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Quality of life evaluation of elderly people with HIV assisted in referral services

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Abstract *This study aimed to evaluate the quality of life of elderly living with HIV in Recife (PE), Brazil. This is a descriptive, quantitative cross-sectional study with convenience and random sample of 241 subjects. The HIV/AIDS Target Quality of Life (HAT-QoL) instrument was applied. The quality of life was compromised in the areas of confidentiality (51.89), sexual function (63) and financial concerns (64.74). The best scores were medication concerns (87.91), health concerns (86.80), and HIV acceptance (82.78). Men scored for a better quality of life in all realms. We can conclude that among the factors associated with better quality of life in men are schooling, financial situation, self-perception and HIV-related stigma, which seems to be stronger compared with women.*

Key words *Quality of life, Elderly, Elderly aged 80 years and over, HIV*

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Introduction

A change in the structure of the population pyramid has been noted in recent years worldwide and even in Brazil. This change reflects the trend of population aging according to data from the Brazilian Institute of Geography and Statistics[1]. Considering that this increase of the elderly population is taking strides, it is essential to reflect on some challenges: the weakness of the social security and health systems and the tendency to decreased family size, which leads to a deficit in the care and social integration of these individuals.

This "demographic transition" process is inevitably accompanied by the "epidemiological transition", and we then experience a higher burden of chronic noncommunicable diseases (NCDs). Other diseases, such as the Acquired Immunodeficiency Syndrome (AIDS), whose epidemiological data reveal that the number of older adults infected by the Human Immunodeficiency Virus (HIV) is on the rise[2].

Thus, HIV infection in older people appears as a public health problem, since they are more physically and psychologically vulnerable, face greater difficulty in accessing health services, and are treated with invisibility regarding their exposure to risk, both sexually and through the use of illicit drugs.

This condition in old age means more than a disease, that is, it becomes a social phenomenon of great proportions since it impacts moral, ethical and religious principles. It is commonly thought that the elderly individual no longer has as many skills and is unfit to perform some functions alone. Thus, it is also difficult to think that older adults can relate sexually. This resistance and difficulty in seeing the elderly person as "being sexually active" means that most of the social programs geared to this public are aimed at socialization[3].

Elderly living with HIV and facing the difficulties imposed by the serological condition concerning the quality of life becomes a significant challenge since, besides coping with the aging hardships, these people also coexist with a disease that is stigmatized, with no cure, and ruled by prejudice[4].

Considering that this research is fundamental for the knowledge about its social representations, as well as the influence of this condition on the process of aging and the well-being of aging people, a study was developed in Recife (PE), Brazil, to evaluate the quality of life of older adults living with HIV.

Methods

This a descriptive, quantitative, cross-sectional study conducted at the services of reference for the treatment of HIV in Recife (PE). The population consisted of seniors of both genders infected by HIV enrolled in the services as per data provided by the State Health Secretariat of Pernambuco – STD/AIDS State Program.

The expected prevalence for the HIV event was 50%, since, despite maximizing the sample, studies on the quality of life of HIV-infected older adults found in the specialized literature fail to reach a consensus regarding this magnitude.

The Finite Population Correction Factor was used, so the sample size was established at 241 individuals who were selected by convenience sampling, as per the agenda of the outpatient clinic attendances, with the distribution of antiretrovirals by pharmacies and with the agenda of the establishments' laboratories.

This study included individuals who had been using antiretroviral therapy (ART) for at least four weeks and excluded those with cognitive impairment, which was investigated through the Mini-Mental State Exam (MMSE).

The HIV/AIDS – Target Quality of Life (HAT-QoL) was used to evaluate the "Quality of Life". It is a specific instrument for those with HIV, comprising 34 questions, covering the last four weeks, divided into nine realms: general function, life satisfaction, health concerns, financial concerns, medication concerns, HIV acceptance, concerns with confidentiality, trust in the professional and sexual function[5].

Each question contains five choices of answers (all the time, most of the time, sometimes, rarely, never) with scores ranging from 1 (worst) to 5 (best), where only the answer that best describes the last four weeks should be checked. After the answers, the values assigned to each item of each of the nine realms were added to obtain the total score of each. Then, the values were transferred to a scale of 0 to 100, where zero (0) corresponds to the worst score and one hundred (100) to the best score.

