

Prejudice, Vulnerability, Adhesion Process, Religiousness Regarding the Life Routine with AIDS: Life Stories

ORIGINAL

Deyla Moura Ramos Isoldi¹, Clélia Albino Simpson¹,
Francisco Arnaldo Nunes de Miranda¹, Felismina Rosa Parreira Mendes²,
Antônia Oliveira Silva³, Francisca Patrícia Barreto de Carvalho⁴,
Amélia Carolina Lopes Fernandes⁴, Fábio Claudiney da Costa Pereira¹

Abstract

Objective: To communicate life stories of people who suffer from acquired immunodeficiency-syndrome with a higher vulnerability registered at the Municipal Secretary of Social Assistance and the diagnostic's influence on their daily routine.

Method: Descriptive and exploratory study based on oral life history. Thirteen people with AIDs took part in the study via a semi-structured interview. The narratives were analyzed using Bardin's thematic content analysis.

Results: Three thematic axes emerged from Bardin's content analysis: prejudice and discrimination regarding the life routine with aids; Reaction when facing the diagnostic and the adhesion process for the antiretroviral treatment; Confrontation of religion and religiousness on people with aids.

Conclusion: The people living with aids, a chronic and stigmatizing disease, need the support of multidisciplinary teams and an improvement in relation to the access, the coverage and the meaning assigned to the disease, besides a better quality of life and social assistance. We conclude that religion did not contribute to facing these people's conditions. It brought blame, incorrect information that may impair the treatment and their follow-up. One infers that health education regarding HIV/AIDS needs to be remodeled on all of society's segments.

1 Universidade Federal do Rio Grande do Norte. Natal, RN, Brazil.

2 Universidade de Évora, Portugal, PT.

3 Universidade Federalda Paraíba. João Pessoa, PB, Brazil.

4 Universidade do Estado do Rio Grande do Norte. Mossoró, RN, Brazil.

Contact information:

Francisca Patrícia Barreto de Carvalho.

Address: Rua Pinto Martins, 1044, Areia Preta, Natal, Rio Grande do Norte, Brazil.

✉ patriciabarreto36@gmail.com

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Introduction

The outbreak caused by HIV has become a milestone in human history representing a global, dynamic and unstable phenomenon, whose form of occurrence at several regions of the world, depends, among other factors, on the individual and collective human behavior. The acquired immunodeficiency-syndrome is highlighted by its magnitude and the damage extension caused to the population, in particular, the ones living under social vulnerability [1].

HIV transmission is related to the forms of interactions and beliefs of different population groups. Besides individual, local and personal factors, the HIV/Aids vulnerability is determined by a general context of the country's development, which includes the population's level of income, the respect of fundamental human rights, access to social, health and education services, and its circumstances [2].

The stigma looming over the illness may affect the life of people with Aids and, consequently, their network of social support and parenthood. Besides fearing their life's end, one also begins to fear the social death that runs through the belief of ceasing to exist for society. This condition is a deterioration in the condition of people with HIV/Aids since it makes the infected to keep the disease to himself, because of fear or in an attempt to avoid suffering [3].

The concept of vulnerability has been widely focused as far as the epidemic of HIV/Aids has been approached from multiple factors, whose influence on the virus infection surpasses the model based on the epidemiologic concept of risk [4].

The vulnerability related to Aids is, bound to three aspects: individual (related to behavior that may ease getting sick and/or the infection); social (related to the access to information and socio-political aspects) and programmatic (authorities commitment, intersectoral actions, adequate funding, among others) [4].

As shown, the Aids affects the physical and emotional people's sides. The diagnostic effects bring certain fears, such as the unknown, social rejection, the disease itself, death, abandonment from the family, partner and friends, anxiety, low self-esteem, loss of control and social place, in addition to stigmatization [5]. This diagnostic is almost always interpreted as an alert signal about the end of dreams, plans and life possibilities [6].

One understands that the confrontation, as well as the adaptation to physical, psychological, social and spiritual changes imposed by the living with HIV/Aids, runs through the effective psychosocial support of the family. The representation about the families arise as one of the patient's highest support network, in other words, it is perceived as a relevant role to deal with several stressful aspects of the disease [7].

Consequently, despite the progress achieved regarding the treatment of infection by HIV and Aids, the virus persists as a critical health issue.

The antiretroviral therapy (ART) modified the disease's perspective and, although Aids still is a lethal disease, it has its chronicity controlled. The medication's universal and free distribution was a right acquired by the unending fight from society in the face of the condition that the disease caught up in Brazil. This milestone brought hope and the possibility of a better quality of life to the diagnosed [3].

