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Line of care for children and adolescents living with HIV: participatory research with professionals and managers[a]

Linha de cuidado para crianças e adolescentes vivendo com HIV: pesquisa participante com profissionais e gestores

Línea de atención para niños y adolescentes con VIH: investigación participativa con profesionales y gerentes

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ABSTRACT

Objective: To build a network for the health care of children and adolescents living with HIV. **Method:** Participatory research developed through the focus group technique with 23 professionals and managers of the primary and specialized care services, in a city in the south of Brazil. The empirical data was subjected to thematic content analysis. **Results:** The fact that health care provided to this population is mostly performed in specialized services fostered the discussion about the conceptual, structural and social aspects of the theme. It was agreed that the assistance should be performed centered on the user and shared among the services, considering the qualifying attributes of care. The assignments of each service, the articulations and the operationalization were defined for integration among the network points. The validation of the main ideas culminated in the construction of a care network for children and adolescents living with HIV. **Conclusion and implications for practice:** The implementation of this product, adapted to the municipalities' daily assistance practice, requires strategic actions for integrating the points of care and for qualifying health care for this population.

Keywords: Comprehensive Health Care; Child Health; Adolescent Health; HIV; Acquired immunodeficiency syndrome.

RESUMO

Objetivo: Construir uma linha de cuidado para a atenção à saúde às crianças e adolescentes com HIV. **Método:** Pesquisa participante desenvolvida por meio da técnica de grupo focal com 23 profissionais e gestores da atenção primária e especializada, em município do Sul do Brasil. O material empírico foi submetido à análise de conteúdo temática. **Resultados:** O fato de a atenção à saúde para esta população ser realizada, majoritariamente, nos serviços especializados fomentou a discussão de aspectos conceituais, estruturais e sociais acerca da temática. Pactuou-se como deve ser realizada a atenção centrada no usuário e compartilhada entre os serviços, considerando os atributos qualificadores da atenção. As atribuições de cada serviço, as articulações e a operacionalização foram definidas para a integração entre os pontos da rede. A validação das ideias centrais culminou com a construção da linha de cuidado para crianças e adolescentes vivendo com HIV. **Conclusão e implicações para a prática:** A implantação desse produto adaptado ao cotidiano assistencial dos municípios requer ações estratégicas para a integração dos pontos de atenção e para qualificação da atenção à saúde dessa população.

Palavras-chave: Assistência Integral à Saúde; Saúde da Criança; Saúde do Adolescente; HIV; Síndrome da Imunodeficiência Adquirida.

RESUMEN

Objetivo: Construir una línea de cuidado para la atención a la salud de niños y adolecentes con VIH. **Método:** Investigación participativa desarrollada a través de la técnica de grupos focales con 23 profesionales y gestores de la atención primaria y especializada, en un municipio del Sur del Brasil. El material empírico se sometió a un análisis de contenido temático. **Resultados:** El hecho de que la atención de la salud de esta población realizarse principalmente en servicios especializados, fomentó la discusión sobre los aspectos conceptuales, estructurales y sociales del tema. Se ha definido como debe realizarse la atención centrada en el usuario y compartida entre los servicios, considerando los atributos calificativos de la atención. Los atributos de cada servicio, las articulaciones y las operacionalizaciones se definieron para la integración entre los puntos de la red. La validación de las ideas centrales culminó con la construcción de la línea de cuidado para niños y adolescentes que viven con VIH. **Conclusión e implicaciones para la práctica:** La implantación de este producto, adaptado a la asistencia diaria de los municipios exige acciones estratégicas para la integración de los puntos de atención y para la calificación de la atención sanitaria de esta población.

