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Research Article

Challenges of care practices in Primary Health Care for people living with HIV

Desafios das práticas de cuidado na Atenção Primária à Saúde a pessoas que vivem com HIV

Desafíos de las prácticas asistenciales en la Atención Primaria de Salud para personas que viven con VIH

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Abstract

Introduction: In the context of care and challenges involved in shifting the care for people living with the human immunodeficiency virus (PLHIV) to Primary Health Care, objects, actions and meanings are involved in the relationships established in this scenario of practices. **Objective:** To analyze different care relationships in the development of practical success and impasses in the care for this population within this context. **Methods:** Participant observation and semi-structured interviews with healthcare professionals and patients at a Family Clinic in the city of Rio de Janeiro, Brazil, involving Annemarie Mol's concept of "practicalities," which explores the operational, attitudinal, and relational arrangements observed from the logic of care and the logic of choice. In the logic of care, practicalities act as mediators that seek to overcome moral, technical, and social limits, without predetermining or transferring responsibility for the results, which happens in the logic of choice. **Results:** The issues involved in the care arrangement for PLHIV in Primary Health Care may involve barriers to access and adherence to treatment related to confidentiality, but they can also provide opportunities for deepening these issues. **Conclusions:** Different elements can mediate new care relationships for PLHIV.

Keywords: HIV; Ethics, medical; Primary health care; Integrality in health; Retention in care.

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Resumo

Introdução: No contexto do cuidado e dos desafios presentes no deslocamento da assistência a pessoas que vivem com o vírus da imunodeficiência humana (PVHIV) para a Atenção Primária à Saúde, objetos, ações e sentidos estão envolvidos nas relações desenvolvidas neste cenário de práticas. **Objetivo:** Analisar diferentes relações de cuidado no desenvolvimento do sucesso prático e os impasses na atenção a essa população, nesse contexto. **Métodos:** Observação participante e entrevistas semiestruturadas com profissionais de saúde e pacientes em uma Clínica de Família no município do Rio de Janeiro, envolvendo o conceito de "praticalidades" de Annemarie Mol, que explora os arranjos operacionais, atitudinais e relacionais observados da perspectiva da lógica do cuidado e da lógica da escolha. Na lógica do cuidado, as "praticalidades" atuam como mediadores que buscam superar limites morais, técnicos e sociais, sem predeterminar ou transferir a responsabilidade dos resultados, como na lógica da escolha. **Resultados:** As questões envolvidas no arranjo assistencial às PVHIV na Atenção Primária à Saúde podem envolver barreiras ao acesso e adesão ao tratamento relacionadas ao sigilo, mas também podem viabilizar oportunidades de aprofundamento dessas questões. **Conclusões:** Diferentes elementos podem ser mediadores de novas relações de cuidado para com as pessoas que vivem com o HIV.

Palavras-chave: HIV; Ética médica; Atenção primária à saúde; Integralidade em saúde; Retenção nos cuidados.

Resumen

Introducción: en el contexto del cuidado y de los desafíos presentes en el desplazamiento de la atención a las personas que viven con VIH para la Atención Primaria de Salud, objetos, acciones y significados están involucrados en las relaciones que se desarrollan en este escenario de prácticas. **Objetivo:** analizar diferentes relaciones de cuidado en el desarrollo de éxitos prácticos y de impasses en el cuidado de esta población en este contexto. **Métodos:** observación participante y entrevistas semiestructuradas con profesionales de la salud y pacientes de una Clínica de la Familia de la ciudad de Río de Janeiro, involucrando el concepto de "practicalidades" de Annemarie Mol, que explora los arreglos operacionales, actitudinales y relacionales observados desde la lógica del cuidado y la lógica de la elección. En la lógica del cuidado, las "practicalidades" actúan como mediadores que buscan superar los límites morales, técnicos y sociales, sin predeterminar ni transferir la responsabilidad por los resultados, como en la lógica de la elección. **Resultados:** las cuestiones involucradas en el arreglo del cuidado de las personas que viven con VIH en la Atención Primaria de Salud pueden implicar barreras de acceso y adhesión al tratamiento relacionadas con el secreto, pero también pueden brindar oportunidades para profundizar en estas cuestiones. **Conclusiones:** diferentes elementos pueden mediar nuevas relaciones de cuidado para las personas que viven con VIH.

