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Factors associated with the vulnerability of older people living with HIV/AIDS in Belo Horizonte (MG), Brazil

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Abstract *The objective of this article was to identify the factors associated with the vulnerability of the elderly aged 60 years or older to HIV/AIDS, based on the perspective of older people living with the virus. Interviews were conducted with 20 participants, including 12 women and eight men, who were patients from a public hospital in Belo Horizonte, Minas Gerais, Brazil. The elderly interviewed had a low education level and low income, were currently or previously in a marital union, had perceptions and behaviors grounded in structural gender relations with power asymmetry and had a low capacity to respond to vulnerability. Most of the elderly interviewed were sexually active, but few reported protecting themselves by using condoms, and the lack of information reached all levels of vulnerability studied. The picture revealed by this article is worrying, underscoring the need to demystify the sexual invisibility of the elderly, ensuring them their right to a healthy and continuous sexual life.*

Key words *Elderly, HIV, Acquired Immunodeficiency Syndrome, Health Vulnerability*

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Introduction

This article discusses the binomial elderly and HIV/AIDS, from the perspective of elderly individuals living with the virus. This study proposes[1] to demystify the idea that the elderly do not have sex and to show that the incidence of HIV/AIDS is also present in individuals 60 years of age or older. The research question was "which factors are associated with the vulnerability of the elderly to HIV/AIDS?". Vulnerability was defined through the reporting of those who are living with HIV/AIDS, with prioritization of some thematic lines.

To discuss elderly sexuality is to break taboos. Sexual activity is not a prerogative exclusive of the young[2]. Thus, several studies have referred to the sexual invisibility of the elderly[2-6], a belief shared even by health professionals[7-9] and which explains the smaller number of studies and publications about this topic, as noted by other studies as well[2,5,10].

The HIV/AIDS epidemic is increasing in incidence in various populations of elderly individuals, as reported by Sankar et al.[10] and others[11-17]. Less common, although increasing, is the focus on populations aged 60 years or older, which constitutes the investigation of this study.

In Brazil, the incidence of HIV/AIDS among the elderly is increasing[4,18-20]. Some case studies have also concluded that the number of elderly individuals with HIV/AIDS is increasing in certain areas of Brazil, such as Gross[21], Rio de Janeiro (RJ) and Barbosa[22] in greater São Paulo (SP).

This article seeks to advance the discussion on the topic and, for this purpose, the concept of vulnerability operationalized by Mann et al.[23], contemplating the individual, social and programmatic levels adopted. The logic of the conceptual framework is that individual behavior is the strongest determinant of HIV infection, and this behavior is modifiable and socially determined.

The first analytical level of the framework of Mann et al.[23] is individual vulnerability, including the individual's condition, which may be affected by cognitive and behavioral factors, in relation to the context. The second level is collective vulnerability, which is divided into social and programmatic categories. Social vulnerability is related to economic, cultural and social aspects (gender, religious beliefs, social inequality and democracy); programmatic vulnerability relates to policies, organization of services, access to information, education, health and social assistance[24]. The authors[23] call attention to the fact that individuals, although living in a same location, can exhibit different degrees of vulnerability related to different individual needs for information, education, health and support social services, as well as in their capacity to confront risk[24,25].

For Mann et al.[23], reducing vulnerability entails its antithesis: empowerment. To empower means to offer social and health services that allow individuals to make decisions[26]. In regard to sexual practices, the authors[23] recognize that these decisions are made, usually, in conjunction with a partner. However, HIV interventions are focused on the individual.

Thus, the discussion is broadened to consider the existence of identities (and practices) constructed intersubjectively, assuming that there are intersubjective contexts in which vulnerability to HIV/AIDS[27] is affected, contemplating the relational component. "We are because the other is, we are as Another is; we are not if before Another[27]".

Vulnerability, therefore, based on Brazil[28] and Mann et al.[23], is the set of biological, epidemiological, social, cultural, economic and political factors whose interaction extends or reduces the risk or the protection of a population group to a certain disease, condition or injury[28]. Some aspects of this set, i.e., the three main dimensions of vulnerability – individual, social and programmatic[25,28-31], are included in this article.