The people affected by Aids are targets of stigma, prejudice, and social exclusion, simultaneously, arise undesirable feelings, that may unleash the psychic sicken. Under this perspective, the surveys that guided this research were developed: To what extent the positive diagnosis for HIV/Aids affects the daily routine? What feelings appear during the discovery? What are the experiences obtained after the positive diagnostic? What is the meaning of being seropositive today?

To answer these proposed surveys, the following objective as made: To tell the life history of people with Aids with higher social vulnerability registered

at the Municipal Secretary of Social Assistance and the diagnostic's influence at their daily routine in Parnamirim/RN.

Method

It is about a descriptive and exploratory study, with a qualitative approach, that focused on oral life history as methodologic referential, to tell the life trajectory of people who lives with Aids. Approved by the Committee of Ethics in Research of Universidade Federal do Rio Grande do Norte, with report number 719.926 and CAAE: 30408114.5.0000.5537.

Among the modalities of Oral History, Oral Life History was chosen since it prizes the individual's memories, via promoted freedom to the collaborators at listing the statements of lived experiences [8]. This study was composed of two parts: Thematic and theoretical fundamental (Theme, reason, and network formation choice) and the Operational Step (the interview itself and post-interview) [8].

In this work, the population was composed by people with Aids registered at the Municipal Secretary of Social Assistance on the city of Parnamirim, Rio Grande do Norte (RN), Brazil with 186 people back then; the collaborators, chosen from the starting point [8], via the following inclusion conditions: People with Aids; both sex; with legal age; and with cognitive, intellectual and emotional conditions preserved totaled 13 people. The data gathering occurred in November 2014 and was finished by the condition of data saturation.

The initial interview guided the network formation nominated as the starting point, which is understood as the collaborator that has wide knowledge about what is wanted to be researched in the group's history or from who wants to do the central interview [8]. In this perspective, the program's oldest person was selected to be the study's starting point [9].

After the first contact with the collaborators and research's objectives presentation, the explanation

about their participation, the information regarding the recording and their privacy guarantee, the interviews occurred at a place chosen by the collaborator, without external interference. For the interview's recording, audio recorders were used and they were asked to sign a Term of Consent and Concession Letter, authorizing the study's development.

The semi-structured research was divided into two parts: the first one corresponds to sociodemographic data and the second, to the following guiding questions: For how long do you know about being seropositive? How was your life before the positive diagnostic of HIV? What does it mean to be seropositive today? What do you feel about the future?

To assure the information's secrecy and anonymity, the research's collaborators were identified by the letter "C", followed by an Arabic numeral, following the interview's order.

The recordings were exhaustively heard, subsequently, transcribed, then, after a second contact with the collaborator, transcribed again, and, finally, checked by the collaborators themselves, making it possible for them to take part in the text's final revision. Bardin's Thematic Content Analysis was followed following the following steps: pre-analysis; content exploration or codification; treatment of the results; inference and interpretation. [10]

One highlights that the pre-analysis corresponds to the organization step itself via systematization of ideas, through reading of all the transcribed material to identify the converging and significative points to the theme. [9] On the other hand, at the content exploration, the gathered data was transformed on thematic contents, the interviews were codified, determining and grouping the themes that were the focus of discussion, insofar as the treatment of the results, inference, and interpretation includes the analysis cycle [10].

Results

The thirteen collaborators were mainly from the state of Rio Grande do Norte, with an age group of 19 to 62 years old. From this group, they stated themselves, regarding their gender condition, as three men, two women, one transvestite, and seven homosexuals. Most of them, said to have: incomplete primary school, single, with a stable job, not gaining more than one minimum wage at the time and six of them had made use of alcohol, weed and crack. The collaborators' dependence on using drugs will not be an object of this study.

From one side, the socioeconomic data are worrisome for this sample, given the relation to the education level and low income, particularly the vulnerability condition and social risk. These indi-

cators' reflection contributes to the low quality of life and brings difficulties in maintaining adequate housing and feeding. On the other hand, three theme axes were identified base Oral Life History submitted to steps of theme content analysis, shown in **Table 1** for better visualization and understanding of the content analysis, in addition to the highlight for some subcategories that support each one of the following: Prejudice and discrimination regarding the life routine with aids; Reaction when facing the diagnostic and the adhesion process for the antiretroviral treatment; and Confrontation of religion and religiousness on people with aids.

Table 1. Demonstrative of the thematic axes and sub-categories.

