

## PERCEPTION OF AIDS AMONG THE ELDERLY ATTENDING COMMUNITY CENTER IN TERESINA – PI

A PERCEPÇÃO DO IDOSO DE UM CENTRO DE CONVIVÊNCIA DE TERESINA – PI SOBRE A AIDS

PERCEPCIÓN DEL SIDA DE PERSONAS MAYORES DE UN CENTRO DE CONVIVENCIA DE TERESINA – PI

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### ABSTRACT

Acquired Immunodeficiency Syndrome (AIDS) among elderly people in Brazil is currently a public health problem. The increase in life expectancy, the decline in fecundity and mortality rates and longer sexual life expectancy might explain the current situation. The present study aims at describing and analysing the perception of elderly people on AIDS in Teresina, Piauí. It is a qualitative study that deals with human meanings, motivations, actions and relationships. The research was carried out at a community centre in Teresina with 13 male and female subjects aged 60 or over. Data was collected through semi-structured interviews with open-ended questions, recorded and transcribed in its entirety. After skimming the text and pre-analysing the data, the researchers chose the units of meaning, selected counting rules and categories. Three categories emerged: "AIDS meaning disease and associated with sexual practices"; "Fear, suffering, rejection and death: subjects' perception on AIDS"; and, "AIDS: the prevention as a form of protection". Even though the research population did not have a profound knowledge of AIDS, they did not seem indifferent to it and portrayed it as an infectious, incurable and sexually transmitted disease. The research dealt with the sadness, fear, exclusion, discrimination and death associated with the disease as well as highlighted the importance of prevention.

**Keywords:** Senior; Acquired Immunodeficiency Syndrome; Sex; Nursing.

### RESUMO

A síndrome da imunodeficiência adquirida (AIDS) em pessoas idosas no Brasil tem emergido como um problema de saúde pública. A justificativa para tal problema encontra respaldo no aumento da expectativa de vida, além do fato de os idosos terem desejos, prazeres e serem sexualmente ativos, tendo, portanto, riscos inerentes à prática sexual. O estudo teve como objetivos descrever e analisar a percepção dos idosos sobre a AIDS. Trata-se de um estudo de natureza qualitativa por abordar o mundo dos significados, motivos, ações e relações humanas. Foi realizado em um centro de convivência de Teresina-PI, tendo como sujeitos 13 idosos com 60 anos ou mais, de ambos os sexos. A coleta de dados foi realizada a partir de entrevistas com um roteiro contendo perguntas abertas, gravadas e transcritas na íntegra. Após leitura flutuante dos dados e pré-análise, foi realizada a exploração do material, que consiste na escolha de unidades de significação, seleção de regras de contagem e escolha das categorias. Os resultados foram organizados em três categorias: AIDS – sinônimo de doença e associada a práticas sexuais; medo, sofrimento, rejeição e morte – percepções de idosos sobre a AIDS; e AIDS – a prevenção como forma de proteção. Concluiu-se que a população desta investigação, mesmo não tendo conhecimento mais aprofundado sobre a temática da AIDS, não se mostrou alheia à doença, retratando-a como uma doença infecciosa, incurável e sexualmente transmissível. Abordou, ainda, manifestações e sentimentos associados à doença, tais como, tristeza, medo, exclusão, discriminação e morte, além de destacar a prevenção como forma de proteção.

**Palavras-chave:** Idoso; Síndrome de Imunodeficiência Adquirida; Sexo; Enfermagem.

### RESUMEN

En Brasil, el síndrome de inmunodeficiencia adquirida (SIDA) entre las personas mayores se ha convertido en un problema de salud pública. La justificación para este problema se respalda en la esperanza de vida, además del hecho que los ancianos tienen deseos, placeres y una vida sexual activa y que, por lo tanto, enfrentan los riesgos inherentes a la práctica sexual. El presente estudio tuvo como objetivo describir y analizar las percepciones de las personas mayores sobre el SIDA. Se trata de un estudio cualitativo que enfoca el mundo de los significados, motivos, acciones y relaciones humanas. La investigación fue realizada en un centro comunitario de Teresina-PI, con 13 personas mayores de 60 años de ambos sexos. La recogida de datos se realizó a través de entrevistas con un guión y preguntas abiertas, grabadas y transcritas textualmente. Después de la lectura de los datos y del análisis preliminar se llevó a cabo la exploración del material que consiste en la selección de las unidades de significado, selección de las reglas de cómputo y elección de las categorías. Los resultados se organizaron en tres categorías: SIDA: sinónimo de enfermedad y asociado

