

Late diagnosis under the perspective of therapeutic itineraries: level 2 physical disabilities in Hansen's disease

O diagnóstico tardio na perspectiva do itinerário terapêutico: grau 2 de incapacidade física na hanseníase (resumo: p. 18)

El diagnóstico tardío desde la perspectiva del itinerario terapéutico: grado 2 de discapacidad física en la enfermedad de Hansen (resumen: p. 18)

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There are remarkable numbers of new leprosy cases with 2 (GIF 2) degree of physical disability, demonstrating the inefficient timely detection. This article presents case reports, based on a qualitative study, regarding four patients with Hansen's disease and a GIF 2 level at the time of diagnosis, analyzing the late diagnosis from the perspective of therapeutic itineraries (TI). The cases came from two municipalities in the Metropolitan Region of Baixada Santista: Praia Grande and São Vicente. Three men and one woman participated, between 45 and 61 years old. The researcher performed documentary analysis and in-depth interviews. Resulting data was submitted to content analysis and four thematic categories were identified: health care; body in leprosy; disabilities in leprosy; late diagnosis. The results reveal intricate therapeutic itineraries with obstacles for reaching a diagnosis. Lack of information about Hansen's disease and professional inability to diagnose increased both individual and collective risks, in addition to the negative impact on the subjects' daily lives. Thus, a late diagnosis due to the frailty of care strongly concurs to keep Hansen's disease as a stigmatizing and disabling disease.

Key words: Public health. Hansen's disease. Disabled person. Late diagnosis. Therapeutic itinerary.



Introduction

Leprosy (Hansen's Disease) is a transmissible disease whose etiological agent is the *Mycobacterium leprae* and manifests itself through dermo-neurological signs and symptoms. It is considered a public health problem for being incapacitating and causing psychosocial impairment^{1,2}.

Brazil is an endemic country for this cause, presenting a high burden for leprosy, being the second country with the highest number of new cases registered in the world, not having reached the elimination targets determined by the World Health Organization (WHO)^{3,4}. During 2016, 25.218 cases were notified and although there is a reduction in the prevalence of the disease, there is a continuous notification of new cases, heterogeneously distributed in the regions of the country, reaching a significant number of people presenting large percentages of grade 2 physical disability identified at diagnosis^{4,5}.

It is important to emphasize that, besides individual predisposition and contact with an untreated patient, leprosy is sensitive to social vulnerability and prevalent in populations living in precarious living and health conditions, a reality in developing countries, being part of the list of neglected tropical diseases^{5,6}.

The diagnosis of leprosy is mainly clinical and the evaluation of signs and symptoms, previous history and complete physical examination are essential⁴.

According to the Brazilian Ministry of Health (MS), the degree of physical disability (GIF in the Portuguese acronym) is a measure indicating the existence of loss of protective sensibility and/or visible deformity as a result of nerve damage and is used as a guide for the development of disability prevention and rehabilitation practices. It is an epidemiological indicator used in the evaluation of the leprosy surveillance program, determining the earliness of diagnosis and the success of activities aimed at interrupting the chain of transmission⁷. The disability assessment, which identifies and describes the sensory-motor impairments in the eyes, hands and feet, is classified into GIF 0, 1 and 2, where grade 2 is determined by the presence of visible impairments in the assessed segments of the body⁷.

It is understood, therefore, that people diagnosed with leprosy and GIF 2 have a late diagnosis. Acquired physical disabilities are considered the main causes of stigma and social isolation and have a strong economic and psychological impact on the lives of those affected^{7,8}. Therefore, and in order to reduce the burden of leprosy, there were established goals to reduce GIF 2 at national and global levels, with the incorporation of strategic actions aimed to ensure comprehensive care^{3,9}.

In view of the above, the objective of this article is to analyze the late diagnosis from the perspective of the therapeutic itinerary (TI) of emblematic cases. According to Alves¹⁰, TI is one of the central concepts in socio-anthropological studies in health, being a term used to designate the activities developed by individuals in the search for treatment for disease and/or affliction. The TI is, therefore, a form of engagement in a given situation and requires new learning and abilities¹⁰⁻¹².

