Original Article

doi: https://doi.org/10.1590/1983-1447.2023.20220083.en

Culture circle with community health workers about (lack of) knowledge and stigma of leprosy

Círculo de cultura com agentes comunitários de saúde sobre (des)conhecimentos e estigma da hanseníase

Círculo de cultura con agentes comunitarios de salud sobre (des)conocimiento y estigma de lepra

RGE Revista Gaúcha de Enfermagem

Dorlene Maria Cardoso de Aquino[a]
Estela Maria Leite Meirelles Monteiro[b,c]
Nair Portela Silva Coutinho[a]
Vanessa Moreira da Silva Soeiro[d]
Tamyris Arcoverde Santos[c]
Eudijéssica Melo de Oliveira[a]
Débora Lorena Melo Pereira[a]
Arlene de Jesus Mendes Caldas[a]

How to cite this article:
Aquino DMC, Monteiro EMLM, Coutinho NPS, Soeiro VMS, Santos TA, Oliveira EM, Pereira DLM, Caldas AJM. Culture circle with community health workers about (lack of) knowledge and stigma of leprosy. Rev Gaúcha Enferm. 2023;44:e20220083. doi: https://doi.org/10.1590/1983-1447.2023.20220083.en

ABSTRACT

Objective: To describe the construction aboutthe (lack of) knowledge and stigma of leprosy by Community Health Workers participating in the Culture Circle.

Method: Qualitative, action-research type study supported by the Paulo Freire Culture Circle framework, carried out with 21 Community Health Workers. Data collected in November 2021, in the municipality of São Luís, Maranhão. The following categories were evidenced: knowledge about leprosy, signs and symptoms, stigma.

Results: The participants had knowledge about the disease, but they verbalized people's disinformation about leprosy, disbelief in relation to the cure, and situations of prejudice and stigma that are still present today.

Final considerations: The culture circle enabled the intertwining of scientific and empirical knowledge in the construction of a critical and reflective knowledge committed to welcoming and comprehensive care for people and families affected by leprosy.

Keywords: Leprosy. Social stigma. Education, continuing. Community health workers. Primary health care.

RESUMO

Objetivo: Descrever a construção sobre o (des)conhecimento e estigma da hanseníase pelos Agentes Comunitários de Saúde participantes do Círculo de Cultura.

Método: Estudo qualitativo de tipo pesquisa-ação apoiado pelo referencial do Círculo de Cultura de Paulo Freire, realizado com 21 Agentes Comunitários de Saúde. Dados coletados em novembro de 2021, no município de São Luís, Maranhão. Foram evidenciadas as categorias conhecimento sobre a hanseníase; sinais e sintomas; estigma.

Resultados: Os participantes possuíam conhecimento sobre a doença, mas verbalizaram a existência de desinformação das pessoas sobre a hanseníase, descrenças em relação à cura, além de situações de preconceito e estigma ainda presentes atualmente.

Considerações finais: O círculo de cultura possibilitou o entrelace dos saberes científicos e empíricos na construção de um conhecimento crítico e reflexivo comprometido com o acolhimento e atenção integral às pessoas e famílias afetadas pela hanseníase.

Palavras-chave: Hanseníase. Estigma social. Educação continuada. Agentes comunitários de saúde. Atenção primária à saúde.

RESUMEN

Objetivo: Describir la construcción sobre (des)conocimiento y estigma de la lepra por parte de los Agentes Comunitarios de Salud participantes del Círculo de Cultura.

Método: Estudio cualitativo, de tipo investigación-acción, apoyado en el marco del Círculo de Cultura Paulo Freire, realizado con 21 Agentes Comunitarios de Salud. Datos recolectados en noviembre de 2021, en el municipio de São Luís, Maranhão. Se evidenciaron las categorías conocimientos sobre la lepra; signos y síntomas; estigma.

Resultados: Los participantes tenían conocimiento sobre la enfermedad, pero verbalizaban la desinformación de las personas sobre la lepra, la incredulidad con relación a la cura y situaciones de prejuicio y estigma que aún hoy están presentes.

Consideraciones finales: El círculo de cultura posibilitó entrelazar saberes científicos y empíricos en la construcción de un saber crítico y reflexivo comprometido con la acogida y atención integral de las personas y familias afectadas por la lepra.

Palabras clave: Lepra. Estigma social. Educación continua. Agentes comunitarios de salud. Atención primaria de salud.

[a] Universidade Federal do Maranhão (UFMA), Programa de Pós-Graduação em Enfermagem. São Luís, Maranhão, Brasil.

[b] Universidade Federal de Pernambuco (UFPE), Centro de Ciências da Saúde, Programa de Pós-Graduação em Enfermagem. Recife, Pernambuco, Brasil.

[c] Universidade Federal de Pernambuco (UFPE), Centro de Ciências da Saúde, Programa de Pós-Graduação em Saúde da Criança e do Adolescente. Recife, Pernambuco, Brasil.

