Reconnecting lives: health care practices from the perspective of People Living With HIV/AIDS

Reconectando vidas: práticas de cuidado em saúde sob o olhar de Pessoas Vivendo com HIV/Aids

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ABSTRACT The study aimed to identify strategies to qualify the practices of health care destined to People Living With HIV/AIDS (PLWHA), especially the accompanying at health care services. Four pedagogical workshops were carried out, between September 2021 and February 2022, in which PLWHA who live in Belo Horizonte and Metropolitan region were invited to share their experiences regarding HIV/AIDS and to reflect about how formal and informal groups, represented graphically by the technique of Venn Diagram, can contribute to qualify health care practices destined to PLWHA. Twenty PLWHA joined the study; thirteen cisgender men, six cisgender women and one trans woman. The elements included at the Diagram have been categorized at dimensions: structural, informational, and relational. The results demonstrate that, despite the advance at structural dimension, we have evolved very little when it comes to main elements from relational and informational dimensions. The morals metaphors about HIV/AIDS and the stigma remain modeling practices of health care for PLWHA, emphasizing the urgent reconstruction of these practices. We comprehend that this reconstruction demands the rescue of the participation and citizenship, consolidated by the empowerment of assistance policies and prevention to HIV/AIDS as well the assurance of human rights.

KEYWORDS HIV. AIDS. Humanization of assistance. Social stigma. Community participation.

RESUMO *O estudo teve como objetivo identificar estratégias para qualificar as práticas de cuidado em saúde destinadas às Pessoas Vivendo com HIV/Aids (PVHA), sobretudo o acolhimento nos serviços de saúde. Foram realizadas, entre setembro de 2021 e fevereiro de 2022, quatro oficinas pedagógicas em que PVHA residentes em Belo Horizonte e Região Metropolitana de Belo Horizonte foram convidadas a compartilhar suas vivências com HIV/Aids e a refletir sobre como grupos formais e informais, representados graficamente pela técnica do Diagrama de Venn, podem contribuir para qualificar práticas de cuidados em saúde destinadas às PVHA. Participaram do estudo 20 PVHA, 13 homens cisgênero; 6 mulheres cisgênero e 1 mulher transgênero. Os elementos incluídos nos Diagramas foram categorizados nas dimensões: estrutural, informacional e relacional. Os resultados demonstraram que, apesar de avanços na dimensão estrutural, evoluiu-se muito pouco no que diz respeito a elementos centrais das dimensões relacionais e informacionais. As metáforas moralizantes sobre HIV/Aids e o estigma permanecem modelando práticas de cuidado à saúde de PVHA enfatizando a urgência da reconstrução dessas práticas. Compreende-se que essa reconstrução exige o resgate da participação e da cidadania, alicerçada pelo fortalecimento das políticas de assistência e prevenção ao HIV/Aids e pela garantia dos direitos humanos.*

PALAVRAS-CHAVE *HIV. Aids. Humanização da assistência. Estigma social. Participação da comunidade.*

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Introduction

The production of Ricardo Ayres[1,2] guided these reflections on comprehensive and humanized health care. The following snippet is his.

> Taking care of someone's health is more than building an object and intervening on it. In order to take care, it is necessary to consider and build projects... So it is imperative to know what is the happiness project that is in question, in the assistance act, mediate or immediate[1(19)].

This passage, specifically, reveals essential elements used by a research group in discussions about health care practices, especially the reception of People Living with HIV/AIDS (PLWHA) in the health services of Belo Horizonte and the Metropolitan Region of Belo Horizonte (RMBH).

The first element concerns the limitation of the practice of care as an 'intervention on an object', which would link care to a purely technical dimension, disregarding its inexorably ethical, affective and aesthetic dimension[1].

The place of subjects in health practices is the second element present in the passage, related to the identity of the recipients of health care practices, understood as authentic beings, with needs, life projects and diverse capacities, including the production of their own history[1].

Based on these elements, this study assumed health care practices as those immediately interested in the illness experience of PLWHA and with the practices of health promotion, protection and recovery[2], thus enabling the establishment of a relationship of listening with sharing of experiences and joint construction of different strategies to improve health.

Reception is understood as a dimension of comprehensive and humanized health care.

This article presents the results of pedagogical workshops carried out with PLWHA, which aimed to identify strategies to qualify care practices for PLWHA, with an emphasis on reception in health services.

