ARTICLE

QUALITY OF LIFE IN THE CONTEXT OF HIV/AIDS:

A COMPARATIVE STUDY WITH THE GENERAL POPULATION

QUALIDADE DE VIDA NO CONTEXTO DO HIV/AIDS: UM ESTUDO COMPARATIVO COM A POPULAÇÃO EM GERAL

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ABSTRACT

Introduction: The introduction of antiretroviral therapy has allowed an increase in life expectancy of HIV-positive patients with HIV/AIDS, characterizing it as a disease amenable to control the long-term, thus influencing well-being and quality of life of these subjects. **Objective:** To evaluate the perceived quality of life of people with HIV/AIDS compared with that of people without the diagnosis for HIV. **Methods:** We counted with the participation of 561 people with HIV and 286 people without the diagnosis. Specific socio-demographic and clinical questionnaires, beyond the scale of quality of life WHOQOL-HIV-Bref were applied. **Results:** The quality of life was assessed positively by 59% of seropositive, being the dimensions spirituality and future prospects the better evaluated. Of the participants with no HIV diagnosis, 61% positively evaluated the quality of life, being the dimensions spirituality and independence the better evaluated. Regarding the domains of quality of life, both groups showed positive evaluation for all dimensions. However, the seropositive group evaluated more negatively the domains environmental and independence compared to the group without diagnosis. **Conclusion:** Results suggest that the diagnosis of HIV seropositivity is not a sufficient condition for the perception of quality of life to differ from people in general. Moreover, the less positive assessment on health for HIV-positive group seems to indicate that, for these subjects, health is related to aspects associated with organic etiologies and the psychosocial consequences of living with HIV/AIDS.

Keywords: quality of life, AIDS, soropositivity.

RESUMO

Introdução: A introdução da terapia antirretroviral vem permitindo um aumento na expectativa de vida dos pacientes soropositivos ao HIV, caracterizando a AIDS como uma doença passível de controle a longo prazo, influenciando assim no bem-estar e na qualidade de vida desses sujeitos. **Objetivo:** Avaliar a percepção de qualidade de vida de pessoas com HIV/AIDS comparando-a com a de pessoas sem o diagnóstico para o HIV. **Método:** Contou-se com a participação de 561 pessoas soropositivas e 286 pessoas sem o diagnóstico. Foram utilizados um questionário sociodemográfico e um clínico, além da escala de qualidade de vida WHOQOL-HIV-Bref. **Resultados:** A qualidade de vida foi avaliada positivamente por 59% dos soropositivos, sendo mais bem avaliadas as dimensões espiritualidade e perspectiva de futuro. Dos participantes sem o diagnóstico para o HIV, 61% avaliaram-na também positivamente, sendo mais bem avaliadas as dimensões espiritualidade e independência. Com relação aos domínios da qualidade de vida, ambos os grupos apresentaram avaliação positiva para todas as dimensões. Entretanto, o grupo soropositivo avaliou de forma mais negativa os domínios ambiental e independência em comparação ao grupo sem diagnóstico. **Conclusão:** Os resultados sugerem que o diagnóstico de soropositividade para o HIV não é condição suficiente para que a percepção da qualidade de vida seja diferente das pessoas em geral. Além disso, a avaliação menos positiva sobre a saúde pelo grupo soropositivo parece indicar a ideia de que a saúde para estes sujeitos está relacionada aos aspectos associados às etiologias orgânicas e às consequências psicossociais da convivência com o HIV/AIDS.

Palavras-chave: qualidade de vida, AIDS, soropositividade.

INTRODUCTION

Living with HIV seropositivity (human immunodeficiency virus) deeply affects the lives of individuals afflicted by it, be it in their general health conditions or in their social and family lives, and can cause isolation and social rejection, feelings of losing control of their future and diminished financial resources required to treat the disease(1).

However, advancements in the struggle against the epidemic and in treatments for its symptoms have showed positive responses for seropositive individuals, as is the case with antiretroviral therapy (ART). Since its inception in the 1990's, ART has enabled an increase in life expectancy for seropositive patients (HIV+) and a reduction in the stigma of AIDS as a synonym of imminent death and is now characterized as a chronic disease subject to long-term disease control and social coexistence(2). In this sense, it is not only necessary to think about the means to fight HIV/AIDS, but also how seropositive living affects the lives and well being of those infected by it. With this in mind, over the last years there has been an increase in academic interest regarding the connection between HIV/AIDS and the quality of life of HIV+ individuals(3–5).

The World Health Organization's(6) definition of quality of life comprises an individual's perception regarding his or her position in life. As such, it comprises a variety of conditions (physical, psychological, environmental, social and spiritual) which can affect the way individuals perceive their daily routines, affecting their feelings and behaviors, and not limited to their health conditions(3,7). Furthermore, it also takes into account the cultural context and the values by which individuals live, their goals, expectations and concerns.

