RESEARCH

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Aids in the elderly: reasons that lead to late diagnosis

Aids em idosos: motivos que levam ao diagnóstico tardio

Sida en personas seniles: motivos que llevan al diagnóstico tardío

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ABSTRACT

Objective: to investigate elderly living with HIV/Aids and health professionals, what are the reasons that lead to late diagnosis of HIV infection in the elderly. **Method:** prospective, qualitative study, conducted at a specialized outpatient clinic with elderly living with HIV/Aids, diagnosed age over 60 years and in the Family Health Strategy units with nurses and physicians. Data were collected through interviews and verified by content analysis, using the theoretical framework of vulnerability. **Results:** a total of 11 elderly, 11 nurses and 12 physicians participated in the study. Three empirical categories emerged: the late diagnosis of HIV happens against the health service; invisibility of the sexuality of the elderly; and weaknesses in the anti-HIV serology request for the elderly. **Conclusion:** there are health professionals who see the elderly as asexual, causing the diagnosis of HIV to happen in the secondary and tertiary service instead of primary care.
Descriptors: Aged; HIV; Delayed Diagnosis; Disaster Vulnerability; Health Personnel.

RESUMO

Objetivo: investigar entre os idosos vivendo com HIV/Aids e os profissionais de saúde, quais são os motivos que levam ao diagnóstico tardio da infecção pelo HIV nos idosos. **Método:** estudo prospectivo, qualitativo, realizado em ambulatório especializado com idosos vivendo com HIV/aids, diagnosticados com idade igual ou superior a 60 anos e nas Unidades com Estratégia Saúde da Família com enfermeiros e médicos. Os dados foram coletados por meio de entrevistas e verificados por análise de conteúdo, utilizando o referencial teórico da vulnerabilidade. **Resultados:** participaram 11 idosos, 11 enfermeiros e 12 médicos. Emergiram três categorias empíricas: o diagnóstico tardio do HIV acontece na contramão do serviço de saúde; invisibilidade da sexualidade do idoso; e fragilidades na solicitação da sorologia anti-HIV para os idosos. **Conclusão:** há profissionais de saúde que percebem os idosos como assexuados, fazendo que o diagnóstico do HIV aconteça no serviço secundário e terciário e não na atenção primária.
Descritores: Idoso; Vírus da Imunodeficiência Humana; Diagnóstico Tardio; Vulnerabilidade; Profissional de Saúde.

RESUMEN

Objetivo: realizar una investigación entre personas seniles que conviven con VIH/Sida y profesionales de la salud, para reconocer los motivos que llevan al diagnóstico tardío de la infección. **Método:** estudio prospectivo, cualitativo, realizado en un centro de salud especializado y en Unidades con Estrategia de Salud de la Familia, entre enfermeros, médicos y personas mayores diagnosticadas con VIH/Sida, de edad igual o superior a los 60 años. Los datos se recolectaron mediante entrevistas y se comprobaron a través del análisis de contenido utilizando el marco teórico de la vulnerabilidad. **Resultados:** participaron 11 personas mayores, 11 enfermeros y 12 médicos. Surgieron tres categorías empíricas: postergación del diagnóstico del VIH por el servicio de salud; invisibilidad de la sexualidad en la persona senil y fragilidad en la solicitación de la serología anti-VIH. **Conclusión:** muchos profesionales de la salud perciben a las personas mayores como asexuadas; por lo tanto, el diagnóstico del VIH ocurre en la atención secundaria y terciaria, y no en la primaria.
Descriptores: Persona Senil; Virus de Inmunodeficiencia Humana; Diagnóstico Tardío; Vulnerabilidad; Profesional de la Salud.

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INTRODUCTION

Sexuality in old age is still a sensitive issue to be discussed in the context of research and academic discourse, which is reflected in the care of this population. The increasing number of elderly living with HIV/Aids in Brazil and other countries shows the necessity and importance of health professionals to "reflect" about their work practices, including the approach to elderly sexuality.

Researches indicate that elderly maintain an active sex life and are exposed to sexually transmitted infections (STIs), especially the human immunodeficiency virus (HIV)[1-2].

However, it is emphasized that sexual practice does not increase the vulnerability of the elderly in relation to HIV infection, but unprotected sexual practice, a fact that is attributed to all ages, not just the elderly[3].