The workshops are part of the Reconnecting Lives Project, developed by the research group Health, Education and Citizenship (SEC, as it stands for Saúde, Educação e Cidadania), of the René Rachou Institute of the Oswaldo Cruz Foundation, in the area of public health. Reconnecting Lives was launched in a webinar in August 2020, with the participation of PLWHA linked to social movements in Belo Horizonte, RMBH and Rio de Janeiro. In addition to the workshops, the project uses other methodological approaches, such as documentary production, letter writing and project developments with health professionals. The Project was approved by the Research Ethics Committee of the René Rachou Institute – opinion number 4,696,228.

Material and methods

The qualitative approach guided the study, as it would allow, as Minayo[3] points out, to understand the internal logic of groups on cultural values and representations about their history and specific themes, regarding relationships between individuals, institutions and social movements and regarding historical processes, and the implementation of public and social policies.

Constructions in pairs

The project team had the participation of two PLWHA, activists of social movements linked to the theme of HIV/AIDS. In addition, one of the team participants also worked in the Health Care Network of the Municipality of Belo Horizonte, performing the reception of PLWHA. All participated effectively in all stages of the study: conception, writing, execution.

Pedagogical Workshops

Supported by the production of educator Vera Maria Candau[4], pedagogical workshops were held as collective spaces for expression and

construction of knowledge. For the educator, the workshops are productive units of knowledge based on a concrete reality, to be transferred to that reality in order to transform it.

The two PLWHA members of the research team were responsible for most of the invitations to participate in the project, with the exception of two participants who were invited by another member of the research team with insertion in social movements. It is believed that the possibility that the invitation was made by peers contributed to the adherence to the study.

The PLWHA were invited to participate in the workshops and, when accepted, they filled in the Free and Informed Consent Term (FICT) via e-mail.

The distribution criterion of participants in each workshop was availability to participate. In each workshop, we sought to form a heterogeneous group with regard to sex and place of residence.

All workshops were recorded in audio and video. Participants were asked to keep the cameras open throughout the workshop. At times, due to connectivity problems, some participants had to close the cameras, but always during the testimonies, the cameras were opened.

During the workshops, held between September 2021 and February 2022, in online format due to the Covid-19 pandemic, two techniques were used: Tree of Life[5] and Venn Diagram[6].

The Tree of Life consists of a collective narrative practice in which traumatic situations, values and skills are worked from the tree as a metaphor[5]. This technique inaugurated the workshops and had the intention of contributing to the process of externalizing the experience of living with HIV/AIDS by the participants, starting with the time they searched for a diagnosis. We began with the assumption, presented by Paschoal and Grandesso[5], that, by building a metaphor, it is possible to realize the understanding of a situation as external to itself and to visualize possible alternatives to it, favoring, even, the construction of new meanings.

Each participant was asked to talk about the components of their tree, and the member of the research team responsible for conducting this stage of the workshop recorded the statements on the jamboard. Each part of the tree represented an aspect of the participant's life: the roots represented traditions and origins – ethnic, religious, places where they come from, among others; the soil in which the tree is planted referred to the place where the activities in which people are involved on a daily basis were recorded; the trunk encouraged people to talk about their skills and values; the branches signified the hopes, dreams and desires of the participants in relation to their future; the leaves of the tree represented important people in life, both living and dead, or even pets, historical characters, leaders or others; and, finally, the fruits represented the gifts that were given to the person. Added to this methodology, the seeds invited the participants to think about what they would like to leave as their contribution – a kind of transcendence.

After building the Tree of Life, workshop participants were invited to use a dialogue tool called Venn Diagram[6]. We consider the Venn Diagram as a 'dialogue tool'. This denomination was used as a reference to the compilation by Faria and Ferreira Neto[6] on Participatory Rapid Diagnosis (DRP) techniques and to the understanding that the acronym DRP can represent, as in this study, techniques that motivate Dialogue, Reflection and Planning and also that:

> there are no dialogues without subjects, without those who expose themselves and are willing to exchange, who express themselves and open themselves to the ideas and concepts of someone else, in the search for new understandings[6](9).

The Venn Diagram corresponds to a diagram of circles of different sizes, arranged to represent the relationships between them. Each circle represents a formal or informal group in society. During the construction of the Diagram, two aspects should be considered: 1) size of the circle: referring to the power of the group, its effective capacity to achieve its objectives; 2) positioning of the circle: referring to the relationship between different groups that make up the Diagram. If the groups are partners, for example, they are located close, and may even overlap one another, partially or fully. If the groups have different objectives, conceptions and/or antagonistic practices, they must be located far from each other[6].

The construction of the Venn Diagram was guided by a question: how could the correlation of forces represented by the Diagram contribute to the implementation of qualification strategies for the reception of PLWHA?

