

ORIGINAL ARTICLE

INTERPRETATION SYSTEMS, THERAPEUTIC ITINERARIES AND REPERTOIRES OF LEPROSY PATIENTS IN A LOW PREVALENCE COUNTRY

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ABSTRACT

Objectives: In Peru, despite the small number of cases, there is evidence of late diagnosis and hidden prevalence of leprosy. In this context the objective of the study was to know the interpretation systems on leprosy, itineraries and therapeutic repertoires of patients diagnosed with leprosy who are in treatment or who have finished treatment. **Materials and methods:** A qualitative study was carried out, applying semi-structured interviews to patients diagnosed with leprosy from the Loreto and Ucayali regions. **Results:** 30 patients were interviewed. Most did not know the mechanism of leprosy transmission. In relation to therapeutic itineraries, patients generally went to health facilities on the recommendation of third parties who knew the disease. In some cases, health personnel made a bad diagnosis. The importance of the treatment indicated by the “Ministerio de Salud” (Ministry of Health) is recognized; however, economic factors and the distance to health facilities negatively affect adherence to treatment. In addition, it was evidenced that stigma persists towards the disease. **Conclusions:** Patients recognize the importance of treatment; however, they express misconceptions about the pathogenesis of leprosy, and weaknesses in the health system are also identified. These problems would lead to delay in diagnosis and treatment. It is recommended to strengthen control strategies and decentralize the care of leprosy with the participation of the community, patients, health personnel and healers, considering the identified barriers and a probable underdiagnosis in women.

Keywords: Leprosy; Health services; Perception; Therapeutics; Qualitative Research; Disability; Socio-demographic Factors; Stigma; Perú (source: MeSH NLM).

INTRODUCTION

Leprosy, considered to be a worldwide public health problem, was reportedly eliminated as of 2000. By 2005, most countries had achieved this goal; however, in several countries, it continues to be a problem at the regional level⁽¹⁾.

The Ministry of Health (MINSA in Spanish) of Peru reported a progressive decrease in prevalence, although there are still new cases detected. Despite this, rates of less than 1 per 10,000 inhabitants have been achieved in the provinces.

Most of the cases are circumscribed in the Peruvian jungle, specifically in Loreto and Ucayali, because the disease entered these regions through the border with Brazil in the 20th century⁽²⁾. In this context, the government policies on the control of leprosy facilitated the introduction of anti-leprosy drugs, and achieved the control of the disease, but not its eradication⁽²⁾. In 2017, the MINSA reported eleven new cases, including some leprosy-associated grade 2 disability, which evidences a late diagnosis and the hidden prevalence of the disease.

Underdiagnosis and late diagnosis are associated with the lack of follow-up, no active search for cases and disinformation of people and healthcare personnel, all of which have negative consequences influencing leprosy control⁽³⁾.

Due to people's financial problems, late diagnosis is a result of their delay in seeking medical attention⁽⁴⁾, and their therapeutic itinerary (what they do and where they go to maintain or

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restore their health)⁽⁵⁾. Traditional medicine should also be considered as influencing late diagnosis since it covers different conceptions of health and comprises the experience and cooperation of family groups and community⁽⁶⁾. The search for treatment, in contexts where different healthcare systems coexist, is influenced by the complexity, costs and sociocultural and geographical proximity of the health offer, which means that patients can combine the different offers of each health system⁽⁷⁻⁹⁾.

Leprosy control also requires knowing the therapeutic repertoires (procedures and resources) of each healthcare system and how patients use them⁽¹⁰⁾. Likewise, adequate adherence to treatment is required; however, it depends on socioeconomic, cultural, psychosocial, and behavioral factors, and on adverse drug reactions^(11,12). In this context, the systems of interpretation of the disease vary within and between cultural groups, and influence the way people prevent and treat the disease^(6,13-17). In this concern, the objective of the study was to understand the systems of leprosy interpretation, itineraries and therapeutic repertoires of patients diagnosed with leprosy under treatment or after completion of treatment.

MATERIALS AND METHODS

A qualitative study was carried out, using intentional non-probability sampling, in which semi-structured in-depth interviews were applied to leprosy patients under treatment or after completion of treatment. The interviews took place between October and November 2015. Previously, the interviewer and those responsible for the National Health Strategy for Tuberculosis Component Lepra had a meeting with patients in order to explain in a simple and clear way the purpose of the investigation.

