










Narratives of pregnant women with AIDS: in search of a theoretical model for medical practice problems

Narrativas de mulheres gestantes com AIDS: em busca de um modelo teórico para os problemas da prática

Regina Rocco¹ , Silvia Teresa Carvalho de Araújo² , Isis Vanessa Nazareth² , Luís Paulo José Marques¹ ,
Valéria Cristina Soares Furtado Botelho¹ , Teresa Tonini¹ , Leila Rangel da Silva¹ ,
Angela Maria Bittencourt Fernandes da Silva³ , Nêbia Maria Almeida de Figueiredo¹ 

ABSTRACT

Introduction: In the care of pregnant women with acquired immunodeficiency syndrome (AIDS), it is often not clear who these patients are, how they behave in the face of diagnosis and pregnancy, how they live their disease, what it means for them to carry a child at risk, as well as the possibility of spreading the virus and not being able to breastfeed. **Objective:** To analyze the life memories of pregnant women with AIDS. **Methods:** This qualitative cartographic study sought to trace, touch, and understand what these women feel or remember about their lives through life narratives. **Results:** The sample consisted of ten women whose narratives generated three categories of living in the different life stages. The study produced a concentration of 515 units of analysis and analyzed 160 statements, with 11 themes related to memories about family dynamics and its problems. **Conclusion:** We expect to contribute to the renewal of the practice, discourse, and language, as an exclusive work and teaching network about the importance of listening to the human being when obtaining data outside our area of knowledge.

Keywords: Pregnancy. AIDS. Health. Perinatal care.

RESUMO

Introdução: O cuidar da mulher gestante com AIDS, muitas das vezes não se percebem quem são elas, como se comportam diante do diagnóstico e da gestação, como elas vivem sua doença, o que representa gestar um filho, colocando-o em risco e a possibilidade de transmitir o vírus e não poder amamentar. **Objetivo:** Analisar as lembranças de vida de mulheres gestantes com AIDS. **Métodos:** Estudo qualitativo baseado na cartografia, que buscou rastrear, pousar, tocar e compreender o que estas mulheres sentem ou lembram do seu viver, por meio da narrativa de vida. **Resultados:** Trata-se de resultado de pesquisa para obtenção do título de Doutor. Participaram dez mulheres, cujas narrativas geraram três categorias de viver nas diferentes etapas da vida. A categoria gerou uma concentração de 515 unidades de registro, 160 unidades com 11 temas sobre as lembranças que estão relacionados a dinâmica familiar e seus problemas. **Conclusão:** Espera-se que se possa renovar a prática, o discurso, a linguagem, como rede exclusiva no trabalho e no ensino, sobre a importância da escuta do ser humano, quando se obtém dados fora da área de conhecimento.

Palavras-chave: Gravidez; AIDS, Saúde, Assistência perinatal.

INTRODUCTION

Women's condition in the current world is permeated by several problems involving many types of violence, physical and emotional abuse, and issues related to sexuality, work, education, etc. These problems are further aggravated when women are pregnant and seropositive for human immunodeficiency virus (HIV), generating socioeconomic and spiritual situations for which "clinical-medical semiology" is not enough.

Acquired immunodeficiency syndrome (AIDS) is the most advanced stage of the infection caused by HIV and is characterized by the weakening of the body's defense system and the emergence of opportunistic diseases⁽¹⁾. In the case of pregnant women with AIDS, the daily treatment practice does not often take into account who they are as people with rights and duties and how they behave in the face of diagnosis and pregnancy. These patients are not seen as unique people who live their disease in a personal and particular way, especially when intertwined with issues about what it means to carry a child at risk, the possibility of spreading the virus at any moment, not being able to breastfeed, and how to experience their

sexuality in these conditions. These issues are not usually part of visits involving obstetrics and AIDS.

Pregnant women with AIDS want to live, be, raise their children, love, and be loved, but they normally only reflect on these issues when asked. The proper way of doing this questioning involves paying attention to the signs expressed by gestures, understood as body language, throughout patient care.

Replacing the disease discourse with the discourse of the body with health deviation becomes a challenge since the disease knowledge domain is insufficient when it does not take into account the person who expresses themselves in their uniqueness, contrasting with the representation of these individuals in the collective unconscious and their own imagination by discourses that pierce their bodies throughout their lives, inhibiting their possibilities as "desiring women".

