UFSM

REUFSM
REVISTA DE ENFERMAGEM DA UFSM

ISSN 2179-7692
OPEN ACCESS

Rev. Enferm. UFSM, v.13, e34, p.1-22, 2023 •
Submission: 6/19/2022 • Acceptance: 9/4/2023 • Publication: 10/6/2023

Original Article

Best practices in the care provided to people living with HIV in different care models*

Melhores práticas no cuidado às pessoas que vivem com HIV em diferentes modelos de cuidado

Mejores prácticas en la atención a personas viven con VIH en diferentes modelos de asistencia

Fernanda Karla Metelski[I], Ianka Cristina Celuppi[II], Betina Hörner Schlindwein Meirelles[II], Bruna Coelho[II], Marcelle Miranda da Silva[III], Wilson Jorge Correia Pinto de Abreu[IV]

[I] Universidade do Estado de Santa Catarina, Departamento de Enfermagem. Chapecó/SC, Brasil.
[II] Universidade Federal de Santa Catarina, Programa de Pós-Graduação em Enfermagem. Florianópolis/SC, Brasil.
[III] Universidade Federal do Rio de Janeiro, Escola de Enfermagem Anna Nery. Rio de Janeiro/RJ, Brasil.
[IV] Escola Superior de Enfermagem do Porto. Porto, Portugal.

Extracted from the thesis 'Best practices in the management of care for people living with HIV/AIDS in the healthcare network of a municipality in the western region of Santa Catarina,' and from the dissertation 'Best management practices in the care of people living with HIV in a capital city in southern Brazil,' both from the Graduate Program in Nursing, Federal University of Santa Catarina, in 2022 and 2021, respectively.

Abstract

Objective: to understand the meanings attributed to best practices in the care of people living with HIV in two different care models in priority municipalities from southern Brazil. **Method:** Constructivist Grounded Theory, with 52 in-depth interviews conducted in 2020 and 2021, involving professionals from primary and specialized care, managers and people living with HIV. **Results:** the phenomenon of "Signifying best practices as gradual and consistent across different priority municipalities" allows for an understanding that actions related to health prevention and promotion, counseling, early diagnosis and referral are developed in the centralized care model. In the decentralized model, the emphasis is on expanding the role of nurses and family physicians in infection management, establishing connections, ensuring care continuity, and providing comprehensive care. **Conclusion:** best practices in different care models require a succession of different moments that respect the perspectives and input of both health professionals and individuals living with HIV.
Descriptors: HIV; Nursing; Health Care Models; Primary Health Care; Grounded Theory

Article published by Revista de Enfermagem da UFSM under a CC BY-NC-SA 4.0 license.

Resumo

Objetivo: compreender os significados atribuídos às melhores práticas do cuidado às pessoas que vivem com HIV em dois diferentes modelos de cuidado em municípios prioritários do sul do Brasil. **Método:** Teoria Fundamentada nos Dados Construtivista, com 52 entrevistas em profundidade aplicadas em 2020 e 2021, para profissionais da atenção primária, especializada, gestores e pessoas que vivem com HIV. **Resultados:** o fenômeno "Significando as melhores práticas como gradativas e consistentes em diferentes municípios prioritários", permite compreender que no cuidado centralizado são desenvolvidas ações de prevenção e promoção da saúde, aconselhamento, diagnóstico precoce e encaminhamento, e no modelo descentralizado destaca-se a ampliação da clínica do enfermeiro e do médico de família no manejo da infecção, vinculação, longitudinalidade e integralidade. **Conclusão:** as melhores práticas em modelos distintos de cuidado requerem uma sucessão de diferentes momentos, que respeitem as falas dos profissionais e das pessoas que vivem com HIV.

Descritores: HIV; Enfermagem; Modelos de Assistência à Saúde; Atenção Primária à Saúde; Teoria Fundamentada

Resumen

Objetivo: comprender los significados atribuidos a las mejores prácticas de atención a personas que viven con VIH en dos modelos de asistencia diferentes en municipios prioritarios del sur de Brasil. **Método:** Teoría Constructivista Fundamentada en los Datos, con 52 entrevistas en profundidad realizadas en 2020 y 2021, para profesionales de Atención Primaria y Especializada, administradores y personas que viven con VIH. **Resultados:** el fenómeno de "Representar las mejores prácticas como graduales y consistentes en diferentes municipios prioritarios" permite comprender que se desarrollan acciones relacionadas con prevención y promoción de la salud, asesoramiento, diagnóstico temprano y derivaciones en el modelo de atención descentralizado. En el modelo descentralizado, el énfasis radica en expandir el rol de los enfermeros y médicos de familia en el manejo de infecciones, establecer conexiones, garantizar continuidad de la atención y brindar asistencia integral. **Conclusión:** las mejores prácticas en distintos modelos de atención requieren cierta sucesión de diferentes momentos que deben respetar los discursos de los profesionales y las personas que viven con VIH.

Descriptores: VIH; Enfermería; Modelos de Atención de Salud; Atención Primaria de Salud; Teoría Fundamentada

Introduction

In mid-1980s, the care provided to people with HIV was offered in specialized services, polyclinics and hospitals. Later on, Testing and Counseling Centers (CTAs) were established, and only in the 2000s did HIV management gradually begin to be implemented in Primary Health Care (PHC). Due to the territorial reach of these services, PHC has gained prominence in HIV-related actions.[1-3]

In PHC, the care provided to people living with HIV is initiated by developing prevention and counseling actions. In 2012, rapid tests began to be offered, contributing to early diagnosis of the

disease.[4] The decentralization strategy has been gradually advancing, and clinical management with risk stratification of people living with HIV in Primary Health Care (PHC), including those on Antiretroviral Therapy (ART), constitutes the final stage of this process, with the participation of nurses.[2-3] As a result, PHC takes on the responsibility for the complete or partial monitoring of asymptomatic stable patients, depending on the moral, technical, internal and external organizational challenges and on the political context in each Brazilian scenario.[2]

Despite the inherent challenges of decentralizing HIV assistance to Primary Health Care (PHC), it can be considered an important strategy for improving disease control indicators. It also contributes to organizing and structuring the care network, with efficient management, professional qualification and an expanded range of health actions offered in PHC.[1,5] This approach enables the development of matrix support and shared care between specialized and primary services.[6]

