Esc Anna Nery 2021;25(5):e20210033

RESEARCH | PESQUISA

Construction of a line of care for the health care of women living with HIV[a]

Construção de uma linha de cuidado para atenção à saúde de mulheres vivendo com HIV

Construcción de una línea de cuidado para atención a la salud de mujeres viviendo con VIH

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Abstract

Objective: To build a line of care for the health care of women living with HIV. **Method:** Participatory research developed through focus groups with 11 professionals and health service managers in a city in southern Brazil. Content analysis was applied to the data collected. **Results:** Professionals and managers listed difficulties and facilities to promote access to health services for women living with HIV. They identified the decentralization of care, the articulation of services in Health Care Networks and the constitution of the line of care for women living with HIV as strategies to enhance the quality of health care for this population. **Conclusion and implications for practice:** It is considered that the line of care must be flexible, horizontal and take into consideration choices and autonomy of women in the access to health services. The construction of this product, mediated by the effective participation of professionals and managers in this research, indicates the potential for reorganization of network services.

Keywords: Comprehensive Health Care; Health Services Accessibility; HIV; Women's Health; Maternal and Child Health.

Resumo

Objetivo: Construir uma linha de cuidado para a atenção à saúde de mulheres vivendo com HIV. **Método:** Pesquisa participante desenvolvida por meio da técnica de grupo focal com 11 profissionais e gestores de serviços de saúde em município do Sul do Brasil. Os dados foram analisados a partir da análise de conteúdo. **Resultados:** Os profissionais e gestores elencaram dificuldades e facilidades para promoção do acesso das mulheres que vivem com HIV aos serviços de saúde. Identificaram a descentralização do cuidado, os serviços articulados em Redes de Atenção à Saúde e a constituição da linha de cuidado para mulheres vivendo com HIV como estratégia para potencializar a qualidade da atenção à saúde para essa população. **Conclusão e implicações para a prática:** Considera-se que a linha de cuidado deve ser flexível, horizontal e levar em consideração escolhas e autonomia das mulheres no acesso aos serviços de saúde. A construção desse produto, mediado pela participação efetiva de profissionais e gestores em pesquisa participante, indica o potencial para a reorganização dos serviços em rede.

Palavras-chave: Assistência Integral à Saúde; Acesso aos Serviços de Saúde; HIV; Saúde da Mulher; Saúde Materno-Infantil.

Resumen

Objetivo: Construir una línea de cuidado para la atención a la salud de las mujeres viviendo con VIH. **Método**: Investigación participativa desarrollada mediante la técnica de grupo focal con 11 profesionales y gestores de servicios de salud en un municipio en el Sur de Brasil. Se aplicó el análisis de contenido a los datos producidos. **Resultados**: Los profesionales y gestores enumeraron dificultades y facilidades para promoción del acceso de las mujeres que viven con el VIH a los servicios de salud. Identificaron la descentralización del cuidado, los servicios articulados en las Redes de Atención a la Salud y la constitución de la línea de atención a las mujeres viviendo con VIH como estrategias para mejorar la calidad de la atención a la salud de esta población. **Conclusión e implicaciones para la práctica**: Se considera que la línea de atención debe ser flexible, horizontal y tener en cuenta las opciones y la autonomía de las mujeres en el acceso a los servicios de salud. La construcción de este producto, mediada por la participación efectiva de profesionales y gestores en la investigación participativa, indica el potencial para la reorganización de los servicios de la red.

Palabras clave: Atención Integral de Salud; Accesibilidad a los Servicios de Salud; VIH; Salud de la Mujer; Salud Materno-Infantil.

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Submitted on 03/04/2021.
Accepted on 07/06/2021.

DOI:https://doi.org/10.1590/2177-9465-EAN-2021-0033

INTRODUCTION

Illnesses related to the human immunodeficiency virus (HIV) infection remain the leading cause of death among women of reproductive age (15-49 years) worldwide, although coverage and adherence to treatment contribute to the continued decline of AIDS-related deaths[1]. Such situation may occur during the pregnancy-puerperal period, which implies the need for changes in the organization and provision of health care for women living with HIV, especially during pregnancy[2].