The Shapiro-Wilk's test was used in the definition of the use of non-parametric and parametric tests. No normality was found in any of the HAT-QoL realms. The non-parametric Mann-Whitney test was used to verify the hypothesis that two groups would have equal distribution, and the non-parametric Kruskal-Wallis test was used when the comparison was between three or more groups.

The result of this test indicates the rejection or not of the null hypothesis. Rejection indicates that at least one of the groups is different from the others, but does not report which. Thus, to find out which groups were different, the multiple comparison tests described by Campbell and Skillings were used[6]. The significance level of 5% was used for all tests. The "Cronbach's alpha" coefficient was used to verify the level of correlation between the items of the data obtained through the HAT-QoL.

The research developed is linked to the project "Identification of the social and epidemiological profile of elderly infected by HIV/AIDS assisted in reference services", submitted and approved by the Research Ethics Committee of the Federal University of Pernambuco.

Results

A total of 241 seniors participated, of which 151 (62.7%) were men and 90 (37.3%) were women, with a mean age of 64.9 years ranging from 60 to 82 years of age. Of these, 83 (34.4%) self-declared as single, 74 (30.7%) as married and the remaining as widowed and separated. There was a prevalence of those who had between 1 and four years of schooling (28.6%), followed by those who had between five and eight years of schooling (24.5%) and illiterates (10.4%) ranked last. We noticed that men have higher schooling and women stood out among the illiterates. The dominant race was brown with 147 (61.0%) individuals and the diagnosis time ranged from 6 months to 30 years, with a mean of 12 years.

Regarding the HAT-QoL data, the realms means ranged from 49.59 to 86.35. The realm with the highest average was "medication concerns" and the lowest was found in "concerns with confidentiality". The first consists of five questions that assess the impact of using ART in the last four weeks. Also with five questions, the second investigates the actions against confidentiality in the family and professional environment.

In the internal consistency evaluation, we obtained a high coefficient of Cronbach's alpha, which was higher than 0.7 in all realms except for the "general function", which had a coefficient of 0.65 (Table 1).

Regarding the mean scores, the standard deviation and the Mann-Whitney's test result for each HAT-QoL domain by gender, we observed that males scored better in all realms, and the realm "sexual function" had the greatest difference between means. A statistically significant difference was also noted in the realms "general function"; "life satisfaction"; "health concerns" and "financial concerns" (Table 2).

When evaluating the quality of life by the variable "age", we observed that a statistically significant difference was found only in the "financial concerns". In this realm, the elderly (65-70 years old) had the best mean (65.4) of the score. The group of elderly over the age of 70 achieved the best means in the realms "concerns with confidentiality" and "trust in the professional", with 55.7 and 80.7, respectively.

The "marital status" had a statistically significant difference only with "life satisfaction" and "sexual function". In the former, married people obtained a better mean (80.6), whereas separated people scored a better mean in sexual function (65.7). In the multiple comparisons, a statistically significant difference was found between the married and single groups in the "life satisfaction" realm, and in the separated group compared to widowers in "sexual function" realm.

"Schooling" was statistically significant in "general function", "life satisfaction", "financial concerns", "trust in the professional", and "Sexual Function". The multiple comparisons identified that the illiterate or with up to four years schooling had comparatively lower means against those with more than five years of study.

Regarding "race" there was a statistically significant difference in the "HIV acceptance" and "sexual function" realms. The best scores in these realms were those who self-declared as brown, yellow or indigenous. When performing multiple comparisons, only "HIV acceptance" showed a statistically significant difference between the groups of brown, yellow or indigenous people and the group of white people.

Elderly with a "diagnosis time" of more than 20 years achieved better means in the realms "general function", "life satisfaction", "health concerns", "financial concerns", "medication concerns", "HIV acceptance" and "trust in the professional". A statistically significant difference was found only in "financial concerns" (0.049) and "HIV acceptance" (0.002). Multiple comparison tests showed a statistically significant difference only in the "HIV acceptance" realm, in which those with a diagnosis time of fewer than five years had a lower score when compared to the others.