Palabras clave: Atención Integral de Salud; Salud de los niños; Salud del adolescente; VIH; Síndrome de Inmunodeficiencia Adquirida

INTRODUCTION

The report in response to the 2030 Agenda, regarding the third Sustainable Development Goal, shows progress in improving the health of millions of people, reducing maternal and child mortality, and combating communicable diseases.[1] However, among the universal human immunodeficiency virus (HIV) infection control targets, one points to a decline below the levels needed to meet the Joint United Nations Programme on HIV/AIDS (UNAIDS) Global Strategy 2016-2021.[2]

The UNAIDS Action Plan includes the following strategic lines: expanded and equitable access to services for HIV infection control, with integrity and quality. Ensuring such expanded access requires adapting the model of service delivery to the needs of priority vulnerable populations, based on local conditions of the epidemic. Still regarding service delivery, it should be adapted based on person-centered and community-based approaches, as well as on integrated health service networks, aiming at improving maternal and child health.[3]

In order to fulfill these goals and the action plan, the Brazilian Unified Health System (SUS), supported by the Health Care Networks (HCN) model, proposed the decentralization of clinical follow-up of the Acquired Immunodeficiency Syndrome from specialized services.[4,5] The decentralization process is enhanced by co-responsibility and not by the transfer of responsibilities,[6] and demands the integration of the actions offered in the services (horizontal) and among the services (vertical). This process, besides being an emergency, is a challenge for the organization of services and the functioning of teams.[7]

To address maternal and child health, more specifically the health of children and adolescents, it is essential to recognize the relevance of co-responsibility among services for antenatal HIV testing and timely prophylaxis in order to reduce the incidence of vertical transmission. It is also essential to monitor the early treatment of infected children and adherence to treatment so that their effectiveness increases life expectancy, characterizing the chronic condition of the infection. Therefore, the population of HIV-infected children and adolescents, which needs growth and development follow-up, has expanded the request for a permanent routine of clinical and laboratory follow-up and of adherence to drug treatment, which happens mostly in specialized services.[8]

The integration between services becomes a strategy to qualify health care[9] and can be established through a flow of children in the health system. It is essential to strengthen the capacity of communication between services and to define the attributions of each service (HCN point) in order to guarantee access, to fully and longitudinally meet the demands of this population, and to coordinate referrals.[10] This study aimed to build a line of care for the health care of children and adolescents living with HIV.

METHOD

A participatory research[11] mediated by the Focus Group (FG) technique.[12] This technique provided a discussion of the participants' opinions, an exchange of experiences about the care of children and adolescents living with HIV and the development of strategies for solving the practice problems reported by the group in the sessions.

The scenarios for data collection were the Primary Health Care (PHC) services, 18 Basic Health Units (BHU) and 13 Family Health Strategies (FHS) and 2 specialized services (SS) (municipal and federal) in the city of the central region of Rio Grande do Sul. At the stage of recruitment of participants, a formal invitation was sent to the services and some were visited for the definition of the best strategy for recruitment. A list (name/contact) was created with the interested professionals who met the inclusion criteria: belonging to the permanent staff and not being away from work. There was no delimitation of length of experience and/or professional category.

The field stage was developed in four group sessions, in afternoon hours, central location, with adequate structure, from May to June 2015. The sessions were conducted by a moderator and two observers with experience in the FG technique and the HIV theme, lasted an average of two hours and were recorded. The discussions were guided by questions related to the objective of each session: Which actions are developed in your service for the health care of children and adolescents living with HIV? And which actions could be developed in your service? What is the responsibility of my health service in assisting this population? How can assistance to this population be considered in the municipality? The validation of the central ideas took place from the presentation of the synthesis of all sessions to the participants and was centered on the line of care (LC) for children and adolescents living with HIV, a product of the collective construction of the FG.

The database consisted of the transcripts and records of field journals submitted to content analysis.[13] This project was approved by the Research Ethics Committee (opinion No. 924.646/2014). For the presentation of results, codifications were used: P for Participants; FHS, BHU or SS for indication of the service; and FG-S1 for indication of the FG session.

RESULTS

The participants were 23 professionals, 11 from FHS, four from BHU, two from the municipal SS, four from the federal SS and two managers belonging to the Municipal Health Secretariat (SMS), who held positions of coordination of PHC and HIV/AIDS Policy. Most professionals had up to five years of experience in their service, and their education level was undergraduate and graduate. These data were collected based on the personal presentation of each professional during the FG sessions.