Nurses' role stands out in Primary Health Care (PHC), as they have been considered the key professionals for conducting rapid testing for HIV and other Sexually Transmitted Infections (STIs), as well as for counseling, delivering the diagnosis and following up on the treatment.[5] In PHC, nurse-prescribed Antiretroviral Therapy (ART) has contributed to reducing viral loads and spread of the virus.[7]

In Brazil, health care is considered a universal right guaranteed by the 1988 Federal Constitution. It is the State's duty to provide health care through free public policies with a focus on social and economic aspects. In the world, other countries like Australia, Canada, United Kingdom, France and Sweden also provide health care services free of charge and universally. However, they have specific approaches to caring for people living with HIV, and there are differences in the adoption of recommendations from the World Health Organization (WHO).[8]

All of these countries, including Brazil, offer free HIV testing for diagnosis. However, when it comes to therapy, each country adopts its own approach and also takes into consideration the local circumstances and needs of people living with HIV. The agreement to eradicate HIV has treatment adherence and retention among its guiding principles. In fact, Brazil has adopted the care cascade continuum, whereas Canada pioneered the U=U (Undetectable = Untransmittable) campaign, which means that a person with an undetectable viral load cannot transmit the virus, thereby reducing stigma. Data sources on people living with HIV are obtained through health identifier data linkage in Brazil, whereas data are collected through laboratory systems in Canada.[8]

In 2020, 37.7 million people were living with HIV worldwide.[9] With modernization of the antiretroviral treatment and the increase in life expectancy of people living with HIV, the infection is now considered a chronic health condition.[10] This means that these individuals will require lifelong care. Thus, the best practices can contribute for these care actions to be of good quality and for people to lead long and healthy lives.

The quality of care and access to healthcare services can be compromised due to the stigma and discrimination faced by people living with HIV.[11] The stigma and discrimination associated with this chronic condition highlight the importance of studying best practices to propose safe and supportive environments for people living with HIV/AIDS.

Furthermore, HIV/AIDS has been included in the Sustainable Development Goals as a global concern.[12] Therefore, studies involving health care delivery models for people living with HIV/AIDS in different contexts, while also considering nurses' role in Primary Health Care, can elucidate how professionals can implement continuous improvements in the care model.

The objective of this article was to understand the meanings attributed to best practices in the care of people living with HIV in two different care models in priority municipalities from southern Brazil.

Method

This is an exploratory and qualitative study conducted using the Constructivist Grounded Theory (CGT) approach. CGT seeks to understand the meanings and actions of participants and researchers alike, which are constructed through interactions and jointly contribute to data creation.[13-14]

This presentation offers an alignment of results obtained through two research studies. The first one is a PhD thesis titled "Best Practices in Care Management for People Living with HIV in the Health Care Network of a Municipality in Western Santa Catarina", and the second survey pertains to an MSc dissertation titled "Best Management Practices in the Care of People Living with HIV at a Capital City from Southern Brazil". The data from both research studies were organized and analyzed to meet the objective of the current article.

The research was conducted in two municipalities considered as reference points for actions aimed at HIV/AIDS control and deemed a priority for curbing AIDS spread due to their status as regional health centers. They shall be called “Scenario A” and “Scenario B” from now on.

Scenario A operates from the perspective of a centralized care model. It has a population of approximately 227,000 residents and 89.24% Family Health Strategy (FHS) coverage across 26 Health Centers, and serves as a reference for the care of people living with HIV and their sero-different partners for 36 cities in the region. In Scenario B, the care model is decentralized. It has a population of approximately 508,000 residents and 115.44% FHS coverage spread across 48 Health Centers.

Throughout the study, two sample groups were assembled in each of the scenarios. The participants in Scenario A were 35 health professionals, whereas 17 took part in Scenario B. In both scenarios, the first sample group consisted of clinical nurses and/or study participants who worked in the Health Centers that are part of Primary Health Care (PHC). They were all selected consecutively, meaning that data collection and analysis were carried out successively, and it was determined whether data saturation had been reached. After that, the next professional was invited to participate in the study. Given nurses' leading role in this performance area, in both scenarios the first sample group was essentially comprised by nurses.

The second sample group was defined based on the analysis of interviews. In Scenario A, it consisted of professionals working in the Specialized HIV/AIDS Care Service (*Serviço de Assistência Especializada*, SAE), whereas in Scenario B, it included managers working at the Municipal Health Department.

The inclusion criteria for the initial sampling in both scenarios were as follows: the participants needed to be engaged in activities related to HIV/AIDS and had to have been working in their current service for at least six months at the time of the research. Only one exclusion criterion was adopted, namely: being distanced from work due to any reason at the time the research was conducted. Among those invited to participate in the study, 11 individuals in Scenario A and five in Scenario B refused to participate. Some of them did not engage in any HIV/AIDS-related activities, whereas others chose not to participate without specifying their reasons.

The participants were approached through email and phone contacts by the health care service coordinators. They were interviewed individually using remote formats on platforms such as *Microsoft Teams*® and *Google Meet*®, and in-person when allowed, taking into consideration the COVID-19 pandemic control measures. In Scenario A, in-person data collection was only possible at the Specialized HIV/AIDS Care Service (SAE). Both in 2020 and in 2021, in-depth interviews were conducted with the assistance of a semi-structured instrument. The first interview

in both scenarios and for both sample groups was considered a pilot, with minimal adjustments required only for the first sample group in Scenario A. All interviews were conducted by two researchers, each one responsible for one scenario, and lasted approximately 45 minutes on average. The researchers attended courses on the topics of management, chronic diseases and the Constructivist Grounded Theory (CGT) theoretical-methodological framework. They also participated in discussions and knowledge-sharing sessions within the research group. As part of this training, the researchers engaged with the scenarios to establish a productive relationship and to present the study proposals along with their rationales.

The question that initiated the discussion in both scenarios was as follows: "Talk to me about the best care practices targeted at people living with HIV". With this question as a starting point, others gradually emerged in order to deepen on the topic under study. Additionally, memos were written and diagrams were prepared during data collection and analysis.

In Scenario A, the primary hypothesis that emerged from the data and led to the second sample group was that clinical management of people living with HIV is primarily carried out in specialized care by a multidisciplinary team. In Scenario B, the hypothesis delineated was that care for people living with HIV materializes through the implementation of institutional support from municipal management, resorting to protocols, training and matrix support from specialized care.