Methods

The present research is a case report based on a qualitative study, a fragment of the master's degree research entitled "Therapeutic itinerary of people with leprosy and acquired disability"¹³, developed in the Graduate Program in Health Sciences Education, professional modality, at the Federal University of São Paulo (UNIFESP) Baixada Santista campus.

The research was developed in the period from 2017 to 2019, and the participants were four patients diagnosed with leprosy and GIF 2, cases notified in two specialized leprosy services in 2016. Their research sites were, in Praia Grande the Reference and Care Center for Tuberculosis and Leprosy (CRATH) and in São Vicente, the Center for Tuberculosis and Leprosy Care (CATH), both located in the Metropolitan Region of Baixada Santista (RMBS), belonging to the Epidemiological Surveillance Group (GVE XXV - Santos), of the state of São Paulo, Brazil. This region reached the goal of eliminating the disease in the year 2006.

The epidemiological data of the year surveyed reported that in Praia Grande thirteen new cases were recorded in 2016, two with GIF 2, corresponding to 15.38% of cases. In São Vicente twelve new cases were registered, two with GIF 2, corresponding to 16.66% of cases.

The research data were obtained through in-depth interviews and documentary analysis of secondary sources, submitted to content analysis, thematic category, with focus on TI.

The participants signed the Informed Consent Form (ICF) and the Research Ethics Committee of UNIFESP and Plataforma Brasil approved the research under opinion no. 3.272.503/2019.

Results and discussion

Characteristics of participants

The participants were four persons with leprosy and GIF 2 stage. The sociodemographic characteristics, place of birth, education, employment status and income at the time of the research are presented in Frame 1.

Frame 1. Sociodemographic characteristics. Data collection conducted in 2018.

IDENTIFICATION	LUIZ	AMÉLIA	JOSÉ	JOÃO
Sex	Male	Woman	Male	Male
Year of Birth	1970	1957	1973	1973
Born in	São Vicente/SP	Tabaraí/SP	Santos/SP	Umari/CE
Schooling	Elementary School, Incomplete	Elementary School, Complete	High School, Complete	Elementary School, Incomplete
Marital Status	Single	Married	Married	Single
Race	White	Brown	White	Black
Municipality giving treatment	São Vicente	Praia Grande	São Vicente	Praia Grande
Profession	Agricultural machine operator	Clerk	Shop worker	Autonomous Seller
Employment status at diagnosis	Working	Working	Medical Leave due to other causes	Working
Employment status at interview	Retirement by disability	Retirement by disability	Retirement by disability	Working
Monthly Income based on minimum wages scale	± 1.7	±2.3	±1.2	±1.9

Source: Unifesp, Hespanhol (2019)

Thematic categories

The results will be presented in four categories: health care, the body in leprosy, delayed diagnosis and disabilities in leprosy¹³. Fictitious names were used to identify the speeches: Luiz, Amélia, José and João.

Health care: experiences of getting sick and using health services

Regarding the experience of falling ill, it can be noted that the participants' understanding of health care is related to the access to medical professionals. The initial consultation was motivated by a disturbance in the general state, i.e., the understanding of health as the absence of disease prevails: "Yeah, I never gave it much importance. I started to give it importance after I started to feel a lot of pain in my foot" (Amélia).

Social vulnerability interferes in the dimensions of life and in what is related to health care⁶, as described by Luiz, in the period when he lived in a situation of indigence: "I didn't worry about health, because drugs use complemented it. I didn't feel symptoms, because cocaine baffle them..." (Luiz).



Among the participants, the male population predominated. This reality resembles the epidemiology, with higher incidence of cases, besides reflecting the absence of health care for this specific population¹⁴.

About what triggered the search for health care, it was noteworthy the individuals' need to overcome the ruptures caused by the disease. The lay action stands out¹¹:

People are driven by their health needs, understood in its broadest sense, including the preservation of autonomy in the way they live their lives, the search for a link and care, well-being, an end to pain, joy of life, beauty. (p. 93)

The participants did not have primary care as a reference; in a certain way, they did not know the resources and did not use them, as observed in the speeches:

I was not looking for it. I went a few times, because I could get a few days off. (Luiz)

I went and at the same time I didn't go, I went for another situation, to measure blood pressure or a gynecologist. (Amélia)

The Health Center? to be honest, I find it a bit complicated.