Materials and methods

This was a qualitative study that included in-depth, semi-structured interviews[32] to describe the phenomenon in detail and to allow for the possibility of interaction among multiple perspectives. The point of view of the individual and individual interpretations about the topic were recorded[33]. Individuals with different education levels were interviewed[34]. The knowledge of meanings, which have the role of structuring and organizing people's lives[35], allowed better understanding of the study object.

A total of 20 interviews were conducted with elderly individuals living with HIV/AIDS who were seen at the Eduardo de Menezes Hospital, Minas Gerais Hospital Foundation of (HEM/FHEMIG), in Belo Horizonte, Minas Gerais state, Brazil. Twelve women (3 were institutionalized) and eight men agreed to participate in the study and signed a free and informed consent form. The interviews were conducted between February and April 2014 at HEM/FHEMIG.

Ciência & Saúde Coletiva, 21(11):3331-3338, 2016

The recorded mental health state of the elderly individuals was that defined by the hospital staff, in view of the difficulty of defining mental health states[36].

Additionally, the sample saturation criterion for qualitative research was adopted[37,38], similar to other studies[39,40], and thus, interviews were conducted until no new data were obtained[37]. The inclusion criteria were aged 60 years or older; having knowledge about their serological status; presenting physical and mental conditions for participation; and agreeing to participate by signing the free and informed consent form.

The qualitative analysis of the discourses was performed based on the thematic networks approach[41] which, after reading, included six steps: code material, identify themes, construct thematic networks, describe and explore thematic networks, summarize themes and interpret the patterns recorded.

The analyses were based on the hermeneutic-dialectic method[42], which takes subjectivity into account, an intrinsic aspect to the study of sexuality. The speeches of the individuals, the social actors, is understood within the context, and the starting point is the "interior of the speech" whereas the end point is "the specific and totalizing history that produces the speech"[42]. According to hermeneutics, to understand the contextualized reality is to understand the other. In turn, dialectic considers the foundation of communication to be the historically dynamic, antagonistic and contradictory social relations between classes, groups and cultures[42].

This study meets the necessary ethical principles of research with humans, with approval by the Ethics in Research Committees of the Federal University of Minas Gerais and HEM/FHEMIG.

Results

Most of the respondents were receiving antiretroviral therapy (ART) (90%), had been or were married (85%), had contracted HIV/AIDS through sexual contact (90%), considered their adherence to ART good (70%) – adherence defined as "good" is that in which the individual takes all prescribed medications (concept adopted by the medical team), had an active sex life (65%), did not reveal their serological status (90%) and were not admitted to the hospital due to HIV-related diseases (55%). For half of the respondents, the diagnosis was discovered before they reached 60 years of age.

Although selected excerpts are individually mentioned throughout the text, the criterion adopted was representativeness, that is, the content of the excerpts reflects the hegemonic positions of all respondents.

Discovery of the serological status

Among the elderly respondents, it was possible to distinguish five scenarios regarding the discovery of serological status. The first was the discovery of HIV infection due to the diagnosis of the partner or partner (husband) death from AIDS.

It was a very strong pain. And I felt pity, and I felt anger, hatred, I thought it was good because his illness told me that he was cheating on me. Oh, I suffered a lot. And so I drank a lot! I would look at him and think he was paying for it, you know?! Paying for it... but, I felt pity. I had to take care of him, right?! And I did, until the final day. And I was forced to take the test. Then, it was more pain. But all anger. Because I got it from him...and today still, when I have to take the medicine, sometimes I get angry...And I drink... And then I get more angry with him. And he's just a soul today...[laughs] (82 years old, widowed, illiterate, diagnosed 15 years before).

The second condition was the discovery of the virus because of an opportunistic disease, such as the experience of an elderly woman who was treated for tuberculosis and, because she was not improving, was referred for additional tests that detected the HIV/AIDS infection:

So I got this crazy diarrhea... That pain in the belly like, oh... The pain went across here and came to under rib here and would go tchummm and I oh... I would go to the bathroom... Then, I went to see a friend... my daughter's godfather... I consulted with him... [Explains how the consultation went]. *But the diarrhea was too much! So it's the bathroom for sure... The clothes get it, if I can't find a bathroom* [whispers]. *And this thing* [the HIV test]*... it showed that business* [HIV/AIDS] *and they're talking about what it is...* (71 years old, widowed and in a relationship, illiterate, diagnosed five years before).