Thus, at the end of the pedagogical workshops, in addition to the constructed diagrams, there were also proposals for strategies for the qualification of health care practices, especially the reception of PLWHA.

The construction of the Venn Diagram started with a circle representing the PLWHA group already drawn on the jamboard screen, signaling the centrality of the group in the methodological process of the research and, more than that, the understanding of the importance of the participation of PLWHA in the processes of elaboration, implementation and/or strengthening of public policies aimed at PLWHA.

As the participants added new elements to the Venn Diagram, a member of the research group recorded them on the jamboard. In this way, the Diagram was drawn synchronously.

It is understood that the process of constructing the Venn Diagram was suggested by the research team, and that it should allow reflection on health care practices aimed at PLWHA. However, in spite of this, the participants were the ones responsible of carrying out the construction process, discussing and deliberating on the components of each circle, their dimensions, size and distance between them.

It is noteworthy that the members of the research team who had direct contact with PLWHA, whether in social movements or in health services, acted as rapporteurs during the pedagogical workshops. The conduction was performed by other team members to avoid possible biases.

Study participants

Considering that in qualitative studies the sample must be representative of the relevance of the phenomenon under study in terms of experience and involvement of participants with the phenomenon of interest[7], an intentional non-probabilistic sample was used. The inclusion criteria for the study were: living with HIV/AIDS; be over 18 years of age, agree to participate in the study after signing the informed consent; reside in Belo Horizonte or RMBH. Understanding the exclusion criteria as a characteristic or circumstance that prevents the inclusion of the subject in the study, despite meeting the inclusion criteria, there was no such criterion in this study.

The diversity of participants, with regard to gender, sexual orientation and form of infection with the virus, ensured experiences and expressions that made it possible to understand the empirical framework involved with health care practices related to HIV/AIDS, fundamental for the propositional attitude of the pedagogical workshop for the identification/construction of qualification strategies of reception of PLWHA in health services.

All participants were invited to participate in the study initially via telephone contact (call or message) by one of the

participants of the research group linked to social movements. Subsequently, the email was sent with the detailed description of the project and the FICT for signature.

Data Analysis

Initially, an analysis was made of the diagrams elaborated in each of the four pedagogical workshops held, in order to categorize the elements included by the participants. Based on this analysis, the elements of the Diagrams were categorized into three dimensions: a) Structural; b) Informational; and c) Relational.

The categorization was not intended to be static and defining, some elements are interchanged between dimensions, forming a web of relationships and meanings inherent to the complexity of health care practices related to PLWHA.

Results and discussion

Characterization of the participants

Four online workshops were held between September 2021 and February 2022.

Thirteen (65%) cisgender men participated in the workshops; 6 (30%) cisgender women and 1 (5%) transgender woman. Among men, 1 (7.7%) was heterosexual; and 12 (92.3%), homosexuals. Among women, 6 (85.7%) were heterosexual; and 1 (14.3%), bisexual.

Regarding ethnicity, the male participants declared themselves: Arab (1 – 7.7%); white (2 – 15.4%); Latin (1 – 7.7%); brown (5 – 38.4%) and black (4 – 30.8%). The female participants declared themselves: white (2 – 28.6%); brown (2 – 28.6%) and black (3 – 42.8%).

Table 1 presents the characterization of the participants according to age group.

Table 1. Characterization of the participants of the pedagogical workshop according to age group and sex, Belo Horizonte, September 2021 and February 2022

Age group	Men N (%)	Women N (%)
18 to 24 years	-	1 (14.3%)
25 to 34 years	8 (61.5%)	3 (42.8%)
35 to 44 years	4 (30.7)	1 (14.3%)
45 to 54 years	-	2 (28.6%)
55 to 64 years	1 (7.8%)	-
Total	**13 (100%)**	**7 (100%)**

Source: Self elaborated.

The participants' education ranged from complete higher education (12 – 60%); incomplete higher education (1 – 5%); graduate (4 – 20%) and high school (3 – 15%). *Table 2* presents the characterization of the participants according to income.

Table 2. Characterization of the participants of the pedagogical workshop according to income, Belo Horizonte, September 2021 to February 2022

Income	Number	Percentual
1 to 2 minimum wages	11	55%
2 to 3 minimum wages	3	15%
3 to 4 minimum wages	1	5%
4 to 5 minimum wages	3	15%
5 to 10 minimum wages	1	5%
More than 10 minimum wages	1	5%
Total	**20**	**100%**

Source: Self elaborated.