[d] Universidade Federal do Maranhão (UFMA), Centro de Ciências Biológicas e da Saúde, Curso de Enfermagem. Pinheiro, Maranhão, Brasil.

INTRODUCTION

Leprosy is a chronic infectious-contagious disease, caused by *Mycobacterium leprae*, an acid-alcohol resistant bacillus, which can affect people of both genders and any age. Transmission occurs mainly through the upper respiratory tract through close and prolonged contact between susceptible people and patients affected by the multibacillary clinical forms of the disease (virchowian and dimorphous) who have not yet started treatment. The disease, without treatment in the early form, almost always evolves slowly and progressively and can lead to physical disabilities(1).

According to the World Health Organization (WHO), in 2020,127,396 new cases of the disease were registered worldwide, with 19,195 in the Americas; of these,17,979 were reported in Brazil(2) where the disease has a heterogeneous distribution and cases are registered throughout the national territory, but with a greater concentration in the Midwest, North and Northeast regions, with the highest detection rates being observed in the states of Mato Grosso, Tocantins and Maranhão(3,4). The high number of registered cases and the occurrence of neural damage that may cause physical disabilities make leprosy an important public health problem(4,5), also encompassing issues related to stigma, discrimination and social exclusion associated with the disease(3,4).

Stigma and prejudice still permeate the lives of people affected by leprosy(6,7), and the trajectory and imaginary constructed by society regarding the disease favor late diagnosis and treatment abandonment(8). Stigma, linked to the historical factor of social isolation in the past, can lead leprosy patients to isolate themselves, contributing to failure in early detection and continuity of treatment.

Dealing with late diagnosis and treatment abandonment is a challenge for Primary Health Care (PHC) services, whose priority strategy is Family Health. It is worth to emphasize the need for leprosy control actions to be based on PHC attributes, so that care is no longer centered on the disease. Thus, the PHC should be the main gateway to the Health System to carry out the longitudinal and comprehensive follow-up of the person, the family and the community(1,3). Early detection, improved acceptance of diagnosis and adherence to treatment and self-care practices can be achieved by reducing prejudice in the community(2).

The Community Health Worker is part of the Family Health Strategy team and is responsible for performing disease prevention and health promotion activities(9). This professional, in the context of leprosy, develops activities that include: providing guidance on self-care, identifying signs and symptoms and referring suspected cases to the Basic Health Unit (BHU), providing guidance on the need to treatment conclusion, carrying out an active search, forwarding contacts for evaluation at the BHU, carrying out health education activities for the population and completing the family registration form(9).

Despite the attributions of the CHW, it has been observed that training on leprosy are limited, indicating the need for courses on the subject based on a critical reflective methodology for a significant change in the epidemiological scenario of leprosy(10). In this sense, Paulo Freire's Culture Circle is a proposal that promotes horizontal relationships between the educator-learner relationship and values local oral cultures(11).

This study aims to describe the construction about the (lack of) knowledge and stigma of leprosy by the participating Community Health Workers in the Culture Circle.

METHOD

This is a qualitative action-research study supported by the framework of Paulo Freire's Culture Circle in the development of educational action to train Community Health Workers on leprosy. Action research, as a participatory research, concerns with solving a collective problem, for which researchers and participants in the investigated situation are involved in order to contribute to the transformation of reality(12).

The culture circle is a dialogical teaching-learning strategy, in which participants exchange knowledge and develop new hypotheses for interpreting the world with a democratic and liberating manner and with a proposal for comprehensive learning, promoting horizontality and valuing the existing culture(13).

The study constitutes a stage of the macroproject entitled: "INTERGRAHANS MARANHÃO: comprehensive approach to clinical, epidemiological (spatiotemporal), operational and psychosocial aspects of leprosy in a hyperendemic municipality in Maranhão" which investigates clinical and epidemiological aspects of people affected by leprosy and their household contacts, evaluates the structure of the services, the epidemiological and operational indicators, and also the actions developed by PHC professionals for disease control.

The study was conducted through the application of five Culture Circles held on consecutive days from 9 am to 12 pm, addressing the theme. In this study, the description of the first circle is presented, which had as generating questions: What do you know about leprosy?What symptoms can a person with leprosy present? How do you evaluate prejudice/stigma towards patients with leprosy?

The study was conducted in the city of São Luís - MA, in the Itaqui-Bacanga area, which has 58 neighborhoods and 185,000 inhabitants, with Community Health Workers from five Health Units (HU) in the referred area. The choice of units was since they have a higher number (97) of CHW in the FHS, with a sample consisting of 21 CHW.

The participants' selection considered the following inclusion criteria: working in the districts that compose the study scenario; assuming the role for over a year and show interest in participating in the Culture Circles by requesting one of the four vacancies offered for each unit and having availability from the directors. There were no losses of participants during the Circles, with a regularity in the number of participants.