In the group discussion, the participants understood that the organization of health care for this population passes through the following elements: conceptual, structural and social (Chart 1). The elements were synthesized from the analysis of the content of the statements recorded in the FGs.

Among the assistance conceptual elements, the participants discussed the understanding that the infection is now considered a chronic health condition that can be monitored in PHC services.

Chart 1. Synoptic chart of discussions with professionals and managers about health care for children and adolescents living with HIV. Brazil, 2015.

ELEMENTS		
CONCEPTUAL		
Chronic health condition of the person with HIV; Decentralization of health care from the specialized service; PHC co-responsibility and specialized service in this assistance; Territorialism and affiliation of the specific population to the PHC service.		
STRUCTURAL		
Management	**Physical**	**Personnel**
Overcrowding; Local and regional demand for assistance; Transfers between services.	Restricted.	Shortage of specialist professionals; Lack of training on the subject.
SOCIAL		
Stigma; Prejudice; Professional ethics.		

Source: Focus Group, own elaboration.

> *[...] Today we have to understand that HIV is a chronic disease like any other. And that before, we didn't want the diabetics to have PHC either [...] we know that this patient (with HIV) is ours, we need to welcome them, we need to treat them, we need to monitor them [...] [P7/SS FG-S3]*

For the participants, due to the complex chronic condition, the assistance to the health of children and adolescents living with HIV is concentrated in specialized services or hospital services. This results in the centralized practice of professionals, which meets the users' desires. The participants discussed how much infected children and adolescents need to be monitored by the infectious disease specialist, and another conceptual element emerged: the decentralization of health care from the specialized service.

> *[...] Most of their assistance is provided in specialized services and not in PHC* [P15/FHS FG-S1].
>
> *[...] we do tests and counselling and all patients come for assistance in the specialized service* [P20/SS FG-S2].
>
> *[...] When the children came with their vaccination cards and it said: "maintain vaccination in the specialized service", they took over and we did not question it* [P10/FHS FG-S2].
>
> *[...] it would be interesting for people with HIV to have basic health units as references, and she (the user) told me: what does the doctor at the health clinic have to offer me? I need an infectious disease specialist* [P8/FHS FG-S1].
>
> *[...] Actually, the adolescent does everything at the specialized service* [P21/SS FG-S1].

Another result of this research was the recognition of the element of co-responsibility between the PHC services and the specialized service by the professionals. This indicates the need to establish changes in the organization of these services.

> *[...] it seems as if HIV patients are properties of the specialized service, especially children. This has created a culture we need to change* [P8/FHS FG-S1].
>
> *[...] She [FHS doctor] told me that she had never assisted a child with HIV, that is, they are or should be assisted also in basic health units [...]* [P1/SS FG-S1].

This study indicates the existence of barriers to the development of such co-responsibility, which involves the concept of territorialization and user adscription. This result is present in the report of PHC professionals who revealed they were unaware of the registration of children and adolescents with HIV assigned to the territory of their health service.

> *[...] In our area, we think we do, but we don't know who these people [with HIV] are in our territory* [P8/FHS FG-S1*].*
>
> *[...] Honestly, I can't tell who are the children [with HIV] in this FHS* [P17/FHS FG-S1].

With regard to the analysis of the structural elements, information have emerged from the management, physical and personnel spheres. The management structural element is the overcrowding in the specialized service and the assistance of local and regional scope. This is due to the reception of other municipalities and other Health Coordination Offices of the region.

> *[...] we receive patients who come from other municipalities, not only the 4th coordination office, and we have to assist them* [P1/SS FG-S1].

The professionals reported difficulties in the transfer of users between specialized and PHC services, including the lack of a single medical record and a computerized communication system. In the child population, professionals recognize the challenge of transferring the pediatric infectious disease service to that of adults.

> *[...] If you send the child to another service, you don't know if they went, if they arrived and what the response was* [P1/SS FG-S2].
>
> *[...] And, many times, we don't even have the information that the patient is HIV, because it is not computerized, it doesn't have the reference of the service used, we don't know if the patient is stable, so we even need to ask for the tests* [P2/FHS FG-S2].
>
> *[...] the specialized service somewhat manages to contemplate pediatric care [...] adolescents are becoming adults, and there are problems in scheduling appointments, the schedule accepts up to 20 years-old [...] it would be very good to have a doctor responsible for the assistance in this transition [...] maybe it is time to transfer them to the network* [P1/SS FG-S1].

