



## Coping strategies adopted by elderly people with HIV in Brazil

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### Abstract

*Objective:* It aims at unveiling the coping strategies adopted by the elderly people in the course of their lives to overcome the difficulties experienced by the condition of being a person with HIV. *Methods:* Qualitative study based on the oral history method. Six older adults with HIV from a city in the great west mesoregion of Santa Catarina took participated in it. Data was collected through in-depth interviews at the Specialized Care Service (SAE) and the elderly people's homes. Data analysis was performed through thematic content analysis. *Results:* The coping strategies adopted were centered on the support of health care professionals (formal network) and the part of relatives and friends (informal network). Some adopt the confidentiality of the diagnosis as a way of facing discriminatory acts and prejudice, while spirituality strengthened resilience and faith in treatment and recovery. *Conclusion:* The coping strategies adopted by the elderly patients contributed to living more adapted to this reality, with less suffering and greater resilience.

**Keywords:** Elderly.  
Human Immunodeficiency  
Virus. Coping Strategies.  
Acquired Immunodeficiency  
Syndrome. HIV.

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## INTRODUCTION

In Brazil, the number of elderly people with HIV (Human Immunodeficiency Virus) has increased throughout recent years. Only in 2020, until June, there were 528 new cases of HIV in the elderly and 666 cases of AIDS<sup>1</sup>. Living with HIV, even today, is permeated by prejudice and social discrimination<sup>2</sup>. A sexual life without information or care makes the elderly individual more exposed to HIV, which, after infection, becomes a stressful event<sup>3</sup>, which leads him/her to adopt various strategies to cope with the adversities of being an elderly person with HIV.

Folkman and Lazarus' coping theory emphasizes that, among these strategies, one can find a set of cognitive and behavioral actions taken by people to cope with and adapt to adverse or stressful life circumstances in an attempt to increase psychological well-being and reduce distress. The coping model assumes that, when an individual is faced with a stressful event, evaluative thinking is triggered to analyze whether or not it is a threat to him/her well-being, after which choices are made in an attempt to control this event<sup>3</sup>.

Coping strategies are configured in an adaptive response that the individual builds to better adapt to stressful situations, which may be due to illness or loss of a person, or that emerge in situations of prejudice and discrimination<sup>4,5</sup>. Accordingly, the question that guided this research was: What were the coping strategies adopted by the elderly individuals, throughout their lives, to overcome the difficulties experienced by the condition of being a person with HIV?

Systematic integrative review, which systematized the production on HIV in the elderly population, concluded that most research brings data related to the clinical profile, with epidemiological studies, of a quantitative nature, with few studies focused on the experiences or the more subjective and qualitative elements of living with HIV as an elderly person, which is an epistemological gap that needs to be investigated<sup>6</sup>.

It is also considered that, by identifying these strategies and the main stressful factors of living and coexisting with this disease, important information

will be compiled for planning care actions in the care services, as well as for empowering the elderly individuals in their trajectories of living with HIV, in order to better live and coexist with this chronic disease<sup>7,8</sup>.

By giving voice to the elderly people with HIV to report the coping strategies adopted, it is possible to better portray this reality of life and give visibility to the demands of this group. In this perspective, it is proposed to unveil the coping strategies adopted by the elderly citizens with HIV in the course of their lives to overcome difficulties.

## METHODOLOGY

This is a study with a qualitative approach, which took thematic oral history as a research method<sup>9</sup>. Oral history records individual memories and experiences, by listening to multiple and different storytellers, who, when brought together, give visibility to a group, since the memory of one person can represent the memory of a collective<sup>10</sup>.

Oral history makes it possible for a social segment to be heard, for a certain group to move and speak for itself, it is not just a documental record or a technique to capture interviews, it involves the knowledge of what is experienced on a daily basis<sup>9</sup>.

The population of this study was constituted by convenience. Six elderly people with HIV living in a city in the west mesoregion of Santa Catarina, Brazil, were part of the research. Three were women and three men, with an average age of 70 years (65-83 years) and a diagnosis of 18 years (12-25 years). Elderly people aged 65 years or older, who had lived with HIV/Aids for more than five years, with a longer time of diagnosis, males and females, and who had previous knowledge about their diagnosis were included. They should also present preserved cognitive function, as tested by the Mini-Mental State Examination (MMSE)<sup>11</sup>.