Some elements are crucial for this analysis, such as: 1) the afore-mentioned *multi-dimensionality*, which comprises diverse areas of human life; 2) the *bi-polarity*, since the perception of quality of life can range from a negative dimension (unsatisfactory) to a

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positive dimension (satisfactory) and 3) *subjectivity*, which is considered from the standpoint of the individuals and the importance of their perception and active role in their own health.

Studies(1,4,5,8) have shown that the analysis of quality of life within an HIV/AIDS context is very important, because it enables HIV+ individuals to express the perception they have regarding their lives and provides health professionals with better means of treating the adversities resulting from the disease.

The emphasis on quality of life for seropositive individuals can comprise, among other things, the manner in which HIV+ individuals perceive and deal with day-to-day situations, as well as their commitment to the treatment and the effect of these treatments in the well being of these individuals, especially regarding their mental health(9,5).

However, despite the relevance of this connection, understanding the factors that affect the quality of life evaluation of HIV+ individuals is quite difficult, especially when considering how the perception of quality of life is determined by the seropositive condition or due to a set of clinical manifestations, or even if it is an association of these factors with other dimensions of life, such as social, psychological or environmental dimensions(10).

OBJECTIVE

Assess the perception of quality of life for HIV+ individuals and compare it to the perception of quality of life of same-age individuals within the general population without the HIV/AIDS diagnosis.

METHODS

Guidelines

This was a cross-sectional study and can be regarded as a descriptive epidemiological study.

Participants

A sample of 561 HIV+ individuals, between 18 and 69 years of age (*M* = 39.4; *SD* = 10), where 56% of them were male; and 286 individuals from the general population, with the same socio-demographic characteristics of the former population, with an average of 35 years of age (*SD* = 12), where 56% of them were female. The selection of the HIV+ participants was non-probabilistic and accidental, and occurred in hospitals treating HIV/AIDS patients in the city of João Pessoa / PB and Campina Grande / PB, and in Specialized Care Services in the metropolitan area of João Pessoa / PB.

Tools

Initially, both groups of participants were subjected to a socio-demographic questionnaire with the purpose of characterizing the participants' profiles. The questionnaire contained variables such as age, gender, education level, family income, marital status, level of religiosity, among others. HIV+ participants were also subjected to a questionnaire containing clinical aspects pertaining to the HIV/AIDS infection, with variables such as: when the diagnosis of the infection occurred, period of ongoing treatment, how the infection occurred, period of ongoing ART, medications used, related diseases, among others.

To evaluate the quality of life in both groups we applied the Abbreviated Scale of Quality of Life for the context of HIV/AIDS – WHOQOL-HIV-Bref(11), developed by the World Health Organization and validated in Brazil by Fleck(3). This scale has 31 items grouped into six domain scores: physical, psychological, level of independence, social relationships, environment and spirituality. Of the total items of the scale, five of them are related to the context of HIV/AIDS; only two make direct mention of HIV/AIDS and the rest have a more general character. Participants from the general population did not answer these questions and blank answers were calculated as missing values, a procedure applied for questions in which the variable does not apply for the individual. The scale also has two questions related to quality of life in general: the global perception of individuals about their quality of life and their global perception about their own health.

The questions were individually scored in a five-point Likert type of scale, where the lowest value indicates low and negative perceptions and the highest value indicates high and positive perceptions. Therefore, higher scores indicate a better perception of quality of life by participants.

Procedures

After the approval of the study by the Ethics Committee for Research of the Hospital Universitário Lauro Wanderley, at the Universidade Federal da Paraíba (CEP – HULW/UFPB), we contacted the boards of all health institutions involved in the project's development. The questionnaires were conducted individually and according to the ethical procedures of "Resolution #196/96, concerning Research involving Human Beings". Therefore, participants were informed about the research, and the voluntary characteristic of their participation was made clear, and they signed terms of consent. The confidentiality of all responses was properly secured.

Data analysis

The data was analyzed using descriptive statistics (mean, standard deviation and range) and inferential statistics (the Student *t* test) to check for differences between the averages of the participating groups.

RESULTS

Profile of participants

Of the 561 HIV+ individuals, most of them were male (56%), married (41%), with low levels of education (49% of them with only primary education) and low family incomes (75% with less than two minimum wages). At the time, 57% were employed and reported being moderately religious (44%).

As for the general population participants, most of them were female (56%), single (44%), and had completed high school (45%). They were also employed (71%) and reported being moderately religious (51%).