The issue of physical structure refers to the limited space in the service, and the personnel issue refers to the shortage of pediatric infectious disease professionals and professionals from other specialties in the PHC staff, in addition to the lack of training on the subject for the assistance to this specific population.

> *[...] the structural limit also does not allow the service to be expanded* [P21/SS FG-S1].
>
> *[...] the greatest difficulties are physical and personnel structures [...]* [P20/SS FG-S1].
>
> *[...] everything arrives fot them [PHC professionals] and has to be absorbed by a small team of a general practitioner, a nurse and a technician [...]* [P7/SS FG-S2]
>
> *[...] There are only seventeen pediatric infectious disease physicians for the entire state* [P1/SS FG-S1].
>
> *[...] most of the top professionals need training* [P7/SS FG-S2]

In addition, the prejudice from both users and professionals and the lack of ethics among professionals who do not respect the right to confidentiality represented, for the participants, barriers to the access and to the link with the PHC service.

> *[...] They don't want to reveal that they are HIV, they are afraid of being discriminated against in their community* [P8/FHS FG-S1*].*
>
> *[...] The basic network staff has this notion that they [children's family members] don't want to be assisted in the basic network, it is not only because they don't trust the professional, they are afraid of prejudice* [P7/SS FG-S2].
>
> *[...] Some services welcome them and others don't, for various reasons, including prejudice from the health professionals* [P20/SS FG-S2].
>
> *[...] the biggest problem with prejudice is that it causes non-adherence to treatment* [P1/SS FG-S3].

The participants indicated the discussion on the attributions of services in the constitution of a HCN and the articulation and operationalization of health care (Chart 2). Finally, based on the synthesis of central ideas and the joint validation of these ideas at the FG, the participants expressed the agreement between the synthesis and the ideas discussed. Thus, the proposal of a LC for children and adolescents living with HIV took place.

It was agreed that the assistance must be user-centered, shared between the services and carried out in the perspective of building the HCN, considering the quality of assistance from the access, longitudinally, comprehensiveness and coordination attributes. Then, the professionals defined the knots between the HCN points. The first knot would consist in defining attributions between levels of care, aiming at sharing assistance, as a way to ensure a more comprehensive response to the epidemic. Concerning specialized services: to provide diagnosis, counseling, assessment and treatment. The PHC was defined as the responsible for welcoming users, performing its role of care manager and coordinator, and developing assistance through prevention, promotion and health education. This led to the choice of risk stratification as an initial strategy for a shared assistance. Such stratification considered the levels of CD4, which is the cluster of differentials 4, and of VL, which are biological markers for the analysis of the infection clinical picture.

The second knot consisted in the articulation between the services, organizing the demand according to age. The third knot consisted in the operationalization of actions: transfers of users between points, telephone contact for the coordination of care, active search and monitoring the population assigned, registration of users in the services, a reference professional in the services and flow in the network. Finally, the FG participants illustrated the LC (Figure 1).

DISCUSSION

The discussion on the chronic HIV condition was based on increasing the survival of infected children and adolescents and on expanding care, and the routine of monitoring the infection was added to the usual development care on a permanent basis.[8] However, the organization of the SUS, the functioning of the services and the assistance developed by professionals still focuses on assistance to acute health conditions.