It is important to highlight that 12 (60%) of the participants were involved in some way with social movements. Four (20%) participants were diagnosed with HIV less than five years ago, and one (5%) of them received the diagnosis less than one year ago.

The forms of transmission of the virus were: vertical (1 – 5%); needle sharing during injection drug use (1 – 5%); and sexual (18 – 90%).

Five people participated in each of the four workshops. *Table 3* presents the characterization of the participants according to the pedagogical workshop.

Table 3. Characterization of the study participants according to the pedagogical workshop, Belo Horizonte, September 2021 to February 2022

	Workshop 1 N (%)	Workshop 2 N (%)	Workshop 3 N (%)	Workshop 4 N (%)
Gender				
Cisgender woman	2 (40)	2 (40)	1 (20)	1 (20)
Transgender woman	-	-	1 (20)	-
Cisgender man	3 (60)	3 (60)	3 (60)	4 (80)
Education				
Complete higher education	3 (60)	2 (40)	4 (80)	3 (60)
Incomplete higher education	1 (20)	-	-	-
Post-graduation	1 (20)	2 (40)	-	1 (20)
High School	-	1 (20)	1 (20)	1 (20)
Age				
18 to 24 years	-	-	1 (20)	-
25 to 34 years	3 (60)	3 (60)	2 (40)	3 (60)
35 to 44 years	2 (40)	1 (20)	1 (20)	1 (20)
45 to 54 years	-	1 (20)	-	1 (20)
55 to 64 years	-	-	1 (20)	-
Income				
1 to 2 wages	2 (40)	3 (60)	4 (80)	2 (40)
2 to 3 wages	1 (20)	-	-	2 (40)
3 to 4 wages	1 (20)	-	-	-

Table 3. (cont.)

	Workshop 1 N (%)	Workshop 2 N (%)	Workshop 3 N (%)	Workshop 4 N (%)
4 to 5 wages	-	1 (20)	1 (20)	-
5 to 10 wages	-	-	-	1 (20)
More than 10 wages	1 (20)	-	-	-

Source: Self elaborated.

Tree of Life

The elements used by the participants during the metaphorical construction of the Tree of Life were taken up again during the construction of the Venn Diagram, since the reflection on health care practices permeates the experiences of PLWHA, especially with health services.

In addition, the technique contributed to the construction of a favorable environment for approaching the theme, which mobilizes people's life stories so closely and which is still so permeated by stigmas.

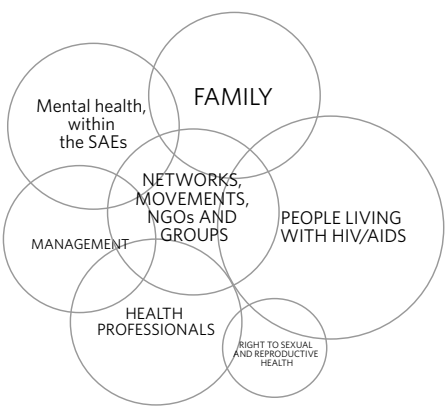
Venn's Diagram

Although the triggering question was the same, each Venn Diagram contained particularities that reflected the life story of each participant and the relationship established between the participants of each workshop. As Faria and Ferreira Neto6 point out, the richness of the dialogue tool is found in the paths taken for its elaboration, in the discussions, guidelines, questions, discoveries and proposals arising from this process.

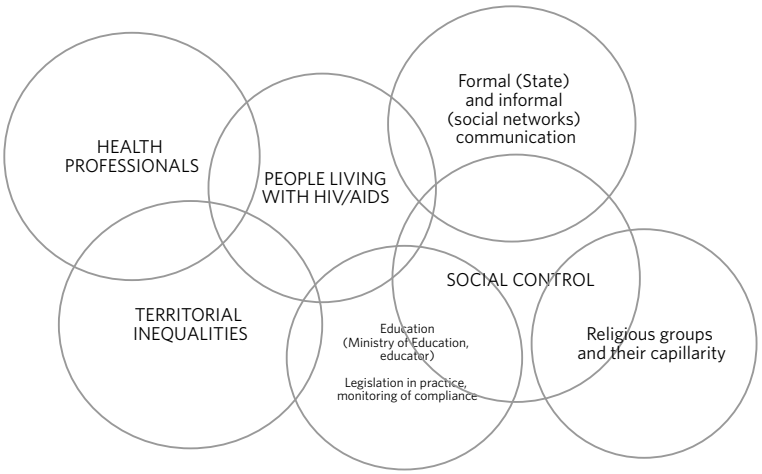
The graphical representations of the Diagrams (*figure 1*) demonstrate that the participants inserted, in addition to formal and non-formal groups, as requested at the beginning of the workshops, other elements that cannot be identified exactly as groups. Some examples are: institutions (Ministry of Education, Teaching and Research Institutions); social variables (territorial inequalities; education); principles of the Unified Health System – SUS (social control); means and forms of communication (media, dissemination of science, formal communication); areas of knowledge (science, mental health).