The third condition was based on the discovery of infection during a medical check-up, a medical examination for work or a routine examination:

I went to have everything looked over. And I told the doctor that my partner is a womanizer, that a friend of mine saw him with a strange woman... I never thought about it, never thought

it could be in me, you know? Then, it certain! The doctor sent me here. But it took me time to believe it, even though my partner is a cheater... (63 years old, widowed, functionally illiterate, diagnosed almost three years before).

The fourth condition added to the discussion the issue of violence against women and drug users. Examples of this scenario include an elderly woman who stated that the diagnosis was positive six months after being raped (elderly widow and sexually abstinent for more than 10 years, until the rape) and an elderly man who claimed he was diagnosed after being beaten on the street because of drugs.

It happened like this... I was raped near my house, when I was going to the pharmacy... There were two men, they raped me and tore me up... there was a huge hole in me, from the vagina to the anus. Then, I was taken to Júlia Kubitschek hospital and took the cocktail and underwent perineoplasty. I was hospitalized for two months, was discharged and went home. Six months later, the hole opened again... I came to the hospital, bleeding and, when I got there, they tested me and found out I was had this disease... (64 years old, widowed, 4th grade level of education, diagnosed three years before).

The fifth condition brought a new element to the debate: the discovery occurred while making a blood donation:

It was the funniest thing [sic], *I found out through a blood donation... I always, donated, and the last time, in 2001, the result was that I was had the disease...* [when asked about the likely form of virus contraction, she responds] *My husband died 10 years ago, and when I still married, I had a relationship with a person, I think it was from him that I got it, he already died, but I don't know from what...* (62 years old, widowed with a partner, 3rd grade level of education, diagnosed 13 years before).

In almost all of these scenarios, the exposure category was sexual contact. The exceptions were an elderly man who claimed to have contracted HIV by sharing a piercing-cutting instrument contaminated with blood and another individual who contracted HIV through drug use.

The multiple meanings for AIDS and treatment

Among the respondents, the affirmation that AIDS is a normal disease was recurrent, including among the institutionalized elderly women. In this perspective, the revelation of an elderly user of crack drew attention: *To me, it doesn't affect me, it's not here nor there!* He displayed total disregard of the infection, resulting in several episodes of treatment abandonment.

For some elderly respondents, the meanings are manifested by multiple feelings, such as anger, hatred, mistrust, disrepute, cocktail of drugs and life that follows. Religion has no association with these meanings, with the exception of one woman who, because of her religion, did not believe that AIDS exists. This elderly woman was asymptomatic for HIV/AIDS. She liked to talk and discussed details and expressed her belief that AIDS does not exist, at least not in her. Her religiosity is notable in her speech and in the symbols she carries. For another elderly woman who did not accept the diagnosis, blocked out the disease and did not mention the name of the infection, religiosity had the effect of making her forget:

I was Catholic, now I'm starting to become Evangelical to see if it improves... Let's see, right? Because I need something that makes me forget this... I want to disappear. (61 years old, single, 4th grade level of education, diagnosed eight years before).

Serological status is associated with the reality of taking medication, which is bothersome because it interferes with everyday life. The stigma constructed in the context of HIV/AIDS is present in the lack of care for the self, in episodes of depression and self-loathing and in the lack of acceptance because contracting the infection was not planned; it was not the reason they were with the husband or boyfriend.

It's a lot of medication... I have to stop sewing and go take it... my brother makes me do it, he wishes me well. I want to drop everything! The rest of my life like this... But, how could I have guessed? I liked him, we got along. (67 years old, single, complete primary education, diagnosed five years before).

A woman who was raped by two men did not know how to define AIDS and had feelings of fear, anger and dread as a result of the rape and in relation to men in general.

As a matter of fact, I don't know the disease. I want to ask the doctor, to know what happens, because I don't feel anything... I never know what it is... I know that I don't want man in my life anymore. When I imagine a man looking at me, I get crazy, really scared. I'm scared of man. I can only face the doctor, and my children... The last time I did something [sex] *was when the rape happened...* (64 years old, widowed, 4th grade level of education, diagnosed three years before).