No, rarely. I didn't need to, I had no reason, I didn't have to go. (João)

The absence of links with the health service made it impossible to observe the health needs. According to Cecílio¹⁵, "health needs are socially and historically determined/constructed, they can only be captured and worked out considering their individual dimension" (p. 118).

In the care trajectories analyzed, it was observed that primary health care (PHC) provided guides, and this occurred due to the practice of regulated referrals for access to specialized services. However, referral should be understood as a follow-up procedure, since the services surveyed work with walk-in open doors, although included in the category of specialties.

The body in leprosy: functional and aesthetical changes as a triggering condition for the search of formal health care

According to Ferreira¹⁶, health specialists highlight the importance of the studies on the diseased body, considered as a depository of biological processes, indicators of health and disease. The body is thus understood as a sign. Therefore, certain messages emitted by the body, such as experienced symptoms and signs observed in the clinical and medical examination come to represent meanings: the disease. The symptoms, differently from the signs, are the invisible character of the disease, as they portray

sensations, which the individual experiences and expresses. The sign, on the other hand, is the objective manifestation and is part of the visible aspect of the disease, observed through physical examination¹⁶.

It is noted that the signs and symptoms of leprosy were identified, with their perception of functional and aesthetic alterations, before the diagnosis was revealed. They mentioned spots, lumps and areas of hypoesthesia in the skin; numbness, muscle weakness and shock-like pain in the upper limbs (UL) and lower limbs (LL), with impairment of activities of daily living (ADL) and work activities.

To understand what triggered the search for health care, the physical assessment performed at diagnosis was related to the participants' perception of their body.

The participant Luiz was referred as a suspected case of leprosy, with diagnosis of peripheral polyneuropathy of upper limbs. In the anamnesis, he reported shock-like pain in the right upper limb (RUL) for three years. In the physical evaluation, he presented diffuse infiltration in the face; right claw hand; in the left upper limb (LUL), ulnar neuritis, muscle atrophy and hand injury; in the right lower limb (RLL), decreased muscle strength, pain on palpation of the tibial and fibular nerve, calluses, scar from plantar perforating disease (PPD) and edema in lower limbs (LL).

In Luiz's case, the disease manifested itself with areas of hypoesthesia on the skin and neurological impairment, and the trigger for care was the functional alterations:

The hands and feet... The problem would be the numbness in the body, in the hands. There were no spots, just numbness. And the pains started to bother. [...] The main thing was because I was seeing that my hand was beginning to atrophy, and the other hand to have numbness, cramps, so I said, I'll go. (Luiz)

Amélia reported that three years ago (2013) red spots appeared on her body; she went to the dermatologist at a public health clinic and was diagnosed with allergy. However, in 2015, she noticed numbness in her arms and legs. In the physical evaluation, she presented diffuse infiltration and supraciliary madarosis; in the RUL hypoesthesia in forearm; in the RLL absence of protective sensitivity and in the left lower limb (LUL) tibial neuritis, with decreased muscle strength and clawed fingers.

In Amélia's case, the aesthetic alteration was the main discomfort, and the functional alteration was perceived in a daily task:

It was the skin that showed some lumps, with secretion. And then the foot started to tingle, here a little (showing the forearm), here (elbow), so much that I hold the pan and stayed for a while without going to the stove, because I almost burned myself [...]. (Amélia)

And despite undergoing treatment, she noticed the dermatological worsening:



It was before 2016, I did all that and I didn't find out. I stayed two years away, as if I had an allergy [...] then a lot of lumps started coming out, so much that I have all the marks, there was secretion and I started to realize that my skin was getting old. The doctor said it was allergy and I thought it was the medicines. (Amélia)

The presence of deformities in the face started to be noticed; however, the functional alterations related to leprosy were only identified at diagnosis:

One day, an acquaintance of mine told me: did you look yourself in the mirror today? Did you see how is your ear? I said: what's wrong with my ear? My ear looked like a rabbit ear, already deformed. At that time my hair was tied up, I loosened it. It fell down and I ran to the mirror and it was like that, really [...] (Amélia)

In turn, José reported cracks on his feet for three years (2013), which turned into wounds. Five months before the diagnosis, he noticed the reddish and spots with hypoesthesia all over his body. The participant reported that he had a contact examination in 2002 (mother had leprosy treatment), but did not perform BCG revaccination as recommended, demonstrating the weakness of contact control.