Figure 1. Control diagrams prepared by the participants of the pedagogical workshops, Belo Horizonte, September 2021 to February 2022

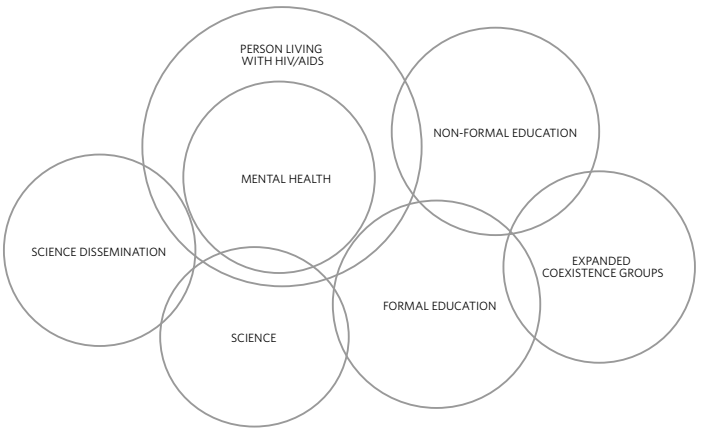
1st workshop



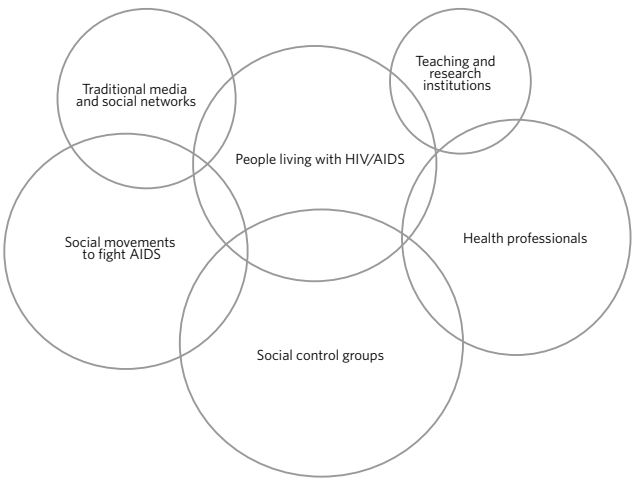
2nd workshop



3rd workshop



4th workshop



The dimensions of Venn Diagrams

STRUCTURAL DIMENSION

> [...] his victim's own social being is then called into question – his citizenship is put in parentheses[8].

The following elements were included in the Structural Dimension: Territorial inequalities; Mental health and mental health within the Specialized Care Services (SAE); Right to reproductive and sexual health; Formal Education and Education including execution and enforcement (*figure 1*).

The elements of the Structural Dimension put in play the discussion about citizenship, which is suspended, as Sontag[9] points out, because the biological body is affected by a disease populated by stigmatizing metaphors. However, it was also suspended by political, economic and social contexts that were averse to its full exercise, as in the emergence of AIDS in Brazil, in which society sought to re-establish a participatory democracy after two decades of authoritarian rule[10], as well as in the conformation of 'a space without citizens'[11], plagued by inequalities of access to structural elements of the Diagrams such as Education and Health. Furthermore, there is no way to isolate the analysis of these social inequalities from territorial inequalities. Therefore, as Santos[11(151)] points out,

> [...] their treatment cannot be alien to territorial realities. The Republic will only be democratic when it considers all citizens as equals, regardless of where they are. The citizen is the individual in a place.

Access, for example, to more organized Health Care Networks (RAS), with well-established shared care flows, differs according to location. Workshop 2 participants were residents of Belo Horizonte and/or RMBH and had access to an organized RAS. However, reports of PLWHA who move the treatment site to another health region, municipality and even state are not rare, especially when they live in small municipalities, so as not to be recognized in the queues by neighbors, family, bosses and co-workers, thus revealing the stigma surrounding positive serology.

The suffering and deprivations experienced in the daily life of PLWHA when faced with the possibility of breaking the confidentiality of their diagnosis were highlighted by Sciarotta et al.[12] in a study that aimed to analyze elements related to the management of HIV diagnostic confidentiality in a scenario of decentralization of care of PLWHA in Primary Health Care (PHC). The authors consider the ambiguous repercussion of the territoriality of the Brazilian PHC in the care of PLWHA, since it can increase access and the risk of breach of confidentiality, being fundamental the reorganization of care practices, as well as the implementation of public policies of coping with discrimination and stigma[12].