We recognize that there is an indication to organize the health system towards the assistance to chronic conditions, without overlooking other demands. Consequently, it leads to challenges for health professionals and services supported by public policies such as the HCN.[14,15] To this end, it is essential to promote the permanent education of health professionals and

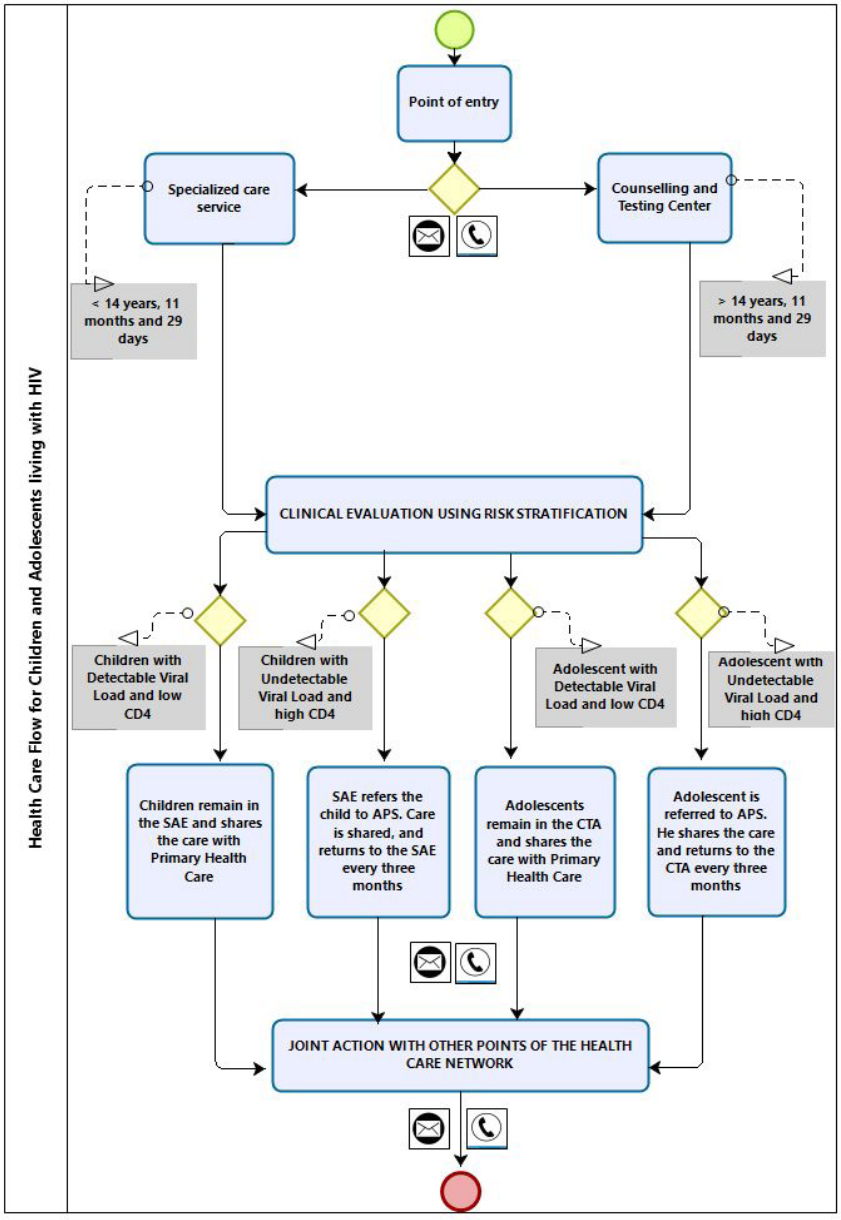
Chart 2. Attributions of each service in the constitution of the Health Care Network for children and adolescents with HIV. Brazil, 2015