Building foundations on the body of pregnant women with HIV as a category of study is to deconstruct the look and the listening for disease treatment and diagnosis, transforming it into a provocation when working in the traditional practice of the disease and its effects, treatment, and results, without considering the subjectivity aspects that unnoticeably influence lives because they are in hidden (physical) structures of the body under care⁽²⁾.

In fact, the body is much more clinically interesting than commonly imagined, and to create a highly complex practice of understanding/doing and of knowledge beyond the health area, one must

¹Universidade Federal do Estado do Rio de Janeiro – Rio de Janeiro (RJ), Brazil.

²Universidade Federal do Rio de Janeiro – Rio de Janeiro (RJ), Brazil.

³Instituto Federal do Rio de Janeiro – Rio de Janeiro (RJ), Brazil.

aim the discourse at looking at this body as unique, whole, different in distinct movements, emotional, that has a variety of desires, suffers, yearns for care.

This practice is complex because it involves successes and mistakes, as stated by Morin⁽³⁾: “complexity that can only express embarrassment, confusion, inability to define plainly, to name clearly, to put ideas in order [...]”. The “complex” care of these pregnant and seropositive bodies could identify situations suggestive of problems not expressed by them, which until then had not mastered the reading of their language in the medical field.

Thus, this article focuses on the relationships between the life history and routine of women before and after receiving the HIV seropositive diagnosis, which necessarily includes their sexuality, seeking to identify whether the day-to-day outpatient care supports these women in their life issues, if it favors the cross-sectional view regarding experiences lived, the reality, the world, and the life expectancy of each patient treated in the obstetric clinic of a university hospital, reference in the care of women with AIDS in Rio de Janeiro. We aim to find complementary knowledge, integrate contributions, build convergences, and establish connections and reconnections.

The basis of this study was: bodies with unique sensibilities and desires, capable of building discourse on the presence of pregnant women with AIDS treated for more than 32 years at the obstetric outpatient clinic of Hospital Universitário Gaffrée e Guinle, including internal medicine professors, particularly those from the 10th ward and maternity ward, which has become one of the pioneers in the care of these women. Over the years, skills and knowledge were constructed to care for these pregnant women with a diagnosis and treatment plan focused not only on the disease but also on the person.

To make them speak was to give them a voice so that this cry could achieve and lead to attitudes that could change their lives in all aspects, including their sexual life, allowing them to have new meanings. As a professor, physician, and researcher associated with obstetric and gynecologic surgery, it was time to give new meanings to the experience lived up to this moment and try to identify how was the daily life of these women who visited the outpatient clinic every month, but of whom little was known outside the hospital.

Not forgetting the space lived and experienced by them before they arrived at the outpatient clinic was essential. Herein, we present the ideas of Bollnow⁽⁴⁾, a German architect and philosopher, who studied the individual's relationship with space. For him, the act of inhabiting aims at building a reference space. Therefore, this living space is directly related to the household, the home; the household, in turn, represents the place from where the individual could depart in search of their survival and of meeting other individuals.

It is also the place of return, when you come back safely to evaluate the journey. Moreover, the living space allows the appropriation of new spaces to be explored for survival and self-care so that they can circulate the city, the world space where they could find non-foreign elements, connecting to them, producing new identifications, meanings, and physical and subjective relationships.

It is in the city space that seropositive pregnant women find the obstetric outpatient clinic, where they are treated and wait for their babies until the day of birth; on the other hand, it is also a space to work and teach for those who practice medicine, with the development of procedures and techniques (surgery, deliveries, routine examinations, prenatal care) and the production of many movements

because, in the outpatient clinic, women, students, and employees circulate and create different flows in human relations.

From these spaces, where the woman moves in her daily life, we sought to answer the following guiding research question: how do pregnant women with AIDS describe their daily lives, and how do they feel as transmitters to their partners and children?

OBJECTIVE

To analyze the life memories of pregnant women with AIDS through life narratives.

METHODS

This is a qualitative cartographic study⁽⁵⁾ from the perspective of content analysis. We analyzed the life narratives of pregnant women with AIDS based on Passos and Barros⁽⁵⁾, who states that data reveal the universe of meanings, beliefs, values, attitudes, perceptions, opinions, and the way of living and relating to people.

Cartography is based on methodological reversion, which proposes not a path toward set goals, but a path that traces its goals along the way, regarded as research-intervention and grounded in the discussion about knowledge as the construction of the larger reality, especially when this practice is done from the encounter of women with AIDS and what they express in this encounter. Therefore, investigations of this nature call for more open and inventive methodological strategies and investigative procedures to fit the subjectivities of each one of them.