Assessment of quality of life

Quality of life was positively assessed by 59% (n = 329) of HIV+ participants and 64% (n = 360) reported they were satisfied with their health, with the dimensions of spirituality and future prospects, which for this group had the highest scores, unlike the dimensions related to environment and independence, which had the lowest scores. As for the general population group, 61% (n = 123) had a positive assessment of quality of life and 68% (n= 136) were satisfied with their health, therefore obtaining a better assessment for the dimensions related to spirituality and levels of independence, and a lower score in the dimension related to physical conditions and future prospects within this group. Comparing the averages obtained between the HIV+ participants and the general population participants, we noticed that there were no statistical differences between the groups in relation to their overall quality of life, with differences appearing only in the dimension related to satisfaction with health, which was better evaluated by the general population group (**Table 1**).

In relation to the quality of life dimension, the HIV+ group and the general population group reported positive assessments. Furthermore, there was no statistically significant difference between the averages of these groups in relation to the psychological or spiritual dimensions, but there were significant differences in all other dimensions, as shown in **Table 2**.

Considering only the HIV+ group of participants we noticed that, on a scale of 1 to 5 points, the factors that most contributed to a negative assessment of quality of life were related to the concrete aspects of survival, specifically insufficient financial gains (M = 1.97; SD = 1.97), dependence on medical (M = 2.31; SD = 0.89) and psychological treatments, and a sense of lack of enjoyment in life (M = 2.85; SD = 0.88) and difficulty to concentrate (M = 2.94; SD = 0.06).

Concerning the psychological and spiritual dimensions, although there were no significant differences between the groups, we observed a higher score for quality of life in the spiritual dimension and a lower score in the psychological dimension among the HIV+ participants.

DISCUSSION

Although the majority of HIV+ participants were male, it is important to emphasize the phenomenon of "feminization" of the epidemic, considering that the proportion of men for each woman in this study was below 2:1, confirming national data. Moreover, the larger number of participants with low education levels and low income corroborates the results of former surveys(12,13) that show how AIDS is spreading among the poor. These studies show

Table 1 – Assessment of the overall quality of life and satisfaction with health conditions among groups of participants with HIV AIDS and the general population.

Dimensions and aspects	General population	HIV+	p-value
	M (SD)	M (SD)	
Overall quality of life	72.7 (16.2)	72.0 (17.1)	0.61
Satisfaction with health	74.8 (17.8)	70.2 (20.2)	0.01

M: Mean; SD: Standard deviation; Significance level - $p < 0.05$.

Table 2 – Self-assessment of quality of life among groups of participants with HIV AIDS and the general population.

Dimensions and aspects	General population	Seropositive for HIV	p-value
	M (SD)	M (SD)	
Dimension 1 - Physical (Pain and discomfort; energy and fatigue; sleep and rest; HIV symptoms)	59.8 (11.2)	71.2 (17.2)	0.00
Dimension 2 - Psychological (Positive and negative feelings; cognition; self-esteem; body image)	73.1 (11.7)	71.3 (13.7)	0.07
Dimension 3 - Level of independence (Mobility; capacity for daily chores; capacity for work; dependence on medication/treatment)	76.5 (11.4)	67.1 (13.7)	0.00
Dimension 4 - Social relationships (Social relationships; social support; sexual activity; social inclusion)	76.0 (11.0)	72.8 (11.3)	0.01
Dimension 5 - Environmental (Safety; shelter; finances; access to health services; information; leisure; physical environment; transportation)	64.7 (9.5)	66.4 (11.1)	0.05
Dimension 6 - Future prospects (Sense in life; forgiveness and guilt; concern about the future; death and dying)	62.5 (11.3)	75.8 (18.3)	0.00
Dimension 7 - Spirituality (Spirituality, religion, personal beliefs)	78.7 (12.9)	79.1 (12.0)	0.80

M: mean; SD: Standard deviation; Significance level - $p < 0.05$.

that these variables should be considered determinant factors in contracting HIV/AIDS, as they are directly connected to an individual's health condition, to limited access to material goods, health services, information and to the necessary resources to prevent infection. Taking into account the labour conditions of participants, we observed that the HIV+ group had fewer employed individuals. Furthermore, considering seropositive living, it should be noted that the number of employed HIV+ individuals may be related to advances in antiretroviral therapy, which contributes to greater control of the disease and, consequently, higher capacity for work(14). For individuals suffering from HIV/AIDS, working is not only a means of obtaining food, shelter, medicine and health, among other things, but also has social and subjective value, especially when taking into consideration a complex and broad perspective of health.

Moreover, it is important to consider the low monthly income observed among participants, with 75% of the individuals sampled with a family income of only 2 minimum wages. In addition to the conditions related to its value and its service region, low incomes may be due to the health and functional status of the individuals, which would hinder their further integration into the labor market.