The paradoxical effects of territorial logic, as well as the need for new arrangements to organize work processes that avoid the expansion of vulnerabilities, were also pointed out in a study that sought to analyze the implications of the decentralization of care for PLHA in PHC[13].

The inclusion of mental health in the Venn Diagram, specifically within the SAE, as a strategy to qualify the reception, shifted care practices towards health professionals through the recognition of the weaknesses and health demands experienced by this category.

Ayres[1] invites us to reflect on the reconstruction of health care practices in a 'reconciliatory' way, based on the understanding that

> There is a potential for reconciling care practices and life, that is, the possibility of an open and productive dialogue between medical technoscience and the free and solidary construction of a life that one wants to be happy[1(62)].

It is understood that this reconciling movement will require attention and commitment to the 'other' and 'oneself', and the attentive look of the study participants towards the professionals indicates that it is possible to reconstruct health care practices, with emphasis on humanized reception.

Although the circle that contains the element Right to reproductive and sexual health is the smallest in Diagram 1 (*figure 1*) – as well as when compared to the other Diagrams constructed – we emphasize that the theme assumed centrality in the discussions of the pedagogical workshop in which it was prepared due to to the experiences of two participants with the theme. One of them was part of the team of a study with HIV-positive women who wanted to get pregnant and reported the unpreparedness of health professionals to deal with the issue. Another, a young participant who lived with doubts and anxieties around the desire for motherhood and the full exercise of her sexuality – anxieties enhanced by the disastrous reception received in a health service.

Among the many senses and meanings embedded in the non-recognition of the right to reproductive and sexual health of HIV-positive women, it is believed that the metaphor of morality resonates strongly. As Sontang[9](98) points out, "The dangerous behavior that produces AIDS is seen as something more than weakness. It is irresponsibility, delinquency..." and, therefore, would disqualify the woman from exercising motherhood.

The structural dimension is addressed, to a certain extent, in the publication from the 'I Amazon Seminar on HIV/AIDS, Gender and Sexuality: policies and practices of prevention, testing and counseling' by emphasizing the need for political responses to vulnerability vectors such as poverty, racism and misogyny, from a perspective centered on the logic of human rights[14].

INFORMATIONAL DIMENSION

> Images plague me, Insidious metaphors tear me apart[15].

Formal and Informal Communication; Traditional Media and Social Networks; the science; the Dissemination of Science; the Teaching and Research Institutions and the Religious Groups and their capillarity and Management were the elements inserted in the Informational Dimension.

Keeping their specificities, these elements were related by the participants to the access of people from different demographic profiles to reliable information about HIV/AIDS, which directly affects the care practices provided to PLWHA, especially reception.

The media marked the trajectory of AIDS in Brazil, as Daniel and Parker[10](17) warn,

> Even before AIDS actually became statistically significant... it attracted attention, particularly from the media, and by extension became an important topic of conversation even in everyday life.

Misinformation and/or distortion, initially based on scientific ignorance about the disease and lack of effective treatment, formed catastrophic and moralizing metaphors about AIDS, causing panic and fear and legitimizing the oppression of already stigmatized groups, such as homosexuals and prostitutes[9,10].

The maintenance of the historical and stigmatizing association of male homosexuality with descriptions of risk and contagion by HIV/AIDS was evidenced in a study conducted by Ferreira and Miskolci[16] on bioidentities produced in the context of the AIDS epidemic.

The narratives of the participants of the pedagogical workshops revealed that the misinformation and metaphorization of AIDS continue to shape social responses to the

epidemic and care practices for PLWHA, as in the cruel and unreal sentence given by a health professional to one of the participants about the impossibility of experiencing their sexual and reproductive life and the attitude of one of the participants in not revealing, in their work environment, the reason for their absence when attending appointments with the infectious disease specialist.

According to Oliveira[17], during the historical construction of the HIV/AIDS care policy, stigma and normatization gained expression in disputes and plots about politics, care and the life of subjects, conditioning the production of subjects by fear and exclusion.

The evocation of Science and Scientific Dissemination, as well as the incorporation in Diagram 4 (*figure 1*) of Teaching and Research Institutions in direct intersection with the circle of Health Professionals, registers, to a certain extent, the boiling of new knowledge that, according to the participants, need to be included in the scope of care practices for PLWHA, including new Antiretroviral Therapies (ART) and undetectable load.