Health professionals, especially physicians and nurses that attends the elderly, are not prepared to identify the vulnerability of these people to HIV/Aids and have not requested serological tests[1,4-5], which may be related to lack of research on the sexual activity of the elderly[4-6], consequently, causing late diagnosis of HIV/Aids in this population.

Also, many elderly seek health services showing signs and symptoms of opportunistic infections that occur in Aids and they are neglected by health professionals, which ultimately assign the symptoms to other more prevalent morbidities in the elderly[7].

During weekly nursing consultations with elderly living with HIV/Aids in specialized outpatients clinics, it was possible to identify that the diagnosis of HIV/Aids takes place in other health service, not primary care, for the most part, even if it is late, diagnosis of HIV occur in the secondary service, instead of the primary service. This shows that there are weaknesses in the network of health care for the elderly.

Faced with these questions, it is important to know the reasons that lead to late diagnosis of HIV/Aids in the elderly. However, the concept of vulnerability is the theoretical framework adopted to meet the objective of this study, since it considers the chance of exposure of people to illness as a result of a number of aspects, not only individual but also collective and contextual, which lead to increased susceptibility to infection and illness[8]. In this context, the concepts of individual, social and programmatic vulnerability emerge, which are considered as interdependent plans of determination and apprehension of greater or lesser vulnerability of the individual and the collective[8].

Thus, the present study aims to investigate the elderly living with HIV/Aids and health professionals working in the Family Health Strategy (FHS), which were the reasons that led to late diagnosis of HIV infection.

METHOD

Ethical aspects

The study was approved by the Research Ethics Committee of the Botucatu School of Medicine/UNESP. The research process followed the ethical principles, while maintaining the anonymity of the participants, the confidentiality of information, in addition to signing the Informed consent form, in two copies, one of the research subject and another for the researcher.

Type of study

Prospective qualitative study.

Study scenario

The study scenarios were the Specialized Outpatient Service for Infectious Diseases (SOSID) and FHS units in a city of about 130,000 inhabitants located in the south central region of the State of São Paulo.

Source of data

Data were collected through interviews with elderly living with HIV/Aids, and physicians and nurses working at the FHS.

The inclusion criteria for the elderly were: people with HIV/Aids of both genders, treated at SOSID, aged over 60 years who were diagnosed with HIV/Aids when they were already elderly and with no cognitive impairment, evaluated by the Mini Mental State Examination (MMSE)[9] applied after the consent to participate in the research and before starting the interview. For the identification of cognitive impairment through MMSE for the illiterate individuals, we considered the total score less than 20 points, and among literate, total scores less than 25 points[9].

In January 2011, there were 527 elderly living with HIV in SOSID, and 30 participants were aged less than 60 years, from these, 15 found out about HIV/Aids when they were already older than 60 years and were invited to participate in the study. The sample consisted of 11 elderly, since four did not meet the inclusion criteria, and two were not aware of the infection and the presence of cognitive impairment, and two refused to participate.

Regarding health professionals, the inclusion criteria were: being a physician or nurse; working in the FHS for at least one year; working with the elderly; and consent to participate. These professionals were chosen because they are responsible for the HIV serology request for the elderly according to the protocol established in the city, supported by the Brazil's Federal Council of Nursing (COFEN) through Resolution 358/2009[10]. This document clarifies the nursing process, which is private to nurses, nursing diagnosis and the prescription of actions or nursing interventions. The city, during the research, had 13 FHS units, which had at least a physician and a nurse per team. All professionals were invited to participate in the research, totaling 26 professionals.

The sample comprised 23 professionals (11 nurses and 12 physicians), since two nurses were on maternity leave, and one physician was transferred to the hospital emergency unit during the study.

Sample and data collection

After contact via telephone and prior appointment, the interviews for the two populations (elderly and health professionals) were individualized and were conducted in a private environment by trained and qualified professional, lasting about 45 minutes. Data were collected from January to December 2011.

Two instruments were used, one for the elderly and one for health professionals. Both were composed by two parts. The first, with questions related to socio-demographic factors. The second with guiding questions: 1) to the elderly – "Tell me how you found out you were infected with HIV"; and 2) to the health professionals – When you are caring for the elderly, is there any time you talk about sexual health?", "under what circumstances do you request the HIV serology for the elderly"?. The interviews were recorded and later completely transcribed.

