Quality of life in women with HIV/AIDS in a municipality in the State of São Paulo

ABSTRACT
High potency antiretroviral therapy brings benefits to people with HIV/AIDS, related to survival, chronicity and quality of life. The objective of this quantitative and cross-sectional study was to assess the quality of life of women with HIV/AIDS, using the WHOQOL - HIV bref and its association with sociodemographic variables. The study was performed in outpatient clinics specialized in care to HIV/AIDS patients. Of the 106 interviewed women, 99.1% were heterosexual and 92.4% were infected sexually. Among the domains of quality of life, spirituality had the highest score (65.7), followed by physical (64.7), psychological (60.6), social relationships (59.5). Level of independence (58.6) and environment (54.5) scored the lowest. The factors low socioeconomic and educational levels were associated with different domains of quality of life, showing the relationship between quality of life and living conditions. Challenges persist in the scope of social, affective and financial relations, which require effective interventions regarding empowerment of women with HIV/AIDS.

KEY WORDS

RESUMO
A terapia antirretroviral de alta potência beneficia os indivíduos com HIV/aids na sobrevida, cronicidade e qualidade de vida. Este estudo de corte transversal, com abordagem quantitativa, objetivou avaliar a qualidade de vida de mulheres com HIV/aids, utilizando o WHOQOL - HIV bref e sua associação com variáveis sociodemográficas. Foi realizado em dois ambulatórios especializados no atendimento a indivíduos com HIV/aids. De 106 mulheres participantes, 99,1% eram heterossexuais e 92,4% foram infectadas por via sexual. Dentre os domínios de qualidade de vida, espiritualidade obteve maior escore (65,7), seguido pelo físico (64,7), psicológico (60,6), relações sociais (59,5). Menores escores foram atingidos nos domínios nível de independência (58,6) e meio ambiente (54,5). Evidenciou-se que os fatores baixo nível socioeconômico e educacional tiveram associação com diferentes domínios, denotando a relação entre qualidade de vida e condições de vida. Concluiu-se que persistem os desafios no âmbito das relações sociais, afetivas, financeiras, requerendo intervenções efetivas focando o empoderamento das mulheres com HIV/aids.

RESPONDER
La terapia retroviral de alta potencia es beneficia para los individuos con HIV/AIDS en su sobrevida, cronicidad y calidad de vida. Este estudio de corte transversal, con abordaje cuantitativo objetivó evaluar la calidad de vida de mujeres con HIV/AIDS utilizando el WHOQOL-HIV BREF y su asociación con variables sociodemográficas. Fue realizado en dos ambulatorios especializados en la atención a individuos con HIV/AIDS. De 16 mujeres participantes, el 99,1% eran heterosexuales y el 92,4% fueron infectadas por vía sexual. Entre los dominios de calidad de vida, espiritualidad obtuvo el mayor puntaje (65,7), seguido por el físico (64,7), psicológico (60,6), relaciones sociales (59,5). Menores puntajes fueron alcanzados en los dominios nivel de independencia (58,6) y medio ambiente (54,5). Se evidenció que los factores bajo nivel socioeconómico y educacional estuvieron asociados con diferentes dominios, denotando la relación entre calidad de vida y condiciones de vida. Los desafíos persisten en el ámbito de las relaciones sociales, afectivas, financieras, requiriendo intervenciones efectivas, enfocando al empoderamiento de las mujeres con HIV/AIDS.
INTRODUCTION

In our country, from 1980 to June of 2009, 544,846 cases of AIDS were notified, 356,427 (65.4%) cases among men and 188,396 (34.6%) among women. It is observed that the ratio of gender (men: women) in Brazil has decreased throughout the historical series, changing from the male/female proportion of 26.7:1 in 1985 to 1.5:1 in 2008(1).

The incidence of AIDS is still kept at high degrees – 19.5 cases in 100 thousand inhabitants – basically due to the persistence of the growth tendency of cases among women, which evidences their vulnerability in face of the epidemics, whereas the mortality rate has been decreasing, as observed after the introduction of the policy of universal access to the antiretroviral treatment that combines drugs to different types of action (HAART – highly active antiretroviral therapy)[1].

