

The 'secrecy' about the diagnosis of HIV / Aids in Primary Health Care

O "segredo" sobre o diagnóstico de HIV/Aids na Atenção Primária à Saúde (resumo: p. 16)

El 'secreto' sobre el diagnóstico de VIH/Sida en la Atención Primaria de la Salud (resumen: p. 16)

Daniely Sciarotta^(a)

<dany.sciarotta@gmail.com> 

Eduardo Alves Melo^(b)

<eduardo.melo@ensp.fiocruz.br> 

Jorginete de Jesus Damião^(c)

<jjdamiao@yahoo.com.br> 

Sandra Lúcia Filgueiras^(d)

<filgueiras.sandralucia@gmail.com> 

Mônica Villela Gouvêa^(e)

<monicagouvea@gmail.com> 

continue on page 13

^(a) Programa em Saúde da Criança e da Mulher, Instituto Fernandes Figueira (IFF), Fundação Oswaldo Cruz (Fiocruz). Avenida Rui Barbosa, 716, 4º andar, Prédio Mário Olinto, Flamengo. Rio de Janeiro, RJ, Brasil. 22250-020.

^(b) Departamento de Administração e Planejamento em Saúde, Escola Nacional de Saúde Pública (ENSP), Fiocruz. Rio de Janeiro, RJ, Brazil.

^(c) Departamento de Nutrição Social, Instituto de Nutrição, Universidade do Estado do Rio de Janeiro. Rio de Janeiro, RJ, Brasil.

continue on page 13

This study analyzed the process of decentralizing of care for people living with HIV / Aids (PLHA) in the city of Rio de Janeiro, RJ, Brazil, emphasizing secrecy. We conducted interviews with patients and workers, focus groups with professionals and participant observation in two Primary Health Care units. Guided by a socio-anthropological approach, the results addressed the reasons for secrecy for PLHA, the management of confidentiality among PHC health professionals and the repercussions of secrecy for healthcare practices, highlighting the singular position of community health agents. The study reveals the implications of the territorial characteristic of Brazilian PHC for the care of PLWHA, increasing access, albeit risking a breach of confidentiality, showing the need for management to face stigma and improve care.

Keywords: Secrecy. Primary Health Care. Decentralization. Care. HIV / Aids.



Introduction

The care for people living with HIV/Aids (PLHA) in the Brazilian National Health System (SUS) was configured in the 1980s in the Specialized Care Services (SAE). As of the 2000s, some municipalities - such as Rio de Janeiro and Curitiba - began to adopt decentralized models, becoming the recommendation of the Ministry of Health for the organization of care for PLHA¹⁻⁵. In these models, assistance is also provided in Primary Health Care (PHC), in a scenario where the SAE appears as a back up for more complex cases or those with higher clinical risk, through “risk stratification”.

In this regard, considering care from an “insider” perspective, the family health team is expected to invest in building relationships of trust with individuals and family members, which involves, among other things, the preservation of privacy. The literature on HIV/Aids and primary care⁶⁻⁹ reveals an important paradox that guides this discussion. On the one hand, the implementation of decentralization facilitates physical access to the unit and improves the care practices insofar as it produces greater knowledge of the users' reality. On the other hand, due to stigma and discrimination, it poses the need for secrecy and acceptance on the part of the user as a major challenge for the implementation of the policy.

This article seeks to analyze the management of secrecy about HIV diagnosis and its implications for the care of PLHA in PHC. Reflecting on this theme is key in order to make adjustments in the models of care according to the territorial reality, with the profile of the epidemic in the contemporary world. Above all, it is needed to deconstruct the permanence of stigma and discrimination that continue to constitute barriers to the exercise of the right to health as a pillar of citizenship.

Method

The article is linked to the research “The care for people with HIV/Aids in the health care network”, a qualitative investigation whose data were produced from participant observation techniques, in-depth interviews with health professionals, focus groups (doctors and community health agents) and formal and informal interviews with PLHA. We conducted 80 interviews, three focus groups and participant observation in units and territories.

The fieldwork was carried out in the municipality of Rio de Janeiro between April 2018 and November 2019 in Programmatic Area (PA) 1.0, which has approximately 300,000 inhabitants. The study involved two PHC services and 13 of 75 family health care teams (FHCT). One of the primary health care units (BHU1) had approximately 100 PLHA with known diagnosis, while in the other (BHU2), there were 84 PLHA enrolled.

The units are located in the central region of the city and suffer from the impacts of armed violence in the territories, inhabited mostly by low-income population, especially in the hills, where most of the registered population resides.