Palabras clave: VIH; Ética médica; Atención primaria de salud; Integralidad en salud; Retención en el cuidado.

INTRODUCTION

The process of decentralizing care for people living with the human immunodeficiency virus (PLHIV) was part of the movement to strengthen Primary Health Care (PHC) in Brazil[1], from 2002 onwards. Access to tests (including rapid tests)[2] and the free distribution of Antiretroviral Therapy (ART) by the Brazilian Unified Health System (SUS)[3] have facilitated this displacement.[1,2] In Rio de Janeiro (state of Rio de Janeiro, Brazil) and other municipalities with greater PHC structure, this process intensified as of 2013.[1,4] Outpatient clinics specialized in infectious diseases began playing a secondary role as a reference center for more complex situations, but they also maintained the care of people already followed up before the decentralization policy.[1]

The attributes of PHC[5] are believed to have potential to tackle treatment-related difficulties and the social, moral, and emotional repercussions related to the disease,[1,2] guaranteeing access, comprehensiveness, and equity, in addition to protecting the rights of the most vulnerable people.[6,7]

This potential faces difficulties resulting from the physical and relational proximity of the teams to the territory and families. These have been little investigated in the literature, which emphasizes the managerial aspects of this shift of care for PLHIV[2] to PHC. However, this approach seems insufficient to tackle the issues emerging from this new context.

Participants from PLHIV[8] groups also point to gaps in care experiences in PHC. Confidentiality and bonding, for example, are repeatedly described as challenges, representing barriers to access and continuity of care for patients and Family Health teams (FHT).

In this study, we aimed to investigate the ethical and practical challenges and dilemmas of the care for PLHIV in PHC. For this purpose, the perspective of Annemarie Mol[9] on "practicalities" was considered, which represent the observation and interpretation of the relationships between people and their relationship with the objects involved in care. According to Mol,[10] practices would not be defined beforehand. Reality would be modeled based on them, on interactions, moving away from fixed positions, recognizing and integrating the connection between multiple performances of reality, instead of isolating them.[10]

In the relationships and meanings established on a daily basis between patients, services, procedures, and healthcare professionals, Mol[10] understands the existence of two logics: that of choice and that of care. According to the logic of choice, patients are responsible for determining aspects such as places of care, adherence to treatment, sharing of the diagnosis, established bonds, among others, and, consequently, they are also responsible for the results. A symmetry is assumed between the parties involved in care, regardless of conditions of suffering, vulnerability, and limitation due to illness. Conversely, the logic of care is based on the perspective of sharing decisions and results. Care is not limited to results; it encompasses experiences and can be understood based on the performances of those who are involved and of what is involved in care.[9,10]

This research was based on the perspectives and performances of PLHIV themselves and healthcare professionals. We sought to analyze the different care relationships for the development of practical success[11] and to investigate impasses produced in the care for PLHIV in the context of PHC.

METHODS

This is an exploratory study with qualitative methodology that analyzes the aspects involved in the PLHIV care process in PHC, by the participant observation[12] of consultations and procedures, as well as semi-structured interviews[13] with FHT professionals and patients, based on the researcher's master's thesis entitled *Estudo das relações de cuidado de pessoas que vivem com HIV na Atenção Primária à Saúde no município do Rio de Janeiro* ["Study on care relationships between people living with HIV in Primary Health Care in the city of Rio de Janeiro, Brazil"].

The study setting was a family clinic — a health center in the city of Rio de Janeiro (state of Rio de Janeiro, Brazil) — with six FHT, representing a comprehensive and more qualified PHC context[14,15] because it comprises a residency program in Family and Community Medicine (*Programa de Residência em Medicina de Família e Comunidade* – PRMFC), among other aspects. This clinic, inaugurated in 2010, is located in a neighborhood with a very low human development index, which is the scene of recurrent armed conflicts.