*a prácticas sexuales; miedo, sufrimiento, rechazo y muerte – percepción de las personas mayores sobre el SIDA; y SIDA: la prevención como forma de protección. Se llegó a la conclusión de que la población objeto de este estudio, si bien no tenía conocimiento muy profundo sobre el SIDA, tampoco era ajena a la patología, describiéndola como una enfermedad infecciosa, incurable y de transmisión sexual. Se discutieron, también, las manifestaciones y sentimientos asociados a la enfermedad, tales como la tristeza, el miedo, la exclusión, la discriminación y la muerte, además de hacer hincapié en la prevención como forma de protección.*

**Palabras clave:** Envejecimiento; Síndrome de Inmunodeficiencia Adquirida; Género; Enfermería.

## INTRODUCTION

Population ageing is a global phenomenon initiated in developed countries since the late 1940s due to the decline in infant mortality, better health care services, sanitation and nutrition improvement as well as technological advances.<sup>1</sup>

Brazil is considered a developing country and its senior population grows steadily, mainly because of recent demographic and epidemiological changes, decline in fertility and mortality as well as increase in life expectancy. The term “elderly people” refers to those over the age of 60-3.

Increase in life expectancy results in ageing population; it is estimated that, by the year 2050, 63 million people will be over 60 years of age.<sup>4</sup>

Ageing is a sequential process. It is a specific, cumulative, irreversible and non-pathological deterioration of a mature organism, common to all species that, with the passing of time, becomes less able to cope with environmental stress and, therefore, has a higher probability of dying.<sup>2</sup>

It is important to notice that not all changes experienced by older adults are due to natural ageing since this may delay the detection and treatment of certain diseases. On the other hand physiological ageing cannot be treated as a disease that demands unnecessary tests and treatments against usual signs and symptoms of senescence.<sup>2</sup>

Therefore, health professionals, particularly nurses, should be able to distinguish physiological from pathological changes for the implementation of educational and reflective practices directed to the elderly and their families.<sup>5</sup> Good quality of life in youth and adulthood means healthy ageing. The onset of diseases in old age is characterized as pathological ageing or senility.

Declining in physical functions leads to loss of independence and increasing frailty and susceptibility to acute and chronic health problems, which usually result from several factors. Diseases such as hypertension, diabetes *mellitus*, cardiovascular diseases and AIDS are common during this stage. The latter is becoming increasingly frequent. Health professionals tend to consider the elderly as asexual beings and do not address the issue during visits, thus delaying diagnosis and the implementation of prevention campaigns.<sup>6</sup>

In this context the incidence of AIDS among seniors in Brazil constitutes a public health problem. In the state of Piauí, from 1986 to 2010 there were 302 notified cases of AIDS among individuals aged over 50. Though in the big picture the number is not significant, it demonstrates that it is a growing health concern amongst the age group.<sup>7</sup>

Given this situation, characterized by the fast ageing of the population and the rising of AIDS amongst seniors, the following guiding question arises: “How do the elderly of a community centre in Teresina perceive AIDS?” The present study intends to describe and analyse this perception.

## METHOD

This is a qualitative study, a type of research characterized by the ability to obtain information on feelings, thinking processes and emotions difficult to extract or ascertain through other research methods.<sup>8</sup>

It was carried out at a community centre in the south of Teresina, State of Piauí. The facility has 200 registered senior members: 22 were male and 178 female. The inclusion criteria were people aged 60 or over, of both sexes, registered in the centre. The individuals were invited to participate voluntarily in the study; they read and signed the Statement of Informed Consent. The research subjects could withdraw their participation at any time, in accordance with National Health Council Resolution No. 196/96. Individuals that did not meet the previous criteria were excluded from the study.