The combined use of two methods has increased in several fields of knowledge since they are complementary and broaden the analysis of results, leading to rich paths for exploration⁽⁶⁾. Thus, subjectivity ceases to be connected only to the representation and interiority domains and starts to relate viscerally to social groups⁽⁷⁾. In turn, the individual is not a universe but a contingent product of strength diagrams and subjectivities that affect them.

The choice is related to the assumption of using a human method, of the materials so chosen, based on curiosity about experiences lived by women with AIDS who visit the obstetric outpatient clinic, a sector defined as a data production space. As a result, a life narrative is also a particular way of interviewing the participant so that she can recount all or part of her experience.

The inclusion criteria were women with AIDS, aged 18 years or older, who agreed to participate in the study and signed the informed consent form (ICF) after being informed about the research questions.

The study was carried out at the obstetric outpatient clinic, particularly the 10th ward, and at the maternity ward of Hospital Universitário Gaffrée e Guinle, from April to June 2021. Most of the time, only the researcher and the participant were present at the site; however, on some occasions, internal medicine professors and students from Universidade Federal do Estado do Rio de Janeiro also attended, totaling no more than four people per interview.

For data collection, we initially administered a questionnaire divided into two parts: the first covered sociodemographic data, while the second involved the participant's clinical trajectory. In addition, we searched medical records to identify the social, disease, and treatment history, the elaboration of diagnosis, and social-spiritual data. These searches aimed to find highlights of the aspects

involving the daily life of these women. The interview followed a detailed roadmap, with eight open questions. During the questionnaire, the researcher paid attention to all details involved in the interview, needing to know how to look, listen, and keep quiet, only intervening when necessary to expand the material produced.

In this regard, we sought to increase the various clinical possibilities of hearing, listening, and touching (feeling), based on the discussion of the patient's relationship with life, relatives, partners, friends, and children, involving kept objectivities and the subjectivities, so that they could build their personal narrative with their own style and content to broaden the health-disease discourse.

RESULTS AND DISCUSSION

The following results are part of the doctoral research entitled "*Mulheres gestantes com AIDS: um estudo sobre narrativas do cotidiano de viver e suas implicações para o ensino-prática da medicina*" (Pregnant women with AIDS: a study on narratives of daily living and their implications for the teaching-practice of medicine), developed in the Graduate Program in Nursing and Biosciences of Universidade Federal do Estado do Rio de Janeiro.

Each interview lasted, on average, 60 minutes, totaling 600 minutes or 10 hours. Ten narratives were produced, transcribed, and assessed at different times.

First, we followed the three guidelines of content analysis⁽⁵⁾. The first guideline is pre-analysis, which consists of skim reading to get the "general impression" of what the women said. At that moment, three fundamental themes stood out to store the contents-units of analysis found, called content storage, which, for the author, represents describing the closest and most subjective contents to objectively highlight the nature and relative strengths of the stimuli they were submitted.

The second guideline was characterized by narrative codification based on the identification of the meaning nuclei that composed it, listing selections (of meaning and not of the form) because we were interested in identifying motivations, beliefs, trends, and feelings of women, as they were allocated. The third guideline started the analysis, producing units of analysis (UA).

Despite the difficulties pointed by Bardin⁽⁶⁾ regarding knowledge production, organization, and data analysis, we "have discovered" and continue to discover how far we are from knowing customers as sensitive, special beings and that we know nothing about their daily lives.

In this sense, pregnant women with AIDS arrive at the doctor's office with a variety of memories of their lives. The codification produced 515 units of analysis, subdivided into 11 themes about memories related to family dynamics and its problems. Results were organized into three subsections, covering issues associated with:

1. Vulnerabilities in childhood and adolescence;
2. Coping with life situations; and
3. Challenges faced during pregnancy.

Vulnerabilities in childhood and adolescence

For Scott⁽⁹⁾, there are two gender dimensions: the first considers gender a constitutive element of social relations based on the perceived differences between genders; the second presents it as the

main way of signifying power relations, allowing us to visualize symbolic and social representations grounded in a binary, complementary, and opposite relationship, in which the woman is relegated to a position of subjugation, observed even in her affective relations, so that it seems more easily accepted for a man to have a more active sexual life, as shows the statement of one of the participants: "Men were wolves". (Participant 2).

Thus, the presentation of this category starts by showing that these women kept to themselves what most concerned them in their lives: issues involving living conditions, basic human needs, health, food, a place to stay, lie, and sleep, someone belonging to them, desires, many losses, and abandonment (**Chart 1**).