The research was triggered by the researcher's previous experiences as a family and community physician in the care of PLHIV and the participation in PLHIV support groups at a university outpatient clinic. The flexible study design[12] enabled to recognize gaps and barriers to be analyzed for the qualification of care.

Participant observation[12] took place weekly, from September to October 2018, with records in a field diary. The aim was to understand interprofessional relationships — between patients and professionals and with everyday clinical care settings/actions such as offices, waiting rooms, rooms for exams and other procedures, and drug dispensing.

In the interviews with patients, the authors sought to focus on their narratives about aspects and meanings of living with HIV and care experiences. Among healthcare professionals — family and community physicians from the PRMFC, community health workers (CHW), and pharmacists —, perceptions, doubts, and feelings regarding care for PLHIV were investigated.

The interviews were recorded and transcribed, with pre-analysis, skimming, and thematic analysis,[16] elaborating categories of analysis.[13,16]

The project was approved by the Research Ethics Committee: Certificates of Presentation for Ethical Consideration — CAAE 95390918.3.0000.5238 and 95390918.3.3001. Informed Consent Form was applied to participants, mediated by the assistant team.

RESULTS AND DISCUSSION

The triangulation between material from the field diary, interviews, and theoretical references enabled us to identify the meanings of the developed practicalities, comprising four analytical categories, presented and discussed next:

Challenges and practicalities of living with HIV in vulnerable situations

Six professionals aged between 30 and 41 years, with gender identity of cisgender women and men, were interviewed. Characterizing the professionals' gender identity may reflect the appropriation of different social dynamics and the resignification of the spheres of sexual practices and social perceptions of PLHIV.[17,18]

The four interviewed patients were cisgender men aged 24 to 40 years. Women's absenteeism from appointments made their interview unfeasible. Half of the patients were mixed-race and the other half were white.

The vulnerability of the interviewed patients was strongly associated with violence, even on the part of the State.[19,20] Structural violence and social inequality are reflected in health due to the exposure of PLHIV to conditions of negligence, discrimination, physical violence, and the imposition of moral and behavioral norms that echo the power relations involved.[22,23]

> My community is already poor, it's already violent, and we keep thinking about the accumulation of vulnerabilities, right? Women, Black people, the poor, [...] and living with HIV [...] it's really tough. (Physician 1)

The diagnosis of HIV infection involved direct repercussions, such as fear of reactions in the community, and indirect ones such as difficulty accessing healthcare services.

> I just wanted to disappear, I wanted to kill myself [...]. It was only recently, in the last few weeks, that I decided to take care of myself. (Patient 2)

For healthcare professionals, the marks of infection may reflect an exclusively biotechnological approach: tests with positive results, medical reports, ART prescriptions, and disease codes, disregarding people's perceptions and experiences.[24] For patients, objective and subjective marks at the time of diagnosis are contextual and relational, in addition to influencing the preparation of their therapeutic itinerary.[25,26] Such involves routes and arrangements through spaces and elements including attention, an itinerary planned to deal with each experienced situation.[27,28]

In these arrangements, elements interact, organize, and enable actions such as mediators, promoters, or inhibitors of care.[29] They may be individuals, professionals, patients, exams, medications, groups, or other resources relevant to the articulation of health actions that interfere, either directly or not, as inhibitors (perpetuating conflicts) or collaborators (supporting the process)[30]. According to Mol,[10] these actions and interactions comprise practicalities: affective and social relations, bodily manifestations and their implications.

> Besides, do you know what I heard from my husband today? That I'm ugly, that I'm thin like a "crackhead." (Pharmacist 1, mentioning a woman contaminated by her husband)

Situations involving gender-based violence against women[31] and related to sexual diversity,[32] associated with stigma, impact the experienced suffering and the therapeutic itinerary of PLHIV. In fact, the impact on the various spheres of life of those who discover the infection may involve changes, resignifying, and reformulations of the everyday life.