The circles were preceded by the training of three female judges, members of the research group. The responsible researcher conducted the training addressing the methodology of culture circles and the techniques necessary for capturing and recording data with the participants. The study was conducted from November 2021 to March 2022, with data collection in November 2021. For data collection, a compilation of techniques was used such as a questionnaire to collect sociodemographic data and information on the training and experience of the CHW. Data was also collected through recordings, field diary entries, and a Flip Chart used to record participants' statements and photographs of their individual and collective productions.

The data produced were captured through audio recording and then transcribed and reviewed. Subsequently, it was performed the codification, grouping of data into themes, production of the final report and thematic analysis(14). The following thematic categories were evidenced, arising from the generating questions, knowledge about leprosy; Signs and symptoms; prejudice/stigma towards the patient with leprosy.

The educational intervention in health adopted the eight cyclical and interrelated phases(15), adapted from Paulo Freire's Method. Initially, the Thematic Investigation was conducted with a survey of the vocabulary universe and the group's expectations; this stage precedes the circle and can be present during its development, in order to instrumentalize a flexibility in the planning of the Circles to meet the demands and interests that emerge from the group. The second phase, called 'Awareness Dynamics', was based on the use of a playful approach to raise awareness among the participants. In the Problematization, the generating question was presented, which allowed knowing and valuing the group's previous knowledge.

The Theoretical Foundation, the subsequent phase, consisted of deepening prior knowledge in dialogue with scientific knowledge presented in didactic strategies and motivating language to ease understanding. Subsequently, the Theoretical-Practical Reflection provided opportunities for a critical and reflective discussion on the scientific knowledge apprehended, allowing the Collective Elaboration of Answers (resuming the generating question for a collective construction of the answer) and for the Synthesis (moment in which the circle facilitator records on a poster the key points that participants considered most relevant during the circle). Finally, during the Assessment, playful and participatory approaches were used in order to encourage self-assessment of the educational experience, allowing to guide the planning of the subsequent Circle.

The study complied with the requirements of Resolutions CNS/MS No. 466/12 and No. the 510/16, being approved by the Research Ethics Committee of the University Hospital of the *Universidade Federal do Maranhão* under opinion No. 4.980.071 Amendment 3; CAAE 70717517,1,0000,5086. To ensure the anonymity of the participants, the CHW were identified by number. The activity was conducted strictly respecting the health measures established to control the COVID-19 pandemic with the use of masks, distancing, and hands hygiene by all participants.

RESULTS AND DISCUSSION

The Culture Circle as an arena for exchanging knowledge

The development of the circle started with the presentation to the CHW of the proposal for the mentioned permanent education, followed by the "History of the Name" dynamic, with the objective of providing a first contact and association with the group members. The dynamic was initially carried out in pairs, which were composed by choosing figures of animals and characters. They were guided to talk about the meaning and origin of each one's names. Next, they presented information about their partner, constituting a group presentation strategy.

After the dynamics, the "problematization" stage was carried out, when the facilitator presented the generating questions that instigated group participation and discussion according to the records of the statements presented in the study. In this circle, the following generating questions were used: What do you know about leprosy? What symptoms can a person with leprosy present? How do you evaluate prejudice/stigma towards patients with leprosy?

To support the construction of analysis categories, the recording of the CHW statements was incorporated into this process, showing opinions and expressions, in addition to the group's previous knowledge, considering the specificities of each generating question.

Generating question: What do you know about leprosy?

It is noticed, in the statement of the CHW, that they have knowledge regarding the etiological agent, the transmission, signs and symptoms of leprosy, when reporting their previous knowledge with scientific notions in an accessible language, in order to compose a consistent corpus in the understanding of the disease.

> *Disease caused by a bacillus is transmitted through sneezing.* (CHW 1)
>
> [...] *a chronic, contagious disease that affects the skin and nerves a lot and is transmitted by the Hansen's bacillus.* (CHW 3)

A quantitative study identified a satisfactory level of knowledge about leprosy, in some issues, however, in others they had negative evaluations, demonstrating the need for articulations of permanent education strategies aimed at training and updating the CHW in approaching the community user affected by leprosy(16). The interest in recognizing the professionals' knowledge and limitations supports the planning of more effective permanent education strategies for disease control.

The discussion on leprosy contributed to the report that it "*is a very old disease*", which "*was known as lepra*". The lower tone of voice, when mentioning the name "lepra", may be associated with historical issues, concern with stigma and prejudice, which still permeate people's imaginary. The CHW highlighted the extreme need of families due to their low purchasing power, as well as the lack of information among individuals regarding health issues, such as leprosy.

> *Leprosy is a very old disease. In my area it is. So, the name that was known by everyone knows 'lepra'* (lower voice). *So, when we talk to our users, they keep asking: but what is leprosy* (name of CHW)*? So, let's talk on common language. Leprosy is leprosy; so, we talk about what leprosy is.* [...] *which is caused by the bacillus, but it has treatment, right! So I always ask: why are there still people with leprosy in our country?* (CHW 5)

To expand their knowledge in health, professionals need to seek an understanding beyond the disease through research to apprehend the social context in which the individual is inserted, in order to understand it in its comprehensiveness(17).