ATTRIBUTION		
Establishment of functions (assignments) between the points of assistance.		
PHC (FHS/BHU)	**SPECIALIZED SERVICE**	
	Municipal (CTC)	**Federal (UH)**
Combating prejudice; Raising awareness among the population regarding prevention, promotion, diagnosis and assistance; Carrying out counseling for testing and adherence to ART.		
	Offering psychological and nutritional treatment; Laboratory tests.	
Guaranteeing access to the most vulnerable populations; Performing rapid testing; Promoting social inclusion.		
Performing active search; Performing home visits; Establishing partnership with schools; Developing health groups; Assisting family planning; Assisting childcare; Treating common diseases of age; Performing immunizations; Offering routine clinical appointments; Offering dental treatment.	Treating adolescents with low CD4 and high VL; Offering routine STI appointments; Treating STIs; Trainning the team for testing.	Treating children with low CD4 and high VL; Dispensation of medication; Treating opportunistic infections.
ARTICULATION		
Organizing appointments by age: >14 years 11 months and 29 days old in HU and <14 years 11 months and 29 days old in CTC; Conducting gradual transition of the adolescent to the CTC; Establishing risk stratification to share the assistance between the points: low CD4 and high VL remain in the specialized service, and childcare/adolescence health care is shared with the PHC. For high CD4 and undetectable viral load, the specialized service will transfer the assistance to PHC, with quarterly assessment at the HIV clinic.		
OPERATIONS		
Establishing the transfer of users between health care points; Making telephone contact between the points for the coordination of care; Performing active search and monitoring children/adolescents with HIV in the PHC territory; Registering users at health care points; Establishing a reference professional in the services; Implementing a transfer tool between the points, with the user's history.		
VALIDATION OF KEY IDEAS		
Line of Care for Children and Adolescents Living with HIV		

Key: PHC = Primary Health Care; CD4 = cluster of differentiation; CTC = Counseling and Testing Center; VL = Viral Load; FHS = Family Health Strategies; HIV = human immunodeficiency virus; UH = University Hospital; STI = Sexually Transmitted Infection; ART = Antiretroviral Therapy; BHU = Basic Health Units.
Source: Focal Group, own elaboration.

to encourage multidisciplinary work with proper monitoring of processes and results, which can be mediated through the use of information technologies.

The scientific evidence shows how the health monitoring of children and adolescents living with HIV in specialized services or hospitals has been happening. In the health care for this population, the biologicist and doctor-centric approach predominates, with a focus on clinical control and treatment,[7,16] whilst in the PHC services there is an emphasis on counseling, health education and distribution of prevention materials. However, there is a scarcity of actions for people living with HIV.[4] In addition, there is the barrier of a disarticulated PHC,[17] therefore we recognize that the actions for this population are developed in a fragmented manner, with advances in the assistance for clinical emergencies resulting from



Key:

Beginning of the flow – entry point – services such as: Primary Health Care, Specialized Care Service, Counselling and Testing Center, Hospitals, Prompt Services, Prompt Service Units.

Decision making by health professionals

End of flow

Association of information that justify decision-making

Sequence flow: show the order in which the activities will be carried out

Paths between the points of the Health Care Network. Communication should be made by telephone and writing, via e-mail, between health professionals.

Figure 1. Line of care for children and adolescents living with HIV. Brazil, 2015.
Source: elaborated by the authors, 2020.

the infection, especially by the link with the specialized service. The latter is another conceptual element discussed among the participants of the present study.

The fragmentation in the organization of health care intensifies the search for services of higher technological density, which maintains the lack of recognition of the PHC as a source of first contact, in addition to the family's perception of the lack of preparation of professionals to deal with the chronic condition and the lack of resolution in PHC. This further weakens the bond, generates dissatisfaction and increases the discredit of PHC services.[18]

It is understood that the establishment of links between users and professionals presupposes the access to the PHC service and continuous contact, which results in trust. Furthermore, the development of resolving actions can have repercussions on the maintenance of PHC as a regular source of assistance and can even reduce the use of specialized services.

It is important to emphasize that the choice of the regular source of assistance is given by the easy access to the specialized service and by the inefficient system of transferring users between the HCN points.[7] However, the strengthening of the SUS implies the coordination of the flow of users and the establishment of co-responsibility among professionals. In order to obtain resolute actions in comprehensive health care, it is recommended that specialized services work jointly with the PHC[6,16] to promote, monitor and support treatment retention and adherence.[5,15]

In order to minimize fragmentation[18] and characterize a strengthened HCN,[9] health care must be reorganized through strategic actions that promote access and enhance the connection of the users to health services. Such reorganization should be operationalized through reception guidelines and built collectively among the services. This is the point that converges with the National Humanization Policy of SUS,[19] for which welcoming means maintaining the relationship between teams and services based on the analysis of work processes.