The interviews lasted a mean of 30 minutes and were audio-recorded. They were then transcribed into Word® text files and validated by the respective participants through email or WhatsApp®, according to each participant's preference. The *Atlas.ti* 9® software and *Google Docs®* were used to organize the data. Data analysis followed the initial and focused coding stages.[11] In addition to the main researchers, the supervisor of the studies also acted as data coder. Data saturation was verified based on the closure technique[15] and discussed by the other authors at the evaluation moments in the PhD and MSc courses. Considering the objective of the current study, in Scenario A saturation was reached in interview number 31 and, in Scenario B, in the fourth interview.

The studies respected all the ethical principles recommended in resolutions No. 466/2012 and No. 510/2016 of the National Health Council. The interviews were only initiated after obtaining each participant's acceptance, which was formalized through signing an Informed Consent Form or via recorded verbal consent at the start of the interview. Codes comprised by letters and numbers were assigned in order to ensure confidentiality of the participants' identities and their

privacy. The interviews were coded according to the scenario and to the data collection order. The projects were approved by the Research Ethics Committee of the Federal University of Santa Catarina. The first project was approved under protocol number 3,956,203 and the second one, under protocol number 4,063,338.

Results

A total of 52 health professionals took part in the study. In both study scenarios, participants aged between 30 and 39 years old were predominant. They were mostly female, worked as nurses, held graduate degrees, had up to nine years of experience in the service, and fulfilled roles both in assistance and/or in coordination, either cumulatively or separately (Table 1).

Table 1 - Socioprofessional characterization of the participants in the studies carried out in the two priority municipalities from southern Brazil, 2020-2021.

Variables	Description	Scenario A		Scenario B	
		First Sample Group (n=24)	Second Sample Group (n=11)	First Sample Group (n=12)	Second Sample Group (n=5)
		n (%)	n (%)	n (%)	n (%)
Age	25-29 years old	5 (20.8)	-	1 (8.33)	-
	30-39 years old	10 (41.7)	5 (45.5)	5 (41.66)	1 (20)
	40-49 years old	8 (33.3)	3 (27.3)	6 (50)	4 (80)
	50-57 years old	1 (4.2)	3 (27.3)	-	-
Gender	Female	23 (95.8)	10 (90.9)	10 (83.33)	3 (60)
	Male	1 (4.2)	1 (9.1)	2 (16.66)	2 (40)
Profession	Nurse	21 (87.5)	3 (27.3)	12 (100)	-
	Nursing Assistant	1 (4.2)	2 (18.2)	-	-
	Nursing Technician	-	2 (18.2)	-	-
	Physician	1 (4.2)	1 (9.1)	-	5 (100)
	Surgeon-Dentist	1 (4.2)	-	-	-
	Social Worker	-	1 (9.1)	-	-
	Pharmacist	-	1 (9.1)	-	-
	Psychologist	-	1 (9.1)	-	-
Time working in the Service	6 months-4 years	7 (29.2)	5 (45.5)	12 (100)	1 (20)
	5-9 years	7 (29.2)	5 (45.5)	-	4 (80)
	10-14 years	5 (20.8)	1 (9.1)	-	-
	15-19	3 (12.5)	-	-	-
	20-24 years	2 (8.3)	-	-	-
Current function	Care	8 (33.3)	9 (81.8)	8 (66.66)	-
	Coordination	16 (66.7)	1 (9.1)	2 (16.66)	-
	Administrative	-	1 (9.1)	-	-
	Intern	-	-	2 (16.66)	-
	SMS coordinator	-	-	-	5 (100)

n: Absolute number; %: Percentage; SMS: *Secretaria Municipal de Saúde* (Municipal Health Department).

Two categories and respective subcategories emerged in the study, as shown in Chart 1.

Chart 1 - Categories and subcategories arising from the different HIV care decentralization stages in two priority municipalities from southern Brazil, 2020-2021.

Category 1 – Scenario A	Category 2 – Scenario B
Developing care for people with HIV in a leading way, and seeking conditions to decentralize it in a centralized scenario	Implementing the expanded clinic and longitudinal care for people with HIV in a decentralized scenario
Subcategories	
Surveying benefits, challenges and conditions to make decentralization a reality	Decentralizing the care provided to people living with HIV to Primary Health Care services
Having a health team for the care to be provided to people with HIV diagnoses	Caring for people who live with HIV with the participation of nurses, family doctors and the community
Revealing nurses' leading role by means of the countless duties developed in the care provided to people living with HIV	Implementing nurses' expanded clinic in management of the HIV infection
Emphasizing that training programs are required for the clinical management of people with HIV	Training nurses and family doctors and the community in clinical management of the HIV infection
Noticing the need to use instruments and technologies for the care to be provided to people living with HIV	Using support instruments for clinical decision-making
Expressing nurses' work overload in PHC	Fear of assuming new responsibilities

Surveying benefits, challenges and conditions to make decentralization a reality

The advancement of decentralization is gradual and requires matrix support to horizontalized actions across different care levels, which, according to the participants, needs to take into account the capabilities of the services.

> *I think that Basic Care had to assume that too! But we need logistics, we need human resources, because we're not going to take on more responsibilities and won't manage without resources.* (CA-E20)

> *I support decentralization, but I also think that improvements are indispensable, as well as Basic Care qualification, improving the resources, human resources, physical space, structure.* (CA-E13)

Having a health team for the care to be provided to people with HIV diagnoses

The teamwork perspective in Scenario A reveals shared care during the HIV infection diagnosis through nurses' initiative to involve other professionals in the service. This allows for the support of the team to assist individuals with positive results and distribution of responsibilities.

> [...] *It is essential to identify factors or situations where it is necessary to involve other specialties, such as the Family Health Support Center (Núcleo de Apoio à Saúde da Família, NASF), psychologists, social workers, and other members of the family health team.* (CA-E13)

> [...] *when we work as a team, we don't overload each other; we share the workload and responsibilities. For me, I believe that Nursing provides a lot of support, and it's definitely of extreme value, without a doubt!* (CA-E21)

Revealing nurses' leading role by means of the countless duties developed in the care provided to people living with HIV

The participants from Scenario A exemplify nurses' leadership role in Primary Health Care (PHC) through the countless tasks they undertake, with particular emphasis on rapid tests – considered a milestone for nurses' work in PHC in the HIV/AIDS context.