Axis 1
Prejudice and discrimination regarding life routing with Aids
Changes in People's behavior regarding the infected
The main change is regarding the prejudice of people, because many of them have [...] the people that you used to know before looked at you in a way, after it, they start to look differently [...]. It definitely, changes! (C1).
The negative changes are, in a certain way, when you arrive at certain places and the people keep giving strange looks at you, it happened to me [...] the doctor, when he consulted me, I told him that I carried the disease and he saw in the paper that I was seropositive, he said nothing else to me after this (C10).
[...] the disease is still extremely discriminated, people think that you can get contaminated with a handshake, sitting in the same place. [...] think that if you have Aids, you need to be isolated, the worse is not even the disease, but the people's prejudice [...] (C9).
Friendship bonds shattered
Regarding my Family, our relationship changed a little bit, because my mother does not want to talk to me anymore, she left. My sister is afraid of me when I go to her place and if I pee there, she is afraid and no matter how much I explain, she will never understand and thinks that her son will get the disease too (C13).
Keeping quiet about the serological situation
It was a terrible burden because I had to give up my dream (C6).
I was going to do a program to be a florist, and my mother had bought all the material. I felt a lot of prejudice [...] (C8).
Social isolation, being afraid of getting together with other people
When I knew that I had this problem, my priorities were to hold, a bit more, my sexual desires (C3).
Sometimes it is annoying, because every time that shows up a person that you want to get close and you get that fear, that yearning for the person, of transmitting the disease and all that situation comes back again (C5).
Since I knew that I had this problem, I never hook up with anyone, because I got afraid of getting more diseases, something like that, even if I used a preservative [...] (C12).

Axis 2

Reaction when facing the diagnostic and the adherence process for the antiretroviral treatment

Difficulty at maintaining the treatment

From time to time I walk around, taking my medication in the right way and then, I snap out of reason and pass two, three days roaming and stop the medication, the first thing I stop is the medication[...]. (C3).

Changes: Lifestyle, treatment's duration, and the collateral effects

And the medication, only at the beginning gave me a strong reaction, very powerful, I used to take the medication and then went to sleep feeling well and then used to wake up intoxicated, each lump in my skin gave me goosebumps, they were huge, really huge [...] (C12).

When I started taking the medication, I could not sleep, it was really painful, my skin was itching, my eyes used to burn, I had an urge to vomit (C7).

Reactions in front of the positive diagnostic

When the result came out, we did not give up... I said: it is negative, is not it? And then, the receptionist said: I am sorry to inform you... she knew how to explain, to raise my awareness, but I could not handle at the moment and passed out, it was a huge shock for me, really heavy, something that I could not even think about, something supernatural and our mind is so supernatural that everything had has changed, I thought that I was going to die [...] (C6).

[...] I tried to commit suicide three times, but I did not do it because I knew that if I killed myself, I would go to hell [...] (C7).

Axis 3

Confrontation of religion and religiousness on people with aids

Religiousness permeates the dilemmas of the disease condition

[...] Because, as I am a man and I had that strength, but then, it was God that had a proposal for me and her, saying: you look at her, take care of her because what happened between you two it is not something that will make the world fall apart, it is possible to control (C3).

Importance of the religion and the religious leaders concerning life

And he (the minister) said to me: "God is here revealing to me that someone did witchcraft to make you ill and it is also because a lot of people are jealous of you and since you are weak, the load upon you gets very heavy, you get weak, does not want to eat, does not want to go out..." (C7).

The disease as a process of change in their lives

As I believe in God, I mean, I always had faith in God. As I said, since there is a doctor here that will only know when he receives the evidence in his hands, because he questions God, and in the meantime, I took part in a circle of prayer and inside it, God came and healed me.

God said that I was healed because the disease was work of the enemy and said that I just needed to be patient, I had to stay quiet and keep taking the medication and all the exams would be alright, all the results would be negative. Therefore, as I really believe in God, and I believe that I am healed, I do not have the HIV/Aids anymore (C7).

Discussion

Because of the author's choice, the thematic axes will be discussed in its current form without highlights for the sub-categories as shown in **Table 1**.

Axis 1

Prejudice and discrimination regarding the life routine with Aids

The collaborators said they noticed the people's change when they discovered that there is someone close to them infected with HIV. The discrimination and prejudice at which they are exposed

unleashes psychological problems, as shown on the cuts on the collaborators' narratives.

Although the transmission forms are well defined by the scientific community, such as blood and sperm, the collaborators reported the experiences with their families, where co-habitation rules were imposed, such as the estrangement and reduction of physical contact with other people.

In a revision study about the experiences of people's sicken that lives under transmittable chronic conditions, the stigma was identified as the experience with the highest impact on the subjects' life, which reverberated in negative feelings [10]. Associated with prejudice, many people tend to distance themselves from social coexistence, as a form of protection. The different form of stigma and discrimination related to HIV/Aids occurs because of the disease's characteristics that causes great impacts on the infected people's life [11].

