

Memories in the elderly living with the immunodeficiency virus

Memórias de idosos que vivem com o vírus da imunodeficiência humana

Recuerdos de ancianos que viven con el virus de la inmunodeficiencia

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Abstract: Objective: to understand the experiences of the elderly with Human Immunodeficiency Virus on the main factors that mark their memories. **Method:** this is a qualitative study with a narrative method, conducted from April to May 2018 in a medium-size city in the inland of the state of São Paulo with eight elderly individuals with Human Immunodeficiency Virus. The analysis was performed by means of content analysis, in the thematic modality. **Results:** four thematic categories emerged: Life context before the diagnosis; Way of infection, HIV suspicion and confirmation by the elderly; Living with HIV and Family/Social relations: among supports and preconceptions. **Conclusion:** the elderly individuals interviewed revealed the disease as a condition that exceeds their biological aspects, since it essentially involves the social, family and psychological contexts.

Keywords: Elderly; Acquired Immunodeficiency Syndrome; Life Cycle Stages; HIV; Nursing.

Resumo: Objetivo: compreender as vivências dos idosos com o Vírus da Imunodeficiência Humana acerca dos principais fatos que marcam as suas memórias. **Método:** trata-se de um estudo qualitativo com método narrativo, com oito idosos vivendo com Vírus da Imunodeficiência Humana, em um município de médio porte do interior paulista, no período de abril a maio de 2018. A análise foi realizada por meio da análise de conteúdo na modalidade temática. **Resultados:** foram identificadas quatro categorias temáticas: Contexto de vida antes do diagnóstico; O modo de infecção, a suspeita e a confirmação do HIV para o idoso; A convivência com o HIV e Relações familiares/sociais: entre apoios e preconceitos. **Conclusão:** os idosos entrevistados revelaram a doença como uma condição que vai para além de seus aspectos biológicos pois envolve, essencialmente, o contexto social, familiar e psicológico.

Descritores: Idoso; Síndrome de Imunodeficiência Adquirida; Estágios do Ciclo de Vida; HIV; Enfermagem.

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Resumen: **Objetivo:** comprender las experiencias de ancianos que viven con el Virus de Inmunodeficiencia Humana mediante el relato de hechos que han quedado en su memoria. **Método:** se trata de un estudio cualitativo con método narrativo, realizado en el período de abril a mayo de 2018 con ocho ancianos que tienen el Virus de la Inmunodeficiencia Humana, en un municipio de mediano porte del interior del Estado de San Pablo. Se realizó el análisis de contenido, en modalidad temática. **Resultados:** se identificaron cuatro categorías temáticas: Contexto de vida antes del diagnóstico; El modo de infección, sospecha y confirmación del VIH por el anciano; Convivir con el VIH y Relaciones familiares/sociales: entre apoyos y prejuicios. **Conclusión:** los ancianos entrevistados manifestaron que la enfermedad es una patología que supera el ámbito de lo biológico, puesto que involucra esencialmente al contexto social, familiar y psicológico. **Descriptores:** Anciano; Síndrome de Inmunodeficiencia Adquirida; Etapas del ciclo de vida; VIH; Enfermería.

Introduction

Population aging has accelerated due to changes in morbidity and mortality patterns and technological advances. In Brazil, the population aged 60 years old and over in 2015 represented 14.3% of the total population.¹ Aging is a process of biological, physiological, social and psychological changes that happen heterogeneously in the population, since it involves multiple determinants.²

Technological and scientific innovations both increased longevity and enabled achievements that were not allowed to the elderly, citing the rediscovery of sexuality as an example.³ However, society still considers the theme as taboo, which contributes to the practice of unprotected sexual relations. Thus, their exposure to Sexually Transmitted Infections (STIs), especially the Acquired Immunodeficiency Virus (HIV), is observed.

In Brazil, HIV infection is considered a public health problem, even though since 2012 there has been a reduction in its detection, in the year 2018 17,248 new cases were reported. In the elderly population, in the same year, 627 HIV diagnoses were made, representing 3.6% of the cases identified in this period.⁴ Thus, HIV infection in this age group is of concern, and the stigma associated with it leads this population to experience feelings of fear, anguish, despair, loneliness and panic. In addition, family and social prejudice further reinforces more feelings.⁵

In a search for information about the living and health conditions of the elderly living with HIV in national and international databases, it was identified that there are few studies that

address the daily life of this portion of the population. However, there is an indication of difficulties in overcoming and accepting the disease, which is more related to the stigmas and prejudices than to the physiological effects of the disease. They seek strategies for overcoming interpersonal relationships and social support.⁶⁻⁷

Given the complex context that permeates the lives of elderly people with HIV and the scarcity of studies that deepen this approach, the need to know the reality of these people is reinforced by the following question: What are the main facts that mark their lives? This study aims to understand the experiences of the elderly living with the human immunodeficiency virus about the main facts that mark their memories.