> *What struck me a lot, I can't remember how long ago it was, but at the time, we gained access to rapid HIV/AIDS tests, which I think was a very important milestone when nurses were given access to these tests to perform them for their users.* (CA-E12)

> [...] *moreover, when it comes to diagnosis, it's what nurses mainly focus on in Primary Health Care: identifying risk factors, offering testing whenever a user visits the Health Center, providing support and counseling on Sexually Transmitted Infections (STIs).* (CA-E13)

Emphasizing that training programs are required for the clinical management of people with HIV

In Scenario A, the participants emphasize that training programs are indispensable to qualify the care provided, especially for the clinical treatment of HIV. In other clinical situations such as syphilis, nurses are in charge of the clinical management following the protocol implemented in the municipality.

> *So, if they [people with HIV] were to visit the Health Center through decentralization, I think that we could have better control over our patients, closely monitor them. However, my doubt is whether we'd be adequately trained for this, because I believe that neither nurses nor doctors have much training to closely monitor HIV/AIDS patients.* [...] *I think that it's a really cool strategy, but everyone should be duly trained first!* (CA-E19)

Noticing the need to use instruments and technologies for the care to be provided to people living with HIV

Using technology in the care of people with HIV/AIDS is perceived as an aspect that needs strengthening in Scenario A. Adherence to an HIV protocol supports and partially subsidizes the decentralization process. However, other aspects need consideration, such as organization of the care continuum, integration of access to electronic health record data between primary and specialized care, deficiencies in information systems that allow the generation of partial reports on the conditions that the professionals need to monitor, and acquisition of computer equipment that meets the demands of health care services.

> *I believe that if there was a really sound protocol, if everyone spoke the same language, why not? Yes, but training and protocol for sure!* (CA-E21)

> *We don't have information [about people with HIV/AIDS] in the electronic records, and among other spaces in the municipal health care network, we can communicate a lot through electronic health records.* (CA-E6)

Expressing nurses' work overload in PHC

The professionals' worries can be understood as the uncertainties and challenges that permeate the professional practice. In Scenario A, these concerns are evident in the concern and anxiety regarding workload, the accumulation of both clinical and managerial responsibilities in Primary Health Care (PHC), and the fear of taking on additional responsibilities related to the treatment.

> [...] *I feel quite anxious in the sense of not being able to, even more in my character of a clinical and coordinating* [nurse]. (CA-E6)

> [...] *I believe that, as nurses, we're still very apprehensive about taking on a patient. Most nurses are afraid to conduct a Nursing consultation, to perform a thorough patient evaluation.* (CA-E20)

Decentralizing the care provided to people living with HIV to Primary Health Care services

In Scenario B, decentralization is a reality and there is evidence of care continuity and longitudinality. However, as is often the case in any change process, it is accompanied by the challenge of educating the population to recognize this new way of managing their condition.

> *When the monitoring of HIV patients was decentralized, when it left the Polyclinic and came to the basic units, that was quite a step forward* [...]. *I was in the unit during the transition process* [...], [I used to see] *patients that never attended consultations, that never underwent tests* [...]. *Today, we still face some difficulties [...], but for me, it's almost nothing when I look back and see what these patients were like years ago.* (CB-E04)

Caring for people who live with HIV with the participation of nurses, family doctors and the community

In Scenario B, shared clinical care is revealed from a perspective centered on two professions, namely: family/community physicians and nurses. This involves task and responsibility sharing, seeking help from support networks, the Family Health Support Center (NASF, and family members in the follow-up care of people living with HIV, primarily in Primary Health Care (PHC).

> *Care management is shared with the team* [...] *both doctors and nurses, we work a lot together. We say that we have a shoulder-to-shoulder working relationship. We divide tasks for active searching and monitoring of these patients and use our team meetings, which are weekly, to discuss the more complex cases where we face greater difficulties. We need to expand our outreach and support within the network, whether it's within the family or with other professionals, including those from the NASF* [*Núcleo de Apoio à Saúde da Família*]. (CB-E04)

> *I also think that we're never alone, then this support thing between doctors and nurses helps a lot in treating the patients, they only enjoy gains with this care.* (CB-E05)

Implementing nurses' expanded clinic in management of the HIV infection

In Scenario B, nurses provide individualized clinical care for people living with HIV during Nursing consultations. In addition to conducting rapid tests, the progression of the care model decentralization involves the incorporation of new actions.

> *Qualified listening, a caring perspective, building connections, care continuity and cultural components, among others, are classic Primary Care responsibilities that fall on nurses. Clearly, they have clinical competence and the ability to manage life, clinical management of cases, which is essential for promoting health. I have no doubt about it, and it's not just me saying this; it's something that has been observed in experiences worldwide.* (CB-E13)

> *Specific HIV care in relation to test requests, treatment, it's been more recent. I think that I've come closer in the last three or four years. What I used to do before was diagnosis because we already performed rapid tests in the unit, and we had this responsibility of delivering the diagnosis and doing screening.* (CB-E04)

Training nurses and family doctors and the community in clinical management of the HIV infection

In Scenario B, training on HIV infection management is conducted periodically. These training sessions have expanded nurses' knowledge regarding clinical aspects, enhanced Nursing consultations, and integrated the residency program and continuous education moments for the team. The *Practical Approach to Care Kit* (PACK) was an instrument used for HIV clinical

management and in the training programs.

> *We also underwent training last year, before the pandemic. We had several meetings with doctors and nurses from each unit across the entire network for training on using the PACK. Some situations, clinical cases were given, and we'd discuss the management that was given to that situation of the patient according to the PACK. The meetings were once a week for three months, and they were very clarifying. Several types of cases were worked on, even HIV ones,* [...] *for us to be able to offer adequate management.* (CB-E01)

Using support instruments for clinical decision-making

In Scenario B, the technologies mentioned for the care of people living with HIV include the PACK and Nursing protocols. These technologies provide professional practice security and empower clinical decision-making.