Religious groups were associated, in the participants' reflections, less with the moralizing metaphor of AIDS as a divine punishment[9] and more with the potential to access the people of a community due to its capillarity and legitimacy in specific territories. Understanding that the interventions of these religious groups would be more ethical than scientific, in the sense of bringing values such as respect and solidarity to the center of the discourse.

Regardless of the communication channels, the Informational Dimension invites us to reflect on Inácio's[18] position when evaluating and historicizing the cooling of representations of AIDS in Literature and Culture: "why talk about it now/yet?".

In the context of health care practices, one could answer, based on the pedagogical workshops, that there is still much to be said about living with HIV/AIDS, so that there is a reconstruction of health practices in the sense proposed by Ayres1 as a 'reconciliator', committed to a kind of care that involves, but is not limited to, technical skills and tasks.

Thus, for the transformation to take place, the management, understood by the participants as managers of health services, must be committed.

RELATIONAL DIMENSION

> *...nothing has made me more human than knowing that I am human...*
>
> (Pedagogical workshop participant, 2022)

The Relational Dimension included the following elements: Family, Networks, Movements and NGOs, Groups; Health professionals; Expanded coexistence groups, Social control groups; Social movements to fight AIDS and Social Control.

The Family was identified as a fundamental group of care and reception for PLWHA, especially by the participants of the pedagogical workshop in which Diagram 1 was constructed (*figure 1*). The life trajectory, the sharing of the diagnosis with the family and the support network formed from there were listed as central aspects.

The participation of families is an important health care management tool. In his reflections on a health assessment that considers the multiple dimensions of health care management (individual, family, professional, organizational, systemic and societal), Cecílio[19] locates the family dimension in the world of life, having family members, friends and neighbors as privileged actors.

However, the experience of sharing the diagnosis with the family was not the keynote of the pedagogical workshops, corroborating data from the Stigma Index in relation to PLWHA. Used to detect and measure changes in trends in relation to HIV-related stigma and discrimination, the Index, applied for the first time in Brazil in 2019, revealed that, in general, the condition of living with HIV/AIDS tends

to be shared with wives, husbands, and partners. Among the survey respondents, 80.4% reported having shared the diagnosis with these people. This percentage reaches 66.4% when sharing is carried out with children, and 75.8% with other family members[20].

Stigma was the foundation of the construction of health care practices aimed at PLWHA and continues to reverberate in the daily life of health services. During the pedagogical workshops, the participants shared the experience of episodes of embarrassment, judgments and lack of reception, corroborating the data from the Stigma Index in Brazil, which show that 15.3% suffered some type of discrimination by health professionals because they were PLWHA, and that 6.8% noted that the health professional avoided physical contact or made negative comments about users because they were PLWHA[20].

The imminent fear of men who have sex with men of going through stigmatizing experiences in different places, such as in Basic Health Units, which should be a place of reception and listening, was also reported by participants in a study conducted in Curitiba on attachment to the treatment of HIV/AIDS[21].

The processes involved in the construction and justification of stigma reveal how difficult its dissolution can be. According to Goffman[22(15)],

> we build a theory of stigma, an ideology to explain its inferiority and to account for the danger it represents, sometimes rationalizing an animosity based on other differences, such as those of social class – [we add – in the specific case of HIV/AIDS – sexuality].

Even so, there were exciting reports of care in action, the result of the meeting of the health professional and the PLWHA. During the pedagogical workshops, narratives were woven about how reception, especially at the time of diagnosis, was fundamental in the process of acceptance, adherence and continuity of treatment. In this regard, it is worth emphasizing the importance of sharing information on the combined prevention of Sexually Transmitted Infections (STIs) and HIV for the rescue of self-esteem, for the emancipation and protagonism of patients[23,24].

The meanings associated with the different denominations inserted in the Diagrams: Networks, Movements and NGOs, Groups; Expanded coexistence groups, Social control groups; Social movements to fight AIDS and Social Control were not discussed by the participants, although at times it was possible to identify political and activism connotations associated with Social Movements to fight AIDS.

It is noteworthy that the denomination Social Control, used in Diagram 2, and Social Control Groups, used in Diagram 4 (*figure 1*), did not have direct correspondence, in the participants' discussions, with the principle of social participation of the SUS.

Reception, counseling, sharing experiences, the possibility of talking openly about their serological situation and obtaining information about HIV/AIDS, placing these elements in articulation with the Informational Dimension of the Diagrams, were the points highlighted by the participants when referring to what is being called here more comprehensively as movements.

