



Dialogues on the decentralization of the leprosy control program in an endemic municipality: a participatory evaluation^a

Diálogos sobre a descentralização do programa de controle da hanseníase em município endêmico: uma avaliação participativa

Diálogos sobre la descentralización del programa de control de la lepra en un municipio endémico: una evaluación participativa

Cristal Marinho Corrêa¹

Fernanda Moura Lanza²

Ana Paula Mendes Carvalho³

Francisco Carlos Félix Lana¹

1. Universidade Federal de Minas Gerais, Programa de Pós-Graduação em Enfermagem. Belo Horizonte, MG, Brasil.

2. Universidade Federal de São João del-Rei, Programa de Pós-Graduação em Enfermagem. Divinópolis, MG, Brasil.

3. Secretaria de Estado de Saúde de Minas Gerais. Belo Horizonte, MG, Brasil.

ABSTRACT

Objective: to evaluate the decentralization of the Leprosy Control Program (LCP) in Governador Valadares. **Method:** the theoretical and methodological framework was the Fourth Generation Evaluation, with a qualitative-participatory approach. The study involved 30 subjects divided into four groups: managers of the LCP; professionals of the Reference Center (RC); primary care professionals and users. Data were collected through interviews, using the Hermeneutic-Dialectic Circle technique. Subsequently, three workshops were held for data validation and negotiation. The Constant Comparative Method was used for the analysis. **Results:** the maintenance of the vertical model of leprosy care was evidenced, sustained by social-historical-cultural determinants that are expressed in: the permanence of the gateway to spontaneous demand in the RC; the routine referral of the user to secondary care; the inefficiency of counter-reference; the centralization of multidrug therapy; the belief in the need for specialized care, and stigma. Weaknesses in the link with primary care were evidenced. **Conclusion and implications for practice:** The sustainability of decentralization requires political and institutional involvement focused on strengthening primary care, reorienting the role of the services in the leprosy care network, and health education. The decentralization of the LCP involves tension between the actors of each health care point, generating disputes of knowledge and health practices.

Keywords: Decentralization; Health Evaluation; Leprosy; Primary Health Care; Qualitative Research.

RESUMO

Objetivo: avaliar a descentralização do Programa de Controle da Hanseníase (PCH) em Governador Valadares. **Método:** o referencial teórico-metodológico foi a Avaliação de Quarta Geração, de abordagem qualitativo-participativa. O estudo envolveu 30 sujeitos divididos em quatro grupos: gestores do PCH; profissionais do Centro de Referência (CR); profissionais da atenção básica e usuários. Os dados foram coletados por entrevistas, utilizando-se a técnica do Círculo Hermenêutico-Dialético. Posteriormente, realizaram-se três oficinas de validação e negociação dos dados. Utilizou-se o Método Comparativo Constante para a análise. **Resultados:** evidenciou-se a manutenção do modelo vertical de atenção à hanseníase, sustentado por determinantes sócio-histórico-culturais que se expressam: na permanência da porta de entrada à demanda espontânea no CR; no encaminhamento rotineiro do usuário para a atenção secundária; na ineficiência da contrarreferência; na centralização da poliquimioterapia; na crença na necessidade do atendimento especializado e no estigma. Evidenciaram-se fragilidades no vínculo com a atenção primária. **Conclusão e implicações para a prática:** a descentralização do PCH envolve a tensão entre os atores de cada ponto de atenção à saúde, gerando disputas de saberes e práticas de saúde. A sustentabilidade da descentralização requer envolvimento político e institucional focado no fortalecimento da atenção primária, na reorientação do papel dos serviços na rede de atenção à hanseníase e na educação em saúde.

Palavras-chave: Atenção Primária à Saúde; Avaliação em Saúde; Descentralização; Hanseníase; Pesquisa Qualitativa.

RESUMEN

Objetivo: evaluar la descentralización del Programa de Control de la Lepra (PCL) en Governador Valadares. **Método:** el marco teórico-metodológico fue la Evaluación de Cuarta Generación, con un enfoque cualitativo-participativo. El estudio involucró a 30 sujetos, divididos en cuatro grupos: gerentes del PCL; profesionales del Centro de Referencia (CR); profesionales de atención primaria y usuarios. Los datos fueron recolectados a través de entrevistas, utilizando la técnica del Círculo Hermenêutico-Dialético. Posteriormente se realizaron tres talleres de validación y negociación de los datos. Para el análisis se utilizó el Método Comparativo Constante. **Resultados:** se evidenció el mantenimiento del modelo vertical de atención a la lepra, sustentado en determinantes socio-histórico-culturales que se expresan en la permanencia del ingreso a la demanda espontánea en el CR; en la derivación rutinaria del usuario a atención secundaria; en la ineficiencia de la contrarreferencia; en la centralización de la poliquimioterapia; en la creencia en la necesidad de atención especializada y en el estigma. Se evidenciaron debilidades en el vínculo con la atención primaria. **Conclusión:** la descentralización del PCH involucra la tensión entre los actores en cada punto de la atención en salud, generando disputas sobre conocimientos y prácticas de salud. **Implicaciones para la práctica:** la sostenibilidad de la descentralización requiere de una participación política e institucional, enfocada en el fortalecimiento de la atención primaria, reorientando el rol de los servicios en la red de atención a la lepra y en la educación para la salud.

Palabras clave: Atención primaria de salud; Evaluación en salud; Descentralización; Lepra Investigación cualitativa.

Corresponding author.

Ana Paula Mendes Carvalho.
E-mail: carvalho.anapaulam@gmail.com

Submitted on 04/23/2021.

Accepted on 10/04/2021.