Despite of the increase in the survival of individuals with HIV/AIDS, the study of the quality of life cannot be limited only to a probable longer life. When facing this disease, the individual is treated in an excluding and stigmatizing way, suffering a rupture in their affective relationships, problems with the sexuality and the lack of social and financial resources. As a consequence, this compromises their mental and physical health, welfare and quality of life(2).

Women are still the most vulnerable gender to this compromising in the quality of life of individuals with HIV/AIDS. This female vulnerability refers, among other factors, to the remarkable differences in the cultural, social and economical aspects, which give them unequal opportunities of health maintenance, promotion and protection(3).

In a general way, the World Health Organization (WHO) defines quality of life as the individual’s perception of his position in life, in the context of the culture and systems of values in which he lives regarding his objectives, expectations, standards and concerns. This is a comprehensive and multidimensional concept that involves several domains (physical, psychological, social, environmental, spiritual)(4).

Regarding the health area, the main idea of the term quality of life is the promotion of health, supported by the perception of the fundamental, material and spiritual human needs(5).

Instruments that measure the quality of life generically related to the health area have been used to evaluate the quality of life of people with HIV/AIDS in developed countries. Studies evidence that the quality of life of women with HIV/AIDS is compromised when compared to that of men; however, few studies about this thematic have been developed in developing countries, and few studies analyze women(5-6).

Therefore, given the feminization of AIDS, its high incidence and the decrease of deaths, it is vital to observe the quality of life of women with HIV/AIDS.

In face of the exposed facts, the present study was developed aimed at evaluating the quality of life of women with HIV/AIDS, users of the public health system, using the WHOQOL – HIV bref and its association to sociodemographic variables.

METHOD

This is a cross-sectional study with quantitative approach developed in two outpatient clinics specialized in care to HIV/AIDS patients in a municipality in the state of São Paulo. It was developed in the period from May 2007 to June 2008.

The study had the participation of women with HIV/AIDS, users of the public health system, who met the following inclusion criteria: being aware of their diagnosis of infection by the HIV/AIDS for at least six months; being older than 18 years old; being in outpatient clinical monitoring in the services in study; attending the medical appointments scheduled in the period of study; presenting physical and emotional condition to participate in the interview; consenting to participate in the study and signing the term of free and clarified consent.

Data were obtained from individual interviews with women infected by the HIV/AIDS, with the use of the WHOQOL HIV bref. This instrument was elaborated by the World Health Organization, translated and validated in Brazil, and it is used as a specific instrument to evaluate the quality of life of individuals with HIV/AIDS. It is an abbreviated version and presents 31 questions distributed into six domains: physical; psychological; level of independence; social relationships; environment; spirituality(5).

The collection of sociodemographic and clinical data was guided by a questionnaire that was specifically built for this study and validated by three specialists as for its form and content. It contemplated the items: social, demographic and clinical data that may interfere and relate to the quality of life of the individuals.

Data were organized in Excel spreadsheets and exported to the program Statistical Package for Social Science, version 15.0. The syntax was used to calculate the scores of each item of the instrument, offered by the Group of Study in Quality of Life in Brazil, version in Portuguese. The internal consistency for the instrument domains was calculated through Cronbach’s coefficient of reliability. The authors tested the normality in groups that were formed for comparison under 30, the test of Kolmogorov-Smirnov was per-
formed in order to test the normality of distribution of the sample means. In order to compare the sample means of the scores of quality of life, the authors used Student’s t-test and ANOVA.

The study project was analyzed and approved by the Committee of Ethics in Research of the Nursing School of Ribeirão Preto (Protocol no. 0699/2006 EERP-USP). The participants of the interviews were informed about the study objectives and signed the Term of Free and Clarified Consent, guaranteeing the confidentiality and anonymity of the information.