The study included patients over 18 years old with a leprosy diagnosis made in MINSA healthcare facilities, who resided at the time of the study in the city of Iquitos (department of Loreto, province of Maynas, districts of Belen, Punchana and San Juan Bautista) those who resided in the city of Pucallpa (department of Ucayali, province of Coronel Portillo, districts of Calleria, Yarinacocha and Manantay). The eight profiles established for patients in each region included leprosy treatment (under treatment or treatment completed), domicile (urban or rural), and sex (female or male).

The interviews were held by a healthcare professional with experience in community work in several native communities and qualitative study conduction, who had an induction regarding the research topic by the team of researchers (anthropologist and infectious disease experts in the management of leprosy patients). The interviewer also

KEY MESSAGES

Motivation for the study: In Peru, a country with a low prevalence of leprosy, patients are still diagnosed with a leprosy associated grade 2 disability, which suggests a late diagnosed disease.

Main findings: Since patients do not know the mechanism of transmission of leprosy, most of them go to hospital following the recommendation of those who identified the disease.

Implications: Strategies are required to control leprosy, considering the identified limitations of the health sector and the patients' lack of knowledge about the disease.

lived in one of the included regions, which allowed an easier understanding with patients, since he knew the mores and cultural terms used to communicate colloquially. It is worth mentioning that all the interviews were carried out at patients' homes, ensuring privacy and confidentiality.

Considering the theories of Chrisman⁽⁵⁾, Kleinman⁽⁶⁾, Young⁽⁷⁾, Schartz⁽⁸⁾ and Good⁽¹³⁾, three study dimensions were proposed: leprosy interpretation systems, therapeutic itineraries, and therapeutic repertoires used by patients with leprosy diagnosis, including adherence to treatment. A total of 20 codes were proposed for each dimension, based on the objective and the study dimensions. In addition, the interview guide was prepared and reviewed by an expert leprosy dermatologist and by a healthcare worker with experience in community work, and modified according to their suggestions. The final version of the guide was applied to people who voluntarily decided to participate in the study. The interviews were carried out until reaching the saturation point of information (30 interviews).

An inductive analysis was proposed, for which the interviews were transcribed, and a content analysis of each one was carried out, in Excel, finding information only on 16 of the 20 codes initially proposed. During this analysis, an additional dimension of analysis was found: the impact of leprosy on people's lives, but it was not considered because it was not the object of the study. The 16 analysis codes were validated by two specialists on the subject (coordinator of the leprosy control program nationwide and a dermatologist from the Regional Hospital of Iquitos). A descriptive analysis of the sociodemographic characteristics of the study subjects was performed, summarizing the numerical variables according to their median and the categorical variables according to their percentage. Later, researchers traveled to Loreto and Ucayali to triangulate the data and to get feedback from the participants about the findings.

This study was approved by the Ethics Committee of the National Institute of Health of Peru (INS in Spanish) through Memorandum 080-2015-CIEI-INS (Code OI-052-14). In addition, patients who agreed to participate in the study were asked to sign the informed consent.

RESULTS

Thirty patients were included (10 of whom were women) —10 from rural areas and 20 had completed their treatment. Most of the patients who had completed the treatment were over 50 years old and received their first treatment at the San Pablo leprosy hospital (Table 1).

Interviews were conducted for the following profiles: under treatment urban man (7 patients), under treatment urban woman (1 patient), under treatment rural man (2 patients), urban man with treatment profile (7 patients), urban women with treatment profile (5 patients), rural man with treatment profile (4 patients) and rural woman with treatment profile (4 patients). The analysis by dimensions is presented, considering the codes of the most relevant findings. The complete analysis is attached as a supplementary material: annex 1, 2 and 3.

Interpretation systems on leprosy

Regardless of patient's sex, age and area of origin, various responses were identified regarding the form of leprosy transmission, i. e., presence of a strange person or a sick person at home, washing a sick person's clothes or shaking hands with them, sexual contact with a sick person, leaving their communities, exposure to polluting agents, such as sewage or forest diseases, or the intake of certain foods (such as the Amazonian tapir or the armadillo), "divine will", and hereditary factors.