The number of collaborators was defined according to the theoretical saturation criterion, which suspends the inclusion of new participants when the obtained data begins to present, in the researcher's evaluation, a certain redundancy or repetition<sup>12</sup>.

After approval by the ethics committee, following all health standards and recommendations regarding the risks of infection by COVID-19, the approach to the research field was started in the Specialized Care Service (SAE, as per its Portuguese acronym). Data collection took place from November 2020 to January 2021.

The first contact with the elderly person was made by the SAE professional. He explained the objectives and intentionality of the project and identified which elders agreed to have their identity and serology revealed, after which they were put in contact with the researcher, who was already in another room. Among the 16 consulted elderly citizens, 10 did not agree to participate because they had no time available or did not want their serology to be revealed.

The researcher was a professional physiotherapist and, at the time of the interview, a doctoral student in Health Sciences, with experience in qualitative research with the elderly population. In the first contact, the research objectives, the form of data collection and use, the use of the audio recorder, and the guarantee of anonymity and freedom of choice as to whether or not to participate in the study were explained. Those who agreed to participate signed the free and informed consent form in two copies.

Firstly, the MMSE was applied, and for those who had their cognitive functioning preserved, the next meeting was organized, which could be at home or at the SAE, according to the elderly person's choice. Of the six collaborators, four carried out the interviews at home and two at the SAE, because they had an open diagnosis with their relatives. There was no other person present at the data collection, only the participants and the researcher.

The next meeting sought to establish a closer bond with the elderly person. An observation/conversation was made about his/her home, his/her social networks, his/her family group, his/her socioeconomic conditions, his/her medication use,

among other information, recorded in a field diary.

The in-depth interview was conducted based on a pre-designed script and previously verified by a pilot test, conducted in the semester prior to data collection, in order to test the script and make changes. The script contained questions about the experiences of the elderly person with HIV and about the coping strategies adopted in the process of living and coexisting with this syndrome. The duration of each interview was from two to four hours, carried out in an average of three visits. At the end of each meeting with the elderly person, immediately after ending the interview, the researcher recorded the field observation notes in a Word file.

After the recorded version, it was transcribed in full and delivered on the second visit in printed form, and read in full to the collaborator, so that he/she could validate it, add new information, or exclude unwanted lines. In each step of the interview, this organization was respected: recording, transcription and validation.

After concluding all the interview stages, a complete version of each collaborator's oral history was given to him/her, and after reading it in its entirety, the elderly person authorized its publication by signing the Letter of Authorization and Use of Interviews. The passage from oral to written was divided into three moments: transcription, textualization and transcription<sup>9</sup>, and data analysis followed Minayo's proposition<sup>12</sup>, using the thematic content analysis technique. All were identified with tree names (In Portuguese), according to their choice. The project was approved by the Ethics Committee on Research Involving Human Beings of the University under number 4,379,290.

## RESULTS AND DISCUSSION

After analyzing the oral histories, five analytical categories emerged that represent the coping strategies adopted by the elderly person who participated in the study, as displayed in chart 1.

**Chart 1.** Categories of analysis of the coping strategies adopted by the elderly person to live and coexist with HIV, Chapecó, 2022.

Analytical Categories	Number of elderly people who have adopted this strategy
Maintaining the confidentiality of HIV diagnosis in order to avoid discrimination/prejudice	Six
Relying on friends and relatives to (co)exist with HIV	Four
Anchoring yourself in formal support networks after HIV	Six
Strengthening spirituality and religiosity to overcome this phase	Five
Nurturing optimism about life and recovery	Four

Source: Designed by the authors.

### Maintaining the confidentiality of HIV diagnosis in order to avoid discrimination/prejudice

In an attempt to reduce suffering and increase psychological well-being after the discovery of HIV, all collaborators in this study firstly preferred to keep the diagnosis confidential in order to avoid prejudice and discrimination, an aspect still present in society. The reports below highlight this issue:

“[...] even today, there is a lot of prejudice, if people know about the diagnosis of the other, they already look at it differently, move away, feel afraid to sit down or pass by [...] that’s why I’m very careful not to tell anyone, so I don’t have to go through this discrimination and/or isolation. [...]” (Ipê-roxo, 18 years with HIV, emphasis mine)

“Because, unfortunately, there is still a lot of prejudice today; for this reason, few people know about my diagnosis, [...], because if they did, they would probably look at me with another gaze, especially people who have a very closed mind, they will be moving away for fear of being contaminated or even avoiding hugging, so to face it better, just talk to the right people [...]” (Ipê-amarelo, 12 years with HIV, emphasis mine)

The HIV diagnosis in the lives of the elderly citizens may be accompanied by feelings, such as fear and shame, which generates apprehension about living with this condition. Studies have shown that prejudice against HIV is still present in society today because the disease is stigmatized, which sometimes makes the elderly person face embarrassing and discriminatory situations alone<sup>13,14,8</sup>.