The two units function as internship settings for undergraduate students, however, from the organizational point of view, they are quite different from each other. While the BHU1 works only with the family health model with 8 FHCTs covering about 25 thousand people, the BHU2 has 3 FHCTs and some medical specialties covering approximately 14 thousand people. BHU1 does not administer antiretroviral drugs (ARV), although this type of supply is performed by BHU2. Another difference is that BHU2 already collects CD4 and viral load monitoring tests, while BHU1 started to do so during the course of the research.

In this article we discuss three categories related to the management of secrecy that emerged from the empirical data: (1) Stigma and the Territory; (2) The impact of secrecy on PHC relationships and finally; (3) Implications for the care of PLHA. We seek to analyze secrecy guided by authors such as Simmel¹⁰ and Elias & Scotson¹¹, which discuss secrecy as a constitutive element of social relations, considering elements related to morality, subjectivity, and social interaction. The management of the secrecy of the HIV/Aids diagnosis in the care relationships in PHC, seen through these perspectives, raises some questions about the concealment of the diagnosis of PLHA in the intra-team context, the meanings produced by this concealment, and the possible impacts on the care of PLHA.

The research followed the ethical recommendations of the Resolution 510/16¹² of CONEP, and was approved by the Research Ethics Committees of the proponent institution and of the RJ Municipal Health Secretariat under opinions number 2.309.404 and 2.559.884, respectively. The participants were informed about the research objectives and consented to participate.

Results e discussion

Stigma and the territory

Goffman¹³ defines stigma as a characteristic of the subject that, socially transformed into a negative attribute, disqualifies them and creates obstacles to their access to material and symbolic goods. Parker^{14,15} reviews this concept in the context of the HIV/Aids epidemic, from a perspective that also considers the political, economic, and historical dimensions. In this approach, he argues that it is necessary to perceive stigma not only as a negative mark, but also as a social process. According to the author^{14,15}, PLHA tend to be invisible and stigmatized, so many do not share the diagnosis even with their families. Other authors show how stigma can also generate feelings of worthlessness and compromised self-esteem¹⁶.

It is worth recalling with Susan Sontag¹⁷ that the processes of stigmatization of many diseases were built on the perceived inappropriateness of the behavior of those affected. The stigma related to the Aids epidemic stems from historical processes of homophobia, social rejection of the use of some drugs, and the practice of sex for money by women.



The federal Law nº 12.984/2014 establishes discrimination against PLHA as a crime, penalizing it even in professional environments¹⁸. But despite many advances, especially biomedical ones, in fact discrimination and prejudice still substantially affect PLHA. Parker¹⁵ recalls that, with the benefits of antiretroviral therapy, it was believed that the stigma would disappear, which didn't happen. The moral notions still mark the epidemic and harm people's social life, so many prefer to keep their condition a secret. This also overlaps with other inequalities, such as racial, gender, and class inequalities. These synergies make the stigmas worse and harder to address¹⁵.

Bearing in mind the decentralization of care for PLHA to PHC, the fear of exposure of intimate and private life issues and/or the stigma attached to the disease may make users prefer to be followed in units far from their homes or, in the case of those who continue to be cared for in the territory where they live, it may mean a constant attempt to keep their condition confidential. The issue becomes evident when doctors tell us that "It's hard for some patients", because being seen in a BHU close to home can generate fear for most PLHA:

...this patient, he was terrified of the possibility that the community may be knowing his diagnosis. Terrified. Terrified.

...he (the patient) thinks that if he comes (to the unit), some neighbor, someone will get to know.

Let's consider the case of a 42-year-old black woman who hides her diagnosis from her family members, evidencing her fear of not fitting into an "ideal motherhood" model¹⁹: "I don't want to ruin the way my children see me". Other reasons for keeping her condition of living with HIV a secret are related to her profession as a manicurist. She believes that if people knew about her diagnosis, she would lose many clients, especially since most of them live in the same community. Another respondent said that he has to keep his HIV status hidden because he is a baker, near where he lives, and fears that revealing his diagnosis could be seen as harmful to a person who works handling food.

The statements bring us reflections about the power of territorialized care for PLHA and reveal that the stigma of HIV, as well as different forms of discrimination, manifest themselves according to the patterns of sociability as deployed in different territories. It is needed to remember that the basic health network structured on the territorial logic includes not only the physical dimension of territory, but also in the existential dimension, where life is produced²⁰.

The findings presented here indicate aspects of the strategy of decentralization of care for PLHA to PHC, pointing to the need for deeper social changes that allow the confrontation of Aids stigma, an essential condition for the control of the epidemic.