The diagnosis of HIV infection in women occurs mostly during pregnancy, and implies expanding the screening of the virus through actions developed by health services based on policies such as the Stork Network (*Rede Cegonha*, in Portuguese). This network has among its strategies to ensure access to health services and coverage of rapid testing for HIV and other health problems in pregnant women and their partners in Primary Health Care (PHC), considering that it is the responsibility of health teams to carry out rapid tests during prenatal care[3,4].

In other countries, as well as in Brazil, prenatal care is a key moment for intensifying screening, since during appointments there should be space for guidance on the importance of testing and the benefits to maternal and child health regarding early diagnosis, both for the control of maternal infection and for the prevention of vertical transmission of HIV[5,6]. Therefore, the Unified Health System (UHS) is required to provide sufficient and articulated services in the Health Care Network (HCN). The operationalization of the HCN depends on the articulation between its constituent elements: defined population/health region, operational structure and logical functioning system determined by the health care model[7].

Currently, the HCN is focused on the assistance to acute conditions; however, it must be a system capable of facing the new demands that have emerged with the intensification of chronic conditions, including HIV infection[8]. For the fulfillment of the HCN, it must include the access to services as one of its pillars, in addition to ensuring that care coordination is developed. This is an attribute of the quality of care provided by health services that should be able not only to direct the user within the network, but also to coordinate the path taken between the different points of care in a timely manner[9]. Although PHC services represent the preferred gateway into the health system for people living with HIV, including pregnant women, the access to and coordination of care are still insufficient actions[10].

In a study developed in the southern region of Brazil, 74.4% of the participants who were pregnant women living with HIV mentioned PHC services as a regular source of health care. These women considered that the PHC was the service that knew them best and the one that had the greatest responsibility for their health during pregnancy. These aspects defined the degree of affiliation with the PHC service, and the users considered that the quality of care received was unsatisfactory both in primary care (6.50) and in specialized care (6.35)[11].

In order to overcome the barriers of access and communication between health services, which often constitute obstacles to the functioning of the HCN for people with HIV, the implementation of a line of care (LC) could act as an efficient strategy. LC is a strategy, in response to epidemiological needs, to articulate resources and health practices between the points of care, aiming at the timely, agile and singular referral of users for diagnosis and therapy[7].

Although this strategy is indicated in national[7] and state[12] guidelines, there is a gap in the construction of a LC that considers the local and epidemiological specificities of this illness in this population, as well as in the provision of health services. A LC adapted to the local context can help health professionals in directing actions and decision-making, considering the path of this population in the HCN and the possibilities of transfers between these services. Thus, the research question "how to develop, in a participatory way with decision makers, a strategy that promotes access to health services in the city?" culminated in the **objective** of building a LC for the health care of women living with HIV.

METHOD

Study with a qualitative approach of the participatory type. It was guided by the Knowledge-to-Action Framework[13,14], which intends that the research results go beyond the dissemination among peers, promoting the exchange of knowledge in a participatory manner through the creation and application of tools to qualify care and thus fill the gap between what is known and what is done.

The model has two components: Knowledge Creation and an Action Cycle. This research was based on the Knowledge Creation component, which includes the following phases: knowledge inquiry, developed through participant observation in health services and interviews with women living with HIV; knowledge synthesis, developed with the triangulation of research data[15] and a review study[16]; and knowledge products/tools, developed in the focus group (FG) (Figure 1). The last phase is the focus of this article.

Data production took place in a city in the central region of the southern State of Rio Grande do Sul (RS), Brazil. In this municipality, health care for women living with HIV is offered through the primary and specialized care networks. The PHC has 31 services, of which 18 are traditional Basic Health Units (BHU) and 13 are Family Health Strategy (FHS) units. The specialized service is a Federal University Hospital and a municipal outpatient clinic.

Inclusion criteria were: being a manager or health professional working in PHC or specialized services, providing care actions to women's health. Those not belonging to the municipality permanent staff or with a medical leave or other work leave during data collection were excluded. Three managers from the Municipal Health Department and eight professionals from PHC services and from the municipality's specialized service participated in the FG, including nurses, psychologists and Community Health Agents (CHA).