The performance of these movements was fundamental in the construction of the Brazilian response to the AIDS epidemic and in the demand for comprehensive and humanized health care practices for PLWHA. Since the foundation, in São Paulo, of the AIDS Prevention Support Group (GAPA), a pioneer in the voluntary organization of support for PLWHA, through the formation of the Brazilian Interdisciplinary AIDS Association (Abia), a series of new organizations have emerged, and the work of Gapa and Abia was expanded. In Belo Horizonte, Gapa MG[25] was the first NGO to organize and dedicate itself to fight against AIDS and the third Gapa created in the country, after São Paulo and Rio de Janeiro. Over time, its role was strengthened in Minas Gerais, and

participation became effective with the organization of the Network of People Living with HIV/Aids – RNP+ MG[26], the National Movement of PositHIV Citizens – MNCP MG[27] and the State Network of Adolescents and Young People Living with HIV/AIDS[28].

Regardless of the movement, it should be considered that, in these spaces, there is no segregation between 'them' (seronegative) and 'us' (seropositive) that marked the HIV/AIDS epidemic[8,29]. There is, therefore, a sense of belonging reaffirmed by the participants' proposition that the approximation between social movements and health professionals would form a powerful strategy to qualify the reception of PLWHA.

In this direction, it is worth highlighting the successful experiences of some Specialized Care Centers that have used peer care as a management tool for the care of chronic diseases[30].

As presented in the methodology, during the construction of the Diagram, two aspects should be considered: 1) size of the circle: referring to the power of the group, its effective capacity to achieve its objectives; and 2) positioning of the circle: referring to the relationship between different groups that make up the Diagram.

Only the circle referring to the Right to sexual and reproductive health presented a discrepant size in relation to the other circles included in the same Diagram (*figure* 1), as discussed in the Structural Dimension.

With regard to positioning, four circles were not included close to or intersecting with the circle referring to PLWHA: Management; Mental health within the SAE; Religious groups and their capillarity and extended coexistence groups, however, presenting a direct connection with other elements directly linked to PLWHA.

It can be said that each Diagram formed a 'conglomerate' of elements that contribute to thinking about the strategies, already discussed, of reconstructing health care practices and qualifying the reception of PLWHA.

Final considerations

The analysis of the dimensions of the Diagrams invited us to go through the history of the AIDS epidemic in Brazil, making it possible to identify that, despite advances in the structural dimension, very little has evolved with regard to central elements of the relational and informational dimensions. Thus, strategies to qualify care practices for PLWHA require efforts in these two dimensions, corroborating Pereira et al.[21] in the sense that health care for the groups most vulnerable to HIV/AIDS requires not only macrostructural action in the health policies and programs, but, above all, a micropolitical action to change attitudes and posture in the approach to care and in the defense of life.

It is understood that the fight against HIV/AIDS, including the re-signification of health care practices and overcoming the effects of stigma and discrimination, requires faster and more reflective responses, encompassing leaderships at all levels, both governmental and of PLWHA.

In this sense, it is essential to rescue participation and citizenship, always thought from the perspective of strengthening HIV/AIDS care and prevention policies, guaranteeing human rights and producing knowledge. In this regard, it is noteworthy that the effective participation of two PLWHA in the research team was important for the design and methodological construction of the study and fundamental for the adherence of the study participants.

The moralizing metaphors about AIDS and stigma continue to shape health care practices for PLWHA, emphasizing the urgency of reconciling these practices. This is Ayres' proposal when he invites us to "[...] know what is the project of happiness that is in question there, in the assistance act, mediate or immediate"[1(23)]. It is believed that the movement of knowledge production 'together' and not 'for' PLWHA strengthens the reconstruction and sustainability of these care practices.

Added to the reconciling reconstruction is the solidarity pointed out by Daniel and Parker[10] as the only possible way to rewrite a new history of the AIDS epidemic in Brazil.

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Collaborators

Carmo RF (0000-0001-9703-8547)* participated in the study design, collection, analysis and interpretation of data; writing, critical review and approval of the final version of the manuscript. Moura HC (0000-0002-2082-1354)* and Ribeiro RS (0000-0001-5946-0413)* participated in the project design, data collection, analysis and interpretation; critical review and approval of the final version of the manuscript. Santos LC (0000-0002-0074-9164)* and Fonseca CMS (0000-0002-5921-6178)* participated in data collection, analysis and interpretation; critical review and approval of the final version of the manuscript. Luz ZMP (0000-0002-0819-3025)* participated in the study design, critical review and approval of the final version of the manuscript. ■

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