The lack of differentiation between the averages of the overall quality of life evaluation among HIV + groups and the general population can be explained by the fact that the first group perceives their quality of life beyond complaints or clinical aspects, addressing the construct more comprehensively. The same did not occur when they were questioned about their health, which had a lower score among the HIV+ group. This may be connected to the idea that health is related to factors associated with organic etiologies and the psychosocial consequences of living with HIV/AIDS. With this in mind, Fleck(3) stated that the overall quality of life assessment encompasses global considerations related to the life conditions and perspectives of individuals. Therefore, assessments of specific dimensions for individuals living with HIV/AIDS are, apparently, more sensitive in the differentiation of subjects with similar magnitudes. For example, when comparing symptomatic and asymptomatic patients within the HIV+ group, there was a lower rating (albeit positive) for the overall quality of life in symptomatic patients ($p = 0.05$), with diagnosis time below 2 years ($p = 0.04$) and opportunistic infection already present ($p = 0.05$). This figure shows how the experiences of the illness tend to affect the perception of the quality of life of these subjects.

As for the dimensions shown in **Table 2**, it is important to note the higher negative assessment in the physical dimension by the general population group, unlike the HIV+ group. Due to aspects related to pain and discomfort, energy and fatigue, sleep and rest, and also due to the characteristic symptoms of living with HIV, we expected an inversion in these averages. However, this data corroborates the statement that the HIV+ group evaluates their quality of life beyond the clinical and symptomatic aspects of their lives. This does not mean that these individuals do not suffer or feel, in some degree, a lack of functionality, but that these losses are not perceived as huge problems in their day-to-day lives. This demonstrates that it is not solely the diagnosis of a certain pathology that affects the quality of life assessment, but also the nature of the disease and the social beliefs related to this disease. In the HIV/AIDS context, for example, individuals tend to assess their quality of life taking into account there seropositivity, and this is frequently linked to the idea of imminent death. Therefore, some of these physical symptoms, such as pain, may represent a higher importance if compared to the general population group, and be of greater relevance for this group, since their assessments may be based on their condition as "healthy" individuals.

In the same manner, the future prospects dimension had a lower evaluation by the general population group, which was not the case with the HIV+ group, emphasizing the thesis that HIV+ patients have a better perception of their life conditions, even when facing the difficulties and adversities caused by the disease, especially among those under antiretroviral treatment, since this enables control of the symptoms and increases life expectancy. Therefore, the fact that the majority of HIV+ participants in this study use ART (83%) and are asymptomatic for AIDS (68%), possibly contributed for their positive assessment in the physical and future prospects dimensions.

However, it is known that the impact of the disease for individuals with HIV/AIDS diagnosis is more significantly reflected in the realm of these individual's social lives, in aspects related to autonomy and management of their daily needs, such as food and medication costs, among other things. In this sense, the environmental and independence dimensions had the worst assessment by this group of participants. In this respect, we consider that living with a chronic pathology demands medical care and continued use of medication, which contributes to the necessity for financial support that, when lacking, may become a stress factor for these individuals. In the case of the HIV+ participants we noted that they had low monthly incomes (two minimum wages), which may have contributed to a negative assessment of these factors.

Regarding independence, it enables the inclusion of individuals in social activities, especially within the community, which encourages the exchange of experiences needed to create support networks, capacity for work and autonomy. Therefore, the lack of a job or the fear of losing one, diminished self-esteem and independence may lead to a series of complications for the health-sickness process, which are capable of hindering the quality of life for these individuals(8).

It is possible that these quality of life dimensions are related to the clinical experiences of patients afflicted with diseases, however, this evaluation may vary according to the stage of the health-sickness process. An international study conducted by the WHOQOL SRPB Group(11), in 18 countries, with the goal of analyzing how spirituality, religion and personal beliefs relate to the quality of life of individuals observed that these variables are more connected to the quality of life of individuals with unfavorable health assessments. However, the majority of participants in this survey was under ART and still presented positive health assessments, as formerly discussed.

The results suggest that the seropositive for HIV diagnosis is not enough to affect the perception of quality of life for people in general. However, among the participants with HIV/AIDS, the asymptomatic and symptomatic stages affected their quality of life assessments, especially for the latter group.

The best overall quality of life assessment and the lowest assessment related to satisfactory health conditions among individuals with

HIV/AIDS seems to indicate that the global perception of quality of life is larger in scope than the health status per se, and can be specifically influenced by dimensions such as environment and independence, where the latter is related to work capability and performing chores and tasks. Therefore, we observed that within the HIV/AIDS context the perception of satisfactory health conditions is not necessarily connected to the absence of symptoms, but to the capability for work and performance of activities that an individual can engage in despite the diagnosis. Moreover, autonomy to perform activities is related not only to the symptoms of the disease, but also to the adequacy of the medication according to an individual's routine. This factor also indicates the importance of the participation of health professionals in promoting quality of life for individuals with HIV/AIDS.

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Conflict of interests

The authors declare no conflict of interests.

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