Data analysis

The interviews were analyzed according to the methodological reference of the Content Analysis in representational aspect and thematic of Bardin, as the stages proposed: pre-analysis, analysis and exploitation of the material[11].

The empirical categories that emerged to analyze the problem of late diagnosis of HIV/Aids in the elderly are grounded in the theoretical framework of vulnerability, advocated by Ayres[8], using as categories of analysis the individual, social and programmatic dimensions, which allows thew identification, in addition to individual aspects, collective and contextual aspects responsible for leading increased susceptibility to infection, illness and, finally, the availability or not to different resources for the protection of the individual or collective.

In the intention to preserve the anonymity of each participant, we chose to identify them by the words: "Elderly", "Nurse" and "Physician", following the numerical order of the interviews.

RESULTS

Among the 11 elderly who participated in the study, eight men and three women were included, a ratio of 2.7 men for every woman, aged 60-75 years, with a mean of 68 years. They had low education, one was illiterate, six had elementary school education, two had incomplete secondary education and two had completed secondary education. Six were married, and the predominant occupations were truck driver and rural workers (crop/tractor driver). There were many people who were not working at the time of interview or were retired. Seven elderly had incomes of one to two minimum wages and seven lived with wives and children.

Among health professionals, the age range was 24-57 years, mean 32 years. There were 17 women and six men. Most had started their career in primary care less than five years before the interview, working in the FHS.

The process of discourse analysis of the participants, according to content analysis, with the aspect of vulnerability three categories emerged: late diagnosis of HIV goes against the health service; invisibility of the sexuality of the elderly and weaknesses in the application of anti-HIV serology for the elderly.

Late diagnosis of HIV goes against the health service

Health professionals reported that requesting anti-HIV serology for the elderly was not a routine adopted in the primary health service. This fact was evidenced when the elderly sought the health service with signs and symptoms, often suggestive of opportunistic infections that occur with people who has Aids, still, health professionals would first investigate other conditions and did not request the anti-HIV serology. It is noteworthy that elderly living with HIV/Aids took 42 days to a year to obtain diagnostic confirmation, which only occurred in the secondary and/or tertiary service, thorough emergency service or during hospitalization. The excerpts of health professionals and the elderly translate this situation:

> [...] *saying that it is a routine to offer HIV testing for the elderly, we don't offer it* [...] *and to say that's I spontaneously and routinely offer the test, I would be lying, I should ask, but I don't.* (Physician 5)

> [...] *the patient was very old, he was losing weight and getting worse every day. He had been in the family health unit and he seemed that no one thought of the possibility of HIV* [...] *and after a while of investigating, we ended up asking for HIV for this elderly and it was positive, but when we got the results he was dead already.* (Nurse 9)

> [...] *what happened is that I traveled a lot* [patient was truck driver], *my food was scarce* [...] *until one day I was very sick and at the health unit, no one found what was wrong with me. It took 6 months, and then my wife took me to the hospital in São Paulo and then they found this virus in the blood.* (Elderly 2)

Invisibility of elderly sexuality

Questions regarding the sexual life of the elderly remain veiled in the care of health professionals. The fact they believe that the elderly do not have an active sex life lead physicians and nurses to not hold discussions or questioning on issues related to their sexual life. Questions about sexual health of the elderly appeared only after the diagnosis of HIV/Aids, with the purpose of informing only about the preventive measures and that the elderly does not transmit the infection to their partners.

However, among the existing barriers in the sexual health discussion of the elderly is the age difference between the health professional and the elderly, and also the gender issue, as the statements below show:

> [...] *we think that the sexuality of the elderly is zero. We put this as a reality of the elderly ... so we do not ask anything about their sexual life.* (Physician 8)

> [...] *I do not feel 100% comfortable talking to the elderly about sexuality* [...] *I feel much more at ease talking to a teenager, with a woman than talking to an old man.* (Nurse 7)

> [...] *no, I did not ask anything about my sexual life* [...] *no professional said anything about it. Only after I was sick they told me to use a condom.* (Elderly 5)

Weaknesses in anti-HIV serology request for the elderly

As noted earlier, the request of anti-HIV testing is not a routine in the primary health service. There were health professionals who did not request the anti-HIV serology for the elderly routinely. As a strategy to request this test, they used the campaign "Be aware", which - since 2003 has the support

from the Brazilian Ministry of Health, National Program of STD/Aids and Surveillance Secretariat of Health - aiming to raise awareness to the population about the importance of performing the anti-HIV serology. This campaign takes place once a year, on December 1st- World Aids Day.