After being approved by the Research Ethics Committee at NOVAFAP (protocol No. CAAE 0165.0.043.000-11), data collection was initiated. The researchers used open-ended questions that allowed the interviewee to discourse freely on the subject and the interviewer to keep the subject within the limits of the research topic, i.e. directing the participant to the topics related to the research subject.<sup>9</sup> The guiding questions were: “What do you know about AIDS?” and “What do you know about AIDS in old age?”.

Data was collected between July and August 2011, in the auditorium of the centre, via individual interviews with an average duration of 30 minutes – the interviews were conducted in the afternoon; 13 elderly people were invited and agreed to participate as study subjects.

Interviews were completed when data saturation occurred; however, repetition of meanings was taken into account as well as the uniqueness of the experiences. In qualitative researches this aspect is considered a criterion that ensures the study's representativeness as it encompasses the issue and, therefore, investigates its multiple dimensions.<sup>9</sup>

Data was analysed by content analysis, which consists in understanding the meanings in the context of utterance, seeking to go beyond the merely descriptive sense to infer a deeper interpretation. Results were obtained via the operationalization of thematic analysis that followed three stages.<sup>9</sup>

The pre-analysis consisted in a comprehensive reading of the selected material; in the second stage, the selected material was examined and analysed; in the final stage, an interpretive synthesis that could dialogue with the research's objectives, questions and premises<sup>9</sup> was elaborated. Data was then organised into three thematic categories.

After categorization of data, results were interpreted and articulated with the theoretical framework as well as other notions and concepts of AIDS in old age.

## RESULTS AND DISCUSSION OF DATA

The thematic analysis led to the following categories: "AIDS synonymous with disease and associated with sexual practices"; "Fear, suffering, rejection and death: perceptions of the elderly about AIDS"; "AIDS: prevention as a form of protection".

### AIDS: SYNONYMOUS WITH DISEASE AND ASSOCIATED WITH SEXUAL PRACTICES

The number of cases of AIDS in the elderly is increasing. Elderly people have desires and, in most cases, are still sexually active; however it is not sexual activity that makes people more vulnerable to the disease, but unprotected sexual practices.

This context caught the interest of researchers that started to investigate how older adults perceive the disease; many elderly people still lead a sexually active life – condition considered indispensable to a good quality of life.<sup>10</sup>

This category highlighted the individuals' perception about AIDS as a disease associated with sexual practices (prevalent mechanism of transmission in the participants' opinion). The following statements show such perception:

*They say it's a dangerous disease for which there is no medicine (S1).*

*It kills a lot of people! [...], I think it is an infectious disease, bad, everyone is afraid. [...] AIDS is a strong and incurable disease; there is no cure for it (S5).*

According to these interviewees, AIDS is an infectious and dangerous disease that kills many Brazilians and has no cure; it affects their well-being and quality of life.

The increase in life expectancy brought significant social implications worldwide. Brazil experiences important epidemiological changes: from a mortality scenario characteristic of a young population (i.e. predominance of infectious diseases) to one in which chronic diseases predominate. These diseases are multiple and complex (such as AIDS) and require knowledge and high-cost treatments.<sup>11</sup>

In recent years the increase in notifications of HIV transmission among seniors in the country characterizes it as a serious public health issue.<sup>12</sup>

AIDS is caused by infection with HIV-1 or HIV-2; it is a clinical disease that generates an immunodeficiency syndrome in the infected organism.<sup>13</sup>

In the initial stage of the infection, flu-like symptoms appear (fever, malaise) that are often overlooked. Then comes the asymptomatic stage, characterized by strong interaction between immune cells and the constant and rapid virus mutations; it does not, however, weaken sufficiently the organism to allow the emergence of new diseases and it can last many years. The last one is the symptomatic stage, the body becomes increasingly weak and vulnerable to opportunistic infections; main symptoms are fever, diarrhoea, night sweats and weight loss<sup>14</sup>. This emerges in the following statement:

*Well, I know that AIDS is a sexually transmitted disease [...], when someone is seropositive, life is full of limitations; people cannot catch infections because it accelerates the body's deterioration process and it affects the organs (S10).*

According to the 2010 Epidemiological Report, in individuals aged 60 and over there is a significant increase in AIDS cases in both sexes – it went from 394 cases in males and 191 cases in females in 1999 to 938 and 685 cases in 2009, respectively. In Piauí, the context is not different: from 1986 to 2010, 302 new cases in the over 50's age group were notified.<sup>7</sup>

Although there is more than one mode of HIV transmission sexual contact with an infected person is the most frequent one. As a result of increase in life expectancy, better quality of life, and a longer sexually active life expectancy, that mechanism of infection becomes the most common whilst the others are often overlooked.