DOI:<https://doi.org/10.1590/2177-9465-EAN-2021-0114>

INTRODUCTION

Leprosy is an endemic disease in Brazil that unequally affects people of different ethnic groups living in precarious living situations, especially those with low income and education¹. The reduction of the global burden of leprosy depends on the degree of organization of the health services for the expansion of the offer of actions such as: epidemiological investigation for the timely diagnosis of cases; treatment with polychemotherapy (PCT) until cure; prevention and treatment of physical disabilities; health education focused on fighting stigma and on the continuing education of health professionals and examination of household and social contacts².

In the leprosy care network, the Primary Health Care services (PHC) are the main entrance gateway and care organizer in order to detect the disease early, facilitate the user's access, reduce stigma and ensure comprehensive care³⁻⁴.

The challenge of decentralization (or integration) of Leprosy Control Actions (LCA) in PHC is a reality in Brazil⁵ and in the world⁶ and is reflected in the high concentration of diagnosis and treatment in specialized outpatient clinics⁷.

Evaluative studies on decentralization of LCA in Brazilian PHC have focused on monitoring epidemiological and operational indicators⁸, the normative evaluations⁹⁻¹⁰, the degree of implementation of the Leprosy Control Program (LCP)¹¹⁻¹² and the presence and extent of PHC attributes in the realization of LCA¹³⁻¹⁵. In the diversified theoretical and methodological framework of evaluation studies, the emerging approaches have been proposed as an alternative to enable participatory evaluation models that also take into account the role of social actors inserted in the sociopolitical and cultural context of health programs and policies¹⁶. It is believed that these relations, historically and socially established, determine the construction of the health care model, delimiting the role of the services in the municipal network and the conditions of sustainability of the decentralization process.

The justification and relevance of this study is the need to understand the aspects that stand in the way of decentralization of LCA in Governador Valadares (Minas Gerais) because it is a highly endemic municipality and one of the pioneers in implementing LCP in Brazil¹⁷. From this perspective, the objective of this study was to evaluate the decentralization of the Leprosy Control Program in Governador Valadares.

METHODS

This is a qualitative, participatory research, based on the responsive constructivist paradigm of Fourth Generation Evaluation¹⁸.

This is a health assessment, with an emergent evaluative approach¹⁶, in which the parameters and limits of the evaluation are not determined in advance by the evaluator, but are established through an evolving, interactive and iterative process that involves negotiation with stakeholders potentially affected by the evaluation,

favoring dialogue, critical reflection and mutual understanding of the different social actors involved¹⁹.

The study was developed in Governador Valadares, one of the municipalities in Minas Gerais with a high concentration of cases, whose detection coefficient of new leprosy cases, in 2019, was 32.7 cases/100,000 inhabitants, which classifies its degree of endemicity as very high².

The municipality of Governador Valadares implemented the LCP still in 1943 through the actions of the Special Public Health Service (SPHS)²⁰. The municipal leprosy care network is composed mainly of the Municipal Hospital of Governador Valadares, the Reference Center for Special Diseases and Programs (CREDENPES) and the basic health units distributed throughout the municipality's health regions.

The research was conducted in seven stages: presentation of the research proposal to the Municipal Health Secretariat of Governador Valadares; organization and planning of the fieldwork; entrance of the researcher into the field and identification of stakeholders; application of the Hermeneutic-Dialectic Circle and simultaneous data analysis; data re-analysis; Negotiation and Validation Workshops¹⁸.

Semi-structured scripts were developed containing triggering questions about the performance of primary, secondary and tertiary care services in LCA and about the decentralization process of LCA in the city. Four pilot tests were carried out with nurses and Community Health Agents (CHAs) in a Health Center in Belo Horizonte, which allowed us to identify the need for language adaptations in the instrument to favor critical reflection by the actors.

The inclusion of participants in the study occurred a posteriori, after the researcher entered the field, between June 14 and 17, 2015, through a negotiation process that involved managers and health professionals of various categories and municipal positions through three meetings with the researcher in different services.

The following aspects negotiated with the actors were taken into consideration: the spontaneous interest in participating in the study, the inclusion of municipal political leaders, characters involved in the historical militancy of the LCP in the municipality, and the importance of the variability of professional categories.

The participation of users in the evaluation was considered relevant, opting for the random selection of subjects who completed treatment at most one year from the date of collection and whose entry into the LCP occurred by different means, including spontaneous demand and referral by the PHC. It is noteworthy that, at the time of the research and in a retrospective period of two years, there were no users who were accompanied by PHC in the municipality. Initially, the SINAN follow-up forms were used as a source to obtain information about the users, and the professionals from the local reference service - CREDENPES - were asked to make the first contact to invite participation in the study and to authorize later contact by the researcher responsible for scheduling and interviewing.

The participant negotiation process resulted in the previous selection of 30 subjects (stakeholders) divided into four interest

groups: municipal managers (four); reference center professionals (11); PHC professionals (nine) and users (six).

The first stage of data collection occurred between June 14 and 29, 2015 after the identification of stakeholders and corresponded to the application of the Hermeneutic-Dialectic Circle with the four stakeholders. This tool consists of conducting individual interviews overlapped from a circle dynamic that allows subjects to confront their opinions and positions about the object of investigation¹⁸.

Figure 1 represents the diagram of the dynamics of the application of the Hermeneutic-Dialectic Circle.

Initially, an interview was conducted with an initial respondent (R1), triggering guiding questions from the semi-structured script. The central themes, concepts, ideas, values, problems, and questions proposed by the respondent (R1) were analyzed by the researcher in an initial formulation designated (C1). Then a second respondent (R2) from the same interest group was interviewed. After the presentation of his initial questions, the themes of the analysis (of R1) were introduced and R2, invited to comment on them. As a result, a re-elaboration of positions, relativization and/or reaffirmation of initial concepts by R2 was observed, allowing a richer and more sophisticated construction designated (C2). The process was repeated by adding new informants until the conclusion of the interviews of all the members of the same group, thus closing the circle¹⁸.