In the participant recruitment stage, a formal invitation was sent to the services and a meeting was scheduled to define

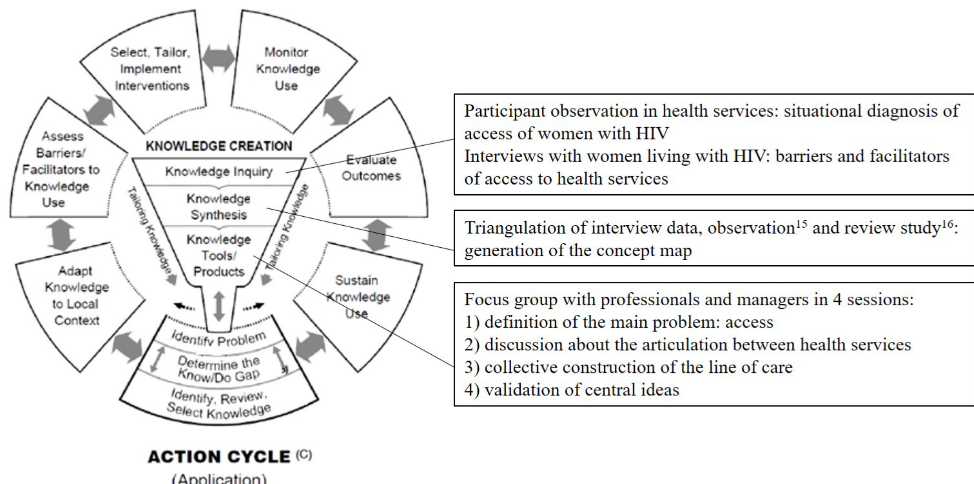

Figure 1. Participant research trajectory with professionals and managers in the development of the line of care for women living with HIV. Brazil, 2018.
Source: adapted from Vieira et al.[14].

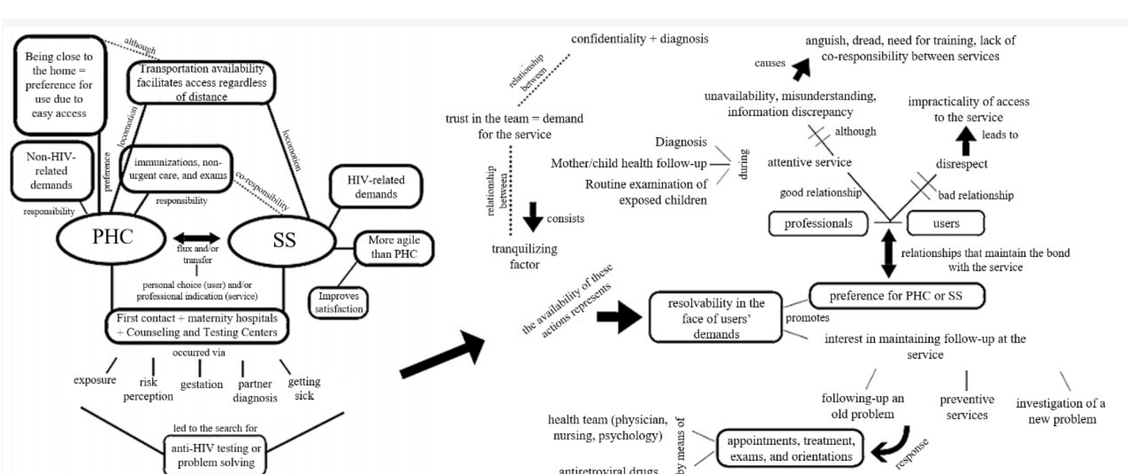

Figure 2. Concept map presented to participants to guide discussions in the 1st focus group session. Brazil, 2018. Key: PHC = primary health care services; SS = specialized services; CTC = Counseling and Testing Centers
Source: prepared by the authors, 2018.

the best strategy for the FG meetings. A list (name/contact) of interested professionals who met the inclusion criteria was created.