Patients' household and consanguineous contacts are more susceptible to the disease, requiring enhanced and active surveillance to control the disease, with an expanded look beyond the individual with the diagnosis⁸.

In the physical evaluation, José presented pain on palpation of the ulnar nerve in the RUL; in the LUL, neuritis of the tibial and fibular nerve; in the LL, edema, absence of protective sensitivity and bilateral plantar perforator mal-perforation. With a history of severe orthopedic problems, functional alterations were associated to this impairment:

It was the column, the legs and the arms. It's like when we sleep over a leg, without any sensitivity and shock, the leg also gave shocks, it still does, many things that the doctors associate with the spine. (José)

The functional alteration was noticed when riding a bicycle. However, the previous diagnosis and the work routine made it difficult to relate these complaints to leprosy:

One day, riding a bike I felt my foot tingling, then from then on I started to notice these problems. From then on I started associating them, because my back was hurting, we are under heat at work, we don't even see. (José)

However, the aesthetic alteration was relevant, since the other complaints were considered orthopedic and related to the cause only after the diagnosis:



So, because the pains were increasing, the numbness and this hole in the foot. Then, when this spot appeared, people said it was impinge, and as it didn't disappear, I decided to look for care. (José)

Finally, João presented a hypochromic lesion on the skin at RUL five years before (2011). In 2015, erythematous patches appeared on his body and numbness in the left foot. In the physical evaluation, he presented diffuse infiltration on the face and body; pain and thickening on palpation of the tibial and fibular nerve in the RLL; foot drop in the LLL, with absence of protective sensitivity in the feet.

The patches spread all over the body were not taken seriously in a medical consultation with a specialist in a public health clinic:

He had patches on his arm, on his stomach, practically all over his body: [...] Through the spots and my client, if it was her too, I wouldn't find out, because I did a private examination and nothing came out [...] (João)

The perception of a treated person enabled the diagnostic hypothesis of the disease:

[...] I really found out through a client of mine who saw the spots and said that the way I looked it seemed that it was leprosy. (João)

At the time of diagnosis, the participants had acquired disabilities: Luiz had claw hands; Amélia, claw feet; José, bilateral plantar perforating mal-perforation; João had a fallen foot. These disabilities negatively influenced the performance of daily activities even before the diagnosis, thus generating disabilities.

Disabilities in leprosy: the impairment of daily life due to the acquired disability

According to the Secretariat of Health Surveillance (SVS), leprosy generates physical disabilities that affect the routine, the performance of ADLs and work and affect the quality of life in several ways, leading to psychosocial problems⁷.

The symptoms made it possible to identify that the disease generated impacts on daily life even before diagnosis. All of them reported changes in body structures and functions, with activity limitations and restricted social participation.

Participant Luiz highlighted the difficulties in performing ADLs, with difficulty to grasp objects due to his clawed hand:

Because the atrophied hand already lost a part, let's say, to write, sometimes it is difficult to pick up a spoon, a glass, sometimes it falls from my hand I don't feel it. (Luiz)

The impediment to work occurred due to the intensity of the pain. In Luiz's case, this factor was fundamental for the identification of the health problem:



Yes, I was going to work and I couldn't stand to work. This machine is not a machine that you climb on top of. You have to walk with it hanging on your side or on your back. (Luiz)

Amélia revealed nervousness and shame, so she lived in isolation to avoid exposure and speculation about her health, demonstrating concern with transmissibility:

I didn't take it off because I was ashamed... it was because of what I had in my body, because I work in the shop I was afraid that people would see it and say, she has a disease that I am going to catch. (Amélia)

Participant José reported the difficulties in remaining active at work:

It was very bad, because my work is already a bit heavy, only that I needed to work. (José)

José, who cited losses even before the diagnosis, also reported the practice of leisure:

I stopped doing a lot of things like that. One thing I really like is to play football, I haven't played for a while. (José)

Despite the presence of physical discomfort, João reported continuing his work activity:

I used to work, but it bothers me, those spots on my body hurt, it hurts a little, it bothers me a little. (João)

In this research, work was considered as the exercise of an occupation with remuneration, classified as formal and informal. It is important to highlight that the labor situation was recorded both at the diagnosis and at the time of the research. At diagnosis, it was identified that three participants were working; one was away with another clinical diagnosis¹⁷.