The interviews lasted an average of one hour. The analysis occurred concomitantly with the collection and was repeated after the end of the Hermeneutic-Dialectic Circle in order to amplify the identification of information possibly unnoticed during the dynamic

process of its application. The interviews were transcribed in full. As an analysis technique, the Constant Comparative Method was used, initially formulated by Glaser and Strauss' Grounded Theory²¹, with later theoretical reformulations to incorporate the principle of interpretation, a characteristic mark of constructivism²², and adapt the method to the Fourth Generation Assessment¹⁸.

The analysis took place in five stages: transcription of the interviews; floating reading of the empirical material; coding of the data and its constant comparison with the content of new interviews added; development of theory through the construction of heuristic categories and subcategories; verification of saturation of the qualitative data for the decision on the continuity or interruption of the Hermeneutic-Dialectic Circle¹⁸.

The maintenance of conflicts of interest and the critical points of disagreement about the object of evaluation, after the Hermeneutic-Dialectic Circle dynamics, were the criteria that directed the researcher's choice for the preparation of negotiation agendas. Thus, the second stage of data collection consisted of three negotiation and data validation workshops with the participants, one with PHC professionals, one with professionals from the reference center, and one with managers, which took place between December 3 and 4, 2015. The purpose of the workshops was to discuss the disagreements on the agenda, broaden the consensus or clarify the points of disagreement, and share with the actors the analysis made by the researcher, seeking the participatory validation of the evaluation results. Each participant was given, 48 hours in advance, a copy of the transcript of the interviews held in the Hermeneutic-Dialectic Circle along with an agenda report containing the divergences

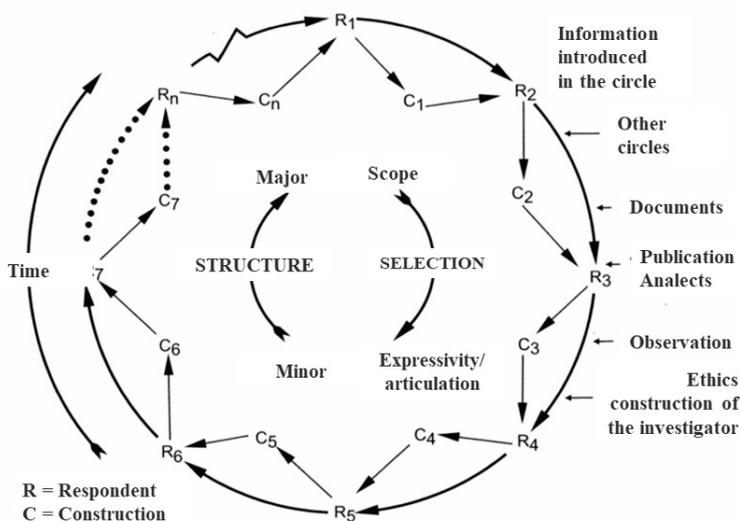


Figure 1. Hermeneutic-Dialectic Circle. Source: Guba and Lincoln^{18:169}

that would be discussed. The goal was to provide the necessary material for the actors' critical reflection before their immersion in the workshops, and also to give them the opportunity to point out possible errors in the transcription of their interviews.

During the workshops, the model for building the categories was presented through explanatory charts, containing thematic nuclei (categories), information units (subcategories) and examples of fragments of the interviewees' statements, sharing with the subjects the categorization logic used by the researcher. The workshops lasted an average of two hours, were recorded, and the content related to the negotiations and pacts was consolidated in the form of text in minutes. There were no requests for changes in the final document of the workshops.

This research was conducted by researchers from the Center for Studies and Research in Leprosy (NEPHANS) of the Federal University of Minas Gerais (UFMG). It followed the norms of Resolution 466/2012 of the National Health Council and was approved by the Research Ethics Committee of UFMG with the Consent Opinion No. 1.076.302. The participation of subjects was voluntary by signing the Informed Consent Form after being informed about the objectives and possible risks of the study. The participants' speeches were coded in the text by alphanumeric acronyms with randomized order for managers (MAN), Reference Center Professionals (RCP), PHC Professionals (PHCP) and Users (US) in order to protect the participants' anonymity.

RESULTS

The data from the individual interviews conducted through the Hermeneutic-Dialectic Circle will be presented, validated in the negotiation workshops, which composed the thematic nucleus "Dialogues about the leprosy care model: the problem of decentralization in the view of municipal actors".

In the first phase of the study, 30 subjects participated in the Hermeneutic-Dialectic Circle interviews. The managers group (MAN), composed of four subjects, included professionals who held management positions in the municipal PHC, technical references and professionals from the Epidemiological Surveillance sector.

In the group "Reference Center Professionals" (RCP), 11 subjects were included, among them, two doctors, a nurse, a nursing technician, a social worker, an occupational therapist, a psychologist, a biochemist, a health visitor, an administrative manager, and a former employee of the service claimed by the actors due to his history of militancy for the LCP in the municipality.

The nine subjects that composed the "Primary Health Care Professionals" (PHCP) interest group were composed of three physicians, three nurses, and three CHAs. In the users group (US), four subjects were included.

In the second phase of the study, nine of the 11 RC professionals (82%) interviewed in the first phase of the study, seven of the nine PHC professionals (78%) and three of the four managers (75%) participated in the Negotiation and Validation Workshops, as well as listeners claimed by the actors and accepted by the researcher after negotiation.

One of the points most debated as an obstacle to decentralization was the historical maintenance of the CREDENPES entrance door - a secondary care unit - to spontaneous demand in the municipality.