Method

This is a qualitative study with a narrative method, with elderly living with HIV who are followed up in a specialty outpatient clinic of a teaching hospital in the inland of São Paulo. The option for a qualitative research was chosen given that it enables the understanding of the experiences as a whole. Thus, the description of the human experience, as it is lived and felt by the actor himself, enables the knowledge about the individuals.⁸

The individual narratives focus on sharing unique experiences which, even if they follow the same line of events, can never happen the same way, as each situation is unique to the individual.⁹ Therefore, one seeks to construct and deconstruct discourses in narrative research, allowing the researcher to understand the truth immersed in other truths, being also a moment in which one can perceive the transformation of personal changes related to the experiences of the subject who lives with the disease throughout their life.¹⁰

In the outpatient clinic where the data were collected, which is a reference for 62 municipalities, in 2017, a total of 268 people living with HIV underwent medical consultation, of which 43 (16.0%) were over 60 years old. For data collection, the non-directive interview was used. This interview format, because it is a technique focused on the interviewee,

allowed him to talk freely about his experience.⁹ Initially, the participants were identified as to: age, ethnicity, time since diagnosis, marital status and education. In order to explore the memories of the elderly through narrative that reveal the experiences, the following trigger was used: “Talk about the key facts that have been striking in your life”.

A pilot test was conducted with the support of two experienced researchers in qualitative research, one with a doctor's degree and the other with a master's degree, to evaluate the interview script built with the help of an infectious disease specialist.

Data was collected from April to May 2018. The criteria for inclusion were the following: 60 years old or older; have been under care for at least one year at the selected outpatient clinic; and residing in the same municipality in which the outpatient clinic is located, with a view to facilitating contact with the elderly and scheduling interviews. Participants with cognitive impairment that made it impossible for them to provide information were excluded.

The construction of the sample took place intentionally. After checking the inclusion and exclusion criteria, telephone contacts were made and the research objectives were explained. By showing interest in participating in the research, the locations and times were agreed upon according to the participant's availability. The interviews conducted by two trained researchers took place during home visits and on the premises of a municipal state college in private rooms. Due to the complexity of the subject and the small number of elderly patients in the municipality, there was resistance from users to participate in the research, being possible to conduct eight interviews. These, which had an average duration of 45 minutes, were recorded in audio and transcribed in full.

The analysis and interpretation of the material produced was performed through the technique of content analysis in thematic mode, aiming at a deep interpretation of the context of the speeches. In this sense, it took place according to the following steps: a) pre-analysis; b) exploration of the material; and c) treatment of the results obtained and interpretation.⁸

Thus, initially, each interview was read, aiming at the organization of the material to be analyzed and the recognition of the initial ideas of the text. After this stage, the material was submitted to a detailed study, aiming at the cutout of each interview in record units, that is, the coding, which allowed the classification and aggregation of data to elaborate the meaning cores. Finally, the relations and deductions supported by reflection and theoretical foundation were established.⁸

The study was approved by the Research Ethics Committee of the proposing institution, Opinion No. 2,538,085, in compliance with Resolution 510/2016. All participants signed the Informed Consent Form. For submitting the results and preserving the identity, the participants were coded by I followed by increasing numerical sequence (I1... I8).

Results

Eight elderly aged 61 to 74 years old participated in this study, four women and four men; three brown, two black and three white; two single, two married, two divorced and two widowed and all discovered the disease 11 years or more ago. As for education, one is illiterate, four have incomplete elementary school and three have completed elementary school. Data analysis led to the construction of four meaning cores: Life context before diagnosis; The mode of infection, suspicion and confirmation of HIV for the elderly; Living with HIV and family/social relations: between supports and prejudices.