The recognition of leprosy as a neglected disease portrays the context of social inequalities such as low housing conditions, income and precarious education experienced by families with high cases of the disease, thus constituting challenges for the eradication of leprosy(18).

Therefore, it is important to establish systematic strategies for disseminating information about the disease to reduce the population's fear of contracting it, breaking the cycle of perpetuation of social stigmas(6).

> *And we also realize that leprosy is linked to the social issue, to the community's conditions* [...]. *In the cases that I have already followed, we notice that the situation of poverty is very high. Also, another thing, people's misinformation. So, we can see this, where people are most affected. I notice these two sides of the people I've followed. I saw the issue of information and conditions...* (CHW 2)
>
> [...] *all of us, health workers, deal with innate poverty; spiritual, money, everything, violence, drugs, all kinds and sometimes we have nothing; so we go with our face and courage.* (CHW 5)

The physical disabilities resulting from the disease, late diagnosis, the occurrence of reactions and difficulties in treatment adherence compromise the understanding that leprosy is curable.

The search for a diagnosis can lead to difficulties in accessing health services and health professionals for the management of the disease, contributing to situations of a long journey and late diagnosis(19). A study carried out showed that in leprosy the problems related to access to health care, delays in diagnosis and stigma are continuous(20).

Barriers to care for leprosy are the difficulty of access due to the population's lack of knowledge about the signs and symptoms of the disease, the unpreparedness of professionals, as well as operational failures and the way health services are organized(21).

One of the requirements for services organization is the monthly availability of the therapy called Uniform multi-drug therapy (U-MDT), whose composition associates the drugs rifampicin, dapsone and clofazimine both in paucibacillary (PB) and multibacillary (MB) cases for the cure of leprosy(22).

Thus, the records of successful patient discharge constitute an indicator that allows to consider the quality of care provided by health services to people affected by leprosy, expressing the effectiveness of services in promoting treatment adherence(23). This data reflects a process of welcoming and monitoring by family health teams and outpatient actions developed by primary health care. Promoting treatment adherence is a challenge for the services and professionals involved in view of the difficulties experienced both by the person affected by leprosy and by the specificities of the disease and its therapy.

> *There are patients who do not believe that leprosy has cure. He says 'I don't believe it. Because I have leprosy until today'. Because it had sequels; before, people took a long time to look for it and were affected by this late search.* (CHW 8)
>
> *I don't know if I agree with the issue of leprosy having a cure. Because I know patients who underwent the entire treatment and were interns at Bonfim, passed through the team, and were discharged. After a while, this person had another relapse of leprosy. And then I'm like, I don't know if I believe it.* [...]:*As a Health Worker, I say there is a cure, but I really don't believe in a cure for leprosy.* (CHW 12)
>
> *I have a patient in my area who underwent treatment, and she keeps coming back, keeps coming back. Her skin is horrible with the spots, that redness* [...] *she feels a lot of pain in her nerves. If she complains that she can't do things anymore, food. She has a lot of heat and pain.* (CHW 11)

Cases of signs and symptoms that characterize the occurrence of a leprosy reaction or relapse process are related. Leprosy reactions can occur before, during or after treatment, with Type 1 reactions being characterized by inflammation of the lesions, which become more visible and erythematous, are elevated and/or enlarged and the nerves may be inflamed, causing a reduction in strength, sensitivity and sweating(24).

Generating question: "What symptoms can a person with leprosy present?"

The description of the signs and symptoms for the CHW was emphasized by the presence of spots and changes in sensitivity caused by the action of the bacillus on the peripheral nerves, however, the appearance of signs (lumps) that are observed in the most severe form of the disease (Virchowian) was mentioned. The signs and symptoms reported by the CHW are among the cardinal signs of the disease, which are sensitivity loss in a skin lesion, changes in the peripheral nerve and a positive skin smear(24).

> *Spots, insensitivity, numbness in the skin…* (CHW 7)
>
> *Numbness in extremities...* (CHW 13)
>
> *Lumps in the ear! And when it is very advanced it loses the nose cartilage; then it already impairs breathing. Apart from the numbness of the skin and spots.* (CHW 1)

In the experience of the participants, it was also reported identification of the disease in individuals who do not present the classic clinical picture.

The absence of classic signs of the disease does not exclude the leprosy diagnosis, as some patients do not have easily visible injuries on the skin and may only have injuries on the nerves (primary neural leprosy)(1).