The formats of sociability revealed in the researched territories are configured based on spatial and human geographical arrangements. The proximity of the houses and sharing of spaces can sometimes hinder any kind of privacy, besides encouraging very close relationships between neighbors²¹. However, the true understanding of privacy is compromised due to the configuration of the social norms prevailing in the territories²². In other terms, the alternative to share or not is often a collective decision, including HIV diagnosis.

We define “gossip” in a sense close to that of Elias & Scotson¹¹, as “ more or less derogatory information about others, transmitted by two or more people to each other” (p. 121). If we take the ideas of these authors to the field of HIV we see that gossip has as its main social functions to inform the reputation of the residents of a place, consolidating or damaging its public image and reinforcing the social cohesion of networks²³. HIV-related gossip can contribute to devaluing one’s social image, since the epidemic is still associated with deviant behavior, thus contributing to accentuate its stigma. Thus, as with the findings of Silva & Vieira²⁴, the interviewees tended to conceal their diagnosis in the BHU, as they consider the unit as part of their neighborhood network, and therefore as a potential agent of gossip transmission.

Considering the territorial settings where the PLHA who participated in the research live, we note that symbolic violence and armed violence are combined in them. The stigma has a great impact on social relations and can bring fear of losing a job, family fights, and, in the most extreme cases, situations of violence and risk of death, as one professional reported referring to the case of a person he works with: “if they find out I have HIV they will kill me, because I had sex with so-and-so and so-and-so”.

The speech below, from a Community Health Worker (CHW), summarizes the marked presence of stigma in these territories and points us to some challenges for care:

Nobody will want to say that he has HIV, even more an actor (drug dealer), because he lives a very promiscuous life. An actor has several women. Do you understand? Also, because people still think that HIV can also be caught by touch, by hugging, by kissing. Can you believe it? That guy is at the peak of his popularity with several women, several young girls. He can't, because he is sick. None of them wear condoms.

The management of secrecy, organization of care and PHC relationships

Faced with the problem of diagnostic disclosure, both health professionals and users employ strategies to try to maintain HIV confidentiality. They often do not record the diagnosis in open medical records and conduct more careful home visits so as not to draw attention to a person or household. People who come to the reception to revalidate their antiretroviral prescription often use subterfuge to get care, such as writing ‘HIV’ on a piece of paper to tell the CHW that they need a specific type of care, or reporting a symptom of non-existent disease to quickly access medical care.



Although there are situations related to the ways of organizing the work process and the routine flows of services that can break the confidentiality of HIV diagnosis. The seriousness of the clinical condition or the result of tests may lead the PLHA to need immediate care. In an attempt to find it, the physician may end up confiding in the CHW about the patient's positive status. Also in prenatal care we identify this paradox when faced with the HIV diagnostic revelation.

We observed among the professionals some daily strategies when faced with the impasse of diagnostic disclosure. According to a CHW, "the procedure had to be in a place (...) more reserved", because, as another CHW revealed to us, the difficulty of maintaining confidentiality within the unit is due to the work processes themselves:

Especially because of the protocol, the way things are done, you know? You get the paper from the rapid test and go to the procedure. Then, I'll wait for their procedure. Meanwhile, the person is sitting there at the door. Then, they get the prescription and go there. Then, the girl from the pharmacy goes there, gives them Penicillin. Then, they go there and take Penicillin. Then, they leave with their ass hurting. So, everyone in the waiting room already knows. Already knows (that it could be syphilis)

In the excerpts below, the physician discusses the distrust that a patient's transfer raises for the CHW and the tension that can exist in intra-team disclosure.

And the patient was referred to (SAE Y), because the HIV pregnant woman will be referred. And then she said, "And why is the pregnant woman going to (SAE Y)?"

Then with the CHWs I would talk to them like this: 'No patient is forced to tell you about their diagnosis [...], you have to help your team, the nurse or the doctor in charge. You have to help in the following way: if the doctor comes to you and says: Oh, look for so-and-so, I need you to pick them up at home and bring them to my appointment. You don't need to know what it is.

The concealment of information from certain people can contribute to making it have a special value, according to Simmel¹⁰. Since HIV/Aids is a health condition generally not shared between the CHWs and the rest of the team, the moments when the secret is ratified (as in the speech above) can simultaneously be understood as possible forms of disclosure.

Keeping the diagnosis secret from some of the team may paradoxically compromise the guarantee of professional confidentiality, giving room for those who do not "officially" know not to commit to confidentiality. In addition, the opportunity to work on this issue in the team, and to strengthen the desired interdisciplinary work may be lost.