Life context before diagnosis

Through the narratives of the interviewed elderly it was possible to infer that their lives were marked by difficulties since childhood, passing through the early insertion in the job market to the detriment of schooling. In this trajectory of difficulties, in which rural work

predominated, the search for improvement in living conditions was symbolized by the dream of moving to the capital, as observed in the following narratives:

My childhood was very sad. I lived in the place, my father was very sick and we were in great need. (I6)

because I had to work, because I wasn't supposed to study[...] He has never studied [the father] and was living; I completed that year and didn't study anymore. (I3)

At that time we hunted the best place. It was any young person's dream: 'I'm going to Sao Paulo' I thought going to São Paulo was better. (I1)

The mode of infection, suspicion and confirmation of HIV for the elderly

All respondents contracted HIV through sex. Some of them cannot identify who was the HIV-positive person with whom they were related, indicating contact with different partners in environments marked by the diversity of coexistence, whether straight or homosexual. However, it was possible to identify that some respondents were exposed to the virus by their colleagues:

I'll tell you something, I'm homosexual and I got to have sex. Only that I don't know with whom it was. (I2)

it was as a result of a travel, such things; sleeping outside the house, including drinking, I was living in various environments; everywhere you can imagine, we used to go. I was not careful. I thought it happened to others, but less to myself. (I4)

when I broke up with him, I got into a relationship and in this relationship the guy had HIV. (I6)

Some of the interviewees claimed lack of knowledge about the form of transmission or disbelief in its veracity. Thus, they did not use condoms in all sexual relations, being more vulnerable to HIV infection.

At that time you didn't know much about things. He contracted HIV and I didn't know about and we lived together, that's when I found out. (I7)

I used a condom sometimes yes, sometimes no, but at that time it was not so widely publicized, the comments were that it was bullshit can happen or can't happen. (I8)

The interviewed elderly also verbalized that the first suspicions of the disease occur with the manifestation of signs and symptoms or the discovery of the partner's disease, which resulted in the disclosure of extramarital relationships and betrayal of the partner:

Because I thought he was sick, it was around that time that a lot of AIDS advertising started to come out, to be careful, to use condoms, so I said that he knew, he saw the ads, it was not possible that if he was doing it will not use. It didn't take long, he even appeared with his face all marked but it is only that I never imagined in life what it was. I think it was already from the disease. (I3)

There came such a reaction of weakness, then came the urge to puke, all that stuff. Stomach, everything mixed like that. I made the appointment, then asked for a blood test and the result was AIDS. (I4)

When they perceived HIV positive, they stated that many feelings permeated their experiences, involving the impact of the diagnosis, despair, guilt, sadness, non-acceptance, denial, omission, the search for coping resources, acceptance and joy to be alive:

It's a landslide, it seems the world falls on you. It looks like it was going to end that day. The feeling is just to have passed to my wife. We didn't know, so it ended up being like this [...] that's what hurts the most. (I4)

I was very sad, because it is not an accepted thing, [...] my son and my daughters pray, they are very catholic too, you know? Some day I don't even remember, believe me? I do not even remember! (I7)

I didn't have so much conflict with myself about accepting or not accepting. I have accepted and am managing to live, whether I like it or not in the face of many facts of people who went upstairs, I am alive! I feel good! I am having quality of life and I am living my life. (I8)

Illness you can never talk about it and accept it, you have to despise it, make it not in you, so anyone who came up and said it was a lie to me. But I let few people know just when I went to a doctor, [...] who really cared, didn't let it, didn't tell anyone.. (I6)

Living with HIV

The elderly interviewed verbalized that in the trajectory of living with HIV, they face difficulties, especially in relation to the adaptation to the drugs. In addition, there have also been changes in the way we view life. The use of drugs is seen by them as a sacrifice as they face undesirable effects. In addition, they sometimes cease to make use of alcoholic beverages, as observed in the following statements:

I never got sick, I started up to take medicine after 63 years old because my immunity fell, then it was my suffering because I didn't want to take it, I didn't want to take a cocktail at all! Still, she passed me one and I did not give it to myself, because I was hallucinating, then she changed to another I started taking and started throwing up every day, and that's what ended me, it developed a reflux. (I3)

I have already changed the medicine about 4 or 5 times and I don't know, it all depends on your body, the adaptation, the side effects, so they changed that and that according to what I was feeling, because we make an exam each 5 months. I don't know if it was a headache or if it was a drug effect, I didn't have an erection. (I8)

I don't take the medicine right, because I take some portions of sugarcane brandy. (I2)

The interviewed elderly indicate that the disease taught to value life more, act more moderately and expand health care.

Willpower to live [...] it was after I had AIDS that I got it. Because before I could not, I would stick in the bar and have a beer. I think the disease taught me that when I wasn't sick, that when I was healthy, money had no value to me. (I1)

I say that when I found out, I ended up getting healthier, syphilis was killing me, after I got the treatment I stopped those pains I had, I just feel bad that I can't donate blood. (I3)

I have always taken care of myself, but when we know that we have a contaminated blood, we eat better, without worrying about getting fat or this and that other. (I5)

Family and social relationships between supports and prejudices

In the approach on social and especially family relationships, it was possible to notice that the reactions with the disclosure of the diagnosis were diverse, including rejection, indifference, acceptance and support.

