Life with HIV/AIDS in Family Relationships

A Vida com HIV/AIDS nas Relações Familiares La Vida con VIH/SIDA en las Relaciones Familiares

RESUMO

A maioria dos estudos sobre HIV/Aids foca principalmente na pessoa vivendo com HIV, pouco se estuda as relações familiares destas pessoas. Objetivo: analisar como se configura o HIV nas relações familiares de pessoas vivendo com HIV. Método: Trabalho realizado em um Ambulatório de Infectologia de São Paulo/SP com 37 idosos PVHIV e 19 familiares. Resultados: mostram que o HIV nas relações familiares podem ser coadjuvantes ou determinante destas relações. Coadjuvante quando outras problemáticas familiares mostram-se maiores e o viver com HIV não interfere nas relações familiares. Porém, outras famílias vivem em alerta constante com medo de contaminar alguém, medo de que outras pessoas venham a ter conhecimento e limita as relações, ocasionando isolamento familiar. Conclusão: O HIV nas relações familiares revela a qualidade destas anteriormente ao HIV de modo que aflora algumas mudanças que precisam ser enfrentadas a fim de promover o protagonismo de seus membros. **PALAVRAS-CHAVE:** Idoso; HIV/Aids; relações familiares.

ABSTRACT

Most studies on HIV/AIDS focus mainly on people living with HIV, with little study of these people's family relationships. Objective: To analyze how HIV is configured in the family relationships of people living with HIV. Method: Study conducted at an Infectious Diseases Outpatient Clinic in São Paulo/SP with 37 elderly people living with HIV and 19 family members. Results: Show that HIV in family relationships can be a supporting factor or a determining factor in these relationships. It can be a supporting factor when other family problems are more serious and living with HIV does not interfere with family relationships. However, other families live on constant alert for fear of infecting someone, fear that other people will find out and limit relationships, causing family isolation. Conclusion: HIV in family relationships reveals the quality of these relationships prior to HIV, so that it brings out some changes that need to be addressed in order to promote the protagonism of its members. **KEYWORDS:** Elderly; HIV/AIDS; family relationships.

RESUMEN

La mayoría de los estudios sobre el VIH/SIDA se centran principalmente en las personas que viven con el VIH, y hay pocos estudios sobre las relaciones familiares de estas personas. Objetivo: Analizar cómo se configura el VIH en las relaciones familiares de las personas que viven con VIH. Método: Estudio realizado en un Ambulatorio de Enfermedades Infecciosas de São Paulo/SP con 37 ancianos que viven con VIH y 19 familiares. Resultados: Muestran que el VIH en las relaciones familiares puede ser un factor de apoyo o determinante en dichas relaciones. Puede ser un factor de apoyo cuando otros problemas familiares son más graves y vivir con el VIH no interfiere en las relaciones familiares. Sin embargo, otras familias viven en constante alerta por miedo a contagiar a alguien, temor a que otras personas se enteren y limitan las relaciones, provocando aislamiento familiar. Conclusión: El VIH en las relaciones familiares revela la calidad de estas relaciones antes del VIH, de modo que pone de manifiesto algunos cambios que es necesario abordar para promover el protagonismo de sus miembros.

RECEIVED: 02/12/2025 **APPROVED:** 03/03/2025

How to cite this article: Lima Neta MIF, Kahhale EMSP. Life with HIV/AIDS in Family Relationships. Saúde Coletiva (Edição Brasileira) [Internet]. 2025 [acesso ano mês dia];15(94):15179-15192. Disponível em: DOI: 10.36489/saudecoletiva. 2025v15i94p15179-15192 Maria Irene Ferreira Lima Neta Master's and PhD in Clinical Psychology from the Pontifical Catholic University of São Paulo (PUC/ SP) in the fields of Psychosomatics and Hospital Psychology.

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 $(p. 213^4)$

INTRODUCTION

call family, first we understand that:

he literature on HIV is immense, in different areas, themes and languages, however, the same does not happen when it comes to talking specifically about the family relationships of those living with HIV.¹

Living with a person with HIV in the family causes changes that may be related to the quality of the family's functioning and structure. This is because this diagnosis will cause changes that improve or worsen relationships in the family dynamics.