It was shown that the serological situation was maintained in an agreement of silence between people with HIV/Aids and the health professionals by the fear of living the society's prejudice. The patients force themselves to social isolation and reported to have difficulties of having sexual relations because of both, fear of transmitting the disease to the partner and worsening their health condition. They reported to not want to feel guilty by the disease's transmission; a few abstained from sexual contact alleging this to be a therapeutic necessity.

There is no doubt that the subjects experienced negative sensations and feelings upon knowing about the diagnostic, by their organism's fragility, by the maintenance of the condition that makes them more vulnerable to discrimination, prejudice, and stigma [11].

For being a disease that was initially associated with homosexuals and promiscuity, the Aids has been accompanied by situations of discrimination. Therefore, the diagnostic has a disastrous representativeness and a meaning loaded with moral fee-

lings that entails the infected with a sensation of guilty and victimization [12].

This period lead to disorders, uncertainties regarding daily life. The process of suffering caused by Aids may, many times be a result of the lived discrimination and prejudice, thus, bringing with it the loss of capacity to work, the interruption of a family and personal project.

It is suitable to bring light to this study's findings about the gender condition that the measures meet these findings related to homosexuals, little was produced about the theme of internalized prejudice, defined as the homosexual individuals' acceptance of the negative attitudes driven by the society concerning gays and lesbians [14].

Axis 2

Reaction when facing the diagnostic and the adherence process for the antiretroviral treatment

The treatment of HIV with antiretroviral (ART) is essential to maximize the results favorable to health and the advances among people that live with HIV, highlighting the importance of staying in the assistance. The introduction and extension of antiretrovirals' availability provided great advances in the treatment of Aids, transforming the infection in a chronic and manageable condition observed by the relevant reduction of morbimortality associated with HIV reflected by the improvement of the individuals' physical and emotional conditions [15-16].

The adherence to the antiretroviral treatment results in maintaining the quality of life of people living with HIV/Aids. With adequate medical therapy, many benefits are brought, such as reduction of morbid events, individual vulnerability, and frequency of hospitalizations [17].

However, one observes that although all advances achieved by the antiretroviral therapy, the people living with Aids shows a huge difficulty in maintaining the adequate treatment for several

reasons, one of them is the use of psychoactive substances.

Since 1996, Brazil has been assuring the free distribution of antiretroviral medication via SUS. From then on, the free access to the diagnostic of HIV has been expanded and, consequently, the treatment of Aids too. The success in the fight against the epidemic in Brazil, reflected by the decrease of the indicators of mortality and morbidity, by the availability of antiretroviral medications and developed prevention actions, were an achievement of the government, the organized civil society and the health professionals involved with the struggle against the epidemic [18].

During the narratives, the interviews revealed questions related to the infection's discovery and how were the reactions in the face of the positive diagnostic, for most of the interviewed, it was hard because it is an unexpected situation, bringing feelings of sadness and despair.

The study regarding antiretroviral therapy had the purpose of comprehending the psychosocial determinants involved in the evaluation of the quality of life on people living with HIV/Aids. However, the ones that showed a better quality of life were satisfied with the hospital's health services, with a highlight for the psychological dimension, the CD4 cells census, and the environmental dimension. The authors recommended the public politics of health regarding HIV/Aids that embrace the psychosocial factors [19].

The unexpected diagnostic of HIV/Aids renders the person weakened since they do not see themselves as vulnerable. This is associated with the surprise and uncertainty about the form of exposure to the virus [20]. The knowledge of the positive diagnostic surprised many individuals.

One observes that what brought suffering to the collaborators was having to face the constraints imposed not only by the pain related to the sick body, but also by the distress of prejudice and the discrimination enacted by society.

A descriptive study with a qualitative, representational approach about the concept of vulnerability in the perception of young people identified as homosexual or bisexual, the results pointed out that they lived repeated situations of aggression over their childhood and adolescence, perceiving the sexual, family and institutional violence as the most painful and with a difficult treatment, and that represents a relation to the vulnerability to HIV/Aids [21].

Although the study's findings are mostly single, it is suitable to highlight the condition of vulnerability and risk. A study about factors associated with the infection by HIV/Aids among teenagers and young adults and their partners, statistically verified that among female, there were more associations between seropositivity and use of drugs and alcoholic drinks, meanwhile, among male, there were more associations between seropositivity and the use of drugs and being homosexual/bisexual. The study concluded an association with a partner that is a user of drugs and/or Sexual Transmittable Disease and/or HIV [22].