However, the professionals from the PHC services who participated in this study did not identify and do not assist children and adolescents living with HIV in their territory. Sometimes, they are also unaware of the actions performed by the specialized HIV service. These are barriers to the coordination of health care for these users. The coverage is intended to be carried out through FHS; however, nationally, the distribution between traditional FHSs and BHUs is still heterogeneous.[20]

It can be inferred that the professionals from PHC do not know these children in their territory because the families do not access it or do not reveal the diagnosis. We agree with the effort to establish multi-territories for the assistance to this population, associated to the qualification of the professionals' practices, with the preservation of confidentiality of information and respect for human rights. In addition, we understand that it is essential to respect the families' preferential point of access, due to the right to confidentiality of the diagnosis and to protection against prejudice and discrimination.

Public policies, on their own, presuppose the territoriality and affiliation of users. In addition, they ensure the link and easy access to the health unit by users.[15] It is necessary both to employ efforts to expand FHS coverage and to reflect on this assumption, considering the social and subjective aspects associated to the HIV epidemic.

The HCN has, as a basis of its processes, the population under its responsibility, according to its specific needs. However, territorial proximity can both help and hinder access, and the search for health care can take place outside the local community. The extraterritorial nature of the bond, based on relationships of trust and acceptance, must be considered. Therefore, there is the possibility of a multi-territorial perspective, offering diverse possibilities of entry points for access.[21]

The disruption of the imposition of access to the PHC service, established by territorialism according to spatial criteria, is corroborated. However, we consider the relational aspect as an enhancer of longitudinality, due to the family's preference and with the flow of information, communications and people between the services for the coordination of care.

However, when breaking with the territorial imposition, there is an overcrowded specialized service. This condition converges to the experiences of other cities in situations of care for 95% of the population living with HIV.[22] This is often due to the demand for resources, such as a team of professionals with experience and structure in the service, as well as technology for clinical and laboratory monitoring.[23]

There is also a lack of definition of the LC and of transfer flows between the services,[24] which indicates the need for articulation between the HCN points. Transfers are considered unsatisfactory/insufficient, especially regarding the lack of definition on which points are indicated for referring the results of the appointments between the teams.[25]

This leads to the unsatisfactory evaluation of the coordination attribute - integration of care, according to the families of children with chronic conditions.[26] We have learned that, in order to preserve the continuity of care at any point of assistance, regardless of technological density, it is necessary to make the medical record available, electronically or not, in addition to matrix support.

The professionals participating in the FG reported that one of the situations contributing to keeping a service centered on specialities is the limit of physical structure and personnel. The limited physical structure is reported in care services for people living with HIV, in which the reduced space hinders privacy and comfort. The specialized services are overloaded due to the centrality of care, as well as due to the lack of human resources and adequate infrastructure.[5,26,27]

The professionals' work overload has passed through the context of specialized services and FHS teams also due to having to take responsibility for another area of action, which

requires a reconfiguration of the work process. In addition, there are incomplete teams in BHUs, restricting access to the population. These aspects make it difficult to connect, refer, and take responsibility for the service over the territory in which it operates, which are considered PHC qualifiers.[6]

In services with higher technological density, the scarcity of specialists is one of the difficulties for the development of an assistance based on attributes of comprehensiveness and coordination.[6,28] Regarding PHC services, a high staff turnover hampers longitudinality, in addition to requiring that more public resources be spent on hiring, training and preparing new professionals.[29] Nevertheless, there is a lack of consensus among PHC professionals about this population belonging to their field of action. This reappears in issues that, theoretically, should have been overcome, such as the implementation of the rapid test.[30]

The difficulty of affiliation to PHC for people living with HIV is justified by the lack of professional preparation to develop assistance to this population and by the stigma.[4,24,31] There is a need for awareness, monitoring and qualification. These recurring situations demand a permanent education as an inducer of changes in the work processes, in order to involve the components of the various points of the HCN[15] in the responsibilities and to achieve sharing, instead of purely transferring responsibilities in the decentralization process. This involves, in addition to the commitment from professionals, the structural conditions for the process to be developed.[6]

We understand that, in order to promote the integration of services, it is necessary for the team to establish the objective of a collaborative care, strengthened by the capacity of communication. In addition, it is necessary to define the attribution of the actions of each service, the commitment from the government regarding a policy and legislation, including those collaborators coming from sectors not related to health. However, such perspectives imply the development of continuous education for the qualification of PHC professionals.