Data production was carried out through the FG[17] technique with four sessions, with an interval of approximately one month between them, from May to October 2018. The number of participants varied by session, and there were no refusals or withdrawals during the production of data. At the opening of each session, the participants were welcomed and the group agreed on the ethical commitment and the operationalization or dynamics of the FG, and the research objective was presented. The coordination team was composed by the moderator and two observers with experience on the topic of HIV and PHC, as well as on group technique. A field diary was used for recording observations, and the duration of each session was of approximately two hours.

In the first session, the main problem to be discussed was defined, and then the results of previous research were presented (Figure 2) in order to guide the discussions about women's access to health services in the city. The theme was defined by the group.

The debate was mediated by guiding questions (Chart 1) and a synthesis was carried out at each session. The second session was a discussion about the articulation between health services. In the third one, the LC was developed collectively. Then, in the fourth one, the central ideas were revisited and validated in the participatory discussion.

Through the interaction between researcher and professionals from the different services that provide care to women living with HIV, the FG enabled the collective construction of the research results, which are represented by the elaboration of the LC for

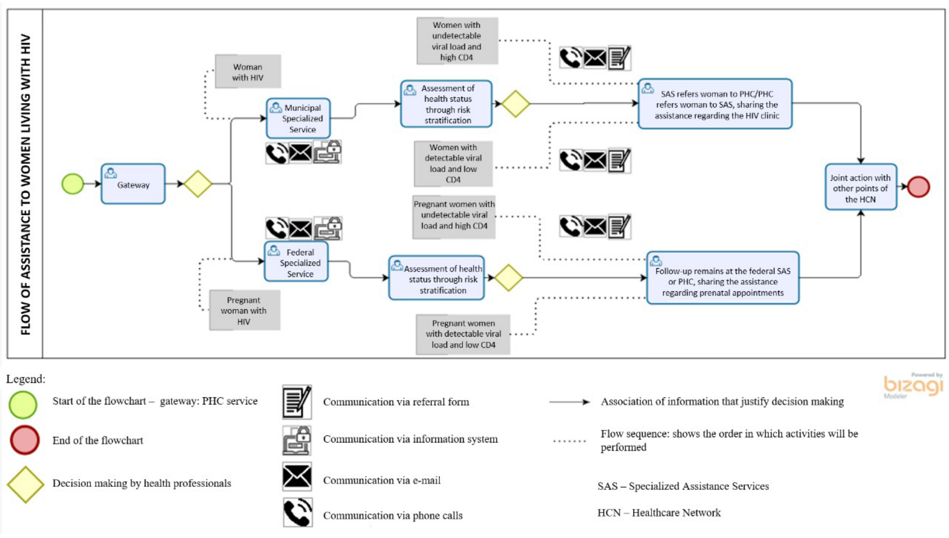

Figure 3. Line of care for women living with HIV. Brazil, 2018.
Source: prepared by the authors, 2018.

Chart 1. Triggering questions for the focus group with professionals and managers. Brazil, 2018.

SESSION	TRIGGERIING QUESTIONS FOR DEBATE
2	What do you understand by HCN? And what about LC and decentralization of care? What should a LC contemplate?
3	How to develop the LC?
4	Validation of main ideas: LC for women living with HIV.

Key: HCN = health care network; LC = line of care

women living with HIV (Figure 3), structuring the HCN for this population in the city.

Thematic content analysis[18] was developed in three phases: 1) the pre-analysis comprised the initial selection of transcribed notes from the FG sessions to constitute the corpus for analysis, as well as the pre-extraction of units of meaning; 2) exploration of the material: the previously selected units of meaning were grouped and regrouped in order to discuss the perspective of HCN for women living with HIV; 3) for data processing and interpretation, the results were revisited, deepened and discussed with the scientific literature.

The ethical precepts contained in CNS Resolution 466/12 were met. Participants read and signed the consent form. This research was approved by the Ethics Committee of the Federal University of Santa Maria, under the Certificate of Presentation for Ethical Appreciation No. 57042216.0.0000.5346, opinion 1,635,237. In order to maintain anonymity, the code FGN (Focus Group Note) was used followed by the number corresponding to the session (1-4) and the letter P (participant).

At the end of the research, an official letter from the Research Group was sent to the municipal health management with the line of care product and its production context.