The study's participants mentioned the sexual act as the disease's main mode of transmission:

*Sex is without restrictions, it's found freely, so I don't think there is a way against the disease [...] AIDS happens to*

*older people that still like sex, that are still active, they think it is important, they go after it and then it happens (S3)*

*People get contaminated through sex. [...] I know that old people, many women, sometimes due to anxiety, desire, loneliness, no husband, no nothing, they don't choose properly a partner to have sex with, so they have sex and then get infected. Men as well; thing is, with men they have sexual desire as well but are not satisfied with only one woman, or either they want to be young again (S7).*

For these respondents, AIDS comes associated with sex. Some reported that sex is currently very commonplace, "open and free", which facilitates transmission. According to the interviewees, seniors are infected because many of them are still sexually active and do not protect themselves adequately. They also mentioned the anxiety and loneliness of old age that, coupled with sexual desire, prompt them to seek any partner, increasing the risk of infection.

Some authors<sup>6</sup> claim that HIV is transmitted through contaminated body fluids (blood, semen, vaginal secretions, amniotic fluid and breast milk) and through a transplacental mechanism although it is not transmitted by casual contact. It can also be contracted through blood via contaminated syringes and needles or by blood transfusion. Although this latter form is very rare, some cases still occur in the so-called window period, which may last from three to twelve months.

HIV transmission occurs when the mucosa comes into contact with infected body fluids; sex is the most common form of contact between "mucous and secretions," when mouth, vagina, anus or the glans penis itself come into contact with fluids carrying HIV-1. The study subjects are aware of other modes of HIV transmission, as highlighted by the following respondent:

*[...] They say it only happens during sex although kisses and such things are ok. There is also the problem of the injections, isn't? (S11).*

When AIDS emerged, there were the so-called risk groups – homosexuals, prostitutes and drug users; at that time those groups were considered to be the only ones susceptible to the disease, therefore, targeted by prevention campaigns.<sup>10, 17</sup>

The concept of risk behaviour – people engaging in unsafe sexual practices – was adopted later. Anal sex is a high-risk practice since bleeding is quite frequent. This does not mean that unprotected vaginal sex is safe for it also involves the exchange of fluid and vaginal secretions that may carry the virus.<sup>13</sup>

At present, vulnerability is the preferred concept. AIDS does not choose colour, race, creed, sex, age or social class, and

it affects society as a whole. Lack of preventive practices focused on the senior population may be one of the determining factors for the increase of the disease amongst this group.<sup>10, 17</sup>

Even if the research population does not present an extended knowledge on AIDS, they are not indifferent to the disease. They understand that it as an incurable and infectious sexually transmitted disease and that the main mode of transmission is sexual intercourse. They are also aware of the inherent risks to unprotected sexual relations.

## FEAR, SUFFERING, REJECTION AND DEATH: PERCEPTION OF AIDS AMONGST THE ELDERLY

AIDS, typified as lethal and the cause of intense suffering, carries strong social stigma, which labels the infected as someone improper, immoral and socially unacceptable. That individual is stigmatized, rejected and treated in a reductionist way, which can lead to social isolation: it makes them suspicious, depressed, hostile, confused, anxious, and thus susceptible to what others think about them<sup>18</sup>.

