professional in front of the attention focused on the egress of the PCT.

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