RESULTS

Based on the concept map presented to the participants to guide the discussions in the first FG session (Figure 2), the group agreed that the topic of discussion would be the "access" attribute of PHC, which includes the structural element "accessibility" and the procedural element "use"[9]. It was also discussed what could be done/what actions could be carried out to promote accessibility and use, and the difficulties and facilities to promote access pointed out by professionals were listed.

> *[...] They [women living with HIV] feel at ease, welcomed [in the PHC service]. (FGN1 P1)*

> *[...] The issue of access is quite related to welcoming. (FGN1 P2)*

> *[...] It is important for the specialized service to give them this guidance [that the woman should return for routine follow-up in the PHC] there [in the specialized service during pregnancy]. (FGN1 P7)*

> *And we're only talking about [the city where the research took place], in every city we see this difficulty that still exists of losing the bond [with PHC services]. (FGN1 P2)*

> *[...] I think there is a lack of training for [health] professionals who didn't assist [women with HIV] in these units [PHC services]. They don't have to refer everything to specialized assistance. (FGN2 P9)*

The discussions in the second session were based on the presentation of a synthesis of the previous meeting in a slide show and involved questions about HCN, LC and decentralization of care.

[...] I kept thinking about the referral and counter-referral. How good it is when we receive the counter-referral, everything all right, from the pregnant women, when they have the baby. (FGN2P7)

[...] With the protocols, you know that in any place [health service] they will be assisted in the same way. [...] in the prenatal training we had, I saw that [...] the way I assist [at the PHC service] is the same way they assist [at the specialized service]. They also use the Ministry [of Health] protocols, there is no mystery, everyone will assist in the same way as it should be done. (FGN2 P7)

[...] I think they [professionals from different health services] need to speak the same language, it's one of the things I think are important [...] [health services] keeping contact, having a dialogue. (FGN2 P5)

From the discussions of the second session, the participants suggested that the moderator seek articulation with the city management and both the municipal and federal services to propose the construction of a LC for women living with HIV. To this end, an outline of this proposal was prepared. The objective of the third session was thus to discuss with professionals from the specialized and PHC services and managers about how to develop the LC.

[...] to articulate the services, everyone to sit together and manage to define strategies, working together. All levels of assistance, in order to build, organize this network. It's not management alone, it's not specialized service, it's not basic care, it's everyone. And I think it's possible. [...] I think this is what was lost over time, sitting together, talking, dialoguing, being able to discuss, the flows, how to organize everything, in order to improve the service. (FGN1 P2)

[...] In the federal specialized service, it's not the same [communication] system as ours [from PHC], so we [PHC health professionals] have no way of knowing [the outcomes of users in the federal Specialized HIV Assistance Services (SAS)]. (FGN3 P4)

[...] The HIV [pregnant women] who had, from the Stork Network, from the prenatal technical note, only HIV, if they had no other problem, should be assisted by Primary Care, with specialized follow-up at Casa Treze. But there isn't such structure and everything is going to the [federal SAS]. (FGN4 P3)

[...] The pregnant woman goes to the [federal specialized service], but goes back to the [PHC] unit. In a month, she will have twice as many appointments, [she will visit] both places. (FGN4 P4)

In the fourth session, the final version of the LC for women living with HIV was presented to the group for validation (Figure 3).

[...] [It is necessary] for [health] services to talk. (FGN2 P7)

[...] The federal specialized service has to give the unit a feedback [PHC service] on those who haven't been showing up [...] including prenatal appointments, others that have scheduled it, those users who aren't picking up medication. (FGN2 P3)

[...] I don't think it's the word "referral" [in the line of care], I think it's "shared". She [woman with HIV] goes back to primary care, but it [health care] is shared. She visits both. [...] An assistance shared with Primary Care [and SAS]. (FGN4 P4)

[...] In Primary Care, if the viral load is detectable or undetectable, she [woman] is positive, she will be shared with the [municipal SAS]. And the pregnant woman will be shared with the [federal SAS] [...] whether pregnant or non-pregnant, regardless of whether the viral load is detectable or undetectable, her reference will always be Primary Care. (FGN4 P4)

DISCUSSION

One of the first strategies to decentralize assistance to people living with HIV was the diagnosis of HIV infection in PHC, making it the preferred gateway for rapid testing, in order to expand possibilities of access. However, by expanding the range of services qualified to perform anti-HIV testing, issues such as confidentiality and disclosure of diagnosis can generate conflicts between professionals and users, which may imply in the fragility of the relationship with the user[19-21].