Despite recent achievements in controlling the disease, the terror that characterized the beginning of the epidemic continues to exist and has singular repercussions even today.<sup>19</sup>

Thirty years after it was first recognised, the stigma created around HIV/AIDS is still present, mainly because the disease is infectious and incurable. Consequently, some of the research subjects, when asked about their perception about AIDS, associated it with feelings of fear, sadness, grief, rejection, prejudice and death, as can be seen in the statements below:

*[...] People die mainly of sadness [...] they have AIDS and after much struggle, much effort they eventually die. It is a very discriminatory disease and there is much prejudice going on [...] it is sad in one's youth and it is much worse in old age (S7).*

*In old age, it must be even worse. The elderly are badly treated by the family when they are ill and it is still worse if they have AIDS. Then they suffer a lot more (S8).*

*It is very sad [...]. I pray to God never to have it. It is very sad (S12).*

In these respondents' opinion, AIDS does not depend on age and, particularly in old people, it causes much pain, social exclusion, death, suffering, sadness, rejection and prejudice. According to them the disease hits harder in old age due to their often weakened and vulnerable condition. It is therefore a much-dreaded disease and they do not want it for themselves nor their families.

A HIV-positive diagnosis leads to feelings of surprise, disappointment, sadness, despair and fear of the unknown; it equals the end of dreams, plans and life's possibilities.<sup>20, 21</sup> These reactions are strongly influenced by myths, beliefs and values cultivated by the individual and by their social group, as can be seen in the following statements:

*Holy Mother of God! I am very much afraid, only that, thanks be to God, I have nothing to do with it. I dread AIDS, Mother of God, like panic, you know? Sometimes people, even relatives, get it, God help them! I have heard a lot about AIDS, and even some singers died from it. It is dreadful! (S4).*

*[...] It is a disease that makes people unwanted; people are isolated, abandoned and everybody is scared. Mother of God! If he has the disease he can be counted as dead! (S11).*

Some studies demonstrate that the difficulties people face with AIDS causes them insecurity and fear of the disease's effect in their lives. People with HIV/AIDS tend to hide their seropositive status and fear any situation that may expose it so to avoid rejection, prejudice, discrimination and social exclusion, which are already rooted in the sociocultural imaginary.<sup>22</sup>

The coping with the disease and its assimilation in the process of living, by patients and relatives alike, are issues that usually cause anxiety, fear and suffering. From this point of view, AIDS is more significant in terms of psychological, social, cultural, political and economic impacts than in strictly biological terms; the perception is of being inserted in a social drama.<sup>23</sup>

Regardless of age, AIDS diagnosis shatters the individual's emotional relationships, their family ties and friendships. It sounds like a threat to be deprived of the feeling of touching and being touched; it resembles a punishment.<sup>12</sup>

Thus, HIV/AIDS diagnosis is to family and close relations a process of coping, often painfully, since there is great fear of social isolation and loss of support from important people, besides the risk of living with discrimination. Therefore patients fear not only having the virus but, most of all, exposing the diagnosis to other people.<sup>21</sup>

The diagnosis of a disease such as AIDS has a psychological impact on anyone. At this moment, the patient needs support, comfort and help; it is a delicate moment for any human being.

Although the discovery of AIDS is entering its fourth decade, myths, taboos and prejudices persist in the sociocultural imaginary and increase the stigma associated with the disease. Feelings like sadness, fear, exclusion, discrimination and death refrain the HIV-positive from revealing the condition.

## AIDS: PREVENTION AS A FORM OF PROTECTION

Risk behaviour is an important factor in AIDS transmission. Health authorities worldwide are seeking solutions and concentrating efforts in the implementation of strategies aiming at controlling the spread of the disease.<sup>24</sup>

The adoption of prevention practices to reduce contact and, consequently, HIV transmission is one of the strategies. In Brazil, prevention campaigns favour the supply of scientific information to the population. The idea of these campaigns is that an educated public can recognize mechanisms of transmission<sup>25</sup> and make informed decisions regarding safer sex, as exemplified by the following respondent:

*These messages on how to avoid AIDS are for people to be more careful and use condoms! We see it on the TV, in posters: use condoms (S7).*

The government is committed to disseminate information on how to protect against AIDS; however, this is not enough. The number of infected people is still increasing, which proves that information does not ensure a safer sexual behaviour. The implementation of more efficient practices to control the number of HIV-infected people is necessary.