[...] We hear the discourse, right [...] - "Oh, no, but primary care doesn't do it" - but why doesn't it do it? Because there are those who do! Why does prenatal care do it? Why does hypertension and diabetes do it? Can you imagine if I had a polyclinic with an open door endocrinologist? It would be the same thing. Have you ever thought if there was a CVV (Centro Viva Vida) with an open door for prenatal care? It would be the same thing. [...] **MAN2**

[...] It comes directly. If you want to control an infectious disease, you have to make it as easy as possible, if you make it difficult, you lose the patient. [...] You're going to send him to the clinic, complicating his life? [...] **RCP11**

[...] If CREDENPES is closed, closed, I mean, the door, if access to CREDENPES is made difficult, where you can only go with a referral, what will happen? This patient will not come to the clinic because: - "I don't want to expose myself, the CHA [Community Health Agent] is my neighbor, she talks a lot, she is going to tell everyone that I went to the clinic because of a spot, so I won't go, I prefer to go straight to CREDENPES". What will happen? If the door to CREDENPES is not open, this patient can be smear positive, will be spreading it at home, in the neighborhood, etc. etc. I think that the spontaneous demand for CREDENPES should continue to exist **PHCP2**

From the user's perspective, stigma appears as an important aspect whose psychosocial repercussions interfere with their quality of life. However, more than the fear of suffering prejudice, it was observed that the difficulty of access, the fragility of the link and dissatisfaction with the service generated, over time, the discredit in PHC services, resulting in the search for care in CREDENPES and/or the refusal to counter-reference after diagnosis for continuity of treatment in PHC.

[...] I didn't trust them! [She (**referring to the nurse of the Family Health Strategy - FHS**) said - "Do you want me to call there (**CREDENPES**) so you can take the medicine here? No, I don't want to! No, I don't want to, my daughter, you didn't even want to see me to look at the paper if I have leprosy or not. Because I talked to her like this: Look, here, for me, if it is really leprosy, it is worse. - No, I can't right now, only Friday". "Only Friday? So, Friday and Monday will pass and I won't come! I will not come!" [...] I don't think that I have much confidence with the nurse there. I am afraid [...] **US5**

In general, CREDENPES was highlighted as a service that offers better care than PHC, especially in terms of welcoming,

psychosocial support and resoluteness in relation to the user's demands.

[...] I have nothing to complain about here (**CREDENPES**), thank God, you know? I was always very well attended, since the first appointment that I arrived [...] a good conversation, always a smile, always welcoming, you know? [...] They didn't let me lack anything! If I had to come here, as I had two moments of reaction to the medication, I came without an appointment. When I called, they said: "No, you can come, we'll manage, we'll put you in the middle of someone else", so, I was always very well assisted and they were always ready to assist me whenever I needed them. [...] It even seems like a lie, right? Talking about the public service. [...] **US4**

Notwithstanding this, it is valid to highlight that the user's search for better care in secondary care makes him/her voluntarily assume the financial burden of traveling to CREDENPES, leading to difficult access and possible repercussions such as delayed treatment.

I took medicine for a year [...] there were days that I had to come here. I took money and kept it for me to come here, otherwise, how could I come, right, without money? [...] There is Bolsa Família, it is very little, but I get ten reais, twenty... [...] I don't have much, I earn a little, a hundred and twenty a month. That's good. [...] I wanted here (**CREDENPES**) because here no one mistreats anyone [...] **US5**

It was also evidenced the naturalness, on the part of PHC professionals, in pointing out CREDENPES as the ideal and most appropriate place for leprosy care in the municipality of Governador Valadares, besides the difficulties of PHC in performing leprosy-related actions, such as treatment and post-discharge follow-up.

[...] I've been here (**FHS**) for three years, I never received a patient to take a dose here [...] Because, as CREDENPES is a confidential place, even for us they can't know that they told me this story [...] So, it is complicated even for us to approach this patient. [...] Sometimes, in CREDENPES, I had four, five (**referring to the number of patients registered in the FHS that were followed up in Credenpes**), but knowing, I had 1 [...] **PHCP4**

[...] Às vezes, demora, às vezes, nem tem a contrarreferência que a gente precisa saber [...] Os próprios pacientes que depois falam com a gente, "ah, eu tô tratando, eu tratei de hanseníase, já me deram alta", entendeu? A gente não tá tendo essa contrarreferência. **PHCP7**

Operational aspects that influence the current model of leprosy care in the city were discussed, such as the lack of technical preparation of PHC, the low supply of training and the turnover of

trained professionals. However, it was pondered that the routine practice of referring the user is cultural and has also been done by trained professionals. In this sense, actors mentioned aspects such as the lack of interest of PHC professionals, especially doctors.

[...] We have doctors and nurses that, as far as I know, have already been trained and they don't do it. [...] What is this, they go through training and don't learn? It's a lack of interest, "amiga"! Lack of involvement with what they came here for, with the training itself [...] **RCP8**

According to the actors, the appropriation and sustainability of the knowledge acquired in the trainings are also compromised by the passivity in the active search and the habit of direct referral to CREDENPES.

[...] I have forgotten everything. [...] I agree. Because it is not such a prevalent disease and we still refer... [...] **PHCP6**

Accommodation, from the PHC professional's perspective, is also justified as a result of the work overload in the units, the volume of activities inherent to the various programs, and the instability of the human resources, which generates a feeling of "eternal restart" of the work process after the departure of doctors and other team members.

However, the naturalization of the current model of care centralized in CREDENPES and the distorted understanding of professionals that there is an "instituted flow" by the municipal management that legitimizes the practice of referral to secondary care were observed.

[...] Here, we centralize. [...] Immediate referrals. Here, it is more like active search, evaluation and referral of the suspected case. After that, I don't even know what happens. [...] There is also this flow, it is already established in the city. Maybe, for this reason, I never took over before. [...] they ask me to forward it, you know? [...] The coordination itself prefers, you know, to send it to CREDENPES [...] The whole municipality refers it. Is there a place that is treating in the basic unit? [...] **PHCP6**

Also discussed was the resistance encountered to the change in the model proposed by the decentralization, understood as the loss of control of CREDENPES by the leprosy cases in the municipality. Among the consequences, it was pointed out the fear of underreporting of the disease by PHC, which would no longer perform the suspicion to avoid the responsibility for the continuity of care.