These changes will depend on several factors, such as: which family member is living with HIV; the form of infection; who knows about the diagnosis; how they found out; what relationships were like before the diagnosis; whether there was already a family member and/or acquaintance/friend living with HIV in the family, among others.

> Each family moves in a unique way, interpreting the situation based on its culture, codes and rules, which will influence the behavior and communication process between its members $(p. 154^2)$

The society in which the family lives is a guide for individual, family and social behaviors so that, within the family, the person living with HIV (PLHIV) may be discriminated against and/or excluded from this coexistence, or seek ways to cope and overcome in an attempt to restructure themselves in the face of the new reality of health and illness.³

It is important to consider what we

The family is the social device responsible for reproduction, care and education, which involves the socialization of new generations in the three dimensions of the human being: consciousness, affections and activity. And like every social device, it has social prescriptions to follow, such as ethical and moral values (solidarity, respect, among others). These will be structured according to the way each person will deal with their affections, actions and conscience in their daily lives in this space that is the first space of belonging. $(p. 210^4)$

To Martín-Baró⁵ (p. 2, our translation) "Groups develop their own rules of coexistence so that each person can find their social function in a harmonious universe." And with that:

> (...) we will assume that the family has dialogical and contradictory relationships between its members that can develop intimacy, education, respect, support and protagonism. Contradictorily, these same relationships can generate emotional distances, deconstruct powers and generate physical and psychological suffering, nullifying protagonism. Dialogical and bonding relationships by themselves do not have a single quality and direction, but are dynamic constructions that undergo the most diverse influences (...)

We understand that families live in a dialectic between constructiveness and destructiveness, since we can have families that are constructive in terms of the professional aspects of a family member and destructive in terms of the emotional and sexual relationships of this same person.

The search for constructive relationships does not necessarily mean breaking away from the biological family, since the individual may not feel like they belong to their family and may break away from it through actions of distancing themselves and thus establish bonds with other people who come to be considered as their family. However, the family in which the individual was raised and developed does not cease to exist in their symbolic process and this needs to be integrated, otherwise there will always be an unresolved relationship, generating psychological suffering.

According to Silva, Villela-Neto, Silva and Carvalho⁶ Family relationships are one of the factors that influence the quality of life of people living with HIV. The family represents one of the most important support networks for people living with HIV⁷ together with friends, neighbors, relationships with the religious community as well as support group relationships. If these integrations do not exist or only partially exist, the experience of social stigma can become more difficult than life with HIV itself.⁸

In China, children of HIV-positive parents became the heads of the family, being forced to stop going to school and work because of the difficult socio-

DOI: 10.36489/saudecoletiva.2025v15i94p15179-15192 💽 👔

economic situation they experienced, in addition to the fact that these parents were unable to work and support their families. This makes these children mature, which does not happen to children who do not live with HIV/ AIDS in their family.⁹

Sousa, Kantorski and Bielemann ¹⁰ state that the behaviors presented by the family are influenced by the meanings of stigmatization involved in HIV/AIDS that were socially constructed, which the family group can add to their beliefs and values formed throughout their existence and, thus, disseminate them within the family.

Stigma is the limitation of an individual to just one categorization without taking their entirety into consideration.

> An individual who might have been easily received in everyday social intercourse possesses a trait that can command attention and alienate those he meets, destroying the possibility of attention to other attributes of his. They possess a stigma, a characteristic different from what we had anticipated. We and those who do not deviate negatively from the particular expectations in question will be called normal by me. (p. 14¹¹)

Stigma can be directed at a single person, or an entire family can become stigmatized when we think about family relationships with people living with HIV.

An individual affected by a disease cannot and should not be seen unilaterally; its constitution is global, so the sick person must be seen in their entire network of relationships. And this view cannot and should not be differentiated in the case of HIV/AIDS.¹⁰

However, in the case of living with HIV, socially, HIV is still seen as predominant in the life of the individual in order to reduce or restrict the individual to HIV. Medical advances in HIV now allow us to talk about HIV as a chronic disease and no longer as a death sentence, as it was in the 1980s. Before, HIV was predominant in the life of the person in such a way that it was restricted to diagnosis, but with the advances, HIV no longer has this appearance and today it is considered a chronic disease in which, by taking the medications as prescribed by a doctor, it is possible to reach the level of undetectable and, therefore, untransmittable. However, socially, there is still no such progress, so it is still common for society to restrict the life of a person living with HIV to the virus and not to first see the person in their singularity and then see that they live with a chronic disease, such as diabetes or hypertension.