In this respect, Kehl⁽¹⁰⁾ points out that "the inscription of the individual (women) was another's discourse that was not strictly fixed. It involves changes throughout history that, if they do not alter the language structure, they certainly alter language use, some meanings, the roles that culture attributes to individuals." In this context, women, for example, hold the place of innocence or sin, castration or omnipotence, uncontrolled and threatening sexuality or the natural inclination toward modesty and chastity.

Therefore, these women went through childhood, reached adolescence, and in adulthood, they recall the experiences of when the pedophile activities started, building new ideas about life, probably shaped after their memories, as the following statements indicate.

We are living in my grandmother's house (Participant 8)

Not to become another ignorant (Participant 5)

I don't know. So far, life hasn't treated me that well. (Participant 10)

I don't like to remember my childhood (Participant 4)

I didn't want to stay anywhere close to home. (Participant 9)

These women's childhood memories were full of meanings that marked their "bodies" and "souls", full of their own interventions and attempts at silencing or forgetting. They continued to create their social settings and expressions, adapting to a world they did not know.

Thus, the memories produced these sign systems when childhood experiences were full of pain and suffering originated in their living place, their home, and in every possible type of abandonment, raising concerns about the territories where these patients lived and the spaces where they played, danced, or worked.

In addition, all of them lost their virginity very early; most of them because they wanted to know what it was and how it was to "have sex", "take it up the ass", learn the workings of sexual relations and other oral practices they did not desire because they had no knowledge about them. Their desire, however, was of little importance, as can be noted in many statements. On the subject, we can present the following observation from Kehl⁽¹⁰⁾: "[...] the woman does not have a penis, she offers herself to be taken, as people say, from a place of absolute absence, from where only a man's desire can rescue her."

Coping with life situations

Housing and abandonment issues were the most reported complaints by the participants, who may have difficulties improving their schooling and remaining at work after the diagnosis, intensifying and increasing the challenge of having a stable household with water, electricity, waste collection, and sewage disposal. This scenario can be observed in the following statements, which go against the demands analyzed by cartography.

My mother’s boss used to send her children’s used books. (Participant 2)
 I’m not working now. (Participant 9)
 My older brother was good at getting water and putting it in the tank. (Participant 4)
 My mother gave me this... I don’t like to remember my childhood. (Participant 3)
 I started school late... They called me nappy haired Black girl. (Participant 1)
 She was stupid, and after getting older, she started using drugs. (Participant 5)
 Dad didn’t like that. We never had money. (Participant 8)
 I understood that nothing would change if someone knew who it was. (Participant 6)

In this sense, we can note that, in their narratives, the women do not hide their risky way of living, permeated by socioeconomic and emotional situations that originate from both their individual and collective space. We could see that it was not easy for these women to talk about their own lives: the text was full of “loose ends”, language “disconnections”, a mix of good and bad feelings, loaded with problems that encompassed not only clinical aspects but also socioeconomic, social-affective, and social-political difficulties. This category involves the most comprehensive — macro — knowledge of women, corresponding to their socioeconomic and environmental conditions, presented in **Figure 1**.

The “women” of this study had life narratives permeated by much suffering, fear, and sexually promiscuous and risky life, indicating the antagonism between culprits and victims of virus “infection”, somehow showing the existence of a hierarchy between people and their sexual practices, leading to some being more victims than others.

Suffering did not generate conflicts because the participant questioned her relationship with what shattered her beliefs and control, allowing the act to happen and producing this suffering⁽¹¹⁾. The situation she was experiencing had the potential for pleasure, and she