[...] I understand that decentralization would lead to better care for the patient, because he would be diagnosed at his place of residence, but sometimes I notice that it is not done there and not referred here. Because then the question comes up: if I diagnose, I have to treat, then it is

better that I don't even see the disease, because then I don't treat, diagnose or refer it. So, I question this issue. I understand that it is good, but I question the effectiveness of decentralization [...] **RCP9**

[...]I think that some people don't want to allow it, many times, because of the capacity presented by primary care. [...] I realize that the thermometer they have there is that if you release, decentralize, there will be a lack of control. [...] **RCP2**

Regarding PHC professionals, the resistance points to the stigma related to leprosy and the belief in the need for specialized care, aspects that generate the distancing of professionals.

[...]In my opinion, I think it is something very... it is a disease... right? [...] very specific: infectious, dermatological... I think it should stay there. Because it is a highly contagious disease and here, sometimes, we [...] can pass it on to the rest of the people. So, I think it is better that the specialists stay there [...]. When I get that little spot, [...] topical corticoid, come back in 15 days to see if it is better. If it got better, fine! If it is not better, I send it to the dermatologist. I don't stay with the patient here because if I don't I'll get it and everyone else who is there waiting will get it too. [...] Like this, I, if I were the owner, secretary of health, owner of the business, I would not decentralize in any way [...] **PHCP9**

Regarding municipal management, despite the recognition of the importance of decentralization, it was observed, dialectically, the accommodation with the vertical model of the LCP in CREDENPES, sustained by the fear of discontinuity of care in PHC, especially in the face of turnover and difficulty of supervision of PHC teams.

[...]I think that... fear. [...] it is easier to control centrally. Because the charging and everything, it stays very much in the reference center. [...] If I decentralize, I lose a little bit of how this is going to be. [...] For us too, I have 57 teams. [You manage all this is much more complex. So, giving support to everyone is much more complex! It is a dream, I think that is what has to be done, it is a dream, it is a will, but I think there is also a great fear of doing it, of losing, you know? [...] **MAN1**

An evidence of the accommodation of the municipal management with the vertical structure of the LCP is the centralization of multidrug therapy in CREDENPES seen, by the professionals, as an operational hindrance to decentralization.

[...]should have the medication exactly right, like they send it to us, send it to the FHCs, because they get it here (CREDENPES) [...] they should have the medication there too, right? Not be our responsibility here, which is the reference center. Because they come to get the medicine, sometimes the patient is late, there is no one to get the medicine, understand? We go through this here. [...] **RCP4**

DISCUSSION

Decentralization of LCP persists as a challenge in Brazil^{3,5,8,11,23} although policy guidelines reinforce the need to strengthen the provision of LCA in PHC services to reduce the disease burden^{2,23}. Research has found weaknesses in the access to diagnosis^{8,13,14} and follow-up of the disease by PHC^{3,8,12,24}, resulting in the user's displacement to services distant from his/her residence^{5,9}, as well as in late diagnosis^{5,8} and difficulties in case follow-up^{3,5,8}.

A study that analyzed the epidemiological situation of leprosy in Brazil and its association with the decentralization of control actions showed that the diagnosis of leprosy cases in PHC had a statistically significant association with the increase in the annual detection rate of new leprosy cases per 100,000 population, of the annual detection rate of new leprosy cases in the population between zero and 14 years old per 100,000 inhabitants and the rate of new leprosy cases with grade-2 disabilities at the time of diagnosis per 100,000 inhabitants²⁴.

In Minas Gerais, the decentralization of the LCP has been encouraged by the investment in the expansion of the coverage of the Family Health Strategy (FHS)¹⁹, in the training of PHC professionals²⁵ and in the formulation of the state plan for leprosy control²⁶.

Research that evaluated the presence and extent of PHC attributes in the performance of LCA in Governador Valadares showed that the municipality has a high general score orientation, but with weaknesses in the attributes that make up the derived score (family, community and professional orientation) according to the experience of managers, physicians, nurses and CHAs²⁷.

Dialectically, the results show that the technical-assistance design of the leprosy care network in Governador Valadares still reproduces the logic of centralization of care for the user, since it is under the responsibility of specialists under the discourse that there is a lack of technical preparation of PHC and a low offer of training.

Therefore, the normative institution of the decentralization policy^{23,28}, by itself, is not able to reorient the leprosy care model⁸, since the study participants still "maintain articulation of everyday actions without changes in symbolic orders"^{27:8}.

The adequate response of PHC to the needs of prevention and control of the leprosy endemic involves the competencies, attitudes and skills of professionals in carrying out LCA^{4,15} to promote the rupture of practices that weaken the effectiveness of PHC as an organizer and coordinator of care in the healthcare network²⁹.

The experience of PHC professionals in providing care to suspected and confirmed cases and to leprosy contacts is determinant for the service to be a provider of disease control actions oriented towards PHC attributes.¹⁵ These activities comprise the continuous offer of actions to the user, the family and the community^{2,23,28}, whose sustainability can be made possible through the exchange of experiences with reference professionals^{5,11}.

However, the evidence points to important weaknesses in professional training to deal with this important neglected disease^{3,5,8,9,11,12,13}. A limited potential of the capacity building strategy in the sustainability of the decentralization process of municipal programs was also evidenced²⁰, expressed by increased detection in training and campaign periods³⁰, with a subsequent trend toward “recentralization” of diagnosis and treatment in reference centers²⁰, demonstrating the complexity of reversing the leprosy care model.

In addition to the turnover^{3,8}, the fragility in the structure of PHC units as to material resources, drugs and supplies for leprosy care^{9,10,11}, the work overload of the professionals¹¹ and the “bottleneck” of spontaneous demand in PHC for chronic non-communicable diseases³¹ have been pointed out as determinants that contribute to the referral of users with leprosy to reference centers^{9,31}.