"Maybe my ancestors had it. You know the genetic order, it never disappears, it follows its rhythm maybe your children don't get it, but your great-grandchildren may..."

55-year-old urban man from Ucayali, under treatment.

Another perception was that the microorganisms causing leprosy or other diseases are with the person since they are born and it develops depending on their immune response.

Transmission by air was also mentioned by three patients who reported that leprosy spreads when talking to an infected person; however, they do not show security in this response, since they later justify their contagion by other ways. It was also possible to identify that the perception that leprosy is a highly contagious disease still present (46-year-old rural man); while other interviewees reported that it was not contagious (76-year-old rural woman and 78-year-old urban woman).

Regardless their area of origin and sex, patients aged between 70 and 79 years old reported four ways to prevent spreading the disease —not having sex with an infected person, sleeping separately, not kissing on the mouth, burning mattresses and sheets after healing, have separate personal supplies and eat well.

"Did you say 'I should sleep apart', or your wife told you to do so? I said it should be better if I sleep apart because maybe she can catch it from me..."

41-year-old urban man from Ucayali, under treatment.

Regarding the consequences of abandoning treatment, the responses comprised relapses, death, disability and death from complications. This speech was held by all patients regardless of their area of origin, sex and age.

"If you stop the treatment, it can happen again, (...) maybe you don't take medication, you might get sick again, death can happen too".

71-year-old rural woman from Loreto, cured.

Usually the discourse used is that leprosy, following polychemotherapy, is curable; however, an 81-year-old rural patient mentioned that it was incurable since the disease is permanently in the blood. On the other hand, it is recognized by patients that before there was no treatment for leprosy and that patients died.

"Well, he told me that this disease can be cured, it is not incurable. There is a cure, many people (...) I have talked with the doctor then he indicated to me what it is that I must do"

58-year-old urban man from Loreto, under treatment.

Therapeutic itineraries in leprosy

Regardless of sex and age, the patients stressed that family support (especially from the wife) is important for them to go to a health facility and comply with the treatment and controls. However, a 71-year-old woman from the rural area stated that her relatives turned their backs on her for fear of contagion. Another patient stated that his teacher identified the spots and took him to the hospital for diagnosis.

A misdiagnosis due to the lack of experience of health personnel can cause the patient to lose confidence and seek other treatment options, which may lead to delayed diagnosis. This finding was identified in two young urban patients under the age of 35.

Three patients under 50 years old (two from rural areas and one from urban areas) with treatment completed reported having consulted a local non-medical healer (curandero/witchdoctor) when they did not find improvement in symptoms. A 26-year-old male patient from the urban area mentioned that the local non-medical healer referred him to the

Table 1. Sociodemographic characteristics of patients included in the study.

Variable	Loreto		Ucayali	
	n= 16	%	n=14	%
Sex				
Male	9	56.3	11	78.6
Female	7	43.7	3	21.4
Area of Origin				
Urban	11	68.7	10	71.4
Rural	5	31.3	4	28.6
Marital Status				
Married	6	37.5	3	21.4
Single	2	12.5	4	28.6
Divorced	1	6.3	3	21.4
Cohabitant	5	31.2	4	28.6
Widow/er	2	12.5	0	0.0
Treatment Status				
Completed	12	75.0	8	57.1
Under treatment	4	25.0	6	42.9
Age (years), Median (IQR)	60.5 (23.2)		56 (27.7)	
Number of family members living at home, median (IQR)	5 (2)		No data	
Interview duration time, median (IQR)	40 (31)		61 (26.2)	

IQR: interquartile range

hospital. He stated that he did not believe in witchdoctors, but that he was taken to one by his sisters.

“Did you go to the medicine man? Yes, of those who cure witchcraft (...) I went because my sisters recommended me when they saw that I had not improved. I went after the treatment, I thought that once treatment is completed, then leprosy was over, but not really, it takes time to disappear from your body.”

26-year-old urban man from Ucayali, under treatment.

Regardless of the area of origin and sex, patients think that healthcare for leprosy is limited, with difficult geographical access and that there is a lack of specialists. Those are their barriers against an early diagnosis and treatment.