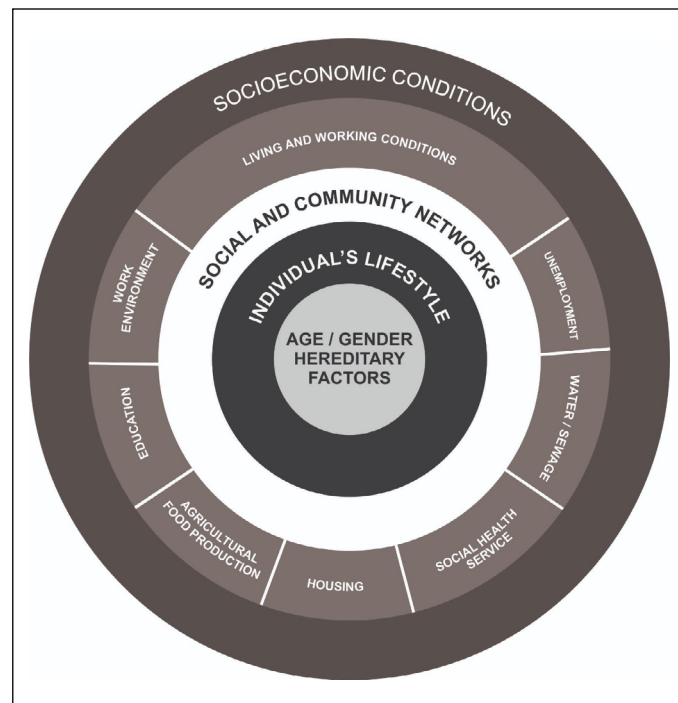


Figure 1 – Socioeconomic and environmental conditions

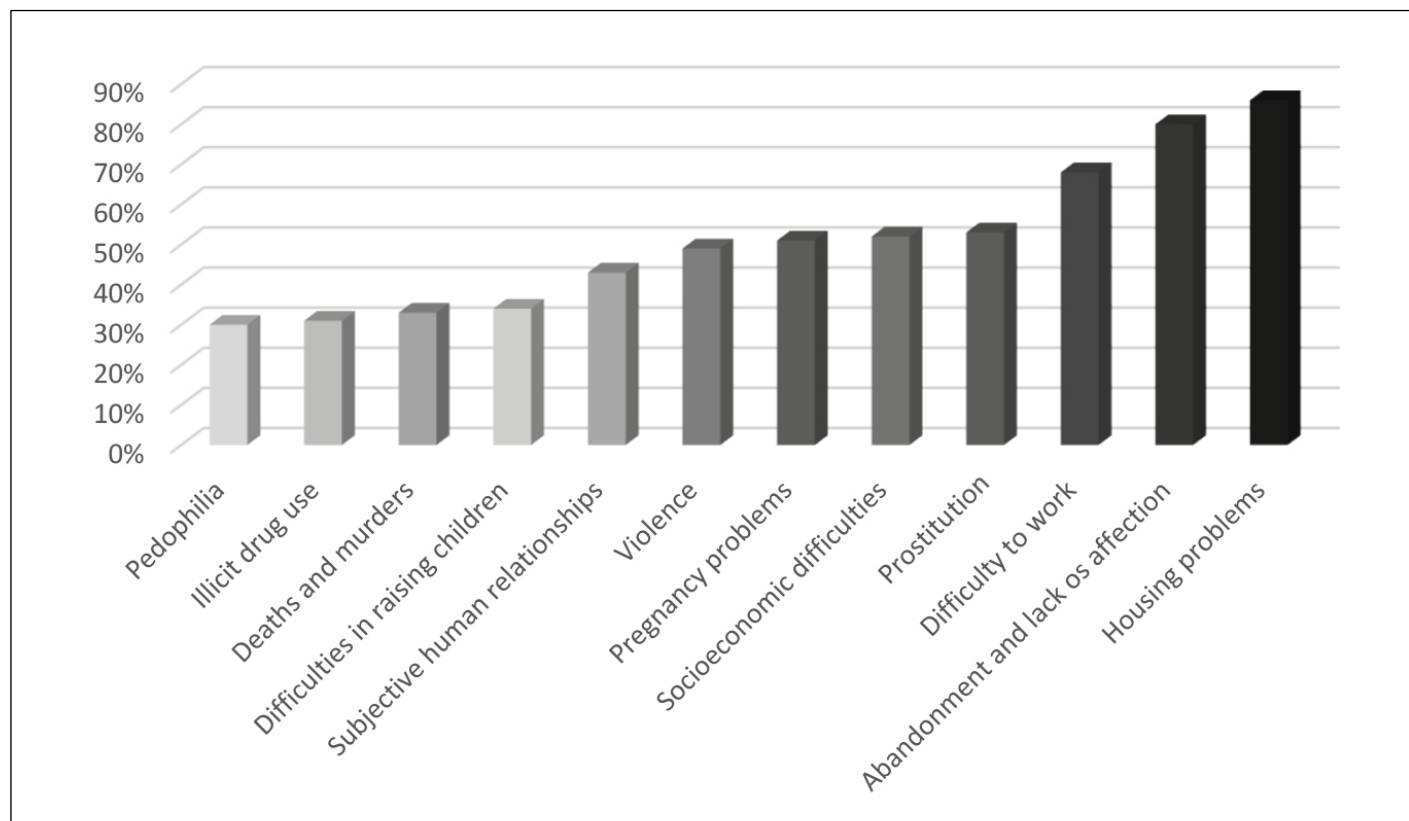


Chart 1 – Percentage of patients subject to vulnerability factors in childhood and adolescence.

is encouraged to consider what she will think in the future if her choice has a negative consequence.