Interviewer: [...] you also talked about team meetings. [...] HIV/Aids is talked about in a team meeting?

CHW: No. The subject is talked about like this: 'M, look, I need such and such patient, who is in a more delicate situation; I want you to go after him. Sometimes they say something or another, and then you connect the dots.

The perception about the professional practice of CHWs when faced with HIV cases was evident in the interviews. On the one hand, some professionals defended the need for CHWs to know about all diagnoses, as one physician pointed out: "they need to know, after all, they are part of the team". Other professionals reported that the CHWs do not have access to the medical records and diagnosis, or that they do not record the serological status in the medical record to prevent the CHWs from accessing such information.

In some teams the CHW responsible for the family of the PLHA has access to the diagnosis, but most of the time the technicians only reveal it to the CHW in extreme situations, when they need help in contacting the users. The CHWs figure, therefore, as the people who are closest to the 'breach of confidentiality', both in the imaginary of health professionals and the population. The presence of the CHWs often seemed to increase some people's feelings of insecurity, as we see below:

... she was diagnosed as positive, the first thing she said was, "I don't want my community health worker to know."

we gave her the option: "do you want us not to put it in the medical record?" [...] She said it was okay, but that the only restriction she wanted was for the community workers not to know, that she was afraid that this story would leak within the community, and the community would see her in a different way.

Although health professionals have highlighted the importance of CHWs in the units, recognizing them as links to the community, some narratives show that they are seen in a pejorative way "we know that the CHWs are very gossipy". There was even some talk of "CHWs and technicians unprepared or misguided" who make comments that are "prejudiced, derogatory, and even offensive." Referring to a unit in another part of the city, a doctor tells us:

There was a unit in which the CHW [...] was the ex-girlfriend of the current boyfriend of a young girl who was pregnant, so if the pregnant girl did the test and it was positive, the CHW wanted to know. Did you get it?

In turn, representatives of social movements also report problems with confidentiality in PHC by linking them to CHWs:



I chose to be an activist, I chose to show my face and show my experience and my serology. People in the territory are not necessarily forced to do that. They do it if they want to, when the service imposes this to be done, as it often happens in cases that we receive from community workers who reveal the diagnosis: “So-and-so, your HIV is ready”; “Go there. Go get your antiretroviral”.

Privacy is a right of PLHAs, and the communication or not of the diagnosis to the CHWs is a patient’s decision, according to the norms of the municipal management of Rio de Janeiro⁵. Although the CHWs are one of the FHCT members responsible for the care of the users of the unit and professional-ethical confidentiality is also required of them, the disclosure of information regarding HIV diagnosis to them results in concern.

Despite the fact that there are strategies to hide the HIV diagnosis from the CHWs, they do find out who the PLHAs are within the territory, sometimes in a procedural and indicative way. Throughout the times that we talked to the CHWs in the research camps, they expressed that even if doctors, other health professionals, and/or patients try to hide the diagnosis, they eventually find out, as one of the CHWs expressed during a focus group: “at some point we will know”.

The CHWs mentioned that they connect the facts, are suspicious of some conversation and deduce according to prescriptions, notice frequency in the BHU, regular visits to the pharmacy or other things:

...you start to notice, the patient comes regularly, takes the medicine regularly. I think that the TIG (immunologic pregnancy test) is more eye-catching because we have already seen the rapid test, it already gives you an idea of maybe you have (HIV), maybe not.

Meanwhile, as at some point this information “will end up reaching” the CHWs, they told us that they have to manage the secret of the diagnosis, even pretending that they don’t know about it.

Some professionals argued that knowing the diagnosis qualifies their performance:

... there are some that don’t want to talk. We know they have it, but they don’t want to talk. Do we know why? We are a team. And in team meetings cases are discussed. It is a team secret. ... even if he doesn’t want to talk, I won’t tell him, you have it. No, I will respect that.

That is what I say in the welcoming room. What is your complaint, what is the purpose? Oh, I need a prescription. Prescription for what? A prescription for continued use. And you don’t want to talk. But we end up knowing, because of these meetings that we have and that we discuss the cases. And so, even because they have to get the prescription, we have to know who is who in order to give priority. No, this one has to be seen today.



The concern with maintaining the confidentiality of the diagnosis and the possible consequences of its disclosure in the community demonstrates the importance of this theme being included in the continuing education processes and in the daily management of the work and care process. In addition, the development of formative activities for the care of PLHAs with the participation of CHWs can help deal with the paradox of territorialization, since they occupy a strategic position in this relationship between service and community, since they belong to both²⁵⁻²⁶.