In order to minimize such fragility, we understand that it is necessary to rethink the form of organization and management of work in health services, which could involve the discussion and implementation of a strategy such as the LC, with a view to qualifying care for people living with HIV, as well as include it in the continued training and education of health professionals. Additionally, such fragility is due to the fact that the assistance provided to this population is often based on the knowledge that professionals acquire from their work experience, through informal learning and the exchange of information with other professionals in the team[22].

Considering assistance in PHC, it is known that this point of care has potential for the assistance of users living with HIV as well as of other chronic health conditions, and covers everything from diagnosis to treatment. Therefore, there is a need for investment beyond soft technologies, incorporating diagnostic and therapeutic technologies, as well as the articulation of PHC with the specialized service[10,23], thus configuring the LC as a strategy for guiding users at the health care points.

Depending on the assistance received, the choice and preference for continued access to the health service represent important quality indicators, as they reflect the degree of service performance and of satisfaction from those who access it.[24] Moreover,

because health professionals represent the secondary support network for these women, welcoming and bonding can contribute to this choice[19,25]. In addition, the care provided to people living with HIV also presupposes considering the different health needs of this population. Therefore, we must consider the work with the LC as a guide with the shared involvement of different access points, especially PHC with support from specialized services[26].

This implies cooperation between health services, a characteristic related to comprehensive health care, and refers to the interdependence of points, which are the services. In other words, it is understood that no service has, in isolation, all the resources and skills to solve the diversity of health problems of the population that accesses a service network[27].

To that end, the integration between services will enable the cooperative and shared engagement of health actions, and this way of reorganizing health care systems presents itself as a strategy for the qualification of care. From this perspective of care for people living with HIV, the SAS represents a fundamental point, but not the only one. Thus, the LC design includes new health services and strategies, such as the support of specialized services for PHC and shared care between SAS and PHC, ensuring greater access for users to the health system[12-28].

Therefore, communication across multiple sectors will be essential for breaking with disarticulation, and for PHC, especially the FHS, to be able to take co-responsibility for the care of this population. This implies, among other attributions, knowing the population living with HIV assigned to the unit, taking responsibility for the care and monitoring the treatment. Thus, the specialized service needs to promote and guide the use of PHC services, considering that the degree of integration between the services is decisive for guaranteeing access[29].

Regarding national recommendations for maternal and child health care, the Stork Network is committed to the detection of HIV and to Antiretroviral Therapy (ART) during pregnancy, childbirth, puerperium and for children exposed to HIV. However, there are no guidelines that specifically organize a LC for women living with HIV, nor during pregnancy. The establishment of service flows between the care points can help pregnant women living with HIV understand the need for shared monitoring[30] between the points that make up the LC.

At the state level, the State Department of Health of RS, through the State Coordination of Sexually Transmitted Infections (STIs) and AIDS, created the "Line of care for people living with HIV/AIDS (PLHA) and other STIs". With this document, they pointed out general guidelines and recommendations in order to support the definition of attributions between the points of care, seeking the sharing of care between PHC, Testing and Counseling Centers (TCC), Outpatient Clinics and Specialized Assistance Services for HIV/ AIDS (SAS) as an attempt to provide a more adequate response to the epidemic[12].

However, pregnant women living with HIV were not included in the stratification, since the assistance to this population is not conditioned to clinical criteria, that is, these are specific situations that need monitoring both in PHC and by the specialized service, regardless of the severity of the illness. This reveals the importance of thinking about coordinated and consistent actions, such as the implementation of the LC, with the reality of services based on local possibilities and considering the fundamental participation of health professionals working in these services, as well as the managers who coordinate the actions aimed at this population[12].