For the elderly men interviewed, AIDS did not denote a strong meaning for them, and for

one of the men, AIDS was a serious, grave disease *that gets in the way of dating* [laughs]. *And I like dating!.* Conversely, for one elderly woman, living with HIV/AIDS was a serious disease; medications had to be taken, and the doctor's orders had to be followed, which established a strong doctor-patient bond. A complete lack of information and meaning was also observed, with a lack of knowledge about AIDS, including for the elderly who had been positive for a long time.

That's AIDS... It's normal. And I take care of my children's and grandchildren's clothing... I wash everything separate. I don't know... (62 years old, widowed with a partner, 3rd grade level of education, diagnosed 13 years before).

Sex life and condom use

Some women became sexually inactive after the diagnosis, as reported in some speeches.

In my bed, only him... it was the promise of love for a lifetime! I don't want men anymore, I don't want to do these things... Dating... I say that, even though he was the only one, I got this disease, imagine if I find another guy to give me a headache... we live without it. We live... (64 years old, widowed, illiterate, diagnosed 14 years before).

One of the elderly respondents was not celibate, but he stated that he greatly reduced his number of sexual relations. Another elderly man stated that he had a bad sex life because he had to use condoms and because of the side effects of ART in erectile function, as cited in Cooperman et al.[43].

With regard to unprotected sex, some elderly women revealed that their partners know their serological status and still refuse to wear a condom, or the lack of condom use is a consensus between the couple. The partners of some elderly women are living with HIV/AIDS. One of them, for example, does not use ART, another undergoes the treatment, and there is still another case who never underwent the test and does not want to.

Look... My partner does not want to use a condom... he knows that I have this disease, and doesn't want to use it. He also doesn't want to do the test. The doctor asked him to come do it, he didn't come. He's pigheaded! Stubborn. Doesn't want to do the test, doesn't want to use protection, prevent, or how do you say it? Doesn't want... (60 years old, widowed and in a relationship, illiterate, diagnosed seven years before).

I go to the dances! I date at the dances. And a condom, for what? It's dumb... [laughs] *There never a need for it!* (61 years old, separated, illiterate, diagnosed two years before – institutionalized).

One elderly woman who was depressed, failed to adhere to ART and was unhappy with life stated that she uses condoms in sexual relations, according to guidance received from the care team when she returns to HEM/FHEMIG seeking medications. In regard to unprotected sex, some elderly also confirmed no constant condom use, even after the diagnosis.

I am careful with my wife, now, one year ago, since I found out that I have this disease. But, I don't stop dating. And every time there is a condom, it gets in the way, that's the truth. (66 years old, married, illiterate, diagnosis for one year before).

My lover is 40 years old and does not have HIV. So, sometimes I fail to use a condom, but sometimes I use it. (61 years old, separated and has a lover, 7th grade level of education, diagnosed 16 years before).

One elderly man, with three years of higher education who has had positive serology for HIV since 1993, stated that he never stopped using a condom with his wife and never cheated on her (he claims to have contracted the virus by using a piercing-cutting instrument contaminated with blood). He is emphatic in stating: *I would never do that to her!* In this sense of being aware of the possibility of transmission of the virus during unprotected sex, another elderly man with a 5th grade level of education stated:

To me you have to use a condom, and another thing... Knowing that there is a problem and deciding whether to move forward... Only if the person is out of their mind, right? It is not human... Right? (60 years old, separated, 5th grade level of education, diagnosed for 13 before).

Discussion

The trend observed in the results differs from misconceptions related to HIV/AIDS, such as the association of HIV/AIDS with imminent death, which is surprising, particularly in a country such as Brazil where access to ART is universal via the Public Health System[44]. This association is the basis for stigma, prejudice, anger and other feelings when the serological status of the partner becomes known. AIDS as a punishment is also an ingrained concept[45], and the list of misconceptions also includes the comparison of AIDS with cancer, dangerous and lethal[15], as the embodiment of an evil that represents foretold death[46].