Therefore, the presentation of this category starts by showing that the patients keep to themselves what most concerns them: issues involving living conditions, basic human needs, health, food, a place to stay, lie, and sleep, someone belonging to them, desires, many losses, and abandonment. They live walking a “tightrope” without a “safety net” underneath.

The living nature of these women was not health production because their lives were marked by emotions, feelings, and suffering resulting from abandonment, violence, constant change of partners, and changes in living spaces; in addition, many live far from their work and the outpatient clinic where they are treated.

Challenges faced during pregnancy

When approaching these women to know them better, thinking about the disease, the medications, and the baby, we found that the discourse of health production presented many tension lines, which, for Barros⁽¹²⁾, represent “flying beyond the wings”, with vectors running free, constituting an external threat; but first, the desire for pre-defined representational control schemes is released, causing it to flee.

My mother suffered during delivery... I was born after a difficult delivery, 900 grams. (Participant 6)

My son spent 30 days in the ICU... When my son was discharged, I felt such fear and guilt. (Participant 3)

I couldn't breastfeed my daughter... Fear of infecting. (Participant 4)

My infectious disease specialist was also afraid because there was a possibility of the baby coming with HIV. (Participant 10)

It was essential for this discussion to lead to a health production as a culture built for those who care for sick people. In this regard, Azevedo and Castilho Sá⁽¹³⁾ clarify that managerial work is like “living work in acts” carried out among individuals, whose basis is the psychoanalytic reading of the leadership to construct the social bond. The intersubjective role that managers/directors play in organizations stands out, but we can also explore the limits and possibilities in the field of health management, such as the modalities of social organizations found in the psychic dynamics of participants, whose (narrative) contents are permeated with sociocultural elements.

Pregnancy challenges call for collective health and primary care for the participants, who are at permanent risks both inside and outside their homes, in the streets, schools, bars, or clubs.

We noted that the access to these women was very far, indicating the need for other policies to produce health through public health practices and spaces. The current care model must incorporate into its practices the positive concept of health, the integrality of health care, and the perspective of the exchange of knowledge and doings with the community to which it is linked. Thus, we expect that methodologies capable of capturing the variability of interests and context dynamics can be adopted, especially in education and health, transforming the Brazilian public health system (*Sistema Único de Saúde* — SUS) into a place of help, which will care for these women since childhood to build systematic changes in practice and teaching dynamics or to produce health for them.

There was a sense of being “adrift” when thinking of how to care for women, how to “protect them”, which required the willingness

of “hearing” to “listen” to the noises of the person's sociocultural life systems and of their individual relationship with affective energies and suffering that are part of life.

This category affected the knowledge and clinical practices in the face of women who receive treatment/care, without being able to expand the actions, either for the lack of knowledge of how to awaken to more advanced actions or for fear of changing what was held as truth, as it involved obstetric care.

Narratives rich in imagination and meanings emerged, speaking more frequently about the presence of home. The living scenario was the most reported in the memories of people who lived with these women: a place that was not safe, where connections more negative than positive, or even traumatic, were created, marked by past generations that were always in their recollections, that they did not forget and let escape in their narratives⁽¹⁰⁾.

It was necessary to know the living movements, flows, and dynamics of these women and their families in a country devastated by embezzlement, particularly in the health field. It is also crucial to consider the extreme poverty in which most women in this social class live, a key element in perpetuating the same problems. Most of the women interviewed were in critical situations: in addition to HIV infection, which worsens when they have more children without knowing what their destinies will be, many live without a home, without parents, without school, without affection, surrounded by all kinds of possible violence. Thus, the statements of these patients are unstructured, full of displacements, and marked by the lack of basic health.

Here, we can readapt or reconstruct what Mendes⁽¹⁴⁾ reveals about medical specialty centers: they are part of a fragmented health care system, which usually does not have smooth communication between the different points and levels of care, since the previous history of the patient is not known. In general, no bonds are established because visits can be scheduled with different professionals of the same specialty depending on the day. This system is full of reworking and redundancies, making it not only ineffective but very inefficient, as at each visit, personal and family histories are recollected, tests are requested again, and medication is continued.