Existing campaigns are directed to a younger population, since they are considered the group most likely to contract the virus. As for the seniors, who are not considered at risk, preventive measures guaranteed by the Statute of the Elderly are disrespected since educational activities regarding this population are virtually inexistent. The increase of cases among the elderly may be related to the lack of effective educational measures<sup>10</sup>, as highlighted by the following interviewee:

*[...] The danger lies in not knowing how to protect yourself [...]. In Teresina many old people have the disease, for lack of knowledge (S9).*

Studies<sup>26</sup> demonstrate that most campaigns do not target the elderly reinforcing the idea that AIDS is a disease restricted to the young and that elderly people are asexual.

However, scientific studies debunked the notion that sexual activity after the age of 50 is non-existent; 72.4% of the present study's participants informed that they led a satisfactory sexual life in the six months prior to the survey.<sup>27</sup>

The elderly deserve the attention of public policies for the prevention of AIDS, since they are at risk as much as young people. The study's subjects knew about HIV prevention practices, even though preventive policies aiming at this group are deficient and the use of condoms was not as widespread at the time of their youth as it is today:



*You catch it during sex [...], there are condoms, so people don't get it (S6).*

*[...] We have to protect ourselves against it, we have to use condoms; in the past I knew it existed, but people didn't know how to prevent it (S11).*

Sexual transmission of HIV/AIDS is the most common one. Safe sexual intercourse via the use of condoms is vital. The study population was aware that practices such as kissing, hugging, drinking from the same cup and eating from the same plate are not mechanisms of transmission. They also knew that the most effective way to prevent against the disease is the use of condoms:

*You don't get AIDS through kisses, hugs, food, clothes [...]. It is recommended to have sex with a woman with condoms (S13).*

*I hear that you don't get it with kissing, hugging, and this sort of things. Now, during sex you must use condoms to avoid getting it [...]. (S2).*

Previous studies showed that in most cases people knew that the use of condoms prevents HIV transmission, however, more than 80% of those investigated did not use them<sup>28</sup>. Among seniors infected with HIV, heterosexual transmission is significant; therefore prevention and HIV testing for the senior population are essential.

The control of STDs and HIV transmission requires constant information to the population and educational activities focusing on risk perception, changes in sexual behaviour and the promotion and adoption of prevention practices. It is necessary to offer counselling during nursing visits in which the link between STDs and HIV infection should be emphasized. These moments are exceptionally appropriate to talk about prevention.<sup>13, 29</sup>

Prevention goes hand in hand with the concept of health promotion towards increasing self-protection ability of individuals, groups and the community in general and collective coping with social problems.

There are several forms of HIV prevention – individual use of syringes, needles or any sharp instruments, abstinence from breastfeeding by HIV positive mothers, the use of medication during pregnancy to reduce transplacental transmission, and the use of male and female condoms in all sexual relations. Educational campaigns, health promotion and counselling addressed to the elderly could also reduce the rates of the disease among this group.

## FINAL CONSIDERATIONS

The present study described and analysed the perception of elderly people of a community centre in Teresina about Aids. Amongst that group AIDS is feared and, even though they have superficial knowledge about the issue, the disease generates negative feelings. The need for prevention was emphasized.

The results demonstrated that the elderly perceive AIDS as an infectious, contagious and incurable disease. They emphasized that sex is the main mechanism of transmission given that it is free and not restricted.

It is worth mentioning that the participants associated the disease with negative feelings such as sadness, fear, suffering, rejection, prejudice and death, portraying it as a stigmatizing disease that generates myths and taboos. The respondents added that the disease is even worse in old age, due to old people's frailty and vulnerability and that they not wish it for themselves nor their families.

Some participants mentioned AIDS prevention and cited condoms as the main form of protection; they emphasized that practices such as kissing, hugging, drinking from the same cup and eating from the same plate are not mechanisms of transmission.

The research's key objective was to describe the perception of old adults about AIDS and to suggest professors and health professionals, mainly nurses, actions towards a humanized and individualized attention to the elderly, respecting their beliefs, fears, and desires. We recommend an honest and open discussion of this topic, which can be done in individual consultations or in educational lectures in which issues like risk factors, transmission, prevention practices, sexuality and sexually transmitted diseases can be addressed.

The study showed the group's knowledge about prevention and mechanisms of HIV/AIDS transmission. With such knowledge the health team organized discussion groups between the study participants and other seniors to inform about prevention practices, improve quality of life and prevent AIDS.

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