RESULTS

Among 250 women registered in the two services in study until June of 2008, 106 (42.4%) women were interviewed. The prevalent age group was between 30 and 39 years old (44.3%), 48 (45.3%) were married or lived with a partner and 88 (83.0%) had attended school until the elementary grades. Out of the total, 55 (51.9%) did not have a job and 49 (46.2%) had a monthly income between 1.1 to 3 minimum salaries (Table 1).

Table 1 - Distribution of the women with HIV/AIDS, according to sociodemographic variables - Ribeirão Preto, SP - 2007-2008

<table>
<thead>
<tr>
<th>Variables</th>
<th>Female n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 - 29</td>
<td>9</td>
<td>8.5</td>
</tr>
<tr>
<td>30 - 39</td>
<td>47</td>
<td>44.3</td>
</tr>
<tr>
<td>40 - 49</td>
<td>32</td>
<td>30.2</td>
</tr>
<tr>
<td>50 - 59</td>
<td>16</td>
<td>15.1</td>
</tr>
<tr>
<td>≥ 60</td>
<td>2</td>
<td>1.9</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>32</td>
<td>30.2</td>
</tr>
<tr>
<td>Married</td>
<td>19</td>
<td>17.9</td>
</tr>
<tr>
<td>Separated</td>
<td>7</td>
<td>6.6</td>
</tr>
<tr>
<td>Widower</td>
<td>12</td>
<td>11.3</td>
</tr>
<tr>
<td>Living with a partner</td>
<td>29</td>
<td>27.4</td>
</tr>
<tr>
<td>Divorced</td>
<td>7</td>
<td>6.6</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>8</td>
<td>7.5</td>
</tr>
<tr>
<td>Incomplete elementary school</td>
<td>57</td>
<td>53.8</td>
</tr>
<tr>
<td>Complete elementary school</td>
<td>23</td>
<td>21.7</td>
</tr>
<tr>
<td>Complete high school</td>
<td>16</td>
<td>15.1</td>
</tr>
<tr>
<td>Graduation degree</td>
<td>2</td>
<td>1.9</td>
</tr>
<tr>
<td>Income (minimum salary)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No income</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>≤ 1 MS*</td>
<td>35</td>
<td>33</td>
</tr>
<tr>
<td>1.1 to 3 MS</td>
<td>49</td>
<td>46.2</td>
</tr>
<tr>
<td>3.1 to 5 MS</td>
<td>3</td>
<td>2.8</td>
</tr>
<tr>
<td>&gt; 5 MS</td>
<td>1</td>
<td>0.9</td>
</tr>
<tr>
<td>Employment bond</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes/retired</td>
<td>38</td>
<td>35.8</td>
</tr>
<tr>
<td>No/unemployed</td>
<td>68</td>
<td>64.2</td>
</tr>
</tbody>
</table>

*The current minimum salary in the period of the study was R$ 380.00 (three hundred and eighty Reais)

Regarding the reproductive and sexual characteristics, almost all women were heterosexual (99.1%) and 98 (92.4%) were infected sexually. Among the total, 68 (64.2%) women had a sexual partner, 65 (61.3%) considered their relationship as stable, 61 (57.5%) had an active sexual life and 37 (34.9%) always had partners who used condoms.

As for the clinical variables, it was identified that regarding the classification of the infection by the HIV/AIDS, 61 (57.5%) were asymptomatic, 9 (8.5%) were symptomatic and 36 (34%) had developed AIDS. Most of the interviewed women, that is, 85 (80.2%) used antiretroviral therapy and 21 (19.8%) had not started using these drugs.

Through the WHOQOL HIV bref, six domains were evaluated: physical, psychological, level of independence, environment, spirituality and social relationships. Table 2 shows the mean scores obtained in each of the domains and the respective values of Cronbach’s alpha. It is observed that the highest means were attributed to the domains spirituality (65.7) and physical (64.7); whereas the lowest means belonged to the domains environment (54.5) and level of independence (58.6).