And in Brazil we already have some important advances in antiretroviral treatment and with that we are moving towards the end of AIDS in Brazil. UNAIDS¹² (The Joint United Nations Programme on HIV/AIDS, in December 2024, congratulated Brazil for achieving yet another goal. The goals set were to have 95% of people living with HIV being aware of their serology by 2030, 95% of people diagnosed being on antiretroviral treatment (ART) and 95% of people on treatment being undetectable and, therefore, untransmittable. We have already achieved goals 1 (96%) and 3 (95%) and are on track to reach the second goal (82%). Therefore, it is important to highlight the progress made by those living with HIV, but little is said about the family relationships of these people living with HIV.

Sousa, Kantorski and Bielemann¹⁰ (p. 4) reflect on illness as "an intentional manifestation of the body in a process of life movement. It is an opportunity to have contact with our finite body and this enriches our existence." However, according to their results, family members see the situation of living with HIV/AIDS as being difficult to accept, as it does not present compatibility with the social standards accepted for illness. Family members of those living with HIV/AIDS are not affected by AIDS, but their experience is as if they were.

> Having AIDS is not just about having an incurable disease, as is the case with cancer, for example; in addition to the real spectrum it has, this disease also carries with it a huge social stigma. Society not only classifies AIDS as lethal, causing suffering that borders on the superhuman, but also classifies its carrier as inconvenient, immoral or someone who exhibits socially unacceptable behavior, creating in this person the belief that he or she is inconvenient and unacceptable. (p. 40313)

And this stigma does not only apply to the person living with HIV, but also to their family members, who may come to be seen as passive people who "accept" this relationship and, possibly, even cover up for their family member.

> Living with a family member with AIDS means going beyond the physical boundaries that the disease imposes, that is, it means heading towards an invisible world, full of concepts and prejudices based on the representations of this disease in people's lives; it means raising positive and negative impressions about the disease and life with AIDS; it means getting closer to and distancing yourself from the AIDS sufferer, society and the family. (p. 330¹⁴)

The description of these authors is specifically aimed at families and people who are already affected by AIDS, but the same can be inferred for those living with HIV. Daily care for the person living with HIV is also a family matter. However, for some, the burden of constant alertness can be added, which means always being vigilant to see if the family member is taking their medication or even for any injuries, so as not to put others in a vulnerable situation. But it can also be seen as care or lack of knowledge about the forms of infection.

In a health-illness situation, one must analyze how this family, in general, behaves at these times, since it can "be recognized as a health unit" and thus be a point of support, assistance and help for the person living with HIV, fulfilling its family role of care.11. Uma das formas de apoio e ajuda nesta vivência é o cuidar.

> Caring does not only mean satisfying the basic physiological needs of a human being, but includes providing support, living together, listening, understanding others, as well as many other ways of demonstrating feelings for the person receiving care. (p. 404^{13})

In research carried out by Botti et al.¹³ with seven family members, it was found that women, in general, are the ones who take on the care of their family member, often without any extra support, and with this "they seek internal strengths that are greater than their possibilities. It is important to emphasize that care is generally perceived as an integral and natural part of women's lives." (p. 404). These women are fulfilling their gender roles as caregivers, as we saw previously.

It is worth noting that the moment a family member is diagnosed with HIV+ triggers similar feelings and behaviors that everyone who learns of the diagnosis goes through. These include sadness, anguish, feelings of helplessness, sometimes with disorganized behaviors and thoughts, in which one does not know how to act, depression and isolation. Coping mechanisms also become the same, such as silence, denial, and keeping the diagnosis a secret. 15.16.17.18

Darling, Olmstead and Tiggleman ¹⁹ are clear in stating that people living with HIV/AIDS and who have a good family structure and are learning to cope with this situation, were able to obtain a higher level of life satisfaction in relation to people who have a poor family background and little or no learning.

In research carried out by Almeida-Cruz et. al.²⁰ with young people living with HIV showed that a positive family relationship is associated with feelings of happiness and a better quality of life for these people.