> *Here, we follow-up together with the doctor and have empowerment in relation to the protocol to truly act in the treatment, provide listening, support, perform all care, request some tests and monitor medication care and side effects, among other aspects. This whole thing, the protocol, gives us plenty of support.* (CB-E05)

> *There's also the possibility of case discussion, involving the matrixing doctor as well, where we can share care and build a common therapeutic plan for the primary care team and the specialized team.* (CB-E14)

Fear of assuming new responsibilities

In Scenario B, during the initial decentralization stages, nurses also felt insecure when they initiated clinical management of people with HIV, especially when it came to disclosing the diagnosis. They had low self-esteem regarding their clinical capabilities.

> *We still see certain amount of fear [...], much like when we began developing protocols, when nurses started prescribing and requesting tests, and when they expanded their clinical role. That fear was always present* [...]*: and now? Now it's my duty, now it's my responsibility!* [...] *Then we're recently getting out of that.* (CB-E03)

Therefore, it is essential to understanding best practices in different care models for people with HIV as a gradual and consistent phenomenon developed amidst a succession of different moments. It requires considering the teamwork perspectives, acknowledging nurses' work and leadership in providing care to these individuals, training professionals for clinical management, using technologies and tools to support care, and addressing the professional concerns that permeate the entire process. Figure 1 illustrates this phenomenon.

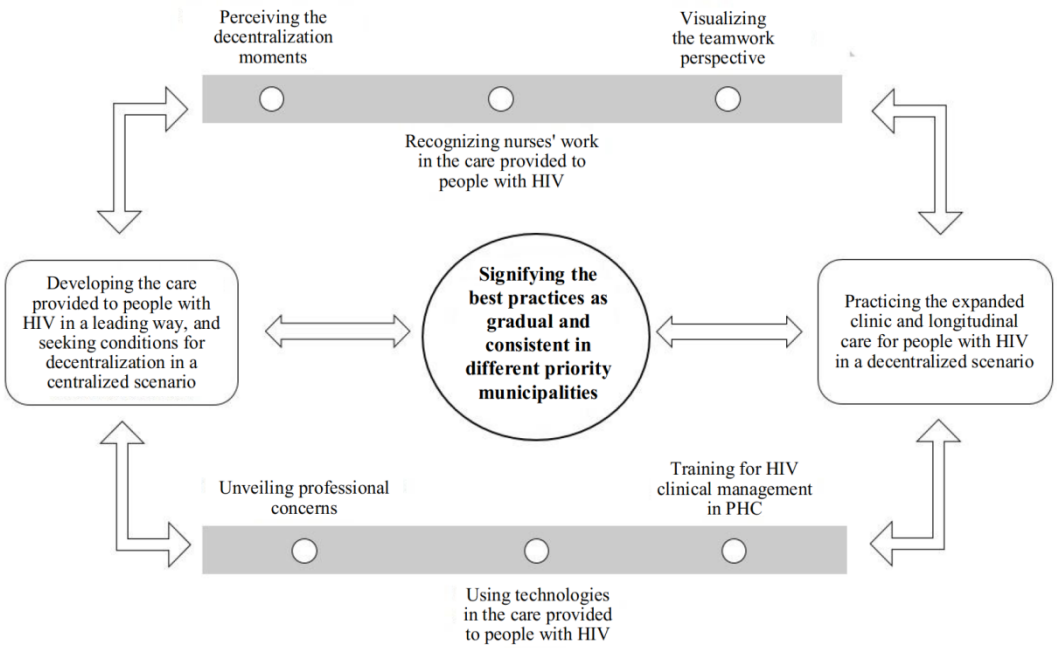

Figure 1 - Diagram representing the phenomenon of the best practices in different priority municipalities for the care provided to people with HIV.

Discussion

Scenarios A and B present different care models for the people living with HIV in PHC. In the centralized model, the best practices focus on testing, early diagnosis, care with nurses' leadership, and efforts to create conditions for decentralization. However, people with HIV are still referred to the Specialized Care Service. On the other hand, in the decentralized model, the best practices are targeted at the expanded clinic, at longitudinal care and at training programs in HIV clinical management.

It is worth mentioning that Scenario B also had a centralized care model in the past and that, to make decentralization a reality today, it required the implementation of gradual actions, organization of the care continuum with physical infrastructure and logistical support, dialogue among professionals, coordinators and users, training, adoption of technologies, and respect for the preferences of people living with HIV. Scenario A has a centralized care model, but it develops PHC actions that reveal an initial decentralization trend.

Thus, although the scenarios present two different care models, the best practices

were observed from the decentralization perspective, with various implementation moments, highlighting progress and challenges present in both scenarios. The shift in perspective from Scenario A to Scenario B suggests that decentralization is possible but, of course, it requires concrete and gradual actions to make it a reality. On the other hand, looking in the opposite direction, from Scenario B towards Scenario A, allows us to see the progress and areas that can still be further developed.

In Scenario B, decentralization is seen to strengthen the bond with individuals in Primary Health Care (PHC), ensuring care continuity and longitudinality. In Scenario A, it is highlighted that it is important to respect people's decisions regarding where they want to be treated, taking into account factors such as the shame and prejudice still associated with HIV diagnosis.

It is important to note that, while commuting long distances in search of assistance and medication can be a barrier for individuals, the stigma associated with HIV can also influence their decision to continue making these trips out of fear of disclosing their serological status in their local community. Despite this limitation, decentralizing care increases access to the Antiretroviral Therapy (ART). The process and shared care with people living with HIV go through an assistance transition phase that should consider each person's preferences, whether related to stigma or familiarity with the location where the treatment was initiated.[16] However, even in a centralized model, with greater involvement of Primary Health Care (PHC) in HIV diagnosis, there is an opportunity to establish important relationships and promote care within PHC.

A study conducted in Florianópolis amidst the decentralization process in 2017 revealed that Primary Health Care (PHC) professionals were actively involved in the HIV diagnosis phase. At the same time, a pilot project was being developed at some health units in each district of the municipality to organize and align the best way to access and manage care for people with HIV/AIDS. The study participants understood the need to decentralize care as fundamental to expand access and improve adherence to ART.[17]

The quest for decentralization follows legal recommendations[18-19] to ensure that the care for people living with HIV is developed across the entire health care network, coordinated by Primary Health Care (PHC), which is the organizer of the Unified Health System (*Sistema Único de Saúde*, SUS).