Table 2 - Distribution of scores of the domains of the WHOQOL HIV bref regarding women with HIV/AIDS - Ribeirão Preto, SP - 2007-2008

<table>
<thead>
<tr>
<th>Domains</th>
<th>Mean (standard deviation)</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>64.7 (21.3)</td>
<td>0.63</td>
</tr>
<tr>
<td>Psychological</td>
<td>60.6 (18.6)</td>
<td>0.74</td>
</tr>
<tr>
<td>Level of Independence</td>
<td>58.6 (17.9)</td>
<td>0.68</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>59.5 (20.0)</td>
<td>0.71</td>
</tr>
<tr>
<td>Environment</td>
<td>54.5 (15.1)</td>
<td>0.77</td>
</tr>
<tr>
<td>Spirituality</td>
<td>65.7 (24.2)</td>
<td>0.59</td>
</tr>
</tbody>
</table>

Table 3 presents the mean scores of quality of life, according to sociodemographic variables. It identified that women between 20 and 29 years old presented the worst evaluation of quality of life in the domain spirituality when compared to individuals in other age groups. Also regarding the age group, it was verified that the worst evaluation in the scores of quality of life in the domain level of independence was among women over 50 years old.

Regarding the variable educational level, a statistically significant difference was verified in the mean scores of the domains level of independence, social relationships, environment and spirituality, and illiterate individuals had the worst scores in these domains.

As for the income, individuals who had no income or whose income was lower than a minimum salary presented the worst scores for quality of life, with statistically significant differences in all domains of quality of life. Regarding the variable employment bond, employed individuals had the best scores of quality of life in all domains of the WHOQOL HIV bref, except for the domain of spirituality, according to Table 3.
Regarding the variables related to the use of antiretroviral drugs, no statistically significant differences were found among the scores of quality of life and the use of antiretroviral drugs in any of the domains. In the group of classification of the infection by HIV (asymptomatic, symptomatic and AIDS) and age, there were differences observed only in the physical domain, evidencing that women with AIDS had a worse quality of life (p=0.03) than asymptomatic women.

DISCUSSION

In Brazil, studies about the quality of life have been developed through the use of several instruments of evaluation of quality of life[8-10]. This fact complicates the comparison of the results found.

Among the six domains of the WHOQOL HIV bref, the one that presented the highest mean score, that is, the best performance, was the domain of spirituality (65.7). Spirituality is a positive strategy for facing the HIV/AIDS and the biopsychosocial alterations that the disease causes in the lives of individuals living with it. This domain evaluated the aspects related to the forgiveness and the guilt due to living with HIV/AIDS and the concern about the future and death.

Another study that evaluated the quality of life of men and women in Africa, using the WHOQOL HIV bref, found similar results, indicating better quality of life in the domain spirituality for both genders[11].

The present study also observed that women aged between 20 and 29 years old, illiterate and who did not have a source of income had the worst mean scores of quality of life (p=0.03) than asymptomatic women.
better quality of life and well-being, even associated to the symptoms of the HIV/AIDS\(^{13}\).

A study developed in the northeast of Brazil found similar results to this study. Younger women are more associated to concrete questions of AIDS, whereas older women are more associated to the religiosity, with the hope and faith to cure this disease. The authors discuss that religiosity may be both beneficial and malefic for the treatment, since it may provide emotional support or encourage the interruption of the medical treatment, due to the belief of cure through faith\(^{13}\).

The physical domain was the second domain of the WHOQOL HIV bref with the highest mean score (64.7), which evaluated the performance of physical activities and the presence of pain and/or physical limitation to live socially. The results in the evaluation of this domain may have been granted by the use of the antiretroviral therapy, causing expressive changes in the course of the infection by the HIV/AIDS, with positive impacts and consequences in the perspective of life and quality of life of these individuals\(^{15}\).