Regarding infidelity and extramarital relationships, the macho culture in which most of the elderly were raised values multiple partners as a socially accepted practice[47]. Some reports testify to the fact that elderly women also conform to the same sexist culture and view themselves as the family woman, whose reference is love/affection and sex and denial of the sexual relationship as a source of pleasure[48]. To take advantage of life, because they are men, because they have uncontrollable sexuality and because they are expected to have multiple partners[49], socio-cultural and behavioral characteristics exist that justify an extramarital affair by the husband. Female sexuality is based on normative references that define sex as a marital duty and pleasure as a right of men[48].

In regard to tuberculosis, there is a challenge in treating patients co-infected with HIV and tuberculosis[50], and here, the issues of culture and the sexual invisibility of the elderly resurface[2,10]. This invisibility is also observed in the personal initiative to undergo the anti-HIV test, indicating that elderly sexuality is invisible even for health professionals[5,7,10]. The absence of the belief of being vulnerable to the possibility of contracting HIV is strong among the elderly, as also observed in other studies[26,51,52]. In turn, rape and violence represent serious violations of human rights and are also police and public health problems, given the magnitude of the facts[53].

Regarding the relationship between religiosity and the denial of the existence of AIDS, Chepngeno-Langat[14] found, in a survey conducted in sub-Saharan Africa, that religiosity is significantly associated with the perception of contracting HIV and that individuals who attend religious events more than once a week have a lower perception of the risk of infection by HIV.

Regarding the physical state, studies such as that by Paiva et al.[54] underscore the difficulty of acceptance and treatment of individuals who have no symptoms and do not feel sick. Moreover, a strong bond with a doctor figure, as denoted in some of the speeches, is in agreement with the findings of Cardoso and Arruda[55] of the existence of a strong bond with patients who adhere to treatment.

As reported in another study[16], the lack of condom usage, even among elderly individuals infected with HIV, must be related to both the symbology and the meaning that the condom has for these elderly individuals[26,56] regarding the issue of gender and woman power[28,57,58]. Overall, the speeches show the complexity and difficulty of the process of negotiating safer sexual practices[59], indicating a lack of association between education level and perceptions about HIV/AIDS among elderly respondents, and this process must go beyond theoretical formulations that women are victims. In some situations, the non-use of condoms is the woman's choice, for reasons that must be investigated because the negotiation of condom use or non-use is dynamic[48].

These are some of the factors associated with vulnerability in the three levels of analysis that, combined with the different biological conditions of each elderly individual and reinforced by their lack of knowledge about HIV/AIDS and the sexual invisibility of the elderly, define the capacity of the individual to respond to vulnerability.

Notably, the social context in which elderly respondents are inserted defines individual meanings and, as an aggravating factor, the lack of information permeates all vulnerability levels. This creates an uncomfortable situation where, on the one hand, the elderly exercise their sexuality with total freedom, in the sense that they do not use protection and feel immune; on the other hand are society and state, who believe that the elderly are asexual.

Overall, the elderly respondents have a low capacity to respond to vulnerability because they have mistaken perceptions and beliefs and behaviors founded in gender relations structured with power asymmetry[48,57,58]. In general, the elderly respondents do not know what AIDS or the infection itself are, and they also do not understand the need for protection to avoid re-infection with another strain of the virus[59,60]. To understand the meanings of AIDS for the elderly is to enter the world of sexuality and conceive it as a social and cultural construct[61].

Public policies that have the provision of information as their foundation are necessary. Word-of-mouth strategies are also necessary, respecting the individuality of each elderly individual and their willingness to talk, including about sex and related topics, which can be an opportunity to discuss the eroticism of condom use. Likewise, public policies aimed at the elderly living with HIV/AIDS and their treatment, as well as for public health agents, are also necessary because ART is distributed via the Public Health System. These actions would allow perceiving the elderly fully, i.e., would demystify their sexual invisibility and accept the interactive character of sexual practices, ensuring them a healthy and continuous sexual life that is rightfully theirs.

Collaborations

MBR Cerqueira participated in all stages of the study and writing of the manuscript; RN Rodrigues provided guidance, performed critical review and approved the version to be published.

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