On the other hand, the differences in the degree of decentralization of control programs in endemic areas reveal not only technological disparities among health services, but also the heterogeneity of programmatic management models and prioritization of leprosy in the municipal policy^{3,11,12,24}.

A study that analyzed the trend of the epidemiological and operational situation of leprosy in Minas Gerais, in the period from 2008 to 2018, showed that the state showed a decreasing trend for the overall detection of new cases, but pointed out caution in interpreting this finding, since it may express a gap in the health care process³².

The effectiveness of health surveillance^{14,15}, in Governador Valadares, is also compromised due to the distancing of PHC professionals in relation to leprosy. The symbolic meaning of stigma expressed in the desire not to identify with the disease and in the understanding that it is a specialty pathology, was evidenced. A survey carried out with professionals from the North and Northeast regions of Brazil indicated that stigma has hindered decentralization more significantly than operational aspects such as turnover and training³³.

The practice of retaining the user in the reference centers, on the other hand, favors the verticalization of leprosy care and is contrary to what is recommended in the guidelines for the implementation of the leprosy care network²⁸. This practice is pointed out as a result of operational factors, especially the technical inability of PHC professionals⁵.

Notwithstanding this, aspects such as the need to maintain local political visibility and the fear of losing work space after decentralization have been pointed out as socio-historical-cultural determinants that influence the practice of user retention in referral services, reinforcing the vertical model of disease care³³.

These aspects become factors of retention and demand in the reference centers, building, over the years, symbolic collective values capable of guiding the flow of local attention³⁴.

The influence of referral services for the population is, among other aspects, related to the local historical contexts of services remaining after municipalization, such as hospitals that, after the implementation of UHS, remained in the health care network as

outpatient clinics, attracting the local demand for new leprosy cases^{34,35}.

Moreover, studies have pointed out the significance of the superiority of referral centers from the user’s perspective, related to technologies and quality of care, associated with the experience of difficulties of access in PHC units²⁰.

The dissatisfaction with the reception of professionals and the fragility of the link in the PHC makes the referral services become the user’s first service of choice, despite the geographic barrier and the financial burden associated with the displacement⁴. There is evidence that “successful practices and experiences, centered on the user and on his needs, can be considered situations capable of modifying meanings”^{27:8} of the care provided to leprosy patients in PHC services.

Vaitsman (2000) reiterated that social-historical-cultural meanings act autonomously, conditioning behaviors within public organizations, and their deconstruction does not involve the formative introduction of vertical policies, this being an important challenge for the introduction of new institutional designs and/or managerial innovations³⁶.

From a macro-structural perspective, the difficulties imposed on the decentralization of the LCP in Brazilian municipalities reveal the dispute between distinct care models, which coexist among themselves, whose technological configuration in the scope of health knowledge and practices is intrinsically different, generating tensions and conflicts of power in the daily care and management of the program.

Despite the expansion of LCA in PHC^{11,13,14,15,37}, the model of care to leprosy historically carries characteristics of hegemonic ideological movements that built public health in Brazil, such as the sanitarian model that gave rise to health campaigns and special programs. These have, as characteristics, the combination of technologies based on biological disciplines, the performance in risk and the most epidemiologically relevant diseases in an isolated and verticalized way. This model exerts an important political and cultural influence on the health professions, the population, and the State, influencing the modes of care production and inducing the reproduction of practices that act as barriers to the consolidation of decentralization and the integrality of care³⁵.

In this sense, it is valid to affirm that the PHC model, based on health promotion, still persists as a challenge in the field of health care practices for the consolidation of the Unified Health System itself, in the sense of consolidating itself not only in its legal-institutional dimension, but mainly as a political-operational paradigm capable of reorienting health care practices towards integrality³⁸.

One of the limitations of the study was the inability to renew the Hermeneutic-Dialectic Circle, which would allow the first participants to have access to the joint constructions that accumulated during the process. However, we tried to remedy this aspect during the negotiation workshops, in which the main topics discussed in the individual interviews, were presented to the participants, in a transparent and careful manner, with the respective fragments of the participants’ speeches. In addition,

there was no field observation period by the researcher, since it was decided to negotiate the participation of the subjects with the professionals and managers themselves, since this is a scenario widely known by researchers, through other studies carried out in the municipality.

The results of the evaluation pointed out both favorable and unfavorable aspects for all stakeholders, showing that the methodology was able to grasp and represent the demands, concerns, and questions of the actors involved.

CONCLUSION

This study evaluated the decentralization of the LCP in Governador Valadares by means of a fourth generation evaluative research with a qualitative-participatory approach. The maintenance of the vertical model of leprosy care was evidenced, sustained by socio-historical-cultural determinants that were pointed out, by the participants, as the aspects that stand in the way of LCA decentralization in the municipality.

The use of the fourth generation evaluative research, with a qualitative-participatory approach, to address the research problem allowed the unveiling of the tensions between the participants of each health care point that determine the implementation of the centralized leprosy care model: on one hand, there is a questioning, by the professionals, of the reference about the effectiveness of decentralization and, on the other hand, PHC professionals, based on the belief of the need for specialized care through the technical unpreparedness of the PHC team, affirm that the referral of the patient to CREDENPS without counter-reference is the flow instituted in the daily work.

In this scenario, PHC is weakened to perform LCA in PHC, its role being restricted to case suspicion and referral. Despite this, PHC is not configured as the preferential entry point for users in the leprosy care network in Governador Valadares, since the secondary care service allows access without referral.

The strengthening of primary care, continuing education in health and the political-institutional support of the municipal management to decentralization are potentially effective strategies to build a network of care in the municipality. The effective participation of PHC depends on the redirection of the role of services with the ordering of the flow of the entry door by PHC, matrix support and community participation in decisions about the modes of care through the creation of effective links with the population. It is believed that these issues will give sustainability to the decentralization process.