Pimentel et al.²¹ and Souza et al.²² analyzed how family relationships can be related to the reduction of stigma and prejudice against HIV and concluded that even with feelings of fear, people living with HIV find a support network in their families.

We can relate these data to constructive and destructive families, with constructive families having a good family structure and learning that helps people cope with life with HIV together with people living with HIV, while destructive families do not help people live with HIV.

HIV in the family can be a determining factor in family relationships, causing separation, discrimination or even defenses to avoid retaliation. In this regard, the intra-family group formed by family members who are aware of the seropositivity bases their behavior on that of other family members who are not aware, in order to ensure that no one else finds out about the diagnosis. If this is a determining factor in family relationships, they cause destructive family relationships, whereas if HIV becomes a supporting factor in relationships, these become constructive.

On the other hand, the HIV diagnosis can be a supporting factor in family relationships, since the family problems suffered before or after seropositivity are greater than life with HIV.

Living alone while living with HIV can become inevitable when faced with the need to distance yourself from family and friends ¹⁷, Living in this reality may involve taking care to avoid infection, as well as discussions about sexual practices and preferences or drug use, which are not always easy topics to discuss within the family. This family rejection can complicate the process of coping with life with HIV, resulting in a decrease in the quality of life of the individual and making it difficult to adhere to treatment.²¹

Research carried out by Costa, Medeiros, Paungartner, Luft, Santos, Paiva and Fernandes ²² on the psychosocial factors involved in adherence to treatment points to the importance of emotional support, in general, provided by the family, which influences the process of adherence to ART.

OBJECTIVE

Therefore, this article aims to discuss how an HIV diagnosis shapes family relationships.

METHOD

This article is an excerpt from the doctoral thesis, entitled "Family configurations of elderly people living with HIV/AIDS", defended at PUC/SP by the first author in 2017 and supervised by the second author. The following people participated in this research: 37 elderly individuals, 25 men and 12 women, aged 60 to 82 years, in addition to 19 family members, 15 women and 4 men, aged 16 to 79 years.

Of these 37 elderly individuals living with HIV/AIDS who participated in the research, we were able to talk to at least one family member with 16 of them, making up the family analysis of 16 families. Three of these elderly individuals allowed us to talk to more than one family member. The family



configurations were eight families with parents, two with conjugality, two with siblings, two with uncle and niece; one family with generational configuration in which there were grandfather and grandson; and one family with cousins.

The research analysis was conducted with four core meanings, namely family pattern; sexuality; HIV in family relationships; and secrecy. For this article, we focused on HIV in family relationships. For each family, we selected a title that is related to family experiences.

This research was conducted at the Infectious Diseases Outpatient Clinic of the Federal University of São Paulo (UNIFESP) - Center for Infectious Disease Control (CCDI) during the implementation of the "HIV and Aging Outpatient Clinic", which aims to provide specialized care for elderly people living with HIV. It is a subproject of the research "Gender Relations and Therapeutic Itinerary: transversality with adherence to self-care in health", a research authorized by the research ethics committee of the Pontifical Catholic University of São Paulo PUC/SP, headquartered at the Monte Alegre campus, under research protocol no. 351/2010.

RESULTS

In this item, families were divided into whether living with HIV was a supporting and/or determining factor in family relationships. The first group - supporting - was made up of 12 families, namely: 1, "United women"; 2, "I live to die"; 3, "My daughter takes care of everything"; 4, "Between the three of us, our family is united"; 5, "My son knows me"; 9, "The husband and wife relationship is over, but the family relationship continues"; 10, "Exchange of care"; 12, "We are each other's guardian angel"; 13, "I am well-known"; 14, "I have no one to talk to"; 15, "Best friends"; and 16, "A relationship between father and son is what best defines us".

And the families in which HIV is a determining factor in family relationships were 4 families: 6, "My extended family is prejudiced"; 7, "The sufferers"; 8, "United we will win"; and 11, "We live in constant alert".

Two families representing each of the configurations of how HIV is configured in family relationships will be used to discuss the results.

DISCUSSION

We begin our discussion by analyzing a family in which HIV plays a supporting role. Family 1, "United Women", Alice (an elderly woman living with HIV) and Marcela (Alice's daughter), is a family dominated by women, so that care behaviors are aligned with the hegemonic, being an unfolding of gender roles.²³

In this family, care is mutual support and mediation of relationships. This care can also mean power and prestige, as Marcela tells us that she knows everything that happens to her children, grandson and mother, as she has taken on the role of the family's centralizer.