At the time of the interview, however, about a year and a half after the diagnosis, three of the four participants were retired for disability. Moreover, all presented a medical report by audits of the National Institute of Social Security (INSS), with diagnosis of leprosy and GIF 2.

The only participant who continued working was an informal worker, which prevented him from leaving work, but he did not feel disabled by adjusting the workload according to his physical condition. Informality is a marker of inequality and brings as a consequence the lack of access to social protection mechanisms linked to formalization, to basic rights such as remuneration by the minimum wage and retirement¹⁷.



Aged between 45 and 61 years, all participants had their working capacity affected by the impairments of the disease, especially important when acknowledging that work is a human occupation, which in addition to providing subsistence can provide personal satisfaction, early retirement brings changes in routine and life projects.

Late diagnosis: the impact of ignorance and misinformation on maintaining leprosy as a neglected disease

In the evaluation of knowledge about leprosy, it was observed a total lack of knowledge about the disease and its possible complications, as exposed in the following statements:

No, even because I never looked for leprosy, I just stayed like that, I knew it was like when people had those spots on the body, I asked what is it: ah, it's leprosy, but until then I did not know that it attacks the nerve, attack the blood. (Luiz)

I didn't even know what leprosy was; I didn't know what it was. (João)

Despite the cases of leprosy in his family, José referred to it as a biblical disease:

Because that's what I remember from the old days, what I saw at the time of Jesus, then I already knew more or less what leprosy was, then when the doctor suspected it, I went to look for a treatment. (José)

In Amélia's case, the fact that she only knew of contact with a person with leprosy after the beginning of her treatment caused her to suspect the source of infection:

I didn't know and nobody said, nobody said what her problem was, and I only found out later when I had... It must have been though the hug she gave me. (Amélia)

About possible contact, Luiz reinforced the seriousness of the disease under the religious perspective:

No, this thing, I never paid attention to it. God prepared me first, if I knew about this disease I could be in another situation. (Luiz)

Participant João claimed never to have met any person with the disease: "No, I never met".

The lack of knowledge about leprosy prevented the participants from recognizing that health problems could be a consequence of it, thus demonstrating the absence of health information on the subject.

For the participants, the misdiagnosis favored the association of signs and symptoms to other causes. It is relevant here to recall that Amélia had the initial diagnosis as allergy and José's symptoms were related to an orthopedic disease:



I couldn't tell much, I had it in my mind that it was allergy. (Amélia)

No. After the dermatologist told me that I started to look for it. Because even when I was treated for the spine and when I had wounds on my feet the doctor associated it with the spine, he never said it might be leprosy. (José)

Regarding the time for diagnosis and treatment of leprosy, the participants identified that it took from three to five years, resulting in increased individual and collective risks¹⁸. However, it should be noted that such identification was illuminated by the current knowledge about the disease, attributing different interpretations to their afflictions¹⁹.

For Amélia, the feeling of impairment and impotence remained, blaming herself for the responsibility for her late diagnosis because she did not pay attention to the signs:

It gets even difficult, because you run on top of something and you feel that you don't have the capacity, you feel a powerless person. Then it started to be shown on TV... Then I said: why didn't I see this, why didn't I stop to watch it? I also feel guilty, if I had given some time and seen it, I would look at myself and say that I have the same symptoms...(Amélia)

Participants reported ambiguous feelings about the changes in life after the diagnosis with sequelae: relief, worry, quiet, normality, guilt, fear, suffering and loss of life goals.