Axis 3

Confrontation of religion and religiousness on people with aids

The religiousness has been considered an important tool in the confrontation strategies of new situations that are imposed in the life of people living with HIV/Aids, enabling the individual to deal with these events with more confidence and reducing the stress and anxiety [23].

Therefore, one recognizes that the religious dimension crosses the disease's condition dilemma and is a relevant factor when facing a disease like Aids. When investigating confrontation strategies of people living with HIV, it was verified that there was a search for religious practice as one of the most used strategies in addition to the increase of self-esteem, optimism, and satisfaction, as well as the reduction of alcoholic drinks by individuals that

maintain a positive relation with God and religion [24].

It is important to highlight that religion may also harm health, considering that beliefs or religious practices may be used as replacements of needed medication or function in a neurotic way, through defense mechanisms [25].

It is observed in the current study the importance of religion and religious leaders in the life of people living with HIV/Aids because, many times, they find themselves in a moment of fragility, seeking answers for their diagnostic.

The religion, religiousness, and spirituality make up a source of fortitude and hope and associate themselves to a higher satisfaction with life and spiritual well-being. In addition to this, they contribute with a higher psychological health, assist the tolerance when facing illnesses; diminishes depression, anxiety, and stress; and mostly, contributes with the acceptance of the illness itself and the fear of death, favoring the chronic condition's confrontation [26].

Spirituality is not directly related to religion and finds itself established in all cultures, on the other hand, religion is defined as experiences, meaning, and characteristics that ease the relation with God, how each one lives and the form of expression of faith.

In a study about social representation of spirituality among people living with HIV/Aids that are assisted at Care centers, the authors concluded that the central elements are faith and God, insofar as the social representation is organized in two poles, divine and human, which have a direct relation or is mediated by religion [27].

When analyzing spirituality expressions of people living with HIV, it was concluded that the diagnostic discovery is tagged by a set of feelings, attitudes, and practices that reveal suffering and difficulty in maintain or rediscover a meaning for life, that served to cultivate spirituality [28].

Most of the time, the collaborators talked about God in the reports in a thankful way, seeking hope

to know how to deal with all the lived suffering. God was the shelter in the seek for strength to live with the chronic and still stigmatized disease. The religiousness was used as a form of the individual's strengthening.

Because of this, on one side it is agreed that the nurse must propose their actions in the seek of improvement of hope for the assisted individual, establishing realistic goals and strengthening the social support [29]. On the other hand, the emergency of strengthening the network support around the individual, in a way of favoring the improvement of the quality of life of people living with transmittable chronic conditions [11].

Conclusion

Aids is represented as a disease that may bring several psychosocial consequences such as, prejudice, segregation, and stigma. The effort against these factors results in great challenges, but a good quality of prevention and nursing assistance is the initial point to diminish/temper the suffering of people living with HIV/Aids.

Most of the study's collaborators reported to have a big emotional impact after the positive diagnostic for HIV/Aids and the devastating effects that this caused in their lives, especially, regarding social co-existence, family bonds, work and above all, the society's prejudice. The marks made by society in the epidemic's course are evident and modifying this representation is one of the most challenging tasks.

The reflections made in this study have no pretension of ending discussions about the life trajectory of people living with Aids, but to stimulate and provoke the construction of other studies to contribute, producing knowledge to overcome the great challenge that is the fight against discrimination and prejudice for a better comprehension of Aids' magnitude.

The current study showed as limitation the reduced number of collaborators, because of the

adopted method and technique, which is not able to hold many collaborators, thus, its structure, that may be understood as a saturation point for what is intended to investigate from the Oral Life History. Another factor is related to the individual's refusal at the initial approach, especially because they are part of, one or all three axes obtained in the current study, in other words, prejudice and discrimination regarding the life routine with aids; Reaction when facing the diagnostic and the adhesion process for the antiretroviral treatment; Confrontation of religion and religiousness on people with aids, even with the anonymity assurance and its sigil.

Under the nursing optic, the research's contributions to the health care of people with Aids under social vulnerability were the following: process of formation and work that are able to improve the access and coverage, the disease's attributed meaning, the hope of a better quality of life, in the social support of people living with transmittable chronic conditions.

People living with Aids, a chronic and stigmatizing disease, need attention of the multidisciplinary team and the improvement of access and coverage, the disease's attributed meaning, hope in the quality of life and standard social support. From the results, it was possible to conclude that religiousness did not contribute to confront these people's conditions. On the contrary, it brought guilt, incorrect information that may harm their treatment and follow-up. One infers that the health education regarding HIV/Aids needs to be revitalized in all segments of society.

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