The participants from Scenario A consider the multidisciplinary teamwork perspective, with integration of professionals from the Family Health Support Centers (NASFs) such as psychologists or social workers, for the moment of disclosing the diagnosis to the individual. In Scenario B, this and other clinical aspects are centered on nurses and physicians, who are now better prepared for this function as a result of the training programs. The importance of continuous education is highlighted because even participants in Scenario B had fears about assuming responsibilities at the beginning of the care decentralization process.

However, it is reasserted that the Family Health Support Center (NASF) is considered a support for the Family Health Strategy (FHS), as it works together as a multidisciplinary team, strengthening articulation and qualification of the Health Care Network (*Rede de Assistência à Saúde*, RAS), contributing to the organization of health, care coordination and continuity, thus developing shared work.[20] The transition to decentralized care should assume the trend that family health teams welcome and assist people living with HIV, recognizing their needs, directing them when necessary, and leveraging other resources and services available in the network, such as NASFs.[17]

Nurses' work in the care of people with HIV highlights advances in terms of care issues in Scenario A, such as performance of rapid tests, laboratory test requests and delivery of test results. However, treatment and monitoring are still not a reality in PHC. In Scenario B there is clinical management integration in Nursing consultations, which turns these professionals into a reference within the team.

In Primary Care, nurses play a fundamental role in the control of Sexually Transmitted Infections (STIs), including HIV, as they are oftentimes involved in the initial evaluation of the patient. Expanding nurses' roles to include diagnosing and treating HIV and other STIs not only increases access but also provides faster care to individuals.[21]

Nurses play a role in the treatment of various infectious diseases and, when specialized in HIV care, they contribute to people's better adherence to their treatments, as they manage the care effectively, provide guidance and support individuals in self-care.[22] Strengthening of the decentralization process in the health care network involves nurses' active participation in the execution of individual and collective actions, as well as in the care provided to people living with HIV.[23]

The experience of decentralizing the care provided to people living with HIV to Primary Health Care in Rio de Janeiro, for example, resulted in an advancement in the implementation of rapid tests in health units, but it also came with challenges for the professionals in terms of providing counseling and disclosing the diagnosis. Other observed aspects included the increase in the number of people living with HIV receiving assistance in Primary Health Care; although heterogeneous, this population is seeking health care centers more frequently. Among the problems are difficulties in access within Primary Health Care, as well as assistance for people living with HIV centralized around family physicians, which should be discussed in terms of the care scope and limitations based on comprehensiveness. Multiprofessional teamwork can expand the ability to understand and analyze people's problems and to organize health services.[3]

Nurses' role in relation to HIV/AIDS has low visibility, with certain unawareness of their actual role in this subject matter, even though they play a role in conducting HIV diagnosis, counseling, monitoring, promotion and adherence to the Antiretroviral Therapy (ART).[24] This highlights the need for expanding nurses' role in the care of people living with HIV, which is still centered around the figure of physicians in many municipalities. Nurses are oftentimes primarily involved in diagnosis but not in the patients' follow-up and ongoing care. It is important to recognize that the achievements in the global health response to the HIV/AIDS pandemic would not have been possible without nurses' active participation.[25]

In the current study, it is highlighted that training programs and ongoing education in HIV-related health care are considered crucial for care quality, professional development and clinical management skills, and they need to be conducted regularly. Continuous Health Education (CHE) is a health policy aimed at guiding the improvement of professional practices and work organization based on local needs, developing skills and competencies, strengthening professional work and enhancing the quality of health care services.[26-28] The development of Continuous Health Education (CHE) actions with health care workers needs to be reflective, participatory and ongoing.[28]

The technologies in the care of people with HIV were understood as the protocols that support the professional practice, the use of instruments like the PACK in Scenario B, the need for integration of clinical records in electronic medical records, information

systems capable of providing reports that contribute to case monitoring, and an organized care path. Clinical protocols are important tools in the care of people living with HIV/AIDS, contributing to the guidance of clinical management and to establishing criteria for referral when necessary.[3]

The use of technologies such as email and *WhatsApp*® for mentoring and case discussions, as well as the implementation of PACK in Florianópolis, were important for decentralizing the care provided to people living with HIV. PACK is support tool and guide for PHC physicians and nurses that seeks to ease the translation of scientific knowledge to the clinical practice.[1,12]

The uncertainties and challenges reveal the professionals' concern about their own duties, added to the clinical management of people living with HIV/AIDS. Issues such as the time required to provide HIV care, whether for someone seeking a rapid test, someone living with HIV, or even a professional who has had a workplace accident, and the fear of assuming new responsibilities, are present in the professionals' statements. A study conducted in Thailand identified that, for the professionals, task shifting can be a challenge for decentralization,[29] which should be managed based on resources adapted to the capabilities of the services.

While the recommendation is to develop shared care between Primary Health Care (PHC) and specialized services, with these latter acting as matrix support for PHC,[6] tensions surrounding shared care between PHC and specialized assustance, fear of exposure and stigma, or even management of confidentiality and diagnosis disclosure, are issues that need to be addressed, considering that the diagnosis and follow-up of people with HIV in PHC are still recent and poorly studied processes. The challenges are of a moral, ethical, technical, internal/external organization and political order.[2-3,30]

The study has some limitations, such as its data collection being carried out by different researchers in each scenario since, in the CGT, the data are co-created by researchers and participants. Consequently, it is believed that joint data collection by the researchers might have triggered new hypotheses. To minimize this limitation, the researchers conducted joint data analysis, creating diagrams and memos during the data collection process, considering that data collection and analysis are carried out simultaneously in the CGT.

Another limitation was that data collection took place during the COVID-19 pandemic, precluding in-person data collection due to social distancing measures and leading to the suspension of some health care activities by the professionals. In addition, the increased workload due to the pandemic may have influenced the data collected.

Among the study contributions, it is understood that care decentralization needs to be organized towards building shared care among different points in the health care network for people living with HIV. This process should take place gradually, with dialogue, care coordination, physical infrastructure, logistical support, respect for people's dignity and preferences and knowing that stigma and prejudice should be addressed, both among people living with HIV and among health professionals, extending to society as a whole.