For Luiz, the diagnosis brought a sense of calm and a decrease in worry:

I was calmer. Now I knew what it was, I was being treated. From the moment you don't know, you have doubts... then you end up worrying, you get upset. Not today, I take it easy, you know? (Luiz)

After the diagnosis, Amelia reported difficulty in finding life goals, identifies the disease as the cause of her social isolation, to the extent that she fears the possibility of not being accepted by her own family:

It changed, I became a person [...] without much purpose, almost every other hour my husband catches me crying [...] Only one sister knows about this problem, because I am afraid to tell the others and I don't know how I will be accepted [...] (Amélia)

For José, the diagnosis brought relief through discovery and treatment. He reports the importance of the attitude he had when he sought the dermatologist and shows satisfaction with the service, although he still has complaints due to the disease:



It brought me relief [...] I discovered the disease and I'm in treatment. If I hadn't [...] gone to the dermatologist and waited for this spot to disappear, I would be a little worse, but my trajectory from there to here, after I discovered it, is great [...] the pains take time. (José)

For João, the diagnosis and treatment were the solution, with a reduction in the spots and improvement in his gait:

I got normal, now it's just taking the medicine and it's good [...] The spots are gone [...] only this foot is more blurred, but even so it's much better than before. I walk safer, I work and walk a lot all day, I think I am well. (João)

It is possible to observe among participants Luiz, Amélia and José the relation between leprosy and the stigma of leprosy, with lack of understanding about the transmission and cure of the disease.

Mantellini, Gonçalves and Padovani point out in leprosy the influence of the religious perspective still in our days. Both Biblical and Buddhist references create the impression of association to sufferers, sinners and criminals²⁰.

For Luiz, the disease and suffering are perceived as something deserved as a result of his past actions:

Today, I am reaping what I planted, we reap what we plant. If today I got this, understand, it is because I did something. (Luiz)

For Amélia, the diagnosis was devastating. Although she acknowledges the support from the health team and some close family members, the fear of revealing the diagnosis prevails, since leprosy can be related to the leprosy stigma:

I am sure that all those around me will move away from me, the only ones who did not move away were my husband and my children. They know what I have, they know the name of the disease, but if I tell someone that it is "leprosy" instead of Hansen's disease, I will have no friendship with anyone else, it is a cruel situation. (Amélia)

For José, the stigma of leprosy is part of the Brazilian culture and generates fear:

So, because if you talk about a disease and the person isn't a little more educated and doesn't have the knowledge about leprosy, he shuns you [...] he gets afraid [...] I think that it is the Brazilian culture to get away from the person when they know what it is. (José)



It was observed a lack of prior knowledge about leprosy. Both the participants and the medical professionals lacked capacities regarding the signs and symptoms of the disease, which thus promoted misdiagnoses and the consequent disqualification of complaints and impairment of autonomy to report the health condition.

The negligence in relation to health needs is presented in the face of difficulty in access to timely diagnosis in leprosy. As a disease of mainly clinical diagnosis in the analyzed TI, the deficit in the initial clinical evaluation is perceived and points to the urgent need of recognizing the human and social condition in health care and careful observation of social determinants, as social inequalities hinder the access to services^{6,12,21}.

Thus, the speeches about the illness and the feelings experienced during the therapeutic itineraries analyzed are compatible with the observation on the user's point of view and their complaints about the health services, as stated by Merhy²²: "[...] users, as a rule, feel insecure, uninformed, helpless, unprotected, disrespected, despised" (p. 3).

Studies conducted in endemic states (Bahia and Pará) cite the existence of negative perceptions about the disease and obstacles to diagnosis. These point to a succession of misdiagnoses and concluded that the IT of people with leprosy is delayed, hazy and conflicting, a result concurrent with the present study^{6,23}.

In the Colombian population, a study concluded that the time elapsed between the appearance of the first symptoms and diagnosis was a key prognostic factor for the presence of disabilities at the time of leprosy diagnosis. It was observed that the longer the delay in diagnosis, the higher the proportion of patients diagnosed with disabilities, both in women and men²⁴.

The barriers to access public health services drive users to seek solutions in the private service, a fact observed in other diseases, such as eye diseases, for example, as in the case of need of surgeries, reversing the assistance trajectories to the public service²⁵. The treatment of leprosy is carried out exclusively in SUS, so there is an automatic reversal of care trajectories to public services, which contributes to the control of epidemiological data, exposing the weakness of health care before the leprosy diagnosis.

The exploratory and quantitative study carried out in three reference centers, pointed out that the non-recognition, by the patients, of the signs and symptoms as severe, as well as the high rates of incorrect diagnosis, are the main factors that contribute to the delay in diagnosis and continued transmission of leprosy in Brazil²⁶.

Thus, leprosy-related disability is a challenge for public health and social and rehabilitation services in endemic countries, and information should include the importance of early diagnosis for the prevention of disability^{26,27}.