We observe that CHWs establish another kind of relationship with professional secrecy because they have to deal with the mistrust of patients and all the problems that this can cause:

So, in the welcoming, no information has ever been leaked, but some of them have already thrown hints or jokes out of insecurity, of thinking that people are going to know, you know? Because you live in the same place.

Faced with those veiled threats, the CHW believes that the users' comments are related to the fear of having their diagnosis exposed, since CHWs and PLHA live in the same territory and are often neighbors. They probably fear that their condition will become 'gossip' in their social environment and degrade their image in that space. The fact that the CHWs live in the community imposes an additional challenge for the management of secrecy: "no matter how much we keep our professional secrecy, we cannot shut the others' (neighbors') mouths".

The CHWs understand the need for confidentiality in their role as health professionals: "We know, but we are also health professionals". During a focus group, when we asked how they deal with the HIV issue in their territory, the answers boiled down to the words "discretion" and "secrecy".

Nonetheless, there are other points to consider, such as the 'laws' of armed violence in the territory, which gain prominence in the narratives about professional secrecy. The fear of disclosing a diagnosis such as HIV is also related to the risk of violence and/or death, both for them and for the patients: "Lawsuit? We will die." Zambenedetti & Both⁸ (p. 49) had already pointed out that, in the territory, among health professionals and users "the word Aids or HIV is not usually mentioned, being a subject underlined in conversations". However, what we present new in this discussion is precisely how the 'unspoken' resonates differently for the CHWs.

The CHWs, besides managing the secrecy of the diagnosis as a consequence of the professional practice, they also need to manage the risks that the secrecy of the users' disease can mean to their lives and to others. The CHWs' reports also evidenced that living in the same territory leads them through nuances of a professional practice affected by the territorial and social proximity with users. As the following CHW's speech suggests:



You can even know that this person has it, through your team, through the doctor, but to closely follow up you have to be able to gain the confidence and trust of this person. For that person to open up to you as well. Because she is a resident of the community. I am also a resident of the community. So, you have to be respectful and keep it very private. Because it is something that sometimes not even the family knows. You know, because you go there, you accompany her and because you have created this bond.

Others, even though they already know the diagnosis, want the patient to reveal it to them. The CHWs understand that the secrecy of HIV can either strengthen ties or undermine social relationships with users.

The following reports speak of how a good management of secrecy can strengthen the bond between CHWs and patients. One example is the episode witnessed by two researchers during participant observation in one of the studied units. One of them asked the CHW if she followed up on any PLHA and the professional told her about the case of a lady that she periodically visited to see if she was taking ARV medications correctly: "I know she does. I don't know if she knows that I know... [pause] But there's no way she doesn't know that I know.... I always bring her medication." The CHW said that the lady never told her about HIV and she never asked either, but that she deduced that the woman imagined that she knew, after all, she took the ARVs, oriented on the use and renewed her prescription, but the topic had never been explicitly addressed by either of them. Months later, the CHW told the researchers that she had talked to the lady about HIV in a transparent way. Resorting to Simmel¹⁰, we can understand that, in this case, the secrecy, in the view of the CHW, could strengthen her relationship with the user and strengthen the bond through a confidence between them. In other words, unlike other health professionals who bond based on an explicit health problem, CHWs cannot always establish a relationship with users for an obvious health reason, as in the case of HIV. The CHW seemed to have been able to approach the user based on the secrecy of the diagnosis. But this does not always happen, especially in territories with problems of gun violence.

Implications for the care of PLHAs

HIV-related stigma reduces access to health care and services, health information and resources, and the ability to enjoy life fully and with dignity²⁷. Fear of society's reaction still causes many people not to get tested, to hide their serology, and not to get treatment.

The secret, according to Simmel¹⁰, characterizes the relationship between those involved. As we have seen, there are many ways of secrecy and revelation of the HIV/Aids diagnosis: between the user and the people of his personal acquaintance (the user decides not to disclose to the people around him/her about his/her serology), between the user and the CHW (the user decides not to disclose to this particular health care team member), between the physician and the CHW (patient choice requires that the physician does not share the diagnostic information intra-team), between the CHW and the user (now on a different track, the CHW knows the diagnosis, but cannot reveal his knowledge to the user), and between the CHW and other people in the patient's



territory (knowing the diagnosis, the CHW must maintain professional secrecy). In the penultimate case, the diagnosis is not the secret itself, but rather the knowledge of unauthorized information.