> *But there was a case in my area of an elderly man who did not have spots, did not have any of that; just a pain in the foot. In the consultation, the clinician prescribed pain medication and it did not solve the problem. And then a person who sells hammocks, talking to this gentleman said: "look, I had a relative who presented this to the dermatologist, who diagnosed leprosy". That was a matter of a month and he passed away, you know? So, I felt powerless and outraged because he, the clinician, thought it was just an orthopedist thing.* (CHW 6)

In the clinical evaluation, the professional will apprehend data reported by the relative and the adolescent or child, as well as perform the dermato-neurological examination, constituting an essential clinical practice for the leprosy diagnosis(17).

> [...] *sometimes what is passed on to us in training is that leprosy has reddish and whitish spots and is not sensitive; so, you stay there.* [...] *we must have a range of knowledge to be able to help those people who need our help. A fortnight after I entered the program, I had a person in the community who did not have any kind of spot. She had super dehydrated, dry skin. So, I sent her to my nurse, and she said: so we're going to do an evaluation here and we're going to do an exam. In the end: she had leprosy and not only her, but also all her contacts.* (CHW 8)

Receiving a leprosy diagnosis and the way this information is conveyed requires communicative competence from health care professionals, as it can trigger emotional repercussions and leave the individual feeling vulnerable in the face of the need to undergo treatment for the disease, as observed in the statement of CHW 21:

> *When I was 24 years old, a very small spot appeared; I ran, at that time it was right here at clinic, which was specialized in leprosy. Then they did those tests on me, touch with a needle, with a pin, with a pen cap, with the hot temperature and everything. Then, on the day of the result, it was positive. I had leprosy, which was tuberculoid. At the time she told me so directly, my world ended. I thought about throwing myself under a car. I didn't even know how to go home. I stayed the whole afternoon in that hospital, until my mother found me. Then I did the complete treatment, which is not easy. Last year, I had another spot (sigh) on my shoulder. I did a biopsy and it showed superficial chronic dermatitis psoriasis. Thank God I was healed.* (CHW 21)

In leprosy, there is a significant impact on the lives and daily routines of affected individuals, especially for those who have visible clinical manifestations in uncovered regions, such as the head and neck(25). However, the impact of the diagnosis can be minimized by welcoming the individual and family, as well as establishing a dialogue for guidance and clarification of doubts and sharing of difficulties and feelings experienced(26).

Generating question: How do you evaluate prejudice/stigma towards patients with leprosy?

Situations of prejudice and stigma were evidenced in the CHW's statements, contributing to the omission of the disease and difficulty for the person affected by leprosy and their family members to treatment adherence. For some CHW, the difficulty to accept the treatment was interpreted as rebellion.

In a research(6), the authors identified that the perpetuation of social stigmas involving leprosy continues to be observed in the omission that patients make regarding their clinical condition, as well as in the negative repercussions on the self-esteem of these individuals, making it difficult to seek health care, in addition to adherence to prolonged treatment of the disease.

Late diagnosis contributes to physical disabilities and exposure to prejudiced behaviors, which reflect old popular knowledge and ingrained beliefs regarding the contagion and disease treatment(6).

> *There is also the issue of discrimination. Many people are treated hidden elsewhere so that no one knows; they are very afraid that someone else will know.* (CHW 13)

> [...] *I had a 12-year-old patient, a child who became very rebellious! She didn't accept the treatment, she didn't accept that medication, because they are ashamed, they don't want to be there, because they know everyone, they don't want to undergo that treatment. Sometimes we only know why they go to the Mixed Unit or to another place, and from there they send a notification to the health Center.*(CHW 6)
>
> *Prejudice is a very old thing. People were isolated. Has the barrier been broken a bit? It was, but there is still a lot. Patients themselves do not accept, do not want to undergo the treatment. Precisely out of fear of prejudice.*(CHW 21)

The statements show an intense emotional suffering experienced by the feeling of angry and disgust to the process of exclusion and isolation socially projected throughout history, compromising early diagnosis, adherence to therapy and belief in cure. The stigma of leprosy found reverberation, also among women with the disease in the middle Jequitinhonha region, with denial, concealment and fear of social identification made explicit in the statements. Thus, everyday situations or even social involvement contribute to a retraction in the individual's social life and omission of the disease(27).

> *A friend of mine went to treat, she had Hansen's. She said: "I don't like to come to this post"; because, when it was time to take her form, she was there in line with everyone, but when it was her turn, they said: "wait a little bit". And her file wasn't there; it was separate, in the other box that had the big-name Hansen in it. Then the people would look at the box and she would be ashamed. So, she left the treatment.*(CHW 8)
>
> *For me, the worst disease is prejudice. When people judge: "Ah, I don't want to be close to that one over there because he has leprosy, he will contaminate me". So this myth that enters people's minds has to be broken. And who has to do that is the public authority, with information.* [...] *I'm not in favor of a one-day campaign.* [...] *You must talk.* [...] *We fight to break this taboo, this prejudice, but it is very deep-rooted".*(CHW 5)

Thus, it is important to emphasize the role of health care professionals and services in welcoming and offering care to control the disease, since early diagnosis and treatment, before the installation of physical sequelae and disabilities, can greatly contribute to the minimization of stigma and abandonment of treatment(28).