AUTHOR'S CONTRIBUTIONS

Study design. Cristal Marinho Corrêa. Francisco Carlos Félix Lana.

Data collection or production. Cristal Marinho Corrêa.

Data analysis. Cristal Marinho Corrêa. Francisco Carlos Félix Lana. Fernanda Moura Lanza. Ana Paula Mendes Carvalho.

Interpretation of results. Cristal Marinho Corrêa. Francisco Carlos Félix Lana. Fernanda Moura Lanza. Ana Paula Mendes Carvalho.

Writing and critical revision of the manuscript. Cristal Marinho Corrêa. Fernanda Moura Lanza. Ana Paula Mendes Carvalho. Francisco Carlos Félix Lana.

Approval of the final version of the article. Cristal Marinho Corrêa. Fernanda Moura Lanza. Ana Paula Mendes Carvalho. Francisco Carlos Félix Lana.

Responsibility for all aspects of the content and integrity of the published article. Cristal Marinho Corrêa. Fernanda Moura Lanza. Ana Paula Mendes Carvalho. Francisco Carlos Félix Lana.

ASSOCIATED EDITOR

Maria Catarina Salvador da Motta 

SCIENTIFIC EDITOR

Ivone Evangelista Cabral 

REFERENCES

1. Nery JS, Ramond A, Pescarini JM, Alves A, Strina A, Ichihara MY et al. Socioeconomic determinants of leprosy new case detection in the 100 Million Brazilian Cohort: a population-based linkage study. *Lancet Glob Health*. 2019;7(9):e1226-36. [http://dx.doi.org/10.1016/S2214-109X\(19\)30260-8](http://dx.doi.org/10.1016/S2214-109X(19)30260-8). PMID:31331811.
2. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde, Departamento de Vigilância das Doenças Transmissíveis. Diretrizes para vigilância, atenção e eliminação da Hanseníase como problema de saúde pública [Internet]. Brasília: Ministério da Saúde; 2016.
3. Lanza FM, Lana FCF. Decentralization of leprosy control actions in the micro-region of Almenara, State of Minas Gerais. *Rev Lat Am Enfermagem*. 2011 jan/fev;19(1):187-94. <http://dx.doi.org/10.1590/S0104-11692011000100025>. PMID:21412646.
4. Lanza FM, Vieira NF, Oliveira MMC, Lana FCF. Instrument for evaluating the actions of leprosy control in Primary Care. *Rev Bras Enferm*. 2014 maio/jun;67(3):339-46. <http://dx.doi.org/10.5935/0034-7167.20140044>. PMID:25054693.
5. Barbieri RR, Sales AM, Hacker MA, Nery JAC, Duppre NC, Machado AL et al. Impact of a reference center on leprosy control under a decentralized public health care policy in Brazil. *PLoS Negl Trop Dis*. 2016;10(10):e0005059. <http://dx.doi.org/10.1371/journal.pntd.0005059>. PMID:27732610.
6. Standley C, Boyce MR, Klineberg A, Essix G, Katz R. Organization of oversight for integrated control of neglected tropical diseases within Ministries of Health. *PLoS Negl Trop Dis*. 2018;12(11):e0006929. <http://dx.doi.org/10.1371/journal.pntd.0006929>. PMID:30462639.
7. Rodrigues RN, Niitsuma EM, Bueno IC, Baquero OS, Jardim CCG, Lana FCF. Hanseníase e vulnerabilidade da saúde em Belo Horizonte, Minas Gerais. *Rev Min Enferm*. 2017;21:e-997.
8. Saltarelli RMF, Seixas DHT. Limites e possibilidades na atenção ao portador de hanseníase no âmbito da Estratégia Saúde da Família. *Rev APS*. 2016 out/dez;19(4):613-22.
9. Sousa GS, Silva RLF, Xavier MB. Hanseníase e Atenção Primária à Saúde: uma avaliação de estrutura do programa. *Saúde Debate*. 2017;41(112):230-42. <http://dx.doi.org/10.1590/0103-1104201711219>.
10. Leite TRC, Lopes MSV, Maia ER, Cavalcante EGR. Avaliação da estrutura da atenção primária à saúde na atenção à hanseníase. *Enferm Foco*. 2019;10(4):73-8.
11. Leal DR, Cazarin G, Bezerra LCA, Albuquerque AC, Felisberto E. Programa de Controle da Hanseníase: uma avaliação da implantação