This silencing around the diagnosis interferes with the elderly’s person ability to structure, together with his/her family and friends, strategies to face this reality of life<sup>15,7</sup>. The elderly people in this study emphasized this concern with the disclosure of the diagnosis; for some, the silence was maintained only for a while; for others, the secrecy remains:

“After the discovery of my diagnosis, it took me six years to tell my family, I thought they would reject me or get very angry with me if they knew, I was also ashamed, feeling bad about that [...]” (Laranjeira, 12 years with HIV, emphasis mine)

“Nowadays, few people know that I have HIV, because I never spoke for fear of rejection, maybe it’s my children, daughters-in-law, grandchildren and a few other people [...]” (Kiwizeiro, 20 years with HIV, emphasis mine)

“[...] I [...] know of some people in the neighborhood where I live who also have the disease, but they don’t manifest it with anyone for fear of suffering prejudice, of not being accepted or being isolated [...]” (Palmeira, 19 years with HIV, emphasis mine)

The fear of being judged and rejected by people after disclosing the HIV diagnosis is strong, mainly due to historically built prejudices<sup>16</sup>. How to face this situation? It seems to us that a comprehensive model of health care for the elderly person with HIV, which does not focus only on the disease<sup>17</sup> and ensures the inclusion of actions that consider the social, cultural, religious, educational, and economic aspects to which the individual is exposed, is a more assertive alternative. It requires a network model

that does not fragment the care of the elderly people with HIV, but rather integrates the health teams and sectors, their relatives and society in general.

In this study, the elderly people who were able to disclose their diagnosis, even if only to a few people, such as some family members and friends, had a greater support base, which made it easier for them to face the care demands that this chronic condition requires, as observed in the following category.

### Relying on friends and relatives to (co)exist with HIV

Elderly people, who shared their diagnosis with relatives and friends, when welcomed and supported, became stronger and more resistant to face this chronic condition, as mentioned in their speeches:

“Other people who later found out about my diagnosis were my sister, who came with us here, and one of her daughters, they were very supportive. [...]” (Ipê-amarelo, 12 years with HIV, emphasis mine)

“[...] My family supported me and helped me a lot, my wife worked at a family home and ended up stopping to dedicate herself to provide my care, I have memories of her and a 12-year-old daughter at the time, carrying me on her lap to the bathroom, they bathed me, they did everything for me.” (Palmeira, 19 years with HIV, emphasis mine)

“[...] There was also a great friend of mine there, we met by chance, he lived in the same building, we started talking, as he was alone, we had lunch together and we got to know each other, by identifying ourselves, so I got more freedom and told him of my diagnosis and it was pretty good, because he took care of himself, we talked about everything openly.” (Kiwizeiro, 20 years with HIV, emphasis mine)

In this study, the support and closeness of relatives and friends was a strategy that promoted well-being and understanding of what it means to be an elderly person with HIV<sup>18,19,8</sup>. International studies conducted in China, with elderly citizens living with HIV, confirm that the family is the main source of support and contributes to a greater adaptability of life after the diagnosis<sup>20,21</sup>.

The family, as a support network, is configured as the key basis in this health-disease process, thus acting as a safe haven, a comfort in critical moments, which contributes to the promotion of resilience, so important for a life with quality<sup>22,23</sup>.

The respect, support and solidarity of the closest people, such as friends, are elements that can contribute to the redefinition of life in this phase, despite the experienced adversities. Thus, when reflecting on a comprehensive care model for the elderly person with HIV, it is considered the importance of the involvement of the interdisciplinary team to map the family context of this person, and thus promote approaches to facilitate these relationships throughout life, as well as inform the elderly individuals and their families about the possibilities of access to care in the lines of assistance. Besides the informal networks, the formal ones are also essential in this process of dealing with HIV.

### Anchoring yourself in formal support networks after HIV

Another coping strategy adopted by the collaborators of the study was the anchoring in formal support networks to overcome the challenges imposed by HIV in their lives. In this network, the collaborators underline the role of health team professionals, from the moment of diagnosis, with a qualified listening, the passing on of guidelines about HIV and the care actions to be followed.