Under Law No. 9,313/96, people living with HIV/AIDS (PLWHA) are now entitled to universal and free treatment with antiretrovirals from SUS. Currently, the instability of the political and economic scenario has led to regression and stagnations in PLWHA care⁽¹⁵⁾ due to the strengthening of conservative movements guided by biomedical and medicalized bias, posing a threat to the human rights perspective. At present, gender, sexuality, and family issues are suffering setbacks with the rise of moralistic views on themes such as health and reproductive rights, HIV/AIDS, and sexual education, with PLWHA as the main pillar for the Brazilian program⁽¹⁶⁾, which has universality, integrality, and equity as principles.

Mendes⁽¹⁴⁾ states that integration ensures effective, efficient, and quality health care, inserting secondary care into the network and generating synergies in the system, with its medical specialty centers transformed into systems that allow open demand. As a result, users start to demand their services directly from primary care, seeking embracement, schedules, and/or re-schedules and rapidly obstructing the agendas of the services because, although health promotion is challenging, identifying social determinants, intermediaries, and health and living conditions is necessary.

Devising a new clinic, different from what is currently done, was another challenge since it was always doomed to failure due to the established system, considering that SUS was at risk of collapse. Creating a casebook (home records) would be important so that these women could contribute to controlling their own health, aiming at building networks that could embrace or teach what it is to live a life of major challenges in a world undergoing a profound social crisis, marked by femicide and/or violence against women.

All women stated that they had only heterosexual relationships. Most reported that they were infected while in stable relationships with their partners. The model of romantic love for women may imply an ideal of love built on personal resignation and submission to men⁽¹⁾. Therefore, although many had previous information about HIV and its modes of infection, they did not use condoms regularly.

This entire scenario involves a large health education program. Morin⁽³⁾ declares that professionals could also teach how to walk this path, to think about life and health, so that the patients can overcome, review, reanalyze, re-encode, and talk about more specific content, such as memories.

In fact, theirs is a world full of uncertainties and acts of women who constantly live it, in an adventure of living with a serious illness and always hoping for their children to be born healthy. To follow these women, we needed to have knowledge, understand what happens, talk about their uncertainties, beliefs, and illusions.

Despite the fragmented diagnosis, both the researcher and these patients had rigid, hard thoughts because they only had eyes for the specific disease and forgot about the complexity/subjectivity that is the human being. As human beings, these women were and are fragile, full of doubts, fears, anxieties; they lack money and do not have their human needs fulfilled. Thus, having a more advanced practical technical clinic was urgent, reflecting something clearer, intrinsically related to the knowledge of other domains and other forms of expression.

The results do not represent “truths” as science demands, not least because this is a first study that needs to be further investigated and replicated; however, they consider and mark the emergence of their temporal truths.

These women touched many aspects involved in living, which depends on: having physical-mental health, fair quality of life to solve complex problems, being able to live with maturity in all respects (things), and having their difficulties handled.

Despite the difficulties of the Brazilian health system, the embracement of these women is a reality because health professionals do the impossible to care for the people who seek them.

We need to think of a routine that makes us review how complex life is. The narratives deserve further reflections on the smallest life details, on events that cause astonishment, as they deal with memories, experiences, and many changes, for the chances that they often offer to rebuild life.

Therefore, it is urgent to develop a solid-based clinic with modern knowledge that promotes reflections on: partnerships with other primary care facilities; full integration of the right to equal care; union of professors, students, and women; review of practices, knowledge, and technological actions; creation of spaces to produce knowledge.

As this was the first research in Brazil involving narratives of pregnant women with AIDS, aimed at developing new care techniques

for medical practice, this study had a limited number of participants. In this sense, more studies should be encouraged in this area, involving other environments and states, so that other women can be heard, and ways of caring that include listening and embracement can be developed.

CONCLUSION

This research prompted reflections and questionings about the dimensions that are part of the health-disease process. The analysis of the memories of pregnant women with AIDS through life narratives identified that, when they reached adolescence and adulthood, they experienced certain situations at the start of their sexual activities and built new ideas about life. The material present in the memories induced many reflections not only for the practice but also the teaching of medicine in the area of AIDS/HIV/obstetrics.

Clearly, the young women participating in this study, for curiosity, desire, or sex, had no knowledge of issues related to sexuality, care, and prevention, issues that were of little importance to them. Therefore, we must think about the limits and challenges of helping these women: how would the optimal care management involving sexual education and the expression of their sexuality be?

We had to know the characteristics of these patients, their connections to health services, and the implications for the dynamics of care and of managing the care system, as well as attempt to deconstruct the discourse of who is guilty of the infection.