With regard to PHC, despite the potential to assist pregnant women living with HIV, the lack of human resources makes access to prenatal care unfeasible[25]. We believe that, even if there is an incentive for this population to jointly access PHC and specialized services, the incapacity of PHC services to meet the health demands makes these women connect themselves to other services, principally the specialized ones[31], weakening PHC as an important point of the LC in the health care of women living with HIV. In addition, it is considered relevant that the referral flow between services be flexible, considering the user's experience and perception on the recommended service. Thus, it will be up to the user to decide which location will be the most suitable for accessing health care[19].

In view of this, during the pregnancy-puerperal period, PHC services must be responsible for providing actions such as counseling, early diagnosis of infections, appropriate treatment, educational actions, treatment guidelines and recommendations for the prevention of vertical transmission, referral of cases not sensitive to this point of care and coordination of the network[32]. Considering the relevance of cooperation between health services and the positive impact of this articulation strategy, the study participants built the LC for women living with HIV with the objective of promoting the access and continuity of care for this population to the health services that are part of the HCN in the city.

This initiative revealed the existence of barriers to access, lack of coordination of care and of the establishment of formal and effective flows. Such barriers consist, for example, in the absence of electronic medical records that integrate and share clinical information between services[33].

In order to overcome these challenges, we understand the need for the different points of health care to be articulated, favoring teamwork between services. However, there is evidence, as a study that addressed the social network of families of children with chronic conditions, on the weakness in the transfer system between the different technological densities, especially to PHC, which reveals the disarticulation and the absence of a network established in the municipalities that can overcome this operational failure[34]. Moreover, there is evidence that the vertical relationship between health professionals and users persists, perceived by the lack of listening and guidance on the access flow, as well as a long waiting time for the user in specialized care, which leads to a search for different means of access to reference services[35].

In addition, there is a need for qualification of PHC professionals to act as care coordinators, as well as the improvement of the health system with regard to the operationalization of integrated and articulated HCNs. For this to be possible, PHC needs to articulate with the different points of care, ensure the preferred gateway and, therefore, be effective for the population's health

needs[31]. In this context, the LC represents an organizational tool that can reduce unnecessary referrals to specialized care, correct failures in information and communication technologies, and replace the use of informal communication methods among professionals.

The limitation of the research is the need to involve more professionals from management and specialized services, since these were less represented in group meetings.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Participants in this study discussed the potential for articulation between health services and defined a path in the health system for women living with HIV, as a line of care. This indicated the need for formal instruments to ensure actions between different points of care. The opportunity for decision-making in clinical practice by professionals in a shared and joint way is envisioned. We emphasize the premise that this line must be flexible and take into account the perspective of users.

The construction of this product, mediated by the effective contribution of professionals and managers in participatory research, indicates the potential for the reorganization of network services. The co-responsibility and commitment of municipal management is essential, since the implementation involves structural changes and strengthening of health care systems.

ACKNOWLEDGMENTS

The authors thank PhD Jaqueline Arboit and PhD student Jacqueline Silveira de Quadros, for their support in the development of the focus group, as participant-type observers, in the field stage of data production of this research.

FINANCING

The present work was carried out with the support of the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (Coordination for the Improvement of Higher Education Personnel) – Brazil (CAPES) – Financing Code 001, doctoral scholarship granted to Raquel Einloft Kleinubing.

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Data analysis. Raquel Einloft Kleinubing. Stela Maris de Mello Padoin. Cristiane Cardoso de Paula. Tassiane Ferreira Langendorf.

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Approval of the final version of the article. Raquel Einloft Kleinubing. Tassiane Ferreira Langendorf. Stela Maris de Mello Padoin. Cristiane Cardoso de Paula.

Responsibility for all aspects of the content and integrity of the published article. Raquel Einloft Kleinubing. Tassiane Ferreira Langendorf. Stela Maris de Mello Padoin. Cristiane Cardoso de Paula.

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[a] Article extracted from the doctoral thesis authored by Raquel Einloft Kleinubing, defended in 2018, Post-Graduate Program in Nursing, Federal University of Santa Maria, under the advisory of Cristiane Cardoso de Paula. Full text available at: https://repositorio.ufsm.br/bitstream/handle/1/18528/TES_PPGENFERMAGEM_2018_KLEINUBING_RAQUEL.pdf?sequence=1&isAllowed=y