Results found in a study developed in eastern Europe says that, according to the evaluation of the physical domain, women with the diagnosis of AIDS had lower scores of quality of life in this domain when compared to those who were asymptomatic. This result agrees with that of other studies found in the literature, which indicate that the clinical deterioration and the appearance of the symptoms of the disease are associated\(^{14}\).

An interesting result identified in our study is that the worst economical conditions and the absence of an employment bond had a negative relation to the evaluation of the quality of life in the physical domain.

Worse economical conditions and the inequality of insertion in the work market between men and women are factors that contribute to a lower quality of life among women. Women are submitted to precarious and badly paid jobs, contributing to the increase in the number of workers in the informal market. It is thus perceived that the low monthly income and the absence of an employment bond are correlated\(^{15}\).

Regarding the domains social relationships and psychological, it is observed that the mean scores were 60.6 and 59.5, respectively. The psychological domain evaluated the positive and negative feelings, the cognition through the capability of memory and concentration, the self-esteem, the body image and the appearance. The domain social relationships evaluated the sexual relationships, the social inclusion and the social support received from friends and relatives.

Women with income higher than one minimum salary and an employment bond had better scores of quality of life in the psychological domain. As for the domain social relationships, it was observed that, besides the factors of income and employment bond, the factor of educational level also had a relation with the quality of life. In other words, women with higher educational level had better scores of quality of life in the domain social relationships than illiterate women or those with low educational level.

It is important to consider that the number of women with HIV/AIDS has greater proportions among the lowest social classes and the lowest educational levels, which happens, mainly, due to the fact that women are treated unequally in socioeconomic, cultural and political terms, with less access to consumer goods, basic social security and, certainly, to the education, which justifies the fact that the infection of individuals by the HIV/AIDS has suffered a transition from high to low socioeconomic and cultural level\(^{15}\).

The educational level is often directly connected to the employment bond and the monthly income, which ends up limiting the purchasing power of women, as great proportions have lower levels of education. Besides generating a financial benefit, the employment bond constitutes a source of social support and structure, bringing a meaning and a feeling of use to the individuals.

A study developed in Estonia concluded that the employment is a very important factor that influences the quality of life, capable of reducing the stress lived in the infection by the HIV and generating psychological health and good social relationship\(^{14}\). Despite of the impact of the infection by the HIV/AIDS in the psychological health and in the social relationships of the infected individuals, as well as in the physical domain, the use of the antiretroviral therapy caused positive consequences in the psychological health, providing the deconstruction of the idea of death resulting from the diagnosis of the HIV/AIDS carriers and the construction of better perspective of life\(^{14}\).

After the arrival of the antiretroviral therapy, living with HIV/AIDS allows to rethink and find a new meaning for the infection by the HIV, deconstructing the idea of death for a more human perspective in which the individual daily lives with the HIV, under the point of view of the chronicity\(^{14}\), which allows the reconstruction of projects in the professional and affective life, with the insertion in the work market and the establishment of affective-sexual bonds\(^{17-18}\).

Regarding the aspects of the affective-sexual life, with the reduction of deaths and the increase of the survival, individuals with HIV/AIDS could reconstruct their objectives of life post-diagnosis, which implicated in the increase of the formation of couples with different serology for the HIV and the desire to have children\(^{17-18}\).

Despite of that, challenges still persist in the area of social and affective relationships, considering the evaluation of the domain of social relationships that are related to the peculiarity of living with the HIV/AIDS and its impact in the social relationships, social support and sexual activity\(^{9}\), specially among women with low social and economical level, since the income, educational level and employment bond had a relation to worse scores of quality of life in this domain.
As for the aspects of the affective-sexual life, it is observed that most of the women have few affective-sexual partners in their lives, which certifies that the female epidemiology of HIV/AIDS increases among women with a stable relationship. A great part of the infected women keep their affective and sexual lives active, however, they still present difficulties in the daily negotiation for the use of condoms, which is more emphasized in heterosexual relationships, and women are more successful when it is made with casual partners rather than fixed partners.