Lastly, we must overcome the stiffness of teaching and practice, freeing rationality so care can happen. So speeches, cries, and pleas for help can be heard, allowing suffering to be recognized and reverberated by other studies, seeking to reflect on and discuss how professional health practices have been produced, and thus advancing in prevention and health promotion, so as not to restrict them by the imposition of decontextualized, prescriptive information that violates human rights.

Approval by the Human Research Ethics Committee

The Human Research Ethics Committee approved this study, under CAEE No. 35013820.0.0000.5258, opinion No. 4191425/2020.

Participation of each author

RR: Conceptualization, Data curation. STCA: Writing – review & editing. IVN: Writing – review & editing. LPJM: Writing – review & editing. VCSFB: Writing – review & editing. TT: Writing – review & editing. LRS: Writing – review & editing. AMBFS: Data curation, Writing – review & editing. NMAF: Supervision, Writing – review & editing.

Funding

The authors declare no financial support.

Conflict of interest

The authors declare no conflicts of interest.

REFERENCES

1. Oliveira MMD, Junqueira TLS. Mulheres que vivem com HIV/ aids: vivências e sentidos produzidos no cotidiano. *Rev Estud Fem* 2020;28(3):e61140. <https://doi.org/10.1590/1806-9584-2020v28n361140>
2. Gonçalves VF, Teixeira DQ, Oliveira PF, Holanda e Sousa T. Mulheres soropositivas para o HIV: compreensão, sentimentos e vivência diante da maternidade. *Rev Bras Promoc Saúde*. 2013;26(2):281-9. <https://doi.org/10.5020/2918>
3. Morin E. Introdução ao pensamento complexo. 2ª edição. Paris: Éditions; 1990.
4. Bollnow OF. O homem e o espaço. Curitiba: Editora UFPR; 2008.
5. Passos E, Barros RB. A cartografia como método de pesquisa intervenção. In: Passos E, Kastrup V, Escóssia L. *Pistas do método da cartografia: pesquisa-intervenção e produção de subjetividade*. Porto Alegre: Sulina; 2009. p. 17-31.
6. Dal-Farra RA, Lopes PTC. Métodos mistos de pesquisa em educação: pressupostos teóricos. *Nuances: Estudos sobre Educação*. 2013;24(3):67-80. <https://doi.org/10.14572/nuances.v24i3.2698>
7. Paiva ACS. Sujeito e laço social: a produção de subjetividade na arqueogenealogia de. Rio de Janeiro: Relume Dumará; 2000.
8. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 2012
9. Scott JW. Gênero: uma categoria útil de análise histórica. *Educação e Realidade*. 1995;20(2):71-99.
10. Kehl MR. *Deslocamentos do feminismo: a mulher freudiana na passagem para modernidade*. Rio de Janeiro: Bomtempo; 2013.
11. Vaz P. Consumo e risco: mídia e experiência do corpo na atualidade. *Comunicação, Mídia e Consumo*. 2006;3(6):37-61. <http://doi.org/10.18568/cmc.v3i6.58>
12. Barros M. *Poesia completa*. São Paulo: Leya; 2010.
13. Azevedo CS, Castilho Sá M. *Subjetividade, gestão e cuidado em saúde: abordagens da psicossociologia*. Rio de Janeiro: Fiocruz; 2013.
14. Mendes EV. *As redes de atenção à saúde*. Brasília: Organização Pan-Americana da Saúde; 2011.
15. Corrêa S. A resposta brasileira ao HIV e à AIDS em tempos tormentosos e incertos. In: Associação Brasileira Interdisciplinar de AIDS. *Mito vs Realidade: sobre a resposta brasileira à epidemia de HIV e AIDS em 2016*. Rio de Janeiro: Observatório Nacional de Políticas de AIDS; UNITAID; 2016. p. 9-17.
16. Nemes MIB, Scheffer M. Desafios da assistência às pessoas que vivem com HIV e AIDS no Brasil. In: Associação Brasileira Interdisciplinar de AIDS. *Mito vs Realidade: sobre a resposta brasileira à epidemia de HIV e AIDS em 2016*. Rio de Janeiro: Observatório Nacional de Políticas de AIDS; UNITAID; 2016. p. 33-8.

Address for correspondence:**REGINA ROCCO**

Rua Mariz e Barros, 775 – Maracanã

Rio de Janeiro (RJ), Brazil

CEP: 20270-004

E-mail: regina.rocco@pobox.com

Received on: 12.08.2021

Approved on: 12.30.2021