Marcela tells her sons to take care of themselves, reinforcing the idea of the male as sexually active. ^{24,25} However, this care is a disguised prevention, as it is only intended to prevent pregnancy and not as self-care for health. In this regard, we see that the family is not recognized as a health unit, as Cardoso, Marcon and Waidan tell us. ¹⁴

In this regard, Alice failed to take care of her health and now lives with HIV. Marcela also fails to keep her sexuality tied to fantasies and romantic love, trusting her partner because of his profession. And Marcela, because her mother failed to take care of herself, takes on the responsibility of caring for her family, but also seems to fail to spread prevention methods to her children just to avoid pregnancy.

Alice lives in contradiction when talking about prevention with her grandchildren, since she does not reveal her diagnosis to them. She lives with a disease that, for society, makes those who live with it seem worthless.

We see that it is a caring family in the sense of support, listening, coexistence, as Botti et al. ¹³ tell us, But regarding preventive care, it is lacking.

One of the changes that occurred in this family was in Alice's family care for Marcela, a fact that Alice does not realize. Not identifying family changes may be related both to the time spent living with HIV, which can lead to the naturalization of living with HIV and, therefore, make her forget what it was like in the beginning, and to the fact that only people she trusts, her daughters, know about her diagnosis.

Even though HIV is a secret between Alice and her two daughters, this does not prevent them from continuing their family relationships, although they are afraid to tell the rest of the family and suffer prejudice and discrimination. HIV appears to be a supporting factor, since the family has other problems, such as financial ones, that seem to be greater than Alice's life with HIV.

HIV is a determining factor for family 8, "United we will win", Marcos (an elderly man living with HIV), Márcia (Marcos' daughter), Conceição (Marcos' serodiscordant wife) and Joaquim (Marcos' grandson), HIV is a determining factor and, therefore, negative in the family relationship, especially for Conceição, the wife, because she always remembers the anger she has towards her husband and this determines her behavior. On the part of Márcia and Joaquim, HIV is a supporting factor, because it does not interfere with their roles as father and grandfather.

One of the ways that Conceição found to vent her anger at her husband's behavior and for not legally separating from him is to separate his clothes when washing them (even though she knows that this is not a form of HIV transmission).

But anger control is a daily task in

this relationship for Conceição and shared with her youngest daughter, who lives with them.

For Conceição, Marcos shows himself to his family in a certain way, and the fact that his HIV diagnosis reveals his sexually free behavior is revolting not only for her, as we have seen, but also for her children, especially her eldest and youngest.

In all of Conceição's speeches we notice her anger towards her husband and this corroborates with Gorinchteyn ²⁶, when he states that HIV, within the family, causes pain to be relived, absences to be charged, anger to be expressed. AIDS is a catalyst for emotions never expressed and, finally, surfaced. This also confirms what was discussed by Cardoso, Marcon and Waidman ¹⁴, that coexistence goes beyond the physical boundaries imposed by the disease.

Conceição continues to fulfill her

hegemonic feminine role of care, but without being able to express her anger, which would alleviate her experience. Educational and welcoming workshops could be effective in working through her anguish, anger and sadness regarding her marital and family relationships.²⁷

With Conceição, we also confirm what Botti et al. ¹³ states: "in the expressions used, caregivers show the living manifestation of being-family, in which the bond existing between its members does not allow them to simply abandon it, as other people do." (p. 402)

For Márcia, his daughter, and Joaquim, his grandson, HIV did not interfere with their paternal and generational role.

For Márcia and Joaquim, since the father fulfilled his hegemonic male role of sexual activity, this did not interfere with their paternal role, since HIV did not cause any anger in them towards Marcos.

CONCLUSION

Finally, we see that HIV is seen as a supporting factor in family relationships when the family's other problems become greater than life with HIV, such as financial problems, some type of addiction, such as alcoholism or even post-stroke (cerebrovascular accident). For families in which this experience is decisive, life with HIV is a burden and everyone who has knowledge is constantly on alert not to tell anyone else, as well as the emergence of disqualified relationships that already existed in family relationships before HIV.

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