> I constantly try to take my medicines correctly. As for having relations, I'm not having it [...], sometimes I'm even afraid of it [...]. I think [HIV] interferes with the job issue as well. (Patient 4)

The interviewees spoke about dealing with social ruptures, the worthlessness caused by stigma, physical limitations, and the different forms of violence to which they are exposed. They portray how they establish a "feeling of victory against life's adversities"[33] (p. 930, free translation), with HIV infection being just one of them. Infection, stigma, medications, tests, and the need to rebuild their life are listed as mediators for the construction of new meanings and ways of living.

Potentialities and limitations of care practices for people living with HIV in Primary Health Care

The attributes of PHC[5,34] should expand access and the approach to vulnerability, stigmas, sexuality, among many others. However, in the studied field, the professionals' concerns were directed to confidentiality, insufficient structural conditions, and pre-existing interprofessional conflicts.

PHC scenarios with high care pressure,[35] practices that do not fully include the person, and limited access may produce barriers (mediators that inhibit care) — such as when a professional regretted that she had not provided adequate advice before a rapid test positive for HIV.

Amid the limitations of the care structure, professionals and patients seek to overcome existing barriers to access and confidentiality, seeking welcoming and care alternatives. An example occurred at the pharmacy, with a room for individual care — which represented a non-human mediator of care, facilitating welcoming, confidentiality, privacy, and affection.[36]

> [The room] is where we approach the patient, [...], place [medicines] in a small bag, they usually give us a backpack and we hold it [...] [it is] a restricted care, but we don't turn it into a circus [...]. (Pharmacist 1)

Medication may also constitute a mediator of care and therapeutic bonds. In the clinic's search for a transcript of the ART prescription, consulting with a resident in Family and Community Medicine became a practicality of care. At this meeting, the physician and patient agreed on the need to request information from the infectious disease specialist about the treatment and, thus, a shared care was structured.

The multidisciplinary activities carried out, when contemplating issues such as confidentiality, privacy, and comprehensiveness, can also expand care and influence the practical success of PLHIV care.[11,33]

Tensions and power of confidentiality in the mediation of care in Primary Health Care

In the configuration of living and becoming ill with HIV, confidentiality and stigma appear as mediators in the relationship between patients with multiple aspects of care.

> We live in a place where being ill, depending on the disease, is a risk to their lives, they can be killed. (CHW 1)

Confidentiality is mentioned as a barrier in relationships between professionals and patients, but it can also involve protagonisms and confrontations. In the current national context, conservative and religiously-based political forces[37] have restricted initiatives aimed at vulnerable populations, undermining care practices, reinforcing stigmas, guilt, and social/moral contempt, and negatively influencing the continuity of the Brazilian response to HIV/AIDS.[38] “In the case of AIDS, this intersectionality of various stigmas intersects and interacts especially with the stigma of non-normative sexuality” (p. 627, free translation).[32]

> Nowadays, the greatest stigma is [...] to hide the fact that you’re HIV-positive simply because a large part of society is cowardly, hypocritical [...]. The country is in drastic decline [...] and this represents a threat both for us, homosexuals, and for those who are HIV-positive. (Patient 3)

Regarding the implications of confidentiality in access, the interviewees reported difficulties adapting to the flows predetermined by the service,[23] flows that did not provide privacy to patients at the reception, causing fear of exposure when informed of the reason for seeking the service.

> [Patients] only seek [us] when they are sick, [...] if they don’t tell it in their own houses, they’ll definitely not tell it there at the reception, with the neighbors who are also in the waiting room listening [to them], you know. [...] (CHW 1)

> I arrive there and [...] I often lie, ‘cause I’m afraid. (Patient 3)

Patients and professionals mentioned the need for flexibility and adaptation of care access/flows[17] in such a way not to compromise confidentiality. When carrying out rapid tests, the importance of confidentiality was also observed. Tests were requested by doctors or nurses and performed by nursing technicians in another room. After testing (sometimes with the door open), the technician covered the devices with paper, then interpreted the result and recorded it. If the result was positive for HIV, the second step was subsequently followed, with different justifications for retesting. Later, the person who requested the test would get the result, or the technician would leave it at the office door. There, a technical device representing a mark of infection was used without considering the specificities of confidentiality or perceptions and repercussions of the test for patients and their relationships with the community.