Secrecy about the CHW knowledge of the diagnosis hinders a dialogical place of care:

There is a patient in my team that we know he has it, the whole team. And he doesn't treat himself and we can't talk about it. And he is in a very exposed position. He does things that not only hurt him, but hurt other people as well. Then, I wonder: "Guys, but why can't we? No, we can't. 'But, there are so many people...'. You can't. I don't want to know what is happening. He has to tell me.

And there are people that the person doesn't even know. [...] two pregnant women that found out during pregnancy, they don't know that I know they have it, understand? I have to keep it to myself... I know that they have it. I know that her partner has it. When he comes here, he comes to get medication. But, under no circumstances, can I ask about the disease, understand? I have to be ethical, do you understand?

In an attempt to preserve diagnostic confidentiality, the CHWs limit the number of home visits so as not to arouse the suspicions of neighbors:

Even because I can't be in that person's house more often than others who don't have HIV. Why is that? We would attract attention. Then the neighbors would say: [...]. Why is the health agent coming directly?

Potential advantages of decentralized care - such as the ease of taking medications in one's own community - are reduced by the need for management of secrecy. In this sense, users with greater difficulties in adhering to treatment demand the involvement of the entire team. In this case, it is necessary to share information about the HIV diagnosis, as indicated by the narratives of the CHWs:

For many people it would be good because they can just cross the street and get their medication here, it is much more practical. But at the same time it can be bad if a neighbor sees that he came here and got HIV medicine. As there is this small distance, the patient can get there, pick it up, put it in his backpack and the issue is over. Here the pharmacy door is always open, the person is being treated here but the person in line is seeing what is going on inside.

Then the agent will know why? [...] The patient has not been to the clinic for two months, we have to do an active search to find out why he doesn't come. So we know what he has in order to do this search.



Knowing the diagnosis of the patient allows the CHW to prioritize the PLHA in the daily care, even allowing the CHW to take ownership of the care from the understanding of the function of their work:

CHW: If six months have passed and he doesn't come, the doctor comes to us to pick him up. [...] Then I tell the doctor: "He said he's coming. But he doesn't come. So he doesn't come on the second or third. On the fourth she says: "So, he is an HIV patient, he needs to be here because of this and this."

Interviewer: There comes a time when things hit the fan?

CHW: It is not a malicious breach of confidentiality; it is because we really have to have access to that patient.

Closing remarks

This article aimed to analyze elements related to the management of HIV diagnostic confidentiality in a scenario of decentralization of care for PLHA to PHC. In this sense, keeping in mind the social construction of stigma, the moralities and power relations that inform it, we highlighted aspects around which sufferings and privations are present in users facing the (possibility of) breaking confidentiality, as in work and community relationships.

In the context of PHC workers, concerns related to confidentiality, including their own physical safety, were evidenced, emphasizing the complex situation of CHWs due to the singularity of their double insertion (neighborhood resident and health worker), strategies to guarantee confidentiality among colleagues and its implications for the multiprofessional teamwork, possibilities of breaking confidentiality generated by the way the BHU is organized and operates, as well as the near impossibility that CHWs do not know the diagnosis, even if this is not made explicit. In addition, we address limitations generated by the need for secrecy for care practices.

The study brings to light the duplicity, and sometimes ambiguous repercussion of the territorial characteristic of the Brazilian PHC for the care of PLHA, which can expand access, but also the risk of breaking confidentiality, signaling the need for care in the organizational and professional practices, as well as the implementation of public policies to combat discrimination and stigma.

In this sense, the investment in continuing education actions with health teams that cover the approach of human rights, including sexual rights, the understanding of the territory in its existential dimension, as well as the processes of vulnerability in it, could favor the production of professional practices and the organization of health services necessary for the management of confidentiality in the territory and the potential of PHC in the care of PLHA.



Authors

Júlia Gonçalves Barreto Baptista^(f)

<juliagbbaptista@gmail.com> 

Rafael Agostini^(g)

<rafael.agostini.vbg@gmail.com> 

Ivia Maksud^(h)

<ivia.maksud@iff.fiocruz.br> 

Affiliation

^(d) Gerência de IST/Aids, Secretaria do Estado de Saúde do Rio de Janeiro. Rio de Janeiro, RJ, Brasil.

^(e) Departamento de Planejamento em Saúde, Instituto de Saúde Coletiva, Universidade Federal Fluminense. Niterói, RJ, Brasil.