- no nível distrital. *Saúde Debate*. 2017;41(esp):209-28. <http://dx.doi.org/10.1590/0103-11042017s16>
12. Souza MF, Vanderlei LCM, Frias PG, Souza MF, Vanderlei LCM, Frias PG. Avaliação da implantação do Programa de Controle da Hanseníase em Camaragibe, Pernambuco. *Epidemiol Serv Saude*. 2017;26(4):817-34. <http://dx.doi.org/10.5123/S1679-49742017000400013>. PMID:29211145.
 13. Sousa GS, Silva RLF, Brasil-Xavier M. Hanseníase e atenção primária: um estudo avaliativo sob a ótica do médico. *Rev Salud Publica*. 2018;20(3):359-65. <http://dx.doi.org/10.15446/rsap.v20n3.56109>. PMID:30844010.
 14. Vieira NF, Lanza FM, Lana FCF, Martínez-Riera JR. Avaliação dos atributos da atenção primária à saúde nas ações de controle da hanseníase. *Rev Enferm UERJ*. 2018;26:e31925.
 15. Vieira NF, Lanza FM, Martínez-Riera JR, Nolasco A, Lana FCF. Orientación de la atención primaria en las acciones contra la lepra: factores relacionados con los profesionales. *Gac Sanit*. 2020;34(2):120-6. <http://dx.doi.org/10.1016/j.gaceta.2019.02.011>. PMID:31053453.
 16. Bosi MLM, Mercado FJ, organizadores. Avaliação Qualitativa de Serviços de Saúde: enfoques emergentes. 3. ed. Petrópolis: Vozes; 2013.
 17. Genovez PF, Pereira FRO. "Drama" da hanseníase: Governador Valadares, as políticas públicas de saúde e suas implicações territoriais na década de 1980. *Hist Cienc Saude Manguihos*. 2016;23(2):379-96. <http://dx.doi.org/10.1590/S0104-59702016000200004>. PMID:27276042.
 18. Guba EG, Lincoln YS. Avaliação de quarta geração. 1. ed. Campinas: Editora Unicamp; 2011.
 19. Hartz ZMA. Histórico da avaliação. In: Brousselle A, Champagne F, Contandriopoulos AP, Hartz, Z. Avaliação: conceitos e métodos. 1. ed. Rio de Janeiro: Fiocruz; 2011.
 20. Genovez PF, Pereira FR. Da lepra à hanseníase: Política pública, o cotidiano e o estigma a partir da memória de seus atores – Governador Valadares (Década de 1980). *Hist Quaestoes Debates*. 2014;60(1):205-28. <http://dx.doi.org/10.5380/his.v60i1.38287>.
 21. Glaser BG, Strauss AL. The discovery of grounded theory. Chicago: Aldine; 1967.
 22. Charmaz K. A construção da teoria fundamentada: guia prático para análise qualitativa. Porto Alegre: Artmed; 2009.
 23. 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: Ministério da Saúde; 2019.
 24. Vieira NF, Lana FCF, Rodrigues RN, Niitsuma ENA, Lanza FM. Avaliação da Atenção Primária: comparativo entre o desempenho global e as ações de Hanseníase. *RECOM*. 2019;9:e2896. <http://dx.doi.org/10.19175/recom.v9i0.2896>.
 25. Leroy FS, Coelho A CO, Niitsuma ENA, Gomes FBF, Lanza FM, Ribeiro G C et al. Educação permanente em saúde: a experiência do uso da educação a distância na capacitação em ações de controle da hanseníase. *Em Rede*. 2017;4(1):235-50.
 26. Lanza FM. Avaliação da atenção primária no controle da hanseníase: validação de instrumentos e análise do desempenho de municípios endêmicos do Estado de Minas Gerais [tese]. Belo Horizonte: Escola de Enfermagem, Universidade Federal de Minas Gerais; 2014.
 27. Silva JF, Fonseca DF, Silva J, Viegas SMF, Lanza FM. O cotidiano de trabalho da estratégia saúde da família: entre o real e o ideal. *RECOM*. 2019;9:e3488. <http://dx.doi.org/10.19175/recom.v9i0.3488>.
 28. Secretaria de Estado da Saúde de Minas Gerais. Coordenadoria Estadual de Controle da Hanseníase. Plano de Enfrentamento da Hanseníase em Minas Gerais, 2019-2022 [manuscrito]. Belo Horizonte: Secretaria de Estado da Saúde; 2019.
 29. Mendes EV. O cuidado das condições crônicas na atenção primária à saúde. *Rev Bras Promoç Saúde*. 2018;31(2):1-3.
 30. Lanza FM, Rodrigues RN, Silva J. Integração ensino-serviço para realização de educação permanente em ações de controle da Hanseníase: relato de experiência. *HU Rev*. 2021;47:1-6.
 31. Alencar CHM, Ramos Jr AN, Sena No SA, Murto C, Alencar MJ, Barbosa JC et al. Diagnóstico da hanseníase fora do município de residência: uma abordagem espacial, 2001 a 2009. *Cad Saude Publica*. 2012;28(9):1685-98. <http://dx.doi.org/10.1590/S0102-311X2012000900008>. PMID:23033184.
 32. Ariana SM, Lago KS, Costa CM, Bueno IC, Rodrigues RN. Tendência da situação epidemiológica e operacional da hanseníase no estado de Minas Gerais (2008 - 2018). *Saúdecoletiva*. 2020;10(56):3122-31.
 33. Raposo MT, Nemes MIB. Assessment of integration of the leprosy program into primary health care in Aracaju, state of Sergipe, Brazil. *Rev Soc Bras Med Trop*. 2012 abr;45(2):203-8. <http://dx.doi.org/10.1590/S0037-86822012000200013>. PMID:22534993.
 34. Smith WCS. Sustaining anti-leprosy activities requires radical changes. *Lepr Rev*. 2010 dez;81(4):281-3. <http://dx.doi.org/10.47276/lr.81.4.281>. PMID:21313970.
 35. Correia CMF, Pimentel NSN, Fialho VML, Oliveira RML, Gomide M, Heukelbach J. Fatores associados à alta demanda de pacientes com hanseníase em centro de referência em Manaus, Amazonas. *Cad Saude Colet*. 2008 jan;16(2):169-80.
 36. Vaitsman J. Cultura de organizações públicas de saúde: notas sobre a construção de um objeto. *Cad Saude Publica*. 2000;16(3):847-50. <http://dx.doi.org/10.1590/S0102-311X2000000300033>. PMID:11035524.
 37. Rodrigues RN, Arcêncio RA, Lana FCF. Epidemiologia da hanseníase e a descentralização das ações de controle no Brasil. *Rev Baiana Enferm*. 2021;35:e39000. <http://dx.doi.org/10.18471/rbe.v35.39000>.
 38. Paim JS. Modelos de Atenção à Saúde no Brasil. In: Giovanella L, organizadora. Políticas e sistema de saúde no Brasil. 2. ed. Rio de Janeiro: Editora FIOCRUZ; 2012.

^a Article extracted from the master's thesis "Evaluation of the Leprosy Control Program in the Municipality of Governador Valadares, Minas Gerais, Brazil", by the author Cristal Marinho Corrêa, under the guidance of Francisco Carlos Félix Lana. Defended in the year 2016. Postgraduate Program in Nursing at the Federal University of Minas Gerais