The complexity generated by the lack of knowledge about leprosy and the discrimination and rejection imposed on people affected by leprosy also affects the family nucleus, which, in the face of fear and historically imposed social pressures and threats about the disease, has the power to imprison and isolate the individual, establishing a process of death in life through commitment in the construction of interrelationships and socio-affective and emotional development.

In leprosy, the diagnosis has specificities for women, because, in addition to the stigma inherent to the disease, there are gender standards socially imposed on this social group(29). Although the literature reports that, for the companions of ill women, leprosy does not cause the separation of bodies, however, there is a barrier to other manifestations of affection, such as kisses and caresses(29) emerged in the discourse of the CHW, history of women with diagnosis being abandoned by the partner.

> *Prejudice also exists at home. There are many cases of couples when the partner knows that the wife has leprosy. I've never seen a woman abandon her partner who had leprosy; now, if when he is a man, he leaves the woman with leprosy.* (CHW 19)

The situation of stigma experienced by individuals with leprosy also interferes with marital relationships and sexual activity, also resulting from shame, silence and lack of interest, which may result in situations of withdrawal or abandonment by the partner and difficulty in starting new affective relationships(30).

Moreover, stigma and prejudice require systematic and interdisciplinary health education strategies in order to ensure access and dissemination of relevant knowledge about the disease and its treatment until cure, with a view to promote health care that is not limited to the biological aspect of leprosy but consider comprehensive care for the person and their family members.

The challenge posed highlights the need for systematic educational actions for health care professionals, allowing the redefinition of aspects related to living with the disease, cure and treatment, breaking the silence and denial caused by prejudice and presenting renewed possibilities in the relationships between the people living with leprosy, their family members, the community health worker and the primary health care team(27).

As limitations of the study, stands out the pandemic moment caused by COVID-19, which restricted the use of strategies that promoted greater proximity between the study participants. The study presents contributions to the practice, management and assistance given the possibility of using culture circles in training and performing educational activities for health care professionals, education and community for the construction and reconstruction of knowledge and practices related to leprosy, strengthening actions for disease control.

FINAL CONSIDERATIONS

The application of the theoretical and methodological framework of the culture circle to the CHW allowed to apprehend the empirical knowledge and experiences of professional practice, promoting the interweaving of scientific knowledge and empirical knowledge in the construction of a critical and reflective knowledge, committed to the welcoming and comprehensive care to the people and families affected by leprosy.

The statements highlighted a sense of concern regarding the reflection on their daily work, when questioning the occurrence of specific campaigns, highlighting the need for systematic health education strategies with the participation of health institutions and public authorities.

The lack of information was also related among primary care professionals, requiring a review of organizational attitudes that contribute to segregation processes, leading to a feeling of low self-esteem and isolation on the part of the person affected by leprosy.

The endemic nature of leprosy, even today, is marked by lack of knowledge about the disease, contributing to disbelief about its treatment, cure, and perpetuation of the stigma.

The development and access of professionals to permanent education about the care process for people affected by leprosy in primary care requires a critical and reflective construction of theoretical knowledge on the articulation with their own professional practice.

The study aims to promote an articulation between permanent education policies and leprosy control policies contributing with changes for a welcoming and inclusive care approach, capable of breaking old and mechanical attitudes, which hinder bonding relationships, so essential when require the involvement and adherence of individuals and their family members in the control and treatment of the disease until cure.