My mother was not nice, not at first. And she flattered me too much. But when I got sick I lay on her bed, I gave her my hand and she looked me like that and said "get up because I don't want "rotten" on my bed", it wasn't nice to me. Nowadays the one who treats her is the rotten one, you know? (I1)

Yeah, my dad said nothing, you know. He thought he had to buy drugs, so I said "no, it's not buying, the government provides the medicine" then he said nothing, he was just like me, he was normal. Mother too, had no reaction, was not angry, was not sad, if she was sad it was inside, but not on the outside, she was the same thing. (I2)

So they all were supportive, and they said, "the lady who knows, if you want to drop the father, we understand, whatever you do, we support you." (I3)

It was terrible when I broke the news it was something that no one expected. At the time it was terrible just to know that someone had HIV so people didn't accept it, and I did! Because I thought: I'm having treatment, I have a life expectancy, got it? (I8)

In the relation with the health professionals, there is both stimulus to treatment and unethical postures when exposing to third parties the diagnosis of positive HIV:

[the health professionals] said “no, it's not like that, and so, there is a drug, you taking it right have your have your survival, your things and such” is not the same in the beginning, when we found out it was already very bad, so we were treating, coming back all. (I4)

only that here most neighbors already knew, you know? Do you know why? The post nurse here opened the exam and told the whole neighborhood. (I3)

Discussion

The elderly living with HIV who were interviewed live with the numerous consequences that have come from this situation for over 11 years, and many of them did not acquire it in old age, thus became elderly with the virus.

Thus, with the free distribution of antiretroviral drugs promoted by Law No. 9,313/96, the Brazilian government, pioneer in access to triple antiretroviral therapy as a public policy, has increased the life expectancy of people living with HIV with longer survival and quality of life.¹¹ The changes in the approach in 2013, with the initiation of treatment for all people from the diagnosis of virus infection regardless of immune status, contributed to this scenario and gave HIV infection a chronic disease character. Thus, the discussions about survival and the imminence of death after diagnosis gave way to advances in quality of life.¹¹⁻¹²

Today, although experiencing difficulties and wear, the elderly show that they can live in a harmonious way with the problem. A study with seropositive people showed a positive

association between the perception of quality of life and the time of diagnosis, indicating that over time they can redefine the perception of the virus.¹³

In the speech of the elderly, it can be seen that childhood was marked by economically underprivileged life contexts, which influenced their youth and adulthood. They lived their childhood in rural areas and were inserted early in the work world, stimulated by the family needs. The parents needed their children's manual support to support their families. The socioeconomic situation and production conditions of the time, together with the absence of educational public policies that stimulated the construction of local schools and/or transportation, contributed to the impairment of these children's schooling.¹⁴

In addition, the 60s, when these elderly lived their childhood, was marked by unemployment and misery of small farmers leading, especially the younger, to migrate massively from the countryside to the city, in search of better living and working conditions. This migratory movement led them to live in a different culture and to take up jobs that required less qualification because they generally had low education, and little access to information, especially relating to sexuality, increased the vulnerability to risk behaviors.^{5,15-16}

All respondents reported having been exposed sexually, following the proportion found between 1980-2017 in the country where 82.9% in men, of which 50.9% in heterosexual relationships, 34.0% homosexual and 15.1% bisexual. In relation to women, in this same period, 93.1% were exposed to HIV through the heterosexual contact.⁴

Thus, the findings of the present study, as well as the aforementioned data demystify the relationship of HIV infection and homosexuality. The high percentage of this infection in the context of heterosexual relationships indicates the need to adopt prevention strategies aimed at this population that often ignores the risk for HIV infection. A study identified the predominance of HIV infection in the elderly who reported single partner and heterosexual relationships, but did not use condoms.⁶

Still, the elderly refer to the lack of information as a factor that led them to contract the disease. If access to information is fast today and there is an attempt to look at sexuality more broadly, in the past the difficulties, sex-related taboos and sexuality, undermined knowledge about HIV. Thus, failure to recognize the virus as a threat and its own vulnerability, which is associated with non-adherence to condom use, increased the chances of infection.⁵

The lack of information about HIV led respondents to discover the virus only with the onset of signs/symptoms of illness. Thus, the diagnosis is made in the late phase of the evolution of HIV infection, usually during hospitalizations of one's own or one's companions.¹⁷