Another patients' exposure was noticed during blood test to assess viral load and CD4 count, which was scheduled for a single day of the week. There was a risk that PLHIV would expose their diagnosis when submitting their requests for tests with other people who performed other tests in the same place and time. Perhaps this fact explains the frequent absenteeism for having a blood test.

> She [physician] asked [me] to do [it]: "Take the CD4 count here" [...]. There was a girl in the place where we do the blood test, she is my neighbor, and I said "it won't work". [...] I haven't done the CD4 test yet, but I don't wanna do it here. (Patient 1)

Therefore, there is a need for professionals to recognize and adapt to the requirements of privacy and confidentiality through new performances involving the subjects, the environment, and objects in care.[29]

> She'll arrive at the clinic and she'll be forced to say she's an HIV carrier, you know, [...] [it is] worse than at her house [...], because it's just me and her outside her house, and everyone is there [at the clinic]. (CHW 1)

"Everyone is there" expresses the perception of the conditions of vulnerability associated with HIV-positivity such as violence, stigma, and fear. This concern about exposure goes beyond the simple idea of choice and involves multiple variables, in line with the logic of care[10]. It is the same case regarding the "preference" of certain PLHIV to seek follow-up at other health centers instead of their referral clinic. These situations corroborate that the preservation of confidentiality is the duty of professionals and the right of patients.[39]

Usually, CHW only have access to diagnosis with the authorization of PLHPV,[39] because their dual position — as people from the community and healthcare professionals — involves uncertainties regarding confidentiality. However, their participation in the care of PLHIV can mediate health care; by getting closer to community and family spaces, they can contribute to strategies that break barriers produced by stigma, encouraging adherence and bonding.[2,23]

Other professionals also recognized limitations and emphasized the need for the care provided in PHC to involve issues such as access to information, confidentiality, and autonomy of PLHIV.

> What does it mean, today, to live with dignity with HIV and to be treated with dignity? [...] To develop this care by dialoguing with this experience of illness. (Physician 1)

When health practices are based on the logic of choice,[10] technical and scientific knowledge and interventions are presented as a menu. It is based on the premise that they would be responsible for deciding on adherence, follow-up professional/service, among other choices. The risk, however, is assuming equality and symmetry in this logic, which disregards fragility, suffering, individual and social vulnerability and, in particular, the fear of exposure of PLHIV.[10] In this sense, this logic may mean a transfer of responsibility to patients and blaming them for the results, increasing distance and compromising the bonds..

In the logic of care,[10] the possible therapeutic objective would be established from the perspective that healthcare professionals play the mediating role, providing the resources necessary for diagnosis and treatment and sharing the achieved results, even when they do not represent technical success.[10,35]

The practice of care beyond preconceived dualities and barriers

During a medical appointment, the physician welcomed the patient with a hug, addressed the requests made that day, and asked about his mother, who was also her patient. Those seeking care have diverse perceptions about services, professionals, and what they can offer. They do not only seek information or predefined interventions; they seek care, support, recognition of the frailties and difficulties that life with and beyond illness imposes on them.

The bond that is established by breaking the barriers of fear and prejudice represents a powerful instrument for a relationship that exceeds the limits related to confidentiality[40] and guarantees confidence to face the itinerary of care.

> The day I found out [that I was sick] was remarkable, you know? That Y (physician), besides being a professional, was a friend right away, he said that I could count on him [...], he cried with me. (Patient 4)

> The nurse [...] gave me all the support I needed at the time, she even offered me to talk to the psychologist. (Patient 2)

The statements demonstrate how confidentiality and the resulting barriers, when considered in their practicalities — such as the flexibility of access, empathetic welcoming, the appreciation of privacy in verbal and non-verbal contacts —[41] can be mediators that enhance care relationships.