The social element was discussed by the professionals, which was the user's own stigma regarding their health condition. This leads to a resistance from the user in revealing their serological condition to the health professionals. They do not reveal it due to fear for their exposure in the community, so they opt for specialized services outside their social context.[32]

People living with HIV are afraid of searching for services close to the place they where live due to the risk of dissemination of confidential data, of being identified, or of running into someone they know.[22] The moral challenge points out the difficulty in understanding HIV as a chronic health condition, still marked by stigma. In addition, there is the ethical challenge related to the importance of confidentiality in a context of territorial teamwork.[4] The lack of trust from users for PHC professionals regarding the confidentiality of their serological condition is also determinant for the preference for specialized services.[33]

The planning of the actions of transfer, welcoming, assistance and communication between the services, as well as the qualification of professionals, requires the development of strategies to manage the information of the diagnosis and the demands for confidentiality, aiming at promoting the access to the services and the construction of bonds and trust between users and professionals.[23]

It is worthy to restate that territoriality widens the possibilities of care and also of exposure to prejudice. Therefore, it represents a challenge of internal, external and political organizational order. The internal one concerns the flexibility of PHC in considering the users' needs in order to adapt organizational manners; the external one refers to the interaction and support between family doctors and infectious disease professionals; and the political one refers to the dialogue between different actors to conduct the agenda.[4]

The professionals discussed how the decentralization of health care could take place, based on the LC[34] guidelines in which the articulation of resources and health practices, such as diagnosis and therapy, is intended among the responses of a certain territory. The LC is a tool to help in the organization of the HCN and aims to identify the multiple possible paths, prioritizing effective and rational ways, narrowing the distance between management and assistance and working based on therapeutic projects. The first step in the implementation of the LC is the agreement between all the entities involved.[15] We understand that it is necessary for managers and professionals to lead the reorganization process of health actions and services.

One of the constitutive elements of the HCN is the operational structure, which consists of the networks' knots and the connections that communicate them. This structure has five components: 1) the communication center – PHC -; 2) the secondary and tertiary points of assistance; 3) the support systems; 4) the logistics systems; and 5) the HCN governance system. Regarding the networks' knots, they correspond to the first three components. The connections that communicate the different knots correspond to the fourth component, and the last is the one that manages the relationships between the first four.[35]

It is known that specialized services develop specific assistance related to the evolution of the HIV infection with the demands of the clinic and therapeutic conduct. However, the coordination of care and the follow-up of the user in their community are attributions of the PHC, and such determination should be clear among the services. This was represented by the participants in the LC (Figure1).

Therefore, health care in childhood and puberty and the immunization schedule should be maintained in the PHC, considering the social and affective network of children and adolescents living with HIV.[10] A previous research in the same city has pointed out that the integration between services must be established through a flow of users in the SUS.[10] It is understood as essential the agreement, contractualization and connectivity of roles and tasks between different services and the respective professionals, from the PHC.[15]

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

We conclude that the participative approach of professionals and managers enabled their leading role, since they collectively built the results of the research. The discussion was fruitful about the constitution of the HCN in search of better results in the health of children and adolescents living with HIV, and it culminated in a viable product to be implemented in daily assistance. However, the implementation of such product, called LC, requires local strategic actions, based on the discussion of the reality of resources, potentialities and weaknesses of services for the integration of the HCN points of assistance.

The existence of challenges is recognized, but there are possibilities for the continuity of actions that advance towards networked assistance, as well as for PHC to become stronger and to be able to count on the support of specialized services in the care of these children, adolescents and their families. In order to overcome the traditional model, the coordination of care needs the co-responsibility of professionals from the different types of services, promoting the comprehensiveness and continuity of individual and collective actions. The limitation of the research lies in the need to include other HCN points as entry points to SUS and/or facilitators of access to children and adolescents living with HIV.

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