REFERENCES

1. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Vigilância das Doenças Transmissíveis. Guia prático sobre a hanseníase [Internet]. Brasília: Ministério da Saúde; 2017 [cited 2022 Oct 16]. Available from: https://bvsms.saude.gov.br/bvs/publicacoes/guia_pratico_hanseniase.pdf
2. Organização Mundial da Saúde (OMS). Estratégia Global de Hanseníase 2021–2030 – "Rumo à zero hanseníase" [Internet]. Nova Delhi: OMS, Escritório Regional para o Sudeste Asiático; 2021 [cited 2022 Oct 16]. Available from: https://www.who.int/pt/publications/i/item/9789290228509
3. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. Estratégia nacional para enfrentamento da hanseníase 2019-2022. Brasília, DF: Ministério da Saúde; 2019 [cited 2022 Oct 16]. Available from: https://www.gov.br/aids/pt-br/centrais-de-conteudo/publicacoes/2020/estrategia-nacional-para-enfrentamento-da-hanseniase-2019-2022/view
4. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. Hanseníase 2022: boletim epidemiológico,número especial. Brasília, DF: Ministério da Saúde; 2022 [cited 2022 Oct 16]. Available from: https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/especiais/2022/boletim-epidemiologico-de-hanseniase-_-25-01-2022.pdf/view
5. Monteiro LD, Alencar CH, Barbosa JC, Novaes CCBS, Silva RCP, Heukelbach J. Limited activity and social participation after hospital discharge from leprosy treatment in a hyperendemic area in north Brazil. Rev Bras Epidemiol. 2014;17(1):91-104. doi: https://doi.org/10.1590/1415-790X201400010008ENG
6. Silva WCS, Costa NL, Argentino S, Oliveira NP, Rodrigues DS. A estigmatização da hanseníase: vivências dos pacientes tratados em uma unidade básica de saúde. Braz J Develop. 2020;6(3):15824-33. doi: https://doi.org/10.34117/bjdv6n3-453
7. Cavalcante MDMA, Larocca LM, Chaves MMN. Multiple dimensions of healthcare management of leprosy and challenges to its elimination. Rev Esc Enferm USP. 2020;54:e03649. doi: https://doi.org/10.1590/S1980-220X2019010703649
8. Lana FCF, Lanza FM, Carvalho APM, Tavares APN. O estigma em hanseníase e sua relação com as ações de controle. Rev Enferm UFSM. 2014 [cited 2022 Oct 16];4(3):556-65. Available from: https://periodicos.ufsm.br/index.php/reufsm/article/view/12550/pdf
9. Presidência da República (BR). Secretaria-Geral. Subchefia para Assuntos Jurídicos. Lei nº 13.595, de 05 de janeiro de 2018. Altera a Lei nº 11.350, de 5 de outubro de 2006, para dispor sobre a reformulação das atribuições, a jornada e as condições de trabalho, o grau de formação profissional, os cursos de formação técnica e continuada e a indenização de transporte dos profissionais Agentes Comunitários de Saúde e Agentes de Combate às Endemias. Diário Oficial União. 2018 jan 8 [cited 2022 Oct 16];155(5 Seção 1):1-2. Available from: https://pesquisa.in.gov.br/imprensa/jsp/visualiza/index.jsp?data=08/01/2018&jornal=515&pagina=1&totalArquivos=92
10. Alencar OM, Heukelbach J, Pereira TM, Barbosa JC. Trabalho do agente comunitário de saúde no controle da hanseníase. Rev Rene. 2012;13(1):103-13. doi: https://doi.org/10.15253/2175-6783.20120001000013
11. Freire P. Educação como prática de liberdade. 20. ed. Rio de Janeiro: Paz e Terra; 1991.
12. Thiollent M. Metodologia da pesquisa-ação. São Paulo: Cortez; 1986.
13. Streck DN, Redin E, Zitkoski JJ. Dicionário Paulo Freire. 4. ed. Belo Horizonte: Autêntica; 2018.
14. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. doi: https://doi.org./10.1191/1478088706qp063oa
15. Monteiro EMM, Vieira NFC. Educação em saúde a partir de círculos de cultura. RevBras Enferm. 2010;6(3):397-403. doi: https://doi.org/10.1590/S0034-71672010000300008
16. Melo NB, Nobre SV, Souza BLO, Machado LDS, Leite TRC. Avaliação do conhecimento de agentes comunitários de saúde acerca da hanseníase em um município hiperendêmico. Vittalle. 2021;33(2):48-58. doi: https://doi.org/10.14295/vittalle.v33i2.12784
17. Oliveira JDCP, Marinus MWLC, Monteiro EMLM. Practices in the healthcare of children and adolescents with leprosy: the discourse of professionals. Rev Gaúcha Enferm. 2020;41:e20190412. doi: https://doi.org/10.1590/1983-1447.2020.20190412
18. Assis IS, Arcoverde MAM, Ramos ACV, Alves LS, Berra TZ, Arroyo LH, et al. Social determinants, their relationship with leprosy risk and temporal trends in a tri-border region in Latin America. PLoS Negl Trop Dis. 2018;12(4):e0006407. doi: https://doi.org/10.1371/journal.pntd.0006407
19. Lima EO, Silva MRF, Marinho MNASB, Alencar OM, Pereira TM, Oliveira LC, et al. Therapeutic itinerary of people with leprosy: paths, struggles, and challenges in the search for care. Rev Bras Enferm. 2021;74(1):e20200532. doi: https://doi.org/10.1590/0034-7167-2020-0532
20. Shyam-Sundar V, Wildt G, Virmond MCL, Kyte D, Galan N, Prado RBR, et al. A qualitative study exploring the perceived impact of race on leprosy-affected persons' experiences of diagnosis and treatment of leprosy in Southeast Brazil. Indian J Lepr. 2021 [cited 2022 Oct 16];93:1-13. Available from: https://www.ijl.org.in/published-articles/14092021205515/1-shyam_sunder_et_al_(1-13).pdf
21. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. Nota Técnica Nº 16/2021-CGDE/DCCI/SVS/MS [Internet]. Brasília, DF: Ministério da Saúde, 2021 [cited 2022 Oct 16]. Available from: http://antigo.aids.gov.br/pt-br/legislacao/nota-tecnica-no-162021-cgdedccisvsms
22. Ribeiro MDA, Silva JCA, Oliveira SB. Estudo epidemiológico da hanseníase no Brasil: reflexão sobre as metas de eliminação. Rev Panam Salud Publica. 2018;42:e42. doi: https://doi.org/10.26633/RPSP.2018.42
23. Belachew WA, Naafs B. Position statement: LEPROSY: diagnosis, treatment and follow-up. J Eur Acad Dermatol Venereol. 2019;22(7):1205-13. doi: https://doi.org/10.1111/jdv.15569
24. Assis DOT, Tavares CM, Alcântara RAA, Ramirez LJ, Brum EHM, Barbosa KGN, et al. Impacto no cotidiano das pessoas com a manifestação de hanseníase na região de cabeça e pescoço. Res Soc Dev. 2021;10(8):e54210817715. doi: https://doi.org/10.33448/rsd-v10i8.17715
25. Silveira MGB, Coelho AR, Rodrigues SM, Soares MM, Camilo GN. Portador de hanseníase: impacto psicológico do diagnóstico. Psicol Soc. 2014;26(2):517-27. doi: https://doi.org/10.1590/S0102-71822014000200027
26. 26. Gonçalves M, Santos KS, Silva SS, Marcussi TCC, Carvalho KV, Fortuna CM. Women and leprosy: interferences and experiences. Rev LatinoAm Enfermagem. 2021;29:e3419. doi: https://doi.org/10.1590/1518-8345.4347.3419
27. Neiva RJ, Grisotti M. Representações do estigma da hanseníase nas mulheres do Vale do Jequitinhonha-MG. Physis. 2019;29(1):e290109. doi: https://doi.org/10.1590/S0103-73312019290109
28. Jesus ILR, Montagner MI, Montagner MA, Alves SMC, Delduque MC. Hanseníase e vulnerabilidade: uma revisão de escopo. Cienc Saude Colet. 2023;28(1):143-54. doi: https://doi.org/10.1590/1413-81232023281.09722022
29. Oliveira MHP, Gomes R. A hanseníase na perspectiva de gênero. In: Barata RB, Briceño-León RE, organizadores. Doenças endêmicas: abordagens sociais, culturais e comportamentais. Rio de Janeiro: Fiocruz; 2000.