The request of anti-HIV serology was asked for only the widowed, people with several sexual partners or drug users, excluding married or elderly in stable relationships. Another weakness found was the lack of training of health professionals in both undergraduate and/or graduate professionals. According to statements, learning about the health of the elderly was directed to the care and treatment of chronic diseases, not focusing on the sexuality of the elderly.

> [...] *I never requested HIV testing for elderly, we only request it in the Campaign "Be aware", then we test everyone of any age.* (Nurse 5)

> [...] *I do not request married elderly because married people do not have much history to speak, because they only have one partner* [...] *I request test when the elderly has multiple relationships and also uses drugs.* (Physician 9)

> [...] *we do not have much training and ease to address the sexuality issue, thinking both HIV and STDs, we do a lot for young people, for the elderly population we think they suffer more with chronic disease* [...]. (Nurse 3)

DISCUSSION

Based on the theoretical framework of vulnerability, which guides the data analysis, it became clear the interdependence of dimensions individual, social and programmatic vulnerability, which are determined by the understanding of people's lives and the community, the individual and the collective that lead to late diagnosis of HIV among the elderly.

The increasing number of Aids cases in Brazil among people aged 60 or over is evident. In 2002, these elderly accounted for 2.5% of the epidemic; in 2013 the number increased to 5%[12]. Among the HIV-infected population, the elderly are being recognized as a substantial proportion of the epidemic worldwide[13-15]. Only in the United States of America in 2011, people aged 50 or over accounted for 17% of new HIV diagnoses and 25% of all Aids diagnoses[16]. However, medical research on HIV in the elderly focus on the aging population already living with HIV, rather than individuals who are newly diagnosed at older ages[17-19].

People with low education tend to assimilate the information improperly, making the acquisition of knowledge about the disease confusing, thus exposing individuals with less education to be more vulnerable to HIV[20]. Low education is also related to the occupation, as low wages and poor socioeconomic status influence the access to better health services in search for quality in the prevention and care of the elderly with HIV/Aids[20]. These circumstances highlight the individual dimension of vulnerability, which brings aspects of the way of life of the people who contribute to the risk exposure. It is related to access to information, understanding and promotion of transformative practices that aim at prevention[8].

The Unified Health System (SUS) states that everyone has the right to universal and free health care, financed with funds from the budget of the Union, the States, the Federal District and Cities. This same system determines that the gateway in health care should be the primary health service, with reference to the network of specialized services to medium and high complexity, if necessary[21].

In Brazil, the request of anti-HIV serology is encouraged to population groups aged more than 18 years in the most vulnerable situation, who are drug users, men who have sex with men and female sex workers[12], but it does not make references to the elderly population, leaving the discretion of the health professional request or not the anti-HIV serology. This is also observed in the United States, where the guidelines for requesting anti-HIV serology match the HIV screening routine for those aged 13-64 years, excluding individuals with 65 years or more[22].

However, the lack of specific guidelines for requesting anti-HIV serology for the elderly has contributed to the failures in the care of this population in health services, especially in primary care, considered the gateway to the health system.

In our study, we found that even the elderly with signs and symptoms suggestive of opportunistic infections evidenced in Aids, health professionals did not request the HIV serology, and the diagnosis of infection happened late, as it can also be observed in a study in the USA[22].

It is noteworthy that the symptoms of the most prevalent diseases in the elderly and in individuals with HIV are similar, and the differential diagnosis becomes a complex process. Thus, the lack of specific symptoms may delay diagnosis in up to 10 months, resulting in the delay of antiretroviral treatment[7,22] thus, harming the control and disease progression.

Failure to request anti-HIV serology during the elderly consultation was also supported by other studies[5,22].

Studies have shown that individuals with 50 years or more were diagnosed at a more advanced stage of the disease, compared to the younger population[22-23].

However it is clear that the late diagnosis interferes with the prognosis of the disease among the elderly, because in addition to HIV infection, acceleration in the progression of comorbidities among the elderly occurs[2,22].

In this study, the invisibility of the elderly sexuality became apparent when health professionals reported that they did not talk with their patients about sexuality during their visits, citing as the main barriers the difference between ages and gender issues.