^(f) Pós-graduanda do Programa em Saúde da Criança e da Mulher (Mestrado), IFF, Fiocruz. Rio de Janeiro, RJ, Brasil.

^(g) Faculdade de Medicina, Universidade Cidade de São Paulo. São Paulo, SP, Brasil.

^(h) Programa em Saúde da Criança e da Mulher, IFF, Fiocruz. Rio de Janeiro, RJ, Brasil.

Authors' contributions

All authors actively participated in all stages of preparing the manuscript.

Funding

The publication of this article was supported by the Research Incentive Project of the Fernandes Figueira Institute - PIP III, process 25384.100377/2019

Conflict of interest

The authors have no conflict of interest to declare.

Copyright

This article is distributed under the terms of the Creative Commons Attribution 4.0 International License, BY type (<https://creativecommons.org/licenses/by/4.0/deed.en>).



**Editor**

Antonio Pithon Cyrino

Associated editor

Dulce Aurélia de Souza Ferraz

Translator

Félix Héctor Rígoli

Submitted on

01/09/21

Approved on

07/21/21

References

1. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de DST, Aids e Hepatites Virais. Caderno de boas práticas em HIV/Aids na Atenção Básica. Brasília: Ministério da Saúde; 2014.
2. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de DST, Aids e Hepatites Virais. 5 passos para a implementação do manejo da infecção pelo HIV na Atenção Básica. Brasília: Ministério da Saúde; 2014.
3. Brasil. Secretaria Municipal de Saúde. Programa das Doenças Infecciosas Sexualmente Transmissíveis. Protocolo para introdução do atendimento ao HIV/Aids na Rede Primária de Saúde do Município do Rio de Janeiro. Rio de Janeiro: SMS-RJ; 2013.
4. Silva G. Situação da linha de cuidado à pessoa vivendo com HIV/Aids na cidade do Rio de Janeiro. In: Maksud I, Melo EA, Rocha F, Damião JJ, organizadores. Anais do Seminário Coro de Vozes numa teia de significados [livro eletrônico]: sobre o cuidado às pessoas vivendo com HIV/Aids na Rede de Atenção à Saúde. Rio de Janeiro: Sem Editora; 2020. p. 75.
5. Rio de Janeiro. Secretaria Municipal de Saúde. Subsecretaria de Atenção Primária, Vigilância e Promoção da Saúde. Superintendência de Atenção Primária. Coleção Guia de Referência Rápida. Infecção pelo HIV e Aids: prevenção, diagnóstico e tratamento na atenção Primária. Rio de Janeiro: Secretaria Municipal de Saúde; 2016. (Série F. Comunicação e Educação em Saúde) (Coleção Guia de Referência Rápida). v. 1.
6. Zambenedetti G. O paradoxo do território e os processos de estigmatização da Aids na atenção básica em saúde [tese]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2014.
7. Zambenedetti G, Both NS. Problematizando a atenção em HIV-Aids na Estratégia Saúde da Família. *Rev Polis Psique*. 2012; 2(1):99-119.
8. Zambenedetti G, Both NS. “A via que facilita é a mesma que dificulta”: Estigma e atenção em HIV-Aids na Estratégia Saúde da Família- ESF. *Fractal Rev Psicol*. 2013; 25(1):41-58.