Conclusion

The study presents best practices in two priority municipalities with different care models for people living with HIV. However, the currently decentralized scenario also once operated from the perspective of a centralized care model and, at some point, began the transition. This allows us to understand that implementing care decentralization for people living with HIV involves gradual and consistent processes, which are expanded as health professionals and citizens have their voices respected, and all the decentralization conditions, challenges and benefits are taken into account in organizing the care continuum.

The scenario where decentralization was implemented showed advances in practices developed in Primary Care, with emphasis on the expansion of nurses' and family and community physician's clinical roles in managing the HIV infection, greater engagement of people living with HIV, care continuity and the comprehensiveness of the practices carried out by the health care team.

In the centralized care scenario, the specialized service focuses on clinical management of the infection, whereas the family health team carries out preventive and health promotion actions, welcoming, diagnosis, counseling and referrals, compromising the bond and care continuity between people living with HIV and the professionals working in Primary Care.

The hypotheses raised can be considered partially accepted since, although there is a care model established in each context, some professionals in the centralized context,

even without having the conditions they consider essential for care decentralization, seek and develop means to follow-up with people living with HIV in Primary Care. This shows that the need for decentralization is felt and arises in the midst of the interaction between professionals and people living with HIV, despite professional concerns.

Finally, the construction of shared care among professionals, different services and people living with HIV/AIDS, which transcends the dichotomy between centralized and decentralized care, is a current challenge. It requires overcoming the stigma and prejudice associated with this chronic condition in order to reconstruct health practices for the better.

References

1. Pinto VM, Capeletti NM. Reorganização do modelo de atenção às pessoas vivendo com HIV: A experiência do município de Florianópolis/SC. Rev Bras Med Fam Comunidade. 2019 Mar; 14(41):1710. doi: 10.5712/rbmfc14(41)1710
2. Melo EA, Maksud I, Agostini R. Cuidado, HIV/aids e atenção primária no Brasil: desafio para a atenção no Sistema Único de Saúde? Rev Panam Salud Publica. 2018; 42:e151. doi: 10.26633/RPSP.2018.15
3. Melo EA, Agostini R, Damião JJ, Filgueiras SL, Maksud I. Cuidado de pessoas vivendo com HIV na atenção primária à saúde: reconfigurações na rede de atenção à saúde? Cadernos de Saúde Pública. 2021; 37(12):e00344120. doi: 10.1590/0102-311X00344120
4. Ministério da Saúde (BR). Gabinete do Ministro. Portaria nº 77, de 12 de janeiro de 2012. Dispõe sobre a realização de testes rápidos, na atenção básica, para a detecção de HIV e sífilis, assim como testes rápidos para outros agravos, no âmbito da atenção pré natal para gestantes e suas parcerias sexuais. [Internet]. 2012 [acceso 2023 jun 18]. Disponível em: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2012/prt0077_12_01_2012.html
5. Caixeta ER, Coimbra MAR, Gomes NS, Santana LC, Delfino FAP, Ferreira LA. Percepção dos enfermeiros quanto ao acolhimento às pessoas que realizam o teste rápido de HIV. Rev enferm UERJ. 2021 Jan; 29:1. doi: 10.12957/reuerj.2021.61479
6. Pinho CM, Dourado CARO, Lima MCL, Maia TS, Silva JFAS, Silva EL. Avaliação das medidas de controle do HIV na Atenção Básica. Revista Eletrônica Acervo Saúde. 2020; 12(8):1-14. doi: 10.25248/reas.e3462.2020
7. Guedes HCS, Silva Júnior JNB, Silva GNS, Trigueiro DRSG, Nogueira JA, Barreto AJR. Integralidade na Atenção Primária: análise do discurso acerca da organização da oferta do teste rápido anti-HIV. Escola Anna Nery. 2021; 25(1). doi: 10.1590/2177-9465-EAN-2019-0386
8. Campos JRN, Costa SS, Costa IS, Jaldin AEM, Uchoa DS, Batista WS, et al. Políticas públicas para o enfrentamento do HIV / AIDS em países com sistema universal e gratuito de saúde: uma análise segundo a UNAIDS. Research, Society and Development. 2021; 10(2):e37310212574. doi: 10.33448/rsd-v10i2.12574
9. Unaids. Estatísticas. 2022. [Internet]. 2022 [acceso 2023 jun 18]. Disponível em:

https://unaids.org.br/estatisticas/

10. Marques SC, Oliveira DC, Cecílio HPM, Silva CP, Sampaio LA, Silva VXP. Qualidade de vida e HIV/AIDS: revisão integrativa. Rev Enferm UERJ. 2020; 28:e39144. doi: 10.12957/reuerj.2020.39144

11. Damião J de J, Agostini R, Maksud I, Filgueiras S, Rocha F, Maia AC, et al.. Cuidando de Pessoas Vivendo com HIV/Aids na Atenção Primária à Saúde: nova agenda de enfrentamento de vulnerabilidades?. Saúde debate [Internet]. 2022Jan;46(132):163–74. doi: 10.1590/0103-1104202213211

12. Celuppi IC, Meirelles BHS, Lanzoni GM, Geremia DS, Metelski FK. Gestão no cuidado às pessoas com HIV na Atenção Primária à Saúde em tempos do novo coronavírus. Revista de Saúde Pública. 2022; 56:13. doi: 10.11606/s1518-8787.2022056003876

13. Charmaz K. A construção da teoria fundamentada: Guia prático para análise qualitativa. Traduzido por Joice Elias Costa. Porto Alegre: Artmed, 2009.