“[...] From the first moment [...] of the discovery of HIV, the doctors and the entire health care team welcomed me very well, explained everything to me; and, after I left the hospital, they directed me to the service that would follow-up me with HIV, there was a nurse from the health center who came to my house and made me walk, so I have a strong affection for them. [...]” (Palmeira, 19 years with HIV, emphasis mine)

“[...] at the health center, where I started to be cared for, I had psychological follow-up, I talked to the nurses, with the doctors and received a lot of guidance, whenever I took my husband to the consultations there at the center, they helped me [...] In the first moment at the health center, they guided me about everything, it was pretty



nice, they talked about how to behave in society, not to pay attention to the gossip of others, they explained that it was a normal disease, they encouraged me to be strong, to face it and take care, care for each other, not to pass on the virus.” (Videira, 23 years with HIV, emphasis mine)

“[...] the day hospital, there they cared for me very well and always gave me a lot of strength, courage and stability to keep on living [...]” (Laranjeira, 12 years with HIV, emphasis mine)

The conversation, commitment and welcoming offered by health teams, both in the discovery, as in the course of life after HIV, contributes to the elderly people feel valued, confident and respected, which helps them to face, accept their condition and adhere to treatment. The involvement of teams in health care for the elderly individuals favors the adoption of self-care actions and lifestyle changes, which enables a healthier aging process<sup>24,8</sup>.

Positive experiences in health services favor the return, engagement and greater adherence of the elderly person to health care after HIV. Therefore, a contemporary health model that efficiently cares for the elderly citizen will advocate actions focused on health education and promotion, prevention of preventable diseases, as well as postponement of diseases<sup>25</sup>. Still, according to the author, it is essential that the line of care for the elderly person integrate specialized services with primary health care, which is the gateway to the system.

An elderly person in this study adopted as a coping strategy to live in a support group, formed by People Living with HIV (PLHIV) of all ages, with different times of diagnosis. Some had already gone through the acceptance process, others were in the stage of insecurities and fears related to life after HIV. The group represented a place for socializing, exchanging experiences and listening, which promoted a new meaning to the negative experience of living with HIV.

“This female doctor and another male doctor, who treated people with HIV in this city, formed a support center where, every 3 months, people who had HIV gathered in a room at the regional hospital [...] there was a moment of listening where

we placed ourselves ‘Look! We are here, you are alive: Oh my God! It is in order to make the person revive a little and forget about the pathology [...]” (Kiwizeiro, 20 years with HIV, emphasis mine)

When faced with a stressor agent, considered HIV in this study, another service that promoted psychological well-being and reduced suffering was the AIDS Support and Prevention Group (GAPA, as per its Portuguese acronym), as observed in the report below:

“[...] the doctor who was accompanying me referred me to the GAPA, and this service helped me a lot, they gave guidance, showed how to keep on living after HIV, they were very attentive to us [...]” (Ipê-roxo, 18 years with HIV, emphasis mine).

In light of the foregoing, it is argued in the direction of strengthening formal support networks, which can be integrated by different services and professionals, in order to know this reality of life and enable the development of bonds with the diagnosed person, thus ensuring the longitudinal follow-up of this person in a quality care pathway. For this care to be effective, it is required to have a look free from prejudice, where the individual is perceived in an comprehensive way, with respect and appreciation.

### Strengthening spirituality and religiosity to overcome this phase

In this study, the coping was also anchored in the strengthening of spirituality and religiosity. Spirituality had a strong presence in the lives of the elderly patients, configured as a cornerstone after HIV, as contemplated in the following speeches:

“[...] In turn, what helped me face life after HIV was my own faith [...]” (Laranjeira, 12 years with HIV, emphasis mine)

“[...] One of my siblings, with whom I had a lot of affinity helped me, and we went to seek spiritual help, we sought in every way, to have strength, I sought a lot of prayers, because what to do? I had to accept [...]” (Videira, 23 years with HIV, emphasis mine)

“[...] I believe that what helped me to face this pathology and move on with my life is very much related [...] spiritism and the words of a spiritist medium that I hear daily, and he brings me many teachings of life and peace [...]” (Ipê-amarelo, 12 years with HIV, emphasis mine)

Spirituality, understood as an existential domain, is a vital and universal force, an intimate presence, an inner movement that assigns meaning and significance to life, occupies a place in the essence of all human beings, and can positively influence the aging process<sup>26</sup>. In older people with HIV, faith contributes to increasing resilience and a person's ability to manage negative emotions, pain and sorrows – whether emotional or physical<sup>24</sup>.