The hospital and leprosy program were identified as the place where the disease is primarily treated. The patients also pointed out other places of care, such as Hospital de la Solidaridad, in Lima, the Institute of Tropical Medicine of Universidad Nacional Mayor de San Marcos and private clinics. Interviewees over 70 years old who completed their treatment identified the leprosarium of San Pablo as the place of care. Pharmacies were not recognized as options either.

“Hives have appeared (...) most people talked, and since in Pucallpa there were also infected people who came by raft, back in Contamana, they picked me up and took me to San Pablo.”

67-year-old rural woman from Loreto, cured.

Likewise, half of the interviewees identified a certain MINSA doctor or technician as the person makes the diagnosis or provides treatment (a single doctor or technician was identified for each of the patient's cities).

Therapeutic repertoire of leprosy and adherence to treatment

In relation to the treatments used, the patients indicated that they took different types of drugs over the years, and in addition, they used vegetables, mud and medicinal plants, such as ayahuasca, chirimasango with sacha garlic, catahua, marco sacha, bark of cedar, etc. Treatments given by relatives or non-medical healers.

“... and at that time my father was still living and said to me: ‘I am going to bring you a remedy that is effective,’ and he brought me a jungle root named male sacha ajoma (...), and then chirisamango. I drank a liter of it, and that numbness disappeared for like ten years”

58-year-old urban man from Loreto, under treatment.

Patients highlighted the importance of starting treatment early as a measure to avoid contagion or complications, but it was also evidenced that patients have the perception that, despite having completed treatment, leprosy could be within them and that it could manifest again.

External factors that negatively affect adherence to treatment: living far from health centers, limited hours of attention from health centers and limited financial resources, especially in rural patients. Side reactions (especially gastrointestinal), patient's lifestyle (drinking and smoking) and presence of other diseases, such as knee joint problems, were also mentioned, as they stated that they could not take as much medicine at the same time (70-year-old urban man).

“No, I did not leave because I practically lived here, I did not have the resources to go to Atalaya, to Pucallpa...”

49-year-old rural man from Ucayali, under treatment.

Approximately half of the patients, state that they have Health Insurance (SIS in Spanish), support from doctors and transfers to health facilities near their town to receive treatment. Regardless of sex, area of origin and age, it was identified that the accompaniment of the family, especially wife and children, favors adherence. It was not possible to identify that friends or neighbors fulfilled this role.

Regardless of patients' area of origin, sex and age, they reported to have avoided eating red meat, or high-fat foods, some fish, chili or drinking beer during treatment in order not to increase liver or kidney disorders associated with treatment. They also avoided eating fish with bones or pork because they associate it with the appearance of lepromatous lesions.

“When you were under treatment what things did you not eat?
When I started to swallow the pills every day, I ate everything,
I just didn't drink beer, I didn't smoke, I didn't eat pig, chili ...”
46-year-old rural man, with treatment completed.

DISCUSSION

Most of the patients who were receiving or had received treatment in a MINSA health facility were unaware of the way in which leprosy spread. Although most of them associated it with a form of contagion, only three patients mentioned airborne contagion. This could be explained by the social representation of the disease, associated with perceptions of incurability and contagiousness, which in turn is related to the stigma associated with physical deformities^(14,15). Most of the interviewed patients had completed treatment, and many had sequelae, due to late initiation of treatment, or because they contracted the disease many years ago when there was no specific treatment, which may explain the perceptions of incurability associated with lack of understanding and knowledge about the disease^(15,16). Despite the fact that, in our study, the interviewees stated that they were cured thanks to polychemotherapy and recognized the consequences of abandoning treatment, this “cured” condition from the perception of the affected person and the community is “misleading,” because some patients continue to feel infected, both among those with or without disabilities⁽¹⁵⁾.

The study showed that the majority of the patients went to the hospitals or smaller medical centers on the recommendation of others. The influence of close family members in seeking help for the diagnosis of the disease was very important. The literature indicates that the influence of social networks motivates patients to seek the definitive diagnosis; otherwise, the affected will not do it by themselves. This behavior could respond two reasons: despite having previous experience with the disease, these patients were not aware of the risk to which they were exposed, or despite suspecting that they have leprosy, they were silent for fear of social rejection; for these reasons, decision-making about whether or not to go to a health center would also be influenced by accumulated negative social experiences^(18,19).