Table 1. Characterization of the sample according to the distribution of HAT-QoL realms. Recife (PE), Brazil, 2017.

HATQoL realms	Items	Mean	Median	(SD)	Minimum	Maximum	Cronbach's Alpha
General function	5	74.24	79.17	22.79	12.5	100	**0.65**
Life satisfaction	4	73.88	75.00	23.79	6.25	100	0.76
Health concerns	4	82.94	93.75	24.03	0	100	0.84
Financial concerns	3	59.20	66.67	34.01	0	100	0.87
Medication concerns	5	86.35	95.00	19.55	0	100	0.72
HIV acceptance	2	80.65	100.00	30.53	0	100	0.85
Concerns with confidentiality	5	49.59	50.00	28.72	0	100	0.76
Trust in the professional	3	74.69	83.33	28.43	0	100	0.91
Sexual function	2	54.25	62.50	42.05	0	100	0.95

SD = Standard Deviation.

Table 2. Sample characterization by distribution of means and standard deviations of the HAT-QoL realms' scores by gender. Recife (PE), Brazil, 2017.

Variables	Male		Female		p*
	Mean	(SD)	Mean	(SD)	
HATQoL					
General function	78.42	(20.02)	67.22	(25.40)	0.001
Life satisfaction	78.52	(20.89)	66.11	(26.33)	0.001
Health concerns	86.80	(21.05)	76.46	(27.25)	0.001
Financial concerns	64.74	(32.79)	49.91	(34.15)	0.001
Medication concerns	87.91	(18.65)	83.72	(20.82)	0.073
HIV acceptance	82.78	(28.31)	77.08	(33.79)	0.355
Concerns with confidentiality	51.89	(29.48)	45.72	(27.10)	0.095
Trust in the professional	74.78	(28.07)	74.54	(29.17)	0.964
Sexual function	63.00	(38.97)	39.58	(43.15)	< 0.001

SD = Standard Deviation * Mann-Whitney's test.

Discussion

According to the Joint United Nations Program on HIV/AIDS, individuals with HIV aged 50 years or older are already considered elderly. However, according to national legislation, this study considered "elderly" those age 60 years and over. Thus, the mean age found in this study was 64.9 years, that is, they are "young elderly" since they are between 60 and 79 years old[7].

As previously mentioned, those in the 65-70 age group achieved a better score in the realm of "financial concerns". We credit this result to the fact that individuals that age are already more likely to have some source of income when compared to those aged 60-65 years. Perhaps this difference is related to some points in the national legislation on retirement and welfare benefits, one of which is the requirement for retirement by age (65 for men and 60 for women living in urban areas), thus a lower concern and a better quality of life in this realm.

Regarding the prevalence of HIV in males, there are several associated factors such as the formation of masculine sexual identity governed by traditionalism, for example, the onset of sexual activity/life with prostitutes; the constant reference to standardized behavior and the need to match friends' social expectations and women's sexual expectations[8].

Regarding the marital situation, we recall that it was not long ago that the low life expectancy after 60 years and the existing prejudice in society regarding divorce in this age group had a misleading connotation about the separation between the elderly, which until recently was unusual[9]. However, as early as the 1990s, an increase in broken marriage rates was forecast as baby boomers aged, which would lead to more single older people (mostly men) accompanied by liberal attitudes and permissive behaviors[10].

We also believe that, in the case of study participants, the existence of HIV infection and related stigma adversely influence establishing new relationships, perhaps because of the fear of

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contaminating the other or being rejected. This fact also applies to widowers, mostly women, of whom much has been contaminated by the partner, an incident that causes great disappointment and anguish and leads to a lack of confidence.

Regarding schooling, the identification at the primary, secondary and higher education level of the respondents was not performed. However, the number of years of study referred to by both men and women was 1-4 years of schooling. These findings are similar to the national profile of HIV infection[11], that is, people with lower levels of education are the most affected. Thus, the level of education becomes an essential component in the social characterization of individuals[12], and may also be related to the improvement or deterioration of people's quality of life[13].

For eight years (2007 to 2015), more than 50% of HIV cases registered in the SINAN were of people who self-declared as black and brown in both genders[11]. A similar result was found in this study, in which the variable "race" only showed a statistically significant difference with the realm "HIV acceptance", and when the multiple comparisons test was carried out, we identified that those with a better acceptance are brown, yellow or indigenous, against those who self-declared as white.