In order to adapt to the various daily circumstances, they also try to strengthen their religiosity and union with the churches, as observed in the reports:

“[...] Religion and faith in God changed everything in my life, and the church really welcomed me after the stroke and the discovery of the virus [...]” (Palmeira, 19 years with HIV, emphasis mine).

“Near where I lived, there were two Catholic churches [...] I always went there, so they said: ‘Ah, he is a saint, he is always in church’, but since I lived alone, why would I stay at home? I liked to go there [...]” (Kiwizeiro, 20 years with HIV, emphasis mine)

“I was always a woman with great faith and I sought the churches and God a lot, after HIV, with a view to getting strength [...]” (Videira, 23 years with HIV, emphasis mine)

Religiosity refers to the way a person expresses his/her faith and spirituality, anchored in their values, beliefs, cults and rituals, which may or may not have a connection to a religion<sup>26,27</sup>. Religiosity and spirituality are a source of psycho-emotional support for people with HIV. Spiritual beliefs and practices, such as prayer and meditation, as well as religious activities, are resources that contribute to coping with the adversities that HIV produces<sup>28,8</sup>.

It should be highlighted the importance of welcoming, which integrates the dimension of spirituality and religiosity as elements of this

expanded look at the life of the elderly person. This can nurture optimism in life and in recovery, a category presented below.

### Nurturing optimism about life and recovery

In this study, nurturing optimism also helped the older people to face and overcome the difficulties they experienced after HIV, as can be underlined in the following reports:

“[...] I believe that what helped me to face this pathology and move on with my life is very much related to my willpower to live, my positive thinking [...]” (Ipê-amarelo, 12 years with HIV, emphasis mine)

“[...] I started to accept and get used to the HIV diagnosis, always with positive thinking and believing that I'd live and that happened [...]” (Palmeira, 19 years with HIV, emphasis mine)

“[...] I'm a person who is always in a good mood [...] I see many people complaining about various things and I always think ‘if only they knew what I had to fight with it; and, even so, I'm here, always seeing the positive side of everything.” (Videira, 23 years with HIV, emphasis mine)

The adoption of positive thoughts, with maintenance of optimism in relation to life after HIV, was another way that the elderly people in this study took over to maintain a normal life. The elderly individual, after the HIV diagnosis need to be encouraged, either by family members, friends and health professionals to keep on living, thus leaving negative thoughts aside<sup>29,30</sup>.

International studies have emphasized that facing life with HIV goes through ups and downs, but remaining optimistic about life and recovery, especially accepting this new chronic condition, is closely related to psychological well-being and hope for a long life<sup>31,32</sup>. It is thought that adopting optimistic behavioral attitudes make people more resilient and able to adapt to stressful factors, such as diagnosis and coexisting with HIV. This fact reinforces the need to develop care strategies that integrate actions aimed at preserving the cognitive status and the psychological

and emotional well-being, within logic of humanized care and longitudinal and comprehensive care.

## CONCLUSION

The coping strategies most used by the collaborators of this study were centered on the support coming from health care professionals (formal network) and from relatives and friends (informal network). Nonetheless, for fear of suffering discrimination and prejudice, some tended to keep the diagnosis hidden, as a way of facing and protecting them from this reality. Spirituality was configured as a strategy that strengthened resilience and faith in treatment and recovery, as well as in the prospect of living a good life.

It is hoped that the results of this research will contribute to the improvement and expansion of knowledge about this reality of life, especially for health professionals who provide care to HIV-positive older people.

The study presented as a limitation the data collection period, which took place in pandemic times, when the elderly people were not regularly attending the SAE, which reduced the audience for the survey.

Finally, it should be underlined that the research did not seek to establish generalizations in relation to the researched situation, nor did it intend to exhaust the possibilities of debate around this theme. Nonetheless, the results described and problematized in this study can contribute to the reorganization of work processes and professional practices, with a view to sustaining actions welcoming, caring for and empowering the elderly individuals who experience this reality. It is emphasized the need for further research to deepen the analysis of the coping mechanisms and the ways of implementing effective actions to overcome the stereotypes, stigmas and prejudices about HIV in an attempt to humanize this reality of life.

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