14. Metelski FK, Santos JLG, Cechinel-Peiter C, Fabrizzio GC, Schmitt MD, Heilemann M. Constructivist Grounded Theory: characteristics and operational aspects for nursing research. Rev Esc Enferm USP. 2021; 55:e03776. doi: 10.1590/S1980-220X2020051103776

15. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. Cad. Saúde Pública. 2011 Fev; 27(2):389-394. doi: 10.1590/S0102-311X2011000200020

16. Fonner VA, Geurkink D, Chiwanga F, Amiri I, Likindikoki S. Long-Distance Travel for HIV-Related Care-Burden or Choice? A Mixed Methods Study in Tanzania. AIDS Behav. 2021; 25:2071-83. doi: 10.1007/s10461-020-03136-1

17. Coelho B, Meirelles BHS. Care sharing for people with HIV/AIDS: a look targeted at young adults. Revista Brasileira de Enfermagem. 2019; 72(5):1341-1348. doi: 10.1590/0034-7167-2018-0248

18. Ministério da Saúde (BR). Caderno de Boas Práticas em HIV/Aids na Atenção Básica. Brasília, DF; 2014. [Internet]. 2014 [acceso 2023 jun 18]. Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/caderno_boas_praticas_hiv_aids_atencao_basica.pdf

19. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Cinco passos para implementação do manejo da infecção pelo HIV na Atenção Básica. Brasília (DF): Ministério da Saúde; 2017. [Internet]. 2017 [acceso 2023 jun 18]. Disponível em: http://antigo.aids.gov.br/pt-br/pub/2014/5-passos-para-implementacao-do-manejo-da-infeccao-pelo-hiv-na-atencao-basica

20. Melo A, Barbosa TM. Activities of the family health support core: the understanding of the family health strategy professionals of a municipality of Santa Catarina. Tempus. 2018; 11(2):25-39. Disponível em: 10.18569/tempus.v10i4.2286

21. Prefeitura de Florianópolis (BR). Saúde. Pack Brasil Adulto: Versão Florianópolis. Kit de Cuidados em Atenção Primária. Ferramenta de manejo clínico em Atenção Primária à Saúde. University of Cape Town Lung Institute's Knowledge Translation Unit, 2020. Título original: Practical Approach to Care Kit - PACK Global Adult. [Internet]. 2020 [acceso 2023 jun 18]. Disponível em: https://knowledgetranslation.co.za/download/15025/

22. Wu X. Promoting nursing development towards health for all: overview and prospect of nursing development in China. International Journal of Nursing Sciences. 2023; 10(1):1-4. doi: 10.1016/j.ijnss.2022.12.011

23. Lima MCL, Pinho CM, Silva MAS, Dourado CAR de O, Brandão BMGM, Andrade MS. Percepção dos enfermeiros acerca do processo de descentralização do atendimento ao HIV/Aids: testagem rápida. Esc Anna Nery. 2021;25(4):e20200428. doi: 10.1590/2177-9465-EAN-2020-0428

24. Colaço AD, Meirelles BHS, Heidemann ITSB, Vilarinho MV. Care for the person who lives with HIV/aids in primary health care. Texto & Contexto - Enfermagem. 2019; 28:e20170339. doi: 10.1590/1980-265X-TCE-2017-0339

25. Guilamo-Ramos V, Thimm-Kaiser M, Benzekri A, Hidalgo A, Lanier Y, Tlou S, et al. Nurses at the frontline of public health emergency preparedness and response: lessons learned from the HIV/AIDS pandemic and emerging infectious disease outbreaks. The Lancet Infectious Diseases. 2021; 21(10):e326-e333. doi: 10.1016/S1473-3099(20)30983-X

26. Gonçalves GF, Cordeiro BC, Dias MM, Messias CM. Permanent education in patient assistance with HIV: an integrating review. Research, Society and Development. 2020; 9(3):e70932426. doi: 10.33448/rsd-v9i3.2426

27. Ministério da Saúde (BR). Secretaria de Gestão do Trabalho e da Educação na Saúde. Departamento de Gestão da Educação na Saúde. Política Nacional de Educação Permanente em Saúde: o que se tem produzido para o seu fortalecimento? 1. ed. rev. Brasília: Ministério da Saúde, 2018. [Internet]. 2018 [acceso 2023 jun 18]. Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/politica_nacional_educacao_permanente_saude_fortalecimento.pdf

28. Ferreira L, Barbosa JSA, Esposti CDD, Cruz MM da. Educação Permanente em Saúde na atenção primária: uma revisão integrativa da literatura. Saúde em Debate. 2019; 43(120):223-239. doi: 10.1590/0103-1104201912017

29. Lujintanon S, Amatavete S, Sungsing T, Seekaew P, Peelay J, Mingkwanrungruang P, et al. Client and provider preferences for HIV care: Implications for implementing differentiated service delivery in Thailand. J Intern AIDS Society. 2021; 24(4):e25693. doi: 10.1002/jia2.25693

30. Kleinubing RE, Langendorf TF, Padoin SMM, Paula CC. Construção de uma linha de cuidado para atenção à saúde de mulheres vivendo com HIV. Escola Anna Nery. 2021; 25(5):e20210033. doi: 10.1590/2177-9465-EAN-2021-0033

Funding: PhD Scholarship from the UNIEDU/FUMDES Graduate Program; PhD Scholarship from the Coordination for the Improvement of Higher Education Personnel - CAPES/PROEX. This paper was carried out with the support of the Coordination for the Improvement of Higher Education Personnel (*Coordenação de Aperfeiçoamento de Pessoal de Nível Superior*, CAPES) - Brazil - Funding Code 001.

Authorship contributions

1 – Fernanda Karla Metelski
Corresponding author
Nurse, PhD in Nursing - fernanda.metelski@gmail.com
Conception and/or development of the research and/or writing of the manuscript; review and approval of the final version.

2 – Ianka Cristina Celuppi
Nurse, MSc in Nursing - iankacristinaceluppi@gmail.com
Conception and/or development of the research and/or writing of the manuscript; review and approval of the final version.

3 – Betina Hörner Schlindwein Meirelles
Nurse, PhD in Nursing - betina.hsm@ufsc.br
Conception and/or development of the research and/or writing of the manuscript; review and approval of the final version.

4 – Bruna Coelho
Nurse, MSc in Nursing - bruninhahcoelho@gmail.com
Review and approval of the final version.

5 – Marcelle Miranda da Silva
Nurse, PhD in Nursing - marcellemsufrj@gmail.com
Review and approval of the final version.

6 – Wilson Jorge Correia Pinto de Abreu
Nurse, PhD in Education - wjabreu@esenf.pt
Review and approval of the final version.

Scientific Editor in Chief: Cristiane Cardoso de Paula

Associate Editor: Aline Cammarano Ribeiro

How to cite this article

Metelski FK, Celuppi IC, Meirelles BHS, Coelho B, Silva MM, Abreu WJCP. Best practices in the care provided to people living with HIV in different care models. Rev. Enferm. UFSM. 2023 [Access on: Year Month Day]; vol.13, e34:1-22. DOI: https://doi.org/10.5902/2179769284152