In relation to the therapeutic itinerary, we found that the quality of health services, especially, first level and private clinics, was inefficient. In some of the cases they gave a bad diagnosis, delaying the start of treatment; this finding agrees with Naaz, *et al.* where it is reported that local professionals have poor knowledge about leprosy, although this study describes little referral to specialized centers⁽¹⁵⁾. These

researchers have indicated that patients who go to the most complex hospitals are 6.6 times more likely to receive timely treatment⁽¹⁵⁾. However, for our reality, and in the search of the eradication of leprosy, it is necessary to strengthen first-level health care facilities to capture probable cases of leprosy, through dermatological screening and home contacts⁽²⁰⁾.

It is important to highlight that the majority of patients report that health services are limited, that there are few specialists, and in several cases, there is difficulty in accessing health facilities, either due to the remoteness of these, or for the economic cost of the transfer. This constitutes barriers to early diagnosis and treatment, and make therapeutic adherence difficult.

In addition, the need to strengthen knowledge about the disease in patients, the community and healthcare personnel has been evidenced, lack of knowledge is associated with delay in seeking medical care and failure to treatment adherence^(21,22). In this sense, only two patients indicated that the initiation of treatment is very important to avoid disability, despite the fact that the relationship between disability, treatment and timely diagnosis is supported by various studies^(15,23). The delay in diagnosis is related to ignorance of the disease by health personnel, therefore, it is important to reinforce education on this pathology in professionals in the provinces with cases of leprosy^(21,22).

Regarding the search for care by non-medical healers, approximately a third sought care with non-medical healers, including patients under treatment. This has been described in other studies, where it was found that the majority of the study participants received the first treatment from witchdoctors and traditional healers⁽¹⁸⁾. Currently, it has been shown that non-medical healers are trusted (although in a limited way), creating the need to incorporate said healer as “a complementary medical support” within the biomedical system⁽²⁴⁾, possibly to fulfill roles of referral mediators between patients and hospitals.

Peru has a low prevalence of leprosy; therefore, the detection of new cases should be accompanied by a strict follow-up of contacts, social participation of those affected and the community, and in addition to trained professionals and surveillance centers for drug resistance^(20,25). However, in our study and other previous studies, two major problems have been evidenced: the lack of experience of healthcare personnel in detecting the disease⁽¹⁵⁾ and disjointed work between health centers, the community, and a specialized hospital, to control leprosy. Likewise, other studies have described that stigma and discrimination are negative psychosocial factors that play an important role in the eli-

mination of leprosy; therefore, public policies should be aimed at establishing measures that address these issues ^(20,25).

Among the limitations of the study, the difficulty of obtaining at least two interviews for each profile stands out. This is related to the decrease of new cases of leprosy in the country, and that the new cases are scattered in remote districts. Likewise, it was observed that there was greater difficulty in encountering female patients undergoing treatment in both rural and urban areas, and this could limit our results regarding their perceptions of leprosy; however, this could be explained by the epidemiology of leprosy in the country, where according to national reports, new cases are mostly in men. Despite the fact that the diagnosis of leprosy has been reported to be more frequent in men than in women, this differs statistically from other countries such as Brazil, where leprosy cases in Mato Grosso are more frequent in women, which should be evaluated with caution due to the possible underdiagnosis of leprosy in women ^(26,27).

Another important limitation of the study was that the person who conducted the interviews did not participate in the design of the project or in the analysis of the interviews. Despite the limitations, we believe that the results are relevant, since similar studies have not been conducted in Peru. These results can help strengthen leprosy elimination strategies at the district level, considering those cities with new cases in recent years.

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In conclusion, patients recognize the importance of leprosy treatment, however, they express misconceptions about the pathogenesis of this disease and weaknesses in the health system are identified. These problems would lead to delayed diagnosis and treatment of the disease. It is recommended to strengthen control strategies and decentralize leprosy care with the participation of the community, patients, healthcare personnel and non-medical healers, considering the identified barriers and a probable underdiagnosis in women. This will influence the eradication of leprosy in the country.

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