9. 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: <https://doi.org/10.26633/RPSP.2018.151>.
10. Simmel G. The sociology of secrecy and of secret societies. *Am J Sociol*. 1906; 11(4):441-98.
11. Elias N, Scotson JL. Os estabelecidos e os outsiders. Rio de Janeiro: Jorge Zahar; 2000.
12. Brasil. Resolução nº 510, de 7 de Abril de 2016. Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais. *Diário Oficial da União*. 7 Abr 2016.
13. Goffman E. Estigma: notas sobre a manipulação da identidade deteriorada. Rio de Janeiro: Zahar; 1980.
14. Parker R, Aggleton P. HIV and Aids-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003; 57(1):13-24. Doi: [https://doi.org/10.1016/S0277-9536\(02\)00304-0](https://doi.org/10.1016/S0277-9536(02)00304-0).
15. Parker R. Estigmas do HIV/Aids: novas identidades e tratamentos em permanentes sistemas de exclusão. *RECIIS*. 2019; 13(3):618-33. Doi: <https://doi.org/10.29397/reciis.v13i3.1922>.
16. André C. Questão de autoestima. *Rev Mente Cerebro*. 2006; 14(164):48-53.
17. Sontag S. Doença como metáfora, Aids e suas metáforas. São Paulo: Companhia das Letras; 2007.
18. Brasil. Lei nº 12.984, de 2 de Junho de 2014. Define o crime de discriminação dos portadores do vírus da imunodeficiência humana (HIV) e doentes de Aids. *Diário Oficial da União*. 3 Jun 2014.
19. Batinder E. Um amor conquistado: o mito do amor materno. Dutra W, tradutor. Rio de Janeiro: Nova Fronteira; 1985.
20. Merhy EE, Feuerwerker LCM, Santos MLM, Bertussi DC, Baduy RS. Rede Básica, campo de forças e micropolítica: implicações para a gestão e cuidado em saúde. *Saude Debate*. 2019; 43(6):70-83. Doi: <https://doi.org/10.1590/0103-11042019S606>.
21. Edmundo K, Souza CM, Carvalho ML, Paiva V. 'HIV vulnerability in a shantytown: the impact of a territorial intervention', Rio de Janeiro, Brazil. *Rev Saude Publica*. 2007; 41(2):127-34. Doi: <https://doi.org/10.1590/S0034-89102007000900019>.
22. Fonseca C. Família, fofoca e honra. Etnografia de relações de gênero e violência em grupos populares. 2a ed. Rio Grande do Sul: UFRGS; 2000.
23. Maksud I. Silêncios e segredos: aspectos (não falados) da conjugalidade face à sorodiscordância para o HIV/Aids. *Cad Saude Publica*. 2012; 28(6):1196-204. Doi: <https://doi.org/10.1590/S0102-311X2012000600018>.
24. Silva L, Vieira M. (Re)pensando o HIV/Aids: novas resposta, velhos dilemas. *Braz J Dev*. 2019; 5(8):11168-88. Doi: <https://doi.org/10.34117/bjdv5n8-003>.
25. Bonet O. "Discriminação, violência simbólica e a estratégia saúde da família". In: Monteiro S, Villela W, organizadores. Estigma e saúde. Rio de Janeiro: Fiocruz; 2013. p. 49-57.
26. Bellenzani R, Santos AO, Paiva V. Agentes comunitárias de saúde e a atenção à saúde sexual e reprodutiva de jovens na estratégia saúde da família. *Saude Soc*. 2012; 21(3):637-50. Doi: <https://doi.org/10.1590/S0104-12902012000300010>.
27. Gulliford M, Figueiroa-Munoz J, Morgan M. Meaning of access in health care. In: Gulliford M, Morgan M, editores. Access to health care. London: Routledge; 2013. p. 1-12.



Este estudo analisou o processo de descentralização do cuidado de pessoas vivendo com HIV/Aids (PVHA) na cidade do Rio de Janeiro, RJ, Brasil, com ênfase na questão do sigilo. Foi realizado por meio de entrevistas com usuários e trabalhadores, grupos focais com profissionais e observação participante em duas unidades de Atenção Primária à Saúde (APS). Guiados por uma abordagem socioantropológica, os resultados abordaram os motivos do sigilo para as PVHA, a gestão do sigilo entre os profissionais de saúde da APS e as repercussões do sigilo para as práticas de cuidado, destacando a posição singular dos agentes comunitários de saúde. O estudo traz à tona implicações da característica territorial da APS brasileira para o cuidado com as PVHA, podendo ampliar acesso, mas também o risco de quebra do sigilo, evidenciando necessidade de seu manejo para o enfrentamento do estigma e melhoria do cuidado.

Palavras-chave: Sigilo. Atenção Primária à Saúde. Descentralização. Cuidado. HIV/Aids.

Este estudio analizó el proceso de descentralización del cuidado de personas que viven con VIH/Sida (PVVS) en la ciudad de Río de Janeiro (Estado de Río de Janeiro), Brasil, con énfasis en la cuestión del sigilo. Se realizó a partir de entrevistas con usuarios y trabajadores, grupos focales con profesionales y observación participante en dos unidades de Atención Primaria de la Salud (APS). Guiados por un abordaje socio-antropológico, los resultados abordaron los motivos del sigilo para las PVVS, la gestión del sigilo entre los profesionales de salud de la APS y las repercusiones del sigilo para las prácticas de cuidado, destacando la posición singular de los agentes comunitarios de salud. El estudio presenta implicaciones de la característica territorial de la APS brasileña para el cuidado de las PVVS, pudiendo ampliar acceso, pero también el riesgo de ruptura del sigilo, poniendo en evidencia la necesidad de su manejo para el enfrentamiento del estigma y mejora del cuidado.

Palabras clave: Sigilo. Atención Primaria de la Salud. Descentralización. Cuidado. VIH/Sida.