Final considerations

In the reports presented, the aesthetic alteration prevailed as the main diagnostic hypothesis of leprosy. Therefore, we realize that leprosy has its incapacitating potential ignored: both the perception and the relationship of the disabilities with the cause (which occurred to the participants at the time of the physical evaluation at the specialized service) exacerbate the negative feelings, adding to the ruptures caused by the experience of the disease.

From the authors' point of view, timing and lack of access to diagnosis and treatment showed to be preponderant factors in the installation of disabilities in leprosy, with increased possibility of transmission of the disease. Time and risk go hand-in-hand and the delay to diagnosis in leprosy increases the individual and collective risks, with negative impacts on the daily lives of the subjects.

However, timing was seen differently by the participants, from those who considered it adequate, even needing to go to several health services, to those who considered it delayed, after an initial misdiagnosis with invalidation of their complaints, thus demonstrating the uniqueness of the experience of illness in each TI analyzed.

The reports exposed the gap between what is recommended and ideal and what is actually offered for the timely diagnosis of leprosy in the municipalities studied. It is a relevant fact that this type of care is relegated to specialized services, which raises the need for further studies focusing on the analysis of disease control actions and intersectoral articulation of the health care network for leprosy care.

The revelations of the intricate therapeutic itineraries raise a question: are disabilities then caused by leprosy or by the weakness in the health care? The proposal of the study of TI showed contributions to the analysis of evaluative processes of qualitative nature in SUS, contributing to the understanding of the phenomena pointed out in quantitative and epidemiological studies, as well as demonstrated the strength of lay action through inequities in health.

The disabilities in leprosy directly reflect the diagnostic and care capacity, imposing themselves as challenges to comprehensive care. The late diagnosis further highlights the neglect of the health needs of the population, therefore contributing to maintain leprosy as an incapacitating and stigmatizing disease.

The reflections emerging from this study suggests further research in order to identify patterns among the factors that contribute to late diagnosis in leprosy.

Authors' contributions

All authors actively participated in all stages of manuscript development.

Conflict of interest

The authors have no conflict of interest to declare.

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Destacam-se casos novos de hanseníase com grau de incapacidade física 2 (GIF 2) que demonstram a ineficiente detecção oportuna. O artigo é um relato de casos e propõe analisar o diagnóstico tardio sob a perspectiva do itinerário terapêutico (IT), com base em um estudo qualitativo. O cenário foram dois municípios da Região Metropolitana da Baixada Santista: Praia Grande e São Vicente. Realizou-se análise documental e entrevista em profundidade com quatro participantes. O material foi submetido à análise de conteúdo e definiram-se as categorias temáticas: cuidado em saúde; corpo na hanseníase; incapacidades na hanseníase; e diagnóstico tardio. Revelaram-se intrincados itinerários terapêuticos, marcados pela fragilidade do cuidado com erro e atraso no diagnóstico, que potencializaram os riscos individuais e coletivos e impactaram negativamente o cotidiano dos sujeitos.

Palavras-chave: Saúde pública. Hanseníase. Pessoa com deficiência. Diagnóstico tardio. Itinerário terapêutico.

Se subrayan casos nuevos de enfermedad de Hansen (lepra) con grado de discapacidad física 2 (GIF 2), que demuestran la ineficiente detección oportuna. El artículo es un relato de casos y propone analizar el diagnóstico tardío bajo la perspectiva del itinerario terapéutico (IT), con base en un estudio cualitativo. El escenario fueron dos municipios de la Región Metropolitana de la Baixada Santista: Praia Grande y São Vicente. Se realizó el análisis documental y entrevista en profundidad con cuatro participantes. El material se sometió a análisis de contenido y se definieron las categorías temáticas: cuidado de salud, cuerpo en la enfermedad de Hansen; discapacidades en la enfermedad de Hansen y diagnóstico tardío. Se revelaron intrincados itinerarios terapéuticos, señalados por la fragilidad del cuidado, con error y atraso en el diagnóstico, que potencializaron los riesgos individuales y colectivos e impactaron negativamente el cotidiano de los sujetos.

Palabras clave: Salud pública. Enfermedad de Hansen. Persona con discapacidad. Diagnóstico tardío. Itinerario terapéutico.