The inequality of the social role between men and women influences negatively the quality of life of women with HIV/AIDS. This negative influence seems to become vehement in consequence of the economical and emotional dependence on the partner, the low educational level and the lack of autonomy over their body, the sexual violence and commercialization, the difficulty to convince the partner to use a condom, the fear to be rejected and to decide to make real the desire to form a family and the change in the routine of the sexual and affective life due to the difficulty to expose their condition as carriers of the virus.

Regarding the aspects of the social relationships, women suffer from hostility and rejection in the work environment and even with closer people, such as family members and other important people in their social relationships. Besides, experiencing several sources of daily stress in the field of human and affective relationships, such as the discrimination and the prejudice, as well as the lack of financial resources that have a negative impact in the quality of life.

The domains level of independence and environment obtained lower mean scores, with values of 58.6 and 54.4, respectively. The domain level of independence evaluated the aspects that comprehend physical mobility, daily activities, aptitude to work and dependence on medication or treatment. It was observed that women over 50 years old, with low social and economical level, also had worse evaluations of the scores of quality of life in this domain.

Life with HIV/AIDS leads women to experience varied symptoms, which causes changes in their daily lives and lifestyle. They stop doing what was once routine and leisure and start living without the same intensity as before.

Women over 50 years old had worse evaluations in the domain level of independence, since age is a limiting factor for the physical mobility and the aptitude for daily and work activities.

On the other hand, the domain environment evaluated the aspects related to the physical security, access and quality of health and social care, computerization, leisure, physical environment and transportation. As expected, the study identified that individuals with worse socioeconomic conditions also had lower scores of quality of life in this domain.

The domain environment was the one that presented the worst score among women with HIV/AIDS. Similar results were also identified in a sample of individuals with HIV/AIDS in the city of São Paulo with both genders.

The low socioeconomic and educational level is directly related to low scores in the domain environment. As previously mentioned, the fact that women are treated unequally in political, cultural and socioeconomic terms influences negatively their purchasing power, and consequently, their housing, physical security, leisure, transportation, access and quality of health, among other things.

The WHOQoL HIV bref presented three domains with Cronbach’s Alpha under 0.70. The poorest coefficients of reliability may be related to the number of items in the analysis. In other words, the higher the number of items the better the reliability coefficient may be. Nevertheless, this instrument is considered an instrument of global evaluation of the QoL.

In face of the results presented, it is evident that it is necessary to improve the empowerment of these women as a strategy to achieve a better QoL. In this context, integral health care is fundamental for these women, besides public health policies that privilege the social inclusion and the fight against prejudice and the discrimination towards people with HIV/AIDS.

CONCLUSION

This study evidenced that the highest mean scores of quality of life evaluated for women with HIV/AIDS were found in the domains spirituality, physical, psychological and social relationships. The worst mean scores of quality of life were found in the domains environment and level of independence. It was identified that the factors low socioeconomic and educational level had an association to different domains of the QoL, indicating the relation between quality and conditions of life.

About three decades since the discovery of the infection by the HIV/AIDS, it is observed that the impact of the HIV in the life of the people affected by the virus has changed, as well as their needs. Despite of the advance, mainly related to the treatment with antiretroviral drugs, many challenges still persist in the area of prevention and care. These individuals live and face countless consequences resulting from the disease, related to the stigma and prejudice, with impact on their social, family, affective and sexual relationships.

The comprehension of the quality of life of people with HIV/AIDS is fundamental, considering the chronic evolution of the infection, the possibility of treatment and longer survival and life with a stigmatizing, transmittable and so far incurable disease, with countless biopsychosocial consequences that interfere in their quality of life.

The infection by the HIV in women deserves special attention, due to the high rate of incidence found over the last years and the inequalities suffered regarding the socioeconomic, cultural and gender contexts, which strengthen several aspects that may influence the QoL.
Therefore, the evaluation of the quality of life of women with HIV/AIDS may contribute to the orientation of actions and interventions of health professionals, as well as public policies to promote the quality of life of this population.

REFERENCES