> Many patients come closer and say: "if I had such a nice care, such a pleasant welcoming [...], everything would be much easier, I think we would be able to live with the disease much better." (Pharmacist 1)

Concern with specific privacy and respect needs contributes to resignifying the stigma and suffering they experience. Nonetheless, lack of care — neglect, helplessness — can aggravate people's suffering and increase the isolation and transmission of HIV, compromising the early diagnosis and maintenance of ART.[36]

> I saw a doctor [infectious disease specialist] who didn't even look at my face, [...] she would enter [the room], do what she had to do, ask for tests, and that was it. [...] People would come into the room all the time and she [...] attending us and talking to other people, it's kind of embarrassing. [...] Then I gave up going [to the appointment]. (Patient 4)

PLHIV surveillance in the territory may represent a duality between the perspective of control and the search for effective care. The latter is not feasible in the face of poor adherence or absenteeism, but seeks loopholes, approaching the life contexts to understand them and welcome people. Mol[10] understands that assuming joint responsibility for care outcomes would not contradict respect for patients' rights and may also represent practicalities that recognize and respect asymmetries, with empathetic care relationships.

> [The patient] had a very bad relationship with this infectious disease specialist of Secondary Care [...]. She had one [...] antiretroviral drug side effect and this was not taken into account [...] and she was unable to think of another service. (Physician 2)

Performances and mediations in care relationships also involve elements of care (medications, side effects, tests, etc.). What Mol[9] calls a multiple body points to the convergence of these distinct and interactive aspects, which balance each other, constituting care.

Practical success surpasses the idea of a dilemma and makes care a "walk together," subject to persistent adjustments in contexts filled with ambivalence.[33] Care cannot be expected to promise a "happily ever after," but recognize the consequences, tensions, and problems along the way, with adaptation and "repair," not of infection, but of life and everything that is part of it.[41]

Thus, issues related to confidentiality must involve all of these conceptions and not only simplistic foundations reduced to choices that do not include elements involved in the care of each person and groups. Hence, we must overcome the dualism posed by the idea of a dilemma to which the discussion on the shift of care for PLHIV to PHC may be limited.

CONCLUSION

In this study, we observed that care for PLHIV in PHC lacks greater qualification. This process involves improving the quality of PHC in Brazil and reflecting on the guarantee of confidentiality, resulting from the characteristics intrinsic to this type of care, which is included in territories and households. These emerging issues in this new PLHIV care arrangement may represent barriers to access and adherence to treatment, but they can also mediate new care relationships.

The challenges for comprehensive and effective care for PLHIV in PHC involve overcoming the impasses that precede encounters and relationships. These are often related to moral conflicts, the lack of recognition and respect for rights and diversity, the transfer of responsibility and/or blaming for non-adherence, healthcare structures and processes that relegate subjective aspects and meanings that compose the experiences of patients in their experience, homogenizing and making care relationships technical.

Professional practices will be qualified as they are guided by care, including the rights of PLHIV. We emphasize that organizations led by PLHIV are potential scenarios for the exchange of this practical knowledge and regulation of care practices. In fact, in addition to individual practices, education and health promotion strategies involving groups working with PLHIV in PHC, respecting confidentiality and privacy, may represent valuable care technologies.

As limitations of the research, it is worth mentioning that the routine of multiple professional activities and the patients' absenteeism (especially women, who would expand the analyses) limited the access to professionals and patients. The moments in which the clinic's activities were suspended in situations of violence in the territory and due to professional strikes also impacted the field research. The focus of the study was directed to practices in PHC, in such a way it did not address focal managers and specialists.

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AUTHORS' CONTRIBUTIONS

CASLS: Conceptualization, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. CAOF: Conceptualization, Data curation, Formal analysis, Writing – original draft, Writing – review & editing.

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