30. Nascimento ES, Coelho VAT, Souza CG, Pereira MCS, Freitas MC, Rocha AP, et al. Auto-percepção da aparência física, das relações conjugais e da atividade sexual de indivíduos com hanseníase. Id on line Rev MultPsi. 2019;13(48):113-29. doi: https://doi.org/10.14295/idonline.v13i48.2145

■ Acknowledgments:

Municipal Health Department of São Luís, Maranhão – Brazil.
Research Support Foundation for Scientific and Technological Development of Maranhão (*Fundação de Amparo à Pesquisa ao Desenvolvimento Científico e Tecnológico do Maranhão* - FAPEMA) - UNIVERSAL PROCESS – number 01347/2017.
PROCAD/Amazônia/CAPES/Notice no. 21/2018, funding code 001. Aquino DMC, Postdoctoral researcher.

■ Authorship contribution:

Project administration: Dorlene Maria Cardoso de Aquino, Estela Maria Leite Meirelles Monteiro.
Funding acquisition: Dorlene Maria Cardoso de Aquino.
Writing - original draft: Dorlene Maria Cardoso de Aquino, Estela Maria Leite Meirelles Monteiro, Nair Portela Silva Coutinho, Vanessa Moreira da Silva Soeiro, Tamyris Arcoverde Santos, Eudijéssica Melo de Oliveira, Débora Lorena Melo Pereira, Arlene de Jesus Mendes Caldas.
Writing - review & editing: Dorlene Maria Cardoso de Aquino, Estela Maria Leite Meirelles Monteiro, Tamyris Arcoverde Santos, Eudijéssica Melo de Oliveira, Débora Lorena Melo Pereira, Arlene de Jesus Mendes Caldas.
Investigation: Dorlene Maria Cardoso de Aquino, Estela Maria Leite Meirelles Monteiro, Nair Portela Silva Coutinho, Vanessa Moreira da Silva Soeiro, Débora Lorena Melo Pereira, Arlene de Jesus Mendes Caldas.
Methodology: Dorlene Maria Cardoso de Aquino, Estela Maria Leite Meirelles Monteiro.
Resources: Dorlene Maria Cardoso de Aquino, Estela Maria Leite Meirelles Monteiro.

The authors declare that there is no conflict of interest.

■ Corresponding author:

Dorlene Maria Cardoso de Aquino
E-mail: dorlene.aquino@ufma.br

Associate editor:
Cíntia Nasi

Received: 05.11.2022
Approved: 10.26.2022

Editor-in-chief:
João Lucas Campos de Oliveira

BY-NC