This result is probably related to the sociocultural context in which our society was built, where "whites" always held a privileged social and economic status, so it would not be easy to accept a disease that is historically related to promiscuous life, low income, low schooling and that is more common in blacks and browns[11].

Regarding the "diagnosis time" (maximum 30 years) found in this study, it could be said that it is a reflection of high efficacy and effectiveness of the Antiretroviral Therapy (ART). This is of paramount importance in response to HIV infection, because it works by preventing the known "opportunistic infections" and consequently death. Thus, if people living with HIV does not stop treatment, they can enjoy a life expectancy of approximately 50 years[14].

Therefore, this increased time of infection could be associated with an improved quality of life, that is, the experience of living with HIV, seen at first as the end, makes each day turn into a learning opportunity. Thus, time is necessary to realize disease acceptance[15].

Most people living with HIV do not feel comfortable in revealing their serological condition; they choose to conceal it most of the time and even their whole life and try to do it in the best way so that they avoid prejudice[16]. This information justifies the lowest score found in this study, which was "concern with confidentiality", which is strongly associated with stigma, prejudice, discrimination, devaluation, and judgment of behavior[17].

Regarding the HAT-QoL domains by gender, males obtained the highest means in all. This may mean that the quality of life of women living with HIV is lower than that of men, one of the main reasons being that females are associated with "fragility", thus preventing female autonomy in social participation. We note that women are still treated, up this day, as "dependent on men (husbands)" and incapable of having and exercising civil rights. Thus, this inequality causes negative repercussions on the quality of life .

When it comes to quality of life, it is worth remembering that sexual function exerts a great influence. Thus, we recall the difference between the means (the highest of all) of the sexual function between men and women, as seen in Table 2. One could associate such discrepancy with the fact that most women, when becoming acquainted with their serology, abnegate from sexual activity for some reasons: concern to "contaminate" the other; the lack of trust; difficulty in negotiating condom use[17].

Another factor related to the result found in this study regarding the sexual function is that taboos directed to the sexuality of the elderly person persist in the twenty-first century, that is to say, this is a subject that remains strongly associated with joviality and thus a body that already shows signs of human aging does not become interesting, nor is it capable of stirring desires, especially when it comes to women[19].

Conclusion

We noticed that the sample of this study shows characteristics similar to the national profile of HIV infections. However, because they are elderly individuals, it has a particular characteristic: infection chronicity. From this information, we can see how much the pharmaceutical industry has advanced in the treatment of this disease, something that can reflect positively in the improvement of the quality of life.

It is worth remembering that the aging process is accompanied by several physical changes, sometimes psychic and almost always clinical. In turn, the latter's main characteristic are chronic non-transmissible diseases, which depending on

the biopsychosocial conditions of the affected individual, may have a higher or lower weight in the quality of life.

However, what about when the chronic disease is HIV infection? What is the intensity of this impact on the quality of life, mainly when it affects older adults? According to the results of this study, there seems to be a higher difficulty on the part of women regarding coping, especially with the issue of "sexual function", since these are elderly women affected by an unresolved (for now) disease linked to an image of promiscuous life.

From this result, we perceive the importance of considering sexual activity as influencing well-being in old age, especially when it is about elderly women, who experience more negatively the difficulty of the society in recognizing the "elderly being" as a sexually active individual. In most cases, self-denial occurs through resistance in feeling attractive or attracted to another person.

This reaction and denial often extend to most families, a fact that contributes to issues such as "safe sex" being addressed only by young people, whereas the discussion is geared to socialization for older adults. Otherwise, we can consider that the long years of living with HIV had a positive influence on the quality of life of the respondents since time is necessary to adapt to the changes caused by this disease. If in the beginning, this epidemic disabled individuals, currently, due to scientific advances, people can live normally, simply by being assiduous in the use of antiretroviral therapy.

Collaborations

KMS Torres worked on data collection, design and final writing; SRA Silva worked on data collection and tabulation; RB Aguiar and MTDB Tavares worked on data collection; Leal MC and APO Marques worked on the final essay.

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