However, the impact of HIV diagnosis on these people is more related to the stigma and prejudice about the disease than its physiological effects.⁶ HIV diagnosis leads them to experience intense and distressing feelings. Initially, feelings of indifference/denial do occur. Such feelings are considered as a temporary defense mechanism so that the person can, over time, become aware and assimilate the necessary modifications and adaptations to this new condition that permeates their life.^{6,16}

The infection by the partner represented double suffering for women, as finding out about the infection also revealed the husband's infidelity. Women in situations of violence and HIV positive verbalized feelings of anger towards their partner, as well as nonconformity with the situation of precariousness and social vulnerability that put them at risk, bringing the disease as a consequence.¹⁸

It is emphasized that conservative and sexist education in which the multiplicity of partners is socially seen as common for males, as well as female submission and sex as a marital duty, lead to contradictory feelings that make it difficult to adapt to the condition of being seropositive.⁶

Other feelings that also arose were those of sadness, guilt, fear of social reactions with consequent omission of the diagnosis. Thus, since AIDS is linked to the idea of fatality/death, upon receiving the diagnosis, the elderly present an initial shock state, with the feeling of

sadness present in all reports. For fear of people's reaction, some seniors decide to disclose the diagnosis to a few people. Thus, while this omission may be a mechanism to protect feelings such as rejection, it may compromise their access to social and health rights.^{5-7,16}

The feeling of guilt contained in the narratives of the elderly is essentially related to the fact that they transmitted the infection to their partner. Guilt is characterized as a disturbance that can potentiate other feelings related to the diagnosis, as they feel responsible not only for their own suffering, but also for the suffering of the other.^{5,7,13,18}

Although HIV diagnosis arouses intense feelings as discussed above, over time, although there are difficulties in dealing with stressors in their daily lives and fears that permeate this new life condition, the desire to live and enjoy life drives them, to persevere in seeking strategies to address and overcome obstacles and their own prejudices about HIV.^{5,7,13} Thus, the respondents explain that by accepting their condition they feel happy to be alive. However, for others, the diagnosis and the myths surrounding it may represent a sense of willingness to give up their lives.¹⁹

Regarding the treatment, it proves indispensable the survival of these people. Thus, adherence to antiretroviral therapy (ART), as well as positive changes in lifestyle and investment in self-care, due to their willingness to live, become the main form of coping with the disease.¹² However, ART side effects, in addition to restricting the use of alcohol can compromise adherence to drug treatment, thus making it difficult for the elderly to live with the disease.¹¹

In this process of living with HIV, social and family relationships indicate a strong impact on their lives. The stigma, discrimination and prejudices present in society about the disease and those who live with viruses promote in the elderly the need to maintain confidentiality regarding their condition, confiding only with close relatives. Thus, the fear of the reaction of others and rejection profoundly interfere in their daily lives.^{5,11,16}

For the families, HIV diagnosis may come to represent antagonistic feelings about the relative, marked by initial rejection and, subsequently, acceptance. The virus infection and its social representation start to impact not only people's life but their entire family. The family members also experience the different stages of adaptation to the positive result of HIV resembling those experienced by the HIV-positive person.^{5-7,10-11}

The family, constituted as a support and as a safe place for vulnerable members, is important for the welcoming of the person living with HIV. Family support reflects on its restructuring and self-acceptance after HIV diagnosis.^{5-6,16}

Thus, given the complexities that permeate the lives of these people, health professionals are important in assisting these individuals and their families, assisting them in adapting to their condition with respect to autonomy.⁷

Conclusion

Through the analysis of the narratives, the elderly living with HIV reflected on their memories and their experience before and after acquiring the virus, thus evidencing that they acquired through sexual contact for over 11 years. These were children inserted early in the labor market and with difficulties in accessing education. In the suspicion and detection of HIV infection, they had feelings of despair, guilt, sadness, non-acceptance, denial and omission. Difficulties with the disease involve the physiological and psychological signs and symptoms, as well as living with the stigma of the disease, which is permeated by prejudice, both in the social and family context. In this trajectory, family support was shown to be fundamental. The elderly show that they had the confrontation, arrived at the acceptance and the feeling of joy for being alive.

This study reveals the experiences of the elderly with HIV infection and their daily difficulties and needs and contributes to nursing actions, especially regarding educational actions, since they are people who need information about diagnosis and appropriate care, aiming at autonomous and conscious decision making.

This study has limitations because it was conducted with only eight elderly people living with HIV who are treated in one place, which may partially portray the complexity of their experiences. However, the reflections on the results are important elements for health practices.

Thus, further studies are needed so that the experiences of these people may be understood in a deeper and more diverse way, making evident the complexity that involves the condition of being elderly and living with HIV.

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