This fact was demonstrated in a study conducted in the UK[4] with physicians and nurses, which revealed the existence of barriers to sexual health discussion with elderly people who attended primary health services, specifically in relation to gender, ethnicity, sexual orientation and the age difference. However, in order to overcome it, the authors suggested the training of professionals, provision of brochures with information for patients and also the use of more nurses, which, according to the authors, also spending more time with patients.

On the other hand, a study with 163 women in the United States, who were 65 years old revealed that they would not like to start a discussion about sexual health, but said they would like the physician to initiate this discussion[6].

In this study, the health professional dialogue with the elderly about sexual health occurred only after the diagnosis of HIV/Aids and this was restricted to information about the importance of condom use, failing to address issues that could highlight the vulnerability of the elderly, as sexual desire, aging and sexual partnerships.

Thus, it is observed that the invisibility of the sexuality of the elderly lead health professionals to not evaluate the vulnerability of this population to STDs, especially HIV/Aids, they do not ask them about sexual health and lose the opportunity to request serology[5]. This situation was observed when professionals reported that anti-HIV serology was only requested to elderly widowers, elderly with several partners and drug users. Not requesting serology for married and/or stable relationship.

Regarding the deficiency in the training of health professionals in undergraduate and graduate programs on sexuality of the elderly, this was also observed in other studies[5,24-25]. In public universities of Nursing in the state of São Paulo, the curriculum does not provide specific subject to teach human sexuality[24]. In the USA and Canadian medical schools, throughout the course, there are subjects which deal with human sexuality, but only 3 to 10 hours[25].

In this context, we verified through the social dimension of vulnerability, that the health-disease process is social and permeates educational and cultural aspects, social policies, gender, translating into behavioral phenomena. In the programmatic dimension, we observed the weak access and the safety net that would make the elderly to reduce exposure to risk, that is, we see how health institutions behave in the face of socially given conditions of vulnerability[8,26] .

Since this is a qualitative study, there are limitations with the impossibility of causal inferences. Thus, we cannot do generalize the results to other health services, where there are professionals who care for the elderly.

As contribution to health practices, the results of this study provide subsidies for nurses and physicians, and other health professionals to rethink their approach during the visits to the elderly and awaken the interest in including issues related to human sexuality, offering opportunities for dialogue, without judgement, and providing evidence of the vulnerability for this group of people.

It is believed that the development of an instrument that is able to highlight aspects of individual, social and programmatic vulnerability, which could be applied by the nurse or physician during consultations with the elderly would facilitate the assessment of the vulnerability of elderly in relation to HIV/Aids and the possibility of raising their individual needs, and when necessary request anti-HIV serology. Thus, it is possible to put into practice the concept of vulnerability in the primary health care setting.

Despite the existence of consolidated public policies in caring for people living with HIV/Aids, it is observed that there are still weaknesses as regards the health of the elderly population. There is a need, through the Department of STD, Aids and Viral Hepatitis of the Brazilian Ministry of Health that public policies are developed to incorporate the application of anti-HIV serology in care for the elderly. However, it is worth emphasizing that, while educational institutions do not incorporate the issue of human sexuality in the curriculum, we will have little improvements because health workers lose the opportunity to experience the vulnerability to HIV/Aids in the elderly population, when they fail to ask questions related to human sexuality.

CONCLUSION

Reasons have been found that can lead to delayed diagnosis of HIV in the elderly population. Among them, the diagnosis of HIV does not happen in primary care, as health professionals request HIV serology only during the campaign "Be aware", or widowed elderly, drug users and who report many partners; failing to request the serology for the elderly with stable relationship. Another reason is that there are health professionals who see the elderly as asexual and do not raise questions about human sexuality. In addition, health professionals emphasize that the age difference and gender issues make it difficult for them to deepen the dialogue with the elderly.

Therefore, the myths and prejudices in behavior and in everyday actions of health professionals, that interfere with thinking and acting, are reflected in the service and resolution of the health of the elderly, making them more vulnerable in the process. In the elderly population, this situation is aggravated because the gap between generations inhibits a broader dialogue of professionals with this population on questions related to sexuality.

Overcoming stereotypes and prejudices on the part of health professionals regarding sexuality of the elderly is directly related to improving assistance provided to this population, which reflect the development of new public policies seeking to reduce vulnerability in this case, specifically, with respect to HIV.

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